



SURVIVE and **THRIVE**

Transforming care for every
small and sick newborn



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FOREWORD

Just about everyone has experienced the joy that a healthy newborn child brings to parents, families and communities. But the arrival of a newborn who is small or sick often results in immediate worry and sadness. When the infant is at high risk of death or disability, these concerns can be a tremendous additional burden.

We remain firm in our vision of a world freed of that burden, a world in which every mother and newborn will survive and thrive. However, we cannot meet the health-related Sustainable Development Goals – and we cannot achieve universal health coverage or people-centred primary health care – without a strong and growing investment in mothers and newborns. This report focuses on inpatient care for the most vulnerable newborns: the small and sick.

The launch of the Every Newborn Action Plan at the Sixty-seventh World Health Assembly in 2014 coincided with a period of great progress. The global neonatal mortality rate declined from 31 deaths per 1000 live births in 2000 to 18 deaths per 1000 live births in 2017. But three years into the era of the SDGs, we are still far from our goal of reducing newborn deaths to 12 per 1000, or less, by 2030. Bending the curve further will require a laser-sharp focus on reorganizing health systems to provide quality care, and continuity of care, for newborns – especially those who are critically ill.

To that end, every pregnant woman and every newborn, without exception, must have access to high-quality, affordable services before, during and after the time of birth. Accessible services are especially important for populations that are underserved and marginalized, including those living in humanitarian settings or in conflict. We also need more comprehensive “specialized and intensive” newborn care services – because services that are good enough for healthy newborns might not suffice for those who come into the world unwell.

While investments in all of these areas are critical, so is the level of investment. We can avert 747 400 neonatal deaths by 2030 in low- and middle-income countries by investing an additional US\$ 0.20 per capita in small and sick newborn care. By providing quality intrapartum care to

95% of all mothers delivering in health facilities, we would, in addition, save many mothers' lives and prevent stillbirths each year.

With such results in mind, *Survive and thrive: transforming care for every small and sick newborn* highlights the need for accurate and reliable data to facilitate planning, to help measure quality, outcomes and impact, and to promote accountability.

This report is a much-needed wake-up call for investing in quality inpatient neonatal care and designating facilities for specialized and intensive newborn care. Simultaneous investments are required to ensure adequate and appropriate human resources, supplies, laboratories and data systems for well-functioning, family-centred, inpatient neonatal care. The care provided during hospitalization and follow-up in the community also needs to be developmentally supportive and nurturing. Supporting healthy brain development during early childhood is the best investment a country and society can make in the future generation – and in continued economic growth.

We are proud that our respective organizations, along with numerous contributors and partners, are part of the joint effort that has reached these conclusions. Our collaboration has already yielded important results. With this report, we call upon governments, health professionals, parents and other partners to join us in supporting continued investment in health systems that respond to the needs of the most vulnerable. In this way, we can – and we will – achieve the vision of a better world for every mother and newborn.

After all, newborns are not just bundles of joy for their families. They are a promise to the future.



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KEY ABBREVIATIONS

AARR	Average annual rate of reduction
BEmONC	Basic emergency obstetric and newborn care
Bubble CPAP	Bubble continuous positive airway pressure
CEmONC	Comprehensive emergency obstetric and newborn care
CPAP	Continuous positive airway pressure
CRC	Convention on the Rights of the Child
CRVS	Civil registration and vital statistics
DALY	Disability-adjusted life year
EmONC	Emergency obstetric and newborn care
ENAP	Every Newborn Action Plan
G6PD	Glucose-6-phosphate dehydrogenase deficiency
HICs	High-income countries
HMIS	Health management information systems
KMC	Kangaroo mother care
LBW	Low-birth-weight
LICs	Low-income countries
LiST	Lives Saved Tool
LMICs	Low- and middle-income countries
MDGs	Millennium Development Goals
MICs	Middle-income countries
MISP	Minimum Initial Service Package for Reproductive Health in Crisis Situations
MPDSR	Maternal and perinatal death surveillance and response
NEC	Necrotizing enterocolitis
NICU	Neonatal intensive care unit
NMR	Neonatal mortality rate
PPROM	Preterm premature rupture of membranes
RMHC	Ronald McDonald House Charities®
RMNCH	Reproductive, maternal, newborn and child health
SDGs	Sustainable Development Goals
SGA	Small for gestational age
SNCU	Special newborn care units (specific to India)
UHC	Universal health coverage
UN	United Nations
UNFPA	United Nations Population Fund
UNICEF	United Nations Children’s Fund
WHO	World Health Organization

KEY MESSAGES

Transforming hospital care for 30 million vulnerable newborns,¹ who are currently being left behind, is a smart investment which will unlock substantial human capital. Achieving the Sustainable Development Goals (SDGs), including universal health coverage (UHC), by 2030 requires action now to provide care for all small and sick newborns.

- **Surviving:** More than 2.5 million newborns – mostly those born small or sick – died in 2017 from preventable causes, most notably prematurity, complications around the time of birth, infections and congenital conditions. Some died because the care they received was of poor quality, others because they received no health care at all. To meet the SDG 3.2 target for newborn and child survival, countries need to transform special and intensive care in hospitals.
- **Thriving:** Every year, 30 million newborns require quality special or intensive newborn care in a hospital setting. These newborns *can* and *will* survive and thrive as productive members of our societies, provided they are given *high-quality* inpatient care at the right time and in the right place, including follow-up care and family-centred care.
- **Transforming:** Cost effective solutions exist for the main causes of newborn death and disability. To achieve UHC, there must be innovation through people-centred care, locally-designed technologies, financial protection, and parent power and partnership. Ensuring the recruitment, training and retention of adequate cadres of skilled nurses is particularly crucial. Social norms also need to be transformed such that newborn mortality is no longer considered as inevitable.
- **Impact with equity:** The lives of 1.7 million newborns could be saved each year by investing in care for every newborn, everywhere, including in humanitarian settings. While maternal and essential newborn care must be considered the foundation of care, the addition of special and intensive care services for small and sick newborns represents a smart investment. Such special and intensive services could save 747 400 lives, reducing newborn mortality by almost half, promoting child development and fostering economic productivity.
- **Counting:** Accelerating change requires improvements in the routine collection of data focusing on service coverage, quality and outcomes, in addition to ensuring better use of existing data, thereby promoting accountability and action.

Survive and thrive: transforming care for every small and sick newborn, focuses on the world's most vulnerable newborns. It outlines the global problem, showcases progress, summarizes what can be done to transform inpatient care for small and sick newborns, and demonstrates the importance of data to guide investment and improve quality and equity.

The report contributes to achieving the objectives set out in *The global strategy for women's, children's and adolescents' health (2016–2030) (1)* and builds on the momentum of *Every newborn: an action plan to end preventable deaths (2)*. It presents a clear call to action to accelerate progress towards the SDGs to ensure every newborn has the chance to live a healthy and productive life.

¹ In this report “newborn” refers to an infant in the first 28 days after birth.

EXECUTIVE SUMMARY

Now is the time to transform care for newborns

The world will not achieve SDG 3 (to ensure healthy lives and promote well-being for all at all ages) unless care for every newborn is transformed. This must include the most vulnerable – the small and sick. To achieve the SDG target to end preventable newborn deaths (with all countries aiming to reduce neonatal mortality to at least as low as 12 deaths per 1000 live births by 2030), countries need to expand provision of care to reach all newborns (Fig. ES.1). However, some countries are far from meeting this target, putting achievement of the global SDG 3 target in jeopardy. Countries can take action now to make more rapid progress.

Every year, 30 million newborns are at risk

Newborns who are born too soon or too small,¹ or who become sick, are at greatest risk of death and disability. Every year, an estimated 2.5 million newborns die during the first 28 days of life (3). Approximately 80% of these

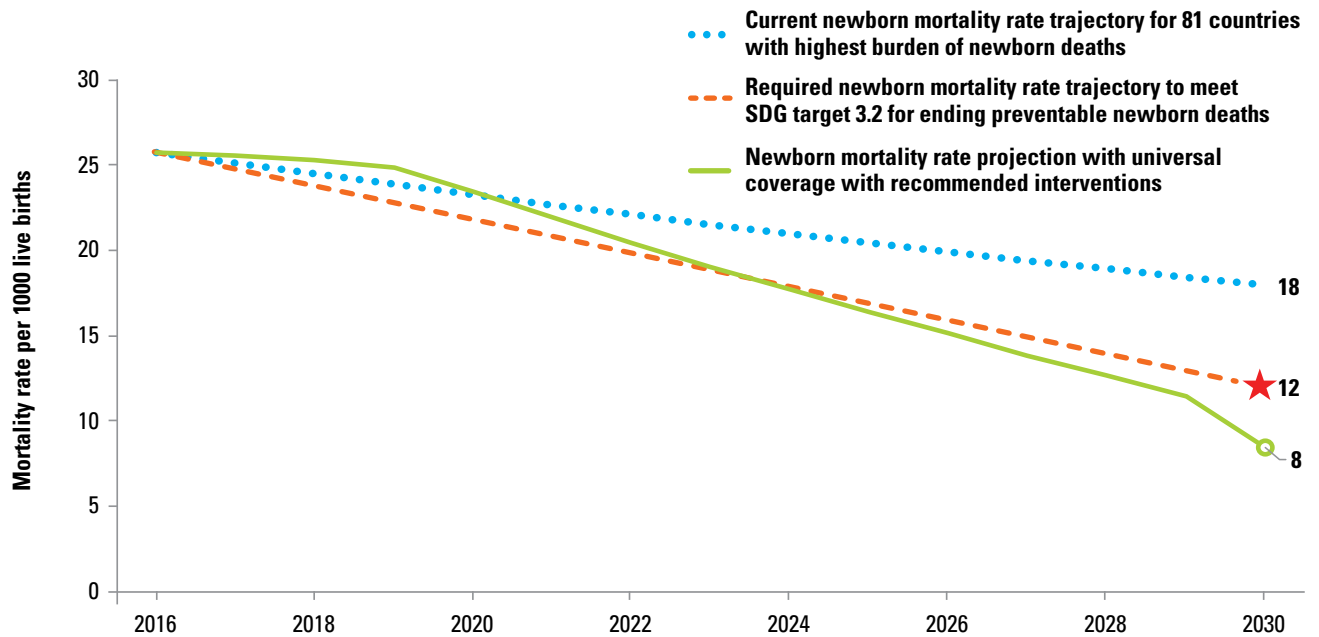
are low-birth-weight (LBW), and two thirds are born prematurely. In addition, a further estimated 1 million small and sick newborns survive with a long-term disability (4).

Globally, up to 30 million newborns require some level of inpatient care each year. This includes newborns with complications from prematurity, intrapartum brain injury, severe bacterial infection and pathological jaundice, and those with congenital conditions. Substantial human potential for lifelong health and well-being is lost through newborn mortality, disability and long-term disease. Furthermore, family members of small and sick newborns are at high risk of long-term psychological and financial problems. These, in turn, can have additional detrimental effects on a newborn’s developmental, social and cognitive growth (4, 5).

Every newborn has the right to survive and thrive

Articles 6 and 24 of the Convention on the Rights of the Child (CRC) emphasize the right of every newborn to the highest attainable standard of health and health care (6).

Fig. ES.1 Scenarios to 2030 for 81 high-burden countries: current newborn mortality rate trajectory; required trajectory to meet SDG target 3.2; and projection with every newborn covered by universal health coverage



Source data: UN IGME 2017 (3); projected trajectory calculated using Lives Saved Tool.

1 In this report, “too soon” refers to newborns at less than 37 weeks’ gestation; “too small” refers to newborns weighing less than 2500 g at birth.



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Unfortunately, these rights are not respected or protected in all settings, particularly for the most at-risk newborns and those who are members of marginalized groups or living in humanitarian settings. To protect newborns, countries need to translate the CRC guidelines into domestic laws and regulations, and then implement them.

UHC is a global imperative to achieve the SDGs; thus everyone – including newborns – should have access to the health services they need without facing financial hardship (7). This is particularly true for the families of small and sick newborns who can face devastating hospital costs due to lengthy inpatient stays.

Overcoming inequities

National neonatal mortality rates (NMRs) vary significantly between countries, from 0.9 to 44 deaths per 1000 live births (3). Almost all neonatal deaths (98%) occur in low- and middle-income countries (LMICs), with 75% occurring in Southern Asia and sub-Saharan Africa. Of the 10 countries with the highest NMRs, 8 are in Africa; the majority have experienced a recent humanitarian crisis (Box ES.1).

The likelihood of a newborn surviving and thriving is determined by where she or he is born. In high-income countries (HICs), newborn mortality is uncommon, and more than 95% of preterm² newborns go on to survive and thrive. In middle-income countries (MICs), the risk of disability for infants born between 28 and 32 weeks

2 In this report “preterm” refers to childbirth occurring at less than 37 completed weeks (or 259 days) of gestation.

KEY TERMS

Essential newborn care: key routine practices in the care of all newborns, particularly at the time of birth and during the first days of life, whether in the health facility or at home.

Special newborn care: key inpatient care (24/7) practices for small and sick newborns, including (but not exclusively) provision of warmth, feeding and breathing support; treatment of jaundice; and prevention and treatment of infection. Special newborn care may include the provision of intermittent positive-pressure therapy. Special care can only be provided in a health facility.

Intensive newborn care: key inpatient care (24/7) practices for very small and sick newborns, including the provision of intermittent positive-pressure therapy. Intensive care can only be provided in a higher (usually tertiary) level facility.

(See Chapter 3 for more details on organizing services by level of care.)

Family-centred care: an approach to care delivery that promotes a mutually beneficial partnership among parents, families and health-care providers to support health-care planning, delivery, and evaluation. The principles of family-centred care include: dignity and respect; information sharing; participation; and collaboration. It can be practiced in health facilities at all levels.

Box ES.1 The special challenge of humanitarian settings

Of the 16 countries with the highest NMRs in the world, 11 have experienced recent humanitarian crises, such as conflict or political instability.

In humanitarian settings, pregnant women and those who have recently given birth must overcome immense obstacles to provide care and safety for their children. At the same time, their own vulnerability to malnutrition, sexual violence, poor mental health and unplanned pregnancy increases, as do the risks related to unassisted childbirth.

To achieve the SDGs, the global community must work to reach the most vulnerable populations in these especially challenging environments. Their programmes should include care for small and sick newborns. An interagency collaboration developed the *Newborn health in humanitarian settings: field guide* to support these efforts (8). It summarizes existing WHO standards of care for newborn health, with additional guidance on how to provide those services in humanitarian settings.

of gestation is nearly double that of HICs. In low-income countries (LICs), disability is uncommon since the smallest and sickest newborns, including those born at less than 28 weeks' gestation, usually die either through a lack of basic care, or the inability of parents or caregivers to afford advanced care when needed.

Marginalized families are most at risk, even in HICs. An analysis of survey data from 63 countries with the highest burden of newborn deaths found that the average national neonatal mortality rate could be reduced by a median of 16% if all households had the same risk of neonatal death as the richest 20% of the population. Closing this equity gap could save the lives of 500 000 newborns annually. To achieve the SDG 3 target, countries must address inequities and protect and promote the right to health set out in the CRC.

Deliver the care they need and are entitled to

Most newborns can survive and thrive, provided they have access to quality health care – including access to appropriate inpatient care. To transform inpatient care for newborns, which fits the purpose of saving the lives

of small and sick newborns, countries should focus on improving care for the conditions that bring the greatest risks of mortality and long-term complications. These include prematurity, neonatal encephalopathy, jaundice, neonatal infections, and congenital abnormalities.

Small and sick newborns require high-quality inpatient care delivered by competent and specialized (where needed) professionals in a dedicated space. Newborns may have different needs depending on their fragility. For example, all newborns require essential care, particularly at the time of birth and during the first days of life, whether in a health facility or at home. Most small and sick newborns can be managed with special inpatient care, which can only be provided in a health facility. Only one in three small and sick newborns requires intensive inpatient care, which can only be provided in a higher-level (e.g. district or tertiary-level) facility. Table ES.1 lists inpatient interventions proven to be effective in preventing newborn mortality and disability, according to the level of care.

Putting people at the centre of transforming care

Good-quality care is evidence-based, safe, well-organized, accessible, adequately resourced, efficient, provided in a timely manner, and people-centred (9). In this report, the person at the centre of care is the newborn who receives treatment from health-care providers, mother, father, other caregivers, or a combination of these. In some cases, the newborn and the mother may be considered at the centre since both may be recipients of care, being treated together or simultaneously. To minimize the adverse consequences of hospitalization for all, mothers and newborns should not be separated and all interactions should be structured to promote healthy development. Maximizing contact with parents, particularly the mother, encourages bonding, supports lactation and feeding with breastmilk and promotes cognitive development (10).

Health workers equipped with newborn care skills

Inpatient care for newborns must be available 24 hours a day, 7 days a week. This care should be delivered by a multidisciplinary team of appropriately trained health-care providers with specialized skills in newborn care.

For many countries, building the neonatal care competencies of existing providers, and creating or expanding their neonatal nursing cadres, will be a crucial step. Many have substantial shortages of nurses and midwives, particularly in rural and hard-to-reach areas. Recruiting, training, mentoring and retaining these health-care providers

Table ES.1 What type of care is needed? Requirements for interventions at different health system levels

Level	Type of care provided	Standards of care and evidence-based interventions
Primary	Essential newborn care	Immediate newborn care (thorough drying, skin-to-skin contact of the newborn with the mother, delayed cord clamping, hygienic cord care); neonatal resuscitation (for those who need it); early initiation and support for exclusive breastfeeding; routine care (Vitamin K, eye care and vaccinations, weighing and clinical examinations); prevention of mother-to-child transmission of HIV; assessment, management and referral of bacterial infections, jaundice and diarrhoea, feeding problems, birth defects and other problems; pre-discharge advice on mother and baby care and follow-up.
Secondary	Special newborn care	Thermal care; comfort and pain management; kangaroo mother care; assisted feeding for optimal nutrition (cup feeding and nasogastric feeding); safe administration of oxygen; prevention of apnoea; detection and management of neonatal infection; detection and management of hypoglycaemia, jaundice, anaemia and neonatal encephalopathy; seizure management; safe administration of intravenous fluids; detection and referral management of birth defects. <i>Transition to intensive care:</i> continuous positive airway pressure; exchange transfusion; detection and management of necrotizing enterocolitis (NEC); specialized follow-up of infants at high risk (including preterm).
Tertiary	Intensive newborn care	Advanced feeding support (e.g. parenteral nutrition); mechanical/assisted ventilation, including intubation; screening and treatment for retinopathy of prematurity; surfactant treatment; investigation and management of birth defects; paediatric surgery; genetic services.

should be a priority for governments. The principles of family-centred care should be included in this health-care training. This will enable health workers to partner proactively with family members from the beginning of the inpatient experience and help build their confidence and skills to continue care after discharge (11).

It is imperative to enhance the linkages between maternity and neonatal services. This should include linking essential newborn care and resuscitation with early initiation of breastfeeding, and emergency obstetric and newborn care with the identification of small and sick newborns and their immediate care.

The power of parents

Family-centred care empowers parents by involving them in caregiving for their newborn. It promotes a mutually beneficial partnership among parents, families and health-care providers to support health-care planning, delivery, and evaluation (12). Strengthening parent skills and competence in caring for their small, sick or high-risk infant reduces stress and anxiety, and benefits the newborn's weight gain and neurodevelopmental progress. Parental skills continue to grow after discharge with the support of in-home visits, outpatient services and ongoing education. Mothers, fathers, families and communities can become powerful agents of change when they harness their passion and commitment positively to influence policies and programmes related to newborn health.

Ensure they thrive

The Nurturing Care Framework for Early Childhood Development, launched by WHO, UNICEF and the World Bank Group, demonstrates that focusing on early childhood development is one of the wisest investments a country can make to boost economic growth (13).

Optimal early childhood development requires attention during the period from pregnancy to 3 years of age. During the first month of life, the brain is highly vulnerable to birth and postnatal complications. Infants who are born small or sick are at risk of disability and poor development and require extra attention to promote optimal development. When a newborn is separated from the mother, father or caregiver, there can be further adverse effects on brain development.

Disabilities can be prevented or mitigated with good-quality, developmentally supportive care. As more small and sick newborns survive, due to increased access to services, countries may experience higher rates of disability due to compromised quality of care.

At-risk newborns require vigilant follow-up to thrive. It is vital to screen and monitor the health and development of children who were born small and sick to identify developmental delays and disability, such as cerebral palsy, retinopathy of prematurity (a leading cause of

preventable childhood blindness), auditory and visual impairments and other developmental delays. It is important to identify potential issues early, so that they can be more effectively addressed and mitigated (14, 15).

Use data for action

Existing data for small and sick newborns can be used to drive action, while efforts are made to improve data quality, availability and use. Numerous opportunities exist to improve metrics and highlight the unmet needs of these newborns. New data have recently become available due to the increasing number of births in health facilities. These can be included both in national health information and management systems, thereby improving birth and death registration (16–18).

Strong data and information systems are vital to improving survival rates and supporting healthy childhood development. To achieve the SDG target and end preventable deaths by 2030, countries must transform measurement to end preventable death by 2030; enhance small and sick newborn care in all settings; and ensure long-term health and well-being. The high-priority data gaps to close

are routine measurement of coverage and quality of care – including the care experience – and how to follow-up and measure long-term outcomes for at-risk newborns. For continuous quality improvement, countries need to collect, monitor, share and evaluate data on small and sick newborns. Only then can decision-makers guide investments and drive action for better outcomes for newborn survival and development.

Innovate and research to accelerate change

Investing in research and development is critical to support the design, testing and scaling-up of new and innovative care approaches. Examples of low-cost products and technologies that could positively impact survival rates in LMICs include bubble continuous positive airway pressure (bubble CPAP) and point-of-service diagnostic tools (19). Facilities can also benefit from ground-breaking process improvements, such as task-shifting roles or applying ergonomic principles to unit set-up. Some innovative partnerships have advanced the rapid roll-out of health interventions, such as the Helping Babies Breathe global public–private partnership.³

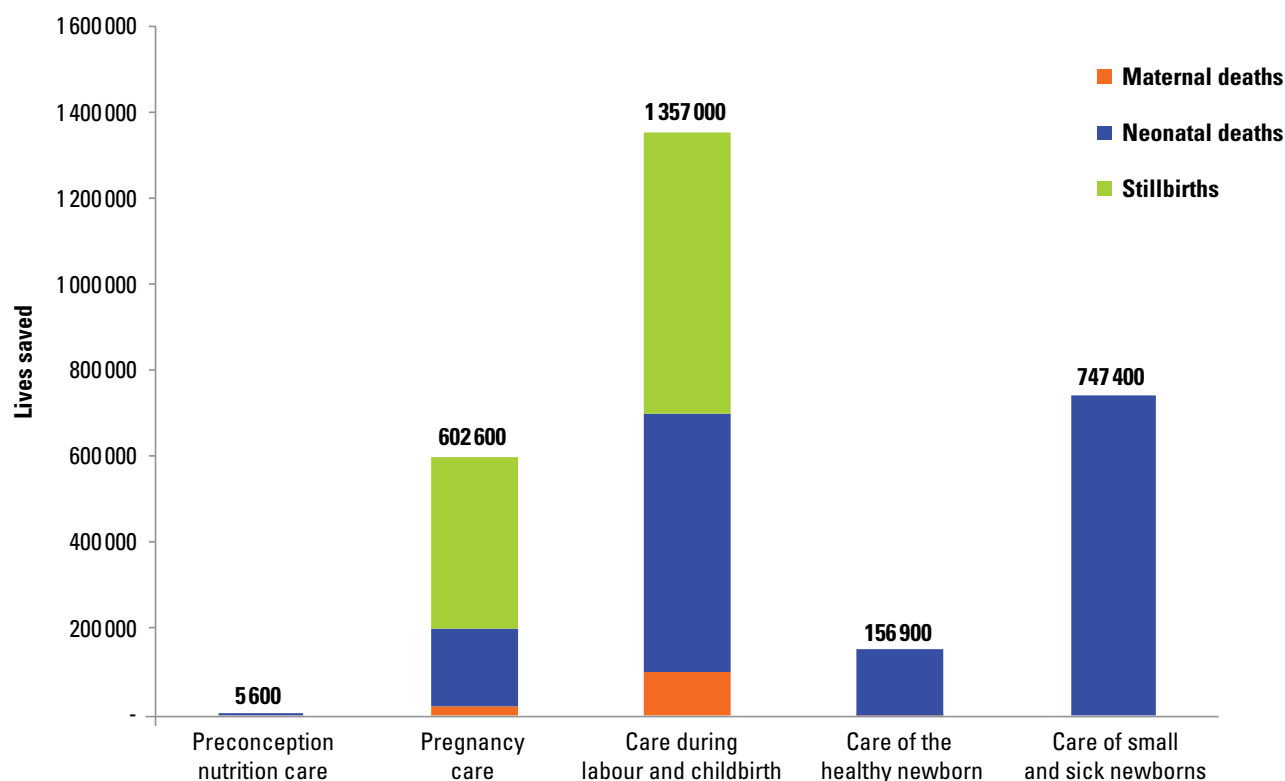
Robust research should be scaled-up to address knowledge gaps specific to certain settings and topics. The vast



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3 See: <https://www.healthynewbornnetwork.org/partner/helping-babies-breathe/>.

Fig. ES.2 Estimated effect of scaling-up interventions on maternal and neonatal deaths and stillbirths by 2030, from a 2016 baseline



Adapted from: Bhutta et al. 2014. Can available interventions end preventable deaths in mothers, newborn babies, and stillbirths, and at what cost? (2).

majority of research on care for small and sick newborns comes from high- and upper-middle-income settings, and requires testing and adaptation to low-resource contexts. Having context-specific data and evidence for intervention effectiveness will provide insights into, and validation of, true needs and environmental nuances (20).

Now is the time to act: 1.7 million newborns can be saved each year

By scaling-up a comprehensive set of interventions along a continuum of care shown in Fig. ES.2 – from preconception nutritional care, to care of small and sick newborns – the annual number of neonatal, stillbirth and maternal deaths could be reduced by an estimated 2.9 million in 81 high-burden countries by 2030. Of these, 1.7 million would be neonatal deaths, or 68% of mortality. Nearly half of the total number of neonatal lives saved (747 400 newborns per year) would result from providing specific interventions for small and sick newborns (i.e. high coverage of quality special and intensive care).

Cost of care for small and sick newborns and return on investment

An increased access to quality inpatient care for small and sick newborns does not need to be prohibitively expensive or out of reach for countries with less-developed health systems.

As shown in Table ES.2, the annual incremental cost of scaling-up the package specifically for inpatient care of small and sick newborns between 2016 and 2025 is estimated at US\$ 959.3 million (US\$ 0.20 per person and US\$ 1700 per newborn death averted).

By investing in the health and development of the next generation, countries can build human capital and accelerate economic development. A healthy start is particularly important for LMICs wanting to capitalize on the demographic dividends of young people for the next generation and national prosperity.

Table ES.2 Incremental cost of the scale-up plan for the year 2025

	Annual costs in 2025 (US\$ million)				
	Capital costs	Drug and supply costs	Workforce costs	Other recurrent costs	Total costs
Comprehensive package*	1 187.3	2 115.5	1 995.3	347 301.0	5 645.3
Care of the small and sick neonatal package	423.8	88.7	335.1	111.7	959.3

* Total package includes preconception nutrition care, antenatal care, care during labour and childbirth, immediate neonatal care, care of the healthy neonate and care of the small and sick neonate.

Table adapted from: Bhutta et al. 2014 (21).

Strategic goals and objectives

The Every Newborn Action Plan set out concrete goals for the years 2025 and 2030 regarding newborn mortality in general and care for small and sick newborns specifically (2):

- **End preventable newborn deaths:** By 2030, in line with SDG 3.2, all countries will reach the target of 12 newborn deaths or fewer per 1000 live births and continue to reduce death and disability, ensuring that no newborn is left behind.
- **Care for small and sick newborns:** By 2025, at least 75% of newborns will be resuscitated if needed; will receive kangaroo mother care (KMC) and other supportive care; and will receive antibiotic therapy if needed. In addition, country-specific targets will be set for comprehensive neonatal intensive care.

To achieve the vision and goals set out in the Every Newborn Action Plan, there needs to be greater focus and attention on transforming care for small and sick newborns. The five strategic objectives from the Every Newborn Action Plan have been adapted for this new, crucial frontier (2):

STRATEGIC OBJECTIVE 1: Strengthen and invest in care around the time of birth, and care for small and sick newborns

In addition to focusing on improved care during labour, birth and the first day and week of life, there must be a focus on expanding access to care and improving quality of care for small and sick newborns. Many deaths and complications can be prevented by ensuring access to high-quality essential care for every mother and

newborn. The SDG 3 target to end preventable newborn mortality will not be achieved if resources and attention are not redirected to improve access to special and intensive neonatal care.

STRATEGIC OBJECTIVE 2: Improve the quality of maternal and newborn care

There is substantial variation in the quality of care for women and children. High-quality care, including high-impact, cost effective interventions are crucial to ensure newborn survival, but also to minimize disabilities and ensure that newborns develop healthily and go on to thrive.

STRATEGIC OBJECTIVE 3: Reach every woman and newborn to reduce inequities

Access to high-quality health care without financial hardship is a human right. Protecting and promoting this right, particularly for the most vulnerable newborns, including those in humanitarian settings, must be a priority. Robust evidence is available on promoting equitable care and ending preventable newborn deaths. Applying this evidence in accordance with the principles of UHC, and using innovative approaches to reach vulnerable groups, can accelerate progress towards equitable coverage of life-saving care.

STRATEGIC OBJECTIVE 4: Harness the power of parents, families and communities

A family-centred approach, where small and sick newborns are the focus of care, requires parents and families to be actively engaged and empowered during hospitalization, at home post-discharge and in the community. Education and empowerment of parents, families and communities to demand quality care, engage meaningfully in that care and improve follow-up care practices are crucial.

STRATEGIC OBJECTIVE 5: Count and track every small and sick newborn

Data and metrics enable managers to monitor progress and take action to improve results. The availability of standardized indicators to monitor expenditures and outcomes is key to promoting accountability. There is a need for accurate, reliable data to facilitate planning efforts and to measure quality, outcomes and the impact of interventions and programmes.

The path to 2030

If appropriate action is taken globally, small and sick newborns can, and will, survive and thrive as future productive members of society. With strategic partnerships, technologies and innovative approaches, the international community can transform all aspects of neonatal care, from its availability and quality to its uptake and affordability.

This requires all stakeholders working together (including governments and partners, competent health-care



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professionals, professional associations, private sector organizations, researchers, empowered parents, and engaged communities) to expand coverage of maternal and neonatal services and to enhance impact through a family-centred approach to inpatient newborn care. Everyone has a role to play in ensuring a thriving next generation.

A PARENT'S STORY

A preterm boy survives and thrives in South Africa

Six months into her pregnancy, Tasmin Bota started bleeding. She went to the closest hospital to rest. A day later, "I was woken up by a gush of blood. The doctors said: 'We need to take this baby out right now.' They did an emergency caesarean section," she recalled.



"It takes a village, and we had a village." Tasmin, pictured with her son Jayceon

Tasmin's son Jayceon was born at 28 weeks' gestation, weighing 1080 g. "It was a total shock. He was skin and bones," Tasmin remembered. "In my mind, I was saying that 'there is no way that someone this small can survive!'"

Jayceon lived 54 days in the hospital. He spent the first week on a ventilator, moving to continuous positive airway pressure (CPAP) until he was able to breathe

independently. Also, Jayceon was treated for jaundice and a mild heart defect (patent ductus arteriosus).

Tasmin spent time in the KMC ward, which she found "tremendously helpful because I cared for him for 48 hours all day and night," which helped her "feel more prepared".

After discharge, Jayceon received medical and developmental follow-up, including physical, occupational and speech therapies. Despite some mild physical delays, the 17-month-old Jayceon is thriving.

Tasmin wishes that there were "psychologists available for parents to speak to in the hospital because it really is a traumatic experience". This need inspired Tasmin to create a Facebook group called Premie Connect, which is a growing resource for other South African families learning to care for their preterm babies.

REFERENCES

1. EWEC. The global strategy for women's, children's and adolescents' health (2016–2030). New York: Every Woman Every Child; 2015.
2. UNICEF, WHO. Every newborn: an action plan to end preventable deaths. Geneva: World Health Organization; 2014 (http://www.who.int/maternal_child_adolescent/newborns/every-newborn/en/, accessed 21 February 2019).
3. UN IGME. Levels & trends in child mortality: report 2018. Estimates developed by the United Nations inter-agency group for child mortality estimation (UN IGME). New York: United Nations Children's Fund; 2018.
4. Lawn JE, Blencowe H, Oza S, You D, Lee AC, Waiswa P, et al. Every newborn: progress, priorities, and potential beyond survival. *Lancet*. 2014;384(9938): 189–205.
5. Moxon SG, Lawn JE, Dickson KE, Simen-Kapeu A, Gupta G, Deorari A, et al. Inpatient care of small and sick newborns: a multi-country analysis of health system bottlenecks and potential solutions. *BMC Pregnancy Childbirth*. 2015;15 Suppl 2:S7.
6. Convention on the Rights of the Child. New York: United Nations; 1989 A/RES/44/25 (<https://www.un.org/documents/ga/res/44/a44r025.htm>, accessed 9 May 2019).
7. UN DESA. Sustainable Development Goals. United Nations Department of Economic and Social Affairs: 2015 (<https://sustainabledevelopment.un.org/topics/sustainabledevelopmentgoals>, accessed 21 February 2019).
8. Inter-agency Working Group on Reproductive Health in Crisis. Newborn health in humanitarian settings field guide. New York: UNICEF and Save the Children; 2017.
9. WHO. Framework on integrated people-centred health services. Report by the secretariat. A67/39. Provisional agenda item 16.1. 15 April 2016. Geneva: World Health Organization; 2016.
10. Gooding JS, Cooper LG, Blaine BA, Franck LS, Howse JL, Berns SD. Family support and family centered care in the neonatal intensive care unit: origins, advances, impact. *Semin Perinatol*. 2011;35:20–28.
11. Moxon SG, Guenther T, Gabrysch S, Enweronu-Laryea C, Ram PK, Niermeyer S, et al. Service readiness for inpatient care of small and sick newborns: what do we need and what can we measure now? *J Glob Health*. 2018;8(1):010702.
12. O'Brien K, Robson K, Bracht M, Cruz M, Lui K, Alvaro R, et al. Effectiveness of family integrated care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial. *Lancet Child & Adolesc Health*. 2018;2(4):245–54.
13. WHO, UNICEF, World Bank Group. Nurturing care for early childhood development: a framework for helping children survive and thrive to transform health and human potential. Geneva: World Health Organization; 2018 (<https://apps.who.int/iris/handle/10665/272603>, accessed 22 November 2018).
14. Purdy IB, Craig JW, Zeanah P. NICU discharge planning and beyond: recommendations for parent psychosocial support. *J Perinatol*. 2015;35 (Suppl 1):S24–28.
15. AHRQ. Transitioning newborns from NICU to home. (Content last reviewed December 2013). Agency for Healthcare Research and Quality (AHRQ) (http://www.ahrq.gov/professionals/systems/hospital/nicu_toolkit/index.html, accessed 21 February 2019).
16. Moxon SG, Ruysen H, Kerber KJ, Amouzou A, Fournier S, Grove J, et al. Count every newborn; a measurement improvement roadmap for coverage data. *BMC Pregnancy Childbirth*. 2015;15 (Suppl 2):S8.
17. WHO. WHO technical consultation on newborn health indicators: every newborn action plan metrics: Ferney Voltaire, France, 3–5 December 2014. Geneva: World Health Organization; 2015.
18. WHO, UNICEF, LSHTM. Every newborn metrics report cards. The Healthy Newborn Network. Published 2017 (<https://www.healthynewbornnetwork.org/resource/enap-metrics-cards/>, accessed 4 March 2019).
19. Kawaza K, Machen HE, Brown J, Mwanza Z, Iniguez S, Gest A, et al. Efficacy of a low-cost bubble CPAP system in treatment of respiratory distress in a neonatal ward in Malawi. *PLoS One*. 2014;9(1):e86327.
20. Herrick T, Harner-Jay C, Shaffer C, Zwisler G, Digre P, Batson A. Modeling the potential impact of emerging innovations on achievement of Sustainable Development Goals related to maternal, newborn, and child health. *Cost Eff Resour Alloc*. 2017;15:12.
21. Bhutta ZA, Das JK, Bahl R, Lawn JE, Salam RA, Paul VK, et al. Can available interventions end preventable deaths in mothers, newborn babies, and stillbirths, and at what cost? *Lancet*. 2014;384(9940):347-70.



Now is the time to transform care for newborns

KEY MESSAGES

- **Every newborn has the right to survive and thrive.** The SDGs and the United Nations Convention on the Rights of the Child guarantee that all children have the right to survive and thrive. This includes the most vulnerable small and sick newborns living in marginalized populations and humanitarian settings.
- **Meeting global targets for the survival of newborns and children aged under 5 years requires adding special and intensive levels of care to well-established obstetric and essential newborn health services.** History shows that “classic” public health approaches must be supplemented by offering individualized obstetric care and essential newborn care on a wide scale. With these as a foundation, additional progress can be made by adding special and intensive care for sick newborns to the overall continuum of care.
- **People-centred care offers proven benefits for newborns, as well as for parents, families and health workers.** The survival and well-being of vulnerable newborns is best served by partnerships between parents, health-care professionals and communities. Family-centred care for small and sick newborns has demonstrated benefits for infants, their parents, and society.



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Every year, more than 30 million newborns globally face life-threatening conditions that require hospital care. Everything that happens to them in hospital matters. It increases their chances of survival, influences their brain development, and can affect their entire life course.

Low-birth-weight (LBW), prematurity, congenital defects and illness can lead to death, acute or chronic diseases, and poor development if newborns do not receive the care they need. Conversely, those who receive nurturing care have a better chance of growing into healthy children and adolescents, and maturing into thriving and productive adults. How can the needs of small and sick newborns be met in this way? How can parents and families be adequately supported during the early critical days and beyond?

This report advances the agenda of the Every Newborn Action Plan, endorsed by 194 Member States at the Sixty-seventh World Health Assembly in 2014 (1). It supports the targets of SDG 3 on health, focusing on the small and sick newborn. It also builds on the Global Strategy for Women's, Children's and Adolescents' Health (2016–2030) (2).

The slow rate of decline in newborn deaths compared with the decline of overall child mortality is one of the most concerning disparities in global health. Mortality among children under the age of 5 years (under-5 mortality) fell 60% during 2000–2017 compared with a 41% drop in mortality among newborns. In the same period, mortality among

infants aged 1–11 months (postneonatal period) declined by 51%. This lopsided progress means that almost half of all under-5 deaths (47%) now occur in the first 28 days after birth (neonatal period) (3). Since its launch in 2014, the Every Newborn Action Plan has emphasized the need to address this disparity by improving access to quality care during childbirth and for small and sick newborns.

The Nurturing Care Framework for Early Childhood Development, launched at the Seventy-first World Health Assembly, shows that focusing on early childhood development is one of the wisest investments a country can make to improve people's lives and boost economic growth (4). During the first month of life, the brain is highly vulnerable to intrapartum and postnatal complications, with further adverse neurodevelopmental effects when the newborn is separated from the mother, father or caregiver. People who receive quality health care that is developmentally appropriate during pregnancy, at birth and in the first months and years will benefit throughout life.

Improving the life chances of those who are born too soon, too small and too sick will help to achieve the SDG 3 target of no more than 12 newborn deaths per 1000 live births by 2030. Most newborns can survive and thrive with access to quality care, but that will require a sustained focus on transforming care in ways that will make a difference for them and their families.

This report offers promising solutions to mobilize constituencies capable of giving voice to the most

vulnerable and fragile citizens and their parents and families. It also includes a call to all stakeholders at the global, regional, national and community levels to intensify their efforts and invest their resources. Furthermore, it proposes specific steps to realize the vision of the SDGs.

To end preventable newborn and child deaths, care for small and sick newborns requires investments in quality, nurturing and responsive health care designed to prevent disabilities, support cognitive function, promote early childhood development and reduce stunted growth. Achieving these goals will mitigate intergenerational poverty and strengthen each nation's human capital.

Action must be taken now to save more than 1.7 million newborns each year.

Who are the most vulnerable newborns?

From a clinical perspective, newborns who are born too soon (< 37 weeks' gestation), too small (< 2500 g birth weight), or acutely ill are most at risk of death (5). From a public health perspective, newborns most likely to die include those born small and sick in the most marginalized groups, rural areas, urban slum environments and humanitarian settings. Added susceptibility may result from factors such as poverty, ethnicity, gender bias, maternal age and educational status, disability, and low literacy of the caregiver.

Newborns who are born too soon, too small or acutely ill are most at risk of death. Social, economic, gender and geographic disparities can worsen the situation.

While the focus on small and sick newborns is a global imperative spanning high-, middle- and low-income countries, vulnerability is most acute in low- and middle-income countries (LMICs), where health systems face specific challenges (6). As a result, a combination of biological, social, environmental and health system factors subject the population in LMICs to even more life-threatening risks. Delivering inpatient care for small and sick newborns is often a challenge in health systems located in LMICs – and even more so in humanitarian settings (see Box 1.1), urban slums and remote rural areas (7).

To address the needs of small and sick newborns and optimize their chances to survive and thrive, health systems must be strengthened and transformed at every level. This must be accompanied by the transformation of social, economic and legal institutions.

Visionary strategies and frameworks

With appropriate care, a large proportion of small and sick newborns could survive and thrive without major complications – but only when health system gaps are addressed. Functional health systems are required for the

Box 1.1 Conflict and disaster: a special note on humanitarian settings

According to the Interagency Working Group on Reproductive Health in Crises, a humanitarian setting is one in which “an event or series of events has resulted in a critical threat to the health, safety, security or well-being of a community or other large group of people. The coping capacity of the affected community is overwhelmed and external assistance is required. This can be the result of events such as armed conflicts, natural disasters, epidemics or famine, and often involves population displacement”.*

Periods of conflict or natural disasters can greatly disrupt health systems and the work of health-care providers. The long-term effects can be particularly serious in low-resource settings where health systems

may already have been weak before the onset of crisis. In such settings, pregnant women are often at increased risk of poor outcomes related to unassisted childbirth. Those who have recently given birth must overcome immense obstacles to provide care and safety for themselves and their children. At the same time, women's vulnerability to malnutrition, sexual violence and unplanned pregnancy increases. Due to the lack of data, however, the true burden is unknown.

To achieve the targets of SDG 3, organizations working in humanitarian settings will need to integrate care for small and sick newborns and their parents into every programme and package designed to reach the most vulnerable.

* IAWG, Inter-agency field manual on reproductive health in humanitarian settings (7).

(provision of quality inpatient care for small and sick newborns, just as they are for essential childbirth and newborn care and emergency obstetric care. While many countries have shown the political will to overcome challenges, a number of misconceptions that restrict the use of lifesaving interventions persist (Box 1.6 at end of chapter).

Considerable strides have been made to improve maternal and newborn health during the last two decades as a direct result of key global initiatives. Chief among these are the global Safe Motherhood Initiative, the Millennium Development Goals (MDGs), and the Sustainable Development Goals (SDGs). The Every Newborn Action Plan and the Global Strategy for Women's, Children's and Adolescents' Health provide frameworks for action and are guided by the Convention on the Rights of the Child (CRC), the principles of universal health coverage (UHC), the WHO Framework on integrated people-centred health services, and the "continuum of care" concept. This report specifically connects these visionary strategies and frameworks to the mission of improving care for small and sick newborns. The following sections provide a contextual overview for each.

The SDG link

In 2014, the Every Newborn Action Plan set newborn mortality and stillbirth reduction targets for 2030, with clear milestones (1). Reducing the neonatal mortality rate (NMR) is one of the targets within SDG 3, and reducing both neonatal mortality and stillbirth rates is included in the Global Strategy for Women's, Children's and Adolescents' Health (2). Emphasis remains on ending preventable child deaths while prioritizing the period from pregnancy to 3 years of age as being critical in early childhood development (4).

Fig. 1.1 maps the 17 SDGs to newborn care to show its important links to broader development issues. The mapping reveals a strong connection to 14 targets within eight SDGs. Goals 1–6 have direct links to newborn care.

Every newborn's rights

The CRC ensures that newborn health is a human rights issue (8). According to Article 24 of the CRC, all children have a right to the highest attainable standard of health and health care, and WHO Member States have an obligation to reduce infant and child mortality. In its authoritative interpretation of Article 24, the Committee on the Rights of the Child "urges particular attention to neonatal mortality, which constitutes an increasing proportion of under-5 mortality" (9). The United Nations Human Rights Council's resolution affirmed the importance of applying

a human rights-based approach to prevent maternal and child mortality and morbidity. It urges Member States to renew their political commitment and act to address the main causes of mortality and morbidity. In addition, the Council has welcomed the preparation of technical guidance on how to apply a human rights-based approach to policies and programmes aimed at reducing and eliminating preventable maternal and child mortality, and which introduces practical steps for integration of human rights standards in efforts to address neonatal mortality.

Professional associations and expert bodies have further defined and described these rights in several other instruments (10, 11). All recognize that newborns have fundamental rights and freedoms, as stipulated in international law. These include the rights to survival, health and development; to a legal identity from birth; to be protected from harm, violence and neglect; and to a caring, loving and nurturing environment – even in humanitarian and fragile settings.

The CRC provides a useful starting point to consider a newborn's legal rights. Governments should translate these rights into domestic laws and regulations, and incorporate them into protocols and guidelines for newborn care. Targeted advocacy and policy efforts, along with engaged and empowered parents' organizations, health professional associations, and civil society organizations, are needed to enforce these legal rights at national and subnational levels.

Universal health coverage

Universal health coverage is a global imperative for achieving the SDGs. The underlying principle is that everyone should have access to the health services they need without facing financial hardship (12). For this report, the UHC ambition is that every newborn everywhere should have access to good-quality respectful health care without financial hardship for the parents and families. This includes universal access to midwifery care, essential newborn care, obstetric care for maternal and perinatal complications, and inpatient care for small and sick newborns – with the promise of quality health services throughout their life course. To ensure UHC, strong partnerships are required between and among parents, health-care professionals, political and civil leaders, and communities.

Integrated people-centred health services

Adopted at the Sixty-ninth World Health Assembly in 2016, the Framework on integrated people-centred health services proposes five interdependent strategies for more

Fig. 1.1

The SDGs:

unlocking human potential and well-being for small and sick newborns

SDG 17 PARTNERSHIPS FOR THE GOALS

Multistakeholder global partnerships on maternal and newborn health is needed to support governments to achieve national SDG targets. Coordinating support and sharing knowledge, technology and financial resources are also essential.

SDG 16 PEACE, JUSTICE AND STRONG INSTITUTIONS

The births of about 25% of children under 5 globally have never been registered.

Registration at birth is a human right. It is the first step in securing a child's recognition before the law, safeguarding their rights and ensuring that any violation of these rights does not go unnoticed.

SDG 15 LIFE ON LAND

Producers sourcing food from land-based food systems should consider the unique needs of mothers and newborns.

SDG 14 LIFE BELOW WATER

Producers sourcing food from the oceans should consider the unique needs of mothers and newborns.

SDG 13 CLIMATE ACTION

Severe climatic events and natural disasters threaten the health and safety of newborns. Their families and communities should prepare for these events and ensure they are resilient and able to adapt. At country level, emergency preparedness should include ensuring strong policies and guidelines are in place for delivery of health services in the aftermath of extreme weather events to ensure mothers and newborns receive the care they need.

SDG 12 RESPONSIBLE CONSUMPTION AND PRODUCTION

A well-nourished mother with a secure, sustainable source of food has a better chance of delivering a healthy newborn, who will in turn have better chances of survival.

SDG 11 SUSTAINABLE CITIES AND COMMUNITIES

Poor living conditions in urban slums make newborns highly vulnerable to environmental hazards and infection, especially given the rise in the number of women and displaced populations living in urban settings.

SDG 10 REDUCED INEQUALITIES

Inequalities compound vulnerability for small and sick newborns, particularly where health systems and lifesaving services are challenged.

SDG 9 INDUSTRY, INNOVATION AND INFRASTRUCTURE

Innovation is key to improving care for small and sick newborns because it delivers new lifesaving technologies and more effective care.

Investments in good infrastructure are essential to accelerate progress for newborn health. This includes health facilities able to provide care without separating newborns from their parents, and adequate roads that enable pregnant women to travel quickly and easily to health facilities. Ease of travel is especially important for women who live in marginalized communities, such as remote rural areas, urban slums and humanitarian settings.



Sources: Nurturing Care Framework (4), March of Dimes, PMNCH, Save the Children, WHO. Born too soon: the global action report on preterm birth (13), UNICEF Joint Malnutrition estimates (14), UNICEF data: monitoring the situation of children and women (15).

SDG 1 NO POVERTY

250 million children under the age of 5 in LMICs are at greater risk of not reaching their development potential due to poverty and neglect.

Investments in maternal and newborn health are the cornerstone of lifelong health and potential. They can help to eliminate intergenerational poverty at the individual, family and community levels.

SDG 2 ZERO HUNGER

151 million children under 5 years are stunted and 273 million are anaemic, robbing these children of cognitive potential.

Optimal nutrition for pregnant women and their newborns, including during times of illness and hospitalization, is key to promoting survival, ending stunting and wasting and reducing the burden of anaemia in women and children.

SDG 3 GOOD HEALTH AND WELL-BEING

47% of under-5 deaths are newborns, and an estimated 80% of these deaths in Southern Asia and sub-Saharan Africa are among small newborns.

Under-5 and newborn survival targets can only be met by transforming care for small and sick newborns.

A healthy pregnancy and start in life, especially the prevention of LBW, supports the prevention of noncommunicable diseases throughout the life course.

Survival, well-being and development of small and sick newborns requires access to quality and affordable maternity and neonatal health services and medical technologies as part of UHC.

Pollution contamination is a proven risk to the health of developing newborns; exposure to cigarette smoking, second-hand smoke and indoor air pollution increases the risk of preterm birth, LBW and spontaneous abortion.

Health-care providers often lack the competencies, support and remuneration required to provide appropriate care for small and sick newborns.

SDG 4 QUALITY EDUCATION

Every year, 30 million newborns require hospital care to thrive and survive.

A child's early environment and experiences have a direct and long-term impact on the way the brain is structured, and lay the foundation for health, learning, productivity and well-being throughout a person's life. A healthy start from pregnancy through childbirth and the first months after birth is essential, including detection of problems for early intervention to prevent long-term disabilities. Investments are needed in areas such as brain development to help newborns realize their full cognitive potential later in life.

SDG 5 GENDER EQUALITY

Newborn boys have greater biological risk of death, whereas newborn girls have greater social risk of death due to cultural norms affecting access to quality care.

Small and sick newborns are fatally vulnerable to gender inequality.

SDG 6 CLEAN WATER AND SANITATION

Infections, including sepsis, meningitis, pneumonia, diarrhoea and tetanus, cause 23% of newborn deaths.

Clean water and good sanitation in health facilities are essential for safe, dignified maternal and newborn care.

SDG 7 AFFORDABLE AND CLEAN ENERGY

Without affordable, sustainable and reliable modern energy, basic lifesaving technologies for the care of small and sick newborns cannot function.

SDG 8 DECENT WORK AND ECONOMIC GROWTH

Education and employment of parents are strong determinants of newborn health. In turn, investments in newborn health improve human health and increase the potential for long-term economic growth.



integrated and people-centred care. The five strategies are: empowering and engaging people and communities; strengthening governance and accountability; reorienting the model of care; coordinating services within and across sectors; and creating an enabling environment (16).

This framework calls for “reforms to reorient health services, putting individuals, families, caregivers and communities at the centre, supported by responsive services that better meet their needs and respect their preferences, and that are coordinated both within and beyond the health sector, irrespective of country setting or development status” (16). It incorporates UHC principles and a human rights approach to ensure access to health care for all citizens. Notably, the framework recognizes the need to empower and engage informal caregivers, with family members and others who play a critical role in health care (see Fig. 1.2).

Evidence shows that the well-being and survival of both mother and newborn are inextricably linked and require

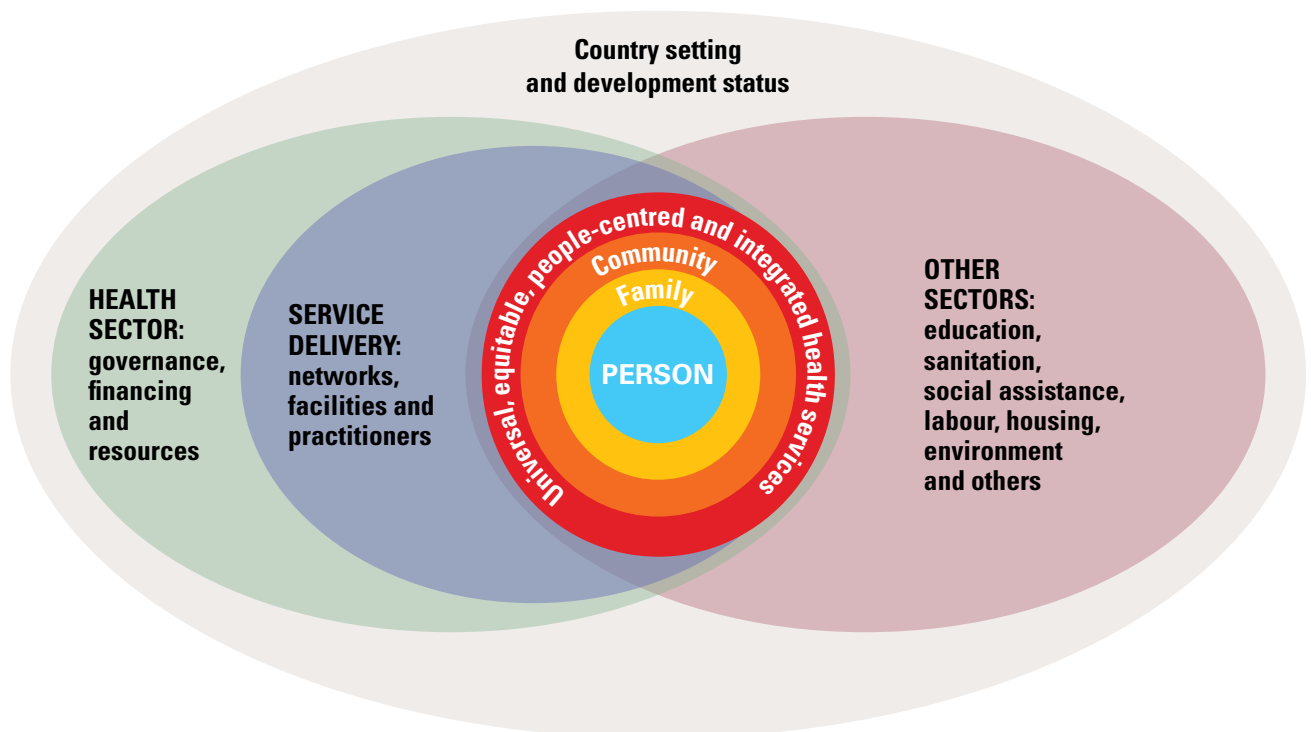
“When my children were born too soon, I experienced an emotional rollercoaster and was struggling with the challenges of preterm birth. A strong partnership between health-care professionals and parents is the best way to face the [challenges] of having a small and sick newborn and to overcome the obstacles.”

Silke Mader, parent, advocate and founder European Foundation for the Care of Newborn Infants

a coordinated, integrated “continuum of care” approach. This not only optimizes their health but also promotes greater efficiency, lowers costs and reduces the duplication of resources (17). If a mother dies, her newborn has an increased risk of hospitalization or even death (18–20).

In this report, the person at the centre is the small and sick newborn who receives treatment by health-care providers, mother, father, other caregivers or a combination. In some cases, both the newborn and the mother may be at the centre of care because they are being treated together or simultaneously. Due to their extreme

Fig. 1.2 Intersecting rings of responsibility within integrated people-centred health services



Source: WHO Framework on integrated people-centred health services (16).

Box 1.2 Family-centred care for newborn health

Family-centred care promotes a mutually beneficial partnership among parents, families and health-care providers for patients of all ages, with an aim to support health-care planning, delivery and evaluation (27, 28).

Most family-centred care efforts for newborn health strive to build upon core concepts from the people-centred care framework. These principles include dignity and respect, information sharing, participation, and collaboration.

Within family-centred care, mothers, fathers or caregivers are active partners in the child's care. The parent and the newborn (in most cases the mother and newborn) are a unit of care which is central to the newborn's well-being and development.

vulnerability and inability to survive or thrive without adult support, newborns depend on a mother, father or other caregiver for protection and nurturing, but other family members may also play an important role. In

some circumstances, such as the case of maternal death or in humanitarian settings, the primary caregiver may be a member of the extended family or someone from outside the family, such as a community member.

Women have a unique role as mothers, but men also have a key role in the care of newborns, as partners/husbands, fathers, caregivers and community members (21, 22). Consequently, for the care of small and sick newborns, an approach that maximizes the role of the parents and family members while the newborn is cared for in the health facility is a relevant application of people-centred care (23–26). This approach, known as family-centred care (Box 1.2), has a growing evidence base in various settings and has demonstrated benefits for infants (such as weight gain and neurodevelopmental progress) as well as decreased parental stress and anxiety and increased caregiving efficacy. Some trials testing comprehensive family-centred approaches have taken place in China (Province of Taiwan), Canada, Australia, the United States of America (USA) and India (Box 1.3) (23, 29–32). Parents can be powerful agents of change, so empowering them through advocacy and support groups and harnessing their passion and commitment can influence policies and the quality of care for newborns (Box 1.4).

Box 1.3 Engaging families in newborn care in India

In 2008, the neonatal intensive care unit (NICU) of Dr Ram Manohar Lohia Hospital, in New Delhi, India, introduced a family engagement programme. Parents were trained in proper handwashing, breastfeeding, assisted feeding and skin-to-skin contact for eligible newborns. They also received guidance on essential newborn care practices and danger signs, and on developmentally supportive care. A randomized controlled trial of the approach documented improved breastfeeding with no increase in hospital-acquired infections or other adverse events (29).

Encouraged by these results, the hospital developed a health education training programme for the families, which included: 1. handwashing skills; importance of infection prevention; protocol for entry to nursery; 2. developmentally supportive care (cleaning, sponging, positioning, nesting, handling and interacting with the newborn; breastfeeding techniques, expression of breastmilk and assisted

feeding); 3. KMC; and 4. preparation for discharge and care at home.

In 2014, with the approval of the Child Health Division, Ministry of Health, Government of India, the hospital collaborated with the Norway–India Partnership Initiative to test the model in five district-level special newborn care units. Based on the study's results, the Ministry led scale-up efforts by issuing a national policy to support family-centred care in all 700 district-based special newborn care units. To date, 85 districts have implemented a family-centred care educational programme reaching more than 13 000 mothers and family members. Of newborns with a birth weight below 2000 g, 86% received KMC and exclusive breastfeeding; 75% continued to receive KMC at home. Post-discharge mortality reduced from 7% to 3%. Now established as a national programme, the family-centred care approach has led to a profound shift in the treatment of sick newborns in India.

Adapted from: Sudan et al. Profile on family participatory care in India (33).

Box 1.4 The power of parent voices

Parents can be powerful agents of change for small and sick newborn care. As they consistently care for their own newborn, they can become “patient experts” with a deep knowledge of health issues. They often observe the newborn’s responses, interact with the health-care team and meet with other parents and parent support groups. Some parents will study their newborn’s condition, engage in health research, and become active with public health and policy advocacy and lobbying. As a result, parents of small and sick newborns are a great asset as advisors to inpatient newborn care units seeking to improve quality, safety and family-centred care.

Historically, parents in the USA, the United Kingdom and Australia have successfully lobbied for family-friendly hospital-wide changes, such as having the right to stay with their children (34). Parents also had a fundamental role in raising awareness among nurses and physicians that even very preterm newborns feel pain (35, 36).

Parent advocacy and support organizations often emerge spontaneously when affected parents decide to raise awareness and share their experiences to help others in the same situation. Groups develop when parents determine that sharing their

experiences with the health system, or in coping with challenges related to their newborn’s care, may empower others. For example, *La Liga de Los Múltiples* (The League of Multiples), a Colombia-based parent organization, was founded by a couple in Bogotá to support parents who have had multiple births, after they had had triplets.

By working with local and regional parent support organizations, health-care providers and facility managers can provide or supplement resources to promote partnerships between parents and health-care teams, and influence policies and practices for affected families.

Support provided by larger, more established groups can nurture new leadership through mentoring and networking at local, national and global levels. One such group, the European Foundation for the Care of Newborn Infants, with membership from more than 50 countries and about 90 organizations, partnered with health professionals and parent representatives to develop the European Standards of Care for Newborn Health project. The French parent group, SOS Préma, established a National Assembly working group for small and sick newborns. This led to a clear policy recommendation that small and sick newborns should receive family-centred care in hospital.

Within the framework on integrated people-centred health services (Fig. 1.2), just beyond the family ring lies the community. This refers to the social network that surrounds the affected family, which may include peer-to-peer support, parent groups, work colleagues, religious institutions, extended family and friends (37). They may provide encouragement, emotional care and practical assistance (e.g. care for other children, prepare food and offer financial assistance). Raising community awareness about care for small and sick newborns can decrease stigmatization, benefit families and improve policies and legislation; this has been demonstrated in some settings such as Malawi (38).

Also noted in Fig. 1.2 are service delivery, the wider health sector, and other sectors. Service delivery includes health facilities with trained staff and equipped with essential commodities and technologies; and a continuous supply of water and electricity to provide high-quality inpatient care for small and sick newborns.

The facility should create a supportive environment for parents and implement family-centred care principles. This includes sleeping-in arrangements and activities to educate parents and build their skills as caregivers for when they return home (see Chapter 3) (39).

Finally, Fig. 1.2 illustrates the complex interplay between families, communities and health-care providers with a broader link to society, policy environments and other sectors. These overlapping influences can either enable or hinder health-care providers and parents in their efforts. Greater alignment is needed across health systems, communities and societal policies to enable and support health-care providers, community health workers and parents to work together successfully to care for small and sick newborns.

The continuum of care

An effective continuum of care for reproductive, maternal, newborn and child health (RMNCH) is needed to

meet the health needs of newborns and children, and of adolescents, women, and men throughout the reproductive years. The continuum must take into account both the time of caregiving – from pregnancy and birth, into the neonatal and postneonatal periods and through childhood and adolescence; and the place of caregiving – households, communities and health facilities (40, 41).

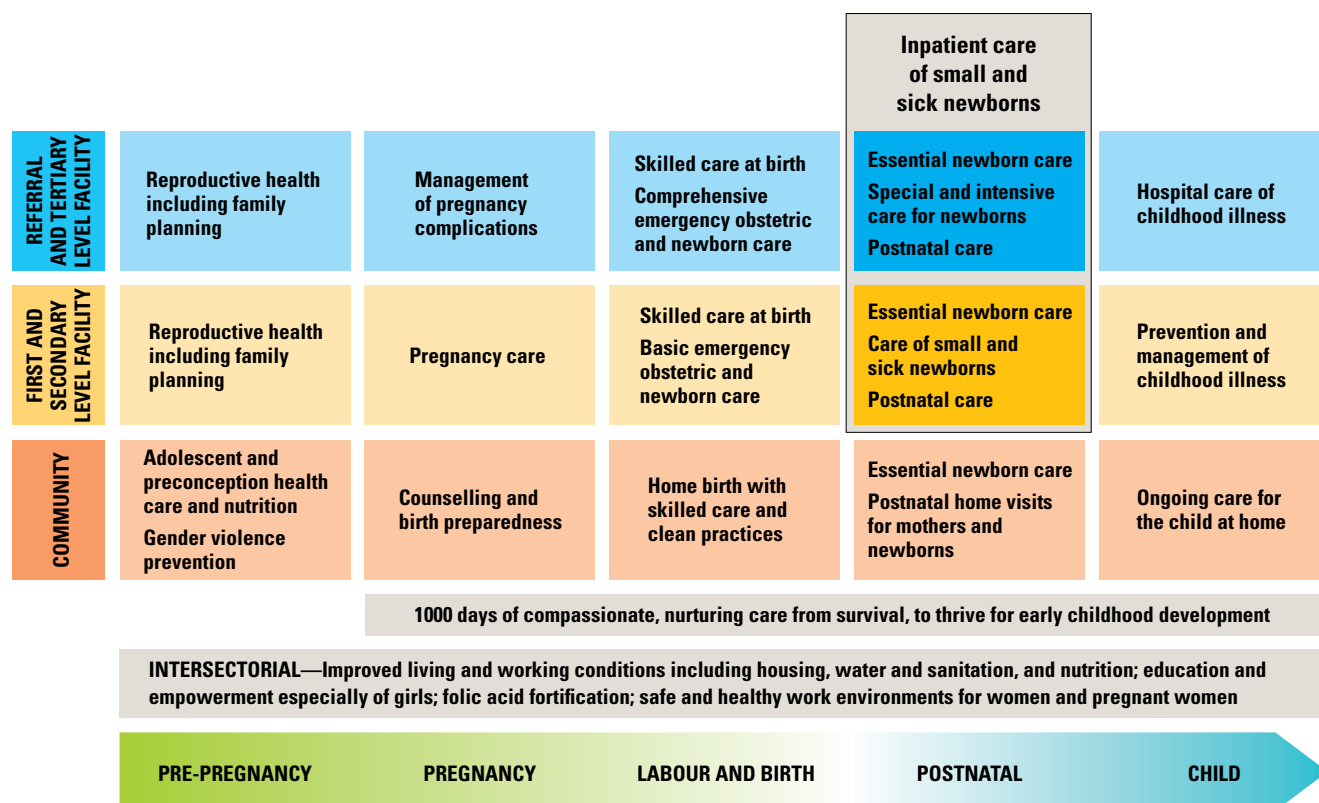
This approach to providing RMNCH services has proven cost effective, including for the prevention and treatment of prematurity (40, 42–45). Interventions with the most benefit for small and sick newborn care can be integrated into health service delivery “packages” at different points in the continuum (40).

Fig. 1.3 presents basic health packages across the continuum at different levels within the health system. It highlights the interventions for inpatient care of small and sick newborns that are the focus of this report. The Every Newborn Action



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Fig. 1.3 How inpatient care for small and sick newborns fits within the continuum of care for women’s and children’s health



Adapted from: Every Newborn Action Plan (1).



Plan applied the continuum of care approach and noted the service delivery packages most likely to end preventable newborn death and stillbirths: care during labour, around birth and the first week of life; and care for the small and sick newborn (1).

The way in which the package of services is delivered is just as important as the content of the package. Among deaths due to poor-quality care and non-utilization of services, deaths from neonatal conditions are second only to cardiovascular disease. An estimated 61% of these neonatal deaths can be averted with good-quality care (46).

If newborns are to thrive as well as survive, programmes are needed to stimulate early

Box 1.5 Historical perspective: How the United Kingdom and the USA reduced neonatal mortality in the past century

In the USA and the United Kingdom, reductions in the NMR occurred through three distinct health-care phases (13).

PHASE 1: Broad public health approaches

From the 1900s to 1940s, high NMRs (40 newborn deaths per 1000 live births) were reduced by approximately 25% through increased handwashing in health facilities and a decline in homebirths without skilled attendants. Health practitioners had limited knowledge of high-impact interventions that are widely promoted today, such as early initiation of breastfeeding, thermal care, and clean cord care. Families, especially women, were responsible for all newborn care in the home (26).

PHASE 2: Improved care in pregnancy, at the time of birth and for newborns

From the 1940s to 1970s, NMRs were further reduced by 50%, with a shift towards the individualized special care of sick newborns. Neonatology became a discipline. Lifesaving interventions, such as oxygen and assisted ventilation, became increasingly available in health facilities. However, the rapid rise of new technologies for such vulnerable children led to problems, such as visual impairment and lung injury, due to overuse of the technology without careful calibration and monitoring. As the hospital environment became more complex in order to improve

survival (e.g. incubators and infection control), parents and newborns became increasingly separated, with parents excluded from caregiving within the hospital (26, 47–49). Separation had adverse consequences, including reduced mother–newborn bonding, the inability to breastfeed, and other physical and emotional issues, such as neglect and abuse (48, 50). By the mid-20th century, these unintended consequences were beginning to be recognized (34, 51). In some countries, reformers have successfully advocated a shift to more parental and family involvement in care and the mitigation of long-term adverse effects (26, 34, 50, 52).

PHASE 3: Special and intensive neonatal care

Between 1970 and 2005, newborn mortality was further reduced in high-income countries by 75%, due to high-quality, individualized, advanced clinical care. Change was underpinned by strong health systems, which included: regulations; policies; financing; human resources; monitoring; measurement; essential technologies and commodities; uninterrupted water and electricity; and the use of patient data to inform quality improvements. From 1980 onward, there was rapid development and promotion of family-centred care as a best practice (26).

childhood development with interventions in the first 1000 days – from pregnancy to 3 years of age (4). Small and sick newborns are at greatest risk of suffering from developmental delays, physical disabilities and poor neurodevelopmental functioning (53). An emerging body of evidence demonstrates that disabilities may be prevented or mitigated with good-quality, developmentally supportive care for small and sick newborns. Parents and family members can serve as important partners in delivering well-timed, consistent and appropriate care with vigilant follow-up of at-risk newborns (see Chapter 4 for details) (54–59).



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Lessons from the past

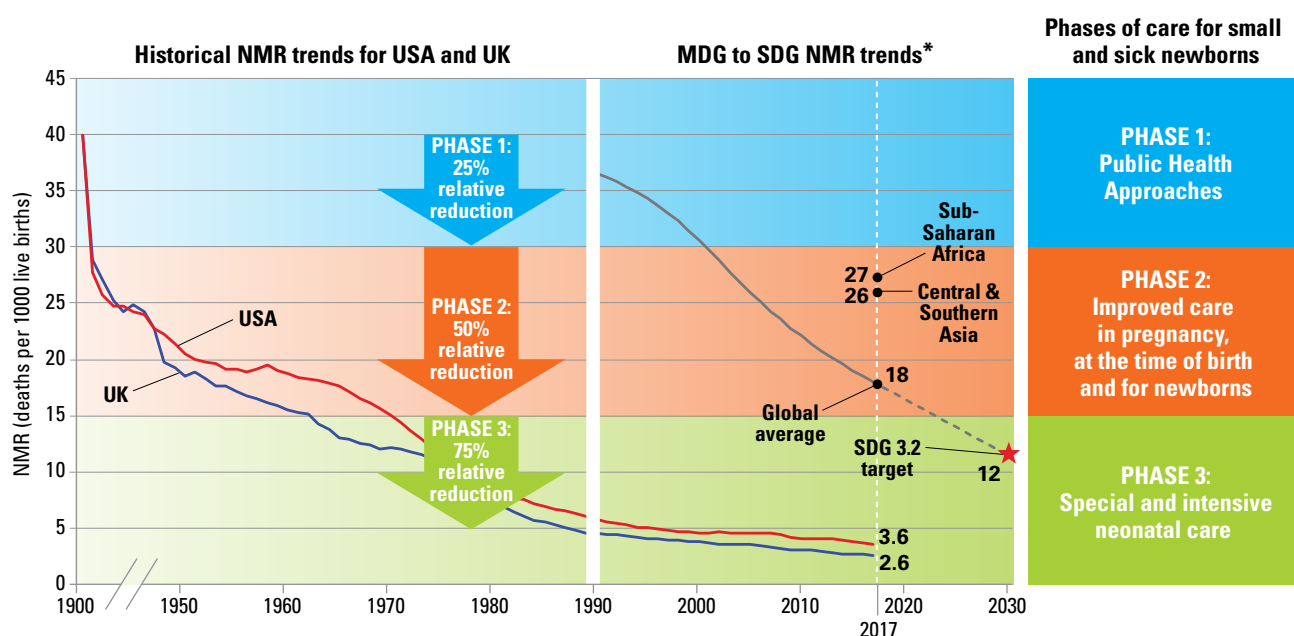
Countries that have substantially reduced newborn deaths can provide guidance for other countries.

The Born Too Soon report shows that the United Kingdom and the USA achieved dramatic declines in NMR in three phases: broad public health approaches; improved care at the time of birth and special neonatal care; and intensive neonatal care (see Box 1.5) (13).

Fig. 1.4 shows the trends in mortality decline for the United Kingdom and the USA as well as the current global trend. Averages for sub-Saharan Africa and Central and Southern Asia are displayed showing how far these regions need to go to meet the SDG target by 2030. Changes across all three phases are required in order to achieve the target.

Progress in reducing NMRs in other high- and middle-income countries followed the same trajectory. However,

Fig. 1.4 Historical and current mortality reductions by phases of care



*SDG 3.2 target: all countries to reduce neonatal mortality to at least as low as 12 per 1000 live births by 2030.

Sources: UN IGME 2017 estimates (3), March of Dimes, PMNCH, Save the Children, WHO. Born too soon: the global action report on preterm birth (13).

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such as the introduction of KMC in Colombia in 1978 and the establishment in 1979 of the mother–infant neonatal unit in Estonia paved the way for facilities globally to adapt and disseminate skin-to-skin contact (52, 61). Changing social expectations in the second half of the 20th century in the USA and Europe led to an increased appreciation of the value of family participation in the care of inpatient newborns. This led to rapid development and promotion of family-centred care in the 1980s and 1990s (26).

it is now well recognized that routine separation places mothers and newborns at risk for medical and developmental complications regardless of setting or level of care (60). For example, promising results by initiatives

Table 1.1 describes the components of care addressed by these successive phases. Today, many countries have implemented these components depending upon which phase they are in. Health policy experts and practitioners should first identify their country’s starting point and priorities, and then determine which lessons can be applied to improve special and intensive care and consider how to integrate a family-centred care approach.

Table 1.1 Components of newborn intervention by phase

Components	PHASE 1	PHASE 2	PHASE 3
Intervention package for newborns	Broad public health approaches (hygiene; breastfeeding; tetanus toxoid immunization; maternal nutrition)	Safe delivery and management of obstetric complications. Essential newborn care (infection prevention; resuscitation; thermal care, including skin-to-skin contact; exclusive breastfeeding and feeding support; vitamin K; eye and cord care; and immunization)	Special and intensive newborn care (thermal care, notably KMC), respiratory support; more advanced feeding support; therapeutic hypothermia; follow-up care for neurodevelopment growth
Health-care providers	Nurses; midwives; physicians; traditional healers; community health workers; lay (family) providers	Skilled nurses; midwives; nurse clinical officers; lactation specialists; physicians; paediatricians	Neonatologists; paediatricians; neonatal nurses; other support staff; multidisciplinary team, including nutritionists; physiotherapists; speech therapists; radiographers; social workers
Parental inclusion	As primary caregivers	Included through “no separation at birth” and family-centred care approaches; parent–newborn as unit of care	Included as the standard approach to delivering small and sick newborn care; parent–newborn as the unit of care

Sources: March of Dimes, PMNCH, Save the Children, WHO. Born too soon: the global action report on preterm birth (13); Maree C, Downes F. Trends in family-centered care in neonatal intensive care (26).

Box 1.6 Myths and facts

Myth: Roll-out of essential newborn care at the current rate will achieve the 2030 SDG target and reduce newborn deaths globally to 12 per 1000 live births.

Fact: Extensive extra measures are needed to achieve the target: effective high coverage of antenatal care; essential childbirth care; essential newborn care; postnatal care; and inpatient care for small and sick newborns. These are needed in all settings, including the most hard-to-reach places such as humanitarian situations, where the burden is highest.

Myth: Effective care of small and sick newborns requires costly, high-tech interventions which are unaffordable in most LMICs. Prevention of preterm birth should be prioritized, as it is more cost-effective than providing special care for small and sick newborns.

Fact: Currently, there are few highly effective ways to prevent preterm births. Promising research efforts are underway to understand prevention further. However, most deaths and disabilities from preterm birth complications can be prevented through highly effective, low-cost interventions, such as breastmilk feeding, KMC and continuous positive airway pressure (CPAP). Special newborn care has a high impact on outcomes and therefore is highly cost-effective.

Myth: To prevent newborn deaths, focus is needed at the community level, not the hospital level.

Fact: Globally, 80% of births now take place in facilities, so strengthening safe and effective facility care is essential. Yet the quality of care in many countries is very poor, with many newborns discharged from hospital too early. Community care is complementary, but is more effective when linked to care in health facilities. This is especially the case when normal community structures are interrupted, such as during a humanitarian crisis.

Myth: Treating small and sick newborns increases the burden of children who survive with disabilities.

Fact: Access to quality treatment for every newborn, including those who are small and sick, is a fundamental human right. Treatment for these newborns prevents both death and disability when



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they experience good-quality care in health facilities, effective post-discharge follow-up, and the early detection and treatment of disabilities.

Myth: Newborn lives have less value and are harder to save, so a better strategy is to save older children first.

Fact: Almost half of child deaths are newborn deaths (47% in 2017) and that proportion is rising (3). Mortality reduction among children aged under 5 years is not possible without tackling newborn deaths. In addition, focusing on newborn health and development now will benefit future generations. A newborn's life and well-being matter immensely to the family, even if they are born small and sick.

Myth: If we allow parents and family members to visit a child in the NICU, they will introduce infections into the unit.

Fact: Engagement of parents and family members in the care of their newborns improves health outcomes; and there is evidence that family-centred care does not increase infections (29). Infection can be prevented with hand hygiene practice and access to human milk.

A PARENT'S STORY

A Ghanaian mother channels her trauma to build an African advocacy organization

King Luther was born at just 31 weeks' gestation. His mother, Selina Bentoom, was having a healthy pregnancy until her waters broke unexpectedly. When she arrived at the private health centre in Accra, an experienced midwife recognized the potential risks and



advocated for her to receive an emergency caesarean section. During surgery, they learned that the umbilical cord was wrapped around his neck twice.

After his birth, King Luther was transferred to a large teaching hospital, a two-hour drive away. For the next three days Selina stayed in the health centre. Being separated from her son was traumatic for her.

"The first time I entered the newborn intensive care unit, they pointed to the baby, and I ran out of the room in uncontrollable tears. I was scared," Selina said. "I just wasn't sure if this boy was going to survive. I felt lifeless, broken, and shattered."

During their hospitalization, nurses taught Selina about Kangaroo mother care.

"KMC made me come to that 'Aha!' moment. It gave me the opportunity to bond. It took me a long time to accept my baby, and KMC helped me feel that connection," Selina said. "It was a beautiful time. It gave us a moment."

Still, her overall experience of inpatient care for her son and herself was very stressful and expensive. Selina had difficulty expressing milk despite her efforts to

pump. She did not receive any lactation support, and King Luther was given formula throughout his infancy. She received no psychological counselling and was only allowed to visit her son during visiting hours.

Despite being only 1.4 kg in size at birth, King Luther progressed well and spent just seven days in the hospital. Impressed with his progress and confident that his family could continue his care in the home environment, his doctors granted him an early discharge. He then received paediatric follow-up and growth monitoring.

Today, King Luther is 3 years old, healthy, and bursting with energy. Selina is now a passionate advocate for premature babies. She founded and became the executive director of the African Foundation for Premature Babies & Neonatal Care (AFPNC). Now she is also an international speaker and a policy advisor to Ghanaian health system administrators and government officials.

Selina strongly believes collaboration between health professionals, the community, and parents is the key to improving newborn survival.



"Now I'm a walking advocacy machine," Selina said. "I find so much fulfilment by channelling my pain positively through finding new avenues to save more babies. We need to let the public know that these babies can survive so that the next generation will have a better story to tell regarding prematurity."

REFERENCES

1. UNICEF, WHO. Every newborn: an action plan to end preventable deaths. Geneva: World Health Organization; 2014 (http://www.who.int/maternal_child_adolescent/newborns/every-newborn/en/, accessed 21 February 2019).
2. EWEC. The global strategy for women's, children's and adolescents' health (2016–2030). New York: Every Woman Every Child; 2015.
3. UN IGME. Levels & trends in child mortality: report 2018. Estimates developed by the United Nations inter-agency group for child mortality estimation (UN IGME). New York: United Nations Children's Fund; 2018.
4. WHO, UNICEF, World Bank Group. Nurturing care for early childhood development: a framework for helping children survive and thrive to transform health and human potential. Geneva: World Health Organization; 2018.
5. Moxon SG, Lawn JE, Dickson KE, et al. Inpatient care of small and sick newborns: a multi-country analysis of health system bottlenecks and potential solutions. *BMC Pregnancy Childbirth*. 2015;15 Suppl 2:S7.
6. Lawn JE, Blencowe H, Oza S, You D, Lee AC, Waiswa P, et al. Every newborn: progress, priorities, and potential beyond survival. *Lancet*, 2014. 384(9938): p. 189–205.
7. IASC. Definition of complex emergencies. Working group XVIth meeting, 30 November 1994. Inter-agency standing committee. 1994.
8. UN. Convention on the rights of the child. United Nations general assembly resolution 44/25 of 20 November 1989 (<https://www.ohchr.org/en/professionalinterest/pages/crc.aspx>, accessed 4 March 2019).
9. UN. General comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health (art. 24). CRC/C/GC/15. 17 April 2013 (https://www2.ohchr.org/english/bodies/crc/docs/gc/crc-c-gc-15_en.doc, accessed 21 February 2019).
10. Bevilacqua G, Corradi M, Donzelli GP, Fanos V, Gianotti D, Magnani C, et al. The Parma charter of the rights of the newborn. *J Matern Fetal Neonatal Med*, 2011. 24(1): p. 171.
11. PMNCH, UNFPA, WHO. Abu Dhabi declaration: for every woman every child everywhere. 2015 (http://www.everywomaneverychild.org/images/the_abu_dhabi_declaration_feb_2015_7.pdf, accessed 21 February 2019).
12. UN DESA. Sustainable Development Goals. United Nations Department of Economic and Social Affairs: 2015 (<https://sustainabledevelopment.un.org/topics/sustainabledevelopmentgoals>, accessed 21 February 2019).
13. March of Dimes, PMNCH, Save the Children, WHO (Howson CP, Kinney M, Lawn JE, editors). Born too soon: the global action report on preterm birth. Geneva: World Health Organization; 2012.
14. UNICEF, WHO, World Bank Group. Joint child malnutrition estimates – levels and trends (2018 edition). Geneva: World Health Organization; 2018.
15. UNICEF. UNICEF data: monitoring the situation of children and women (<https://data.unicef.org/>, accessed 21 February 2019).
16. WHO. Framework on integrated people-centred health services. Report by the secretariat. A67/39. Provisional agenda item 16.1. 15 April 2016. Geneva: World Health Organization: 2016.
17. Lassi ZS, Majeed A, Rashid S, Yakoob MY, Bhutta ZA. The interconnections between maternal and newborn health – evidence and implications for policy. *J Matern Fetal Neonatal Med*, 2013. 26 Suppl 1: p. 3–53.
18. Nair M, Knight M, Kurinczuk JJ. Risk factors and newborn outcomes associated with maternal deaths in the UK from 2009 to 2013: a national case-control study. *BJOG*, 2016. 123(10): p. 1654–62.
19. Moucheraud C, Worku A, Molla M, Finlay JE, Leaning J, Yamin A. Consequences of maternal mortality on infant and child survival: a 25-year longitudinal analysis in Butajira Ethiopia (1987–2011). *Reprod Health*, 2015. 12 Suppl 1: p. S4.
20. Scott S, Kendall L, Gomez P, Howie SR, Zaman SM, Ceesay S, et al. Effect of maternal death on child survival in rural West Africa: 25 years of prospective surveillance data in The Gambia. *PLoS One*, 2017. 12(2): p. e0172286.
21. Harewood T, Vallotton CD, Brophy-Herb H. More than just the breadwinner: the effects of fathers' parenting stress on children's language and cognitive development. *Infant and child development*, 2016. 26(2).
22. Yogman M, Garfield CF, committee on psychosocial aspects of child and family health. Fathers' roles in the care and development of their children: the role of pediatricians. *Pediatrics*, 2016. 138(1).
23. O'Brien K, Robson K, Bracht M, Cruz M, Lui K, Alvaro R, et al. Effectiveness of family integrated

- care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial. *Lancet Child & Adolescent Health*, 2018. 2(4): p. 245–254.
24. Costello A. Quality, equity and dignity for preterm infants through family-centered care. *Indian Pediatr*, 2017. 54(6): p. 451–452.
 25. Raiskila S, Axelin A, Rapeli S, Vasko I, Lehtonen L. Trends in care practices reflecting parental involvement in neonatal care. *Early Hum Dev*, 2014. 90(12): p. 863–7.
 26. Maree C, Downes F. Trends in family-centered care in neonatal intensive care. *J Perinat Neonatal Nurs*, 2016. 30(3): p. 265–9.
 27. IPFCC. Advancing family-centered newborn intensive care: a self-assessment inventory (<http://www.ipfcc.org/resources/downloads-tools.html>, accessed 21 February 2019).
 28. Committee on Hospital Care and Institute for Patient-Family-Centered Care. Patient- and family-centered care and the pediatrician's role. *Pediatrics*, 2012. 129(2): p. 394–404.
 29. Verma A, Maria A, Pandey RM, Hans C, Verma A, Sherwani F. Family-centered care to complement care of sick newborns: a randomized controlled trial. *Indian Pediatr*, 2017. 54(6): p. 455–459.
 30. Byers JF, Lowman LB, Francis J, Kaigle L, Lutz NH, Waddell T, et al. A quasi-experimental trial on individualized, developmentally supportive family-centered care. *J Obstet Gynecol Neonatal Nurs*, 2006. 35(1): p. 105–15.
 31. Ortenstrand A, Westrup B, Brostrom EB, Sarman I, Akerstrom S, Brune T, et al. The Stockholm neonatal family centered care study: effects on length of stay and infant morbidity. *Pediatrics*, 2010. 125(2): p. e278–85.
 32. Yu YT, Hsieh WS, Hsu CH, Lin YJ, Lin CH, Hsieh S, et al. Family-centered care improved neonatal medical and neurobehavioral outcomes in preterm infants: randomized controlled trial. *Phys Ther*, 2017. 97(12): p. 1158–1168.
 33. Sudan, P, Jhalani, M, Gurnani V, Khera A, Prabhakar PK, Maria A, Kumar H, Ashfaq, Dipti. Profile on family participatory care in India. 2018 [webpage] (https://nurturing-care.org/?page_id=784, accessed 21 February 2019).
 34. Alsop-Shields L and Mohay H. John Bowlby and James Robertson: theorists, scientists and crusaders for improvements in the care of children in hospital. *J Adv Nurs*, 2001. 35(1): p. 50–8.
 35. Marchant A. 'Neonates do not feel pain': a critical review of the evidence *Bioscience Horizons: The International Journal of Student Research*. 2014;7(1).
 36. Franck LS, Oulton K, Bruce E. Parental involvement in neonatal pain management: an empirical and conceptual update. *J Nurs Scholarsh*. 2012;44(1):45–54.
 37. Lassi ZS and Bhutta ZA. Community-based intervention packages for reducing maternal and neonatal morbidity and mortality and improving neonatal outcomes. *Cochrane Database Syst Rev*, 2015. 3: p. CD007754.
 38. Banda G, Guenther T, Chavula K, Kinney M, Vaz L, Cundale K, et al. Khanda ndi mphatso: applying social and behaviour change communication to newborn health in Malawi. *Journal of Development Communication*, 2018. 29: p. 111–136.
 39. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. *Crit Care Med*, 2017. 45(1): p. 103–128.
 40. Kerber KJ, de Graft-Johnson JE, Bhutta ZA, Okong P, Starrs A, Lawn JE. Continuum of care for maternal, newborn, and child health: from slogan to service delivery. *Lancet*, 2007. 370(9595): p. 1358–1369.
 41. WHO. World Health Report 2005: make every mother and child count. Geneva: World Health Organization; 2005.
 42. Adam T, Amorim DG, Edwards SJ, Amaral J, Evans DB. Capacity constraints to the adoption of new interventions: consultation time and the integrated management of childhood illness in Brazil. *Health Policy Plan*. 2005. 20 Suppl 1:i49–i57. p. i49–i57.
 43. Atrash HK, Johnson K, Adams M, Cordero JF, Howse J. Preconception care for improving perinatal outcomes: the time to act. *Maternal and child health journal*, 2006. 10(5 Suppl): p. S3–11.
 44. de Graft-Johnson J, Kerber K, Tinker A, Otchere S, Narayanan I, Shoo R, et al. The maternal, newborn and child health continuum of care. In: *Opportunities for Africa's newborns*. Cape Town: Partnership for Maternal, Newborn & Child Health; 2006. p. 23–36.
 45. Sepulveda J, Bustreo F, Tapia R, Rivera J, Lozano R, Olaiz G, et al. Improvement of child survival in Mexico: the diagonal approach. *Lancet*, 2006. 368(9551): p. 2017–2027.
 46. Kruk ME, Gage AD, Joseph NT, Danaei G, García-Saisó S, Salomon JA. Mortality due to low-quality health systems in the universal health coverage era: a systematic analysis of amenable deaths in 137 countries. *Lancet*. Published online 5 September 2018 (corrected version published 20 September 2018).

47. Dunn PM. Stephane Tarnier (1828–1897), the architect of perinatology in France. *Arch Dis Child Fetal Neonatal Ed*, 2002. 86(2): p. F137–9.
48. Duxbury M, Adams LR. Nursing research contributions to improve NICU care. Neonatal intensive care: a history of excellence – a symposium commemorating child health day. NIH Publication No 92-2786, 1985.
49. Anspach RR. Deciding who lives: fateful choices in the intensive-care nursery. Los Angeles: University of California Press; 1997.
50. Gooding JS, Cooper LG, Blaine AI, Franck LS, Howse JL, Berns SD. Family support and family-centered care in the neonatal intensive care unit: origins, advances, impact. *Seminars in perinatology*, 2011. 35(1): p. 20–8.
51. Brandon S, Lindsay M, Lovell-Davis J, Kraemer S. “What is wrong with emotional upset?” – 50 years on from the Platt report. *Arch Dis Child*, 2009. 94(3): p. 173–7.
52. Levin A. The mother-infant unit at Tallinn children’s hospital, Estonia: a truly baby-friendly unit. *Birth*, 1994. 21(1): p. 39–44, discussion 45–6.
53. Vaivada T, Gaffey MF, Bhutta ZA. Promoting early child development with interventions in health and nutrition: a systematic review. *Pediatrics*, 2017. 140(2).
54. Spittle A, Orton J, Anderson PJ, Boyd R, Doyle LW. Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants. *Cochrane Database Syst Rev*, 2015(11): p. CD005495.
55. Evans T, Whittingham K, Sanders M, Colditz P, Boyd RN. Are parenting interventions effective in improving the relationship between mothers and their preterm infants? *Infant Behav Dev*, 2014. 37(2): p. 131–54.
56. Hughes AJ, Redsell SA, Glazebrook C. Motor development interventions for preterm infants: a systematic review and meta-analysis. *Pediatrics*, 2016. 138(4).
57. Morag I, Ohlsson A. Cycled light in the intensive care unit for preterm and low birth weight infants. *Cochrane Database Syst Rev*, 2016(8): p. CD006982.
58. Almadhoob A and Ohlsson A. Sound reduction management in the neonatal intensive care unit for preterm or very low birth weight infants. *Cochrane Database Syst Rev*, 2015. 1: p. CD010333.
59. Provenzi L, Broso S, Montirosso R. Do mothers sound good? A systematic review of the effects of maternal voice exposure on preterm infants’ development. *Neurosci Biobehav Rev*, 2018. 88: p. 42–50.
60. Bergman NJ. The neuroscience of birth – and the case for zero separation. *Curationis*, 2014. 37(2): p. e1–e4.
61. Charpak N, Ruiz JG, Zupan J, Cattaneo A, Figueroa Z, Tessier R, et al. Kangaroo mother care: 25 years after. *Acta Paediatr*, 2005. 94(5): p. 514–22.

What the numbers say

KEY MESSAGES

- The survival of small and sick newborns is the most important item on the unfinished agenda for ending preventable child deaths. It is urgent, and possible, to close this survival gap and thus meet the SDG targets. Every year 1 million newborns die on the day of their birth; 2.5 million die in their first month. Nearly half (47%) of all deaths in children aged under 5 years occur in the neonatal period. Just over a decade remains to meet the SDG 3.2 target for every country to reach an NMR of 12 deaths or fewer per 1000 births. While many LMICs have made impressive progress towards the target, around 40 countries need to more than double their current progress. This is especially true for those affected by humanitarian emergencies, and for many African nations.
- Most newborn deaths and disability are preventable. The leading causes to prioritize are: (1) prematurity; (2) infections; (3) birth complications; (4) congenital abnormalities; and (5) jaundice. Caring for small and sick newborns is crucial for reducing deaths, disability, stunting, and the long-term risk of noncommunicable disease.
- Thirty million small and sick newborns worldwide require care in a hospital each year. Transforming health systems to provide high-quality care of newborns will prevent disabilities, optimize child development, and increase lifelong human capital for millions. Of these 30 million newborns, 8–10 million need intensive care in order to survive and thrive. Long-term disabilities – mostly preventable – are a sensitive indicator of the quality of newborn care. Special and intensive care could, within a few years, halve the number of newborn deaths in hospitals, reduce disability, provide strong returns on investment by reinforcing human capital, and reduce long-term psychological ill health and catastrophic costs for parents and families.



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Care for small and sick newborns is central to the SDG targets for neonatal and child survival, early child development, human potential, and broader social and economic transformation. Improving a child's health and life chances also benefits future generations.

In Chapter 1 the connections between maternal and newborn health and all the SDGs were explored. This chapter looks at currently available data that can help in transforming care for small and sick newborns. Data are categorized under the headings: "Survive," "Thrive," and "Transform" (Table 2.1).

Survive: end preventable deaths

Targets for 2030

Looking at the SDGs, it is clear that there are gaps to close. Progress for survival has been slow around the time of birth when 5.4 million women and newborns die annually. This includes 2.5 million newborns who die within the first 28 days of life; 2.6 million who are stillborn; and 303 000 mothers who die. Most of these deaths occur in the poorest families in the poorest countries, and most are preventable (5). An estimated 2.9 million women, stillbirths and newborns could be saved every year (compared with the 2016 baseline) through

Table 2.1 Global and national targets relevant to small and sick newborns

	SURVIVE End preventable deaths	THRIVE Ensure health and well-being	TRANSFORM Expand enabling environments
SDG targets	SDG 3.2: By 2030, reduce neonatal mortality to at least as low as 12 deaths per 1000 live births; and under-5 mortality to at least as low as 25 deaths per 1000 live births	SDG 3 and the Comprehensive implementation plan on maternal, infant and young child nutrition: By 2025, reduce low birth weight by 30% SDG 4.2: By 2030, ensure all girls and boys have access to quality early childhood development care and pre-primary education	SDG 3.8: Achieve universal health coverage by 2030 SDG 5: Achieve gender equality, empower all women, end gender-based violence
What data are needed to track for newborn health?	Neonatal mortality rates Under-5 mortality rates Stratified by sex, socioeconomic status, urban/rural location, etc.	Birth weight and growth metrics Gestational age Neonatal morbidity and impairment outcomes Child development measures	Birth and death registration Maternal and perinatal death surveillance and response Routine measurement of: <ul style="list-style-type: none"> • Coverage and quality of care, including family-centred care; • Service readiness for small and sick newborn care; and • Child development and disability.

Sources: SDGs (1), Every Newborn (2), QED (3), Every Newborn measurement improvement roadmap (4).



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improved universal coverage of high-quality care at birth and for small and sick newborns (Figure 6.1).

As noted in Chapter 1, the Every Newborn Action Plan aims to end preventable deaths, setting the first ever specific NMR target (6), also included in the SDGs (Table 2.1). This target is for every country to reduce its NMR to 12 or fewer deaths per 1000 live births by 2030, and to reduce stillbirths to 12 or fewer per 1000 total births (2).

Current status

Where do most deaths occur?

In 2017, most neonatal deaths globally (98%) occurred in LMICs; 78% in sub-Saharan Africa and Southern Asia. Worldwide, 12 LMICs account for two thirds of neonatal deaths with 4 countries accounting for almost half of all neonatal deaths: India (605 000), Nigeria (241 000), Pakistan (241 000) and Democratic Republic of the Congo (98 000). Almost all of these countries have set Every Newborn targets to reduce these deaths (7).

Where are newborns most at risk of dying?

NMRs vary significantly between countries, from 0.9 (per 1000 live births) in Japan, to 44 in Pakistan. Of the 10 countries where newborns are most at risk, 8 are in sub-Saharan Africa; 2 are in Southern Asia (7). Of the 16 countries with the highest NMRs in the world, 11 have experienced recent humanitarian crises, such as conflict or political instability (see Table 3.2) (7).

Where has the fastest progress been made?

From 1990 to 2017, the global NMR decreased by 51%, from 37 to 18 deaths per 1000 live births (7). By contrast, mortality rates in children after the first month of life to 5 years of age reduced by 63%. Thus, although there has been a welcome drop in neonatal mortality, the drop has been slower than that for older children. As a result, the proportion of deaths in children aged under 5 years that occur in the neonatal period has risen. Currently, almost half of child deaths globally occur in the neonatal period, ranging from approximately 37% in sub-Saharan Africa to more than 60% in several countries in Southern Asia and in HICs.

Progress in rates of newborn survival has shown substantial regional variation since 1990, from a reduction of 84% in Eastern Asia, to 41% in sub-Saharan Africa. However, every region has a country making rapid progress that neighbouring countries can learn from (Fig. 2.1). For example, Rwanda, in sub-Saharan Africa, made the fastest progress during 2000–2017, reducing its national NMR from 39 to 16 – an average annual rate of reduction (AARR) of 5.1%. Countries making the fastest progress in reducing NMRs overall are China (8.9%), Estonia (8.7%) and Belarus (8.2%)¹ (7).

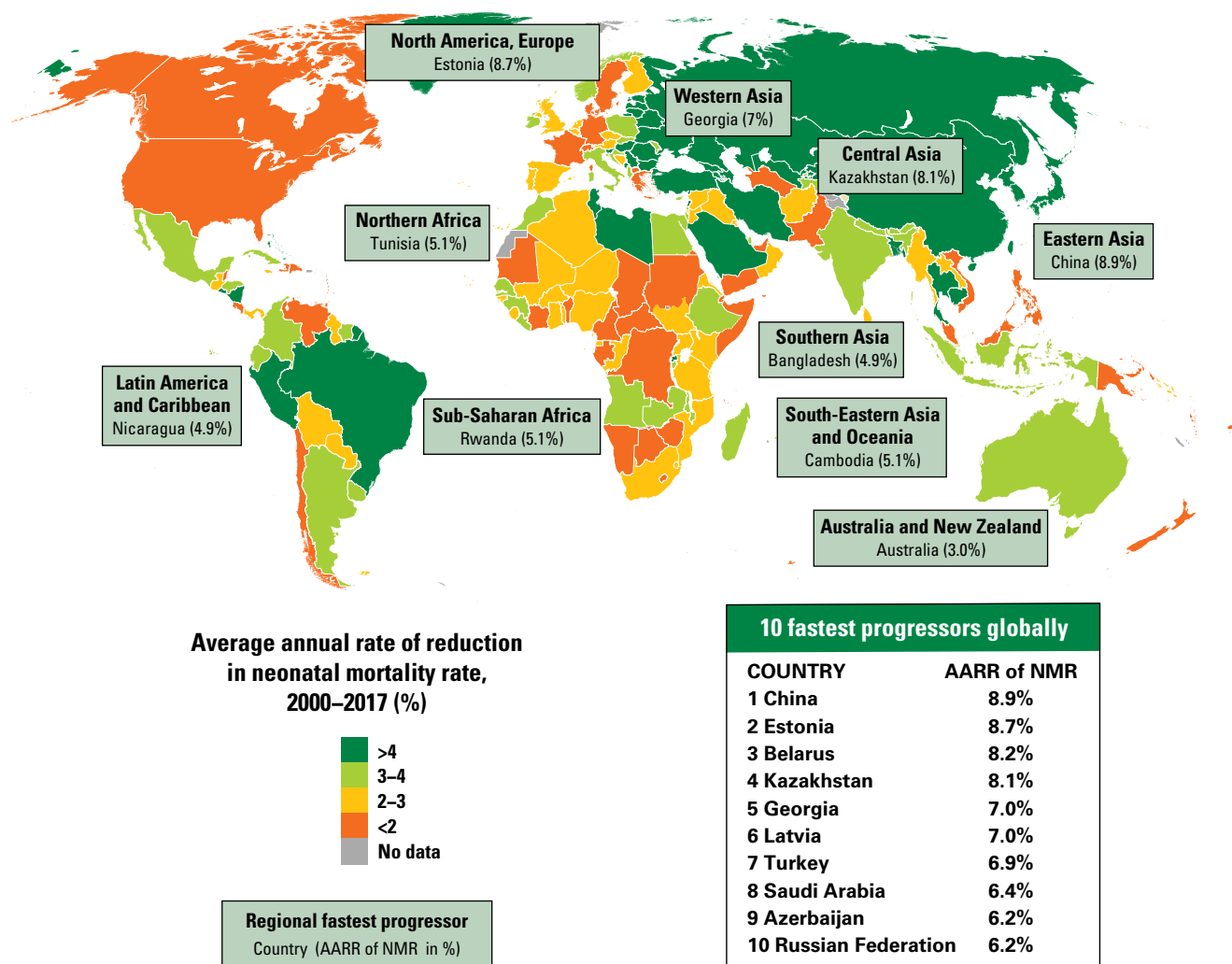
These “exemplar” countries demonstrate that the factors associated with progress reflect the same three phases seen in data from the USA and the United Kingdom (8) (See Chapter 1). Most of these countries started in 2000 with NMRs below 20, apart from Rwanda and Malawi. All exemplar countries (including Rwanda and Malawi) improved their obstetric care and special newborn care, and invested in scale-up of more intensive newborn care, including ventilatory support for preterm newborns. No country has reduced their NMR to fewer than 15 deaths per 1000 without high population-level coverage of intensive newborn care (8).

In most rapidly progressing countries it has taken several decades to improve their NMRs from 20 to fewer than 12 deaths per 1000 live births; however some countries, such as China, Georgia and Kazakhstan, succeeded in about one decade. While these countries saw economic growth and increased gross national income (GNI), they outperformed other countries with higher increases in GNI. Thus, progress was not due solely to increased national wealth but also to the choices made in spending that wealth.

The national NMRs provide an indication of the progress that countries are making towards UHC. These recent

1 Countries with fewer than 10 000 births per year are not included in this analysis.

Fig. 2.1 Average annual neonatal mortality rate reduction (2000–2017), highlighting the countries making fastest progress and the fastest in each region



AARR = average annual rate of reduction; NMR = neonatal mortality rate per 1000 live births.

Projections are not provided for countries with high HIV rates as the AARR is more uncertain.

Countries with fewer than 10 000 births per year are not included.

Data taken from: United Nations Inter-agency Group for Child Mortality Estimation. Estimates for AARR for NMR 2000–2017 (7).

country examples, as well as the historical data, show that countries need to plan now to implement intensive newborn care. Countries with NMRs higher than 30 and with most births occurring at home can make most progress by improving obstetric care and special newborn care, and by planning for their health systems to make the transition towards intensive newborn care, avoiding a major delay in achieving the SDG target.

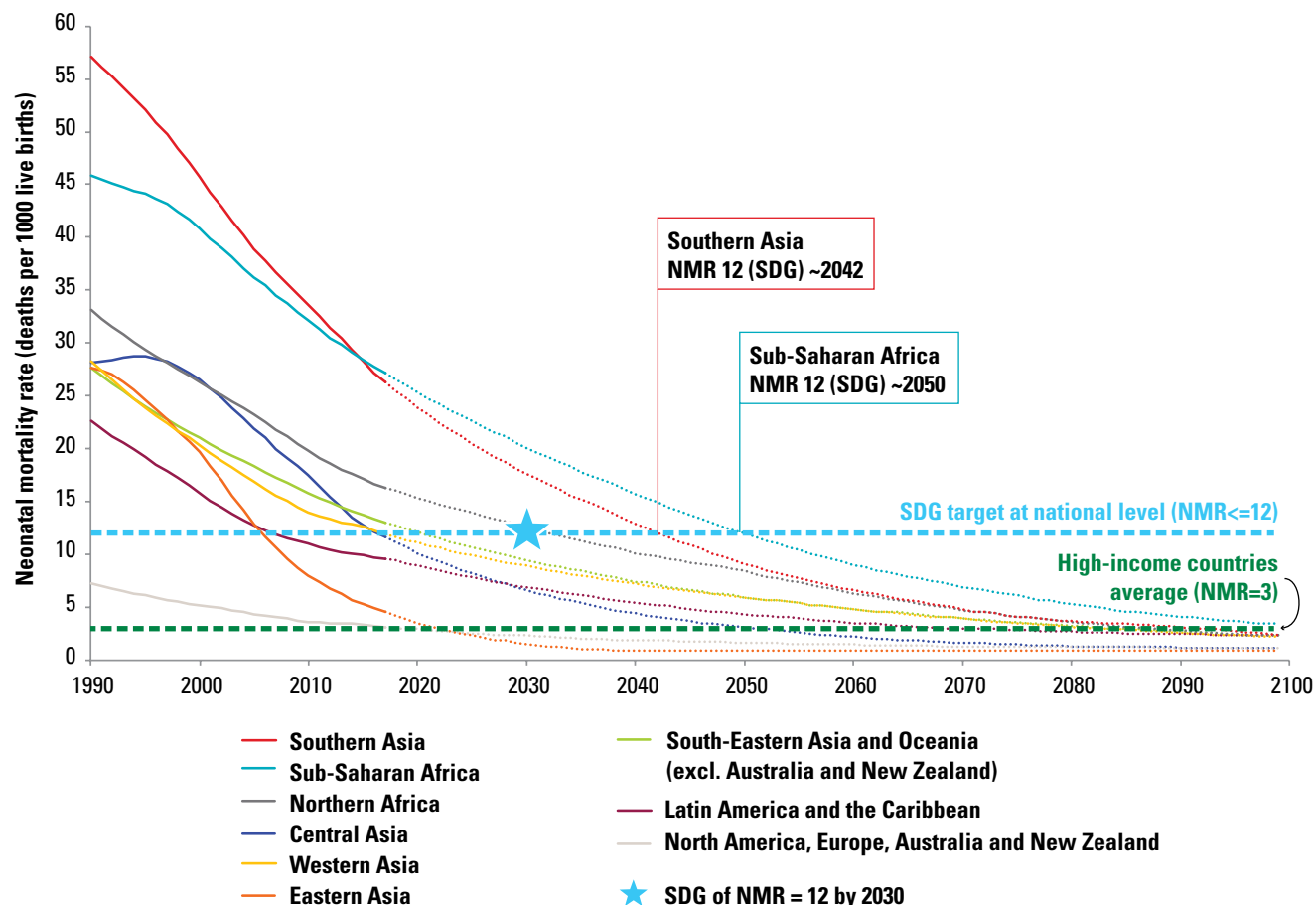
Which regions and countries need to make the most progress?

Although sub-Saharan Africa has the highest risk (highest NMR) and the slowest progress (lowest AARR), a few countries, such as the regional leader, Rwanda, are

making good progress (Fig. 2.1). Assuming that the same AARR per country can be achieved as during 2000–2017, all regions could reach an NMR of 12 deaths or fewer per 1000 live births by 2030 – apart from Southern Asia (predicted to achieve this by 2042) and sub-Saharan Africa (by 2050) (Fig. 2.2).

Countries making the slowest progress are found in sub-Saharan Africa or Southern Asia; all need to at least double their rate of progress to be on track to achieve the 2030 national target of 12 neonatal deaths per 1000 live births (Fig. 2.2). In general, countries that are currently least likely to meet their targets are those affected by humanitarian crises (see Chapter 6).

Fig. 2.2 Projected year that each region will reach SDG national target and equal the average neonatal mortality rate (NMR) for high-income countries



Note: The projections are calculated at the country level using the AARR 2000–2017 and constrained to not exceed the projected under-5 mortality rate and aggregated to the regional levels. After 2030 countries with populations less than 90 000 inhabitants in 2017 are not included in the regional aggregates. Source: Analysis update from *The Lancet Every Newborn* (6). Data taken from: United Nations Inter-agency Group for Child Mortality Estimation estimates for NMR ARR 2000–2017 (7).

Closing the equity gap between and within countries

The SDG era aspires to close the equity gap so that no one is left behind. If this principle were applied between countries, all newborns would have the same chance of survival as those born in countries with an NMR of 3 newborn deaths (or fewer) per 1000 live births. However, at the current rate of progress, it will be the next century before a newborn in sub-Saharan Africa has the same chance of survival as a newborn in Northern America, Europe or Australia and New Zealand (Fig. 2.2).

Governments need to be accountable to apply this equity principle within their own countries, to ensure that all citizens have the best chance of survival. An updated analysis was undertaken for this report based

on *The Lancet Every Newborn* analyses, using the most recent Demographic and Health Survey data from 63 countries, accounting for more than 84% of all neonatal deaths, and having an NMR higher than the SDG target of 12 deaths per 1000 live births. In this analysis, if all households in a country had the same risk of neonatal death as the richest 20% of the population, the NMR in those countries would be reduced by a median of 16%. Closing the equity gap within these countries would result in approximately 500 000 fewer neonatal deaths in these countries and accelerate progress to achieving the SDG target. Countries with the largest relative reductions to make are Jordan (64%), Dominican Republic (57%), Indonesia (53%), Angola (50%) and India (48%). In certain countries, such as Mozambique, Chad and Ethiopia, there is a very small gap between the richest and poorest quintiles.

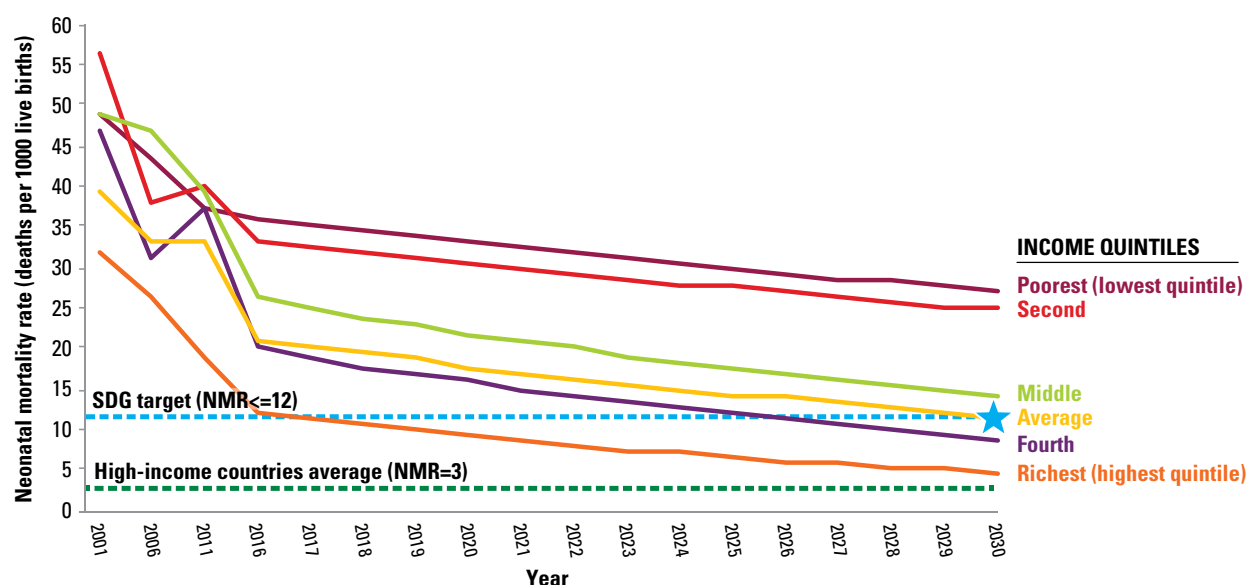
Box 2.1 Nepal expected to reach target for newborn mortality, but inequity may increase

The current national trend in NMR reduction in Nepal is one of the fastest in Southern Asia. Nepal reduced neonatal mortality by more than half between 1990 and 2015 by making changes to policy-making, strengthening the health system, and challenging social norms regarding care for mothers and newborns. Further investment has been pledged by government and international agencies as a part of Nepal's Every Newborn Action Plan.

Evidence from the four demographic and health surveys conducted in Nepal between 2001 and 2016

shows different rates of progress between socio-economic groups (wealth quintiles). The target of 12 deaths per 1000 live births was achieved within the wealthiest groups in 2016. If the pace of AARR in all wealth groups continues, Nepal will reach the national NMR target in 2029, ahead of the SDG deadline. However, this will mask inequities between socioeconomic groups. The poorest groups in Nepal currently have an AARR of 2%. If this does not improve they will not reach the target until 2068. To counter this requires stronger focus on the rural poor.

Fig. 2.3 Progress in Nepal towards the neonatal mortality target, by income quintile



★ SDG of NMR = 12 by 2030

Source: Ashish, Sato, Thapa, et al. Time trends and risk factors associated with neonatal death; projection of neonatal mortality rate for 2030 in Nepal. (Under review) *Maternal and Child Health J*, 2019 (11).

For the more than 100 United Nations Member States that have already achieved the SDG target of fewer than 12 deaths per 1000 live births, the SDGs encourage setting country-specific targets, with an emphasis on reducing inequalities. Closing these gaps will require contextual data and analyses to identify which individuals and populations are lagging behind. The rural poor, the urban poor and certain ethnic groups are likely to be among those most in need (9, 10). Nepal is an example of successful national progress, but it also shows that reaching the NMR target within all population groups will be challenging (see Box 2.1 and Fig.2.3).

Where to focus: at home or in hospital?

The place of birth has changed in the past two decades. Globally, more than 80% of all births now occur with a skilled birth attendant and almost all births occur in hospitals (12), compared with 62% in 2000 (6) with the fastest change in LMICs. However, 44 million births each year still occur outside health facilities, almost all without a skilled attendant (13).

The equity gap has widened in some countries, driven partly by the urban–rural divide. For example, analysis from 56 countries (of 75 countries with available survey

data, tracked by the Countdown to 2030² partnership) shows that urban women have much greater access to skilled birth attendance than rural women, with a median gap of 35% between the two. The slope index of inequality (a calculation of the gap between the richest and poorest, with zero indicating no inequality) is 59%, showing that wealth-related inequality is a significant problem (6). Postnatal care for mothers and newborns is lower, with opportunities to improve through approaches such as pre-discharge hospital checklists.

Neonatal death and intrapartum stillbirths often occur because mothers cannot access care or are delayed in doing so; a few minutes' delay can make a difference. Improved data are needed on where newborns die and how access and quality of care can be improved. This will inform context-specific community and health system strategies. The greatest potential for rapid impact is to ensure hospitals are equipped and ready to provide quality services, and are linked to communications and transport services to reduce life-threatening delays (see also Chapters 3, 4 and 5).

When to focus?

The first week of life for a newborn is the time of highest risk. The proportion of deaths that occur during the first day and week of life is consistent across regions and economic settings (6). An estimated 73% of all neonatal deaths occur during the first week of life, with 36% (1 million) on the day of birth (14).

Boys or girls?

Male newborns are at higher biological risk of neonatal complications that contribute to death than female newborns. Such complications include preterm birth (14% higher than females); severe neonatal infection (12% higher); and intrapartum-related neonatal encephalopathy (42% higher). Hence, boys have a higher risk of death in the neonatal period than do girls (6).

However, in some cultures newborn and older girls are at increased social risk. With the increased availability of ultrasound screening, termination of pregnancy may be based on the sex of the fetus, especially in settings where a male child is valued more highly than a female. After birth, newborn girls may have less access to care than boys, or receive suboptimal care, losing or reversing their biological survival advantage. For example, in India, the 2017–2018 data from nearly 700 special newborn care units (SNCUs) with more than 1 million admissions show that only 41% of newborns were female (15).

Which conditions affecting newborns should be prioritized?

Neonatal conditions account for 47% of deaths in children under 5 years of age, with preterm births the leading cause (Fig. 2.4). The four main causes of newborn deaths are: prematurity (35%); intrapartum or birth complications, mainly through brain injury (previously referred to as birth asphyxia) (24%); neonatal infections (23%); and congenital conditions (11%) (7, 16).

The cause of death profile varies depending on context (Fig. 2.5). In all countries, the leading cause of death is direct preterm complications, especially respiratory immaturity. However, in HICs with neonatal intensive care, the predominant gestational age of those who die is under 25 weeks (four months preterm). In LICs, the majority of those who die are almost at term (32–37 weeks' gestation) (17). In the highest mortality settings, notably humanitarian crises, half of neonatal deaths are due to infections, often caused at the time of birth or related to hygiene, especially through the umbilical cord.

The critical conditions that most threaten newborns

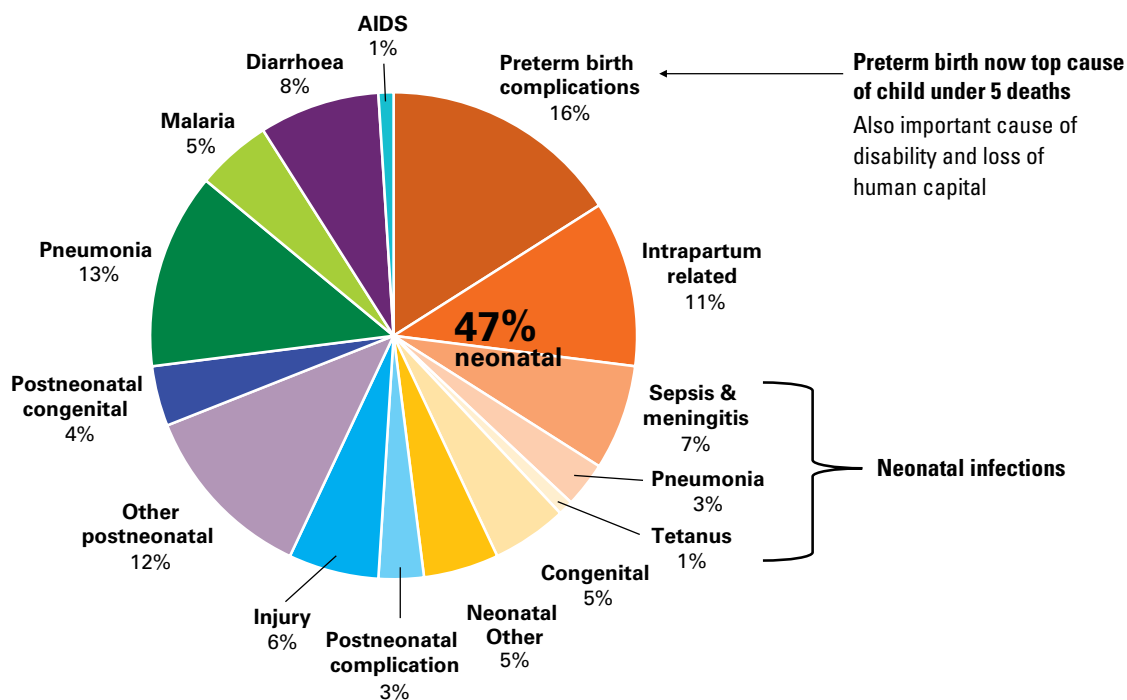
Condition 1: Preterm birth

Deaths: With an estimated 1.01 million deaths per year, preterm birth is now the leading cause of childhood mortality and an important cause of long-term ill-health, including disability and noncommunicable diseases in later life (16). The number of deaths include approximately 909 000 in the neonatal period and more than 100 000 after the neonatal period, often after long hospital stays. In addition to direct prematurity complications, such as respiratory complications, preterm birth greatly increases a newborn's risk of death due to other causes, especially infections. Based on estimates, preterm birth, in particular moderate preterm (32–36 weeks), is a risk factor in more than half of all neonatal deaths (17).

Cases: Global estimates for 2014 report a total of 14.8 million preterm births: about 11% of all live births, which is similar to the 2010 WHO estimates (18). Countries with the largest numbers of preterm births include India, China, Brazil and the USA, demonstrating that preterm birth is significant across all income settings. Preterm birth rates range from 8.7% in the European region to up to 13.4% in North Africa, with far greater variation among individual countries. In settings with more reliable data over time, rising preterm birth rates are related to factors such as higher maternal age, infertility treatments (higher

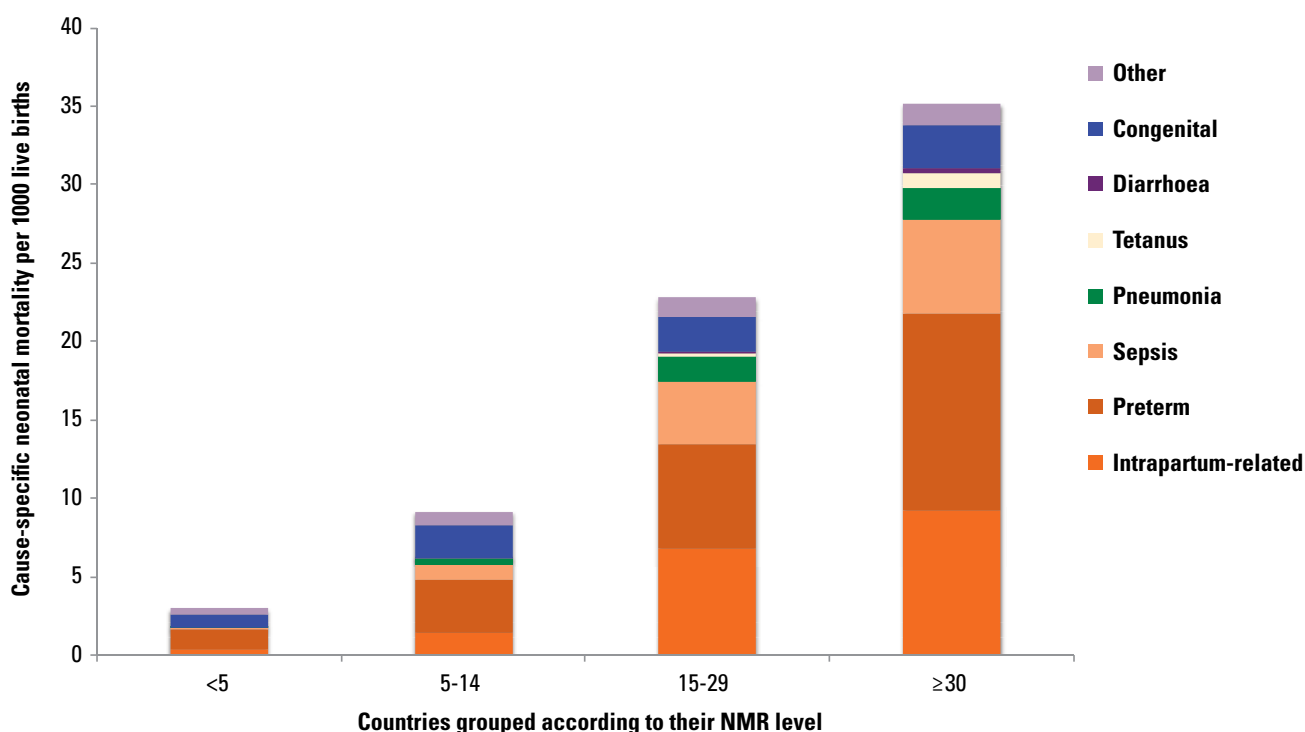
2 See: <http://countdown2030.org>.

Fig. 2.4 Global causes of death in children under 5 years of age



Source: Analysis update from *The Lancet Every Newborn* (6). Source: Data from WHO estimates for 196 countries for neonatal cause of death on WHO Global Observatory (16). Updated analyses for 2016 by Shefali Oza with Joy Lawn. NMRs from United Nations Inter-agency Group for Child Mortality Estimation (7).

Fig. 2.5 Global variation in cause of neonatal deaths, by level of neonatal mortality rate (NMR) (2016)



Source: Analysis update from *The Lancet Every Newborn* (6). Source: Data from WHO estimates for 196 countries for neonatal cause of death on WHO Global Observatory (16). Updated analyses for 2016 by Shefali Oza with Joy Lawn. NMRs from United Nations Inter-agency Group for Child Mortality Estimation (7).

rates of multiple births) and a greater number of caesarean sections, which may be performed too early (18–19).

Potential for impact: All countries that have made progress in reducing preterm mortality have done so primarily through better care of preterm newborns. Up to half of preterm deaths would be averted through providing warmth, feeding support, infection prevention, and treatment supported by KMC. More than 90% would be avoided with special and intensive newborn care, including ventilatory support such as CPAP (5). Most countries with reliable trend data show increases in preterm birth rates and limited scope for preventing preterm births (20). However, there are opportunities to prevent preterm birth, especially in low-income settings, notably through family planning (especially by delaying first pregnancy beyond 18 years, or avoiding pregnancy after 35 years); and by treating infections, such as malaria, during pregnancy (21). Nutritional interventions during pregnancy have shown little impact on preventing preterm birth (20). Evidence shows that women who have received continuity of care from a midwife they know, compared with medical-led or shared care, are 24% less likely to experience preterm birth, 19% less likely to lose their baby before 24 weeks' gestation, and 16% less likely to lose their baby at any gestation (22).



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Condition 2: Neonatal infections

Deaths: Severe bacterial infections in newborns include deaths from three clinically defined syndromes: neonatal sepsis, meningitis and pneumonia – all important contributors to the global burden of disease. An estimated 554 000 deaths per year globally are due to neonatal severe bacterial infections (16).

Cases: Estimates of possible severe bacterial infection in newborns for sub-Saharan Africa, Southern Asia and Latin America suggest a total of 6.7 million (23). Information on organisms causing infections is essential for effective prevention and treatment, yet data are lacking from LMICs, especially in Africa. Better quality and availability of data about differences between regions and countries would help guide antibiotic choices, especially in an era of antimicrobial resistance. Hospital-acquired infections influence the main pathogens for late onset sepsis (i.e. onset after 72 hours) and include *Escherichia Coli*, *Klebsiella*, *Staphylococcus aureus* and *Candida spp.* Early onset neonatal sepsis (i.e. onset during first 72 hours after birth) is usually considered to be from maternal carriage, or during birth, notably *Group B Streptococcus* (24). Some 21 million pregnant women worldwide are “colonized” with *Group B Streptococcus*, which is not only the leading infectious cause of neonatal morbidity and mortality but also of

maternal sepsis, stillbirths and probably of preterm birth. Intrapartum antibiotic prophylaxis to prevent *Group B Streptococcus* infections has been implemented in several HICs, notably the USA. However, this strategy will not reduce late-onset *Group B Streptococcus* or stillbirths, is not feasible without high laboratory capacity, and is likely to increase antibiotic use at a time of higher risk. All of this makes a strong case for a developing a maternal vaccine (25, 26).

Potential for impact: *The Lancet* Every Newborn series estimates that 84% of neonatal deaths due to infections could be prevented (6). However hospitals in LICs face numerous challenges, particularly in terms of infection prevention and control and quality of care (see Box 2.2). Prevention is crucial, especially for hospital-acquired infections by preterm newborns who face long-term admission, as is innovation in promising areas such as maternal immunization. Timely diagnosis and management with appropriate antibiotic treatment could save hundreds of thousands of lives. However, signs of newborn infection can be non-specific and difficult to detect.

Box 2.2 Hospital-acquired infections and antimicrobial resistance in a newborn care unit in West Africa

In sub-Saharan Africa, more than half of births occur in hospitals. Unfortunately, hospitals vary widely in quality of care, and many present unclean environments and poor infection-control practices. Presumed severe bacterial infections account for almost half of neonatal admissions at Gambia's largest referral hospital. Nearly all newborns routinely receive antibiotics, yet only 1–2% undergo microbiological investigations for infection. A hospital-based case–control study was carried out to identify organisms causing serious neonatal infection. *Staphylococcus aureus* was the predominant bacterial isolate, but most infections were due to Gram-negative or nosocomial outbreaks of

Burkholderia cepacia and of multi-drug-resistant *Klebsiella pneumoniae*. Both outbreaks were traced to contaminated intravenous fluids and antibiotics on the neonatal ward.

Infections are a major problem for hospitalized newborns in LIC settings. Routine blood cultures, lumbar punctures and antibiotic stewardship (i.e. optimizing treatment of infections while reducing problems associated with antibiotic use) should be priorities, with standardized protocols to manage newborn conditions. Innovations include simpler bedside diagnostics. New antibiotics and immunizations are urgently required, and more research in this area is needed.

Source: Okomo. PhD thesis (27).

WHO recommends antibiotic treatment for all suspected sepsis cases, but it is likely that less than 25% of these infants actually have severe bacterial infection.

Condition 3: Intrapartum trauma or birth complications

Deaths: Intrapartum trauma or birth complications account for an estimated 627 000 neonatal deaths annually (28, 29), making this the second leading cause of neonatal deaths globally.

Cases: An estimated 5–10% of newborns (7–14 million per year) require some stimulation immediately after birth to help initiate breathing. Approximately 6 million newborns per year require basic resuscitation, including bag and mask pressure ventilation. A much smaller number (< 1% of births) may require advanced newborn resuscitation, including intubation, chest compressions or medications. These newborns may also be very preterm or have a serious brain injury that warrants ongoing inpatient newborn care (30).

In 2010, an estimated 1.15 million newborns developed neonatal encephalopathy associated with intrapartum events (30). Newborns with neonatal encephalopathy show varying levels of consciousness, often accompanied by seizures, which require ongoing inpatient care (e.g. feeding support and anticonvulsants) (31). Newborns who are already growth-restricted are much more at risk of neonatal encephalopathy, especially if there is also an ascending infection.

Potential for impact: Almost 80% of neonatal deaths due to intrapartum-related complications could be averted through primary prevention with obstetric care. Secondary prevention with resuscitation and supportive care for those with neonatal encephalopathy is important but less effective than prevention (5).

Condition 4: Congenital conditions

Deaths and cases: Globally, 9% of under-5 deaths are attributed to congenital anomalies, around 60% of them in the neonatal period (16). Most of these deaths (96%) occur in LMICs. There are four major causes: cleft lip and palate, congenital heart anomalies, abdominal malformations and neural tube defects (32). These result in many years lived with disability. In the past 15 years, deaths due to congenital conditions have reduced at a slower rate than any other cause of neonatal and under-5 deaths.

Potential for impact: Two thirds of deaths due to these conditions are treatable with paediatric surgery and neonatal intensive care (32). Additionally, there are important primary prevention strategies that are feasible at scale. These include folic acid fortification (which can prevent more than 50% of neural tube defects such as spina bifida (33)), rubella immunization (congenital rubella syndrome causes heart defects, cataract and deafness), and genetic counselling. There is growing recognition of the importance of establishing national and regional surveillance systems of birth defects to better guide public health action (see Box 2.3).

Box 2.3 Congenital abnormalities in the Eastern Mediterranean Region

With reduced mortality due to infectious diseases, and a greater proportion of under-5 deaths occurring in the neonatal period, congenital abnormalities (birth defects) are of increasing importance in the care of newborns. This is especially relevant in the Eastern Mediterranean, a region with a high rate of consanguineous marriages, which is a major risk factor. Data on types of birth defects as well as the detection of clusters, which may be due to environmental or other exposures (e.g. Zika virus), are needed to provide a basis for prevention and care.

The WHO Regional Office for the Eastern Mediterranean commissioned a situational analysis

Source: Yunis K, et al. (Under review) *Int J Epidemiol*, 2019 (34).

to assess birth defect surveillance in 22 countries. The analysis suggests that less than half of the countries conduct surveillance, and that multiple barriers to effective surveillance exist including inadequate health management information systems (HMIS), as well as limited human resources, infrastructure and funding.

Governments, local institutions, nongovernmental and civil society organizations need to collaborate to establish surveillance for congenital abnormalities and integrate it into routine systems. These data should also be used for enhanced prevention, service planning and family support.

Condition 5: Jaundice

Neonatal jaundice may be severe enough to cause bilirubin-induced brain injury (kernicterus) resulting in death or long-term neurodevelopmental impairments. Jaundice is caused by prematurity, infections and/or haemolysis (such as rhesus disease, or glucose-6-phosphate dehydrogenase (G6PD) deficiency).

Deaths and cases: Extremely severe jaundice (bilirubin > 25 mg/dL) is estimated to affect 481 000 late-preterm and term newborns annually; 114 000 die and more than 63 000 survive with moderate or severe long-term neurological impairments. The burden varies regionally, with higher risks of severe jaundice in West Africa related to higher prevalence of G6PD deficiency (35).

Potential for impact: Pre-discharge checks of women and their newborns would help identify early jaundice requiring treatment and inform families with at-risk newborns about the importance of returning early if they see jaundice. Effective care requires devices for testing jaundice and giving phototherapy if needed.

Prevention includes identifying women with a blood group that is rhesus-negative and administering a postpartum antirhesus immunoglobulin injection. This will prevent autoimmune breakdown of the blood and jaundice, which will be more severe with each subsequent pregnancy. A critical challenge is lack of low-cost antirhesus immunoglobulins. Regarding G6PD deficiency, neonatal screening using a blood spot has been shown to be effective and is cost-effective in regions with prevalence greater than 5%.

Small newborns, big problem

Being small puts a child at the highest risk of dying in utero, during birth and in the neonatal period from one of the leading causes: prematurity; infections; birth complications; and jaundice. It may also increase risks throughout their lifetime. Being born small is due to two different causes: preterm birth or in utero growth restriction, or a combination of the two. Most neonatal deaths (80%) occur to LBW newborns, of which two thirds are preterm and one third is small for gestational age (SGA) (6, 36).

For centuries, LBW has been used as a threshold to mark the highest risk of mortality and morbidity, although this is simplistic given that risk varies continuously with birth size. The preterm definition of a threshold at 37 weeks is also simplistic, as the risk is much higher for newborns of a lower gestational age (e.g. less than 28 weeks). Very premature newborns have the highest risk of neonatal death, with more than 95% mortality for newborns less than 28 weeks' gestation who do not receive intensive newborn care. Moderately premature newborns between 32 and 37 weeks' gestation have at least a seven-fold risk of neonatal mortality compared with term newborns. Newborns who are term yet also small for gestational age have a two-fold risk of neonatal death compared with their term normal-sized peers. Newborns who are both preterm and SGA are 15 times more likely to die (3, 6). All preterm and SGA newborns also have an ongoing increased mortality risk after the neonatal period.

Potential for impact: More than 80% of neonatal deaths occurred among small newborns, of which 65% were

attributable to preterm and 19% to term SGA. Globally, 20 million LBW infants are born each year (37). The SDGs and Global Nutrition Plan include an ambitious goal to reduce LBW by 30% by 2025, although new trend data suggest very limited progress. Treatment for infections and non-communicable diseases during pregnancy and improved nutrition for young and adolescent girls have potential as interventions with significant impact. In the meantime, it is possible to achieve major and rapid reduction of mortality through improved care for all small newborns (5).

Thrive: ensure their health and well-being

How many small and sick newborns?

More than 30 million small and sick newborns have life-threatening conditions and require inpatient care in hospitals (Table 2.2). An estimated 8–10 million newborns require intensive care, notably respiratory support. This includes preterm newborns with complications, intrapartum-related brain injury, severe bacterial infection, pathological jaundice and those with congenital

conditions. Many may require inpatient care for weeks at a time and some, especially the extremely preterm newborns, may be inpatients for longer. Yet many with life-threatening conditions do not receive even basic warmth and feeding support (see Chapter 3).

In 2010, an estimated 14.8 million infants were born preterm (i.e. less than 37 weeks' gestation). This represented 10.6%, and in some countries more than 15%, of all live births (18, 19). Even moderate to late preterm infants (32–37 weeks' gestation) have an increased risk of immediate complications, and neonatal and infant death. Those who survive to 2 years of age are three times more likely to have language and motor delays, twice as likely to have delays in cognitive development, and likely to have poorer social-emotional skills than infants born at term.

Preventing disability and optimizing child development

Most disabilities among newborns born after 25 weeks' gestation are preventable, although risk of death or disability varies greatly depending on where the birth takes

Table 2.2 Estimates of small and sick newborns who need hospital care and intensive newborn care

Condition	Estimated numbers per year globally (<i>unless otherwise specified</i>)
Prematurity Less than 37 completed weeks' gestation	14.8 million preterm newborns (18, 19) 2.3 million are < 32 weeks' gestation, the majority of whom need intensive newborn care, especially ventilatory support for preterm respiratory complications
Severe infections (sepsis, meningitis, pneumonia)	6.9 million in LMICs with possible severe bacterial infections Approximately 3 million may need intensive care (23)
Intrapartum injury	7–14 million who need basic resuscitation at birth 1.2 million with moderate or severe neonatal encephalopathy/hypoxic ischaemic encephalopathy who need intensive care (30)
Jaundice	481 000 term or near-term newborns who require phototherapy and/or exchange transfusion for severe jaundice (35)
Congenital abnormalities	1.3 million including congenital heart disease, neural tube defects, orofacial clefts and other major abnormalities likely to present in the neonatal period and requiring care, including paediatric surgery (39)
TOTAL	> 30 million* require hospital care at least initially, of whom approximately 8–10 million require intensive inpatient care

* Based on estimates of births in 2016.

Note: due to co-morbidity, especially of preterm cases in which newborns need resuscitation, the lower level of basic resuscitation needs (7 million) is conservative. An additional 10.4 million LBW and SGA newborns (36) are at increased risk of death but have not been added to the total to avoid double counting with other cases, especially infections and birth complications.

place (Fig. 2.6). In HICs (with NMR < 5 per 1000 live births), where high-quality intrapartum and newborn care is typically available, few full-term newborns develop complications. More than 95% of preterm newborns survive and thrive. Even at extreme gestational viability under 25 weeks, more than half will survive with intensive care. Between HICs, there is variability in the risk of disability, strongly influenced by quality of care and effective follow-up.

In MICs, although progress has been made in survival, the risk of disability at 28–32 weeks’ gestation is nearly double that observed in HICs. In most low- and middle-income settings with higher mortality (NMR ≥ 15 per live births), disability is less common because, currently, those with severe complications do not survive without intensive care (40).

As deaths are reduced, and especially once intensive care is widely available, countries may experience a phase of higher disability among survivors, but it is important to emphasize that most disability is preventable. Disability is an even more sensitive measure of care quality, and may place a long-term burden on families with addition medical, psychosocial, educational and socioeconomic needs (see Chapter 4).

Disability after preterm birth: Of 13 million preterm birth survivors annually, 345 000 are estimated to have moderate to severe neurodevelopmental impairment, mostly in MICs. An additional 567 000 have mild neurodevelopmental impairment. There are more children with milder disabilities or suboptimal child development, such as learning or behavioural impairments; these may be under-reported in MICs and especially in LICs (40). An estimated 184 700

Fig. 2.7 Death and disability: the four worlds into which 140 million are born annually



Figure updated from: Beyond Newborn Survival (38); and The Lancet Every Newborn series (6) updated with 2017 data regarding place of birth.

Box 2.4 Retinopathy of prematurity: a major cause of preventable blindness in Latin America and the Caribbean

Over the past decade, retinopathy of prematurity has emerged as a leading cause of blindness and visual impairment among children in MICs, particularly in Latin America and Eastern Europe. Approximately 10% of retinopathy of prematurity cases resulted in blindness or severe visual impairment, most likely caused by the most acute stages of the disease and the absence of advanced treatment. Yet in HICs, retinopathy of prematurity now rarely causes blindness due to improved prevention and early detection and treatment.

Until recently, data on retinopathy of prematurity across Latin America and Caribbean countries only existed for certain cities. A multicountry quantitative and qualitative online survey of medical and public health experts working on retinopathy of prematurity in the region was carried out to estimate

national incidence of the condition and assess four government inputs: existing national policies, guidelines, programmes and financing. The results show great disparity in the coverage of legislation and national data collection systems used for monitoring of the condition. Only two countries in the study reported having all four national-level government inputs on retinopathy of prematurity. Countries with three or four national-level inputs averaged 95% of eligible newborns screened, while those with only one or two national-level inputs averaged 35%.

Standard criteria are required to help health-care providers identify all newborns eligible so that potential cases are not missed. Crucially, health systems need to have the capacity to provide follow-up care, improve technology, and develop a skilled workforce with trained ophthalmologists (43).

preterm newborns in 2010 developed retinopathy of prematurity during the neonatal period; 53 800 progressed to potential vision-impairing disease, 20 000 of whom became blind or severely visually impaired (41). Retinopathy of prematurity is directly related to the quality of inpatient care (see Box 2.4). There are increasing rates in MICs where neonatal care has been scaled up without attention to quality and monitoring systems, or specialist training (41, 42). The limited data suggest that lower retinopathy of prematurity rates in Africa may be due to higher mortality rates of preterm newborns in these settings.

Disability after neonatal encephalopathy:

An estimated 1.2 million newborns suffer neonatal encephalopathy associated with birth injury, of which 96% are born in LMICs. Of the survivors, 233 000 per year are estimated to develop moderate to severe neurodevelopmental impairment (such as cerebral palsy) and 181 000 display mild impairment and suboptimal child development (30).

Disability after neonatal infections:

Neurodevelopmental impairment occurs in 23% of survivors of neonatal meningitis. However, there are no useable data regarding

the burden of disability for survivors of neonatal sepsis, which is a priority research gap (23). Since neonatal sepsis is a common exposure, even a low risk of impairment would have a large population attributable effect.



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Lifelong and intergenerational health

Size at birth is well known to predict health outcomes, even in adulthood. Fetal and early-life environmental influences are important risk factors for stunting, child development and long-term risk of non-communicable disease. Data are scarce for impairment outcomes after SGA but suggest a small increased risk of cognitive delay and behavioural disorders (such as attention deficit hyperactivity disorder) at all gestational ages compared with appropriate-for-gestational-age peers (6, 30). Preterm and SGA newborns have the highest risk of stunting in childhood. Prevalence of cardiovascular disease, obesity and insulin resistance or type 2 diabetes is increasing, with epidemic levels in many countries. Small and preterm newborns have experienced developmental programming in utero (previously known as the Barker hypothesis); this is a strong predictor of noncommunicable diseases for small newborns, both preterm and SGA, especially if they rapidly gain weight. The high rates of SGA, especially in Southern Asia, are contributing to the noncommunicable disease epidemic. However, compared with investment and innovation for treating adult noncommunicable diseases, there is little focus on promoting fetal health and growth gains to prevent these conditions.



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Transform: human capital, societal response and health systems

Acknowledge the loss of human capital

The world loses substantial human capital due to newborn deaths, disability and long-term risk of non-communicable diseases for small and sick newborns (Fig. 2.8). WHO and others use the disability-adjusted life year (DALY) to measure this burden. One DALY can be thought of as one lost year of healthy life. The sum of these DALYs across the population is an approximation of the gap between current health status and an ideal health situation where the entire population lives to an advanced age, free of disease and disability.

WHO Global Health Estimates 2016 estimated neonatal conditions (preterm birth, intrapartum-related, neonatal sepsis, and “other neonatal”) to be responsible for 219 million DALYs, or 8.2% of the global total (44). LMICs, many affected by humanitarian crises, have a higher total of DALYs compared to HICs, with a larger proportion attributed to neonatal conditions (45).

There is also a major and under-recognized loss of human capital and productivity due to the social, economic and emotional burden on parents and families when caring for their small and sick newborns, or if their child dies (46). Compared with the general population, parents of preterm, sick or disabled newborns who require inpatient neonatal care have a significantly higher incidence of depression and anxiety, and a three-fold risk of acute or post-traumatic stress disorders. These families are also more likely to experience marital discord and social isolation (47–50). The economic consequences for bereaved parents include funeral costs and lost productivity (51). Parents may also have to balance out-of-pocket expenditures (from hospitalization, outpatient care, supplies and childcare) with their reduced wages due to missed days of work (46, 52–53). Maternal psychological distress may also have detrimental effects on a child’s developmental, social and cognitive growth (54–56).

Address social norms and broader health determinants

In some societies, newborn death – especially of preterm newborns – is considered inevitable, even by health-care providers. Such fatalism is not based on evidence, since many of these deaths are preventable. Even in high-income settings, the likelihood of active medical intervention is affected by the perceptions of health-care providers of viability and social and economic factors, especially in those born close to the lower gestational age cut-off. Birth and death records are more likely to be missing for very LBW or extremely preterm infants. As noted previously, gender inequity also demands social transformation. This is especially true in cultures with a male gender preference, where girls are at increased social risk for sex-selective termination of pregnancy or reduced health-care access. It is thus crucial to address cultural and social norms, including investing in the education of girls.

Use data to inform action

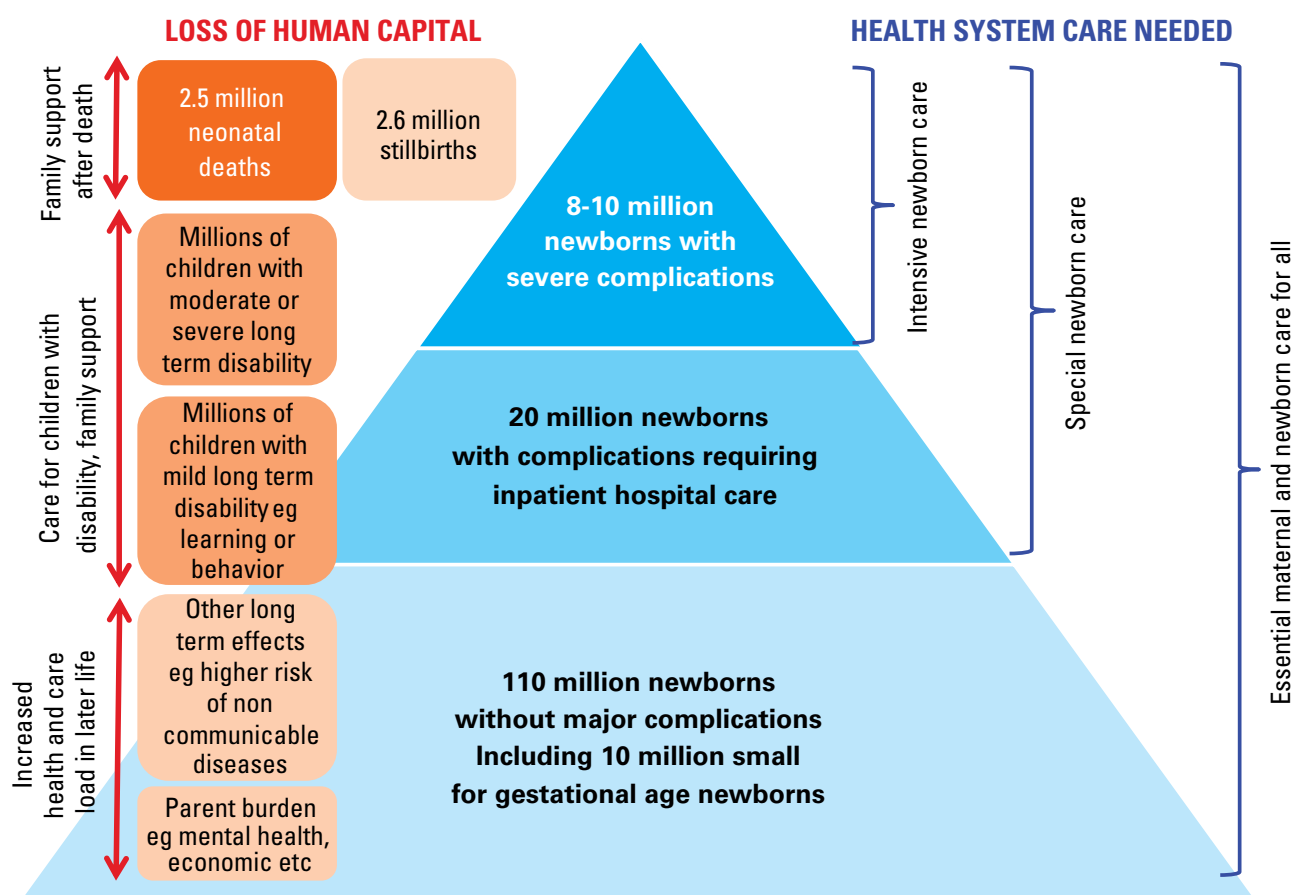
Each of the approximately 140 million infants born per year needs basic, essential care, including effective obstetric and essential newborn care (warmth, breast-milk feeding, hygiene and infection prevention and basic resuscitation). These are best provided by the parents and family with the support of skilled health-care providers. As noted earlier, an estimated 30 million small and sick newborns will have potentially life-threatening conditions and require special newborn care, for example with KMC or antibiotics. Roughly 8–10 million will need intensive newborn care, notably with respiratory support. These standards of care, infrastructure, technology, provider and parental needs are detailed in Chapters 3 and 4.

To plan the appropriate health system response, and to guide health system improvement and reach targets, the details of the problem and numbers requiring care

Most of a person's human capital and physiological development happens early in life. Childhood is thus a key period for human-capital building, and the burden of disease in childhood could have effects that persist throughout the life course (57).

must be understood (Fig. 2.8). Progress towards UHC will require comparability of increasingly complex data in order to track inequalities. There is a strategic objective within the Every Newborn Action Plan to transform the use of data to track coverage and quality of care. The Every Newborn Measurement Improvement Roadmap provides a multi-year, multi-partner pathway to define specific indicators, test validity, develop tools and promote data use (4). Chapter 5 presents opportunities to rapidly improve data systems that track outcomes and enable better care.

Fig. 2.8 Health system responses for small and sick newborns by level of care, with their impact on human capital



Adapted from: Lawn, Davidge & Paul, et al. Born too soon: care for the preterm baby (8).

A PARENT'S STORY

Once prohibited from touching her baby, this mother now advocates for family-centred care in Hungary



With the approval of her obstetrician, a pregnant Hungarian-French woman, Livia Nagy Bonnard, travelled from her home in France to visit her family in Budapest. It was during this trip that she began to have flu-like symptoms. A paediatric nurse, Livia knew that something was wrong. She went to the hospital and was diagnosed with pre-eclampsia. Livia was then transferred by ambulance to another hospital with an NICU. Three hours later, her son Edouard was born via emergency caesarean section. At 27 weeks' gestation, he weighed only 890 g.

The NICU had restrictive visiting policies, only allowing 2 visits a day for 20 minutes at a time.

"The worst part is that I could not touch him," Livia remembered. "They would be telling me that I could give him an infection. You start to believe them ... I felt like I could not do anything for him."

One thing Livia tried to do was provide breastmilk. "I brought my milk to the hospital. I was so proud of what I had pumped. I put it on the table. My son's nurse said 'What are you doing with this milk? You can't give him milk with your pre-eclampsia medication.' And then the nurse poured the milk down the sink. Soon after my milk dried up." During Edouard's 14 weeks in neonatal intensive care, he was never diagnosed with a disability. However, Livia's nursing experience and maternal instincts told her that something was amiss.

"I kept telling people that there was something wrong. I am the expert on my child. But the staff

always found reasons to try and send me to a psychologist," she recalled.

Five months after his birth, Edouard was finally cleared by his Hungarian doctors to make the journey back home to France. Edouard's follow-up care in France was extensive, but his development was slow. "At the age of 2, I was worried he still wasn't walking," Livia said. "I finally saw the paediatrician of my sister who gave us an MRI. Only then did they diagnose him with PVL." Periventricular leukomalacia, or PVL, is a type of brain injury that can result in cognitive and motor disabilities. Now 12, Edouard has had extensive physical, occupational, speech, and animal-assisted therapies. While developmentally delayed, he speaks two languages and is learning to read.

"We are not isolating from the world," Livia says about her family. "We go on vacations. We live our life together." Four years ago, Livia joined as a member of the European Foundation for the Care of Newborn Infants (EFCNI) Parent Advisor Board. She also helped create a Hungarian parent organization called Melletted a helyem Egyesület – (Right(s) beside you!). In these roles, Livia works in partnership with clinicians to bring family-centred care initiatives to Hungarian neonatal care units. "It is my therapy," Livia says about her advocacy work.



REFERENCES

1. UNDESA. Sustainable Development Goals. 2015 (<https://sustainabledevelopment.un.org/topics/sustainabledevelopmentgoals>, accessed 24 February 2019).
2. UNICEF, WHO. Every newborn: an action plan to end preventable deaths. Geneva: World Health Organization; 2014 (http://www.who.int/maternal_child_adolescent/newborns/every-newborn/en/, accessed 24 February 2019).
3. QED: Network for improving quality of care for maternal, newborn and child health website (<http://qualityofcarenetwork.org/about>, accessed 24 February 2019).
4. Moxon SG, Ruysen H, Kerber KJ, Amouzou A, Fournier S, Grove J, et al. Count every newborn; a measurement improvement roadmap for coverage data. *BMC Pregnancy Childbirth*. 2015;15 (Suppl 2):S8.
5. Bhutta ZA, Das JK, Bahl R, Lawn JE, Salam RA, Paula VK, et al. Can available interventions end preventable deaths in mothers, newborn babies, and stillbirths, and at what cost? *Lancet*. 2014;384(9940):347-70.
6. Lawn JE, Blencowe H, Oza S, You D, Lee AC, Waiswa P, et al. Every Newborn: progress, priorities, and potential beyond survival. *Lancet*. 2014;384(9938): 189–205.
7. UN IGME. Levels & trends in child mortality: report 2018. Estimates developed by the United Nations inter-agency group for child mortality estimation (UN IGME). New York: United Nations Children's Fund; 2018.
8. Lawn JE, Davidge R, Paul VK, von Xylander S, de Graft Johnson J, Costello A, et al. Born too soon: care for the preterm baby. *Reprod Health*. 2013;10 (Suppl 1):S5–S5.
9. Victora CG, Boerma T. Inequalities in child mortality: real data or modelled estimates? *Lancet Global Health*. 2018;6(5):e477–e478.
10. Afnan-Holmes H, Magoma M, John T, et al. Tanzania's Countdown to 2015: an analysis of two decades of progress and gaps for reproductive, maternal, newborn, and child health, to inform priorities for post-2015. *Lancet Glob Health*. 2015;3(7):e396–e409.
11. KC, Ashish, Jha AK, Shrestha MP, et al. Time trends and risk factors associated with neonatal death; projection of neonatal mortality rate for 2030 in Nepal. (Under review) *Maternal and Child Health J*, 2019.
12. Survive, Thrive, Transform Global Strategy for Women Children's and Adolescents Health. 2018 monitoring report: current status and strategic priorities. Geneva: World Health Organization; 2018.
13. Lawn JE, Bhutta ZA, Wall SN, Peterson S, Daviaud E. Cadres, content and costs for community-based care for mothers and newborns from seven countries: implications for universal health coverage. *Health Policy Plan*. 2017;32(Suppl 1):i1–i5.
14. Oza S, Cousens SN, Lawn JE. Estimation of daily risk of neonatal death, including the day of birth, in 186 countries in 2013: a vital-registration and modelling-based study. *Lancet Glob Health*. 2014;2:e635–44.
15. Gupta G, et al. Use of real time monitoring system in sick newborn care units in India. UNICEF, 2017 (<https://docplayer.net/64991967-use-of-real-time-monitoring-system-in-sick-newborn-care-units-in-india-subhead.html>, accessed 24 February 2019).
16. WHO. WHO-MCEE estimates for child causes of death, 2000-2016. Geneva: World Health Organization; 2017.
17. Blencowe H, Cousens S, Chou D, Oestergaard M, Say L, Moller AB, et al. Born too soon: the global epidemiology of 15 million preterm births. *Reprod Health*. 2013;10 (Suppl 1):S2.
18. Blencowe H, Cousens S, Oestergaard MZ, Chou D, Moller AB, Narwal R, et al. National, regional, and worldwide estimates of preterm birth rates in the year 2010 with time trends since 1990 for selected countries: a systematic analysis and implications. *Lancet*. 2012;379(9832):2162–72.
19. Chawanpaiboon S, Vogel JP, Moller AB, Lumbiganon P, Petzold M, Hogan D, et al. Global, regional, and national estimates of levels of preterm birth in 2014: a systematic review and modelling analysis. *Lancet Glob Health*. 2019;7(1):e37–e46
20. Chang HH, Larson J, Blencowe H, Spong CY, Howson CP, Cairns-Smith S, et al. Preventing preterm births: analysis of trends and potential reductions with interventions in 39 countries with very high human development index. *Lancet*. 2013;381(9862):223–34.
21. Desai M, ter Kuile FO, Nosten F, McGready R, Asamoia K, Brabin B, et al. Epidemiology and burden of malaria in pregnancy. *Lancet Infect Dis*. 7(2):93–104.
22. Sandall J, Soltani H, Gates S, Shennan A, Devane D. Midwife-led continuity models versus other models of care for childbearing women. *Cochrane Database of Systematic Reviews*. 2016;Issue 4. Art. no.: cd004667. doi: 10.1002/14651858.cd004667.pub5.

23. Seale AC, Blencowe H, Zaidi A, Ganatra H, Syed S, Engmann C, et al. Neonatal severe bacterial infection impairment estimates in South Asia, sub-Saharan Africa, and Latin America for 2010. *Pediatr Res.* 2013;74 (Suppl 1):73–85.
24. Saha SK, Schrag SJ, El Arifeen S, Mullany LC, Shahidul Islam M, Shang N, et al. Causes and incidence of community-acquired serious infections among young children in south Asia (ANISA): an observational cohort study. *Lancet.* 2018;392(10142):145–59.
25. Lawn JE, Bianchi-Jassir F, Russell NJ, Kohli-Lynch M, Tann CJ, Hall J, et al. Group B streptococcal disease worldwide for pregnant women, stillbirths, and children: why, what, and how to undertake estimates? *Clin Infect Dis.* 2017;65(Suppl 2):S89–S99.
26. Seale AC, Bianchi-Jassir F, Russell NJ, Kohli-Lynch M, Tann CJ, Hall J, et al. Estimates of the burden of Group B Streptococcal disease worldwide for pregnant women, stillbirths, and children. *Clin Infect Dis.* 2017;65(Suppl 2):S200–S219.
27. Okomo U. Neonatal infections; a hospital-based study in the Gambia examining aetiology and associated maternal colonisation. PhD thesis completed, London School of Hygiene & Tropical Medicine.; 2018. doi: <https://doi.org/10.17037/pubs.04646824>, accessed 24 February 2019).
28. Liu L, Oza S, Hogan D, Chu Y, Perin J, Lawn JE, et al. Global, regional, and national causes of under-5 mortality in 2000–15: an updated systematic analysis with implications for the Sustainable Development Goals. *Lancet.* 2016;388: 3027–35.
29. Lawn JE, Lee AC, Kinney M, Sibley L, Carlo WA, Paul VK, et al. Two million intrapartum-related stillbirths and neonatal deaths: where, why, and what can be done? *Int J Gynaecol Obstet.* 2009;107 (Suppl 1):S5–18, s19.
30. Lee AC, Kozuki N, Blencowe H, Vos T, Bahalim A, Darmstadt GL, et al. Intrapartum-related neonatal encephalopathy incidence and impairment at regional and global levels for 2010 with trends from 1990. *Pediatr Res.* 2013;74 (Suppl 1):50–72.
31. Moxon SG, Lawn JE, Dickson KE, Simen-Kapeu A, Gupta G, Deorari A, et al. Inpatient care of small and sick newborns: a multi-country analysis of health system bottlenecks and potential solutions. *BMC Pregnancy Childbirth.* 2015;15 Suppl 2: S7.
32. Higashi H, Barendregt JJ, Vos T. The burden of congenital anomalies amenable to surgeries in low-income and middle-income countries: a modelled analysis. *Lancet.* 381:S62.
33. Blencowe H, Cousens S, Modell B, Lawn J. Folic acid to reduce neonatal mortality from neural tube disorders. *Int J Epidemiol.* 2010;39(Suppl 1):i110–i121.
34. Yunis KA, Al Bizri A, Al Raiby J, Nakad P, El Rafei R, Siddeeg K, et al. (Under review) *Int J Epidemiol*, 2019.
35. Bhutani VK, Zipursky A, Blencowe H, Khanna R, Sgro M, Ebbesen F, et al. Neonatal hyperbilirubinemia and Rhesus disease of the newborn: incidence and impairment estimates for 2010 at regional and global levels. *Pediatr Res.* 2013;74:86.
36. Katz J, Lee AC, Kozuki N, Lawn JE, Cousens S, Blencowe H, et al. Mortality risk in preterm and small-for-gestational-age infants in low-income and middle-income countries: a pooled country analysis. *Lancet.* 2013;382(9890):417–25.
37. Blencowe H, Krasever J, de Onis M, Black RE, An X, Stevens GA, et al. National, regional, and worldwide estimates of low birthweight in 2015, with trends from 2000: a systematic analysis. *Lancet Glob Health* (in press) March 2019.
38. Lawn JE, Blencowe H, Darmstadt GL, Bhutta ZA. Beyond newborn survival: the world you are born into determines your risk of disability-free survival. *Pediatr Res.* 2013;74(Suppl 1):1–3.
39. Modell B, Darlison M, Moorthie S, Blencowe H, Petrou M, Lawn J. Epidemiological methods in community genetics and the Modell global database of congenital disorders (MGDb). *UCL Discovery*; 2016 (<http://discovery.ucl.ac.uk/1532179/>, accessed 24 February 2019).
40. Blencowe H, Lee AC, Cousens S, Bahalim A, Narwal R, Zhong N, et al. Preterm birth-associated neurodevelopmental impairment estimates at regional and global levels for 2010. *Pediatr Res.* 2013;74 (Suppl 1):17–34.
41. Blencowe H, Lawn JE, Vazquez T, Fielder A, Gilbert C. Preterm-associated visual impairment and estimates of retinopathy of prematurity at regional and global levels for 2010. *Pediatr Res.* 2013;74(Suppl 1):35–49.
42. Gilbert C, Darlow B, Zin A, Sivasubramaniam S, Shah S, Gianini N, et al. Educating neonatal nurses in Brazil: a before-and-after study with interrupted time series analysis. *Neonatology.* 2014;106(3):201–8.
43. Arnesen L, Durán P, Silva J, Brumana L. A multi-country, cross-sectional observational study of retinopathy of prematurity in Latin America and the Caribbean. *Rev Panam Salud Publica* 2016;39(36):322–9.
44. Global Health Estimates 2016: Disease burden by cause, age, sex, by country and by region, 2000–2016. Geneva, World Health Organization; 2018. (https://www.who.int/healthinfo/global_burden_disease/estimates/en/index1.html, accessed 24 February 2019).

45. World Bank. Harmonized list of fragile situations FY 18 (<http://pubdocs.worldbank.org/en/189701503418416651/fy18fcslist-final-july-2017.pdf>, accessed 24 February 2019).
46. Lakshmanan A, Agni M, Lieu T, Fleegler E, Kipke M, Friedlich PS, et al. The impact of preterm birth <37 weeks on parents and families: a cross-sectional study in the 2 years after discharge from the neonatal intensive care unit. *Health Qual Life Outcomes*. 2017;15(1):38.
47. Pace CC, Spittle AJ, Molesworth CL, Lee KJ, Northam EA, Cheong JL, et al. Evolution of depression and anxiety symptoms in parents of very preterm infants during the newborn period. *JAMA Pediatr*. 2016;170(9):863–70.
48. Vigod SN, Villegas L, Dennis CL, Ross LE. Prevalence and risk factors for postpartum depression among women with preterm and low-birth-weight infants: a systematic review. *BJOG*. 2010;117(5):540–50.
49. Henderson J, Carson C, Redshaw M. Impact of preterm birth on maternal well-being and women's perceptions of their baby: a population-based survey. *BMJ Open*. 2016;6(10):e012676.
50. Roque ATF, Lasiuk GC, Radunz V, Hegadoren K. Scoping review of the mental health of parents of infants in the NICU. *J Obstet Gynecol Neonatal Nurs*. 2017;46(4):576–87.
51. Fox M, Cacciatore J, Lacasse JR. Child death in the United States: productivity and the economic burden of parental grief. *Death Stud*. 2014;38(9):597–602.
52. Hodek J-M, Graf von der Schulenburg JM, Mittendorf T. Measuring economic consequences of preterm birth – methodological recommendations for the evaluation of personal burden on children and their caregivers. *Health Econ Rev*. 2011;1:6.
53. Dutta S, Mahajan R, Agrawal SK, Nehra R, Narang A. Stress in fathers of premature newborns admitted in a neonatal intensive care unit. *Indian Pediatr*. 2016;53(4):311–13.
54. Spencer N, Wallace A, Sundrum R, Bacchus C, Logan S. Child abuse registration, fetal growth, and preterm birth: a population based study. *J Epidemiol Community Health*. 2006;60(4):337–40.
55. Strathearn L, Gray PH, Callaghan F, Michael J, Wood DO. Childhood neglect and cognitive development in extremely low birth weight infants: a prospective study. *Pediatrics*. 2001;108(1):142.
56. Spittle A, Treyvaud K. The role of early developmental intervention to influence neurobehavioral outcomes of children born preterm. *Semin Perinatol*. 2016;40(8):542–8.
57. Bleakley H. Health, human capital, and development. *Annu Rev of Econom*. 2010;2(1): 283–310.



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**Deliver the care
they are entitled to**

KEY MESSAGES

- **Cost-effective, evidence-based solutions are available to prevent newborn deaths and disability.** Newborns are vulnerable and can die within minutes, especially when small and sick. Preventing deaths and disability through inpatient care requires a defined space, adequately staffed with competent nurses and doctors, safe technologies, medicines and diagnostics, and evidence-based processes to ensure quality and sustainability. Moreover, keeping newborn and mother together, avoiding separation from the wider family, and empowering parents and families can have great benefits which include: reduced mortality; better nutrition and well-being; and lower levels of readmission to hospital.
- **Quality care requires an integrated, resilient health system, multidisciplinary teams, and innovation.** Care for small and sick newborns needs to be organized by population size and need, with a network of facilities and varying health system levels connected by functional referral systems. High-quality care requires investment in sufficient numbers of health-care providers with skills to care for small and sick newborns, particularly trained and motivated nurses, working in partnership with parents and families.
- **Reducing barriers and discrimination is crucial to reaching all newborns and their families.** Equitable care requires strengthening existing health services, expanding the workforce with neonatal care competencies, and reaching marginalized populations. Infants born amid humanitarian crises require special attention and investment. Newborn care must be included in financial protection planning within UHC, as newborns and their families may be in hospital for weeks and subject to catastrophic costs.



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Coverage with quality, dignified care

UHC expands access to high-quality, integrated, people-centred health services to reach everyone, with no one incurring financial hardship (1). To achieve the desired neonatal outcomes, UHC packages should include locally-defined, high-impact, cost-effective interventions for the care of small and sick newborns, and multisectoral approaches where appropriate. At the same time, health systems should be strengthened to ensure that increased coverage of neonatal interventions is accompanied by improved quality of newborn services, as poor quality of care contributes to morbidity, disability and mortality and undermines public confidence (Annex 3 provides details of key neonatal interventions).

Quality of care for newborns is defined by WHO as the degree to which newborn health services increase the likelihood of timely, appropriate care for the purpose of achieving desired outcomes that are both consistent with current professional knowledge and take into account the preferences and aspirations of women and families (2). The key components of quality of care for mothers and newborns in health facilities are summarized by the quality of care framework (Fig. 3.1). The framework sets out the values of quality, equity and dignity. It identifies two important components of care: the quality of provision of care; and the quality of care as experienced by women, newborns and families (2). Good-quality care services use evidence-based practices; are well-organized, accessible and adequately resourced;

are safe, efficient, timely and people-centred (2); and ensure optimal clinical, developmental and social outcomes for small and sick newborns.

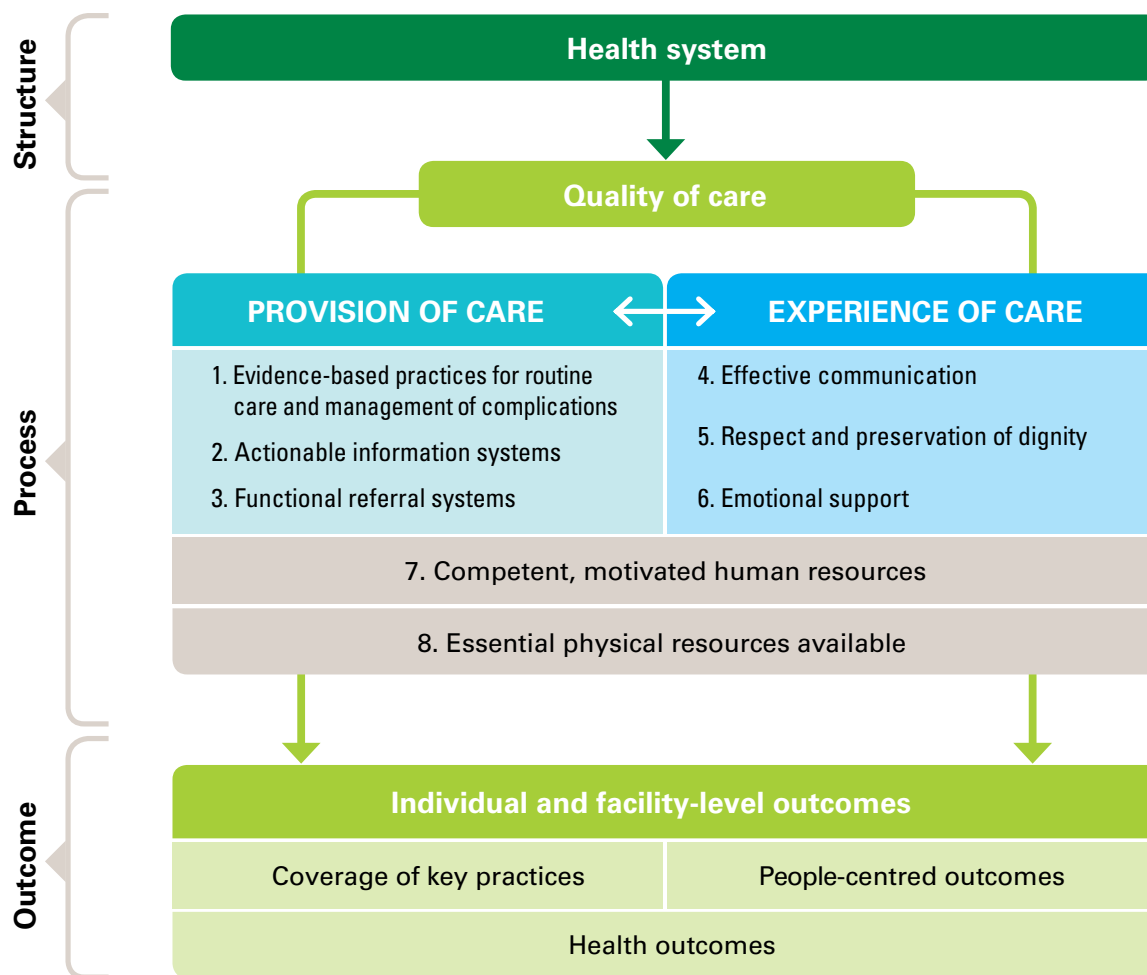
In February 2017, WHO, UNICEF, and their partners launched the Quality of Care Network to strengthen quality and support implementation of maternal and newborn care in 10 countries. The aim of the network is to reduce **maternal and newborn deaths and stillbirths in these countries' health facilities by 50% within five years**. The network provides a unique opportunity to document and share lessons on implementing quality care for small and sick newborns through specific standards and harmonized country support (3).

The importance of evidence-based practice

Consistently safe and effective care for small and sick newborns becomes possible when evidence-based practice is used in routine and emergency care. With evidence based on research, universal standards and guidelines can be developed to support health-care facilities and providers in all settings. Providers are better equipped to deliver high-quality care for small and sick newborns when they incorporate scientific knowledge into practices. This approach requires stakeholder engagement and commitment.

The international standards and guidance published by WHO for newborn care are a good starting point

Fig. 3.1 WHO quality of care framework



Adapted from: WHO. Standards for improving quality of maternal and newborn care in health facilities, 2016 (1, 2).

(2, 5, 6). Countries can use these resources to develop their own national standards that reflect specific disease burdens and available resources. Global WHO standards tailored for the care of small and sick newborns are anticipated in 2019.

For sustainable success, leadership within health-care facilities can help to cultivate a culture of evidence-based

Evidence-based practice is “the conscientious, explicit and judicious use of current best evidence in making decisions about the care of the individual patient. It means integrating individual clinical expertise with the best available external clinical evidence from systematic research.” (4)

practice among providers. Readily available guidelines and protocols, along with training on integrating and interpreting guidelines, are needed at all levels of the health system. Kangaroo mother care, for example, is an evidence-based intervention with demonstrated high impact on survival, brain development and quality of care not yet implemented at scale (see Box 3.1). Given that new evidence continually emerges, it cannot be adequately stressed that there is a need for continued health-care education to ensure that staff are up to date with best clinical practices.

Developmentally supportive care and neuroprotection

Close attention should be paid to delivering developmentally supportive care to small and sick newborns. Excessive handling can disturb a newborn’s sleep,

Box 3.1 Benefits of intermittent and continuous kangaroo mother care

Kangaroo mother care (KMC) is an evidence-based approach, recommended by WHO, for the care of LBW (especially preterm) newborns (7, 8). KMC involves early, continuous and prolonged skin-to-skin contact between the newborn and parents or another caregiver in the “kangaroo position”, with exclusive breastfeeding where possible. KMC should be accompanied by supportive care, early discharge, and appropriate follow-up (see Chapter 4 for more details) (8).

KMC has been shown to reduce mortality by up to 50% in LBW newborns weighing <2000 g when compared with conventional care; evidence for this is particularly strong in LMICs (9, 10). KMC was originally intended for more poorly-resourced and high-mortality settings. However, an increasing body of evidence shows multiple benefits for newborns and their families in all settings, including HICs. Benefits include improved duration of breastfeeding,

weight gain, and physiological stability for infants (9, 11). KMC also supports parent–infant bonding and child development in all settings, including improved longer-term neurobehavioural and psychomotor development and brain maturation (12–15).

In many countries, skin-to-skin contact and KMC are now considered the gold standard for preterm newborns and are regularly integrated into family-centred care approaches to inpatient care (11, 16). As a central family-centred care component, KMC empowers families to care for their small newborns and shortens their length of stay in hospital. Studies also show that KMC can reduce the workload for health-care providers, especially nurses (17). Both intermittent and continuous KMC are beneficial and can be provided alongside other interventions and care, such as CPAP, as appropriate for the newborn’s clinical condition.

well-being, and growth. Health-care providers can minimize disturbance by grouping interventions, which involves “clustering care” into one caregiving period. This practice should be guided by what the newborn will tolerate. Contact with parents, especially mothers, should be maximized to encourage bonding and to support lactation and feeding with breastmilk (18). Care that includes correct positioning of the newborn also protects skin, safeguards sleep, and minimizes stress and pain (19–22) (See Chapter 4 for more details on developmentally supportive care for children).

Evidence shows that pain affects brain development, with potentially long-term effects. Health-care providers should ensure that newborns do not experience unnecessary discomfort or pain, both to optimize brain development and because pain management is also a crucial component of dignified and humane care. Therefore, health-care providers need to be able to recognize pain cues, particularly in small newborns, and know how to prevent and minimize pain (23). Appropriate tools are recommended to assess pain and make decisions on pain and comfort management (24, 25). Increasingly, evidence supports improved comfort management when newborns are breastfed or placed skin-to-skin with a family member during painful procedures (21, 24, 25). For sicker newborns, analgesics may be necessary, although only with full risk awareness

and proper monitoring in place throughout treatment (23) (see Box 3.2).

The term “dignified care” for inpatient newborns implies respectful care for both the newborn and the parents and caregivers. Health-care providers must treat all newborns with respect and sensitivity and ensure their dignity; give them the high-quality care they are entitled to without discrimination; provide age- and culturally-appropriate nutrition; and protect them from any form of violence while in care, including physical abuse, neglect or detainment (6).

Parents and caregivers too should be treated with respect and dignity, kindness, compassion, courtesy and honesty. The health-care providers should respect the rights of parents and caregivers, including access to information, privacy and confidentiality, support for breastfeeding and protection from unnecessary separation from their infants (6).

The concept of respectful maternity care is well defined and covers both the mother and the newborn at the time of birth. Some elements of respectful care for newborns are reflected in the global standards for improving quality of maternal and newborn care and the standards for improving the quality of care for children and young adolescents in health facilities. However,

Box 3.2 Guidelines for pain management

The American Academy of Pediatrics released a policy statement in 2016 recommending that health-care facilities minimize the number of painful procedures performed on newborns, while routinely assessing and treating pain in these patients. In the section on anaesthesiology and pain medicine in the policy statement, the Academy's Committee on Fetus and Newborn states that: "Neonates are frequently subjected to painful procedures, with the most immature infants receiving the highest number of painful events."

Varying degrees of neonatal discomfort or pain may occur during routine patient care (nasogastric tube placement, bladder catheterization or physical examination); in moderately invasive procedures (suctioning, phlebotomy or peripheral intravenous access); and in more invasive procedures (chest tube placement, circumcision or central venous access).

Source: This statement was published online on 25 January 2016 and in the February 2016 issue of Pediatrics as an update of a position paper first published in 2006 (26).

Acute pain is also experienced from skin-breaking procedures, established pain following surgery, and pain from diseases such as necrotizing enterocolitis or epidermolysis bullosa. Pain continues to be inconsistently assessed and inadequately managed in newborn patients (26).

Data of newborns suggest that repeated exposure to pain early in life can lead to abnormalities in both brain development and stress responses that persist into childhood. In its updated policy statement, the American Academy of Pediatrics recommends that each institution should develop its own evidence-based written guidelines. These should address prudent use of procedures, routine pain monitoring, use of drug and nondrug therapies to manage pain during minor procedures, and effective medications to manage pain during surgery.

further articulation of respectful care is required for infants admitted as patients (27). The ongoing Quality of Care Network is well-positioned to expand its focus from care around time of birth to covering inpatient newborn care and strengthening global experience-sharing and learning in this area. Recent studies and reports have highlighted the need to embed such efforts in UHC (28) and the health-system strengthening agenda (29, 30) and have called for investments in implementation research for improving quality of care for small and sick newborns.

What to do when a newborn dies

Mothers, fathers and families need information and support when a newborn dies. Most neonatal deaths occur in preterm infants, newborns with infections, and cases of neonatal encephalopathy or severe congenital abnormalities. It is important to inform the parents as soon as possible if a newborn's condition is deteriorating.

As with end-of-life care for all patients, newborns with untreatable conditions are entitled to a dignified and pain-free death. A newborn should be allowed to die with his or her family in a private, quiet space; parents should be given the opportunity to see and hold their newborn

before and at the end of life as culturally appropriate (31, 32). Good-quality, compassionate bereavement care, including psychological and spiritual support after a newborn dies, reduces the negative emotional, psychological and social effects for parents and staff (33). Steps to create or help preserve memories are important but should be culturally appropriate. In some settings, taking footprints, photos and giving families baby clothing or a cutting of hair in memory boxes can be extremely meaningful (32). Support for the mother on how to stop breastmilk production after her newborn has died may include advice on applying pressure to the breasts (bandages/tight clothing) and discouraging expression of breastmilk. Simple pain relief can be provided if needed to reduce any discomfort. Alternatively, mothers may be offered the option of donating their breastmilk as a precious resource that can be used to support other small and sick newborns. Donation of breastmilk during bereavement respects the great value of breastmilk and may be therapeutic for the grieving mother (34).

It is essential that neonatal deaths are recorded and a death certificate completed. Health facilities can facilitate neonatal death audits and quality improvement by retaining information on the causes and circumstances of death.

Organizing services by level of care

For a small and sick newborn to survive, and thrive in later life, the family must be able to access the appropriate level of care within the health system. In a well-functioning system, care for small and sick newborns is provided across different levels of a network of facilities organized by population size and need.

The simplest organization has three levels, mirroring primary, secondary and tertiary care at the population level: 1) **essential** newborn care is provided at primary care level and in all facilities where births take place; 2) **special** newborn care is provided at secondary level; and 3) **intensive** care is provided at tertiary level (Fig. 3.2). Ideally these levels are interconnected by communication and referral systems. Frequently, there are additional levels or sublevels based on population size, health system context, and capacity.

The level of inpatient care that a newborn receives is determined by their individual clinical needs (Fig. 3.2). As noted in Chapter 1, all levels of care, regardless of the setting and health system capacity, require space, care and referral

protocols. Policies are needed to engage parents and other family members in the newborn's care, with emphasis on minimizing the separation of parents and their newborns.

Essential care

At the primary care level, a facility provides essential care at birth and in the early postnatal period. This is required for all newborns, and includes outpatient services. Up to 1 in 10 newborns will require resuscitation at birth and 5–15% will be preterm or LBW, as discussed in Chapter 2. Even the most basic facility where birth takes place should be prepared to give bag and mask resuscitation to newborns who require it. These facilities should have trained staff; equipment and supplies to provide essential newborn care; postnatal care for the mother and the newborn during the first 24 hours after birth; and a referral system linking the facility to secondary and tertiary levels of care for infants with complications requiring inpatient care. The primary care facility should also provide outpatient services such as routine postnatal care to detect, stabilize and refer infants with high-risk conditions, manage minor problems, and ensure follow-up of the newborn after discharge.

Fig 3.2 Inpatient care for small and sick newborns: requirements for care at different health system levels

Level	Type of care provided	Health system requirements	Standards of care & evidence-based interventions	
PRIMARY	Essential newborn care	Place	<ul style="list-style-type: none"> • Immediate newborn care (thorough drying, skin-to-skin contact of the newborn with the mother, delayed cord clamping, hygienic cord care) • Neonatal resuscitation (for those who need it) • Early initiation and support for exclusive breastfeeding • Routine care (Vitamin K, eye care and vaccinations, weighing and clinical examinations) • Prevention of mother to child transmission of HIV • Assessment, management and referral of: <ul style="list-style-type: none"> ◦ bacterial infections including treatment of Possible Severe Bacterial Infection (PSBI) where referral not possible* ◦ jaundice and diarrhoea ◦ feeding problems ◦ birth defects and other problems • Pre-discharge advice on mother and baby care and follow up 	
		People		<ul style="list-style-type: none"> • Space for childbirth, with specific areas for resuscitation, stabilization and care, and for postnatal care for mother and baby to stay together • Infrastructure for handwashing • Outpatient facility for routine postnatal care and management of newborn problems
		Health technologies		<ul style="list-style-type: none"> • Skilled attendance 24/7 (e.g. midwifery and nursing staff +/- doctors) • Support staff for cleaning
		Support system		<ul style="list-style-type: none"> • Linen/towels for drying and wrapping • Bag and mask resuscitation • Radiant heater, warmth source • Thermometer • Equipment for clean cord care • Vitamin K, eye ointment • Weighing digital scale, tape • Immunization commodities • Antibiotics • Oxygen • Pulse oximeter
		<ul style="list-style-type: none"> • Water, sanitation and hygiene (WASH) and infection prevention and control • Communication and functional referral system • Newborn patient record and facility register • Written policy on zero separation • Easy access to fathers/caregivers 		

Fig 3.2 Inpatient care for small and sick newborns: requirements for care at different health system levels (continued)

Level	Type of care provided	Health system requirements		Standards of care & evidence-based interventions
SECONDARY	Special newborn care	Place	<ul style="list-style-type: none"> A dedicated warm space of a facility, with specific areas for resuscitation, stabilization and care Dedicated area for KMC Accommodation for mothers Electricity supply (e.g. generator back-up) Infrastructure for storage of human milk 	<ul style="list-style-type: none"> Thermal care Comfort and pain management Kangaroo mother care, including follow up* Assisted feeding for optimal nutrition (cup feeding and nasogastric feeding) Safe administration of oxygen Prevention of apnoea Detection and management of neonatal infection Detection and management of hypoglycaemia Detection and management of jaundice Detection and management of anaemia, including blood transfusion Detection and management of neonatal encephalopathy Seizure management Safe administration of intravenous fluids Detection and referral management of birth defects <p><i>Transition to intensive care</i></p> <ul style="list-style-type: none"> Continuous positive airway pressure** Exchange transfusion** Detection and management of necrotizing enterocolitis (NEC)** Specialized follow up of high risk infants (including preterm)
		People	<ul style="list-style-type: none"> Specialized nursing and midwifery staff 24/7 Doctor with neonatal skills on call Support staff (nursing auxiliary and cleaning staff) 	
		Health technologies	<ul style="list-style-type: none"> Oxygen supply, pulse oximeter and newborn oxygen accessories (e.g. oxygen concentrator and blenders) Syringe pump and accessories (e.g. neonatal cannulae) Feeding equipment (nasogastric tubes and cups/spoons) Basic diagnostics (e.g. glucometer, urine dipsticks) and micro-methods Medicines (e.g. antibiotics, caffeine, IV fluids, phenobarbital) Mobile X-ray system Warmers and cots Effective phototherapy equipment (e.g. LED) Continuous positive airway pressure 	
		Support system	<ul style="list-style-type: none"> 24/7 access to the facility for mothers and caregivers Facilities for bathing, laundry and cooking/food Clinical charts and facility register 	
TERTIARY	Intensive newborn care	Place	<ul style="list-style-type: none"> Designated intensive care ward 24/7 uninterrupted electricity Space for mother to room in and stay close to their baby 	<ul style="list-style-type: none"> Advanced feeding support (e.g. parenteral nutrition) Mechanical/assisted ventilation, including intubation Screening and treatment for retinopathy of prematurity Surfactant treatment Investigation and management of birth defects Paediatric surgery Genetic services
		People	<ul style="list-style-type: none"> Nurses with specialized competencies in neonatal care 24/7 Doctors with specialized competencies in neonatal care 24/7 Neonatologist on call Other specialist doctors with competencies in neonatal care (anaesthetics, surgery, radiology, cardiology, neurology, ophthalmology) Allied health professional (physiotherapy, nutrition, speech therapy, occupational therapy, audiology, etc.) 	
		Health technologies	<p><i>In addition to special care equipment and commodities</i></p> <ul style="list-style-type: none"> Intermittent positive-pressure ventilation, high flow oxygen via nasal cannula Monitoring equipment Surfactant therapy Advanced medicines Supplies for advanced nutrition support (e.g. total parenteral nutrition) Specialist equipment and accessories 	
		Support system	<ul style="list-style-type: none"> 24/7 advanced laboratory support and other diagnostics including medical imaging Transport and safe referral if needed Hospital information management system 	

* Outpatient care.

** The interventions listed under special care mark a transition to intensive care. Hospitals providing special care should introduce these interventions before upgrading to intensive care.

Special care

Most small and sick newborns can be managed in a dedicated neonatal unit at the secondary level, or in a district hospital or facility. Fig. 3.2 provides a guide to interventions and services options, and to the accompanying health system requirements needed to establish neonatal units for special care at secondary level. These services are offered in addition to essential newborn care services. Both primary and secondary care levels should be able to identify conditions that require higher-level care.

Intensive care

Neonatal intensive care is required for very small, very preterm, and very sick newborns, whose conditions may not be fully manageable at lower levels of care. In addition to the interventions provided at the special newborn care level, intensive care includes mechanical ventilation, advanced feeding support, paediatric surgical capacity and more invasive monitoring and diagnostic capacity.

Capabilities at levels of care

As the level of care rises from essential to intensive, and cases become more complex, there is a greater need for specialized staff, infrastructure, equipment, support systems (such as more advanced diagnostics and laboratory support) and outpatient follow-up services.

There is often a significant difference in system capacity between different levels of care. However, each can improve upon its capabilities by adding interventions and services as appropriate. For example, while facilities may be able to provide high-quality special newborn care, they may be a long way from having systems in place to provide intensive care.

Once facilities have the capacity, staff, training and skills to provide all aspects of high-quality care within a level, they may begin to take active steps to transition to the next level of care through incremental additions. For example, continuous positive airway pressure is an important transitional intervention that can be added at the special newborn care level. Similarly, facilities that provide essential newborn care can begin to develop special newborn care capacity by adding KMC and assisted feeding as part of their stabilization and

referral efforts. Hospitals that cover larger geographic areas may need to consider a wider range of services than facilities with a smaller catchment area.

Some public-health professionals may believe that inpatient care for small and sick newborns is prohibitively expensive and that it requires access to intensive care units. In fact, intensive care is frequently not necessary, since as few as 1 in 20 newborns requires full intensive care for a limited time. Moreover, research indicates that up to 70% of all preterm deaths would be averted with special care alone. Countries with well-functioning essential and special newborn care capacity might reasonably be expected to set up intensive care units. However, it may be inappropriate where resources are scarce and services not yet available at the lower care levels. In general, health-care systems should prioritize high-quality essential and special newborn care, with regionalized access to neonatal intensive care for the few who may require it – all supported by a strong referral system.

Care coordination

To ensure that all small and sick newborns have access to the appropriate level of care, multisectoral planning and investment is required to create a coordinated regional (or national) referral system across and within public and private sectors. WHO has developed specific standards and indicators for referral of newborns (2, 6). In well-functioning systems, services for newborns are organized in a regional or national network to serve dedicated



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populations. Detailed policies for referral to a higher- or lower-level facility optimize the use of resources, so that a higher-level bed or space is dedicated only to those with specific clinical needs. Clear admissions policies can ensure that newborns receive care at the most appropriate level and as close as possible to their home. They can also help avoid facility overcrowding.

In countries lacking a referral system for small and sick newborns, the existing basic emergency obstetric and newborn care (BEmONC) and comprehensive emergency obstetric and newborn care (CEmONC) models provide a good basis for regional or national planning of a functional network. For example, facilities at and below BEmONC level can focus on high-quality essential newborn care, providing bag and mask resuscitation at birth for those who need it and stabilizing and referring those who require higher-level care. All facilities implementing CEmONC can then aim to have special care and KMC beds based on volume of births and geographic accessibility, while a subgroup of CEmONC facilities may be able to provide intensive care.

Early risk identification

Each newborn's health-care journey depends on their individual needs. The facility where a mother gives birth is the vital starting point. When small and sick newborns access inpatient care, it is usually within the facility where they were born (so called inborn patients). Ideally, high-risk cases such as extreme prematurity, twins, or pregnancies of multiples, are identified antenatally and the mother referred to higher-level facilities (such as CEmONC and intensive neonatal care) that are better equipped to manage complications or emergencies. This ensures timely access to the appropriate care for their newborns.

Referral systems

Not all complications can be predicted before birth. Even in cases with high-quality antenatal and obstetric care, a certain number of newborns will still require inpatient care unexpectedly. In these situations, the newborn's survival relies on the referral system and safe transport, with care to avoid separating mother and newborn at any stage.

Each facility requires a clear written policy describing their level of care, with detailed admission and discharge policies. A written referral plan should be in place to guide cases when a higher level of care is needed, or when a lower level would be adequate. Policies should also address returning every newborn and their family to their local facility as soon as appropriate.



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Transportation

Functional referral systems depend upon affordable transport for transfer of sick or small newborns to higher-level facilities. Transfer carries inherent risks, so transport needs to be safe and timely and accompanied by trained health workers experienced in small and sick newborn care. Small and sick newborns require as much stabilization as possible prior to transfer. The newborn must always be kept warm, and be accompanied by a family member whenever possible. To ensure communication and continuity of care, the referral rationale should be explained and the appropriate documentation sent with the patient. The referring facility should contact the referral centre by phone or radio to alert it of referral and arrival time.

In the absence of advanced transport vehicles, even simple referral plans can improve survival chances and outcomes. For example, where mothers are able and willing, newborns may be transferred in KMC position to maintain warmth and vital signs. Alternatively, simple transport incubators can be used, where clinically appropriate, with a family member and health-care provider alongside the newborn.

What is needed to provide care?

Providing an evidence-based package of quality inpatient care for small and sick newborns requires health facilities

that are prepared – often referred to as service readiness. In addition to ample qualified staff with an appropriate skills mix, service readiness requires a facility to have specific infrastructure, equipment, medicines, supplies, and diagnostics in place. These are described in WHO standards on essential physical resources to provide quality maternal and newborn health care (2). Monitoring systems (detailed in Chapter 5 and Annex 2) should be in place to identify and address service gaps and to ensure health system accountability. Laws, policies and regulations are needed to facilitate access without discrimination. Such legal and policy frameworks support both health-care providers in their duties and parents in caring for their newborns during hospitalization and after.

Infrastructure

Inpatient care of small and sick newborns requires a purpose-built space that is separate from the general paediatric unit and closely connected to the labour, delivery and postnatal wards. Minimum infrastructure for special newborn care includes water and sanitation facilities, and rooms where parents can stay near their small and sick newborns. These should have space, beds and chairs for parents to provide KMC, and access to a continuous oxygen supply, pulse oximeters, basic laboratory testing and diagnostics (35). Intensive care for extremely small and sick newborns requires more infrastructure, including 24-hour uninterrupted electricity and space for more complex technologies, such as assisted ventilation, higher-level laboratory and radiology support. Access to paediatric surgery should also be available. A unit's size depends on the anticipated number of births. As a general rule, a special unit of 8–12 beds is sufficient for hospitals with 3000 births per year. This is based on an estimate of 3 beds per 1000 births, plus 30% additional beds to accommodate referrals from the lower level of care (36).

To promote family-centred care, space at or near the facility for parents or family members is needed. Within hospitals, and in partnership with local volunteer or civil society organizations, adjacent spaces and maternity waiting homes can provide a retreat for rest and peer support.

Health technologies

Uninterrupted service requires a continuous supply of equipment, consumables and medicines. To keep the flow of supplies well-stocked and operational, a facility should accurately forecast needs; plan and distribute items efficiently and systematically; and conduct continuous post-market surveillance to report any problems.

Medicines

The WHO model list of essential medicines for children and the WHO model formulary for children were developed to ensure that medicines for treating common childhood diseases are given at the right dose and for the correct duration for children of all ages, including newborns (37). Many countries have a national essential medicine list, but often this does not include the commodities required for inpatient care of small and sick newborns, such as oxygen or intravenous fluids preparations (35, 38). A literature review on neonatal oxygen therapy in LMICs indicates that maintenance and indirect costs associated with oxygen procurement is a significant barrier to its availability. Even when oxygen therapy is available, there are indications that some hospitals deliver it without pulse oximetry or other necessary monitoring equipment. This exposes the newborn to unsafe oxygen use and the potential of developing retinopathy of prematurity (39, 40). Countries can update their national essential medicine list to reflect the medicines and commodities required for small and sick newborns, such as safe oxygen use (35). Similarly, pharmacies should have standard operating procedures regarding drug and vaccine storage, preparation, transport and inventory (to prevent drug stocks running out).

Equipment

To deliver quality inpatient care, a facility should have well-functioning medical devices and equipment available, so that staff may diagnose, treat, communicate and refer patients in accordance with national standards and regulations. To determine the quantity of medical devices needed, national assessments that consider the following issues can help with planning: health system policies, standards and protocols; health-facility capacity, activities and organization; and existing replenishment/inventory systems for medical devices.

Procurement officials should understand whether medical devices, their installation and ongoing maintenance, are suitable for the specific environment and health needs. Biomedical engineers should be available to assist in equipment selection and maintenance, with regulatory mechanisms in place to ensure technology availability and safety (equipment can break or go unused without the requisite expertise) (41). This is especially important for interventions with specific safety risks, such as respiratory support, which require monitoring equipment (such as pulse oximetry) and humidifiers to be used safely. Equipment and diagnostic kits should always be clean, with adequate room and storage. Temperature and humidity should be monitored as they may affect reliability and

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functionality. If equipment donations are received from other countries, they should be assessed by procurement professionals and biomedical engineers prior to use with any patient – especially small and sick newborns.

Diagnostics

Optimal care management for newborns requires diagnostic investigation to guide treatment of conditions such as infection, hypothermia, hypoxia, hypoglycaemia and jaundice. Lack of access to such services results in incorrect diagnoses. As a result, many newborns do not receive the treatment they need and, in some cases, may receive the wrong treatment. Point-of-care testing can improve quality of care through correct diagnosis, timely treatment, and care management. For example, glucose, haemoglobin, bilirubin and pH-level tests can all be done using a single drop of blood from a heel prick. Adequate and reliable laboratory and diagnostic services, in line with the level of care that the facility offers, are essential for quality care.

WHO has also recently published its first Essential Diagnostics List, which is intended to serve as a reference for countries to update or develop their own list of essential diagnostics (42). In addition, the *Interagency list of priority medical devices for essential interventions for*

reproductive, maternal, newborn and child health provides a useful resource for the diagnostics required at different levels of health care (43).

Innovation

Innovative and cost-effective health-care technologies have the potential to accelerate access to quality care for all small and sick newborns. For example, low-cost bubble continuous positive airway pressure (bubble CPAP) in central and district hospitals would prevent 178 000 neonatal deaths in Africa each year (44, 45). Point-of-care diagnostics would support health-care providers who triage and diagnose newborns and increase the likelihood of their receiving appropriate care (46). Other promising products and technologies include: phototherapy devices such as filtered sunlight; ambula-

tory and culturally appropriate KMC wraps; microwavable seed bags to prevent hypothermia during transportation; triggers/reminders for provider hand hygiene; wearable temperature monitoring devices; and devices to measure jaundice, including bilirubin testing. Durable equipment with long-lasting batteries can help to overcome barriers caused by a lack of biomedical engineers or stable electricity supplies. Mobile technologies and the use of manikins and other equipment to simulate medical scenarios have the potential to increase access to evidence-based training in obstetric and newborn care for all types of providers (47–51). Systematic approaches that use needs assessments, provide support to address local priorities, capacity building and targeted infrastructure development, in partnership with users can bring results in a short time as described in the Neonatal Essential Survival Technology (NEST) programme in Burkina Faso (Box 3.3).

Innovative approaches can be wide-ranging and amplify lessons learned from sectors outside of health. For example, human factors and ergonomics research challenges the health sector to think about the most effective way to lay out the physical structure of newborn units so that staff work efficiently and safely. Such research can guide analysis of how workflow and tasks can be optimized to minimize medical errors (52).

Box 3.3 Nine steps to success in Burkina Faso

The Neonatal Essential Survival Technology (NEST) programme aims to reduce neonatal mortality by improving the quality of care for newborns in several sub-Saharan African countries. The programme launched in 2015 at Saint Camille Hospital in Ouagadougou, Burkina Faso. The programme has nine steps and receives funding from the Chiesi Foundation. Implementation is led by local staff and international experts, with inputs from organizations in regional and national government.

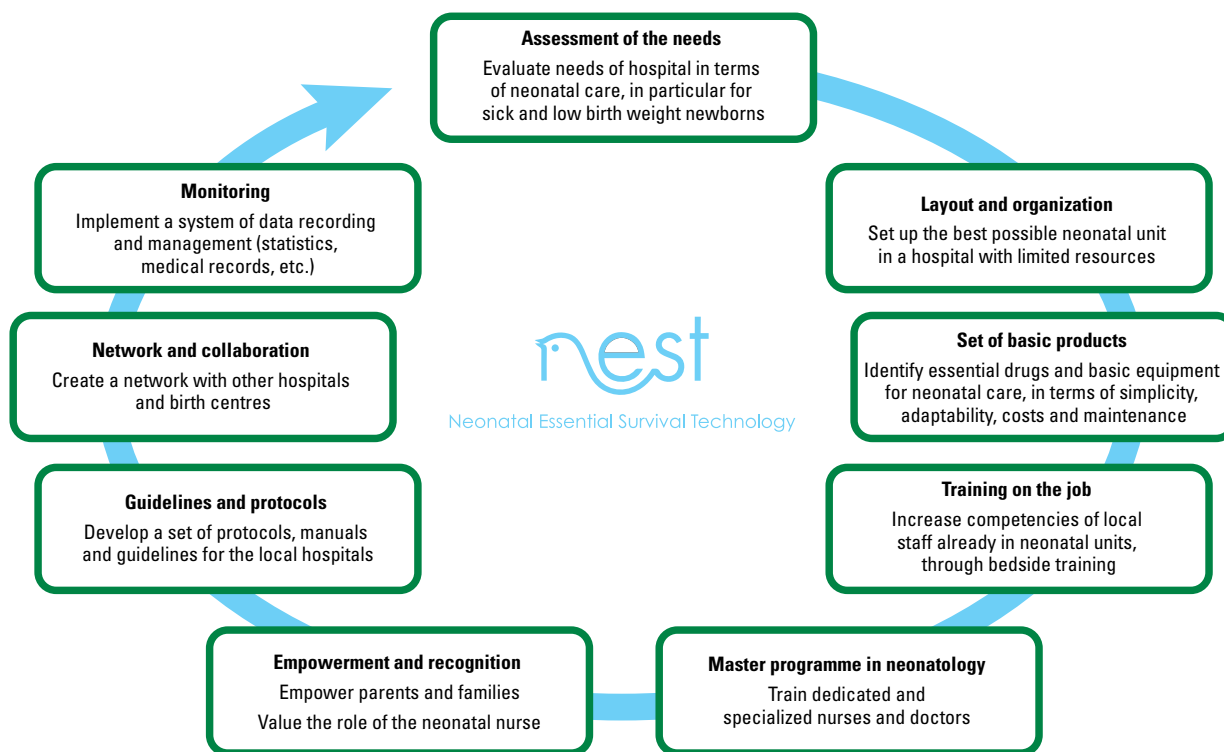
NEST began with a hospital assessment of newborn care services and identified a critical need for adequate layout and organization of the neonatal care unit (Fig. 3.3). Key services including KMC were not being provided, partly due to small room size. A new neonatal care unit was constructed and furnished with appropriate equipment required to provide optimal care. Additional audits helped to prioritize next steps, such as training for local staff and developing guidelines and protocols.

This new unit opened in 2017. While it is too early to assess its full impact on neonatal mortality, the following changes in care practices have already been observed:

- Skin-to-skin contact and KMC are practiced in a dedicated area equipped to welcome newborns and engage parents in care, with the support of dedicated staff;
- Developmental care practices have been introduced, such as correct positioning and nursing care, pain control, and managing the care environment to reduce stress in newborns.

These changes stem from an integrated approach to all aspects of newborn care, with implementation based on local needs and priorities. Initial results show that collaboration between staff and international experts, along with a guiding framework, has the potential to significantly improve care and prompt sustainable change.

Fig. 3.3 Key steps in the NEST programme



Who provides care?

Teams of competent and motivated health professionals

Inpatient care for small and sick newborns requires continuous services, 24 hours a day, seven days a week. Care should be delivered by a multidisciplinary team of appropriately educated health-care providers (primarily doctors and nurses) with specialized skills. In LMICs, this level of care is often absent and there are significant gaps in the health workforce (38). The major areas that require attention are safe staffing levels and competency-based or specialized training (38).

Providers who care for small and sick newborns require specific competencies. The recommended core competencies depend on the level of care to be provided at a health facility (Fig. 3.2). The roles and responsibilities for health-care providers vary between countries; as care complexity increases, so does the need for specialized skills. Special attention should be paid to both staff-to-patient ratios and skills mix.

Nurses

In most countries, regardless of the level of care, nurses and midwives provide most of the clinical hands-on care for small and sick newborns. Research shows that small and sick newborn survival in facilities is closely linked to numbers of qualified nurses working per shift (53). While there are currently no internationally defined standards on safe staffing levels or ratios for neonatal care, India recommends nurse-to-patient ratios of 1:3–1:4 for the special newborn care level (36). These can be used to plan resources to improve inpatient care. The United Kingdom recommends ratios of 1:1 in neonatal intensive care, and 1:2–1:4 in special care (54–56).

Multidisciplinary teams

In order to provide the necessary mix of skills, core multidisciplinary teams should include paediatric or neonatal doctors, nursing assistants, and other support staff, working alongside qualified nurses and midwives (38). A wider multidisciplinary team should include other health-care providers such as nutritionists/dieticians, lactation consultants, speech therapists, occupational therapists, physiotherapists, social workers, and psychologists. Such specialists may not work full-time in newborn inpatient care, but their input can help to enhance feeding, neurodevelopmental and social outcomes (54). They also form part of a broader support system for parents, caregivers and families during and after discharge from inpatient care (see Chapter 4).



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Staff recruitment and deployment strategies

It is impossible to provide quality, people-centred care for small and sick newborns when there are severe staff shortages. There are particular challenges in recruiting specialist staff for remote areas, which can lead to disparities in care and outcomes between urban and rural areas (38). Policies designed to attract and retain health-care providers, especially in rural areas, should include the provision of housing, good working conditions, neonatal skills training, performance recognition and remuneration, and take gender issues into consideration (57).

Hospital rotation policies that move experienced nurses to other patient care units can leave the less experienced caring for small and sick newborns. As nurses are the primary clinical caregivers for small and sick newborns, strategically limiting hospital rotation enables nurses to gain neonatal experience and creates essential opportunities for mentoring and supervision of more junior staff (38).

Task-shifting and task-sharing

In some countries, only physicians may be authorized to provide certain interventions, such as prescribing oxygen or antibiotics. This may limit the availability of interventions for small and sick newborns. Task-shifting and

task-sharing can be useful strategies to cope with small numbers of specialized staff. Task-shifting is “a process of delegation whereby tasks are moved, where appropriate, to less specialized health workers” (58). Task-sharing aims to create “a more rational distribution of tasks and responsibilities among cadres of health workers to improve access and cost-effectiveness” (59).

Such strategies should be designed and implemented in parallel with the removal of restrictive policies or laws. Where implemented, task-shifting and task-sharing should be formalized, to prevent confusion in roles and responsibilities for those who provide care; and be accompanied by training and supervision.

For example, appropriately trained nursing auxiliaries or health-care assistants could support and maintain KMC. This occurs in Malawi where health surveillance assistants are trained to promote inpatient care for sick newborns and provide support to mothers in the KMC units (60).

At the special newborn care level and higher, policies can allow specialized and experienced nurses and midwives to handle a range of tasks or offer training where skills gaps exist. Nursing assistants and auxiliaries can also take on essential and routine nonskilled tasks; for example, to clean equipment and restock shelves. This frees nurses to focus on skilled clinical care.

Training and retention

While the priority is to build the neonatal competencies of existing health-care providers, it is equally important to strengthen pre-service education in neonatal care for all trainee health-care providers, especially doctors and nurses. This requires links between hospitals and universities and a learning environment within hospitals for nurses, midwives, medical students and other people in health training.

As services are developed, countries need to take the important step of creating or expanding their neonatal nursing cadres (38, 61). They should also seek to provide neonatal care courses with competency-based curricula and corresponding accreditation with international standards. Incentives, such as increased remuneration or the establishment of a neonatal nursing cadre, help to recognize the profession, promote responsibility, improve staff retention and increase job satisfaction. In many countries, advanced neonatal nurse practitioners provide primary patient management for small and sick newborns with significant success (62, 63). Specialist doctors are also needed, especially for diagnostics or treatment decisions.

A country’s plans for a national health-care workforce also require guidelines on recruitment, training, deployment, retention, accreditation and certification, supervision, task-shifting, human resource management and leadership (64, 65). They should be written when a country plans and organizes a network of facilities to provide maternity and neonatal services. Countries that have health information systems should also strengthen and manage this function. The system should be updated with staffing norms for inpatient care of small and sick newborns. Data should be used to plan newborn care at all levels within the health system (66).

Education and mentoring to improve quality

Education and meaningful mentoring can greatly improve quality of care and contribute to ongoing professional development. Partnerships between universities and facilities to coordinate health-care provider education for those involved in small and sick newborn care have been shown to have a positive impact on health-care provider competencies, which can ultimately reduce newborn deaths and disability (see Box 3.4).

For example, UNICEF led successful collaborations that involved training and on-the-job clinical mentoring in Tamale Teaching Hospital in Upper East Region,

Box 3.4 Nurses as leaders for quality improvement

“Willingness of health-care providers to change is the key; this is what the science of quality improvement teaches us. Policy statements issued as whips to health-care workers by administrators or publishing guidelines is not enough. We should aim to reach special care, decreasing irrational use of antibiotics, decreasing unnecessary admissions, or addressing local problems applicable to other units. Making quality improvement teams and keeping nurses as the primary drivers of this change in special care is important. With a robust online data system in India, quality improvement implementation will make tracking possible. This will open up collaborative quality improvement networks for special care.”

Extract from a speech given by Dr Ashok Deorari on 26 December 2017 during a Point of Care Quality Improvement workshop at the All India Institute of Medical Sciences (AIIMS). Dr Deorari is Professor of Pediatrics at the WHO Collaborating Centre for Training and Research in Newborn Care at AIIMS.

Ghana, and the Bangabandhu Sheikh Mujib University, Bangladesh. These are tertiary-level facilities with NICUs in district hospitals. Similarly, the WHO Regional Office for South-East Asia supported the creation of Point of Care Quality Improvement manuals and developed a clinical training app, which health-care providers can access online free of charge (67). The All India Institute of Medical Sciences and the American Academy of Pediatrics developed a mobile app for essential care for small newborns under their Helping Babies Survive training programme (68).

The WHO Regional Office for the Western Pacific also has a coaching and mentoring programme, with early essential newborn care guidelines and indicators and a website (69). Early essential newborn care has been introduced in 12 countries including in 8 priority countries that account for 98% of neonatal mortality in South-East Asia (Cambodia, China, Lao People's Democratic Republic, Mongolia, Papua New Guinea, Solomon Islands, the Philippines and Viet Nam). Coaching on early essential newborn care has been found to improve skills

greatly and change practices (see Box 3.5), even where staff have been trained multiple times by other methods. Other resources, such as the Point of Care Quality Improvement manuals and case studies (67), and the Centers for Disease Control and Prevention resources (70) are useful examples for LMICs.

Parental involvement in care

The family experience is a key aspect of quality care. Parents can encounter stress in many ways due to the unsettling environment of a hospital or facility: separation from their newborn and/or family support; medical uncertainties; and difficult decision-making. It is important for health systems to acknowledge the parents' needs, including their physical, physiological and emotional needs, for their own health and well-being and for the care of their newborns. The inclusion of fathers is important as they can play a role as caregivers to the newborn and as a source of support for the mother. The health system's care values, culture and leadership should be supportive of family-centred care, with policies, practices and resources aligned accordingly

Box 3.5 From novice to advanced neonatal nurse specialist

By Pacifique Umubyeyi

My story began in 2011, when I graduated from the University of Rwanda nursing school. I was appointed by the Ministry of Health to work at the Rwanda Military Hospital in the neonatal unit. It was not my choice, my preference being to work with adults, but it was an order I had to follow.

I was terrified to work in the neonatal unit! I did not have the knowledge, skills or neonatal training. It was my first time in a neonatal unit. There was no orientation programme and the senior nurses on the unit were too busy to train me. Consequently, every single day spent on the neonatal unit was filled with worries and anxiety related to my lack of neonatal knowledge and skills. When I was left alone with the newborns, I feared I would harm them.

After one year working in the neonatal unit, I had the first opportunity to be trained in neonatal resuscitation; from there I realized that my poor skills were harmful to newborns rather than helpful. I could not stop thinking about all the newborns I had seen die. With proper skills, I may have been able to save them.

In 2012, I had the opportunity to work with a

neonatal nurse who came to the hospital as a mentor for the human resources for health programme.

Through her mentorship, my abilities and confidence in caring for newborns was enhanced. Since then, caring for them has become my passion! In 2013, the hospital opened a NICU and I became the unit manager, working with my mentor to create clinical guidelines, protocols and policies. After two years of leading our NICU, I had the opportunity to be in the first cohort of Masters of Science in Nursing – neonatology track – students at the University of Rwanda.

Today, I am a qualified MScN neonatal health nurse working at one of the best neonatal units in the country. Despite this, our level of care is limited by a lack of staff and resources. We have many challenges as nurses and midwives trying to establish a professional neonatal career path with no clear scope of practice to guide our care. I am a member of the newly formed Rwanda Association of Neonatal Nurses, or RANN. It is a new association, but I have a strong conviction that it will go far to promote neonatal professional careers and will undoubtedly improve neonatal outcomes in Rwanda.

(71–73). This should include making a charter indicating newborn and associated parental rights clearly accessible to all caregivers.

Parents make unique contributions by being able to observe, monitor and provide care to their small and sick newborns (when appropriate, under supervision and in partnership with the health-care team). Engaging parents and families in this way can provide the following benefits: boost parent–newborn attachment; ensure higher breastfeeding rates; facilitate earlier discharge; improve long-term neurodevelopment; encourage reciprocal, cue-based interactions; promote developmentally supportive care; and improve health-related knowledge and beliefs among parents and communities (74). In such an environment, health-care providers can follow family-centred care principles and demonstrate them during their interactions with parents and family members. Family-centred care helps parents feel confident and better prepared after discharge to succeed as the primary caregivers for their newborns (75). Family-centred care also benefits the mental health of parents (72).

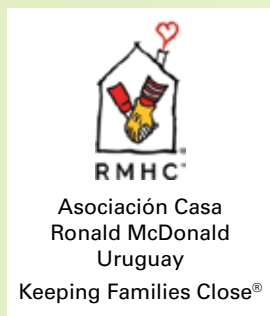
There are several strategies to strengthen partnerships with parents, families and communities in the care of small and sick newborns at all levels of care. Some have already been highlighted in this chapter, e.g. space for families in the rooms and overall parent involvement in daily care, in comforting or feeding their newborn. Parental education on how to care for their newborn, in the facility and after discharge, should accommodate their schedules and learning requirements. Similarly, health-care provider education on family-centred care and the parents' role is critical. Peer support can be another crucial element of a comprehensive family-support programme (Box 3.6).

Ensuring access to quality care for all without discrimination

Under the Convention on the Rights of the Child, it is a fundamental right for newborns and their families to be able to access the health care they need. Unfortunately, this right is not respected or protected in all settings. Currently, there are limited data on the

Box 3.6 Family support programmes in Uruguay

Ronald McDonald House Charities® (RMHC) was established in Uruguay in 2011 as “Asociación Casa Ronald McDonald Uruguay.” The association operates two Ronald McDonald Houses at Hospital Pereira Rossell in Montevideo, the capital of Uruguay, and Hospital de Tacuarembó in Tacuarembó. The latter is a rural area where little health care is available beyond the regional hospital.



Both programmes primarily serve the small and sick newborn care facilities in their partner hospitals. Together they served more than 3600 socially, economically and medically vulnerable children and families in 2017. The Uruguay health sector's relationship to RMHC is a powerful example of potential benefits from a partnership between the public and voluntary sectors to promote family-centred care.

When RMHC began to establish a chapter in Uruguay, it recognized the need to build alliances

with government agencies, the private sector, and other nongovernmental organizations. They would be indispensable for sustainability. Plans started with a needs assessment and direct involvement of both hospitals' boards of directors and the Ministry of Health.

Because of these collaborations, the RMHC programmes were established on hospital premises. Parents can access meals, space for personal hygiene and rest, health education and basic training in computers, reading and writing. Both Ronald McDonald Houses serve four meals per day and are heavily dependent on volunteers. RMHC health education classes are designed to strengthen the families' abilities and skills in breastfeeding and bathing, and to prepare them for the delivery and care of premature infants. Specialists teach parents how best to stimulate premature children and promote attachment.

Executive director Sandra Marcos said: “We prioritize that the family nucleus remains united to take care of sick children. That's why we provide help not only to mothers, but we strongly support parents to take an active role.”

... it is the responsibility of nation states to respect, protect, and fulfil the rights to the health of their populations...The tremendous health inequities that exist are morally unacceptable and “not in any sense a ‘natural’ phenomenon, but the results of a toxic combination of poor social policies and progressive, unfair economic arrangements and bad politics”.

Commission on Social Determinants of Health, quoted in Ottersen et al. (76).

overall proportion of small and sick newborns who can access care. This is due to lack of population-level data on the number of newborns who need care, and to weak

information systems and poor recording of admissions within health facilities (Chapter 5 explores these issues further). Measuring effective coverage can support evidence-based planning to improve access to quality care services (see Box 3.7 and Fig. 3.4).

Barriers to accessing care include inadequate availability of services, and a multitude of social economic, legal and cultural factors. Many of these barriers are the result of persistent discrimination, particularly against vulnerable groups. It is critical to create equal opportunities for all newborns to access care. Discrimination may be related to a variety of parental and/or household factors (e.g. mother’s age; education and marital status; socioeconomic status; urban or rural residence; or ethnicity) and neonatal conditions (e.g. congenital malformations; preterm birth). Newborns

Box 3.7 Effective coverage of newborn services in Nairobi, Kenya

In Nairobi City County, Kenya, 60–70% of the population lives in slums and income inequality is high. An estimated 88.7% of births take place within health facilities, compared with 61.2% at national level. However, the NMR in Nairobi is considerably higher than elsewhere in Kenya (39 compared with 19–25 per 1000 live births). The Nairobi Newborn Study supplied evidence to policy-makers and providers to improve service planning, quality and care delivery.

Based on a literature review and expert input, the study calculated the number of newborns who require care in Nairobi City County in one year (77). It identified all facilities, across public and private sectors, that provide 24/7 inpatient neonatal services. It also assessed facility infrastructure, equipment and supplies, and conducted a review of registers and patient records and circulated a nursing knowledge questionnaire (78).

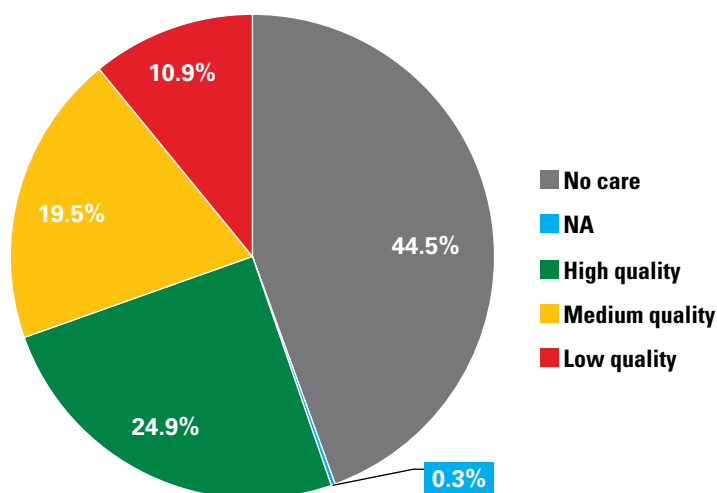
Only 24.9% of small and sick newborns in Nairobi accessed high-quality facility-based care in 2014–2015 (79), while 44.5% of newborns in need did not access any facility-based care.

The majority of facilities identified were private sector (29 out of 33). However, just four public facilities accounted for 71% of all neonatal admissions. These public facilities faced major challenges, such as high patient mortality, understaffing and

overcrowding. Quality-related issues, particularly among small and private facilities, included: lack of care-specific documentation; incorrect prescription of antibiotics, oxygen and feeding/fluids; infrequent monitoring of patients; and absence of equipment and supplies.

Reducing high NMR in this urban, predominantly poor population will require effective long-term, multisectoral planning and investment. This study provides an example of how coverage can be measured effectively and used to support evidence-based planning to improve care access and quality.

Fig. 3.4 Newborn services coverage in Nairobi



with special needs, such as congenital abnormalities, and special circumstances may be deprived access. Abandoned newborns are particularly vulnerable (80).

Migrants and ethnic minorities

Migrant and ethnic minority status, as well as related cultural and socioeconomic barriers, can adversely affect people's utilization and experience of care. Language barriers can compromise communication between providers and ethnic minority parents, which may limit their access to care (81). Hospitals in the United Kingdom's Newborn Improvement Collaborative for Quality adopted quality objectives, indicators and measures to minimize such inequities (Table 3.1) (82).

Girls and boys

To reduce neonatal mortality disparities between boys and girls that are prevalent in many countries, it is essential to address gender bias (see Chapter 2). Advocacy efforts should measure disparities and use evidence to guide the call for pro-female policies and incentives to reverse negative social norms and practices, where they exist. For example, to reduce gender-disparity, UNICEF/India supports the government's

efforts to conduct real-time monitoring of data in special newborn care units (SNCUs) and to identify states with low levels of female admissions compared to male admissions (see "Boys or girls?" in Chapter 2). In addition, the Indian Academy of Pediatrics and many other states in India have taken initiatives to address the gender gap in care-seeking for newborns. The National Neonatology Forum declared 2017 as the "year of the female newborn" and advocated for parents of female newborns to complete their stays as needed in special care and to comply with admission referrals.

Newborns with congenital abnormalities

In many settings, newborns with congenital abnormalities do not have access to the care they need to survive and thrive with minimal disability. That may be due to limited availability of services or to discrimination against these newborns. The result is low levels of care-seeking, family-centred care engagement and medical attention. Many birth defects also require corrective surgery, such as cleft lip/palate, and may remain untreated.

There are several options to address access inequity. These include building surveillance mechanisms for birth

Table 3.1 Indicators in the United Kingdom's Newborn Improvement Collaborative for Quality (2007)

Objectives	Measures
To collect data on race, ethnicity and primary language	<ul style="list-style-type: none"> • Are patient/parental data properly documented in the chart?
To ensure that all patients receive a standard of care that matches their needs	<ul style="list-style-type: none"> • Did the patient (grouped by gestational age, disease process and so on) receive those treatments documented as the standard of care in your unit? • Of those that did not receive the standard of care, stratify by race/ethnicity/language
To improve the cultural competency of staff	<ul style="list-style-type: none"> • Percentage of staff who completed cultural competency training • Results of patient satisfaction surveys
To make appropriate use of interpreter services	<ul style="list-style-type: none"> • Percentage of parents/families who are documented as not having majority language (e.g. English in the United Kingdom) as their primary language and who actually received interpreter services • Results of patient satisfaction surveys
To create and ensure the optimal use of education material	<ul style="list-style-type: none"> • Was parent input a part of the creation/approval process for educational materials used in the hospital? • Results of patient satisfaction surveys

Source: Vermont Oxford Network. Newborn Improvement Collaborative for Quality (82).

defects into national health information systems and developing the capacity to strengthen research on aetiology, diagnosis and prevention (described in Chapters 4 and 5). Cost-effective measures to prevent congenital defects should be incorporated into antenatal care where possible, such as vaccinating against rubella and correcting folic acid, iodine and B6 deficiencies (83).

Abandoned newborns

Abandoned newborns merit special programming considerations. Newborns who are abandoned or separated from their family need “alternative care,” defined as any arrangement, formal or informal, temporary or permanent, for an infant or child who is living away from his or her parent. This should ideally involve close relatives, or competent and responsible foster or adoptive families. Processes should be in place to ensure that all care is delivered with compassion and dignity, and with an approach as close to the family-centred care approach as possible (84). Guidance for how to apply family-centred care principles when a family is absent should be developed.

Guidelines for the alternative care of children were adopted by the United Nations General Assembly in 2010 (84). They should be consulted for policy reform and to strengthen and reform national child protection systems. The legal implications of abandonment, the role of health facilities in caring for abandoned newborns, and their

transition into safe custody and adoption should also be specified in national policies.

Financial barriers

Neonatal mortality is usually highest for those born in the poorest households (81). High out-of-pocket expenses, coupled with the loss of wages when parents are away from work for an extended period, can create barriers to newborn health-care access or its completion. Country policies on UHC should specify guaranteed access to comprehensive, quality interventions and services for small and sick newborns as part of their overall RMNCH policies. Countries should address financial barriers and put in place sustainable plans to finance a defined set of services and to allocate, report and track resources and expenditures. Health financing and prepayment systems, such as a mandatory health insurance system, can be introduced to protect at-risk groups from the severe impact of high costs and debt (38, 85).

Countries should also look to expand existing maternal health schemes (e.g. through end-user incentives, insurance schemes, voucher schemes) to cover inpatient care of newborns, including preterm newborns. For example, in the Philippines, a special prematurity package was added to Phil Health insurance to cover the costs of small and sick newborn care. Phil Health covers more than 90% of the Filipino population (90 million). The prematurity

Box 3.8 China addresses social and financial barriers

Although China is on track to achieve the SDG 3 targets, neonatal death still accounts for 60% of China’s under-5 mortality, with 70% of neonatal deaths occurring in the first week of life (86). In addition, there are great disparities between rural and urban settings (87, 88). To reduce child mortality in a sustainable way, the government recognized technology and hospital services needed to be enhanced, along with changes to culture, attitudes and behaviours within families and communities.

To identify modifiable determinants of child mortality within society and the health system, social autopsies were applied in rural areas of Yunnan and Xinjiang in Western China in 2011. A total of 266 caregivers of newborns who died within 28 days were interviewed using the verbal and social autopsy questionnaire developed by the Population Health Metrics Research Consortium (89).

The results show that approximately 90% of deceased newborns were born in hospital. While most mothers (97.4%) were medically insured, only 7.5% of newborns were insured. Only half of all newborns were breastfed. About half (45%) of newborns experienced first delay (decision to seek care), 7% second delay (accessing care), and 1% third delay (receiving care). First delay was due to high medical costs (54%), poor awareness of the severity of the illness (26%), transportation barriers (21%), and the belief that the newborn’s sickness was incurable (20.4%).

China used these findings to improve its newborn insurance coverage by including transportation and sick newborn care. Advocacy efforts successfully identified an average unit cost for budgeting purposes. The government also raised awareness among caregivers of the danger signs in newborns and developed contingency plans for referrals.

package has benefited newborns who require hospital admission and follow-up support since 2015. Bhutan has a free care policy for preventive and curative services for the entire population, including mothers and newborns, that uses a combination of taxes and a health trust fund for the purchase of essential medicines and supplies. In China, free childbirth care was expanded to cover small and sick newborn care, including transportation costs and broader advocacy efforts to identify small and sick newborns in the community earlier and improve their care (Box 3.8).

Newborn health in humanitarian crises

It is important to reiterate that of the 16 countries with the highest NMR, 11 have experienced recent humanitarian crises, whether via political instability or conflict (see Table 3.2). Countries are also increasingly struggling with natural disasters. Whatever the cause, these crises leave women, newborns and children particularly vulnerable. Any global response to improve maternal, newborn and child health must include an explicit focus on humanitarian settings and mobilizing resources to ensure the delivery of protective and lifesaving services.

Accessing care

Care-seeking both for mobile and static populations during humanitarian crises is a challenge for multiple reasons. Mobile populations may be unfamiliar with their surroundings or the location of the closest health facility, so initial access to a health facility may already be low. This leads to high rates of home births and low rates of care-seeking. Additional factors that may impede care-seeking include: fear that the chance of harm outweighs any benefits of care; restrictions due to curfews, blockades, cultural practices, unsafe roadways (e.g. due to land mines); and uncertainty about availability of required services and whether care will be culturally appropriate (addressing privacy or communication barriers). In addition, families may face limited access due to “statelessness”; damaged infrastructure, lack of transportation, or affordability; and language barriers between emergency responders and beneficiaries. There also may be concerns about disrespectful care experiences (actual or perceived), ethnic targeting and discrimination, and related mistrust about the quality of services and advice provided.

Despite these challenges, emergency responders should work hard to ensure that women have access to care during pregnancy and delivery, and that mothers and newborns receive postnatal care in a timely manner. In the initial phase of an emergency response, many agencies

Table 3.2 High neonatal mortality rate (NMR) and humanitarian crisis or conflict, 2017

Country	NMR, 2017
1. Pakistan	44
2. Central African Republic	42
3. South Sudan	40
4. Afghanistan	39
5. Somalia	39
6. Lesotho	38
7. Guinea-Bissau	37
8. Mali	35
9. Chad	35
10. Côte d'Ivoire	34
11. Mauritania	34
12. Sierra Leone	34
13. Nigeria	33
14. Benin	33
15. Comoros	32
16. Djibouti	32

Sources: World Bank, Harmonized list of fragile situations 2018; United Nations Inter-agency Group for Child Mortality Estimation. Estimates for NMR in 2017.

will deploy the Minimum Initial Service Package (MISP) for Reproductive Health in Crisis Situations. The package outlines crucial actions required to respond to reproductive health needs at the onset of every humanitarian crisis. It details the lifesaving activities, services, equipment and drugs, including for newborn care, that providers should prioritize in an acute emergency response (90).

Guidelines on service provision

Developed via an inter-agency collaboration, the Newborn Health in Humanitarian Settings Field Guide summarizes existing WHO standards of care for newborn health with additional guidance on how to provide the services in the context of a humanitarian setting (91). The field guide prioritizes the most critical health services and supplies to prevent and manage the three main causes of newborn death. It also includes tools to design, manage, monitor and evaluate services and newborn care supply kits (pre-packaged kits containing critical medicines, drugs and supplies – see below).

Officially launched in 2018, it complements the MISP and the *Inter-agency Field Manual on Reproductive Health in Humanitarian Settings* (92).

In a related initiative, the Infant Feeding in Emergencies Core Group – a coalition that includes the United Nations, international NGOs and civil society organizations and others – developed operational guidance that was published in 2017 and endorsed by the World Health Assembly in 2018 (93). This guidance specifies how support for breastfeeding should be provided in emergencies, and how non-breastfed children should be supported without jeopardizing breastfeeding within the rest of the population.

Newborn care supply kits and levels of care for humanitarian settings

Newborn Care Supply Kits are intended to fill the gap caused by disruption to a health system, and to provide a minimum set of equipment and supplies for use in temporary health set-ups such as in camps or temporary/

field hospitals. Newborn care supply kits complement the Reproductive Health Kits, which can be procured through UNFPA. It is recommended that both kits be ordered simultaneously to eliminate waste and improve coordination between agencies.

As detailed in the field guide, the kits are organized across three levels of care: community; clinical or primary health facility; and hospital (Table 3.3). Kits include such items as blankets and hats; KMC wraps; feeding cups for expressed breastmilk; scales; chlorhexidine for umbilical cord care; and gentamicin to treat possible severe bacterial infection. Additional advanced care items can be ordered if a hospital or facility has a dedicated space for advanced neonatal care and appropriately trained staff.

Care coordination and referral in a humanitarian setting

A proactive emergency preparedness plan for small and sick newborn care should include contingencies

Table 3.3 Newborn Care Supply Kits for different levels of care

	Community level kit	Primary level kit	Hospital level kit
Use	Part A: Packaged for distribution to every pregnant woman. Part B: Items to be held and used by community health workers.	Essential newborn care for uncomplicated births, newborn resuscitation, preterm newborns and to stabilize those with severe infection prior to referral.	Referral-level care of newborn infections, newborn resuscitation, and care for preterm newborns with complications.
Instructions	Illustrated instructions and education materials on how to use the kit contents for essential newborn care.	For use by trained personnel. Training should be provided to demonstrate how to use the equipment and how to counsel parents and families.	For use by trained personnel. Items are applicable for most hospital settings. Advanced supplies are available but should not be included in the kit if key competencies are lacking.
Population	Part A: Based on the assumption that in a population of 10 000 with a crude birth rate of 4% there will be 100 deliveries in three months. Part B: Based on the assumption that there will be 10 community health workers for a population of 10 000 people.	Based on the assumption that in a population of 30 000 with a crude birth rate of 4% there will be 300 deliveries in three months. Of these, 18% may be preterm and/or LBW and 20% of those small newborns may develop complications.*	Based on the assumption that in a population of 150 000 with a crude birth rate of 4%, there will be 1500 deliveries in three months. Of these, 18% may be preterm and/or LBW and 20% of those small newborns may develop complications.**
Complementary reproductive health kit	Clean Delivery Kit (Kit 2) of the inter-agency reproductive health kit (United Nations Population Fund, or UNFPA).	Clinical Delivery Kit (6A and B) of the inter-agency reproductive health kit (UNFPA).	Referral Emergency Obstetric Kit (11A, 11B and 12) of the inter-agency reproductive health kit (UNFPA).

*The 300 deliveries are at primary health care/clinic level only and do not include deliveries at community level.

**The 1500 deliveries are at hospital level only and do not include deliveries at primary health care and community levels.

Box 3.9 Saving newborn lives in refugee settings: experience from three countries

Between January 2016 and December 2017, the United Nations High Commissioner for Refugees launched an evaluation of neonatal care services in camp-based settings in South Sudan, Kenya and Jordan. Context-specific adaptations were needed for each setting. It was important to include training and to distribute supplies to the facilities that served the host population, since they were often the main referral point for newborns in the camps.

The evaluation confirmed that KMC is a successful and important intervention for small newborns, as is counselling on newborn danger signs. However, the evaluation also showed that, across all three

countries, care for small and sick newborns faced the same key challenges found at baseline: inadequate space or improper infection control of spaces, dedicated staff, and accommodation for parents.

The evaluation's recommendations for neonatal care services include: initiate a newborn technical working group to support camp-wide policy changes and implementation; improve uptake of KMC; ensure proper management of small and sick newborns; identify critical facilities and invest in adequate space and staffing; investigate the cost-effectiveness of referring stable, small and sick newborns; and improve follow-up for referred newborns.

Source: External evaluation of the UNHCR project, UNHCR unpublished report 2018.

for referral and transport to care. Even in the most ideal situations – for example when facilities are equipped to provide care, trained health-care providers are available, and women are counselled on seeking care – referral systems can be critically hampered during a conflict. Ambulances and other modes of transport may not have access to the patient or to the facility, or the referral path may be unsafe. An ambulance that enters a camp may have trouble finding a woman or newborn in an overcrowded situation with no standard address or roads. Health-care providers may not be available or allowed to travel during periods of conflict or through certain areas, and curfews imposed to ensure safety may interrupt critical access to care. Beyond issues of insecurity, corruption may become a problem, with some workers demanding bribes and making the cost of care too high for women and families. Overcrowding also can mean that newborns needing care are kept in unsafe or inappropriate areas, often separated from parents or other caregivers for long periods of time.

For these reasons, it is important to develop a careful referral network plan, and to liaise and coordinate with other parties to resolve secure access issues and negotiate safe corridors. When dealing with refugees and displaced people, it is important to adapt the response taking into consideration the needs of the host population (Box 3.9). Clear procedures for ambulance requests and contacts

should be available at all hospitals, health centres and camp facilities. Similarly, peer support groups and volunteers can help to minimize referral delays when they are able to identify mothers and newborns in need of emergency care.

WHO is working with Members States and humanitarian partners to strengthen emergency preparedness and response, including the capacity of emergency medical teams. Efforts are ongoing to identify and prioritize research needs for newborn care in humanitarian settings and results are expected to be available in 2019.



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A NURSE'S STORY

“She provides the best patient care” – The story of a Neonatal Nurse

Pakistan has the world's highest neonatal mortality rate (44 deaths per 1000 live births), and nurses, like Anila Ali Bardai, are at the frontlines every day to change this. At the Aga Khan University Hospital in Karachi, Anila has sought to improve outcomes for Pakistan's newborn babies for over 10 years. As the Head Nurse of the Neonatal Intensive Care Unit, she has focused her efforts on the quality of care and improving the training of nurses and students working in newborn health.

Each day, Anila offers counselling to grieving parents and helps new mothers cope with the stress of caring for their sick babies. Her contributions have helped standardize newborn care throughout the hospital and have resulted in improved infection rates, decreased facility-based newborn mortality and reduced length of stay of patients. Anila has also been involved in outreach work for newborn care, gaining wide community respect.

As one colleague says, “She always initiates to provide best patient care ... and makes herself available. She was involved in establishing a step down NICU¹ ... She usually counsels and supports mothers of sick neonates at a very stressful time and provides guidance during breastfeedings, handling and care, maintaining thermal control, and kangaroo care etc.”

Anila's colleagues describe her as an outstanding mentor, teacher and role model, who has helped many young nurses understand both the theory and practice of skilled nursing care. She leads research and



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evidence-based practices in the neonatal care unit and teaches new staff and students.

She has been a catalyst in standardizing the care of newborns in all the hospital's units including Well Baby Nurseries, Patient Counselling and Continuity of Care, and the Intensive Care Unit.

Nurses provide the majority of care to sick newborns in health facilities; yet there is an acute shortage of neonatal nurses internationally and particularly in resource-limited countries. The Council of Neonatal Nurses (COINN) and Save the Children have co-sponsored the International Neonatal Nursing Excellence Award since 2010. Nurse Anila Ali Bardai won the 2013 Winner of International Neonatal Nursing Excellence Award.

1 Intermediate or transitional unit.

REFERENCES

1. UN DESA. Sustainable Development Goals. United Nations Department of Economic and Social Affairs: 2015 (<https://sustainabledevelopment.un.org/topics/sustainabledevelopmentgoals>, accessed 21 February 2019).
2. WHO. Standards for improving quality of maternal and newborn care in health facilities. Geneva: World Health Organization; 2016.
3. Network for Improving Quality of Care for Maternal, Newborn and Child Health website (<http://qualityof-carenetwork.org/about>, accessed 25 February 2019).
4. Sackett DL, Rosenberg WMC, Gray JAM, Haynes RB, Richardson WS. Evidence based medicine: what it is and what it isn't. *BMJ*. 1996;312(7023):71–2.
5. WHO. Recommendations on newborn health: guidelines approved by the WHO guidelines review committee. Geneva: World Health Organization; 2017.
6. WHO. Standards for improving the quality of care for children and young adolescents in health facilities. Geneva: World Health Organization; 2018.
7. WHO. Recommendations on interventions to improve preterm birth outcomes. Geneva: World Health Organization; 2015.
8. WHO. Kangaroo mother care: a practical guide. Geneva: World Health Organization; 2003.
9. Conde-Agudelo A, Díaz-Rossello J. Kangaroo mother care to reduce morbidity and mortality in low birthweight infants. *Cochrane Database Syst Rev*. 2016(8):CD002771.
10. Lawn JE, Mwansa-Kambafwile J, Horta BL, Barros FC, Cousens S. 'Kangaroo mother care' to prevent neonatal deaths due to preterm birth complications. *Int J Epidemiol*. 2010;39 (Suppl 1):i144–154.
11. Nyqvist KH, Anderson GC, Bergman N, Cattaneo A, Charpak N, Davanzo R, et al. State of the art and recommendations. Kangaroo mother care: application in a high-tech environment. *Acta Paediatr*. 2010;99(6):812–19.
12. Ludington-Hoe SM, Johnson MW, Morgan K, Lewis T, Gutman J, Wilson PD, et al. Neurophysiologic assessment of neonatal sleep organization: preliminary results of a randomized, controlled trial of skin contact with preterm infants. *Pediatrics*. 2006;117(5):e909–923.
13. Scher MS, Ludington-Hoe S, Kaffashi F, Johnson MW, Holditch-Davis D, Loparo KA. Neurophysiologic assessment of brain maturation after an 8-week trial of skin-to-skin contact on preterm infants. *Clin Neurophysiol*. 2009;120(10):1812–18.
14. Feldman R, Eidelman AI. Skin-to-skin contact (Kangaroo Care) accelerates autonomic and neuro-behavioural maturation in preterm infants. *Dev Med Child Neurol*. 2003;45(4):274–81.
15. Charpak N, Tessier R, Ruiz JG, Hernandez JT, Uriza F, Villegas J, et al. Twenty-year follow-up of kangaroo mother care versus traditional care. *Pediatrics*. 2017;139(1): pii: e20162063.
16. Vesel L, Bergh AM, Kerber KJ, Valsangkar B, Mazia G, Moxon SG, et al. Kangaroo mother care: a multi-country analysis of health system bottlenecks and potential solutions. *BMC Pregnancy Childbirth*. 2015;15 (Suppl 2):S5.
17. Charpak N, Ruiz-Pelaez JG, Figueroa de CZ, Charpak Y. Kangaroo mother versus traditional care for newborn infants ≤ 2000 grams: a randomized, controlled trial. *Pediatrics*. 1997;100(4):682–8.
18. Belfort MB, Anderson PJ, Nowak VA, Lee KJ, Molesworth C, Thompson DK, et al. Breast milk feeding, brain development, and neurocognitive outcomes: a 7-year longitudinal study in infants born at less than 30 weeks' gestation. *J Pediatr*. 2016;177:133–9.e131.
19. Picheansathian W, Woragidpoonpol P, Baosoung C. Positioning of preterm infants for optimal physiological development: a systematic review. *JBI Libr Syst Rev*. 2009;7(7):224–59.
20. Graven S, Browne J. Sleep and brain development: the critical role of sleep in fetal and early neonatal brain development: a systematic review. *NAINR*. 2008. 8(4):173-9.
21. Shah PS, Herbozo C, Aliwalas LL, Shah VS. Breastfeeding or breast milk for procedural pain in neonates. *Cochrane Database Syst Rev*. 2012(12):CD004950.
22. Johnston C, Campbell-Yeo M, Disher T, Benoit B, Fernandes A, Streiner D, et al. Skin-to-skin care for procedural pain in neonates. *Cochrane Database Syst Rev*. 2017;2:cd008435.
23. Carter BS, Brunkhorst J. Neonatal pain management. *Semin Perinatol*. 2017;41(2):111–16.
24. Pillai Riddell RR, Racine NM, Gennis HG, Turcotte K, Umann LS, Horton RE, et al. Non-pharmacological management of infant and young child procedural pain. *Cochrane Database Syst Rev*. 2015(12):CD006275.
25. Britto CD, Rao Pn S, Nesargi S, Nair S, Rao S, Thilagavathy T, et al. PAIN – perception and assessment of painful procedures in the NICU. *J Trop Pediatr*. 2014;60(6):422–7.

26. Committee on Fetus and Newborn and Section on Anesthesiology and Pain Medicine. Prevention and management of procedural pain in the neonate: an update. *Pediatrics*. 2016;137(2):e20154271.
27. Sacks E and Kinney MV. Respectful maternal and newborn care: building a common agenda. *Reprod Health*. 2015;12: 46.
28. WHO, OECD, World Bank. Delivering quality health services: a global imperative for universal health coverage. Geneva: World Health Organization, Organisation for Economic Co-operation and Development and World Bank; 2018. (<http://www.who.int/servicedeliverysafety/quality-report/publication/en/>, accessed 25 February 2019).
29. HQSS. Lancet Global Health Commission on high quality health systems in the SDG era (<https://www.hqsscommission.org/>, accessed 25 February 2019).
30. Zaka N, Alexander EC, Manikam L, Norman ICF, Akhbari M, Moxon S, et al. Quality improvement initiatives for hospitalised small and sick newborns in low- and middle-income countries: a systematic review. *Implement Sci*. 2018;13(1):20.
31. Marc-Aurele KL, English NK. Primary palliative care in neonatal intensive care. *Semin Perinatol*. 2017;41(2):133–9.
32. Kenner C, Press J, Ryan D. Recommendations for palliative and bereavement care in the NICU: a family-centered integrative approach. *J Perinatol*. 2015;35 (Suppl 1):S19–23.
33. Abraham A, Hendriks MJ. “You can only give warmth to your baby when it’s too late”: parents’ bonding with their extremely preterm and dying child. *Qual Health Res*. 2017;27(14):2100–15.
34. Carroll KE, Lenne BS, McEgan K, Opie G, Amir LH, Bredemeyer S, et al. Breast milk donation after neonatal death in Australia: a report. *Int Breastfeed J*. 2014;9(1): 23.
35. Moxon SG, Guenther T, Gabrysch S, et al. Service readiness for inpatient care of small and sick newborns: what do we need and what can we measure now? *J Glob Health*. 2018;8(1):010702.
36. UNICEF. Toolkit for setting up special care units, stabilisation units and newborn care units. New Delhi: UNICEF; 2009.
37. WHO. WHO model list of essential medicines (20th list); amended August 2017. Geneva: World Health Organization; 2017.
38. Moxon SG, Lawn JE, Dickson KE, Simen-Kapeu A, Gupta G, Deorari A, et al. Inpatient care of small and sick newborns: a multi-country analysis of health system bottlenecks and potential solutions. *BMC Pregnancy Childbirth*, 2015. 15 Suppl 2: p. S7.
39. Edy Siswanto J, Sauer PJ. Retinopathy of prematurity in Indonesia: incidence and risk factors. *J Neonatal Perinatal Med*. 2017;10(1):85–90.
40. Every Preemie – SCALE. Safe and effective oxygen use for inpatient care of newborns – do no harm technical brief. 2017 (https://www.everypreemie.org/wp-content/uploads/2017/07/Oxygen_7.6.17.pdf, accessed 5 March 2019).
41. Diaconu K, Chen YF, Cummins C, Jimenez Moyao G, Manaseki-Holland S, Lilford R. Methods for medical device and equipment procurement and prioritization within low- and middle-income countries: findings of a systematic literature review. *Global Health*. 2017;13(1):59.
42. WHO. Model list of essential in vitro diagnostics: report of the first strategic advisory group on in vitro diagnostics (SAGE-IVD). Geneva: World Health Organization; 2018.
43. WHO. Interagency list of priority medical devices for essential interventions for reproductive, maternal, newborn and child health. Geneva: World Health Organization; 2016.
44. Brown J, Machen H, Kawaza K, et al. A high-value, low-cost bubble continuous positive airway pressure system for low-resource settings: technical assessment and initial case reports. *PLoS One*. 2013;8(1):e53622.
45. Kawaza K, Machen HE, Brown J, Mwanza Z, Iniguez S, Lang H, et al. Efficacy of a low-cost bubble CPAP system in treatment of respiratory distress in a neonatal ward in Malawi. *PLoS One*. 2014;9(1):e86327.
46. Herrick T, Harner-Jay C, Shaffer C, Zwisler G, Digre P, Batson A. Modeling the potential impact of emerging innovations on achievement of Sustainable Development Goals related to maternal, newborn, and child health. *Cost Eff Resour Alloc*. 2017;15:12.
47. Dettinger JC, Kamau S, Calkins K, Cohen SR, Cranmer J, Kibore M, et al. Measuring movement towards improved emergency obstetric care in rural Kenya with implementation of the PRONTO simulation and team training program. *Maternal Child Nutr*. 2018;14 (Suppl 1).
48. Walker DM, Cohen SR, Fritz J, Olvera-Garcia M, Zelek ST, Fahey JO, et al. Impact evaluation of PRONTO Mexico: a simulation-based program in obstetric and neonatal emergencies and team training. *Simul Healthc*. 2016;11(1):1–9.
49. Walker DM, Holme F, Zelek ST, Olvera-Garcia M, Montoya-Rodriguez A, Fritz J, et al. A process evaluation of PRONTO simulation training for obstetric and neonatal emergency response teams in Guatemala. *BMC Med Educ*. 2015;15:117.

50. Edgcombe H, Paton C, English M. Enhancing emergency care in low-income countries using mobile technology-based training tools. *Arch Dis Child*. 2016;101(12):1149–52.
51. OpenSRP. Open Smart Register Platform. (<http://smartregister.org/features-what-is-opensrp.html>, accessed 25 February 2019).
52. Hignett S, Carayon P, Buckle P, Catchpole K. State of science: human factors and ergonomics in health-care. *Ergonomics*. 2013;56(10):1491–1503.
53. Hamilton KES, Redshaw ME, Tarnow-Mordi W. Nurse staffing in relation to risk-adjusted mortality in neonatal care. *Arch Dis Child Fetal Neonatal Ed*. 2007;92(2):F99–F103.
54. BAPM. Service standards for hospitals providing neonatal care (3rd edition). London: the British Association of Perinatal Medicine; 2010.
55. Bliss. Save our special care babies; save our specialist nurses: a Bliss report on cuts to frontline care for vulnerable babies. London: Bliss; 2011.
56. DoH. Toolkit for high quality neonatal services. London: Department of Health; 2009 (http://webarchive.nationalarchives.gov.uk/20130123200735/http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_107845, accessed 25 February 2019).
57. Araújo E, Maedaa A. How to recruit and retain health workers in rural and remote areas in developing countries: a guidance note. Washington DC: World Bank; 2013.
58. WHO. Task shifting to tackle health worker shortages. HIV/AIDS programme booklet (WHO/HSS/2007.03). Geneva: World Health Organization; 2007.
59. WHO. Task sharing to improve access to family planning/contraception. Summary brief (WHO/RHR/17.20). Geneva: World Health Organization; 2017.
60. Blencowe H, Kerac M, Molyneux E. Safety, effectiveness and barriers to follow-up using an 'early discharge' kangaroo care policy in a resource poor setting. *J Trop Pediatr*. 2009;55(4):244–8.
61. Premji SS, Spence K, Kenner C. Call for neonatal nursing specialization in developing countries. *MCN Am J Matern Child Nurs*. 2013;38(6):336–42; quiz 343–4.
62. Hall D, Wilkinson A. Quality of care by neonatal nurse practitioners: a review of the Ashington experiment. *Arch Dis Child Fetal Neonatal Ed*. 2005;90(3):F195–F200.
63. Freed GL, Dunham KM, Lamarand KE, Loveland-Cherry C, Martyn KK. Neonatal nurse practitioners: distribution, roles and scope of practice. *Pediatrics*. 2010;126(5):856–60.
64. EWEC. The global strategy for women's, children's and adolescents' health (2016–2030). New York: Every Woman Every Child; 2015.
65. WHO. Working for health and growth: investing in the health workforce. Geneva: World Health Organization; 2016.
66. Gupta N, Maliqi B, França A, Nyongator F, Pate MA, Sanders D, et al. Human resources for maternal, newborn and child health: from measurement and planning to performance for improved health outcomes. *Hum Resour Health*. 2011;9(1):16.
67. WHO. Point of care continuous quality improvement (POCQI) (<http://www.pocqi.org/>, accessed 25 February 2019).
68. American Academy of Pediatrics and Survive and Thrive Global Development Alliance. Helping babies survive essential care for every baby (app) (<https://itunes.apple.com/us/app/hbseceb/id1028948801?mt=8>, accessed 25 February 2019.)
69. WHO. Coaching guide for the first embrace: facilitator's guide (Early Essential Newborn Care Module 2). 2016 (<http://www.thefirstembrace.org/>, accessed 25 February 2019).
70. CDC. Maternal and infant health. Centers for Disease Control and Prevention (<https://www.cdc.gov/reproductivehealth/maternalinfanthealth/>, accessed 25 February 2019).
71. Yu YT, Hsieh WS, Hsu CH, Lin YJ, Lin CH, Hsieh S, et al. Family-centered care improved neonatal medical and neurobehavioral outcomes in preterm infants: randomized controlled trial. *Phys Ther*. 2017;97(12):1158–68.
72. O'Brien K, Robson K, Bracht M, Cruz M, Lui K, Alvaro R, et al. Effectiveness of family integrated care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial. *Lancet Child Adolesc Health*. 2018;2(4):245–54.
73. WHO. Implementation guidance: protecting, promoting and supporting breastfeeding in facilities providing maternity and newborn services; the revised baby-friendly hospital initiative. Geneva: World Health Organization; 2018.
74. Westrup B. Family-centered developmentally supportive care. *NeoReviews*. 2014;15(8):e325.
75. Vazquez V, Cong X. Parenting the NICU infant: a meta-ethnographic synthesis. *Int J Nurs Sci*. 2014;1(3):281–90.
76. Ottersen OP, Dasgupta J, Blouin C, Buss P, Chongsuvivatwong V, Frenk J, et al. The political origins of health inequity: prospects for change. *Lancet*. 2014;383(9917):630–67.

77. Murphy GAV, Waters D, Ouma PO, Gathara D, Shepperd S, Snow RW, et al. Estimating the need for inpatient neonatal services: an iterative approach employing evidence and expert consensus to guide local policy in Kenya. *BMJ Glob Health*. 2017;2(4):e000472.
78. Murphy GAV, Gathara D, Aluvaala J, Mwachiro J, Abuya N, Ouma P, et al. Nairobi newborn study: a protocol for an observational study to estimate the gaps in provision and quality of inpatient newborn care in Nairobi City County, Kenya. *BMJ Open*. 2016;6(12):e012448.
79. Murphy GAV, Gathara D, Mwachiro J, Abuya N, Aluvaala J, English M, et al. Effective coverage of essential inpatient care for small and sick newborns in a high mortality urban setting: a cross-sectional study in Nairobi City County, Kenya. *BMC Med*. 2018;16(1):72.
80. Otieno PA, Nduati RW, Musoke RN, Wasunna AO. Growth and development of abandoned babies in institutional care in Nairobi. *East Afr Med J*. 1999;76(8):430–5.
81. UNICEF. Maternal and newborn health disparities country profiles. Published 2016 (<https://data.unicef.org/resources/maternal-newborn-health-disparities-country-profiles/>, accessed 25 February 2019).
82. Vermont Oxford Network. Newborn Improvement Collaborative for Quality (<https://public.vtoxford.org>, accessed 25 February 2019).
83. WHO. Birth defects in South-East Asia: a public health challenge: situation analysis. New Delhi: World Health Organization, Regional Office for South-East Asia; 2013.
84. UNGA. Guidelines for the alternative care of children. Resolution adopted by the United Nations General Assembly, 24 February 2010. A/RES/64/142 (reissued for technical reasons on 13 April 2010).
85. Tahsina T, Ali NB, Siddique MAB, Ahmed S, Rahman M, Islam S, et al. Determinants of hardship financing in coping with out of pocket payment for care seeking of under five children in selected rural areas of Bangladesh. *PLoS ONE*. 2018;13(5):e0196237.
86. Feng XL, Guo S, Yang Q, Xu L, Zhu J, Guo Y. Regional disparities in child mortality within China 1996–2004: epidemiological profile and health care coverage. *Environ Health Prev Med*. 2011;16(4):209–16.
87. Yanping W, Lei M, Li D, Chunhua H, Xiaohong L, Mingrong L, et al. A study on rural-urban differences in neonatal mortality rate in China, 1996–2006. *J Epidemiol Community Health*. 2010;64(10):935–6.
88. Yi B, Wu L, Liu H, Fang W, Hu Y, Wang Y. Rural-urban differences of neonatal mortality in a poorly developed province of China. *BMC Public Health*. 2011;11:477.
89. Murray CJ, Lopez AD, Black R, Ahuja R, Ali SM, Baqui A, et al. Population Health Metrics Research Consortium gold standard verbal autopsy validation study: design, implementation, and development of analysis datasets. *Popul Health Metr*. 2011;9:27.
90. UNFPA. What is the minimum initial service package? (MISP). United Nations Population Fund. Published 2015 (<https://www.unfpa.org/resources/what-minimum-initial-service-package>, accessed 25 February 2019).
91. Inter-agency Working Group on Reproductive Health in Crisis. Newborn health in humanitarian settings field guide. New York: UNICEF and Save the Children; 2017.
92. Inter-agency Working Group on Reproductive Health in Crises. Inter-agency field manual on reproductive health in humanitarian settings. World Health Organization: Geneva; 2010.
93. Infant Feeding in Emergencies Core Group. Infant and young child feeding in emergencies. Operational guidance for emergency relief staff and programme managers. Version 3.0. Oxford: Emergency Nutrition Network; 2017.

Ensure they thrive

KEY MESSAGES

- **Every newborn and child's ability to thrive is the direct result of nurturing care and positive interaction with their environment.** The brain is most vulnerable before birth and in the early years. Prematurity, birth complications, and severe infections such as meningitis result in high risk of disability and suboptimal development. Developmentally supportive care improves outcomes for newborns by placing them in a nurturing, family-centred environment with respect, minimal stimulation, and maximum information-sharing between providers and families.
- **Newborns who have had major complications at birth and during the neonatal period require regular follow-up and nurturing care to optimize development.** Parents and caregivers are crucial for short- and long-term success. Early detection of disability or developmental delay through routine follow-up enables the newborn and its family to be supported. These newborns can survive and thrive. The role of empowered parents is key in the hospital setting and in transition from hospital to home.
- **Investments in early childhood development benefit individuals, communities and countries.** Prioritizing developmentally supportive care, and building partnerships with families from the beginning, can reduce adverse outcomes and thus improve economic productivity.



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What does it mean to thrive?

An individual who thrives is able to develop his or her full potential in the first years of life and beyond. As a holistic concept, this age span includes domains of child development such as cognition, social and emotional interactions, and linguistic and motor skills. Various groups working in early childhood development define and categorize domains differently. However, the goal is to describe developmental potential (i.e. what a child should know and be able to do) across an age span (1).

Broad consensus defines early childhood development within two dimensions: the child (age and development), and the environment. The early childhood period begins at conception and ends at school entry, with developmentally distinct phases within that age span.

Often referred to as “the first 1000 days,” the period from conception to 24 months is critical in the context of preterm birth and neonatal illness, when biological circumstances pose challenges to optimal development. Beyond 24 months, children continue to gain skills and abilities throughout their entire early childhood.

Thriving is a maturation process and the result of a positive interaction between the child and its environment. Though developmental processes are similar across cultures, the rate at which children acquire culture-specific skills may vary (2). An important part of a child’s

developmental potential involves having an environment marked by nurturing care (3). The WHO, UNICEF and World Bank Nurturing Care Framework contains five components: good health; adequate nutrition; responsive caregiving (early bonding, secure attachment, trust and sensitive communication); safety and security (protection from violence, abuse, neglect, harm and environmental pollution); and opportunities for early learning (4).

Why is early childhood so significant?

The brain develops most rapidly in the first years of life, when neurons form new connections at upwards of 1000 per second (5). The science underscores that while genes provide the “blueprint” for the brain, it is a child’s environment that shapes brain development. This occurs in a relatively short period of time, strongly influencing future capacity to learn, adapt to change, and develop psychological resilience. Nurturing care is what the infant’s brain depends upon for healthy development, making the role of parents, caregivers and families significant. This period of life is considered foundational for later health and well-being (4).

Infants and children who lack the components of nurturing care tend to have lowered cognitive, language, executive functioning and psychosocial outcomes. This can lead to lower academic achievement in primary school and, ultimately, to more school dropouts (3). Longer-term

consequences can include lower productivity and earnings in adulthood, poor health outcomes and increased engagement in crime.

The latest evidence indicates that early deprivation can affect an individual's genetic endowment and have implications for future generations (6). Early life adversity and exposure to toxic stress has been associated with altered brain architecture and reduced brain volume; this is associated with behavioural outcomes for language and academic achievement (7, 8). However, protective factors such as maternal responsive care can offset some risk factors and protect early brain development (9). Investments in care during these first years of life not only benefit individuals, but also communities and countries through greater social cohesion and stability and higher productivity and earnings.

Developmental outcomes for small and sick newborns

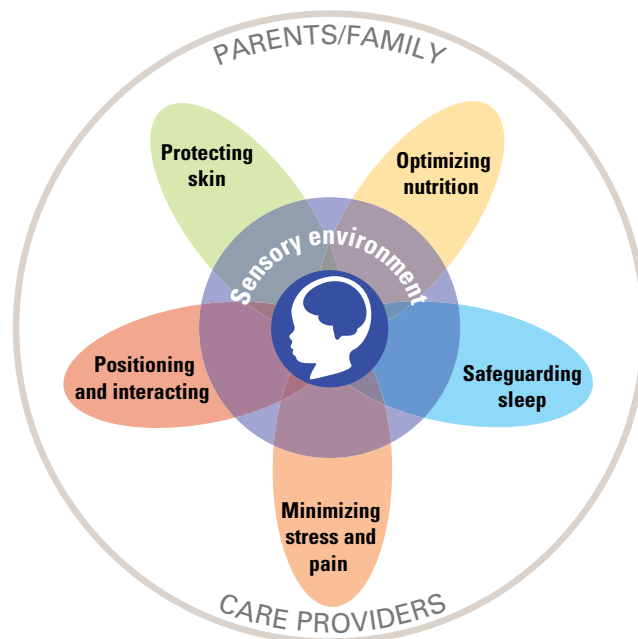
The majority of developmental literature in LMICs focuses on neurodevelopmental outcomes, with reporting gaps noted for vision and hearing impairment outcomes (10). While rates of severe vision and hearing impairment in all preterm newborns in HICs has dropped to 1–2%, severe visual impairment has been measured at 10% in those born at less than 26 weeks' gestation (11). Emerging data indicate that this may be considerably higher in LMICs (12, 13). For example, retinopathy of prematurity is associated with high exposure to oxygen in the newborn period. While many LMIC settings offer oxygen to preterm newborns, they are not able to provide blended oxygen (i.e. less than 100%); this is a potent risk factor for increased visual impairment.

SGA newborns are at risk of long-term neurodevelopmental delays, learning disabilities and behaviour problems (14, 15). In addition, LBW newborns are at greater risk for academic difficulties and behaviour problems compared with newborns of normal birth weight. Newborns who survive neonatal infections, intrapartum-related complications and neonatal jaundice are also more likely to experience developmental delays, difficulties or disabilities (16).

Effective interventions to promote development

Among the 13 million preterm newborns who survive globally each year, an estimated 2.7% have moderate-to-severe impairments and 4.4% have mild neurodevelopmental impairments (17). In HICs, early

Fig. 4.1 Elements of developmentally supportive care



Adapted from: Altimie L, Phillips R. *Newborn & Infant Nsg Rev* 2016; 16:230.

interventions have been shown to improve cognitive and social-development outcomes with effects lasting into childhood and adulthood (18).

As described in Chapter 1, neonatal care has evolved over the past 40 years to become more holistic, maximize outcomes, support family-centred care and recognize linkages between the way in which care is provided and neurodevelopmental outcomes. Much of the early evidence came from recognition that observing newborns provides reliable information and that their cues are useful guides for modifying caregiver behaviours (Fig. 4.1) (19, 20).

In a developmentally supportive care model, the newborn is at the centre of a healing environment that includes the physical surroundings (for example, the facility or NICU) and the sensory environment (for example, temperature, touch, smell, taste, sound, light, vestibular and proprioceptive inputs). Interactions with health-care providers, parents and family affect the environment and can modify it to promote healthy development and minimize adverse consequences from hospitalization.

The actions associated with this model are disease-independent but vital to promoting healthy growth and well-being. They include the following:

- **Optimize nutrition** – Provide human milk; use cue-based, infant-guided feeding; involve parents in feedings to improve breastfeeding initiation and duration (21, 22).
- **Safeguard sleep** – Cluster care; assess and provide care to coincide with sleep and wake cycles; and minimize noise and light (23).
- **Manage pain and stress** – Minimize noise and light; recognize signs of stress and pause intervention when possible; and use positioning and boundaries to provide containment (24–26).
- **Position and interact** – Maintain head in midline with limbs and trunk flexed and tucked; handle with slow, gentle movements; and provide support during transfers (27, 28).
- **Protect skin** – Maintain humidity during skin maturation; monitor susceptible skin/mucosal areas for breakdown; and promote skin-to-skin contact (29).

Health-care providers and parents and families need to have special understanding and skills to optimize nurturing care for small and sick newborns. Nurses in particular must have the ability to interpret the behavioural cues of nonverbal infants and help parents develop the same comprehension. The newborn's complete dependency means that nurses must act on their behalf to structure the environment and incorporate the uniquely responsive and individualized care provided by parents. In order to accomplish this, nurses become guides and teachers of the family as much as direct providers of care. In sum, developmentally supportive, family-centred care can be regarded as the expression of respectful care for the small or sick newborn.

As noted in Chapter 1, lessons learned from studies on the adverse consequences of separating sick newborns from their families, carried out between the 1940s and 1970s in HICs, led to changes in hospital care of newborns; as a result, families were increasingly engaged as partners in care. Building reciprocal partnerships between families and providers is becoming a standard for health-care planning and delivery across the life course in HICs and a few LMICs. The core principles of family-centred care are: dignity and respect; information sharing; participation; and collaboration. While there

are many models of family participation during inpatient care of the newborn, all share a common view that the infant, the parents/primary caregivers, and health-care providers are a unit of care (30).

The newborn period is a sensitive time when parents and their children should form healthy attachments to one another. Establishing a lifelong bond between parent and child is critical for a child's healthy development, as well as the emotional health of all family members. When an infant is born small or sick, however, separation from its parents during hospitalization can disrupt this bonding process. Integrating parents into their newborn's care during hospitalization can maintain infant–parent unity and help form a stable and secure attachment.

Parents can make unique contributions to the care of their small and sick newborns. Under the supervision and mentorship of health-care staff they can provide basic caregiving, such as feeding, bathing and changing diapers. Maternal breastmilk offers significant advantages for a newborn's survival, growth and cognition. The consistent presence of parents provides familiar touch, sights, scents and sounds, as well as increased opportunities for vestibular and proprioceptive stimulation with skin-to-skin care.

By engaging families as part of the health-care team, providers can bolster the confidence and competence of parents as they transition into their role as primary



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caregivers. Parents learn to read their baby's cues, which improves communication with providers and decision-making. Family members gain health literacy, which often translates to better post-discharge compliance with the newborn's follow-up plan and higher utilization of preventative care. Empowerment of mothers and fathers can foster greater emotional coping while improving parenting abilities (31). Chapter 1 (Box 1.3) describes the experience of family engagement in the care of their small and sick newborns in the Dr Ram Manohar Lohia Hospital, in New Delhi, India.

Discharge and beyond: empowering parents and caregivers

Parents and caregivers of small and sick newborns frequently report feeling less than fully confident about caring for them after discharge. Their responsibilities may seem overwhelming with the burden to comply with treatment protocols, attend appointments, seek care, and provide children with ongoing opportunities for development. To provide the support parents need, and for small and sick newborns to thrive long-term, all efforts should be made to support caregiving at home.

This can be addressed through a robust discharge plan that is sensitive to the parents' psychosocial needs (32). Discharge education that accommodates parental schedules and preferred learning styles can build self-confidence (32, 33). Effective education also mitigates the stressful effects of the NICU experience. For example, individualized education programmes that discuss problem-solving, behavioural cues and appropriate interaction lead to higher satisfaction with care and reduced stress in parents of preterm newborns (34). Support forums for parents, including parent-led, peer-to-peer and health professional-led groups, improve the home environment, parental mental health and parental confidence in caring for their child (34). KMC programs with support to families at time of discharge and through follow-up services until 2 years of age, like the one in Bogota, Colombia, show encouraging long term benefits (see Box 4.1).

At-home interventions

In addition to providing developmentally supportive care, early stimulation interventions have shown short-term benefits to cognitive, motor and social-emotional development for LBW infants in LMICs (36). Stimulation interventions in the home encourage development through early learning opportunities that encourage the infant and young child to explore the environment using sight, touch, sound and smell; to manipulate objects; and to interact socially with caregivers (37). Such interventions

may be implemented with parents and family members through home visits or in group sessions, with guidance on sensitive and responsive caregiving and feeding. Responsive caregiving benefits a child's development and academic outcomes, and decreases hospitalizations (38). Global guidelines to support national efforts to improve newborn care at home are described in Box 4.2.

In Jamaica, a randomized controlled trial evaluated the effects of an early stimulation intervention for LBW infants on developmental outcomes, compared with normal-birth-weight infants, at 24 months of age (40). Mothers of LBW newborns were provided with weekly home support visits from birth through the first eight weeks of life, followed by booster home visits from 7–24 months of age. The study reported significant benefits to the development of LBW infants compared with normal-birth-weight infants at 24 months of age, as well as noteworthy improvements in the stimulation and learning opportunities provided by caregivers in the home. A follow-up study of the children at 6 years of age found sustained benefits; children exposed to the early intervention had significantly higher IQ scores compared with the control group (40, 41).

In India, a randomized study of 800 high-risk newborns (LBW, preterm, SGA) divided the infants into two

Box 4.1 Kangaroo mother care: 20 years on

Between 2012 and 2014, a study in Colombia followed up with 264 participants who had weighed less than 1000 g at birth in randomized controlled trials conducted 20 years previously. The earlier study during 1993 and 1996 documented the benefits of KMC on survival, neurodevelopment, breastfeeding and the quality of mother–infant bonding (35).

The later study showed that KMC continued to have significant, long-lasting social and behavioural protective effects 20 years after the intervention. These included more protective and nurturing parenting, higher hourly wages, and reduced school absenteeism, hyperactivity, aggressiveness, externalization and socio-deviant conduct among the now young adults. These effects were magnified by longer duration of skin-to-skin contact and the participation of fathers. Neuroimaging indicated that the 20-year-olds who received KMC as infants also had significantly larger cerebral volumes.

Box 4.2 Global guidelines for community practitioners

WHO and UNICEF have published global care guidelines designed to help meet the needs of newborns, infants and children who have limited access to quality health services, or who live in conditions of poverty, disadvantage and fragility. Community health-care providers can use these guidelines to support parents and caregivers during home visits.

For the at-risk newborn, the primary package is *Caring for the Newborn at Home*. This package is delivered during pregnancy, and for a week after birth, through a series of five home visits. It helps

the community health-care provider to promote antenatal and newborn care. It also addresses special care considerations for LBW newborns.

The additional packages, *Caring for a Child's Healthy Growth and Development*; *Caring for the Sick Child in the Community*; and *Care for Child Development* focus on the development of all children, or sick children who are not necessarily small or preterm. These detail the health and nutritional needs of young children, along with early stimulation and responsive caregiving practices (39).

groups after discharge from the neonatal nursery. One group received standard care and the other received stimulation therapy for one year (42). Evaluation at 2 years of age showed higher development outcomes for children in the early intervention group compared with the control group.

Another study shows that home visits that provide education and assistance positively impact parent-to-infant interactions (43). Analyses of 10 similar studies with preterm infants found that these programmes may lead to reduced parental stress levels, more positive maternal behaviour, and improved maternal–infant interactions (34). Programmes with infant massage, games, skills and more have also been associated with greater maternal feelings of competence and reduced stress (34). In addition to home-support programmes, educational services for parents can mitigate maternal stress and may improve parenting (44).

Early interventions have also been effective in rural disadvantaged settings. A three-country randomized trial in India, Pakistan and Zambia investigated the effects of an early intervention programme on infants who had been resuscitated at birth compared with infants who did not require resuscitation (45). Trained lay individuals visited members of the intervention group at home twice a week over the first three years of life to provide early stimulation and to guide parent–child interactions. The treatment significantly improved the children's cognitive and psychomotor outcomes. A larger body of research over the last two decades shows consistent benefits for disadvantaged children in LMICs (particularly for those at risk of malnutrition) from early stimulation and caregiver skills development (35, 46, 47). Further research is required to understand the long-term benefits.

Screening and monitoring

Although developmentally supportive care with in-home interventions and support are proving successful, progress has been hampered by inadequate screening and monitoring in LMICs to identify children at risk and evaluate service effectiveness. Countries need to provide ongoing screening and clinical monitoring of small and sick newborns to check if they are thriving.

Monitoring involves skilled observation by a knowledgeable professional (e.g. monitoring for developmental milestones at routine child health or immunization visits). Screening involves the use of standardized and validated screening tools for more formal evaluation of a specific aspect of health or development, such as anaemia screening, or use of a standardized developmental–behavioural screening tool.

Early childhood development is rapid and dynamic, so assessments related to pre-, peri- and neonatal traumas or injuries should include investigation through the early development stages, and in some cases into school age. While severe motor and sensory or perceptual differences may be detectable in infancy, mild-to-moderate motor disability may not be obvious before 1 to 2 years of age. Language delays become more apparent between 18 and 30 months. Socioemotional and executive functioning differences may not be detectable until school age. Screening and monitoring in infancy and beyond provides valuable information for the child's care, for research and programme evaluation, and for the larger community or population.

Screening for parental distress

Emotional distress experienced at the NICU can disrupt the infant–parent bonding process and lessen a parent's

sense of self-confidence when it comes to caring for their child (48). Mothers are more at risk for anxiety and depression, which can have long-term negative consequences on the child's behavioural and cognitive development (44, 49).

In humanitarian crises, stress and distress are amplified. For newborns to thrive after discharge, it is essential to

identify those parents who may be anxious, depressed and traumatized. Staff should be trained to recognize families at highest risk, screen them and link them to appropriate care and support (32).

Annex 2 provides an overview of tools for screening and monitoring early childhood development at the individual, programme and population levels.

A PARENT'S STORY

A Mexican mother fights for her twins and goes on to support other parents internationally



Ilein holds her twins Alonso and Camila in the hospital

Early on in Ilein Bolaños Gonzalez's fraternal twin pregnancy, she was diagnosed with a subchorionic haematoma. Ilein spent the next two months on modified bed rest until the complication resolved.

At 32 weeks' gestation, Ilein felt some mild

stomach pain. When she went to her doctor's office, her provider informed her that she was 8 cm dilated.

"I hadn't been feeling the contractions," Ilein recalled. "In less than 40 minutes my babies were born via caesarean section."

Ilein only saw her babies for a few seconds before the doctors whisked them away to the neonatal care unit.

"It was very strange," she remembered. "It was 36 hours until I could see them again. I told the staff to please take a picture for me. That is how I met my twins." The photograph helped prepare Ilein for what was in store. Her son Alonso was 1.5 kg, and her daughter Camila was 1.6 kg.

At the neonatal care unit, the twins received phototherapy, learned to eat and breathe, and gained weight. Ilein struggled with the unnatural separation. "The visiting hours for the neonatal care unit were from 10:00 in the morning until noon and then from 5:00 to 8:00 in the evening," she recalled. "It was terrible to be away from them." Despite their relatively brief hospitalization of 24 days, the family experienced many more challenges after their discharge. At the age of 2, Camila was diagnosed

with nephrotic syndrome, a kidney disorder which has since resolved. Alonso has faced some issues common in children born preterm, including kidney problems as well as difficulties eating, sleeping, and focusing. Both twins have also struggled with sensory processing.

"There was a lack of follow-up care," Ilein says about her experience navigating the health system in Mexico City. She was on her own to obtain the developmental specialist services her children needed to thrive. But Ilein's professional experience as a lawyer prepared her to step into her role as her twins' best advocate. "I am tough and I always fight," she said.

Despite her strengths, Ilein "felt a lack of emotional support when my kids were young." So Ilein started a parent support group at her twins' hospital. Later, she joined forces with another affected mother to build a non-profit organization known as *Con Amor Vencerás* ("With Love, You Will Win"). *Con Amor Vencerás* focuses on improving policies and increasing emotional support for families of small and sick newborns. It has grown to include representatives in 22 cities in Mexico and 5 countries in Latin America. It has also created a manual for parents to develop their own local support groups. Currently, the organization hosts one of the first and largest prematurity-focused online support groups in Latin America.



REFERENCES

1. Britto PR, Engle PL, Super CM, editors. Handbook of early childhood development research and its impact on global policy. Oxford University Press, USA; 2013.
2. McCoy DC, Black MM, Daelmans B, Dua T. Measuring development in children from birth to age 3 at population level. *Early Childhood Matters*. 2016 (<https://bernardvanleer.org/ecm-article/2016/measuring-development-children-birth-age-3-population-level/>, accessed 28 February 2019).
3. Black MM, Walker SP, Fernald LCH, Andersen CT, DiGirolamo AM, Lu C, et al. Early childhood development coming of age: science through the life course. *Lancet*. 2017;389(10064):77–90.
4. WHO, UNICEF, World Bank Group. Nurturing care for early childhood development: a framework for helping children survive and thrive to transform health and human potential. Geneva: World Health Organization; 2018.
5. National Scientific Council on the Developing Child. Young children develop in an environment of relationships: working paper no. 1. Cambridge, MA: Center on the Developing Child at Harvard University; 2004.
6. Shonkoff JP, Garner AS, Siegel BS, et al. The lifelong effects of early childhood adversity and toxic stress. *Pediatrics*. 2012;129(1):e246.
7. Hair NL, Hanson JL, Wolfe BL, Pollak SD. Association of child poverty, brain development, and academic achievement. *JAMA Pediatr*. 2015;169(9):822–9.
8. Hodel AS, Hunt RH, Cowell RA, Van Den Heuvel SE, Gunnar MR, Thomas KM. Duration of early adversity and structural brain development in post-institutionalized adolescents. *Neuroimage*. 2015;105:112–19.
9. Luby JL. Poverty's most insidious damage: the developing brain. *JAMA Pediatr*. 2015;169(9):810–11.
10. Milner KM, Neal EFG, Roberts G, Steer AC, Duke T. Long-term neurodevelopmental outcome in high-risk newborns in resource-limited settings: a systematic review of the literature. *Paediatr Int Child Health*. 2015;35(3):227–42.
11. Larroque B, Ancel PY, Marret S, Marchand L, Andre M, Arnaud C, et al. Neurodevelopmental disabilities and special care of 5-year-old children born before 33 weeks of gestation (the EPIPAGE study): a longitudinal cohort study. *Lancet*. 2008;371(9615):813–20.
12. Thukral A, Sankar MJ, Chandrasekaran A, Agarwal R, Paul VK. Efficacy and safety of CPAP in low- and middle-income countries. *J Perinatol*. 2016;36(Suppl 1):S21–S28.
13. Lissauer T, Duke T, Mellor K, Molyneux L. Nasal CPAP for neonatal respiratory support in low and middle-income countries. *Arch Dis Child Fetal Neonatal Ed*. 2017;102(3):F194–F196.
14. Garfield CF, Karbownik K, Murthy K, Falciglia G, Guryan J, Figlio DN, et al. Educational performance of children born prematurely. *JAMA Pediatr*. 2017;171(8):764–70.
15. Lawn JE, Blencowe H, Oza S, You D, Lee AC, Waiswa P, et al. Every newborn: progress, priorities, and potential beyond survival. *Lancet*. 2014;384(9938):189–205.
16. Vaivada T, Gaffey MF, Bhutta ZA. Promoting early child development with interventions in health and nutrition: a systematic review. *Pediatrics*. 2017;140(2)pii:e20164308.
17. Joy EL, Hannah B, Shefali O, et al. Every newborn: progress, priorities, and potential beyond survival. *Lancet*. 2014;384(9938):189–205.
18. Moster D, Lie RT, Markestad T. Long-term medical and social consequences of preterm birth. *N Engl J Med*. 2008;359(3):262–73.
19. Als H. Toward a synactive theory of development: promise for the assessment and support of infant individuality. *Infant Ment Health J*. 1982;3(4):229–43.
20. Als H, Tronick E, Lester BM, Brazelton TB. The Brazelton neonatal behavioral assessment scale (NBAS). *J Abnorm Child Psychol*. 1977;5(3):215–31.
21. Belfort MB, Anderson PJ, Nowak VA, Lee KJ, Molesworth C, Thompson DK, et al. Breast milk feeding, brain development, and neurocognitive outcomes: a 7-year longitudinal study in infants born at less than 30 weeks' gestation. *J Pediatr*. 2016;177:133–9.e131.
22. Manzoni P, Stolfi I, Pedicino R, Vagnarelli F, Mosca F, Pugni L, et al. Human milk feeding prevents retinopathy of prematurity (ROP) in preterm VLBW neonates. *Early Hum Dev*. 2013;89 (Suppl 1):S64–68.
23. Graven S, Browne J. Sleep and brain development: the critical role of sleep in fetal and early neonatal brain development: a systematic review. *NAINR*. 2008;8(4):173–9.
24. Bergman NJ. The neuroscience of birth – and the case for zero separation. *Curationis*. 2014;37(2): e1–e4.
25. Gudsnuik KM, Champagne FA. Epigenetic effects of early developmental experiences. *Clin Perinatol*. 2011;38(4):703–17.
26. Benoit B, Campbell-Yeo M, Johnston C, Latimer M, Caddell K, Orr T. Staff nurse utilization of kangaroo

- care as an intervention for procedural pain in preterm infants. *Adv Neonatal Care*. 2016;16(3):229–38.
27. Picheansathian W, Woragidpoonpol P, Baosoung C. Positioning of preterm infants for optimal physiological development: a systematic review. *JBI Libr Syst Rev*. 2009;7(7):224–59.
 28. Hunter J. Therapeutic positioning: neuromotor, physiologic, and sleep implications. *Developmental care of newborns and infants*. 2010;285–312.
 29. Hoath SB. The skin as a neurodevelopmental interface. *NeoReviews*. 2001;2(12):e292.
 30. Craig JW, Glick C, Phillips R, Hall SL, Smith J, Browne J. Recommendations for involving the family in developmental care of the NICU baby. *J Perinatol*. 2015;35(Suppl 1):S5–S8.
 31. Committee on Hospital Care and Institute for Patient-Family-Centered Care. Patient- and family-centered care and the pediatrician's role. *Pediatrics*. 2012;129(2):394–404.
 32. Purdy IB, Craig JW, Zeanah P. NICU discharge planning and beyond: recommendations for parent psychosocial support. *J Perinatol*. 2015;35 (Suppl 1):S24–28.
 33. AHRQ. Transitioning newborns from NICU to home. (Content last reviewed December 2013). Agency for Healthcare Research and Quality (AHRQ) (http://www.ahrq.gov/professionals/systems/hospital/nicu_toolkit/index.html, accessed 28 February 2019).
 34. Brett J, Staniszevska S, Newburn M, Jones N, Taylor L. A systematic mapping review of effective interventions for communicating with, supporting and providing information to parents of preterm infants. *BMJ Open*. 2011;1(1):e000023.
 35. Charpak N, Tessier R, Ruiz JG, Hernandez JT, Uriza F, Villegas J, et al. Twenty-year follow-up of kangaroo mother care versus traditional care. *Pediatrics*. 2017;139(1): pii: e20162063.
 36. Engle PL, Fernald LCH, Alderman H, Behrman J, O'Gara C, Yousafzai A, et al. Strategies for reducing inequalities and improving developmental outcomes for young children in low-income and middle-income countries. *Lancet*. 2011;378(9799):1339–53.
 37. Aboud FE, Yousafzai AK. Very early childhood development. *Reproductive, Maternal, Newborn, and Child Health*. 2016:241.
 38. Eshel N, Daelmans B, Mello MCd, Martines J. Responsive parenting: interventions and outcomes. *Bull World Health Organ*. 2006;84(12):991–8.
 39. WHO. Caring for the newborn at home. Geneva: World Health Organization; 2015 (http://www.who.int/maternal_child_adolescent/documents/caring-for-the-newborn-at-home/en/, accessed 28 February 2019).
 40. Walker SP, Chang SM, Powell CA, Grantham-McGregor SM. Psychosocial intervention improves the development of term low-birth-weight infants. *J Nutr*. 2004;134(6):1417.
 41. Walker SP, Chang SM, Younger N, Grantham-McGregor SM. The effect of psychosocial stimulation on cognition and behaviour at 6 years in a cohort of term, low-birth-weight Jamaican children. *Dev Med Child Neurol*. 2010;52(7):e154.
 42. Nair MKC, Philip E, Jeyaseelan L, George B, Mathews S, Padma K. Effect of child development centre model early stimulation among at risk babies – a randomized controlled trial. *Indian Pediatr*. 2009;46 (Suppl:s20).
 43. Goyal NK, Teeters A, Ammerman RT. Home visiting and outcomes of preterm infants: a systematic review. *Pediatrics*. 2013;132(3):502–16.
 44. Zuckerman BS, Beardslee WR. Maternal depression: a concern for pediatricians. *Pediatrics*. 1987;79(1):110.
 45. Carlo WA, Goudar SS, Pasha O, Chomba E, Wallander JL, Biasini FJ, et al. Randomized trial of early developmental intervention on outcomes in children after birth asphyxia in developing countries. *J Pediatr*. 2013;162(4):712.e713.
 46. Aboud FE, Yousafzai AK. Global health and development in early childhood. *Annu Rev Psychol*. 2015;66(1):433–57.
 47. Britto PR, Lye SJ, Proulx K, Yousafzai AK, Matthews SG, Vaivada T, et al. Nurturing care: promoting early childhood development. *Lancet*. 2017;389(10064):91–102.
 48. Boykova M, Kenner C. Transition from hospital to home for parents of preterm infants. *J Perinat Neonatal Nurs*. 2012;26(1):81-7; quiz 88–9.
 49. Zolkowitz P, Na S, Wang T, Bardin C, Papageorgiou A. Early maternal anxiety predicts cognitive and behavioural outcomes of VLBW children at 24 months corrected age. *Acta Paediatr*. 2011;100(5):700–4.



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Use data for action

KEY MESSAGES

- **Every country has data that can be used now to drive action.** Data quantity and quality varies, but every country has data that can be used now to accelerate progress towards mortality targets. These include facility birth data from routine information systems as well as intermittent health assessments and surveys. Regular perinatal death audits, linked to maternal and perinatal death surveillance and response, can improve accountability and quality of care.
- **There are many opportunities to improve birth and newborn data quality and availability.** Today, more infants are born in facilities than in previous years, thus providing opportunities for registering the births and recording birth weights. These, and other data, can be collected through increasingly available routine health management information systems.
- **Gaps in high-priority data must be closed to end preventable deaths (survive); ensure health and well-being (thrive); and change how small and sick newborns are cared for (transform).** To accelerate progress towards targets for the Survive, Thrive and Transform agenda, ambitious change is needed, especially to measure coverage and quality of hospital-based interventions, as well as the experience of care, and how to assess and follow-up long-term outcomes for at-risk newborns.



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Earlier chapters presented a range of data and case studies to underscore a key premise: those born small and sick require special care to survive and thrive. While the available data reveal inequities in access to care and quality of care, there are many gaps in knowledge. To date, there are no adequate metrics for small and sick newborns and the types of care they need or receive – in the first few weeks, in the subsequent months and years, and in all settings.

Unless countries can track coverage of high-quality care for small and sick newborns, the ambitious targets for 2030 for newborn survival will not be met. Beyond survival data, it is critical to measure follow-up care and early interventions. New metrics relating to quality and safety of inpatient care are needed to inform strategies for improving outcomes for small and sick newborns, and to guide decision-making around achieving UHC.

More specific metrics will inform how UHC targets can be met, by linking the data of the Every Newborn Action Plan and Global Strategy for Women's, Children's and Adolescents' Health with data on progress towards the SDGs. This chapter looks closely at current needs, opportunities and priorities to improve the availability and quality of data.

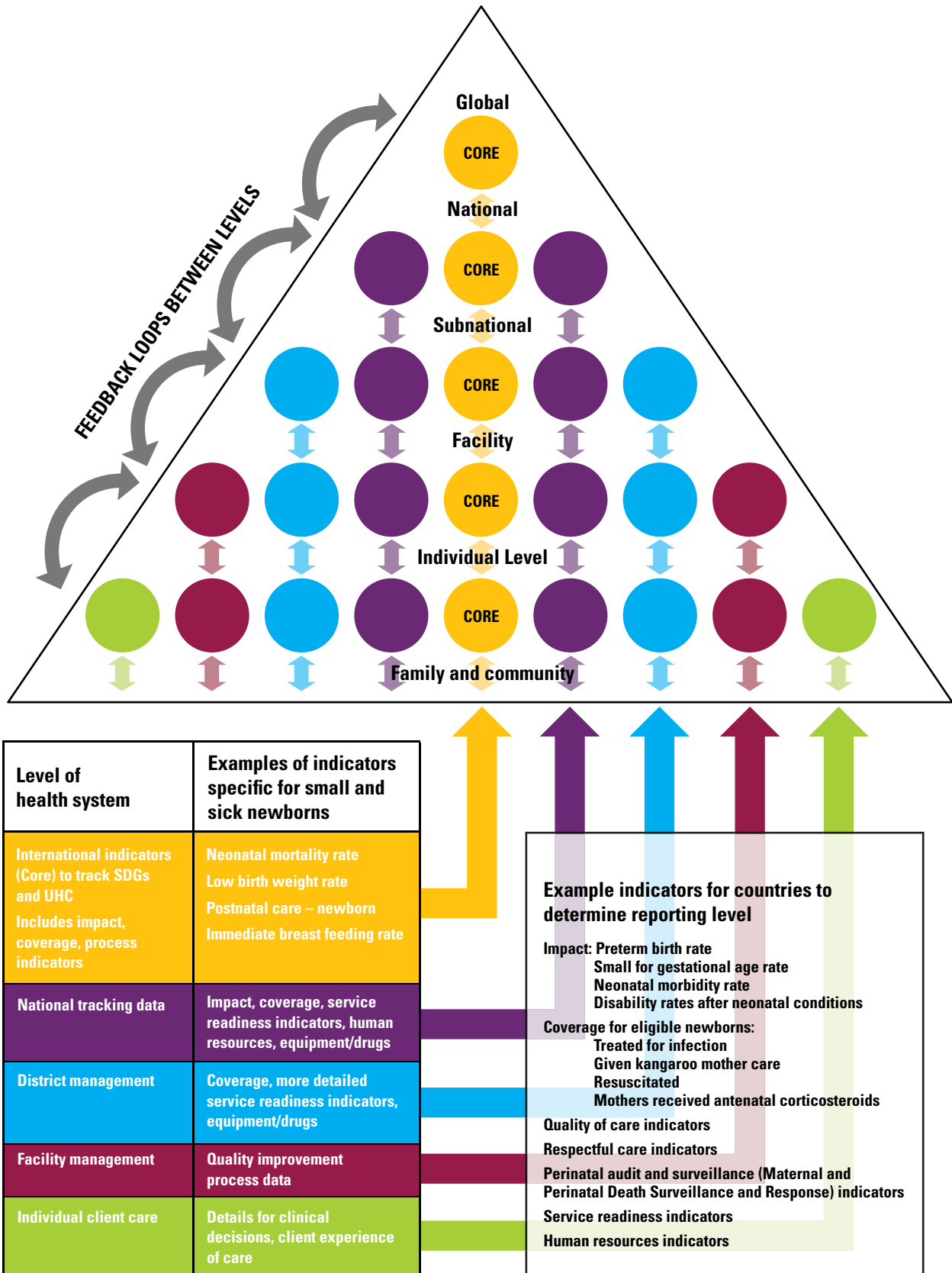
Which data are needed by health system level?

Across the health system, information about small and sick newborns is needed not only by health-care providers, programme managers and policy-makers, but also by parents, families, caregivers and communities. Targeted reporting is necessary to avoid the data-rich, information-poor (DRIP) scenario – a system overwhelmed by too many indicators that do not accurately or reliably give the information needed (1). The routine data needed at all health system levels for small and sick newborns is shown in Fig. 5.1 (2).

Parents, families and communities are positioned at the base of the pyramid to denote a family-centred approach to both care and measurement (as shown in Fig 5.1). The death or illness of a newborn is a major family crisis; good communication and the sharing of meaningful information between families and health-care providers is crucial for high-quality care (3).

Individual-level data about a newborn's health and treatment inform day-to-day clinical decision-making in essential, special and intensive care. Health-care providers with neonatal skills collect detailed information in

Fig. 5.1 The routine data needs of different health system levels, adapted for small and sick newborns



Adapted from: Heywood and Rohde, 2000.

individual patient records as they partner with parents and families in caregiving. This information includes an assessment of the family's confidence to transition home safely, and to communicate with primary health-care services. Measuring the family's experience of care is key to a family-centred care approach.

As described in Fig. 5.1, some individual data should be aggregated and shared at other levels of the health system. Countries should decide which indicators to report and use at the **facility, district/subnational and national levels**. A few specific common (or core) standardized indicators for small and sick newborns need to be tracked at the **national and global levels** for accountability purposes and to monitor progress towards the SDG targets. Core indicators rise from the community and individual levels as shown in the middle of the pyramid.

Most of the 2.5 million newborns who die globally each year are small or sick, or both; neonatal mortality represents nearly half of all under-5 deaths (4). Yet few specific core indicators for small and sick newborns are currently tracked at the national and global levels. Of the 100 WHO core health indicators, only one risk factor – low-birth-weight – relates to small and sick newborns (5). Three additional indicators are tracked for all newborns: NMR; postpartum care coverage for newborns; and early initiation of breastfeeding. Policy-makers who intend to invest in care for small and sick newborns need reliable data for specific indicators in order to track progress towards targets.

What types of data need to be captured?

Data can inform planning, spark prompt action and identify equity gaps (6). The Every Newborn Action Plan strategic objectives include using a measurement improvement roadmap and milestones to transform metrics and use of data (7–9). Core and additional indicators, selected through a multicountry consultation process, include impact, coverage and quality of care with health system input (Table 5.1) (10–12).

Indicators most relevant to small and sick newborns (Table 5.1) are discussed below. Relevant questions

include: Why are these data needed? Which data can be used now? What data are needed?

Measuring impact

Why are these data needed? Impact indicators measure results and enable the tracking of progress towards national and global goals and equity gaps.

Which data can be used now? Global NMR tracking still depends typically on nationally representative household surveys, often stratified by equity metrics (e.g. urban/rural, socioeconomic, geography and education). Routinely disaggregating NMR by sex, as with under-5 mortality, could better track gender equity for small and sick newborns. Since the proportion of births in health facilities now exceeds 75%, birth weights are increasingly available and could be used to report LBW rates. Estimates suggest that more than 80% of neonatal deaths are LBW; tracking NMR by birth weight groups would help countries to understand and respond to mortality patterns.

What data are needed? Additional impact indicators more specific to small and sick newborns are also needed. It is important to know the gestational age of each newborn to assess how preterm and growth restricted or SGA affects them; to guide individual clinical care; and to identify at-risk populations. Innovation is



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Table 5.1 Every Newborn Action Plan: core and additional indicators

Current status	Type of indicators	Core indicators	Additional indicators
Definitions clear – but quantity and consistency of data lacking	Impact	1. Maternal mortality ratio** 2. Stillbirth rate* 3. Neonatal mortality rate**	Intrapartum stillbirth rate Low birth weight rate Preterm birth rate Small for gestational age Neonatal mortality rate Disability after neonatal conditions
Contact point definitions clear but data on content of care are lacking	Coverage: care for all mothers and newborns	4. Skilled attendant at birth** 5. Early postnatal care for mothers and newborns* 6. Essential newborn care (tracer is early breastfeeding)	Antenatal care* Exclusive breastfeeding up to six months*
Gaps in definitions, and requiring validation and feasibility testing for health management information systems use	Coverage: complications and extra care	7. Neonatal resuscitation 8. Kangaroo mother care 9. Treatment of serious neonatal infections 10. Antenatal corticosteroid use	Caesarean section rate Chlorhexidine cord cleansing
	Input: service delivery packages for quality of care	Emergency obstetric care Care of small and sick newborns Quality of care initiatives with measurable norms and standards	
	Input: counting	Birth registration†	Death registration, cause of death

Key: (black text) = indicators specifically relevant to small and sick newborns;
 (grey text) = indicators relevant for all newborns;
 (bold black text) = indicators specifically relevant to small and sick newborns and requiring additional testing to inform consistent measurement;
 (light blue background) = not currently routinely tracked at global level.

* also a core indicator for the Global Strategy for Women’s, Children’s and Adolescents’ Health (2016–2030) (13).

† also an indicator for the SDGs (14).

Indicators to be disaggregated by equity metrics such as urban/rural, socioeconomic, geography and education.

Adapted from: WHO and UNICEF, Every Newborn Action Plan (2014) (7), Mason et al., *The Lancet* (2014) (8), Moxon et al., *BMC Pregnancy and Childbirth* (2015) (9).

required to improve the accuracy of gestational assessment during pregnancy (to avoid nonmedically indicated caesarean section preterm) and to simplify clinical gestational assessments at birth.

The greatest gap in impact data relates to small and sick survivors after inpatient care, who remain at increased nutritional and developmental risk. Research is required to define appropriate indicators for these newborns and to clarify what follow-up care is effective, and for whom, and how often it is needed. A simplified system is urgently needed to track at-risk newborns, including

those who are treated for neonatal jaundice; those at risk of retinopathy of prematurity; and those needing early intervention to avoid suboptimal early childhood development outcomes (Box 5.1).

Measuring coverage and quality of care

Why are these data needed? Coverage indicators measure the proportion of small and sick newborns who receive the care they need. By tracking coverage of high-impact, evidence-based and cost-effective interventions, countries can more effectively plan to improve health outcomes.

Box 5.1 Real-time monitoring of newborn care units in India – measuring for accountability and action

India has 25 million births annually and accounts for nearly 25% of global newborn deaths. Each year, 590 000 newborns die, which is the highest country total. To address this, India has focused on improving access to institutional delivery and strengthening facility-based newborn care. Special newborn care units (SNCUs) have been set up at the district level and newborn stabilization units at the block level. This links with home visits and referrals by accredited social health activist workers, who focus on both home births and follow-up of newborns delivered in hospitals and those discharged from SNCUs. Currently, there are 752 SNCUs treating 1 million newborns each year. These efforts contributed to a 22.5% reduction in neonatal mortality between 2011 and 2016.

However, in the absence of a credible data recording and monitoring system for SNCUs, there were challenges in collating and analysing data, tracking performance, ensuring accountability and initiating corrective action. In addition, there was no system for long-term follow-up of these newborns after discharge from the SNCUs, resulting in suboptimal outcomes for survival, growth and development.

To address these gaps, UNICEF supported the National Health Mission to develop a real-time monitoring system to assess SNCU performance and track newborns post-discharge. This system records vital information related to antenatal care and care in the labour room, SNCU care and post-discharge follow-up care. It provides real-time data for more than 250 parameters, such as admission profile, final

diagnosis and treatment analysis (including antibiotic and oxygen usage, outcomes by weight and maturity, and causes of death). The analysed data can be accessed online. The system was piloted in the state of Madhya Pradesh in 2012 and 2013 and has been adopted by the government for use in all SNCUs. The National Health Mission has budgeted for computers with internet connectivity and data operators. Follow-up occurs for one year, with reminder messages sent to families and community workers.

Currently scaled-up in 28 of 29 states – covering 87% of the SNCUs and with 2.7 million newborns enrolled – this is now one of the largest online databases of small and sick newborns globally. The system is helping the SNCU staff, programme managers and policy-makers to take targeted and timely action. It has helped generate evidence to guide policy decisions, initiate actions related to human resources, increase investments on improvement of labour room care, reduce antibiotics usage, target supportive supervision efforts, and establish follow-up systems.

During 2018, the database will expand to cover all SNCUs in India, with simultaneous expansion into the private sector. The quality of data will be strengthened and promoted for regular use. As facility-based newborn care increases globally, this example offers a scalable solution for other countries with similar challenges and serves as a model for global or regional neonatal registry systems.

Care that is high-quality is measured to be effective, safe, centred on the patient's needs and delivered in a timely fashion. This must be applied to all newborns, wherever they are born in the world. As more newborns receive special and intensive care, indicators should capture the type and quality of care received in order to guide programmatic efforts to improve services.

Which data can be used now? Coverage of care that prevents and treats complications faced by small and sick newborns includes skilled attendance at birth, immediate postnatal care and early initiation of breastfeeding. These are often tracked by nationally representative

household surveys, although quality of data varies. It is more complex to measure content of care through household surveys. Facility-based intervention coverage (using count data and validated denominators) can be collected via a routine HMIS. Measurement and validation research are underway in three LMIC settings for coverage indicators regarding high-impact interventions that include neonatal resuscitation, KMC, treatment of serious neonatal infections and appropriate use of antenatal corticosteroids (15). A consensus-based approach can be highly effective in developing monitoring frameworks for indicators, as was demonstrated recently in Malawi (Box 5.2).

Box 5.2 Kangaroo mother care in Malawi: improving availability, quality and use of routine data

Since 2005, Malawi has scaled up facility-based KMC. However, in the absence of a national system of standard indicators, registers and reports, routine data have been limited and of poor quality. In 2014, the Malawi Reproductive Health Directorate and Central Monitoring and Evaluation Department, with support from Save the Children, began a four-phase process to develop a national routine reporting system for facility-based KMC, with a simple, user-friendly registration and reporting form. The four phases involve:

- Phase 1: prioritizing five core indicators, with data elements reduced from 32 to 8
- Phase 2: redesigning a standard pre-coded register linked to a monthly report form, with instructions
- Phase 3: a two-month pilot testing in 21 facilities across Malawi
- Phase 4: finalized forms using feedback, with package approved by the Central Monitoring and Evaluation Department in mid-2015.

Improved data quality and use: Eight KMC data elements and five core indicators were incorporated into Malawi's District Health Information System 2 (DHIS2). The five core KMC indicators are: (1) KMC initiation rate; (2) KMC referral completion rate; (3) Survival to facility discharge; (4) Death before facility discharge; (5) Left against medical advice.

National training and orientation led to improved rates of reporting: 87% of hospitals reported in 2016 compared with 51% in 2014. Data completeness and timeliness remain a challenge. In 2016, an estimated

15 316 newborns were initiated on KMC, representing approximately 21% of the anticipated number eligible nationwide (calculated as 10% of expected live births) and 44% of reported preterm or LBW newborns. The number of cases initiated on KMC, and the coverage estimates, varied widely by district. This effort led to several key lessons:

- Engage Ministry of Health leadership early and throughout. The Reproductive Health Directorate and Central Monitoring and Evaluation Department (which manages the HMIS) facilitated coordination and instilled buy-in throughout development and roll-out.
- Prioritize indicators and data elements suitable for routine reporting in order to minimize the burden of data collection and reporting. Consult global guidance to help determine which indicators are most important to track.
- Focus on end users by engaging facility and HMIS staff in design and testing of tools.
- Plan and budget for sustained human resources support at national, district and facility levels.
- Collaborate across partners to address common, system-wide barriers to data quality and use which require resource pooling and joint advocacy to mitigate (e.g. poor internet, lack of population-based denominator data, or discrepancies in values between different sources).
- Consider levels of partner support and other district-specific factors when assessing performance.

Source: Save the Children Malawi. Improving availability and quality of routine data for newborns: Malawi's experience with kangaroo mother care. Lilongwe, Malawi: Save the Children; 2018.

What data are needed? The WHO Quality of Care Framework has two interlinked dimensions of provision and experience of care, with clear definitions of what constitutes quality (Fig. 3.1) (3). These quality-oriented indicators need refining for small and sick newborns and require standard definitions with validation and feasibility research. Quality indicators should also measure any unnecessary separation of parents and newborns, with integrated metrics to promote respectful care for both.

Measuring parent and community engagement

Why are these data needed? Assessments of the

knowledge, attitudes and beliefs of parents, and their desired role during their newborn's inpatient care, are central to an effective approach to family-centred care. Assessments should take place at a time and place convenient to parents, as part of a process that supports and guides their growth as caregivers. Programme assessment using evidence-based, family-centred care guidelines can improve the quality of family-centred care (16).

Which data can be used now? There are tools to measure parent and community engagement in the care of small and sick newborns, yet few are standardized and

validated. Family-centred care tools for neonatal units also exist, with options specific to LMICs (17–19). Such tools use staff and family surveys and benchmarking reports (between hospitals, regions and countries) to assess provider perceptions and parent satisfaction at discharge (20, 21). At the societal and policy levels, some toolkits offer suggestions to monitor advocacy activities and results (22).

What data are needed? There is a need for further development of tools to measure the types of support received by parents, families and newborns. Potential questions might include: were measures taken to ensure that parents/caregivers developed the appropriate skills to care for their newborn in facility and after discharge? Do they report a positive care experience in the facility? Do they share information regarding any situations of disrespect and abuse? Are there facilities to help parents stay close to their newborn (rooms for overnight stays, toilets, showers, provision of food)? Are there educational materials available to parents and caregivers? Was the newborn separated at any point from its mother without explanation? Are there community groups to provide support to parents and families? How do facilities link parents to these groups and to community health workers for support after discharge? Do community behaviours and practices towards inpatient care-seeking differ between female and male newborns? What information do parents receive about care for their newborn in the hospital and after hospital discharge? How well informed are community-level services and health workers about the care and developmental needs of small and sick newborns? Were compassionate support and mental health services available for grieving families in the event of a newborn's death?

Measuring health system inputs

Key measurements based on the health system building blocks are described below (12).

Service-readiness measurement


Why are these data needed? Service-readiness measurement assesses the availability of inpatient services for small and sick newborns and their ability to meet a minimum quality standard. Among other valuable contributions, it identifies gaps across five domains: facility infrastructure; health technologies (including equipment, medicines and supplies); care guidelines; human resources; training and routine practices.

Which data can be used now? Currently, logistics management systems and HMIS collect relatively few data on service-readiness for small and sick newborns in LMICs (9). As a result, many countries depend on periodic health-facility assessments as a key source of monitoring. Three widely used assessment tools are: the Service Provision Assessment (SPA) of the Demographic and Health Survey Programme; the WHO Service Availability and Readiness Assessment (SARA); and the Emergency Obstetric and Newborn Care (EmONC) assessment managed by Columbia University's Averting Maternal Death and Disability (AMDD) Programme and supported in many countries by UNFPA (23). While the EmONC assessment has the most detailed newborn content, all tools have limited measurement of more complex clinical care across the five domains listed above. For example, none of the assessments listed include treatment and screening for retinopathy of prematurity and effective phototherapy, and only the EmONC assessment explores alternative feeding if the infant is unable to breastfeed. However, each tool



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Table 5.2 Measuring service readiness for small and sick newborns with Health Facility Assessment tools

	Intervention for small and sick newborn	HFA tools		
		SPA	SARA	EmONC
	Treatment and screening for retinopathy of prematurity	0	0	0
	Continuous positive airway pressure and assisted/mechanical ventilation	1	1	1
	Blood transfusion	1	1	1
	Seizure management	2	2	2
	Effective phototherapy	0	0	0
	Assisted feeding (cup and nasogastric)	0	0	1
	Safe administration of oxygen	1	1	3
	Intravenous fluids and management of hypoglycaemia	1	1	4
	Injectable antibiotics	4	4	5
	Kangaroo mother care	2	1	3
	Immediate newborn care	4	5	5
	Thermal care	4	2	3
	Immediate and exclusive breastfeeding	3	2	4
	Resuscitation with bag and mask	5	5	5

This table shows for each intervention, how many of five domains of service readiness (infrastructure, equipment and drugs, guidelines, training routine practice) are currently assessed in commonly used health-facility assessment tools.

HFA tools = Health Facility Assessment tools; SPA = Service Provision Assessment; SARA = Service Availability and Readiness Assessment; EmONC = Emergency Obstetric and Newborn Care.

Key: (■, 0) = none of the five domains are assessed; (■, 1) = one of five domains is assessed; (■, 2) = two of five domains are assessed; (■, 3) = three of five domains are assessed; (■, 4) = four of five domains are assessed; (■, 5) = all five domains are assessed.

looks at resuscitation with bag and mask across all five domains as well as injectable antibiotics for neonatal infection and immediate/essential newborn care across most domains (Table 5.2).

What data are needed? Health-facility assessment tools could better capture service readiness for small and sick newborns if indicators were standardized and the tools were aligned with simplified data systems. Additional relevant criteria not currently captured might also be considered. This could include alternative feeding methods (cups and nasogastric feeding); phototherapy; retinopathy of prematurity screening; separate space availability; robust referral pathways; and health technologies (essential medicines). The size and cost of health-facility assessments often limit the frequency of their use (24). The EmONC framework is being revised to better represent the needs of parents and newborns. Situational analysis assessment and quality improvement tools have been developed and piloted to collect insights on readiness, perceptions of care and communications capabilities and to inform policy (25, 26).

Health workforce measurement

Why are these data needed? The lack of suitably trained health workers, in adequate numbers, is recognized as a major health system bottleneck for newborn care (27). Countries can use accurate information and evidence about health workers with neonatal skills to shape policies and plan the provision of inpatient care, so that the right workers with the right skills can be in the right place at the right time.

Which data can be used now? Measures of the skills and training of health workers for essential, special and intensive newborn care can be gathered from human resources systems and health-facility assessment data. Typically, however, availability of this data is limited.

What data are needed? Research is needed into creating systems for robust human resources tracking, with benchmarks for competencies and staffing ratios for different levels of neonatal care. It is also critical to understand recruitment, deployment, rotation and migration patterns. Innovation is needed to explore measurement strategies,

including the experience of health workers in caring for newborns. There is also value in determining how health systems measure the support given to these caregivers. Better understanding of such complex issues would help to reverse a trend of trained professionals leaving the workforce due in part to stressful working conditions and burn-out.

Health management information systems

Why are these data needed? A sustainable, reliable HMIS will track routine data from facilities to guide action at all levels within the health system.

Which data can be used now? Rapid expansion of electronic platforms and mobile health offer great potential to unify and align traditionally fragmented information streams (9). The most widely used HMIS across LMICs is currently the District Health Information System 2 (DHIS2) (28). Guidance is emerging on core newborn indicators that can be tracked in HMIS to overcome the lack of data from LMICs (29). Proposed “core tracer indicators” are applicable to all newborns, with indicators for small and sick newborns tracked under optional additional menus (KMC, resuscitation, treatment for neonatal infection, preterm birth rate and perinatal death reviews). In 2017, of 75 countries who reported using the Every Newborn Action Plan tracking tool, only three included four newborn-specific indicators in their national HMIS (30). Research is underway on core coverage indicators for high-impact newborn care to meet the Every Newborn Action Plan’s measurement improvement milestones (15).

What data are needed? Most countries rely on aggregate data; few collect and report individual-level data to allow tracking of specific newborns over time. Routine systems should be able to track individual newborns longitudinally and link them to their mothers, thus supporting a life-course approach to health for small and sick newborns. Advances in infrastructure and software are driving a transition from predominantly paper-based to mixed-format recording systems. Increasingly, even at the clinical level, electronic formats will be the basis of HMIS data, with standardized neonatal inpatient records including care and outcome data linked to a perinatal dataset. This was the foundation for many multisite quality improvement initiatives for neonatal care in HICs. In India, real-time monitoring of SNCUs has already been scaled up, and is measuring equitable access and quality-care indicators and outcomes (Box 5.1).



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Too often, data move up through the pyramid without feedback loops connected to frontline health-care providers. Developing these links within the health system levels is a priority and would provide a more complete picture of care, for example through harmonized dashboards for small and sick newborn data (Fig. 5.1). Implementation research designed to strengthen the relationship of data systems to use data would improve real-time clinical decision-making capabilities for the care of small and sick newborns.

Long-term investment is critical to ensure interoperability of electronic systems, including logistics, human resources and HMIS. When integrated, these systems can reduce the burden on the system for all, from health workers to policy-makers. Brazil’s robust response to the Zika virus epidemic demonstrates the value of integrated HMIS which count births, stillbirths and neonatal deaths, as well as rapidly identifying any increase in birth defects (31).

Health systems finance measurement

Why are these data needed? Financial data are needed to plan service delivery elements, such as infrastructure, health technologies and human resources. For UHC, data are needed to ensure access, determine who is paying, and protect families from catastrophic out-of-pocket expenses (14, 32). It is also important for accountability to track government and donor spending.

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Which data can be used now? Government spending could be tracked through national health accounts data (33). Challenges arise because newborn care is delivered in conjunction with maternal care and it can be difficult to disentangle newborn-related expenditures. Donor spending for RMNCH is tracked by several organizations with different methodologies (34).

Since 2003, specific neonatal analyses have been conducted with time trends (35, 36). The Countdown to 2030 partnership reports on 81 countries with data on equitable coverage of effective health interventions for women, children and adolescents. They include out-of-pocket expenditures for families as a percentage of total health expenditure (37). The Lives Saved Tool (LiST) (38) also includes a costing module which allows countries and researchers to calculate both full financial costs and the impact on mortality rates when interventions for small and sick newborns are scaled up.

What data are needed? Pay-for-performance and results-based financing offer opportunities to link outcomes to investment (e.g. funding from the Global Financing Facility in support of Every Woman Every Child) but require appropriate metrics (39). Regular national tracking of investments in the health of women and children, including newborns, is needed for stronger accountability and for advocacy around UHC financing. This can promote more equitable coverage and reduce death and disability, particularly among poor and marginalized families and communities.

Leadership and governance measurement

Global, national, and local leadership and governance are needed to improve accountability and transparency for small and sick newborns. Indicators could measure whether countries have appropriate policies and strategies for health system governance (12). Examples might include: the existence of an up-to-date national health strategy; national essential medicines policy and procurement; and regular design and dissemination of key health sector documents. Accountability measures can assess work-force norms and standards,

and whether the working environment is conducive for health-care providers to deliver quality care. Good leadership and governance are needed to protect newborns by implementing supportive policies and tracking policy violations. This includes fighting corruption, safeguarding maternity leave, monitoring child protection, and tracking adherence to the International Code of Marketing of Breastmilk Substitutes.

SDG 17 (Revitalize the global partnership for sustainable development) includes a specific target to increase the availability of high-quality, timely and reliable data that are disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts. Multistakeholder global partnerships and support would help governments to improve their data-related efforts and achieve SDG and Every Newborn Action Plan targets.

Opportunities to improve and use data now

This section highlights potential changes in measurement for small and sick newborns that could quickly have a significant impact.

Civil registration of all facility births and deaths

Increasing investments in civil registration and vital statistics (CRVS) systems are enabling a rapid transition to the availability of more timely data on total births and deaths.

Yet, small and sick newborns have often been underrepresented in, or missing from, these systems (41). Globally, more than 75% of births now occur in facilities, so there is an immediate opportunity to close the gap by registering all who are born in a facility (Fig. 5.2). Although most newborns are weighed at the facility, there is another large gap (globally 40.5%, and in least-developed countries 46.5%) in data available for policy-makers to track LBW rates using routine administrative data from HMIS or CRVS. Adding birth weight to birth and death certificates, as registration systems are strengthened, would integrate a health measurement specific to small and sick newborns that could be tracked.

Perinatal death reviews

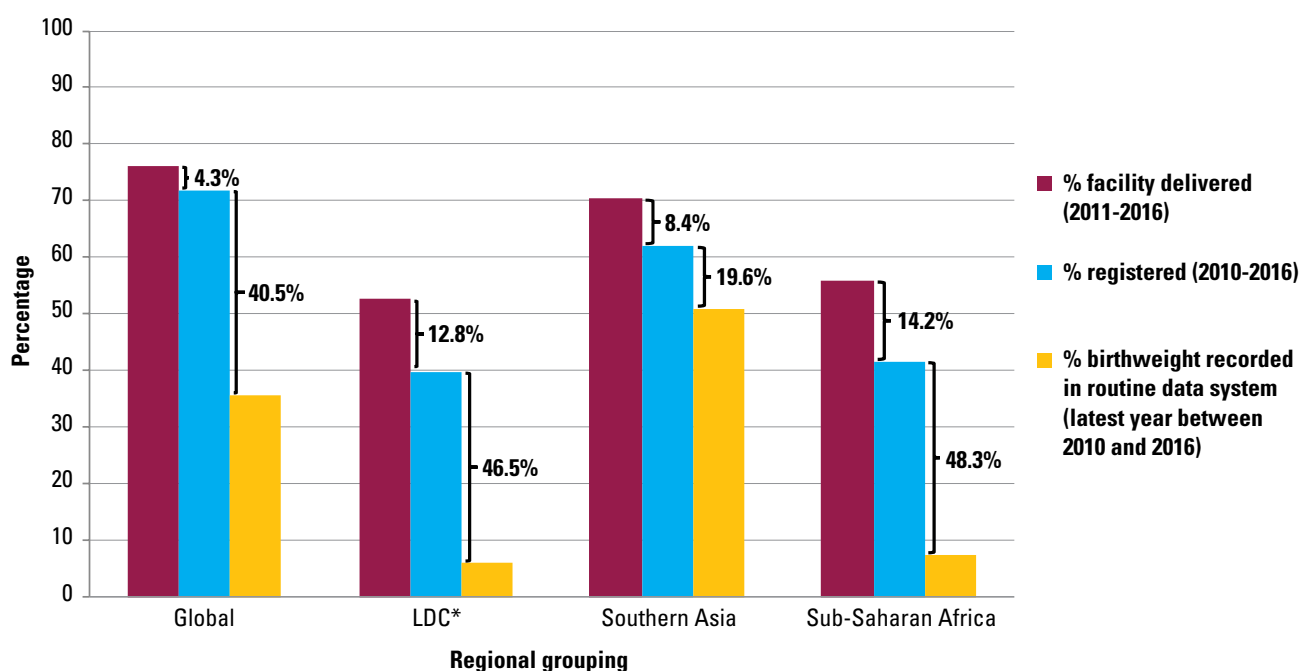
Perinatal mortality audits and reviews are conducted in a systematic process to identify modifiable factors related to the deaths of small and sick newborns. The aim is to use the information gathered to make changes to prevent similar deaths in future. In many settings, it is a complex task to identify a newborn's cause of death, and the factors that contributed to it. However, evaluating mortality trends among small infants is useful for programming in all settings. The perinatal

audit cycle includes specific steps which include the identification and reporting of deaths; the collection of information around the death; review and analysis of the available information; the creation of actionable recommendations; implementation of the recommendations; and finally evaluation and refinement of the audit system (Box 5.3).

Use data to improve quality of care

Counting alone is not sufficient to change practices. Metrics need to be used for action to implement solutions to improve quality of care (3). This action has the power to change lives and make it possible for small and sick newborns to grow into healthy, active and productive adults. The Quality of Care Network (see Chapter 3), promotes the core values of quality, equity and dignity. The monitoring framework will guide quality improvement implementations and the use of data to track outcomes. The Network's intent is to halve maternal and newborn deaths and stillbirths in participating health facilities within five years (50). Since 2014, UNFPA has supported several countries in sub-Saharan Africa to monitor selected maternal and newborn health indicators in EmONC facilities through HMIS to address gaps in availability and quality of care (51).

Fig. 5.2 Gap analysis: newborns that are delivered in a facility, are registered, and have their birth weight recorded in routine data systems



*LDC = Least Developed Countries (World Bank category).

Data sources: Facility delivery and birth registration: State of the World's Children 2017 (42); birth weight: WHO systematic collation of data from routine national HMIS (unpublished).

Box 5.3 Maternal and perinatal death surveillance and response (MPDSR)

It is estimated that a newborn, or a fetus during the last months in utero, dies every six seconds. Every day, 800 women die due to complications during pregnancy or childbirth (8, 43, 44). To investigate these deaths, and prevent similar ones in future, perinatal death reviews are now being integrated with maternal death surveillance and response (MDSR) in many countries. The aim is to create a more holistic record of events and to understand how health system failures can be addressed.

The MPDSR system serves to identify the cause of every maternal and perinatal death, and to register and report it. MPDSR is a continuous action and surveillance system. It links the health information system and quality improvement processes from local to national levels, including maternal and perinatal audit and review (45, 46).

In 2015, 86% of all countries globally reported having policies for notification of all maternal deaths and 85% to review such deaths; 76% of countries had a national maternal death review committee, but only 46% met twice a year, as recommended by MPDSR technical guidance (47, 48). For perinatal deaths, 56 countries reported having a national policy on the review of neonatal deaths, but only 41 had a national policy on the review of stillbirths. This suggests that policy commitment is stronger for mothers than for newborns, and that there is a gap between policy and practice.

WHO and partners are working closely with Member States to support the implementation of MPDSR in order to ensure that information on each death and cause of death is collected and used to improve the quality of care and avert future maternal and perinatal deaths (49).

Data for action: priorities

Certain data gaps need to be prioritized to increase the availability and quality of data for small and sick newborns:

- **To end preventable deaths (Survive)** – Use validated facility-based coverage and quality-of-care indicators for small and sick newborns, integrated into HMIS. Link individual standardized clinical records for newborns to comparable core datasets. Standardize service-readiness tools to include small and sick newborns and connect with HMIS.
- **To ensure health and well-being (Thrive)** – Standardize indicators for at-risk newborns linked to child development and nutrition.

- **To expand enabling environments in all settings (Transform)** – Improve metrics for small and sick newborns in all settings, including those born in humanitarian settings. Measure family experience of care, community demand, and respectful care for newborns, family and health-care providers.

Closing these gaps and increasing the availability and use of quality data for equitable action can drive the necessary action to fulfil the SDG promise for every small and sick newborn – even those born in high-burden settings, those that are marginalized, hard-to-reach, or born into urban slum environments or humanitarian settings (Box 5.4). The following chapter reviews the concrete steps that governments and stakeholders can take during the next 11 years to achieve the 2030 SDG targets.

Box 5.4 Data for action in humanitarian settings

Robust metrics are urgently needed to improve the outcomes for newborns in humanitarian settings. Typically, health-related data are less available for those born during a humanitarian crisis (especially small and sick newborns) than for those born in more stable settings. However, the same data must be made available if UHC is to be rolled out in all settings. These data can guide actions and help emergency responders track progress for vulnerable newborns.

Technical innovation to find ways to link data

from humanitarian settings to stable host communities is also needed; it is crucial to ensure that metric tools (e.g. health-facility assessments) function effectively in all settings. Additionally, while nutrition surveys typically only include infants aged more than 6 months, there is evidence that malnutrition among those aged 0–6 months is highly prevalent (52). Research is needed to improve the prevention and treatment of undernutrition and malnutrition among small and sick newborns.

A PARENT'S STORY

After her newborn son falls ill, a Filipina nurse gains a new perspective

Sebastien Julian arrived at a healthy 3 kg at 38 weeks' gestation. His mother, Kathleen Abordo Rodriguez, delivered at a private hospital in Cebu. This is the same facility where she also worked as a paediatric intensive care nurse. After Sebastien was born, it was clear that something was not quite right.



"They put my son on oxygen because his saturations were low," Kathleen said. "They gave him an IV and started him on antibiotics because they thought that he had a respiratory infection." Sebastien spent his first seven days in the hospital and was diagnosed with jaundice.

The physician told Kathleen that sunlight would correct it and discharged them. However, after they had gone home, Sebastien's skin turned from yellow to orange. A week later Kathleen brought her son back to the hospital.

"As soon as the doctor saw the baby he said, 'We need to bring him to the emergency room,'" Kathleen recalled. "His bilirubin was really, really high." Sebastien required a blood transfusion and spent seven days on phototherapy.

"I felt blank," Kathleen said about her emotions during that second hospitalization. "I remember walking down a long hallway. I didn't even know where I was going. I passed by my son's room. One of my colleagues asked me where I was headed. Suddenly, I burst into tears."

A few weeks into this hospitalization, Sebastien developed pneumonia which further extended his inpatient stay. Eventually he was discharged, but after only a week Sebastien was readmitted after an asthma attack. This routine became a pattern due to Sebastien's allergies and asthma.

"He was in and out of the hospital for two years," Kathleen remembered.

Sebastien is now a friendly and playful 12-year-old. But his family is very protective of him because of what he went through. Through this experience, Kathleen has become a champion for the health of children of all ages. It has also changed the way she nurses.

"I became more of an advocate. I talk to mothers, and I share more." Since her time in the Philippines, Kathleen has gone on to work as a paediatric and cardiac intensive care nurse in Saudi Arabia and the USA. In these higher-income settings, she has witnessed more access to technologies, better follow-up care, and emotional support for parents.



"I wish everyone had access to health care," Kathleen said. "There were many instances in the Philippines where we had to discharge patients that we knew couldn't survive because their families weren't able to pay. There, for the complex cases anyway, you don't get a chance. And I believe that every child deserves a chance."

REFERENCES

1. Goodwin S. Data rich, information poor (DRIP) syndrome: is there a treatment? *Radio Manage.* 1996;18(3):45–9.
2. Heywood A, Rohde J. Using information for action – a manual for health workers at facility level. University of Western Cape/HISP/MSH/EQUITY Project.
3. WHO. Standards for improving quality of maternal and newborn care in health facilities. Geneva: World Health Organization; 2016.
4. UN IGME. Levels & trends in child mortality: report 2018. Estimates developed by the United Nations inter-agency group for child mortality estimation (UN IGME). New York: United Nations Children's Fund; 2018.
5. WHO. 2018 global reference list of 100 core health indicators (plus health-related SDGs). Geneva: World Health Organization; 2018.
6. Dickson KE, Simen-Kapeu A, Kinney MV, Huicho L, Vesel L, Lackritz E, et al. Every newborn: health-systems bottlenecks and strategies to accelerate scale-up in countries. *Lancet.* 2014;384(9941):438–54.
7. WHO. Every newborn: an action plan to end preventable deaths (ENAP). Geneva: World Health Organization; 2014.
8. Mason E, McDougall L, Lawn JE, Gupta A, Claeson M, Pillay Y, et al. From evidence to action to deliver a healthy start for the next generation. *Lancet.* 2014;384(9941):455–67.
9. Moxon SG, Ruysen H, Kerber KJ, Amouzou A, Fournier S, Grove J, et al. Count every newborn; a measurement improvement roadmap for coverage data. *BMC Pregnancy Childbirth.* 2015;15 (Suppl 2):S8.
10. WHO. WHO technical consultation on newborn health indicators: every newborn action plan metrics: Ferney Voltaire, France, 3–5 December 2014. Geneva: World Health Organization; 2015.
11. WHO, UNICEF, LSHTM. Every newborn metrics report cards. The Healthy Newborn Network. Published 2017 (<https://www.healthynewbornnetwork.org/resource/enap-metrics-cards/>, accessed 5 March 2019).
12. WHO. Monitoring the building blocks of health systems: a handbook of indicators and their measurement strategies. Geneva: World Health Organization; 2010.
13. EWEC. Indicator and monitoring framework for the global strategy for women's, children's and adolescents' health. New York: Every Woman Every Child; 2016.
14. UNDESA. Sustainable Development Goals. 2015 (<https://sustainabledevelopment.un.org/topics/sustainabledevelopmentgoals>, accessed 26 February 2019).
15. Day LT, Ruysen H, Gordeev VS, Gore-Langton GR, Boggs D, Cousens S, et al. "Every Newborn-BIRTH" protocol: observational study validating indicators for coverage and quality of maternal and newborn health care in Bangladesh, Nepal and Tanzania. *J Glob Health.* 2019;9(1):10902. doi:10.7189/jogh.09.01902
16. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. *Crit Care Med.* 2017;45(1):103–128.
17. IPFCC. Inventory of structured assessment tools for family-centred care. Institute for Patient- and Family-Centred Care (www.ipfcc.org/resources/downloads-tools.html, accessed 26 February 2019).
18. Healthy Newborn Network. Monitoring and evaluation web page (www.healthynewbornnetwork.org/issue/monitoring-evaluation/, accessed 26 February 2019).
19. US National Perinatal Association. NICU self-assessment tool for comprehensive family support (www.nationalperinatal.org/support4nicuparents, accessed 26 February 2019).
20. Bruce B, Ritchie J. Nurses' practices and perceptions of family-centered care. *J Pediatr Nurs.* 1997;12(4):214–22.
21. Robb J, Greensides D, Kamanga E, Litch J. Formative assessment of community, family and health care provider knowledge, attitudes, beliefs and practices regarding preterm and low birth weight newborns in Balaka District, Malawi. *Every Premie/SCALE*; 2017.
22. Healthy Newborn Network. Every newborn advocacy toolkit (<https://www.healthynewbornnetwork.org/resource/every-newborn-advocacy-toolkit-guidance-manual-ending-preventable-deaths/>, accessed 26 February 2019).
23. Moxon SG, Guenther T, Gabrysch S, Enweronu-Laryea C, Ram PK, Niermeyer S, et al. Service readiness for inpatient care of small and sick newborns: what do we need and what can we measure now? *J Glob Health.* 2018;8(1):010702.
24. Madaj B, Smith H, Mathai M, Roos N, van den Broek N. Developing global indicators for quality of maternal and newborn care: a feasibility assessment. *Bull World Health Organ.* 2017;95(6):445–52i.
25. WHO. Hospital care for mothers and newborn babies: quality assessment and improvement tool. Geneva: World Health Organization Regional Office for Europe; 2014 (<http://apps.who.int/iris/handle/10665/137340?locale=ar&mode=full>, accessed 26 February 2019).

26. Every Preemie/SCALE. Situation analysis of inpatient care of newborns and young infants. Published 2017. (<https://www.everypreemie.org/technical-materials/>, accessed 26 February 2019).
27. Moxon SG, Lawn JE, Dickson KE, Simen-Kapeu A, Gupta G, Deorari A, et al. Inpatient care of small and sick newborns: a multi-country analysis of health system bottlenecks and potential solutions. *BMC Pregnancy Childbirth*. 2015;15 Suppl 2:S7.
28. DHIS2. District health information software 2 (DHIS2) website (<https://www.dhis2.org>, accessed 26 February 2019).
29. WHO, UNICEF. RMNCAH HMIS module: analysis and use of health facility data – guidance for RMNCAH programme managers (https://www.who.int/healthinfo/FacilityAnalysisGuidance_RMNCAH.pdf, accessed 20 May 2019).
30. WHO, UNICEF. Reaching every newborn national 2020 milestones: 2018 progress report. Geneva: World Health Organization and UNICEF; 2018.
31. Teixeira MG, Costa Mda C, de Oliveira WK, Nunes ML, Rodrigues LC. The epidemic of Zika virus-related microcephaly in Brazil: detection, control, etiology, and future scenarios. *Am J Public Health*. 2016;106(4):601–5.
32. WHO. Making fair choices on the path to universal health coverage: final report of the WHO consultative group on equity and universal health coverage. Geneva: World Health Organization; 2014.
33. WHO. Guide to producing child health subaccounts within the national health accounts framework. Geneva: World Health Organization; 2012.
34. Pitt C, Grollman C, Martínez-Alvarez M, Arregoces L, Borghi J. Tracking aid for global health goals: a systematic comparison of four approaches applied to reproductive, maternal, newborn, and child health. *Lancet Glob Health*. 2018;6(8):e859–e874.
35. Grollman C, Arregoces L, Martínez-Álvarez M, Pitt C, Mills A, Borghi J. 11 years of tracking aid to reproductive, maternal, newborn, and child health: estimates and analysis for 2003–2013;13 from the Countdown to 2015. *Lancet Glob Health*. 2017;5(1):e104–e114.
36. Pitt C, Grollman C, Martínez-Álvarez M, Arregoces L, Lawn JE, Borghi J. Countdown to 2015: an analysis of donor funding for prenatal and neonatal health, 2003–2013. *BMJ Glob Health*. 2017;2(2):e000205.
37. Countdown to 2030 website (<http://countdown2030.org/>, accessed 26 February 2019).
38. The Lives Saved Tool (LiST) website (<http://www.livessavedtool.org/>, accessed 26 February 2019).
39. Global Financing Facility website (<https://www.global-financingfacility.org/>, accessed 26 February 2019).
40. Ottersen OP, Dasgupta J, Blouin C, Buss P, Chongsuvivatwong V, Frenk J, et al. The political origins of health inequity: prospects for change. *Lancet*. 2014;383(9917):630–67.
41. McCarthy BJ, Terry J, Rochat RW, Quave S, Tyler CW. The underregistration of neonatal deaths: Georgia 1974–77. *Am J Public Health*. 1980;70(9):977–82.
42. UNICEF. The state of the world’s children 2017 statistical tables. Published December 2017 (<https://data.unicef.org/resources/state-worlds-children-2017-statistical-tables/>, accessed 26 February 2019).
43. Lawn JE, Blencowe H, Waiswa P, Amouzou A, Mathers C, Hogan D, et al. Stillbirths: rates, risk factors, and acceleration towards 2030. *Lancet*. 2016;387(10018):587–603.
44. WHO, UNICEF, UNFPA, World Bank, UNFPA. Trends in maternal mortality: 1990 to 2015. Geneva: World Health Organization; 2015.
45. WHO. Maternal death surveillance and response: technical guidance information for action to prevent maternal death. Geneva: World Health Organization; 2013.
46. WHO. Making every baby count: audit and review of stillbirths and neonatal deaths. Geneva: World Health Organization; 2016.
47. WHO. Time to respond: a report on the global implementation of maternal death surveillance and response. Geneva: World Health Organization; 2016.
48. WHO. Maternal, newborn, child and adolescent health policy indicators webiste (<http://www.who.int/test/forms/mncah/>, accessed 26 February 2019).
49. UNICEF. Skill building on perinatal death reviews for health-facility teams (www.healthynewbornnetwork.org/resource/skill-building-on-perinatal-death-reviews-a-facilitator-guide-and-resources/, accessed 26 February 2019).
50. WHO. Quality, equity, dignity: a network for improving quality of care for maternal, newborn and child health. Geneva: World Health Organization; 2017.
51. UNFPA. Maternal health thematic fund: towards equality in access, quality of care and accountability – phase II (2014–2017) progress report. New York: United Nations Population Fund; 2017.
52. Kerac M, Blencowe H, Grijalva-Eternod C, McGrath M, Shoham J, Cole TJ, et al. Prevalence of wasting among under 6-month-old infants in developing countries and implications of new case definitions using WHO growth standards: a secondary data analysis. *Arch Dis Child*. 2011;96(11):1008–13.



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Immediate action is needed

KEY MESSAGES

- **1.7 million newborn lives could be saved each year by investing in quality newborn care; almost half of this impact (747 400 newborn lives saved per year) would result from providing special and intensive hospital care for small and sick newborns.** Universal access to quality care could prevent 68% of the newborn deaths that will otherwise occur in 2030, as well as reduce stillbirths and maternal deaths by almost half. Importantly, if the quality gap for births already in hospitals were closed by providing special and intensive newborn care, then 667 200 newborn lives could be saved immediately.
- **Reaching the targets of the SDGs and the Every Newborn Action Plan to end preventable newborn mortality by 2030 requires transforming care for small and sick newborns through health system investments, implementation, information and innovation.** While there is a strong evidence base for scaling up many interventions in low- and middle-income countries (notably kangaroo mother care), most research on intensive care for small and sick newborns occurs in high- and middle-income countries. Investing in research and development is critical to support evidence-based, context-relevant scale-up.
- **Everyone has a role to play in transforming care for every newborn, including those newborns who are small and sick.** More commitments, including within the Every Woman Every Child movement, will be needed to build an enabling environment and accelerate progress in all communities and countries. Working together, governments and partners, health-care professionals, empowered parents, and engaged communities can make a brighter future for the next generation.



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Lives-saved analysis

This section presents the results of an updated lives-saved analysis, building from what was published in 2014 as part of *The Lancet* Every Newborn series to inform the Every Newborn Action Plan (1, 2). Some 81 countries were considered for the analysis for this report. They were identified by Countdown to 2030 as priority countries, since together they accounted for 95% of maternal deaths and 90% of deaths among children under 5 years of age. The analysis was conducted with the Lives Saved Tool (LiST) (3), using the most recent country-specific data to project outcomes

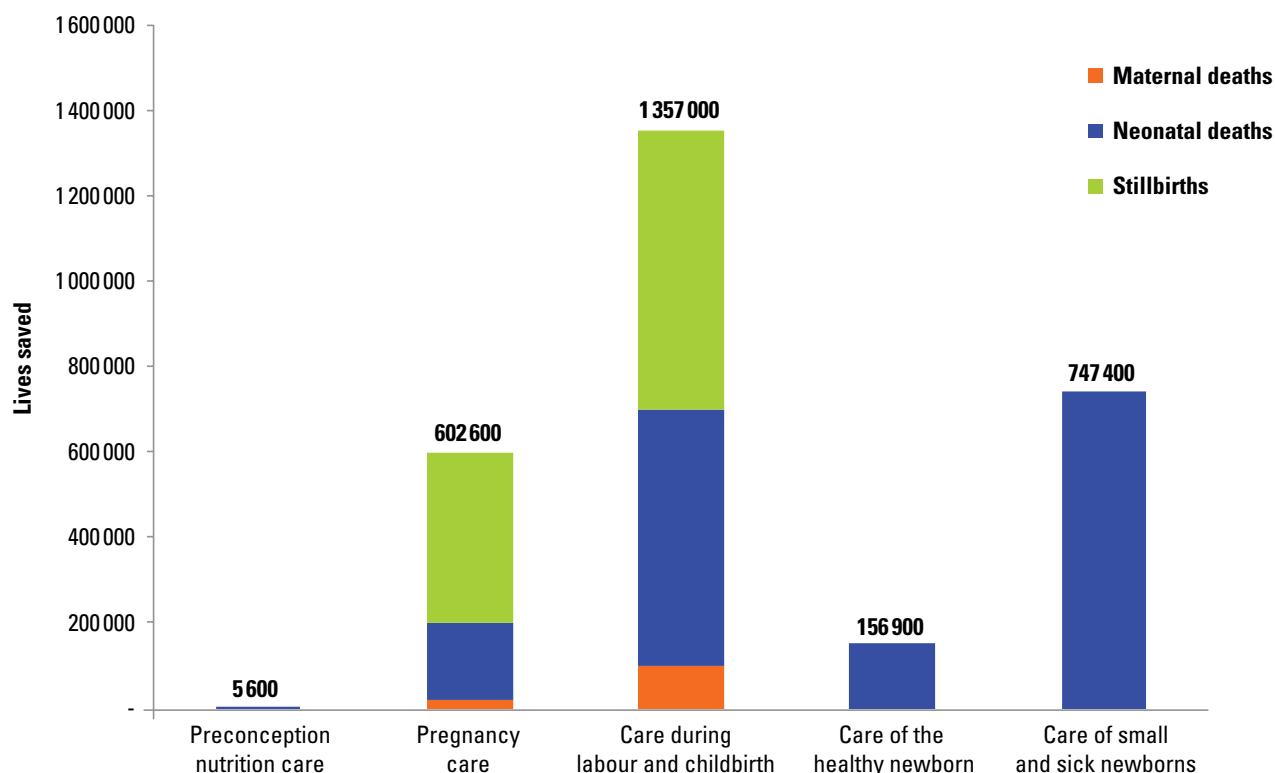
for the period 2016–2030, with interim results for 2020 and 2025. Details of the analysis are provided in Box 6.1 and in Annex 1. Results are presented as lives saved per year.

Expanding coverage of key interventions before, during, and after pregnancy could save the lives of nearly 2.9 million women, stillbirths and newborns by 2030 in the 81 countries. Table 6.1 gives a breakdown of the results, showing that overall high coverage (95% of evidence-based interventions) could avert 54% of all

Table 6.1 Estimated maternal and newborn lives saved and stillbirths averted in 2030, with scale-up to universal health coverage with quality maternal and newborn health care

Lives saved	Number of deaths averted	Percentage of deaths averted
Maternal	134 300	39%
Neonatal	1 691 900 (of which 747 400 are small and newborns)	68%
Stillbirths prevented	1 051 700	43%
TOTAL	2 877 900	54%

Fig. 6.1 Estimated effect of scaling-up interventions on maternal and neonatal deaths and stillbirths by 2030, from a 2016 baseline



Adapted from: Bhutta et al. 2014. Can available interventions end preventable deaths in mothers, newborn babies, and stillbirths, and at what cost? (2).

maternal and newborn deaths and stillbirths. The packages of care with the greatest impact on ending preventable deaths include care at birth and care for small and sick newborns (Fig. 6.1). For small and sick newborns specifically, high coverage of quality special and intensive care could save 747 400 newborn lives. The maximum gains would occur from interventions relating to special and intensive newborn care (44% of all neonatal deaths averted), followed by care at birth (36%) and during pregnancy (11%). This finding signifies the importance of addressing small and sick newborn care within the continuum of care, and as part of UHC and a life course approach to health.

The Every Newborn Action Plan set interim coverage targets for newborn interventions, as a step towards achieving the ultimate goal of UHC by 2030. These interim targets included scaling-up KMC and neonatal resuscitation to priority populations to 50% by 2020 and to 75% by 2025. A LiST analysis looking at coverage increases for the 81 Countdown countries found that expansion of these two interventions to 50% by 2020 could save 72 200 newborn lives; and to 75% by 2025

could save 150 600 newborn lives. However, meeting these two Every Newborn Action Plan interim coverage targets alone will not be sufficient to meet the SDG 3.2 target. The Every Newborn Action Plan also called for countries to set their own interim targets for comprehensive neonatal intensive care.

Reaching the SDG target

The 81 countries need to invest in universal coverage of high-impact interventions for newborn health, including special and intensive newborn care, in order to meet the SDG 3.2 target of 12 deaths per 1000 live births by 2030. Current and required NMR trajectories were calculated using estimates from UN IGME 2017 (6); the projected NMR trajectory was calculated using the Lives Saved Tool. At the current trajectory, these countries would achieve an average of 18 deaths per 1000 live births by 2030. Nonetheless, with the right investments, most could achieve the SDG 3.2 target by 2030, thus reducing the global average NMR to 9 deaths per 1000 live births (Fig. 6.2).

Closing the “quality of care gap” with special and intensive newborn care

The study included an analysis of the current “quality of care gap” between mothers and infants with access to the most effective maternal and newborn care, and those with no such access. It is assumed that the coverage of women delivering in facilities remained at today’s levels but that 95% of these women and their babies will actually receive high quality newborn care by the year 2025, including special and intensive newborn care. This analysis found that 28% of newborn deaths (a total of 667 200 deaths) could be averted in 2025 by addressing the quality gap in special and intensive newborn care. Expanded case management of prematurity would account for half of the impact (Tables 6.2 and 6.3). With only special newborn care available, 11% of newborn deaths (a total of 268 900 deaths) could be averted in 2025, with improved management of labour and delivery as a leading contributor. Provision of high-quality special and

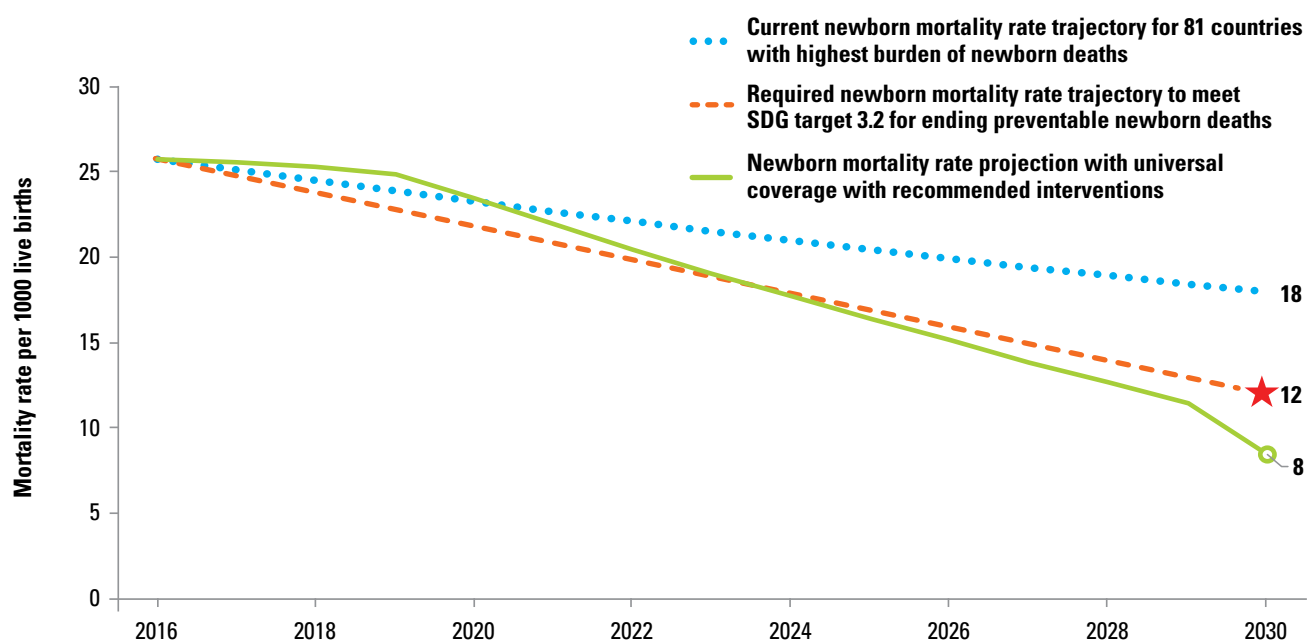


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intensive newborn care in this way would result in a 59% increase in the number of lives saved.

Improving quality among births in facilities would also benefit mothers and prevent stillbirths. This quality gap analysis found that 19% of all maternal and newborn deaths and stillbirths could be averted in 2025, totalling 961 800 newborn deaths, maternal deaths and stillbirths compared to a baseline assuming no coverage change.

Fig. 6.2 Scenarios to 2030 for 81 high-burden countries: current neonatal mortality rate trajectory; trajectory required to meet SDG target 3.2; and projection if every newborn covered by universal health coverage



Source data: UN IGME 2017 (3); projected trajectory calculated using Lives Saved Tool.

Table 6.2 Closing the quality gap: scenarios for total maternal and newborn lives saved and stillbirths averted in 2025

	Quality gap closed for all facility births (with special newborn care)		Quality gap closed for all facility births (with intensive newborn care)	
	Lives saved	Percentage of deaths averted	Lives saved	Percentage of deaths averted
Maternal	46 300	14.3%	46 300	14.3%
Neonatal	268 900	11.1%	667 200	27.6%
Stillbirths prevented	248 300	10.5%	248 300	10.5%
TOTAL	563 400	11.0%	961 800	18.8%

Table 6.3 Closing the quality gap: scenarios for total newborn lives saved in 2025, by intervention

Interventions reaching 95% of mothers who give birth in a facility*	Neonatal lives saved
Quality gap closed for all facility births (with special care)	
Age-appropriate breastfeeding practices due to promotion of breastfeeding	2 500
Antibiotics for preterm premature rupture of membranes (PPROM)	13 600
Injectable antibiotics for neonatal sepsis/pneumonia**	N/A
Kangaroo mother care	68 900
Labour and delivery management	130 600
Neonatal resuscitation	53 400
Quality gap closed for all facility births (with intensive care)	
Antibiotics for PPRM	13 500
Case management of neonatal infection	117 700
Case management of prematurity	352 200
Labour and delivery management	130 600
Neonatal resuscitation	53 300

* Effect of provision of facility care on newborn lives saved by intervention in 2025 if 95% of all facility deliveries received access to CEmONC and special newborn care or intensive newborn care.

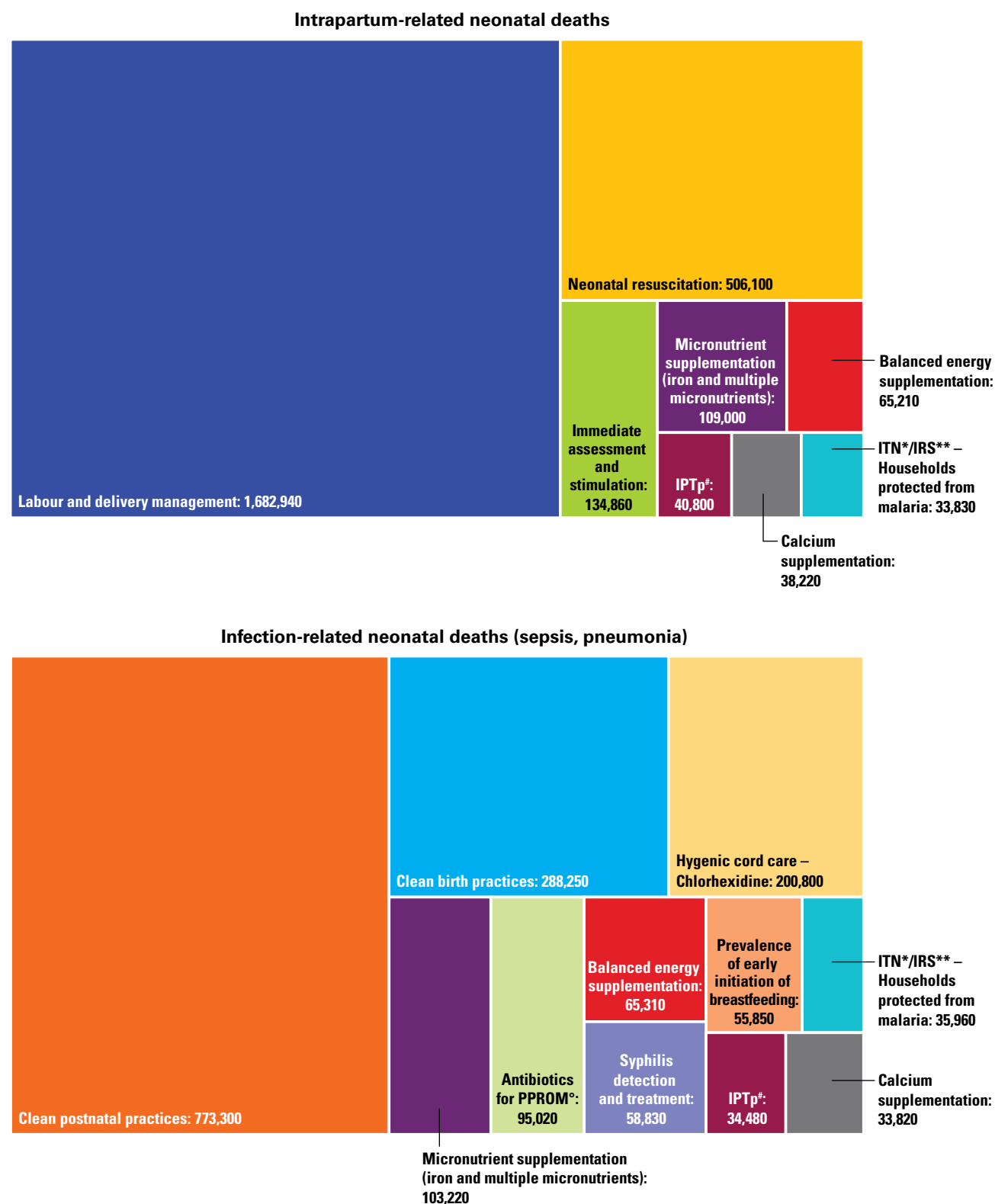
** In the LiST model, facilities are already assumed to offer injectable antibiotics for neonatal infection, so no additional deaths are averted in this model.

Impact on major causes of neonatal mortality

Full scale-up of all interventions could result in an estimated 86% fewer deaths due to prematurity; 76% fewer deaths due to intrapartum-related complications; and 74% fewer neonatal deaths related to serious infections (such as sepsis and pneumonia). Evidence from specific interventions addressing these three major causes of neonatal mortality shows that hospital-based care of preterm newborns,

including those receiving intensive care (75%), averts most preterm-related deaths. Appropriate labour and delivery management (64%) and neonatal resuscitation (19%) are responsible for averting the majority of intrapartum-related deaths. The provision of injectable antibiotics for serious neonatal infections is already assumed to be available to all newborns at health facilities, so scale-up of clean postnatal care practices (48%) and clean birth practices (18%) are the interventions contributing to the highest proportion of averted infection-related deaths (Fig. 6.3).

Fig. 6.3 Estimated effect of interventions on the three main causes of neonatal deaths in 2030

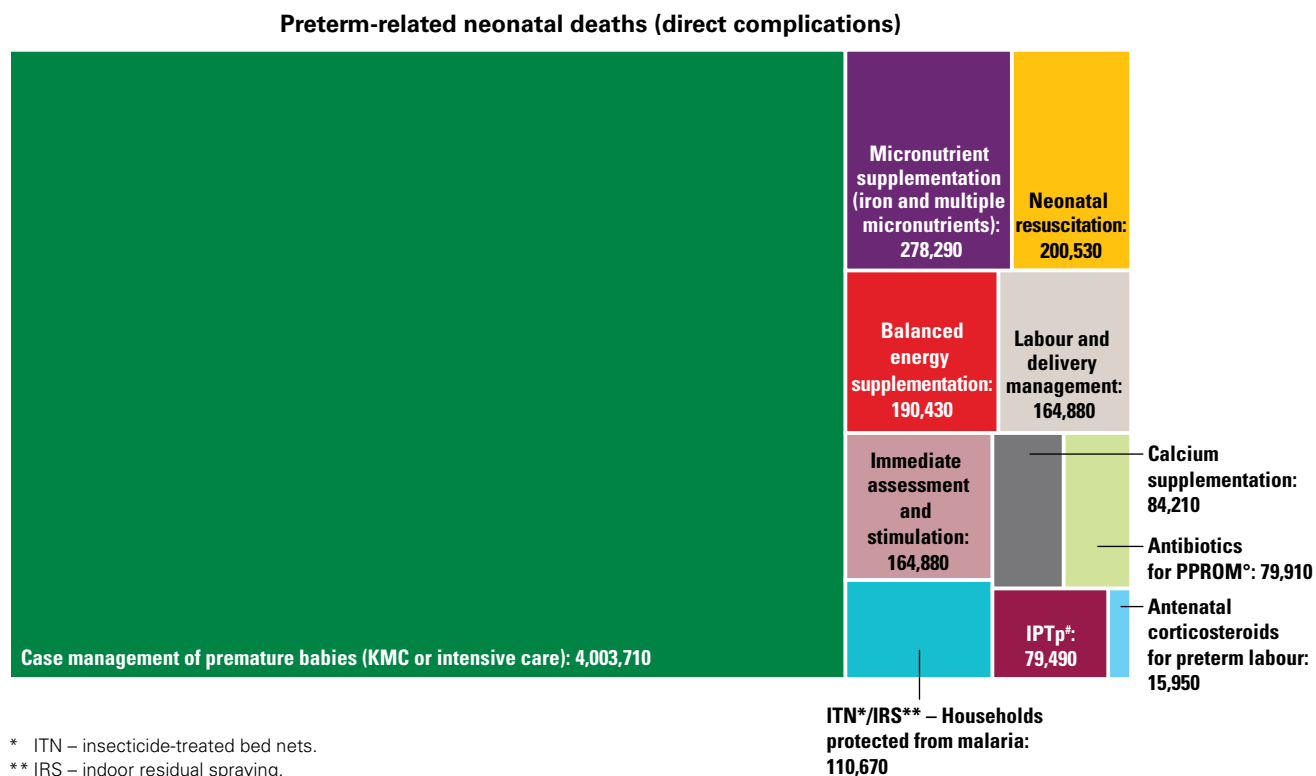


* ITN – insecticide-treated bed nets.

** IRS – indoor residual spraying.

[#] IPTp – Intermittent preventative treatment of malaria during pregnancy.^o PPRM – preterm premature rupture of membranes.

Fig. 6.3 Estimated effect of interventions on the three main causes of neonatal deaths in 2030 (continued)



Cost of inpatient care for small and sick newborns

The results from a comprehensive costing analysis published in *The Lancet* Every Newborn series showing the costs associated with scaling up care for small and sick newborns, according to the methods outlined in Table 6.1 and detailed in the published paper, were used for this report. This analysis indicates that scale-up to 95%

coverage by 2025 of the same comprehensive package of interventions detailed above would cost just over US\$ 5.6 billion (US\$ 1.15 per person) or US\$ 1929 for each life saved (maternal, newborn or stillbirth) (2).

As shown in Table 6.4, the annual incremental cost of scaling-up care specifically for inpatient care of small and sick newborns by 2025 is estimated at US\$ 959.3 million (US\$ 0.20 per capita and US\$ 1700 per newborn death averted).



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The path to 2030

Urgent action is needed to meet the 2030 SDG targets for enabling newborns to survive, thrive and enjoy the highest attainable standard of health. Key tenets set out in this report build on current epidemiology, historical trends and lessons learned. They expand on the Every Woman Every Child movement, the Every Newborn Action Plan and the Global Strategy for Women’s, Children’s and Adolescents’ Health, and complement the UNICEF Every Child Alive campaign (launched in early 2018) (1).

Table 6.4 Incremental cost of the scale-up plan for the year 2025

	Annual incremental costs in 2025 (US\$ million)				
	Capital costs	Drug and supply costs	Workforce costs	Other recurrent costs	TOTAL COSTS
Total cost for comprehensive package*	1 187.3	2 115.5	1 995.3	347 301.0	5 645.3
Subtotal cost for care of the small and sick neonatal package	423.8	88.7	335.1	111.7	959.3

* Total package includes preconception nutrition care, antenatal care, care during labour and childbirth, immediate neonatal care, care of the healthy neonate and care of the small and sick neonate.

Table adapted from: Bhutta et al. 2014 (2). More information on components of these categories and the methods and data sources can be found in the supplementary files of Bhutta et al (2).

Based on this framework, the path to 2030 requires:

1. **Targeted advocacy and policy efforts** in conjunction with engaged and empowered parents' organizations, health-professional associations, and civil society organizations. These efforts should uphold the rights of newborns through comprehensive laws, policies and regulations for protecting and promoting newborn health and well-being at the national and subnational levels, including in humanitarian settings.
2. **A focus on equitable, high-quality and affordable services** along the continuum of care that reach underserved and marginalized populations, including in humanitarian settings.
3. **A family-centred approach**, where small and sick newborns are the focus of care and parents (along with other caregivers, such as those in humanitarian settings) are actively engaged and empowered during hospitalization and in the community.
4. **Health systems that ensure full access to high-quality essential and special newborn care** for the small and sick, with regionalized availability of intensive newborn care for those who are extremely small or very sick, supported by strong referral systems.
5. **Health systems to scale-up their special and intensive newborn care services** and ensure complementary systems are in place for continued medical support during early childhood to minimize development delays and disabilities.
6. **Accurate, reliable data** to facilitate planning efforts; to measure quality, outcomes and impact; and to promote accountability.

Every Newborn Action Plan: strategic objectives

The Every Newborn Action Plan establishes a clear vision to improve newborn health and prevent stillbirths. It calls on all stakeholders to take specific actions to improve access to health care for women and newborns across the continuum of care, and to improve quality of care. In recognition of the transformation already underway in many countries and the need for expanded commitment, this call to action is intended for governments, in collaboration with stakeholders, and builds upon the Every Newborn Action Plan. Illustrative actions are categorized under four action-oriented themes: Invest, Implement, Inform and Innovate (as originally presented in Born Too Soon).

The Every Newborn Action Plan strategic objectives, adapted for this report to focus specifically on small and sick newborns, are to:

1. Strengthen and invest in care around the time of birth and care for small and sick newborns;
2. Improve the quality of maternal and newborn care;
3. Reach every woman and newborn to reduce inequities;
4. Harness the power of parents, families and communities; and
5. Count and track every small and sick newborn.

Strategic objective 1: Strengthen and invest in care around the time of birth and care for small and sick newborns

This strategic objective has been expanded from its original language (strengthen and invest in care during labour, birth and the first day and week of life) to emphasize the provision of care for small and sick newborns. While many lives can be saved with quality maternal and

Box 6.1 Methods for modelling lives saved

In 2014, *The Lancet* Every Newborn series systematically reviewed interventions across the continuum of care that have an impact on newborn mortality and health, and on stillbirths. It then modelled the impact and cost of scaling up these interventions in the countries with the highest burden of mortality (2, 3). LiST is a free and widely used software module that allows users to compare the effects of different interventions on maternal, neonatal and child mortality and stillbirths, as well as stunting and wasting (4). See Annex 1 for more details.

For this report, the Countdown to 2030 priority countries were included in the analysis. These 81 priority countries represent most of the maternal deaths (96%) (5), neonatal deaths (89%) (6), and stillbirths (87%) (7) occurring globally. The analysis was conducted from June to August 2018 using a similar approach to that published in 2014 (2). The main differences include the selection of countries (the earlier analysis involved 75 countries) and updating the model in a number of ways (8). For both analyses, the approach was a standard sequential introduction of the interventions using LiST, which estimates the effect of increased coverage of interventions on deaths from one or more causes, or in reduction of the prevalence of a risk factor. For each of the 81 countries, baseline scenarios were created that represent the most up-to-date details about health status, including mortality rates and stunting and wasting rates from United Nations sources. Baseline coverage

of interventions was drawn from standard maternal and child health indicators, with proxies or medians applied if country-specific data were not available from nationally representative surveys.

A set of five scenarios was created for each of the 81 countries (Table 6.5). For each scenario, health impact was estimated in each country for the period 2017–2030. Demographic parameters, such as population growth and total fertility, follow projections in the United Nations Population Division 2017 revision of world population prospects. HIV/AIDS trends are from the UNAIDS reference group on estimates, models and projections.

For this report the costing analysis published in *The Lancet* Every Newborn series, which were consistent with other multi-country costing work published, were used (2). The analysis used an ingredient-based approach for each Countdown country to estimate the incremental running cost between 2014 and 2025 of the higher coverage for selected interventions in terms of people time, commodities, amortized facility costs, and other inputs (further details are provided in Bhutta et al. 2014 (2)). This calculation did not include additional specific infrastructure investments that might be needed since these are more specific to context.

Additional details about specific interventions and coverage targets for each scenario are provided in Annex 1.

Table 6.5 Assumptions for the five lives-saved scenarios

SCENARIO	ASSUMPTIONS
Baseline	Coverage of all interventions remains constant (2016)
Interim targets	Coverage of two neonatal interventions (neonatal resuscitation, KMC) scaled-up in all countries from baseline to reach 50% in 2020 and 75% in 2025, reflecting the Every Newborn Action Plan interim targets
Quality gap with special care	Coverage of all interventions with impact on essential and special newborn care scaled-up from baseline to reach 95% of all women giving birth in facilities in 2025
Quality gap with intensive care	Coverage of all interventions with impact on essential, special and intensive newborn care scaled-up from baseline to reach 95% of all women giving birth in facilities in 2025
Universal health coverage	Coverage of all interventions that impact neonatal mortality scaled-up from baseline to reach 95% coverage in 2030

The standards and principles of care for emergency or humanitarian settings remain the same as for non-emergency settings. They include heightened attention to improved access to quality services managed by competent providers; awareness and reduction of discriminatory care practices; and ensuring that safe referral transport systems are in place (especially critical in conflict zones).

newborn care, country stakeholders need to plan for, and invest in, inpatient care if they are to improve newborn outcomes further, and avoid delays in meeting global and national targets. To move in this direction, countries need to view neonatal care as inextricably linked to maternal care. They should ensure that all newborns receive essential newborn care, so that those who are small and sick are immediately identified and referred to the appropriate level of care. Countries can start by developing a network of facilities for special newborn care at the secondary level, which is potentially linked to a higher level of care. Special newborn care can be deployed in tandem and as part of quality obstetric care. This is also affordable and achievable for LMICs.

Countries that intend to initiate special and intensive newborn care efforts should identify their starting point and apply historical lessons learned. These include the need to avoid harm to the newborn when new technologies and interventions are introduced, as well as to avoid unnecessary separation of mothers and newborns.

Invest

- Develop or expand national Every Newborn Action Plan strategies and/or action plans to include inpatient newborn care and allocate adequate financial resources to implement the plan.
- Design and invest in facility networks for inpatient newborn care that are backed by functional referral and communication systems and processes. These can be designed to harmonize with BEmONC and CEmONC facility networks.
- Assess available maternal and newborn care services for populations in humanitarian settings; work in partnership with local governments, civil society and international organizations to strengthen services based on actual and projected needs.

Implement

- Ensure international newborn care standards and guidelines are adapted and available in facilities

and that health-care providers are continually trained and mentored.

- Provide and monitor inpatient care for appropriate thermal management; infection prevention protocols and practices; the availability of antibiotics and dosage instructions; optimal newborn nutrition support; and the safe delivery of oxygen and phototherapy when needed.

Inform

- Improve data collection efforts to increase understanding of where, when and why newborns are dying – and how this connects to care delays – as a priority for context-specific community and health system strategies.
- Establish or refine HMIS to track and influence human resource decisions, so that the right health-care providers with the right competencies are available at the right level of care.

Innovate

- Identify and procure diagnostics and equipment that are affordable, safe, effective and appropriate for use in low-resource settings.
- Test innovative parent/community and health-care provider partnership models to expand access to and use of facility-based services and post-discharge follow-up care.

Strategic objective 2: Improve the quality of maternal and newborn care

As detailed in Chapter 2, most births now occur in health-care facilities. This offers a unique opportunity over the next decade to reach women and newborns with improved care. To take full advantage of this opportunity, however, health system investments need to be more intentionally focused on quality. High-quality care is crucial for newborns to survive but is also imperative to minimize disabilities and ensure they thrive.

Quality improvement begins in the special newborn care unit with, for example, active parent engagement, safe oxygen use and infection prevention. Long-term disabilities – largely preventable – are a strong indicator of care quality. To manage disabilities and limit their negative impact

Create a hospital environment that actively welcomes and engages parents in the care of their newborn. Avoid unnecessary separation of parents and other caretakers from the inpatient newborn.

over time demands follow-up care and community-based support that is tied to early childhood development.

Invest

- Ensure each level of care has the necessary staff, equipment, commodities, supplies and diagnostics to deliver quality care; and that the clinical space facilitates the full participation of parents and other family members to care for their newborn.
- Establish or update evidence-based laws, policies and regulations around the newborn continuum of care to ensure non-discriminatory access to high-quality care for all newborns in need. These should also provide the legal and policy framework to support the care of newborns by health-care providers and parents, both in the hospital and beyond.

Implement

- Deploy quality-improvement approaches that advance provider skills and competencies, promote parent engagement and minimize harm to the newborn.
- Encourage a facility ethos and environment that supports dignified and pain-free death for newborns who are too fragile to survive, and compassionate bereavement care for parents and clinical staff.

Inform

- Establish/strengthen MPDSR systems and protocols including notification of neonatal deaths within 24 hours.
- Develop indicators to reflect accurately the content and quality of care, including family engagement, across the spectrum of inpatient services. Refine and validate these indicators using standard definitions and feasibility research.
- Track longer-term outcomes for newborns with disabilities, to better assess the impact of inpatient care and services for early childhood development.

Innovate

- Establish innovative approaches to motivate clinical staff, including coaching, mentoring and continuous education, and identify ways to evaluate the experience of care and to prevent distress and burn-out of health-care providers.
- Design, test and scale-up new and innovative service-delivery approaches and cost-effective health-care technologies, including those specifically designed for low-resource settings.

Strategic objective 3: Reach every woman and newborn to reduce inequities

The risk of dying as a newborn varies greatly depending on where the birth occurs and, in some cultures, whether the newborn is a boy or girl. Equity gaps surrounding household wealth, place of birth, newborn gender, and care coverage at birth have significant and negative consequences. Newborn death is an indicator of the availability of UHC, as poorer families are more likely to experience access barriers.

As highlighted in Chapter 2, if all households had the same risk of neonatal death as the richest 20% of the population within countries that account for more than 84% of all neonatal deaths, it would result in approximately 500 000 fewer deaths, closing the equity gap and accelerating progress to the SDG target. To accelerate progress at country level, financial protection mechanisms are essential to ensure families can access more complex facility-based newborn care. Central to this agenda is the need for leadership and good governance to build accountability and transparency.

Invest

- Develop and enact country policies on UHC, including financial protection mechanisms that guarantee access to a comprehensive package of interventions for small and sick newborns regardless of place of residence, ethnicity and socioeconomic profile.
- Design and implement a comprehensive plan for development of the health workforce that covers education and training, and the distribution, motivation and retention of skilled personnel, including creating or expanding a neonatal nursing cadre.

Implement

- Eliminate social and financial barriers that limit access to care, including for female newborns who are especially vulnerable in some populations.
- Ensure health-care services in humanitarian settings can adequately respond to projected needs, and strengthen the referral process from camps or informal settlements to static hospital facilities.

Inform

- Investigate the sociodemographic characteristics of newborns who are dying and establish national targets to reduce identified equity gaps.
- Use national and subnational data to design context-specific action plans for communities and the health system, which promote equitable access to inpatient and post-discharge follow-up care.

Innovate

- Support implementation research to understand which programmatic interventions work, and why, and to refine services including post-discharge home visits by community health workers and women's groups.
- Design new finance schemes including forms of prepayment and pooled funding to protect families from catastrophic out-of-pocket expenses, and to ensure equitable access to services for poor and marginalized families.

Strategic objective 4: Harness the power of parents, families and communities

Countries will increasingly embrace family-centred care. As part of this, they will engage and empower families and communities as active participants and partners in the design, management and delivery of health care. This will cover not only the stay in hospital but also after discharge as they provide nurturing and developmentally supportive care. Families and communities can also be powerful change agents for improved health-care services and can serve as a bridge from formal facility settings to home-based or community-based follow-up care.

Invest

- Establish policies, laws and regulations that support the newborn and are designed to promote partnerships and coalitions among parents, families and the health-care system.
- Engage the private sector to support multimedia communication campaigns to change social norms, promote zero tolerance for preventable newborn mortality, and advocate for optimal care-seeking behaviours.

Implement

- Promote family-centred care principles in the care of small and sick newborns.
- Design and implement campaigns to raise awareness about the care needs of small and sick newborns and the best ways to support affected families. Deploy social behaviour communication and advocacy in partnership with parent/community coalitions.
- Connect community health workers with local organizations, including parent groups, to broaden community outreach and identify newborns who may need long-term or developmentally supportive care.



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Inform

- Engage affected parents and families to monitor inpatient newborn care services, as well as long-term developmental care for those with more specific needs.
- Develop, validate and contextualize tools that measure the types of support that parents, families, and newborns receive.
- Educate and engage men to understand the needs, risks and danger signs of pregnancy, childbirth and the postnatal period.

Innovate

- Consider and test telemedicine and digital tools to support parents in the care of their newborns.
- Involve patient/parent representatives in the design of new products, programmes and research proposals.

Strategic objective 5: Count and track every small and sick newborn

Too little information is currently available on small and sick newborns, especially in LMICs and humanitarian settings. To address this, it will be necessary to update the way health systems identify, track and measure small and sick newborns. Data should be collected at every level of care, with a clear process for moving that data from the individual, community and facility levels up to the district, national and global levels. A feedback loop should be in place to ensure that lessons learned

are continually used to guide and facilitate programming at all levels.

Invest

- Identify, refine or develop tools to assess service readiness and health outcomes of inpatient newborn care (including the experience of care from the parent and provider perspective) as well as to evaluate referral processes and pathways and to shape resource priorities.
- Support long-term investment in functional and routine systems, such as human resources and logistics, that can be integrated with the national HMIS.

Implement

- Design and use standardized neonatal inpatient records linked to perinatal datasets.
- Support the use of validated indicators in national HMIS.

Inform

- Count every newborn in all settings, including humanitarian settings, using birth (and death) registration.
- Track NMR by gender, for insights into care and gender equity, and by birth weight groups in order to identify and respond to mortality patterns or trends.

Innovate

- Use multi-domain tools to monitor at-risk newborns for complications, such as retinopathy of prematurity.

- Establish indicators to evaluate the effectiveness of follow-up care for ongoing nutritional and developmental health needs.
- Establish metrics to track early childhood development interventions and to guide care delivery, supporting those at highest risk of development delays or disabilities.

A protective legal, regulatory and policy environment

Newborns are protected by human rights laws to the same extent as all other persons, so there should be a protective and supportive legal environment to ensure these rights. These include general rights (such as the right to life, liberty and equality); the right to be free from degrading treatment; and the rights protecting specific groups (such as women, persons with disability, and racial, ethnic and religious groups). To provide effective, quality and sustainable services for newborn care, including in emergency situations, countries are obligated to establish good governance processes and structures, grounded in key principles such as the rule of law; human rights and equity; accountability; participation; and transparency. A country's laws and regulations should assure health security for women and their newborns – including those belonging to the most vulnerable groups such as migrants and refugees – and be aligned with international and domestic human rights standards, most notably the CRC (9).

In the context of newborn health, this requires existing legislative frameworks and structures to be assessed and strengthened. Specific laws should articulate a statutory entitlement to services, regardless of an ability to pay. Policies that promote partnerships between parents, families, communities, institutions and health-care providers are also needed, such as policies on extended family leave or legislation to support breastfeeding (10–12). These efforts should be viewed as integral to policy discussions on newborn health and should engage stakeholders from health, finance and other ministries; civil society (including parent groups); nongovernmental organizations; international agencies; academic institutions; professional associations; and communities.

Small and sick newborns have a wide range of clinical, developmental and psychosocial needs, yet providing the care they require does not need to be prohibitively expensive for countries with less-developed health systems. A large proportion of newborn deaths and disability would be prevented by refining existing systems and ensuring that all newborns and their families are able to access the



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care they need. This health-care transformation should be approached in a way that is rights-based and family-centred, and focused on quality, equity and dignity.

Research and data priorities to guide change

The process of collecting and using data must be made a matter of routine if it is to advance newborn care in low-resource settings. Accurate and consistent population-based and facility-level data are needed to enhance understanding of health-care service readiness and to guide change.

High-quality research is also needed. While a great deal can be learned from successes in high- and middle-income settings, this evidence requires adaptation to low-resource settings. Context-specific data will provide accurate and nuanced insights into, and validation of, the health needs of target populations. Shared learning within and across countries can then inform advocacy and policy change and facilitate safer, more effective scale-up of special and intensive care services and systems for newborns.

In this report, the Description, Discovery, Development and Delivery framework is used to highlight examples of key research priorities. This can inform the design and delivery of care, and ultimately benefit small and sick newborns. Illustrative priorities include issues relevant to general inpatient newborn care, special and intensive newborn care and care in humanitarian settings, as shown in Table 6.6. Table 6.6 also highlights data and research priorities related to follow-up care, with a specific look at priorities for early childhood development. Where feasible, mothers, other parents and community representatives should be included in research design and monitoring processes.

It takes commitment

Considerable commitment will be needed over the next 11 years to eliminate the burden of newborns who die from preventable causes, and to support their development across the life course. It is a commitment of political will, funds, resources, time, focus and dedication. Collectively, as global citizens – and as individual nations – we stand to gain so much from the promise of generations filled with healthy and productive people.

In addition to urging accelerated progress, the Every Woman Every Child movement has called for increased commitment and better alignment across sectors and among partners. The movement reported that a total of

76 commitments made from 2015 to 2017 (25% of all made) referenced the reduction of neonatal mortality in line with the Every Newborn Action Plan. A special analysis conducted by the Partnership for Maternal, Newborn and Child Health (PMNCH) for this report found that nearly one third of these commitments were made by governments, one quarter by civil society organizations and nongovernmental organizations, and roughly one fifth by the business community. Thirty-nine percent were financial commitments for maternal, child and adolescent health targets.

Based on the 2017 Every Woman Every Child progress report, the PMNCH analysis found that a total of seven commitments reached newborns with service delivery activities that included: breastfeeding support; neonatal intensive and emergency care; postnatal care; community engagement and capacity building; and improved midwifery services (13). Unfortunately, these commitments only reached 5 million newborns – just 4% of all beneficiaries reportedly reached by those who responded to the questionnaire.¹ A far larger set of commitments is needed to accelerate progress and effect change.

Fortunately, progress can be achieved in many ways – small and large.

All stakeholders in health and sustainable development should consider their own potential for action, including such options as: collaboration with other stakeholders; raising public awareness; funding and investment; sharing skills and expertise; crafting policies and regulations; finding ways to innovate; conducting outreach; mentoring community health workers; and advocating on behalf of parents and families.

If appropriate action is taken globally, small and sick newborns can and will survive and thrive as future productive members of society. With strategic partnerships and innovative approaches, the international community can transform all aspects of neonatal care, from its availability and quality to its uptake and affordability.

This requires all stakeholders – governments and partners, competent health-care professionals, professional associations, private sector organizations, researchers, empowered parents, and engaged communities – to work together. Everyone has a role to play to ensure a thriving next generation.

1 The 2017 EWEC progress reporting questionnaire for non-state commitment makers was sent to 176 nongovernmental commitment makers and received a 60% response rate (105 in total). Hence, this is very likely an underestimate of the number of newborns reached.

Table 6.6 Data and research priorities for improved newborn care

	DESCRIPTION Characterize the problem	DISCOVERY Find new solutions	DEVELOPMENT Improve existing interventions	DELIVERY Advance equitable access to interventions
Research aim	Descriptive epidemiology and qualitative research to understand determinants, advance definitions	Development of new medicines, preventive interventions or new diagnostics	Adapting or improving existing interventions	Delivery of interventions at scale through innovative approaches
For all inpatient newborn care	<p>Understand where newborns are dying, and related care delays, to establish context-specific health system strategies</p> <p>Implement gap analyses to establish reliable estimations of the magnitude and distribution of newborns needing care</p> <p>Identify health system challenges (including human resources for health, financing, policy and legislative framework, and infrastructure) to design improved service delivery systems for newborns</p> <p>Conduct social research to understand why certain populations are not accessing care for small and sick newborns</p> <p>Explore gender preference in care-seeking behaviours in populations where hospital admissions data indicate a potential gender imbalance</p> <p>Conduct human resources assessments to understand who is providing care and to explore/understand any existing provider and competency gaps</p> <p>Undertake periodic household surveys to obtain data on mortality, intervention coverage and use of services</p>	<p>Explore and develop innovative, cost-effective health-care technologies that are appropriate for low-resource settings</p>	<p>Conduct implementation research to help countries avoid known barriers to delivery of quality services at scale</p> <p>Develop and validate interventions and associated indicators for respectful care for mothers and newborns, families who have a small and sick newborn, newborns with congenital abnormalities, and bereaved families</p>	<p>Conduct implementation research on effective social behaviour change and communication approaches to promote early care-seeking and care for all newborns</p> <p>Evaluate models of care that promote UHC in low- and middle-income settings to determine effectiveness and scalability</p> <p>Assess models of care that promote parent/family engagement during inpatient newborn care to inform best practices in low- and middle-income settings</p> <p>Test new workforce strategies, including task-shifting and task-sharing, in response to identified human resource gaps</p> <p>Evaluate national service delivery indicators and their integration into routine data collection systems and instruments</p> <p>Test innovative mechanisms designed to gather data that will drive information and accountability for newborn care (birth and death registration, coverage and quality, recording neonatal deaths, perinatal surveillance and response, birth weight, gestational age)</p>
Special and intensive newborn care	<p>Comprehensively assess the availability of, and access to, special and intensive inpatient services</p> <p>Using data, establish a better understanding of the disease burden and which conditions require more intensive care. Use data to inform health-care planning and to monitor prevention</p> <p>Assess service readiness and referral processes to inform the prioritization of health-care resources for special and intensive care</p>	<p>Design and test simpler, point-of-care diagnostics for newborn infections</p> <p>Develop new antibiotics to manage newborn infections</p> <p>Explore and identify approaches to measure gestational age that are appropriate for low-resource settings</p> <p>Design and test triage tools to ensure newborns are triaged to the appropriate level of care</p>	<p>Establish the effectiveness of emerging newborn-care innovations and approaches for more advanced care in low-resource settings (e.g. feeding, antibiotic use, monitoring for deterioration)</p> <p>Test quality-improvement approaches that are specifically designed for more advanced newborn care, including safe and effective parent engagement</p>	<p>Explore innovations in the organization of services – where these units should be located, how they should be staffed and equipped – to optimize access to and quality of care</p> <p>Conduct implementation research to adapt and inform scale-up of successful models of inpatient care including innovations in referral systems and approaches</p>

Table 6.6 Data and research priorities for improved newborn care (continued)

	DESCRIPTION Characterize the problem	DISCOVERY Find new solutions	DEVELOPMENT Improve existing interventions	DELIVERY Advance equitable access to interventions
Special and intensive newborn care (continued)	<p>Informed by data on service readiness, establish, strengthen or scale-up high-quality special and intensive care for small and sick newborns</p> <p>Conduct newborn death reviews and assess data by gender to understand gender equity in newborn care</p> <p>Gather population-based information on organisms that cause newborn infections to inform effective prevention and treatment</p> <p>Establish surveillance systems to track congenital abnormalities</p>		<p>Identify and test innovative training methodologies for health workers, including specialized skills in neonatal nursing, physiotherapy and occupational therapy</p> <p>Implement clinical research on optimized feeding and oxygen provision</p> <p>Test methodologies to develop and deploy a neonatal nursing cadre with training optimized for the setting based on burden of disease and specific population needs</p>	<p>Evaluate strategies to prevent and manage hospital-acquired infections, including antibiotic choice</p> <p>Track morbidity and disability outcomes, especially where neonatal intensive care is being expanded</p>
Follow-up care/ early childhood development	<p>Establish data regarding the burden of disability for survivors of neonatal sepsis</p>	<p>Test models of care to determine if community health workers/para-professionals can be trained to deliver early childhood development interventions*</p> <p>Explore cost-effective parenting interventions to promote early childhood development*</p>	<p>Test newborn biometrics for low-resource settings, to improve tracking of newborns during inpatient care and at follow-up</p> <p>Design and test electronic medical records to improve patient tracking and long-term follow-up</p>	<p>Evaluate community-based models of care to ensure newborns are receiving required post-discharge care</p> <p>Explore and establish affordable and scalable strategies for uptake of early childhood development interventions across the continuum from birth to early childhood</p> <p>Explore the most cost-effective parenting interventions to promote early childhood development*</p>
Humanitarian settings Priority research topics**	<p>Establish the additional burden of stillbirth in different emergency situations (e.g. conflict, acute or protracted, natural disaster); establish the additional burden of neonatal mortality in different emergency situations</p> <p>Explore the incidences, causes and outcomes of umbilical and skin infections among newborns in emergency settings as well as the incidence of neonatal sepsis</p> <p>Identify risk factors for neonatal sepsis in emergency settings and explore interventions for mothers and newborns</p>	<p>Evaluate the effectiveness of perinatal audits in reducing the incidence of adverse outcomes related to acute intrapartum events</p> <p>Develop, test and validate simpler clinical algorithms (recognition and management) for infants who require resuscitation at birth, and determine if these algorithms meet the need for resuscitation at birth</p> <p>Develop and test low-cost, robust, simple fetal heart monitors that are more user-friendly than the Pinard stethoscope; explore if the use of such a device improves fetal heart rate monitoring and reduces intrapartum stillbirth and asphyxia-related outcomes</p>	<p>Test diagnostics to improve identification of neonatal complications in health facilities</p> <p>Test the feasibility, cost and effectiveness of setting up newborn care corners in mobile clinics, first referral units and district hospitals</p> <p>Identify new interventions to prevent transmission of infections during childbirth (e.g. chlorhexidine vaginal douche and immune modulators such as zinc for mothers)</p> <p>Explore simpler, cheaper technology to improve supportive care of newborns who require oxygen (such as robust pulse oximeters, oxygen condensers, low-cost CPAP, etc.) and determine their impact on mortality reduction and outcomes</p>	<p>Develop and validate strategies to identify preterm newborns at the community level by health workers and family members</p> <p>Determine the safety, feasibility, effectiveness and cost of managing severe neonatal infections at or close to home (e.g. requiring injectable antibiotics)</p> <p>Evaluate different methods of behaviour change to overcome harmful practices and promote positive cultural and social norms</p> <p>Evaluate the feasibility and effectiveness of quality improvement approaches in hospitals</p>

Table 6.6 Data and research priorities for improved newborn care (continued)

	DESCRIPTION Characterize the problem	DISCOVERY Find new solutions	DEVELOPMENT Improve existing interventions	DELIVERY Advance equitable access to interventions
Humanitarian settings Priority research topics** <i>(continued)</i>	Determine the relative proportion of neonatal infections that are pneumonia, sepsis and meningitis; design and test reliable clinical markers/ combination of markers to distinguish these conditions		Determine the safety, feasibility, effectiveness and cost of managing severe neonatal infections (e.g. requiring injectable antibiotics) at or close to home	Identify the best and most cost-effective approaches for provider training and support during an acute emergency Evaluate interventions designed to prevent mistreatment and promote respectful maternal and newborn care in humanitarian settings
Typical timeline to impact	Near-term (2–5 years)	Long-term (5–15 years)	Mid-term (5–10 years)	Near-term (2–5 years)

* Dua T, Tomlinson M, Tablante E, et al. Global research priorities to accelerate early child development in the sustainable development era. *The Lancet. Global Health*. 2016;4(12):e887–e889.

** Morof DF, Kerber K, Tomczyk B, et al. Neonatal survival in complex humanitarian emergencies: setting an evidence-based research agenda. *Conflict and Health*. 2014;8(1):8.

Table adapted from: Born Too Soon: the global action report on preterm birth.

REFERENCES

1. UNICEF. Every child alive: the urgent need to end newborn deaths. Geneva: United Nations Children's Fund; 2018.
2. Bhutta ZA, Das JK, Bahl R, Lawn JE, Salam RA, Paul VK, et al. Can available interventions end preventable deaths in mothers, newborn babies, and stillbirths, and at what cost? *Lancet*. 2014;384(9940):347-70.
3. The Lives Saved Tool (LiST) website (<http://www.livessavedtool.org/>, accessed 27 February 2019).
4. Boschi-Pinto C, Black RE. Development and use of the lives saved tool: a model to estimate the impact of scaling up proven interventions on maternal, neonatal and child mortality. *Int J Epidemiol*. 2011;40(2):520–1.
5. WHO, UNICEF, UNFPA, World Bank, UNFPA. Trends in maternal mortality: 1990 to 2015. Geneva: World Health Organization; 2015.
6. UN IGME. Levels & trends in child mortality: report 2017. Estimates developed by the United Nations inter-agency group for child mortality estimation (UN IGME). New York: United Nations Children's Fund; 2017.
7. Blencowe H, Cousens S, Jassir FB, Say L, Chou D, Mathers C, et al. National, regional, and worldwide estimates of stillbirth rates in 2015, with trends from 2000: a systematic analysis. *Lancet Glob Health*. 2016;4(2):e98–e108.
8. UNICEF, WHO. Tracking progress towards universal coverage for reproductive, newborn and child health: the 2017 report. Washington DC: United Nations; 2017.
9. UN. General comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health (art. 24). CRC/C/GC/15. 17 April 2013 (https://www2.ohchr.org/english/bodies/crc/docs/gc/crc-c-gc-15_en.doc, accessed 27 February 2019).
10. Heymann J, Sprague AR, Nandi A, Earle A, Batra P, Schickedanz A, et al. Paid parental leave and family wellbeing in the sustainable development era. *Public Health Rev*. 2017;38:21.
11. Greenfield JC, Klawetter S. Parental leave policy as a strategy to improve outcomes among premature infants. *Health Soc Work*. 2016;41(1):17–23.
12. Rollins NC, Bhandari N, Hajeebhoy N, Horton S, Lutter CK, Martines JC, et al. Why invest, and what it will take to improve breastfeeding practices? *Lancet*. 2016;387(10017):491–504.
13. EWEC and PMNCH. Progress in partnership: 2017 progress report on the every woman every child global strategy for women's, children's and adolescents' health. Geneva: World Health Organization; 2017.

GLOSSARY

TERM	DEFINITION AND USAGE IN THIS REPORT
Anaemia	A condition in which the number of red blood cells or their oxygen-carrying capacity is insufficient to meet physiologic needs, which vary by age, sex, altitude, smoking and pregnancy status. (WHO)
Apnoeic episodes	Infant apnoea is defined as an unexplained episode of cessation of breathing for 20 seconds or longer, or a shorter respiratory pause associated with bradycardia, cyanosis, pallor and/or marked hypotonia. (American Academy of Pediatrics)
Bilirubin	A yellow-orange compound that is produced by the breakdown of haemoglobin from red blood cells and excreted in bile.
Birth complications	Also known as perinatal asphyxia, neonatal asphyxia or birth asphyxia; varying complications which result from the deprivation of oxygen to a newborn that lasts long enough during the birth process to cause physical harm, usually to the brain. Also called neonatal intrapartum-related complications (or events).
Broad-spectrum antibiotics	Antibiotics that act on the two major bacterial groups, Gram-positive and Gram-negative, or any antibiotic that acts against a wide range of disease-causing bacteria.
Congenital anomalies	Also known as birth defects, congenital disorders or congenital malformations. Congenital anomalies can be defined as structural or functional anomalies (e.g. metabolic disorders) that occur during intrauterine life and can be identified prenatally, at birth or later in life. (WHO)
Continuous positive airway pressure therapy (also CPAP)	A treatment method used for newborns who have mild respiratory distress and are unable to keep normal oxygen saturation levels. It may also be used for newborns who have sleep apnoea.
Developmentally supportive care	Care of an infant to support positive growth and development, while allowing stabilization of physiologic and behavioural functioning. (National Association of Neonatal Nurses, 2000)
Essential care	Key routine practices in the care of all newborns, particularly at the time of birth and during the first hours of life, whether in the health facility or at home.
Family	For this document, family refers to a newborn's parents, legal guardians, primary caregivers and family members. All are in a unique position to ensure nurturing care and, in the case of mothers, breastfeeding.
Family-centred care	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-centred care include: dignity and respect; information sharing; participation; and collaboration.
Haemoglobin	A red protein responsible for transporting oxygen in the blood. Its molecule comprises four subunits, each containing an iron atom bound to a haem group.
Humanitarian setting	A setting in which an event or series of events has resulted in a critical threat to the health, safety, security or well-being of a community or other large group of people. This can be the result of events such as armed conflicts, natural disasters, epidemics or famine, and often involves population displacement.
Hypoglycaemia	A deficiency of glucose in the bloodstream.
Inpatient care	Care of a newborn patient whose condition requires admission to a hospital.
Intensive newborn care	Key inpatient care (24/7) practices for very small and sick newborns, including the provision of intermittent positive-pressure therapy. Intensive care can only be provided in a higher (usually tertiary) level facility.

TERM	DEFINITION AND USAGE IN THIS REPORT
Intravenous	Existing or taking place within, or administered into, a vein or veins.
Low-birth-weight (also LBW)	A newborn who weighs less than 2500 g (i.e. up to and including 2499 g) regardless of gestational age.
Narrow-spectrum antibiotics	A class of antibiotics used to treat a specific infection when the causative organism is known. It will not kill as many of the normal microorganisms in the body as broad-spectrum antibiotics.
Nasal cannula	A device used to deliver supplemental oxygen or increased airflow to a newborn patient in need of respiratory help.
Nasogastric tube feeding	Feeding through a tube that is passed through the nose and down the nasopharynx and oesophagus into the stomach. It is a technique to be used when the newborn is unable to suckle at the breast.
Necrotizing enterocolitis	A medical condition where a portion of the bowel dies. It typically occurs in newborns who may be premature, small and sick, and are not fed human milk. Symptoms may include poor feeding, abdominal distension, decreased activity, blood in the stool or vomiting of bile.
Neonatal encephalopathy	A clinically defined syndrome characterized by disturbed neurological function in the earliest days of life in an infant born at or beyond 35 weeks of gestation. It is manifested by a reduced level of consciousness or seizures, often accompanied by difficulty with initiating and maintaining respiration and depression of tone and reflexes.
Neonatal intrapartum-related complications (or events)	Perinatal asphyxia, neonatal asphyxia or birth asphyxia is the medical condition resulting from deprivation of oxygen to an infant that lasts long enough during the birth process to cause physical harm, usually to the brain. Also called birth complications. Other intrapartum-related complications may include head trauma, limb fractures, haematomas, bruising, etc.
Neonate	An infant who is in the first 28 days after birth (also see Newborn).
Newborn	The colloquial term for an infant (neonate) who is in the first 28 days after birth. Newborn is used predominantly in this report.
Noncommunicable disease	A medical condition or disease that is not caused by infection. Noncommunicable diseases tend to be of long duration and may progress slowly.
Parents	<p>In this report, parents refers to:</p> <ul style="list-style-type: none"> • individual parents, legal guardians or primary caregivers of a newborn who is born preterm, small for gestational age, with an illness, or who suffers from a birth complication and requires hospitalization during the neonatal period; • persons who represent or express views on behalf of parents of preterm or sick newborns, such as other family members or representatives of parent organizations.
People-centred care	<p>An approach to care that consciously adopts the perspectives of individuals, carers, families and communities, as participants in, and beneficiaries of, trusted health systems that are organized around the comprehensive needs of people rather than individual diseases, and respects social preferences.</p> <p>For this report, the person at the centre of care is the newborn who receives treatment by health-care providers, mother, father, caregivers or a combination.</p>
Preterm birth	Defined as childbirth occurring at less than 37 completed weeks or 259 days of gestation. (WHO)

GLOSSARY *(continued)*

TERM	DEFINITION AND USAGE IN THIS REPORT
Retinopathy of prematurity	A potentially blinding disease caused by abnormal development of retinal blood vessels in the eyes of premature infants.
Sepsis	A life-threatening condition that arises when the body's response to an infection injures its own tissues and organs. Any type of infectious pathogen can potentially cause sepsis.
Severe neonatal infection	Severe bacterial and viral infections in newborns which can result in clinically defined neonatal sepsis, meningitis and pneumonia.
Sick newborn	A newborn who requires medical care.
Small for gestational age (also SGA)	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.
Small newborn	A newborn who is preterm and/or low-birth-weight, or small for gestational age.
Small and sick newborn	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.
Special newborn care	Key inpatient care (24/7) practices for small and sick newborns, including (but not exclusively): provision of warmth; support for feeding and breathing; treatment of jaundice; prevention and treatment of infection. Special newborn care does not include the provision of intermittent positive-pressure therapy. Special newborn care can only be provided in a health facility.
Universal health coverage (also UHC)	Ensuring everyone can access the quality health services they need without suffering undue financial hardship.

ANNEX 1:

Lives Saved Tool (LiST) analysis methods and results

In 2014, a study in *The Lancet* Every Newborn series systematically reviewed interventions across the continuum of care that impact newborn mortality and health and stillbirths. It also reviewed various delivery platforms. It then modelled the impact and cost of scaling-up these interventions in the 75 countries with the highest burden of mortality (1). The results were first published in *The Lancet* Every Newborn series and then used in the Every Newborn Action Plan (ENAP) (endorsed by the 2014 World Health Assembly in Resolution WHA 67.10). Findings from the modelling exercise indicated that high coverage of interventions during pregnancy, around the time of birth, and for small and sick newborns would save nearly 3 million lives (women, newborns and stillbirths) by 2025. The additional running cost for this would be only US\$ 1.15 per person in the 75 countries. The analysis also considered how many lives would be

saved by closing the quality gap in care and ensuring that all women and newborns receive effective care during births in health facilities.

LiST was used to estimate impact and the cost of increasing coverage of individual interventions from most recently reported levels for each country on stillbirth and neonatal and maternal mortality (methods and details found in Bhutta, Das, Bahl, et al. 2014 (1)). LiST is a free and widely used software module that allows users to compare the effects of different interventions on maternal, neonatal and child mortality and stillbirths, as well as on stunting and wasting. The modelling approach has been described (2), and the assumptions that underlie the evidence-based platform are documented in peer-reviewed literature.

For the current report, a similar analysis was conducted from June to August 2018 to assess the potential for saving newborn lives. The approach was closely aligned with that used by Bhutta, Das, Bahl, et al. (2014) (1). The following paragraphs provide an overview of the methodology and a comprehensive presentation of the results.

Methodology

LiST was used to model the impact of various scenarios of intervention scale-up in 81 high-burden countries tracked by the Countdown to 2030¹ collaboration. The sample represents most of the maternal deaths (96%) (3), neonatal deaths (89%) (4), and stillbirths (87%) (5) globally. All models were analysed using the Spectrum modelling system (version 5.71 beta 5) (6).

Description of modelled scenarios

A set of five scenarios was created for each of the 81 countries. For each scenario, health impact was estimated in each country for the period 2017–2030. Demographic parameters, such as population growth and total fertility,

1 See: <http://countdown2030.org>.



Table A1.1 Levels of care according to proxy distribution

FOR INTRAPARTUM INTERVENTIONS			
Health-facility delivery (%)	Level of inpatient care		
	Primary (essential care)	Secondary (BEmONC)	Tertiary (CEmONC)
0–29%	90%	0%	10%
30–49%	50%	30%	20%
50–94%	25%	15%	60%
> 95%	0%	0%	100%
FOR POSTNATAL CARE INTERVENTIONS			
0–29%	90%	0%	10%
30–49%	50%	30%	20%
50–69%	33%	20%	47%
70–94%	17%	10%	73%
> 95%	0%	0%	100%

Table A1.2 Neonatal lives that could be saved if interim ENAP coverage targets are achieved

Intervention	In 2020	In 2025
Neonatal resuscitation	40 600	103 200
Kangaroo mother care	31 600	47 400
TOTAL	72 200	150 600

follow projections from the United Nations Population Division 2017 Revision of World Population Prospects. HIV/AIDS trends are from the UNAIDS Reference Group on Estimates, Models and Projections (UNAIDS) (7). Additional details about specific interventions and coverage targets for each scenario are described below. Table A1.1 shows levels of care; the interventions included in each scenario are provided in Table A1.2.

1. Baseline. In this scenario, coverage of maternal, newborn and child health (MNCH) interventions remains constant from 2016, as the starting baseline year, through to 2030, as the end year.

2. Reaching interim coverage targets. In this scenario, coverage of two neonatal interventions (neonatal resuscitation and KMC) was scaled up in all countries to reach 50% in 2020 and 75% in 2025 according to the ENAP targets (8). For neonatal resuscitation, baseline values were derived from a proxy distribution, which categorized health-facility deliveries into three levels of inpatient care (Table A1.1). Neonatal resuscitation was scaled up for only the proportion of births occurring in either a secondary-level (i.e. basic emergency obstetric care (BEmOC)) facility, or tertiary-level (i.e. comprehensive emergency obstetric care (CEmOC)) facility. Baseline values for KMC were assumed to be zero or were drawn from recent

linking studies conducted in a subset of countries with available data. Coverage for KMC in Bangladesh, Haiti, Malawi, Nepal, Senegal and the United Republic of Tanzania were estimated by combining nationally representative household surveys (i.e. demographic and health survey (DHS)) with data from health-facility assessments (i.e. service provision assessment (SPA)).

3. Closing the quality gap with special care. In this scenario, coverage of health-facility based interventions was modelled to be available at the highest level of birth care (i.e. 95% at CEmOC) in 2025 among all births currently occurring at a health facility. As such, the absolute percentage of deliveries occurring in a health facility was kept constant from baseline (i.e. the overall percentage of deliveries occurring in a health facility was not increased); rather the model assumed that 95% of deliveries would have access to CEmOC, shifting from the essential care level and BEmOC to CEmOC level. Facility-based interventions to reduce neonatal mortality included: antibiotics for preterm premature rupture of membranes; clean birth practices for protection from hospital-acquired infection; management of labour and delivery complications; and immediate assessment and stimulation of the newborn. For KMC, coverage began from a baseline assumed to be zero or a country-specific level for six countries (listed in the previous paragraph) where recent linking studies were conducted to estimate population-level coverage. Expansion of KMC followed a linear trend to reach 95% of all health-facility deliveries in 2025.

4. Closing the quality gap with intensive care. In this scenario, coverage of health-facility based interventions was modelled to be available at the highest level of birth care (i.e. 95% at CEmOC) in 2025 among all births currently occurring at a health facility. The overall percentage of deliveries occurring in a health facility was not increased; rather care shifted from lower levels to CEmOC. Therefore 95% of facility-based deliveries would have access to the following interventions: antibiotics for preterm premature rupture of membranes; clean birth practices for protection from hospital-acquired infection; management of labour and delivery complications; and immediate assessment and stimulation of the newborn. Comprehensive newborn care for preterm was scaled up from a baseline level of 25% of CEmOC births to 95% of all health-facility births by 2025. Comprehensive newborn care to treat infection was similarly scaled up from a baseline level of 50% of CEmOC births to 95% of all health-facility births by 2025.

5. Universal coverage. In this scenario, 29 evidence-based interventions that impact neonatal mortality along the continuum of care were aggressively scaled up from current coverage to reach 95% coverage in 2030. Any intervention already above the 95% target at baseline was held constant. Scale-up included maternal interventions such as tetanus toxoid immunization and nutrition interventions such as calcium, balanced energy protein, and multiple micronutrient supplementation among pregnant women. Folic acid fortification was expanded in countries (9) with legislation to mandate fortification of at least one industrially milled cereal grain (n=46); country-specific values were applied for baseline if available (10). Intermittent preventive treatment in pregnancy for malaria was scaled up only in countries with an existing policy or WHO recommendation in place (n=35).

The percentage of women giving birth in a health facility was expanded to 95% in 2030 with scale-up of related facility-based interventions (i.e. antibiotics for preterm premature rupture of membranes; clean birth practices for protection from hospital-acquired infection; management of labour and delivery complications; and immediate assessment and stimulation of the newborn). Use of antenatal corticosteroids was modelled to increase in only a subset of upper-middle-income countries with more than 50% of births estimated to be in tertiary care facilities (n=12). Comprehensive newborn care for preterm and comprehensive newborn care to treat infection were scaled up to 95% in 2020 as the highest level of inpatient care. Chlorhexidine for newborn cord care was scaled up only in countries identified as being in the implementation/scale-up phase (11) of chlorhexidine activities (n=12). Baseline for chlorhexidine was assumed to be 5% in this subset of countries, excluding Bangladesh.² Promotion of breastfeeding and clean postnatal practices were included as community-based interventions in addition to improved sanitation, handwashing and water connection in the home. Oral rehydration solution, antibiotics for treatment of dysentery, and zinc for treatment of diarrhoea were included for curative care of sick children.

Results

Universal coverage

With universal coverage, an estimated 2.9 million lives could be saved in 2030 in the 81 countries. This represents a 54% reduction with: 39% fewer maternal deaths; 68% fewer neonatal deaths; and a 43% reduction in the number

² Country-specific estimate applied for chlorhexidine coverage at baseline.

Table A1.3 Intervention listing for scenarios: small and sick newborn analysis

Note: Direct impact on cause-specific mortality is indicated by “x”; indirect impact is indicated by “Indirect” and is mediated by birth outcomes such as small for gestational age or preterm birth as contributing risk factors.

Packages	Intervention	Neonatal impact pathway	Interim coverage targets (ENAP)	Closing the quality gap with intensive care	Closing the quality gap with special newborn care (no intensive care)	Universal coverage (UNIVERSAL)	
Preconception nutrition care	Folic acid supplementation/fortification	X	N/A	N/A	N/A	95% in 2030	
Pregnancy care	Tetanus toxoid vaccination	X	N/A	N/A	N/A	95% in 2030	
	Intermittent preventive treatment of malaria during pregnancy	Indirect	N/A	N/A	N/A	95% in 2030	
	Syphilis detection and treatment	X	N/A	N/A	N/A	95% in 2030	
	Calcium supplementation	Indirect	N/A	N/A	N/A	95% in 2030	
	Iron supplementation	Indirect	N/A	N/A	N/A	95% in 2030	
	Micronutrient supplementation (iron and multiple micronutrients)	Indirect	N/A	N/A	N/A	95% in 2030	
	Balanced energy supplementation	Indirect	N/A	N/A	N/A	95% in 2030	
Care during labour and childbirth	Health-facility-based care for labour and delivery	Antenatal corticosteroids for pre-term labour	X	N/A	N/A	N/A	Health-facility delivery to 95% in 2030
		Antibiotics for preterm premature rupture of membranes	X	N/A	Scale up CEmOC to 95% health-facility delivery in 2025	Scale up CEmOC to 95% health-facility delivery in 2025	
		Clean birth practices	X	N/A			
		Labour and delivery management	X	N/A			
		Immediate assessment and stimulation	X	N/A			
		Neonatal resuscitation	X	50% of health-facility delivery in 2020, 75% of health-facility delivery in 2025			
Promotion of breastfeeding	Indirect	N/A	N/A	N/A	95% in 2030		
Care of the healthy neonate	Clean postnatal practices	X	N/A	N/A	N/A	95% in 2030	
	Chlorhexidine	X	N/A	N/A	N/A	95% in 2030	
	Improved sanitation – utilization of latrines or toilets	X	N/A	N/A	N/A	95% in 2030	
	Water connection in the home	X	N/A	N/A	N/A	95% in 2030	
	Handwashing with soap	X	N/A	N/A	N/A	95% in 2030	
	Insecticide-treated nets and indoor residual spraying – households protected from malaria	Indirect	N/A	N/A	N/A	95% in 2030	

Table A1.3 Intervention listing for scenarios: small and sick newborn analysis (continued)

Packages	Intervention	Neonatal impact pathway	Interim coverage targets (ENAP)	Closing the quality gap with intensive care	Closing the quality gap with special newborn care (no intensive care)	Universal coverage (UNIVERSAL)
Care of the small and sick neonate*	Case management for prematurity	Thermal care	X	N/A	N/A	N/A
		Kangaroo mother care	X	50% of health-facility delivery in 2020; 75% of health-facility delivery in 2025	N/A	95% of health-facility delivery in 2025
		Intensive care for prematurity	X	N/A	95% of health-facility delivery in 2025	N/A
	Case management for neonatal infection	Oral antibiotics for neonatal sepsis/pneumonia	X	N/A	N/A	N/A
		Injectable antibiotics for neonatal sepsis/pneumonia	X	No change – already at all health-facility deliveries	N/A	No change – already at all health-facility deliveries
		Intensive care for neonatal sepsis/pneumonia	X	N/A	95% of health-facility delivery in 2025	N/A
	Oral rehydration solution	X	N/A	N/A	N/A	95% in 2030
	Antibiotics for treatment of dysentery	X	N/A	N/A	N/A	95% in 2030
	Zinc for treatment of diarrhoea	X	N/A	N/A	N/A	95% in 2030

* Compared with the packages modelled for the newborn analyses conducted in 2014, assumptions about baseline coverage of component interventions for case management of prematurity and newborn infection have been revised. Coverage for thermal care and injectable antibiotics for neonatal sepsis/pneumonia is assumed to be equivalent to the percentage of births occurring at a health facility as the standard default at baseline.

N/A = Not applicable.

of stillbirths in 2030 (see Table A1.3). In the final target year of 2030, packages of interventions contributing the greatest impact to prevent neonatal deaths include: those provided as care for small and sick newborns (44%); care during labour and around the time of birth (36%); pregnancy care (11%); and care for the healthy newborn (9%). An important though ambitious part of the model relates to expanding comprehensive care for premature births and newborn infection, which would save an estimated 540 400 and 202 300 newborn lives in 2030 at full scale-up. Countries will not achieve newborn mortality targets set out in the SDG agenda without improving access to, and the quality of, neonatal care at this level. The gains estimated by providing these additional elements of

high-quality care for small and sick newborns, beyond basic preventive strategies and care in community settings, are considerable and confirm the importance of this focus.

Conclusion: A total of 2.9 million lives of women and newborns could be saved in 2030, with an estimated 54% of maternal and newborn deaths averted and stillbirths prevented. Interventions for small and sick newborns would account for an estimated 44% of newborn lives saved.

Reaching interim coverage targets

The Every Newborn Action Plan sets interim coverage targets for newborn interventions towards the ultimate goal of UHC by 2030. The authors of this report assessed

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how many lives would be saved by scaling up two neonatal interventions to reach 50% in 2020 and 75% in 2025 according to the action plan targets (Table A1.2). Scaling up KMC and neonatal resuscitation to 50% in 2020 would save an estimated 72 200 newborn lives. Meeting the 75% target in 2025 for these interventions would save an estimated 150 600 newborn lives, averting 6% of all newborn deaths.

Conclusion: Scaling up special care for small and sick newborns has an important contribution; however, countries will need to invest in intensive care in addition to special care in order to meet the SDGs.

Reaching the SDGs

Following current trajectories, neonatal mortality in the 81 countries would decline to an average of 18 deaths per 1000 live births by 2030 – well above the SDG 3.2 target. However, if these countries achieve universal coverage of high-impact interventions for newborn health (including special and intensive newborn care) they will surpass the global average Every Newborn target of 9 deaths per 1000 live births in 2030. On average, these countries will also achieve the SDG 3.2 target (also the Every Newborn national target) of all countries aiming to reduce neonatal mortality to at least as low as 12 deaths per 1000 live births.

Closing the “quality of care” gap with special and intensive newborn care

An important aspirational goal relates to the scale-up of high-quality secondary and tertiary newborn care in facility settings. An opportunity is missed when the quality of care received is inadequate for proper maternal and newborn care. If 95% of all women giving birth in facilities in 2025 receive high-quality effective interventions at the highest level of care (i.e. CEmOC) with intensive care for newborns, this scenario would avert an estimated 46 300

maternal deaths, 248 300 stillbirths, and 667 200 neonatal deaths. When the same scenario is limited to providing only special care for small and sick newborns (e.g. KMC and injectable antibiotics rather than full comprehensive care), special care still averts 268 900 neonatal deaths, reducing neonatal deaths by about 11% compared with a 28% decline with intensive care interventions.

Conclusion: Closing the quality of care gap in facilities has the potential to avert 19% of maternal and newborn deaths and stillbirths in 2025. Providing intensive newborn care in addition to special care increases the number of neonatal deaths averted to 28%.

Limitations

There are several caveats for this type of modelling when it is applied to estimate the impact of scaling up packages of lifesaving interventions. Gains are based on the overall change or expansion in coverage for effective interventions, so interventions with current high levels of coverage at baseline will not feature as prominently, or appear to contribute as significantly, to produce concomitant reductions in mortality. Interventions such as injectable antibiotics, for example, which are very effective for treatment of neonatal infection, are modelled to be available at the same level as health-facility deliveries in this sample of high-burden countries. Setting baseline coverage of this intervention to be equivalent to the level of health-facility delivery differs from the previous work, which assumed a baseline coverage of zero. The findings in this report may appear to be more modest when compared to the 2014 analyses, because earlier versions of the model also incorporated differences in the quality of care by childbirth interventions across different health-facility types. The current version of the LiST model used for this analysis does not assume this heterogeneity according to the level of health-facility birth care.

For the prior work, the Countdown to 2015 countries (n=75) were analysed as a representative global sample. The Countdown to 2030 group (n=81) presented here does not represent an identical sample of countries. An additional 13 countries were selected, however 7 countries are no longer included, several representing large populations (e.g. China, Brazil, Mexico). The total number of births among the Countdown to 2030 countries represents approximately 20% fewer births than the previous portfolio comprised of Countdown to 2015 countries. This will influence the estimated number of deaths, and deaths averted overall.

REFERENCES

1. Bhutta ZA, Das JK, Bahl R, Lawn JE, Salam RA, Paul VK, et al. Can available interventions end preventable deaths in mothers, newborn babies, and stillbirths, and at what cost? *Lancet*. 2014;384(9940):347-70.
2. Boschi-Pinto C, Black RE. Development and use of the lives saved tool: a model to estimate the impact of scaling up proven interventions on maternal, neonatal and child mortality. *Int J Epidemiol*. 2011;40(2):520–1.
3. WHO, UNICEF, UNFPA, World Bank, UNFPA. Trends in maternal mortality: 1990 to 2015. Geneva: World Health Organization; 2015.
4. UN IGME. Estimate of neonatal deaths in 2016. From levels & trends in child mortality. Report 2017. Estimates developed by the UN inter-agency group for child mortality estimation. New York: United Nations Children’s Fund; 2017.
5. Blencowe H, Cousens S, Jassir FB, Say L, Chou D, Mathers C, et al. National, regional, and worldwide estimates of stillbirth rates in 2015, with trends from 2000: a systematic analysis. *Lancet Glob Health*. 2016;4(2):e98–e108.
6. Avenir Health. SPECTRUM wesbite (<https://www.avenirhealth.org/software-spectrum.php>, accessed 27 February 2019).
7. UNAIDS. Reference group on estimates, modelling and projections wesbite (<http://www.epidem.org/>, accessed 27 February 2019).
8. UNICEF, WHO. Every Newborn: an action plan to end preventable deaths. Geneva: World Health Organization; 2014.
9. Food Fortification Initiative. Global progress of industrially milled cereal grains web page (http://www.ffinetwork.org/global_progress/, accessed 27 February 2019).
10. Blencowe H, Kancharla V, Moorthie S, Darlison MW, Modell B. Estimates of global and regional prevalence of neural tube defects for 2015: a systematic analysis. *Ann NY Acad Sci*. 2018;1414(1):31–46.
11. Healthy Newborn Network. Global chlorhexidine scale-up tracker: engagement web page (<https://www.healthynewbornnetwork.org/chlorhexidine-dashboard/>, accessed 27 February 2019).

ANNEX 2: Screening and monitoring

Beyond the acute care phase, evaluation of small and sick newborns in LMICs primarily relies on clinical examinations and identification of potential risks to positive outcomes. While several tools exist for neonatal behavioural assessment, more evidence is needed before routine use with preterm newborns can be recommended (1).

Screening in newborns

Both bilirubin and general newborn screening programmes hold great promise. Kernicterus is associated with significant mortality and morbidity in LMICs (2–4). A growing number of devices for transcutaneous bilirubinometry are being evaluated to better identify hyperbilirubinemia early (5–7). However, a significant limitation of these devices is that they cannot be utilized accurately during phototherapy. Therefore, laboratory evaluation or clinical judgement are also necessary (8, 9).

Appropriate screening and management of G6PD and rhesus disease have been highlighted as important to reduce kernicterus (3). The use of broader laboratory-based screening for metabolic and biochemical disorders is also increasing in LMICs (10), with strong programmes emerging in sub-Saharan Africa related to

congenital hypothyroidism and sickle cell disease. This is noteworthy given there are feasible and beneficial interventions available (10–12).

Screening newborns for vision and hearing prior to discharge is standard in HICs; current efforts are to standardize these practices in LMICs as well. Retinopathy of prematurity screening is more common in MICs, and provider training is also expanding in LICs. This is essential due to the elevated risks of oxygen-related vision impairments. It is suggested that retinopathy of prematurity screening guidelines from HICs be adapted for lower-resourced, higher-risk settings. Additional research on such programmes will also be important (13). Cranial ultrasound to screen for intraventricular haemorrhage in those born too soon or at risk due to asphyxia is also increasingly available and reliable in LMICs (14–17). Recent efforts document its affordability and accuracy (14), and outcomes (17).

Infancy and beyond

While early childhood development milestones are remarkably consistent across cultures and settings, differences related to experience and language can influence the exact age at which milestones are attained (18). Given such differences, providers must take steps to assure high-quality translation, adaptation and validation of screening or monitoring tools. This also matters when conducting cross-group comparisons. In addition, providers must be aware that children identified through screening, and their families, may be stigmatized, particularly in areas where services are not readily available or screening is new (18, 19). Therefore, providers should be sensitive to how they communicate findings and address the needs of the child and its parents and caregivers.

In LMICs, caregivers and community-based providers at all levels will have the most contact with small and sick newborns. Culturally appropriate education on early childhood development milestones, monitoring and surveillance methods must be available



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locally. It may be included as part of early stimulation and supportive caregiving programmes.

Formal monitoring, screening and assessment tools are also increasingly available to evaluate former small and sick newborns. Some were developed in LMICs, others were adapted for these settings. Each tool differs somewhat in its approach (e.g. caregiver interview versus direct assessment) and user requirements (e.g. community health-care provider versus physician/psychologist).

Caregiver report tools

Two caregiver report tools developed in LMICs include the Developmental Milestone Checklist and the International Guide for Monitoring Child Development. The Developmental Milestones Checklist (20) is a 66-item, interview-based, caregiver report tool developed in Kenya to assess the motor, language and personal-social domains of development from early infancy through 2 years of age. It has been expanded and validated in Burkina Faso as part of a nutrition intervention project (21). The International Guide For Monitoring Child Development (22) takes a monitoring, rather than a screening, approach (19) and includes open-ended questions in the domains of language, motor, socioemotional (e.g. interpersonal relating and play) and self-help skills. It is designed for use by trained health-care providers and includes components to support child development and follow-up plans (22).

Direct assessment tools

Three additional tools developed in LMICs involve direct assessment with the child. The Kilifi Developmental Inventory evaluates hand-eye coordination and locomotor skills in children aged 6 to 35 months (23). The Rapid Neurodevelopment Assessment (RNDA) (24) was developed in Bangladesh to assess children from birth to 2 years of age, with expanded validation for older children (25). It is intended for use by trained health professionals and assesses primitive reflexes, motor, cognitive, language and behavioural domains of development, vision, hearing and seizure. In a validation study in Guatemala, the RNDA was successfully administered by community-health workers (26). Finally, the Malawi Developmental Assessment Tool (MDAT) (27) evaluates gross and fine motor, language and social domains in children from birth to 6 years of age, with cognitive items distributed in the language and social sectors. The MDAT is designed to be readily adaptable to the local setting (27).

Early screening and monitoring would include specific evaluation for possible motor disability or cerebral palsy, particularly for small and sick newborns. A recent systematic review found two behavioural tools for infants less than 5 months of age that had strong predictive validity for later diagnosis of cerebral palsy: the Precht Qualitative Assessment of General Movements (GMA; sensitivity 98%) and the Hammersmith Infant Neurological Examination (HINE; sensitivity 90%) (28). For children older than 5 months, the HINE maintained 90% sensitivity. Both tools require training and experience to administer, with the GMA having a more expensive mandatory training and evaluation component for use.

Some examples of screening tools developed in HICs that have been translated or adapted and validated for use in LMICs include the Ages & Stages Questionnaire, 3rd edition (ASQ-3), for children aged 4 to 60 months (29); the Parents' Evaluation of Developmental Status (PEDS) for birth to 8 years (30); and the Denver Developmental Screening Test (Denver-II) for birth to 6 years (31). Since July 2015, the Denver-II has no longer been sold or updated. As screening tools, these cover multiple domains but are not fully comprehensive diagnostic tests. While they do not require a high degree of education or training to administer, all require appropriate translation, adaptation and validation (18). Both the ASQ-3 and PEDS have initial purchase costs. The PEDS has additional per-use charges. The PEDS tool uses caregiver-report only, whereas the ASQ-3 can include direct assessment.

Approaches for programme evaluation

When selecting a tool for programme evaluation, the following should be considered: project purpose; population under study; available staff skills and education; and the tool's psychometric properties (18, 32). Any of the above-mentioned tools could be appropriate for programme evaluation, particularly those involving direct assessment of the child's general or motor development. Additional tools, developed and validated primarily in HICs, have been adapted and used extensively for research in LMICs. All have educational and training requirements.

The Bayley Scales of Infant and Toddler Development (BSID) evaluates fine and gross motor, cognitive and language domains of development in children aged 1 to 42 months (33). The BSID has been extensively used in LMICs. The BSID 3rd edition (BSID-III) was released in 2005; changes in scoring warrant close attention to longitudinal projects or cross-study comparison.

The Griffiths Scales of Child Development, 3rd Edition (Griffiths III) (34) was released in July 2016 and covers an expanded age range from 1 to 72 months. Developmental areas assessed include foundations of learning; language; eye and hand coordination (fine motor); gross motor; and personal-social-emotional. Clinicians and researchers need to be registered users, having completed a Griffiths III course, prior to purchasing this tool. The Mullen Scales of Early Learning (Mullen) evaluates cognitive, language, motor and visual-spatial development for children aged 0 to 68 months (35) and is currently used in multiple LMICs. The Mullen may underestimate the developmental status of some older children who answer all available items correctly, raising concerns that it may not represent the full range of ability in this age group (36).



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Approaches at the population level

Population-level assessments have been created and studied to evaluate early childhood development in a community, region or country. With the introduction of SDG 4.2 in 2015, it has become increasingly important to monitor whether children are developmentally on track and prepared to enter into, and benefit from, pre-primary education (37). The inclusion of the 10-item early childhood development index in the UNICEF multiple indicator cluster survey enabled preliminary multicountry analysis (38). Population-level tools that are more comprehensive are currently available for preschool-age children, with a focus on school readiness assessment (18).

More recently, population-level developmental assessments for infants and children under 3 years of age have been initiated (39–41). Ongoing collaborative efforts hold promise for the development of a psychometrically sound, cross-culturally relevant, and freely available tool that can improve global monitoring of outcomes for small and sick newborns (38).

Gaps in screening and monitoring

As greater numbers of small and sick newborns survive and transition home, there is little formal guidance to support parents in appropriate monitoring for common health and developmental issues. As early stimulation and supportive caregiving programmes expand in LMICs, it will be important to include this type of useful information.

Many individual-level tools, and most at programme level, are costly to purchase and require complex adaptation, administration and training. An important advance would be to develop psychometrically sound, cross-culturally relevant tools and make them readily available without charge.

As the ability grows to assess early childhood development progress accurately and affordably in LMICs, quality early intervention programmes must be developed and supported. This will require local capacity building and sustainability planning, with valuable input from caregivers and community providers (42).

REFERENCES

- Craciunoiu O, Holsti L. A systematic review of the predictive validity of neurobehavioral assessments during the preterm period. *Phys Occup Ther Pediatr*. 2017;37(3):292-307.
- Olusanya BO, Ogunlesi TA, Slusher TM. Why is kernicterus still a major cause of death and disability in low-income and middle-income countries? *Arch Dis Child*. 2014;99(12):1117-21.
- Slusher TM, Zipursky A, Bhutani VK. A global need for affordable neonatal jaundice technologies. *Semin Perinatol*. 2011;35(3):185-91.
- Slusher TM, Day LT, Ogundele T, Woolfield N, Owa JA. Filtered sunlight, solar powered phototherapy and other strategies for managing neonatal jaundice in low-resource settings. *Early Hum Dev*. 2017;114:11-15.
- Chimhini GLT, Chimhuya S, Chikwasha V. Evaluation of transcutaneous bilirubinometer (DRAEGER JM 103) use in Zimbabwean newborn babies. *Matern Health Neonatol Perinatol*. 2018;4:1.
- Olusanya BO, Mabogunje CA, Imosemi DO, Emokpae AA. Transcutaneous bilirubin nomograms in African neonates. *PLoS One*. 2017;12(2):e0172058.
- Yu Z-B, Han S-P, Chen C. Bilirubin nomograms for identification of neonatal hyperbilirubinemia in healthy term and late-preterm infants: a systematic review and meta-analysis. *World J Pediatr*. 2014;10(3):211-18.
- Murli L, Thukral A, Sankar MJ, Vishnubhatla S, Deorari AK, Paul VK, et al. Reliability of transcutaneous bilirubinometry from shielded skin in neonates receiving phototherapy: a prospective cohort study. *J Perinatol*. 2017;37(2):182-7.
- Nagar G, Vandermeer B, Campbell S, Kumar M. Effect of phototherapy on the reliability of transcutaneous bilirubin devices in term and near-term infants: a systematic review and meta-analysis. *Neonatology*. 2016;109(3):203-12.
- Terrell BL, Padilla CD, Loeber JG, Kneisser I, Saadallah A, Borrajo GJ, et al. Current status of newborn screening worldwide: 2015. *Semin Perinatol*. 2015(39):171-87.
- Adeniran KA, Limbe M. Review article on congenital hypothyroidism and newborn screening program in Africa; the present situation and the way forward. *Thyroid Disorders & Therapy*. 2012;1(1):1-4.
- Kuznik A, Habib AG, Munube D, Lamorde M. Newborn screening and prophylactic interventions for sickle cell disease in 47 countries in sub-Saharan Africa: a cost-effectiveness analysis. *BMC health Serv Res*. 2016;16(1):304.
- Visser KE, Freeman N, Cook C, Myer L. Retinopathy of prematurity screening criteria and workload implications at Tygerberg Children's Hospital, South Africa: a cross-sectional study. *S Afr Med J*. 2016;106(6).
- Clay DE, Linke AC, Cameron DJ, Stojanoski B, Rulisa S, Wasunna A, et al. Evaluating affordable cranial ultrasonography in East African neonatal intensive care units. *Ultrasound Med Biol*. 2017;43(1):119-28.
- Ghoor A, Scher G, Ballot DE. Prevalence of and risk factors for cranial ultrasound abnormalities in very-low-birth-weight infants at Charlotte Maxeke Johannesburg Academic Hospital. *SAJCH*. 2017;11(2):66-70.
- Mulindwa MJ, Sinyangwe S, Chomba E. The prevalence of intraventricular haemorrhage and associated risk factors in preterm neonates in the neonatal intensive care unit at the University Teaching Hospital, Lusaka, Zambia. *Med J Zambia*. 2012;39(1):16-21.
- Tann CJ, Nakakeeto M, Hagmann C, Webb EL, Nyombi N, Namiro F, et al. Early cranial ultrasound findings among infants with neonatal encephalopathy in Uganda: an observational study. *Pediatr Res*. 2016;80(2):190-6.
- Fernald LCH, Prado E, Kariger P, Raikes A. A toolkit for measuring early childhood development in low- and middle-income countries. Washington DC: World Bank; 2017.
- Ertem IO. The international guide to monitoring child development: enabling individualized interventions. *Early Childhood Matters*. 2017:83-87.
- Abubakar A, Holding P, Van de Vijver F, Bomu G, Van Baar A. Developmental monitoring using caregiver reports in a resource-limited setting: the case of Kilifi, Kenya. *Acta Paediatrica*. 2010;99(2):291-7.
- Prado EL, Abubakar AA, Abbeddou S, Jimenez EY, Somé JW, Ouédraogo JB. Extending the developmental milestones checklist for use in a different context in sub-Saharan Africa. *Acta Paediatrica*. 2014;103(4):447-54.
- Ertem IO, Dogan DG, Gok CG, Kizilates SU, Caliskan A, Atay G, et al. A guide for monitoring child development in low- and middle-income countries. *Pediatrics*. 2008;121(3):e589.
- Abubakar A, Holding P, van Baar A, Newton CRJC, van de Vijver FJR. Monitoring psychomotor development in a resource-limited setting: an evaluation of the Kilifi developmental inventory. *Ann Trop Paediatr*. 2008;28(3):217-226.

24. Khan NZ, Muslima H, Begum D, Shilpi AB, Akhter S, Bilkis K, et al. Validation of rapid neurodevelopmental assessment instrument for under-two-year-old children in Bangladesh. *Pediatrics*. 2010;125(4):e762.
25. Khan NZ, Muslima H, Shilpi AB, Begum D, Parveen M, Akter N, et al. Validation of rapid neurodevelopmental assessment for 2- to 5-year-old children in Bangladesh. *Pediatrics*. 2013;131(2):e494.
26. Thompson L, Peñaloza RA, Stormfields K, Kooistra R, Valencia-Moscoso G, Muslima H, et al. Validation and adaptation of rapid neurodevelopmental assessment instrument for infants in Guatemala. *Child Care Health Dev*. 2015;41(6):1131–1139.
27. Gladstone M, Lancaster GA, Umar E, Nyirenda M, Kayira E, van den Broek NR, et al. The Malawi developmental assessment tool (MDAT): the creation, validation, and reliability of a tool to assess child development in rural African settings. *PLoS Medicine*. 2010;7(5):e1000273.
28. Novak I, Morgan C, Adde L, Blackman J, Boyd RN, Brunstrom-Hernandez J, et al. Early, accurate diagnosis and early intervention in cerebral palsy: advances in diagnosis and treatment. *JAMA Pediatr*. 2017;171(9):897–907.
29. Squires J, Bricker D. *Ages & stages questionnaire, 3rd edition (ASQ-3). A parent-completed child monitoring system*. Baltimore: Paul H. Brookes Publishing Co.; 2009.
30. Glascoe FP. *Collaborating with parents: using parents' evaluation of developmental status (PEDS) to detect and address developmental and behavioral problems*. 2nd Edition. Nolensville: PEDSTest.com; 2013.
31. Frankenburg WK, Dodds J, Archer P, Shapiro H, Bresnick B. The Denver II: a major revision and restandardization of the Denver developmental screening test. *Pediatrics*. 1992;89(1):91.
32. Semrud-Clikeman M, Romero RAA, Prado EL, Shapiro EG, Bangirana P, John CC. Selecting measures for the neurodevelopmental assessment of children in low- and middle-income countries. *Child Neuropsychol*. 2017;23(7):761–802.
33. Bayley N. *Bayley scales of infant and toddler development: 3rd edition*. San Antonio: The Psychological Corporation; 2006.
34. Green E, Stroud L, Bloomfield S, et al. *Griffiths III manual. Part I: overview, development and psychometric properties*. Oxford: Hogrefe Ltd; 2016.
35. Mullen EM. *Mullen scales of early learning*. Circle Pines: American Guidance Service Inc.; 1995.
36. Yitzhak N, Harel A, Yaari M, Friedlander E, Yirmiya N. The Mullen scales of early learning: ceiling effects among preschool children. *Eur J Dev Psychol*. 2016;13(1):138–51.
37. Global Education Monitoring Report website (blog). Target 4.2 – what is at stake for monitoring progress on early childhood education? Published 26 October 2016 (<https://gemreportunesco.wordpress.com/2016/10/26/target-4-1-what-is-at-stake-for-monitoring-progress-on-primary-and-secondary-education/>, accessed 27 February 2019).
38. McCoy DC, Peet ED, Ezzati M, Danaei G, Black MM, Sudfeld CR, et al. Early childhood developmental status in low- and middle-income countries: national, regional, and global prevalence estimates using predictive modeling. *PLoS Med*. 2016;13(6):e1002034.
39. Gladstone M, Janus M, Kariger P, et al. A tool for providing indicators of infant and young child development (IYCD) for children 0-3 in low- and middle-income countries. International Developmental Pediatrics Association Congress. 2017.
40. McCoy DC, Sudfeld CR, Bellinger DC, et al. Development and validation of an early childhood development scale for use in low-resourced settings. *Population Health Metrics*. 2017;15(1):3.
41. Van Buuren S. Growth charts of human development. *Statistical Methods in Medical Research*. 2014;23(4):346–68.
42. Yousafzai AK, Lynch P, Gladstone M. Moving beyond prevalence studies: screening and interventions for children with disabilities in low-income and middle-income countries. *Arch Dis Child*. 2014;99(9):840–8.

ANNEX 3:

List of interventions

INTERVENTION	KEY COMPONENTS	EXAMPLE GUIDELINES
Thermal care, including KMC	<ul style="list-style-type: none"> Newborns, especially preterm and LBW, need help to maintain their normal body temperature. Preventing hypothermia and its complications starts immediately after birth. Skin-to-skin contact is the ideal care for small, stable newborns (a hat is essential to prevent large amounts of heat loss from the head) (1). In many settings, prolonged and continuous or intermittent skin-to-skin contact for LBW newborns is referred to as KMC (Box 3.1). For very small and sick newborns, incubators and/or infant radiant warmers with dry, clean linens may be needed, but skin-to-skin contact should still be supported and encouraged whenever appropriate and accepted. 	<p>WHO early essential newborn care: clinical practice pocket guide</p> <p>WHO. Kangaroo mother care: a practical guide</p> <p>American Academy of Pediatrics: essential care for small babies</p>
Infection prevention and control	<ul style="list-style-type: none"> Small and sick newborns are at heightened risk of infection, including hospital-acquired infections, and susceptible to antimicrobial resistance. As important interventions in preventing infection, WHO and UNICEF strongly promote handwashing before and after touching a newborn; early and exclusive breastfeeding or breastmilk feeding; and skin-to-skin contact (2). Care should be provided in a clean environment with strict protocols for cleaning equipment and surfaces. Adequate space is needed to minimize crowding, with only one newborn per cot or incubator when the newborn is not in KMC or with the mother (3). 	UNICEF. Infection prevention and control at neonatal intensive care units (slide deck)
Treatment of neonatal infection and use of antibiotics	<ul style="list-style-type: none"> Infections in the neonatal period can rapidly evolve into sepsis and require early, accurate detection and judicious treatment with antibiotics by skilled providers in facilities. Narrow-spectrum antibiotics should be promoted and prescribed over broad-spectrum options to limit antibiotic resistance and unnecessary costs, while maintaining high-quality care (see Chapter 2). It is equally important to avoid the overuse or misuse of antibiotics, such as prophylactic use when inappropriate. The prescription of drugs and fluids in neonates requires accurate measurements, such as the newborn's weight, and age calculations to select the correct type and dosing. 	WHO recommendations on newborn health: guidelines approved by the WHO guidelines review committee
Nutrition and assisted feeding	<ul style="list-style-type: none"> Breastmilk is the biological norm and the best nutrition for all newborns, and is the first nutritional choice for inpatient care. Breastmilk helps to boost immunity, promote weight gain, prevent low blood sugar and support brain development. Mothers of small and sick newborns need special support to initiate and maintain lactation when the newborn is not able to feed at the breast (4). In circumstances where mothers are not (yet) able to express breastmilk for the newborn, donated breastmilk is the preferred, likely temporary, alternative (4, 5). Many preterm newborns have delayed or impaired sucking and swallowing ability and require special help. This can include expressing breastmilk, cup or nasogastric tube feeding, and sometimes intravenous fluids. If expressed breastmilk or other feeds are medically indicated for preterm infants, feeding methods such as cups or spoons are preferable to feeding bottles and teats (5). For preterm infants who are unable to breastfeed directly, non-nutritive sucking and oral stimulation may be beneficial until breastfeeding is established (5). Newborns with severe illness may need intravenous fluids to complement nasogastric tube feeding. In certain situations, those who are unable to feed by mouth or tube may require special nutritional formula intravenously, referred to as total parenteral nutrition. Parents can be taught feeding techniques and cue-based feeding. Support that continues after discharge should include regular growth monitoring to determine nutrition status and adequate weight gain (6–9). 	<p>WHO. Protecting, promoting and supporting breastfeeding in facilities providing maternity and newborn services</p> <p>WHO guidelines on optimal feeding of low-birth-weight infants in low- and middle-income countries</p>

ANNEX 3: List of Interventions *(continued)*

INTERVENTION	KEY COMPONENTS	EXAMPLE GUIDELINES
Oxygen use and breathing support	<ul style="list-style-type: none"> • Many small and sick newborns require breathing support, especially preterm newborns with immature lung function (10). Respiratory support involves safe delivery of oxygen, blended with air, usually through a nasal cannula. • Oxygen is a lifesaving essential medicine for inpatient care of small and sick newborns. Unregulated use of oxygen, however, can lead to long-term complications, including retinopathy of prematurity, a leading cause of childhood blindness (11). Modes of oxygen delivery can also cause damage to a newborn's lungs and lead to bronchopulmonary dysplasia. Oxygen use in newborns requires non-invasive systems for monitoring safe threshold of oxygen levels in the blood (pulse oximetry), oxygen-air blenders to adjust oxygen concentration, and humidifiers. Oxygen also requires safe storage and supply systems and adequate numbers of trained staff who understand its function and proper delivery (12, 13). • Where feasible and appropriate, antenatal corticosteroids for the mother in threatened preterm labour can reduce the severity of respiratory distress in the newborn. • Skin-to-skin contact reduces the frequency of apnoeic episodes (when breathing stops) and helps regulate breathing for at-risk preterm newborns. Apnoeic episodes can also be prevented with medicines (such as caffeine) and careful monitoring and resuscitation as needed (14). • For those born extremely preterm or with serious illness, more advanced breathing support may be required. Continuous positive airway pressure is very effective for small and sick newborns and can be delivered safely in low-resource settings using low-cost technology (known as bubble CPAP) (15, 16). In some cases, mechanical ventilation (with intubation) may be required. • Where oxygen is used, timely screening at one month for retinopathy of prematurity and referral for treatment, as needed, should be part of service delivery to prevent long-term vision problems in children. Trained providers (usually ophthalmologists) can visit inpatient care wards and clinics to ensure that follow-up care is included in inpatient care services and after discharge (see Chapters 2 and 4) (17, 18). 	<p>WHO guidelines on oxygen therapy for children</p> <p>WHO pocket book of hospital care for children</p> <p>Médecins sans Frontières neonatal care guidelines</p>
Supportive care for neonatal encephalopathy	<ul style="list-style-type: none"> • Preventing neonatal encephalopathy requires quality obstetric care and effective neonatal resuscitation. • Any newborn in poor condition or requiring resuscitation at birth should be monitored to detect the clinical signs of neonatal encephalopathy. • Signs and symptoms of neonatal encephalopathy tend to evolve over time and can be classified as mild, moderate or severe. Mildly affected newborns present as hyperalert or irritable with poor sucking and feeding. Moderate and severely affected newborns present with lethargy, reduced level of consciousness, poor or absent sucking and abnormal movements. The more severe cases include clinical seizures that can progress to lack of consciousness and apnoea. • Inpatient care for those affected includes prevention of dehydration and hypoglycaemia (fluids and feeding) and seizure management with anticonvulsant therapy (e.g. phenobarbital). 	<p>WHO guidelines on basic newborn resuscitation</p> <p>American Academy of Pediatrics helping babies breathe resources</p> <p>WHO guidelines on managing newborn problems: a guide for doctors, nurses and midwives</p>
Management of neonatal jaundice	<ul style="list-style-type: none"> • Most cases of jaundice can be treated with effective and safe phototherapy, preferably LED phototherapy (19), and regular monitoring of blood bilirubin levels. • Newborns need to be correctly positioned on white sheets during phototherapy to optimize the amount of light reaching their body surface (20). For effective phototherapy, devices must be properly maintained and kept clean with working lamps. • It is important that a newborn continues to feed, preferably with breastmilk, when receiving phototherapy. Occasionally, intravenous fluids can help if the bilirubin levels are very high. • Severe neonatal jaundice may require exchange transfusions (21), but the need for transfusion can be reduced through improved prevention and management by health-care providers (22). • Strategies should also be in place to prevent rhesus disease and screen for G6PD, both of which are important causes of severe jaundice. The current recommendation is for routine G6PD screening in countries with a prevalence > 5% (20). 	<p>WHO guidelines on managing newborn problems: a guide for doctors, nurses and midwives</p>

INTERVENTION	KEY COMPONENTS	EXAMPLE GUIDELINES
Developmentally supportive care and neuroprotection	<ul style="list-style-type: none"> • Caregivers should pay close attention to developmentally supportive care for small and sick newborns. Health-care providers should minimize handling and group interventions when possible (clustering care), as tolerated by the infant, to maximize uninterrupted time for sleep and growth. • Maximizing contact with parents, especially mothers, encourages bonding and supports lactation and feeding with breastmilk (23). • Correct positioning of the newborn protects skin, safeguards sleep and minimizes stress and pain (see Chapter 4 for more details on developmentally supportive care for children) (24–27). • Health-care providers need to be able to recognize pain cues, particularly in small newborns, and know how to prevent and minimize pain (28). Pain can affect brain development, with potential long-term effects. • Evidence supports improved comfort management when newborns are breastfed or placed skin-to-skin with mother or another family member during painful procedures (27, 29). For sicker newborns, analgesics may be necessary, although only with full risk awareness and proper monitoring in place throughout treatment (30). • Appropriate tools are recommended to assess pain and make decisions on pain and comfort management (30). 	Médecins sans Frontières: neonatal care guidelines

REFERENCES

1. Every Preemie. Safe and effective thermal protection for inpatient care of newborns. Washington DC: United States Agency for International Development; 2017.
2. WHO. Recommendations on newborn health: guidelines approved by the WHO guidelines review committee. Geneva: World Health Organization; 2017.
3. Every Preemie. Safe and effective infection prevention for inpatient care of newborns. Washington DC: United States Agency for International Development; 2017.
4. WHO. Protecting, promoting and supporting breastfeeding in facilities providing maternity and newborn services. Geneva: World Health Organization; 2017.
5. WHO. Protecting, promoting and supporting breastfeeding in facilities providing maternity and newborn services; the revised baby-friendly hospital initiative: implementation guidelines. Geneva: World Health Organization; 2018.
6. Rush Mothers' Milk Club website (<http://www.rushmothersmilkclub.com/>, accessed 27 February 2019).
7. Kaarensen PI, Ronning JA, Tunby J, Nordhov SM, Ulvund SE, Dahl LB. A randomized controlled trial of an early intervention program in low birth weight children: outcome at 2 years. *Early Hum Dev.* 2008;84(3):201–9.
8. Brett J, Staniszewska S, Newburn M, Jones N, Taylor L. A systematic mapping review of effective interventions for communicating with, supporting and providing information to parents of preterm infants. *BMJ Open.* 2011;1(1):e000023.
9. Purdy IB, Craig JW, Zeanah P. NICU discharge planning and beyond: recommendations for parent psychosocial support. *J Perinatol.* 2015;35 (Suppl 1):S24–28.
10. Every Preemie – SCALE. Safe and effective oxygen use for inpatient care of newborns – do no harm technical brief. 2017 (https://www.everypreemie.org/wp-content/uploads/2017/07/Oxygen_7.6.17.pdf, accessed 7 March 2019).
11. Blencowe H, Lee AC, Cousens S, Bahalim A, Narwal R, Zhong N, et al. Preterm birth-associated neurodevelopmental impairment estimates at regional and global levels for 2010. *Pediatr Res.* 2013;74 (Suppl 1):17–34.
12. Duke T, Graham SM, Cherian MN, Ginsburg AS, English M, Howie S, et al. Oxygen is an essential medicine: a call for international action. *Int J Tuberc Lung Dis.* 2010;14(11):1362–8.
13. Every Preemie. Safe and effective oxygen use for inpatient care of newborns. Washington DC: United States Agency for International Development; 2017.
14. WHO. Oxygen therapy for children. Geneva: World Health Organization; 2016.
15. Brown J, Machen H, Kawaza K, Mwanza Z, Iniguez S, Lang H, et al. A high-value, low-cost bubble continuous positive airway pressure system for low-resource settings: technical assessment and initial case reports. *PLoS One.* 2013;8(1):e53622.
16. Kawaza K, Machen HE, Brown J, Mwanza Z, Iniguez S, Gest A, et al. Efficacy of a low-cost bubble CPAP system in treatment of respiratory distress in a neonatal ward in Malawi. *PLoS One.* 2014;9(1):e86327.
17. Grover S, Katoch D, Dogra MR, Kumar P. Programs for detecting and treating retinopathy of prematurity: role of the neonatal team. *Indian Pediatr.* 2016;53 (Suppl 2):S93–s99.
18. Every Preemie. Prevention and screening of retinopathy of prematurity. Washington DC: United States Agency for International Development; 2018.
19. Kumar P, Chawla D, Deorari A. Light-emitting diode phototherapy for unconjugated hyperbilirubinaemia in neonates. *Cochrane Database Syst Rev.* 2011(12):Cd007969.
20. Slusher TM, Day LT, Ogundele T, Woolfield N, Owa JA. Filtered sunlight, solar powered phototherapy and other strategies for managing neonatal jaundice in low-resource settings. *Early Hum Dev.* 2017;114:11–15.
21. WHO. Pocket book of hospital care for children: 2nd edition. Guidelines for the management of common childhood illnesses. Geneva: World Health Organization; 2013.
22. Facchini FP, Mezzacappa MA, Rosa IR, Mezzacappa Filho F, Aranha-Netto A, Marba ST. Follow-up of neonatal jaundice in term and late premature newborns. *J Pediatr (Rio J).* 2007;83(4):313–22.
23. Belfort MB, Anderson PJ, Nowak VA, Lee KJ, Molesworth C, Thompson DK, et al. Breast milk feeding, brain development, and neurocognitive outcomes: a 7-year longitudinal study in infants born at less than 30 weeks' gestation. *J Pediatr.* 2016;177:133–9.e131.
24. Picheansathian W, Woragidpoonpol P, Baosoung C. Positioning of preterm infants for optimal physiological development: a systematic review. *JB Libr Syst Rev.* 2009;7(7):224–59.
25. Graven S, Browne J. Sleep and brain development: the critical role of sleep in fetal and early neonatal brain development: a systematic review. *Newborn Infant Nurs Rev.* 2008;8(4):173–9.

26. Shah PS, Herbozo C, Aliwalas LL, Shah VS. Breastfeeding or breast milk for procedural pain in neonates. *Cochrane Database Syst Rev.* 2012(12):CD004950.
27. Johnston C, Campbell-Yeo M, Disher T, Benoit B, Fernandes A, Streiner D, et al. Skin-to-skin care for procedural pain in neonates. *Cochrane Database Syst Rev.* 2017;2:cd008435.
28. Carter BS, Brunkhorst J. Neonatal pain management. *Semin Perinatol.* 2017;41(2):111–16.
29. Pillai Riddell RR, Racine NM, Gennis HG, Turcotte K, Uman LS, Horton RE, et al. Non-pharmacological management of infant and young child procedural pain. *Cochrane Database Syst Rev.* 2015(12):CD006275.
30. American Academy of Pediatrics (committee on fetus and newborn and section on anesthesiology and pain medicine). Prevention and management of procedural pain in the neonate: an update. *Pediatrics.* 2016;137(2):e20154271.

ANNEX 4:

List of Countdown to 2030 countries included in this analysis

NUMBER	COUNTRY	ISO 3166-1 ALPHA-3 COUNTRY CODE
1	Afghanistan	AFG
2	Algeria	DZA
3	Angola	AGO
4	Azerbaijan	AZE
5	Bangladesh	BGD
6	Benin	BEN
7	Bhutan	BTN
8	Bolivia	BOL
9	Botswana	BWA
10	Burkina Faso	BFA
11	Burundi	BDI
12	Cambodia	KHM
13	Cameroon	CMR
14	Central African Republic	CAF
15	Chad	TCD
16	Comoros	COM
17	Congo	COG
18	Côte d'Ivoire	CIV
19	Democratic People's Republic of Korea	PRK
20	Democratic Republic of the Congo	COD
21	Djibouti	DJI
22	Dominican Republic	DOM
23	Equatorial Guinea	GNQ
24	Eritrea	ERI
25	Ethiopia	ETH
26	Gabon	GAB
27	Gambia	GMB
28	Ghana	GHA

NUMBER	COUNTRY	ISO 3166-1 ALPHA-3 COUNTRY CODE
29	Guatemala	GTM
30	Guinea	GIN
31	Guinea-Bissau	GNB
32	Guyana	GUY
33	Haiti	HTI
34	Honduras	HND
35	India	IND
36	Indonesia	IDN
37	Iraq	IRQ
38	Jamaica	JAM
39	Kenya	KEN
40	Kyrgyzstan	KGZ
41	Lao People's Democratic Republic	LAO
42	Lesotho	LSO
43	Liberia	LBR
44	Madagascar	MDG
45	Malawi	MWI
46	Mali	MLI
47	Mauritania	MRT
48	Morocco	MAR
49	Mozambique	MOZ
50	Myanmar	MMR
51	Namibia	NAM
52	Nepal	NPL
53	Nicaragua	NIC
54	Niger	NER
55	Nigeria	NGA
56	Pakistan	PAK

ANNEX 4: List of Countdown to 2030 countries included in this analysis *(continued)*

NUMBER	COUNTRY	ISO 3166-1 ALPHA-3 COUNTRY CODE
57	Panama	PAN
58	Papua New Guinea	PNG
59	Paraguay	PRY
60	Philippines	PHL
61	Rwanda	RWA
62	Senegal	SEN
63	Sierra Leone	SLE
64	Solomon Islands	SLB
65	Somalia	SOM
66	South Africa	ZAF
67	South Sudan	SSD
68	Sudan	SDN
69	Suriname	SUR
70	Swaziland (renamed the Kingdom of Eswatini in 2018)	SWZ
71	Tajikistan	TJK
72	Timor-Leste	TLS
73	Togo	TGO
74	Turkmenistan	TKM
75	Uganda	UGA
76	United Republic of Tanzania	TZA
77	Uzbekistan	UZB
78	Venezuela (Bolivarian Republic of)	VEN
79	Yemen	YEM
80	Zambia	ZMB
81	Zimbabwe	ZWE

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