

Transforming care for every small and sick newborn

KEY FINDINGS





SURVIVE and **THRIVE**

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KEY FINDINGS





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CONTENTS

FOREWORD	4
ACKNOWLEDGEMENTS	6
ACRONYMS AND GLOSSARY	8
KEY MESSAGES	g
KEY FINDINGS	10
Ending preventable newborn deaths	10
Transforming care for small and sick newborns	11
Putting people at the centre	13
Surviving and thriving	14
Using data to guide better investment	14
Making it fair	15
A time for action	16
The path to 2030	16
REFERENCES	17



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 United Nations 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 the sick.

The launch of *Every Newborn:* an action plan to end preventable deaths at the Sixty-seventh World Health Assembly in 2014 (1, 2) coincided with a period of great progress. The global neonatal mortality rate declined from 31 to 18 deaths per 1000 live births between 2000 and 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 in all countries. 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 will avert two out of every three neonatal deaths by 2030 only if we invest an additional US\$ 0.20 per

capita in low- and middle-income countries. This level of investment would save 1.7 million newborns. 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.

With such results in mind, *Survive and thrive: transforming care for every small and sick newborn (3)* 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, and 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 nurturing to promote the optimal physical and mental development of the child. 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.

Dr Tedros Adhanom Ghebreyesus

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ACRONYMS AND GLOSSARY

Acronyms

CRC United Nations Convention on the Rights of the Child

NEC necrotizing enterocolitis

NMR neonatal mortality rate

SDG United Nations Sustainable Development Goal(s)

UHC universal health coverage

UNICEF United Nations Children's Fund

WHO World Health Organization

Glossary of key terms used in this report

newborn an infant in the first 28 days after birth

parent individual parents, legal guardians or primary caregivers

preterm childbirth occurring at less than 37 completed weeks (or 259 days) of gestation

sick newborn a newborn who requires medical care

small newborn a newborn who is preterm and/or low birth weight, or small for gestational age

universal health a system that ensures everyone can access the quality health services they need

coverage without suffering undue financial hardship

KEY MESSAGES

Transforming care for the 30 million vulnerable newborns who are currently being left behind is a smart investment in the health and development of future generations. It will also significantly move us along the path to achieving the United Nations Sustainable Development Goals (SDGs), through universal health coverage (UHC), by 2030. The efforts required can be distilled into a few key messages.

- **Surviving.** More than 2.5 million babies 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. In order to meet the SDG 3.2 target for newborn and child survival, countries need to transform newborn care.
- **Thriving.** Every year, 30 million newborns require specialized or intensive care in a hospital; those who survive often do so with preventable conditions and disabilities that will affect them for life. These newborns *can and will* 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.
- **Transforming.** Cost–effective solutions exist for the main causes of neonatal death and disability. In line with the drive to achieve UHC, there must be innovation, people-centred care, locally designed technologies, financial protection, and parent power and partnership. Ensuring the recruitment, training and retention of skilled nurses is particularly crucial. Social norms also need to be transformed: neonatal mortality should not be considered inevitable.
- **Investing fairly.** 1.7 million newborn lives could be saved each year by investing in access to quality care for every newborn, everywhere, including in humanitarian settings. While essential newborn care would benefit small and sick newborns, adding special and intensive care services for them would reduce neonatal mortality by almost 50%. It would also promote child development and foster economic productivity.
- **Counting.** Accelerating change requires improving routine collection of data, with a stronger focus on coverage, quality and outcomes. Existing data need to be better used for accountability and action.

This report contributes to achieving the objectives set out in the *Global Strategy for Women's, Children's and Adolescents' Health (2016–2030)* and builds on the momentum of *Every Newborn: an action plan to end preventable deaths (2, 4).*



KEY FINDINGS

Ending preventable newborn deaths

Unlocking human potential and achieving the SDGs

The SDG target to end preventable neonatal deaths obliges all countries to reduce the neonatal mortality rate to 12 deaths or less per 1000 live births by 2030. It is an essential part of SDG 3 (to ensure healthy lives and promote well-being for all at all ages). Unfortunately, some countries are currently making little progress to meet this target, putting achievement of the global SDG 3 target in jeopardy.

Every year, 30 million newborns are at risk

Newborns who are born too soon or too small, or who become sick, are at the greatest risk of death and disability. In 2017, an estimated 2.5 million newborns died during the first 28 days of life (5). Approximately 80% of these had low birth weight, and two thirds were born prematurely. In addition, each year, an estimated 1 million small and sick newborns survive with a long-term disability, including cerebral palsy and cognitive delays (6).

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 or pathological jaundice, and those with congenital conditions. Substantial human potential for lifelong health and well-being is lost through

neonatal mortality, disability and long-term disease. What is more, 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.

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 (7). Unfortunately, these rights are not respected or protected in far too many places. This is particularly true for the most at-risk newborns and for those who are members of marginalized groups or living in crisis or conflict settings. The challenges facing small and sick newborns and their families include scarce services, barriers to care-seeking (such as a lack of awareness, transportation or finances) and discrimination. To protect newborns, countries need to translate the CRC guidelines into domestic laws and regulations, and then enforce them. However, many countries have not yet done this.

Universal health coverage is a global imperative to achieve the SDGs. It means that everyone should have access to the health services they need without facing financial hardship. This is particularly urgent for the families of small and sick newborns, who can face devastating hospital costs due to lengthy inpatient stays.

Overcoming inequities

Neonatal mortality rates (NMRs) vary significantly between countries, from 1 to 44 deaths per 1000 live births (5). Almost all neonatal deaths (98%) occur in lowand middle-income countries, with 78% in Southern Asia and sub-Saharan Africa. Eight of the 10 countries with the highest NMRs are in Africa, and the majority have experienced a recent humanitarian crisis such as a war or natural disaster (Box 1).

A newborn's chances of surviving and thriving largely depend on where she or he is born. In high-income countries, neonatal mortality is relatively rare: more than 95% of preterm newborns survive and thrive. In middle-income countries, the risk of disability for babies born between 28 and 32 weeks of gestation is nearly double the risk in high-income countries (6). In low-income countries, disability is uncommon: the smallest and sickest newborns, including those born at less than 28 weeks gestation, usually die due to a lack of even the most basic care, or affordable advanced care.

BOX 1. Conflict and disaster: a special note on humanitarian settings

Political unrest, conflict or natural disasters place health systems under great stress. Of the 15 countries with the highest NMRs in the world, 10 have recently experienced a humanitarian crisis.

In such settings, pregnant women and new mothers 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. Organizations working in complex humanitarian settings should include care for small and sick newborns in every programme and package designed to reach the most vulnerable. The Newborn health in humanitarian settings: field guide (8), developed by an interagency collaboration, summarizes WHO standards of care for newborn health, with guidance on how to provide this care in humanitarian settings.

Poor and marginalized families are the most at risk, even in high-income countries. Survey data from 63 countries with the highest burden of neonatal deaths tell a disturbing story of inequity: if all households had the same risk of neonatal death as the richest 20% of the population, the national neonatal mortality rate would be reduced by a median of 16% (3). Closing this equity gap could save 500 000 newborns every year. To achieve the SDG 3 target, countries must roll back such inequities, and protect and promote the right to health set out in the CRC.

Transforming care for small and sick newborns

Most newborns can survive and thrive provided they have access to good-quality health care, including admission to a hospital or other health facility. Good-quality care is defined as evidence-based, safe, well-organized, accessible, adequately resourced, efficient, provided in a timely manner, and people-centred.

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

The right care, at the right time, in the right place

Newborns have different needs depending on their fragility. All newborns require *essential care* at birth and over the first days of life, whether in a health facility or at home. The majority of small and sick newborns can be managed with *special inpatient care* provided in a health facility. Only one in three small or sick newborns requires *intensive inpatient care*, which can only be provided in a higher-level (e.g. tertiary) facility. Table 1 lists inpatient interventions proven to be effective in preventing neonatal mortality and disability, according to the level of care.

Both special and intensive newborn care require skilled staff, dedicated equipment, and robust infrastructure. The likelihood that a small or sick newborn will survive and go on to thrive in later life depends on the family's ability to access the right level of care quickly during the newborn period and later on as the child develops. To ensure this access, countries need a resilient, well-connected, coordinated health system with a strong referral network.

TABLE 1. Inpatient care for small and sick newborns: requirements for care at different health system levels (3)

Level	Type of care provided	Standards of care and evidence-based interventions
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.
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. Transition to intensive care: continuous positive airway pressure; exchange transfusion; detection and management of necrotizing enterocolitis; specialized follow-up of infants at high risk (including preterm).
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.

Universal coverage for every newborn

The world now has solid evidence on the burden and causes of neonatal mortality. We also have intervention packages and service-delivery channels that work well, and proven ways to scale up these interventions. High-impact, cost-effective interventions for newborn health form an essential component of integrated health services for reproductive, maternal, newborn, child and adolescent health. Family planning, prevention of mother-to-child transmission of HIV and other sexually

transmitted infections, maternal nutrition, skilled care during birth, and emergency obstetric care also contribute to newborn survival and health. What is lacking is access and quality.

We can save 1.7 million newborns each year

Universal access to quality care could prevent 1.7 million neonatal deaths, or 68% of the deaths that will otherwise occur in 2030. As illustrated in Fig. 1, wide coverage of special and intensive care for small and sick

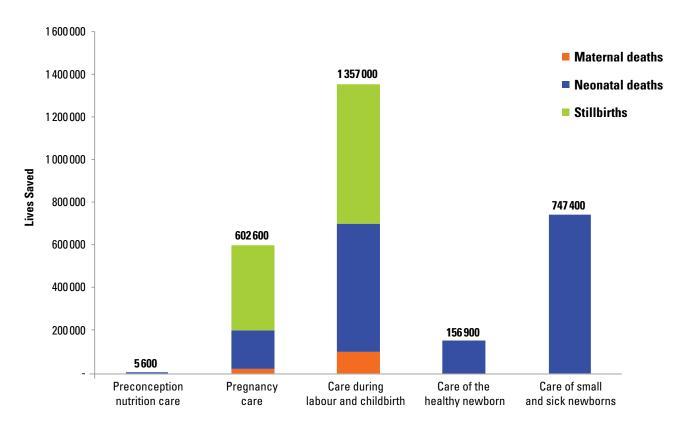
> newborns would contribute nearly half of the total number of newborn lives saved (3). Interventions for both mother and newborn - provided at the same time, in the same place, by the same healthcare provider - will have the highest overall impact, saving 2.9 million women, stillbirths and newborns in 2030 in 81 high-burden countries.

Return on investment from inpatient newborn care

Universal access to quality care promises multiple returns on investment, including improved child survival, growth and development, as well as reduced incidence of disability and noncommunicable disease. A healthy



FIGURE 1. Lives saved 2016–2030 by scaling up to universal coverage of care (LiST analysis)^a (3)



^a Estimated effect of scale-up of interventions on neonatal, stillbirth and maternal deaths in 2030 from the baseline year of 2016.

start is particularly important for low- and middle-income countries wanting to capitalize on the demographic dividends of young people for the next generation and national prosperity.

Increased access to quality inpatient care for small and sick newborns does not need to be prohibitively expensive or out of reach for health systems in low- and middle-income countries. The annual incremental cost of scaling up inpatient care for small and sick newborns between 2016 and 2025 is estimated at US\$ 960 million (US\$ 0.20 per person and US\$ 1700 per death averted) (9). Special newborn care is high-impact in terms of outcomes and is highly cost-effective.

Putting people at the centre

Integrated people-centred care puts people and communities, not diseases, at the centre of health systems, and empowers people to take charge of their own health rather than being passive recipients of services (10). Care for small and sick newborns requires

a family-centred approach. The principles of family-centred care include dignity and respect, information sharing, participation, and collaboration.

Since newborns cannot articulate their needs or preferences, the people at the centre of their care include the newborn and the mother, father, other caregivers, or a combination (3). 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 everyone involved, mothers and newborns should not be separated and all interactions (between mother and newborn, and with medical staff) should be structured to promote healthy development. For example, maximizing contact with parents, particularly the mother, encourages bonding, supports lactation and feeding with breastmilk and promotes cognitive development.

Health workers with the right skills

Inpatient care for newborns must be available 24 hours a day, seven days a week. This care should be delivered

by a multidisciplinary team of health-care providers with specialized skills in newborn care. In most countries, nurses and midwives are responsible for providing the majority of care for small and sick newborns, regardless of the level of care required. Therefore, building the neonatal care competencies of existing providers, and creating or expanding a pool of neonatal nurses, will be a crucial step. Some countries have substantial shortages of nurses and midwives, particularly in rural and hard-to-reach areas. Recruiting, training, mentoring and retaining these health-care providers should be a top priority for governments.

The principles of family-centred care (a component of people-centred care) should be included in this health-care training. Health workers can partner with family members from the moment of admission to the health-care facility, and help build their confidence and skills to continue care after discharge.

The power of parents

A family-centred approach empowers parents by involving them in caregiving for their newborn. This results in a mutually beneficial partnership through which parents, families and health-care providers all support health-care planning, delivery, and evaluation.



"Let the public know that babies can survive so that the next generation will have a better story to tell regarding prematurity."

Selina Bentoom, Executive Director and Founder of African Foundation for Premature Babies & Neonatal Care (pictured with her son King Luther)

Strengthening parents' 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 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 to influence policies and programmes related to newborn health.

Surviving and thriving

The Nurturing Care Framework for Early Childhood Development was launched in 2018 by WHO, UNICEF and the World Bank Group. It demonstrates that focusing on early childhood development is one of the wisest investments a country can make to boost economic growth (11).

Optimal early childhood development requires attention during the period from pregnancy up 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 achieve optimal development. When a newborn is separated from the mother, father or caregiver, there can be further adverse effects on brain development (3).

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. These newborns require vigilant follow-up to thrive. It is vital to monitor their health and development to identify disabilities 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 effectively addressed and mitigated.

Using data to guide better investment

Existing data for small and sick newborns can be used to drive action, while efforts are made to improve data quality, availability and use (3). Numerous opportunities exist to improve metrics and highlight the unmet needs of these newborns. New data have recently become available thanks 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.

Strong data and information systems are vital to improving survival rates and supporting healthy childhood development. The high-priority data gaps to close are routine measurement of coverage and quality of care, and how to follow up and measure long-term outcomes for at-risk newborns. For continuous quality improvement, countries not only need to collect data

A PARENT'S STORY

A preterm boy survives and thrives in South Africa

Six months into her pregnancy, Tasmin Bota started bleeding, and went to the closest hospital. A day later, she was woken up by a gush of blood. The doctors said they needed to take the baby out right away, and did an emergency caesarean section, Tasmin 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 1.08 kg. "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 until he was able to breathe independently.

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

Tasmin spent time in the kangaroo mother care ward, which she found tremendously helpful because she cared for her son for 24 hours, day and night. The help provided in the ward made 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 Preemie Connect, which is a growing resource for other South African families learning to care for their preterm babies.

about small and sick newborns but also to monitor the data systematically, evaluate it rigorously, and – while guaranteeing confidentiality and data security – share it with relevant partners. Only then can decision-makers guide investments and drive action for better newborn survival and development outcomes.

Innovation and research

Investing in research and development is critical to support the design, testing and scale-up of new and innovative care approaches. Examples of low-cost products and technologies that could positively impact survival rates in low- and middle-income countries include Bubble Continuous Positive Airway Pressure and point-of-service diagnostic tools (3). Less dramatic but equally important are process improvements within facilities, such as task-shifting roles or applying ergonomic principles to set up new units or teams. Some innovative partnerships have advanced the rapid roll-out of health interventions, such as the Helping Babies Breathe global public-private partnership.

Robust research is needed to address knowledge gaps specific to certain settings and topics. For example, the vast majority of research on care for small and sick newborns comes from high- and upper-middle-income settings, which requires testing and adapting

to low-resource contexts. Local research is essential to guide policy on how services can be most effectively organized and delivered in each setting. For inpatient newborn care, countries should implement what is known to be effective, and should design, test and scale up alternative approaches to care (3). Models of care that promote UHC and parent and family engagement during inpatient newborn care, such as kangaroo mother care, should also be evaluated to determine effectiveness and scalability. There are currently few highly effective ways to avoid preterm births, yet promising research is under way.

Making it fair

To achieve the vision set out in the Every Newborn Action Plan (2), there needs to be greater focus on transforming care for small and sick newborns. The five strategic objectives of the Plan have been adapted for this especially vulnerable group (3).

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

In addition to improving care during labour, birth and the first day and week of life, there must be a focus on expanding access to care for small and sick newborns. The SDG 3 target to end preventable neonatal mortality can only be achieved if resources and attention are directed to improve access to special and intensive neonatal care.

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

High-quality care, including high-impact, cost-effective interventions, is crucial to ensure newborn survival, but also to minimize disabilities and ensure that newborns develop healthily in later life.

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 for small and sick newborns, including those in humanitarian settings, must be a priority. Robust evidence is available on how to promote equitable care and end preventable neonatal deaths. In line with the principles of UHC, applying this evidence and using innovative approaches to reach vulnerable groups will accelerate progress towards equitable coverage of life-saving care.

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

Improving the care of small and sick newborns requires parents and families to be actively engaged during hospitalization, at home after discharge, and in the community. It is crucial to educate and empower parents, families and communities to demand quality care, participate meaningfully in that care, and improve follow-up care practices.

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. Using standardized indicators to monitor expenditures and outcomes is key to accountability. Similarly, accurate, reliable data help enormously in planning, and makes it possible to measure quality, outcomes and the impact of interventions.

A time for action

Goals from the Every Newborn Action Plan

• End preventable neonatal death. By 2030, all countries will reach the target of 12 or fewer neonatal deaths per 1000 live births and continue to reduce death and disability, ensuring that no newborn is left behind (SDG 3.2 and Every Newborn Action Plan).



• Care for small and sick newborns. By 2025:

- at least 75% of newborns will be resuscitated if they need it;
- at least 75% of newborns who qualify will receive kangaroo mother care and other supportive care;
- at least 75% of newborns with possible severe bacterial infection will receive antibiotic therapy; and
- all countries will have set specific targets for comprehensive neonatal intensive care (2).

More commitment needed

To date, the Every Woman Every Child initiative has received 76 financial commitments (25% of total) referencing the neonatal mortality goal (3). A far larger set of commitments will be needed to accelerate progress and meet its goals.

The path to 2030

Survive and thrive: transforming care for every small and sick newborn maps out a pathway towards 2030 (3). It is built upon epidemiology, historical trends, lessons learnt and evidence-based interventions.

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 newborn 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.

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