

Born too soon

Decade of action
on preterm birth



Women's
Children's and
Adolescents'
Health



World Health
Organization





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ISBN 978-92-4-007389-0 (electronic version)
ISBN 978-92-4-007390-6 (print version)

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Cataloguing-in-Publication (CIP) data. CIP data are available at <http://apps.who.int/iris>.

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Design and layout: Future by Design

Cover photograph: Colin Crowley/Save the Children

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Mother and her preterm baby, Brazil.
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Foreword



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Where you are born, or how much money your family has, should not determine whether you live or die. However, despite progress in the last decade, this is still the reality for many mothers and babies, especially babies who are born too soon.

The 2012 *Born Too Soon* report ignited a movement to improve care for preterm babies. The partnership included stakeholder groups ranging from the grassroots to high-level political champions. The result was accelerated action for maternal and newborn health, including targets in the Sustainable Development Goals (SDGs) on maternal and newborn survival and linked action plans (the Every Newborn Action Plan and the Ending Preventable Maternal Mortality Strategy). The movements for maternal and newborn health have come together under our respective entities, recognizing the need for stronger advocacy and better integrated services for women and newborns.

A decade on, an even larger coalition of partners is uniting through this new version of *Born Too Soon* to call for a healthier and more equitable future for millions of babies, women and families. Much has changed in the past ten years, with new evidence, updated tools and guidance, and inspiring success stories and innovations. Yet, despite this, preterm birth rates continue to raise much concern, with around a million preterm babies dying each year. This signals that we are failing on primary prevention: interventions directed at all women during pregnancy, particularly in the antenatal period, to ensure a healthy pregnancy and detect risks early on. Complications from preterm birth remain the leading cause of death among

newborns, the period where mortality is the highest among children.

The devastating loss to individual mothers and families in every country is a sorrow never forgotten. The loss to national development and human capital is incalculable. What is more, when progress seems possible, efforts have been knocked back by conflicts, the climate crisis, the COVID-19 pandemic, the economic downturn and other adverse events.

Our children are our future. Their right to health, wellbeing and life is the cornerstone of healthy and productive families and societies. As leaders of United Nations agencies and of the largest global alliance for women's, children's, and adolescents' health, we are committed to accelerating progress. This requires working across sectors, in education, and improving the quality of care and financial protection, in the spirit of the SDGs. Most importantly, it requires strong national and subnational leadership and bottom-up mobilization of stakeholders, including civil society and communities.

We are proud that our respective organizations, along with countless individuals and partners, have joined efforts to produce this report and commit to the actions it outlines. Together, we have all the ingredients for sustained progress, and many countries around the world, showcased in this report, have shown how it can be achieved.

The next generation depends on us acting now.

Acknowledgements

This report was developed with contributions from more than 140 individuals from more than 70 organizations. PMNCH coordinated the development of the report, working closely with WHO, UNICEF and many other partners.

The Managing Editors for the report were Anna Gruending (PMNCH, France), Bo Jacobsson (FIGO, Sweden), Etienne V Langlois (PMNCH, Canada), and Joy E Lawn (LSHTM, United Kingdom).

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Abbreviations

ACS	antenatal corticosteroids
CPAP	continuous positive airway pressure
DALYs	disability-adjusted life years
ENAP	Every Newborn Action Plan
EPMM	Ending Preventable Maternal Mortality
FCC	family-centred care
IVF	in vitro fertilization
KMC	kangaroo mother care
LBW	low birth weight
LMICs	low- and middle-income countries
NICU	neonatal intensive care unit
NMR	neonatal mortality rate
OOPs	out-of-pocket payments
PMNCH	Partnership for Maternal, Newborn & Child Health
PPROM	preterm prelabour rupture of membranes
RMC	respectful maternity care
SDGs	Sustainable Development Goals
SRHR	sexual and reproductive health and rights
SSNC	small and sick newborn care
UHC	universal health coverage
UN	United Nations
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
WASH	water, sanitation and hygiene
WHO	World Health Organization



Doris Andongoba is practising kangaroo mother care in the Regional Hospital of Buéa, Cameroon. Her 2-week-old twins Gabriel and Michael were born at 34 weeks.
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Chapter 1

Looking back to inform our future

Worldwide, 1 in 10 babies is born preterm (<37 weeks' gestation) – that's an estimated one baby every two seconds (1). Rates of preterm birth have barely changed during the past decade, and in some places rates are rising. In 2020 it is estimated that nearly 1 million newborns died due to complications of preterm birth (one baby every 40 seconds) and millions more survive with disabilities

that follow them and their families throughout their lives. Preterm birth is the single largest killer of children under 5 years of age, accounting for more than one in three of all neonatal deaths (first month of life) (2), and neonatal conditions are the leading cause of lost human capital in the most recent estimates of the global burden of disease, unchanged since 1990 (Figure 1.1) (3).

FIGURE 1.1 Neonatal disorders: the leading cause of burden of disease, 2000 and 2019

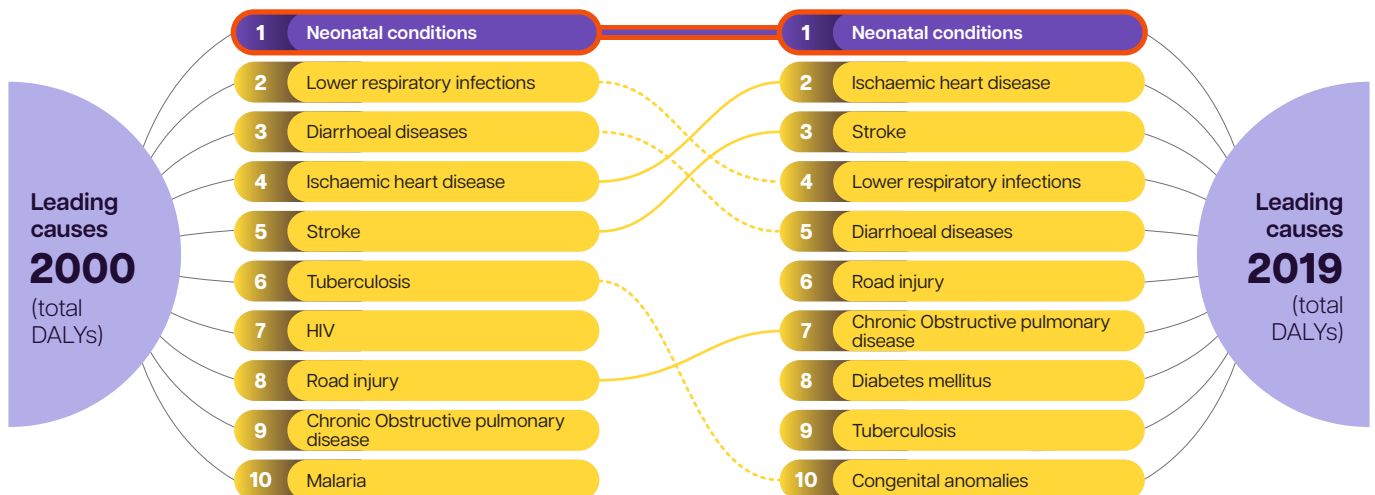


Figure shows global ranking for loss of human capital at all ages measured using disability-adjusted life years (DALYs). DALYs are a time-based measure that combines years of life lost due to preterm mortality and years of life lived in states of less than full health, or years of healthy life lost due to disability. One DALY represents the loss of the equivalent of one year of full health. Source: WHO (<https://www.who.int/data/stories/leading-causes-of-death-and-disability-2000-2019-a-visual-summary>)

It doesn't have to be this way. Preterm babies *can* and *do* survive and thrive – worldwide, millions of survivors of preterm birth attest to this every day. So why then is the world “flat-lining” on the prevention of preterm birth? Why does an immense survival gap persist for babies born too soon, with 9 in 10 extremely preterm babies (<28 weeks) surviving in high-income countries while only 1 in 10 survives in low-income countries (1)? Why are women, babies and their families not uniformly getting the high-quality, respectful care that they need, and that is their right, to survive and thrive?

A decade ago, a global coalition of diverse partners came together and launched *Born Too Soon: The Global Action Report on Preterm Birth* (4). The report shone a spotlight on preterm birth, gaining



media and policy attention all over the world, making the case for the needs of women and their newborns together, given the interconnectedness of their health outcomes, and the care needed for both. *Born Too Soon* presented new data, including the first national

preterm birth rates on the size of the issue, as well as solutions both to reduce preterm birth rates and to improve care.



Antenatal care visit in India.
© White Ribbon Alliance

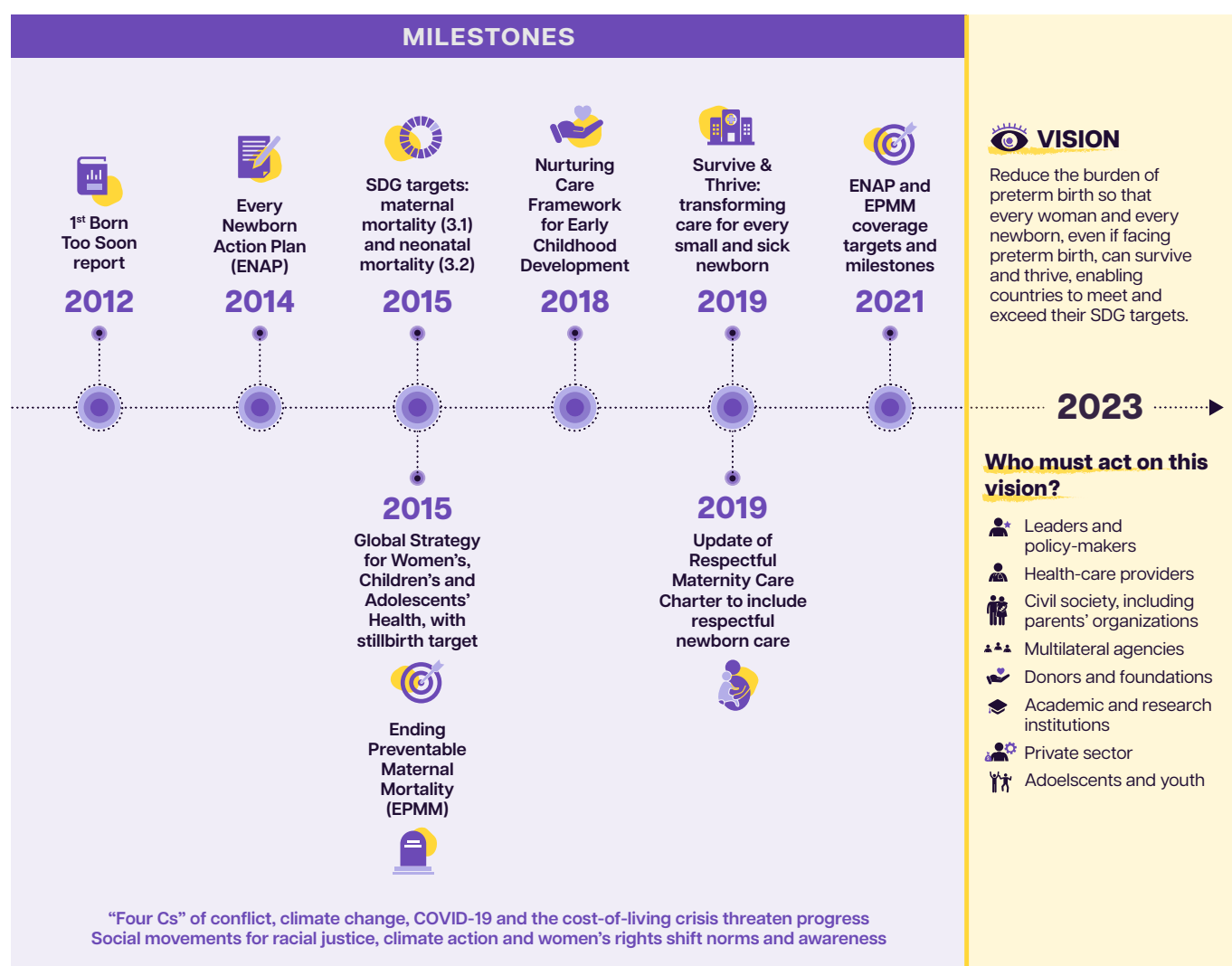
action on preterm birth. Thanks to community mobilization and strong leadership, most countries have adopted mortality targets, and many have national and subnational policies and plans.

The past decade has also witnessed local-turned-global movements for racial justice, climate action, and women's rights and bodily autonomy, to name but a few. These movements have profoundly altered the landscape, shining a light on the groups most affected and on the underlying structural drivers of inequities. They have also shifted norms and increased societal demands for both progress and accountability.

Now, a decade on, the world has made progress on several fronts (Figure 1.2). Countries resoundingly adopted global plans and resolutions on newborn health, including the *Every Newborn Action Plan* (ENAP), and on maternal health, including the *Ending Preventable Maternal Mortality* (EPMM) initiative. These two movements have since joined forces to advocate jointly for action and to track progress. The Sustainable Development Goals (SDGs) included the first ever target to reduce newborn mortality. The *Global Strategy for Women's, Children's and Adolescents' Health* further crystallized the actions required to meet maternal and newborn targets, as well as including a stillbirth reduction target (5). New evidence on life-saving interventions is reflected in updated global guidelines led by the World Health Organization (WHO). Parent groups and health-care professional associations have multiplied and built strong global networks, proving themselves powerful advocates for



A nurse covers a newborn baby at the Special Care Newborn Unit at Cox's Bazar Medical Hospital, Bangladesh.
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FIGURE 1.2 Born Too Soon: timeline of progress from the past decade and vision for the next decade

Progress in peril: stagnation, reversals and 4.5 million maternal and newborn deaths and stillbirths every year

Despite some gains, progress in the past decade has not gone fast enough or far enough. Rates of preterm birth barely changed between 2010 and 2020. Despite some improvements in care, there are still more than 4.5 million deaths of women and babies every year, including more than 2.3 million neonatal deaths, 1.9 million stillbirths and 287 000 maternal deaths (6, 7, 8). Every one of these deaths is a tragedy, and truly unacceptable because the great majority are preventable with high-quality care during pregnancy and birth and for newborns. With less than seven years to realize the SDGs, rates of progress are slower than a decade ago, and in some cases are even reversing. These data should ring alarm bells: 63 countries will fall

short of the SDG newborn mortality target without immediate course correction, of which 55 need to more than double their current rate of improvement to meet the 2030 target (7).

New and intensified challenges loom large (9). The "four Cs" – conflict, climate change, COVID-19 and the cost-of-living crisis – pose distinct but overlapping challenges, and compound existing inequities, especially in places where health systems are already weak. They present life-or-death challenges to those already facing extreme vulnerability, including small and sick newborns (Box 1.1).

BOX 1.1 The “four Cs”: vulnerable women and newborns in the eye of the storm

➤ CONFLICT

By the end of 2022, more than 100 million people worldwide had been driven from their homes by war, violence, persecution and human rights abuses (10), with women and children disproportionately affected (11). In addition to deaths directly caused by conflict, the toll of indirect impacts (e.g. collapsing health systems, restricted access) is often even greater (11, 12). Eleven of the 16 countries with the highest newborn mortality rates have experienced a recent humanitarian crisis (13). Worldwide, a staggering 61% of maternal deaths, 51% of stillbirths and 50% of newborn deaths occurred in countries with a 2023 UN Humanitarian Appeal (6, 14). Small and vulnerable newborns are especially at risk in conflict situations.



➤ COVID-19

The COVID-19 pandemic has destabilized health services for women and newborns. Separation of newborns from their caregivers predates the pandemic but has worsened, threatening high-impact practices such as kangaroo mother care (KMC) and exclusive breastfeeding (19).

In many countries the pandemic has led to a “separation crisis”, with preterm babies routinely being separated from their families if COVID-19 is even suspected. A recent study estimated that if universal coverage of KMC were achieved, more than 125 000 newborn lives would be saved, whereas the risk of newborns catching and dying from COVID-19 would result in fewer than 2000 deaths (20). In many settings, damaging restrictions introduced or accentuated by the pandemic remain in place.

➤ CLIMATE CHANGE

Climate change and related natural disasters are displacing millions of people and the health impacts are wide-ranging and under-appreciated. Air pollutants, such as methane and black carbon, contribute to both climate change and ill health. It is estimated that, in 2019, air pollution contributed to 6 million preterm births and almost 3 million low-birth-weight babies (15). A 2020 global report estimated that air pollution accounts for 20% of newborn deaths worldwide, mostly as a result

of preterm birth and low birth weight (16). Extreme heat, which is increasingly frequent and widespread, is also increasingly being associated with adverse birth outcomes, including preterm birth and stillbirth (17, 18).

➤ COST-OF-LIVING CRISIS

Disruptions to supply chains, caused by COVID-19, conflict and the climate crisis, have dramatically pushed up the cost of living for millions of people (21). Global inflation

rose from 4.7% in 2021 to 8.8% in 2022, and there is double-digit inflation in nearly half the world (22). This is more than a temporary economic squeeze: it is a global public health crisis in its own right.

This crisis deepens the vulnerability of preterm babies and their families. There are reports of discharged babies returning to intensive care because families cannot afford heating and oxygen at home and, in a recent survey, 84% of parents with a baby in neonatal care said the rising cost of living curtailed their ability to travel to and from hospital (23). The impact of this crisis on maternal and newborn health is yet to be fully measured and understood.

About this report: action for the next decade

Why this report, why now?

The setbacks are sobering and the challenges vast, but they need not be the forces that shape the future for the world's newborns and their families. Learning from the past decade shows us that change is possible. Some countries need to triple their rates of decline of neonatal and maternal mortality to meet the SDGs, but they can be inspired by other countries that have succeeded in doing so. Remarkable progress can be achieved when multiple partners mobilize for change, supported by strong political leadership, commitment and investment.

At this crossroads, more than 70 organizations have come together to develop an updated *Born too soon* report. This report, which has involved more than 140 individuals from 46 countries, takes stock of the journey of the past decade – the good and the bad, the challenges and the opportunities. It shines a spotlight on country achievements that can inform and inspire further progress. It roots the agenda for preterm birth within the SDGs, recognizing that progress on maternal and newborn health also depends on collaboration across sectors, and deepening our understanding of factors that affect preterm birth, from climate change to gender equality. And it appreciates the importance of putting affected communities – women, babies and their families – at the centre and working with them as true partners.

Born too soon: decade of action on preterm birth looks to the future, setting an ambitious agenda to reduce the burden of preterm birth by addressing factors outside of the health system that affect preterm birth; and, within health systems, by providing high-quality, respectful care for women and babies so that they can survive and thrive, no matter where they are born. Investment in the right care during this sensitive period can unlock more human capital than at any other time in the life-course, bolstering the case for investing now to gain significant human and economic returns.

Who is this report for?

This report is intended to inspire and support country-led action: politicians, policy-makers and leaders of all stakeholder groups are its primary audience. However, leadership “from the top” often emerges in response to a unified call to action by a broad-based coalition of committed advocates “from the bottom”.



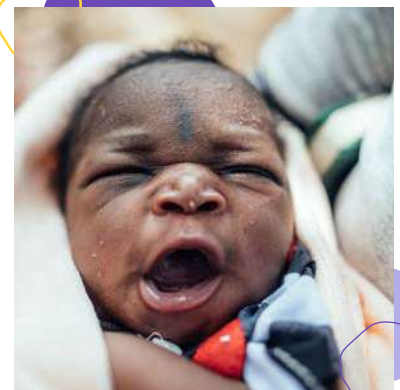
Celebration of World Prematurity Day, Brazil.
© Prematuridade ONG

The 2012 *Born Too Soon* report ignited a movement around preterm birth and maternal and newborn health more broadly. This resulted in a multistakeholder partnership, including parents, health-care professionals, policy-makers, civil society, multilateral agencies, academic and research institutions, donors and the private sector. A decade on, this movement is bigger, stronger and more inclusive, encompassing, for example, more established organizations of parents of preterm babies and stillbirths, new health-care professional associations committed to this issue, and a more vocal and empowered generation of adolescents and young people, including survivors of preterm birth. *Born too soon: decade of action on preterm birth* seeks to equip and energize all of these constituencies with new data: scientific evidence, country learnings and the powerful lived experiences of parents and families, involving both the head and the heart, to make the case for urgent action.

Who is this report about?

The first *Born Too Soon* report focused on preterm birth: on women, their preterm babies (born before 37 completed weeks of gestation) and their families (see Figure 1.3).

While focusing primarily on preterm birth, this decade's edition widens its focus to include a larger group of vulnerable babies, including those with other neonatal complications. Small and sick newborns are treated in the same units by the same people, often require similar interventions, and they, with their families, have



Newborn baby in Borno, Nigeria.
© KC Nwakalor, IRC

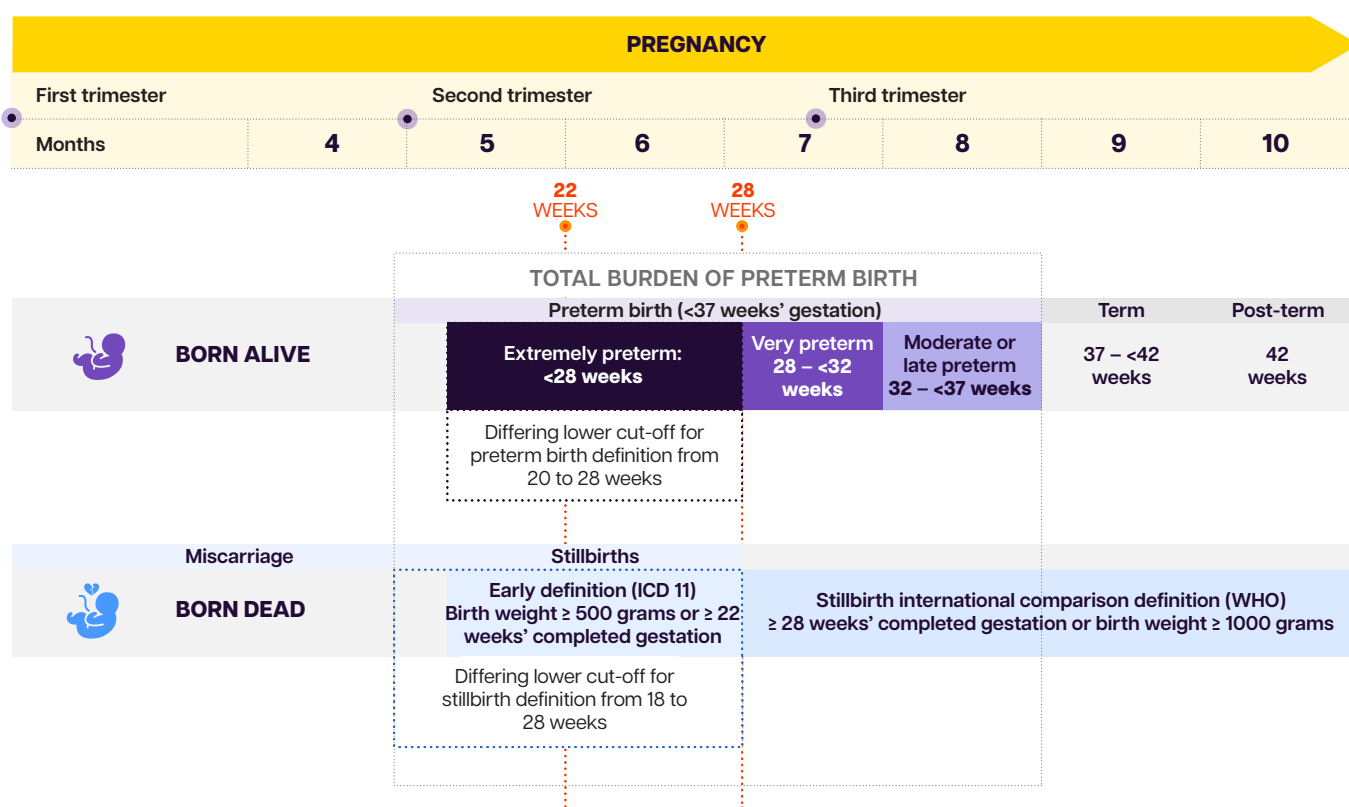
the same right to respectful and high-quality care. The report also includes those born too small for gestational age, of whom there are a large number, particularly in South Asia. That said, the vulnerability of newborns is driven primarily by low gestational age (“born too soon”) causing the greatest risks of both death and disability. Babies who are both preterm and small for gestational age have the highest mortality risk but account for only about 1% of births worldwide (24).

This report also explicitly includes stillbirths. Preterm labour can result in stillbirth, and in-utero fetal death can result in preterm labour. The vulnerability pathways that lead to stillbirth and neonatal deaths are similar. New analyses suggest that around three quarters of stillbirths

after 22 weeks are preterm in high- and upper-middle income settings, yet these issues are rarely addressed together (24).

As with the first edition, this report highlights the foundational importance of women’s sexual and reproductive health and rights (SRHR), including maternal health. It places additional emphasis on adolescent girls, who have an increased risk of preterm birth but often have far less access to the services and care that they need to support their health and well-being. It takes a life-course perspective and recognizes the intergenerational impacts of preterm birth. Finally, it places additional emphasis on the follow-up care and support that is needed for survivors of preterm birth and their families over the course of their lives.

FIGURE 1.3 Definitions of preterm birth and related pregnancy outcomes



ICD - International Classification of Diseases

How is this report structured?

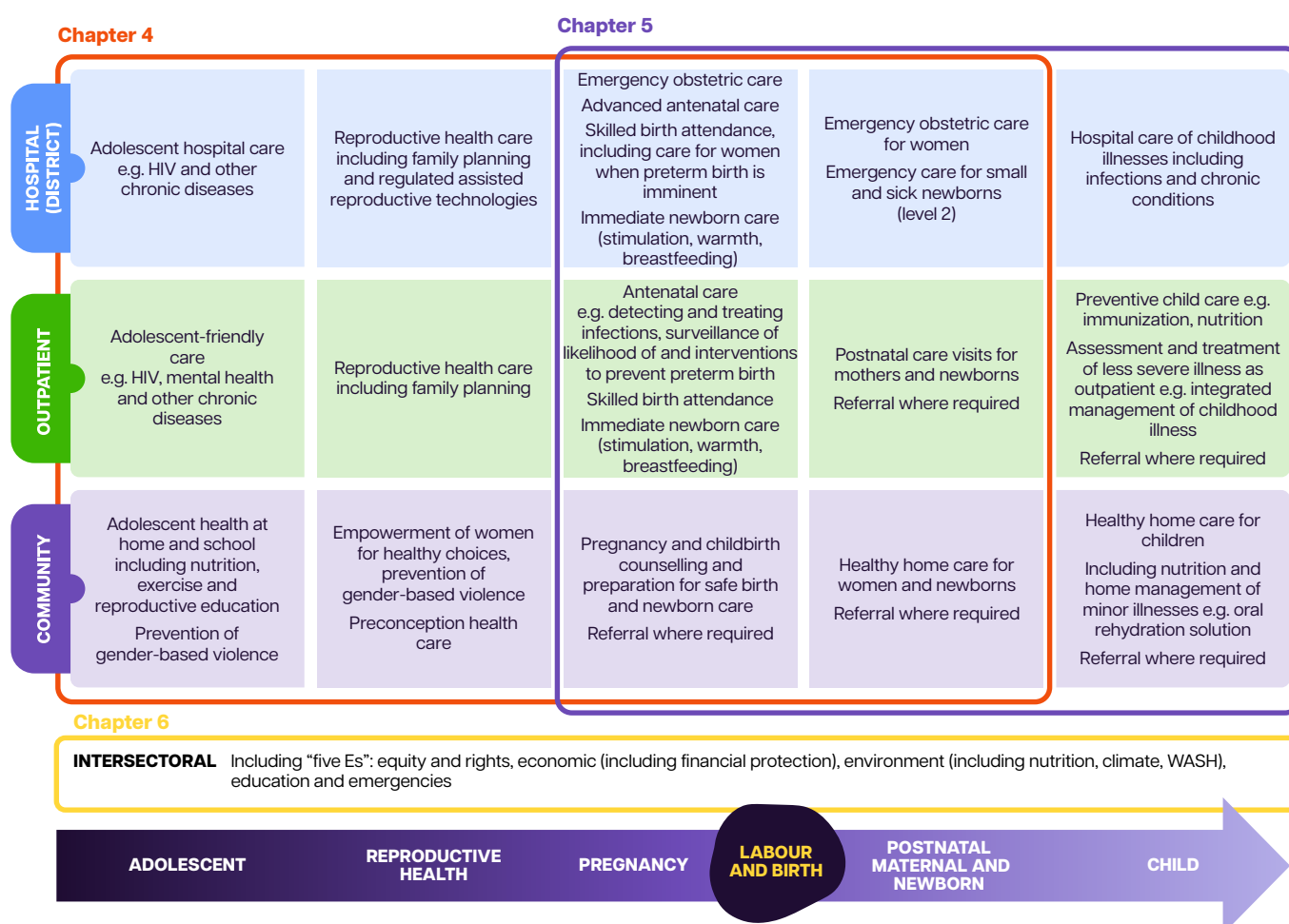
This report is structured around the evidence and actions needed to address preterm birth. The interventions described in Chapters 3–6 follow the continuum of care approach, a useful organizing framework that recognizes that high-quality care is needed for a woman and her newborn over time, with care at different levels of the health system (Figure 1.4) (25, 26, 27). It also recognizes factors outside the health system, including the importance of other sectors and the social and legal enabling environment.

- Chapter 2 presents the new global preterm birth estimates, analysing trends and priorities.
- Chapter 3 takes stock of how a focus on human rights and respectful, family-centred care has profoundly shifted our approach to the understanding and delivery of high-quality care.

- Chapter 4 focuses on the prevention and management of preterm birth, founded on ensuring women's access to high-quality services for sexual, reproductive and maternal health.
- Chapter 5 identifies tangible steps to implement small and sick newborn care (SSNC), which produces a high return on investment.
- Chapter 6 expands on intersectoral factors that influence preterm birth, and what can be done to address these.
- Finally, Chapter 7 presents a clarion call to action for this universal issue that demands attention and action – including by leaders.

Born too soon: decade of action on preterm birth provides a roadmap for what must be done differently in the coming decade to address the unacceptable burden of preterm birth. Together, we can achieve the changes needed by every woman, every baby and every family.

FIGURE 1.4 The continuum of care (23)



Key reading

- Born too soon: global action report on preterm birth. Geneva: World Health Organization; 2012 (<https://www.who.int/publications/i/item/9789241503433>).
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- Protect the promise: 2022 progress report on the Every Woman Every Child Global Strategy for Women's, Children's and Adolescents' Health (2016–2030). Geneva: World Health Organization and the United Nations Children's Fund; 2022 (<https://www.who.int/publications/i/item/9789240060104>).

Behind every statistic is a story

Meet **Jayme** from **Japan**



Randal, Yumi and their son Jayme.

Jayme, the only child of Randal and Yumi Wong, was born in 2013 at 23 weeks' gestation, weighing just 680 grams, slightly bigger than an adult hand. Doctors said there was a high likelihood that Jayme would have a brain bleed or long-term health complications. This was devastating news for Jayme's parents who had already experienced two miscarriages.

Jayme's father Randal had never heard of a baby surviving birth at such a low gestational age. "My son was so tiny and completely covered in tubes. It was a difficult time and there was high anxiety."

“He has amazed us. He not only survived but is thriving.”

Randal felt well supported by the medical staff, who shared information with him and Yumi and dedicated much time and technology to help Jayme survive. After four months, Jayme was able to go home. Thankfully there were no effects on his brain but, because his lungs were underdeveloped, he spent several months using a ventilator. He also had a tumour in his liver and required surgery and chemotherapy when he was only 18 months old.

A decade after being born too soon, Jayme is thriving. "To be honest I am impressed," his father Randal says. "We did not have great hope and were

prepared for the worst. He has amazed us. He not only survived but is thriving." He loves school, has many friends, speaks fluent Japanese and English, and dreams of becoming a Formula 1 racing driver or a basketball star.

Randal and Yumi still worry about how he will fare in his teenage and adult years. Jayme is physically smaller than other children of his age, and they fear that he will be bullied because of his size. But if his first 10 years of life are anything to go by, Jayme is destined for greatness. His curiosity, love of history, and social and presentation skills are marvellous.

It took many years for Randal and Yumi to talk openly about their experience of preterm birth. Yumi says she felt very alone and many of her social relationships evaporated.



Jayme in the NICU.

"Japan is a developed country, but preterm birth is not a topic that is openly discussed." Asked about her wish for the decade ahead, Yumi said she would like to see communities coming together to talk about preterm birth and to share their journeys. "Parents should not have to rely only on the internet for information. Sharing experiences with each other as humans would be great and relatable."



Nairobi, Kenya
© Lieve Blancquaert

Chapter 2

Counting and accounting for preterm births

KEY MESSAGES

Progress

The past decade has seen no measurable change in global preterm birth rates, including in the highest-burden regions. A few countries have reduced their preterm birth rates, but only marginally (0.5% per year). More encouragingly, the availability of preterm birth data has increased in all regions.

An estimated 13.4 million babies were born preterm in 2020, meaning that 1 in 10 babies worldwide was “born too soon”. Preterm birth complications remain the top cause of under-5 child mortality, most recent estimates suggest that these account for about 1 million neonatal deaths worldwide, a number similar to that of 10 years ago (1).

Programmatic priorities informed by the data

Preventing preterm birth is crucial. It could be accelerated by focusing on context-specific risk factors, and addressing spontaneous and provider-initiated preterm births, such as non-medically indicated caesarean sections.

Care of preterm and vulnerable newborns is possible now to prevent 900 000 direct deaths from preterm birth (mostly less than 32 weeks’ gestation).

Stillbirths should be included in data, policies and programmes relating to preterm birth because most stillbirths are preterm and stillbirths take a serious, long-term toll on families and contribute to loss of human capital.

Pivots

Data availability and quality can be improved, but it is also crucial to use data to drive accountability and action, including by:

- counting every baby everywhere, including those stillborn, and accurately recording gestational age and birth weight;
- strengthening national data systems to improve the availability of individual-level data for action, including quality improvement in maternity wards and small and sick newborn care units, plus follow-up for health outcomes, including disabilities, and loss of human capital; and
- using data to strengthen shared accountability at all levels, from the community and facility levels to the subnational, national and global levels.

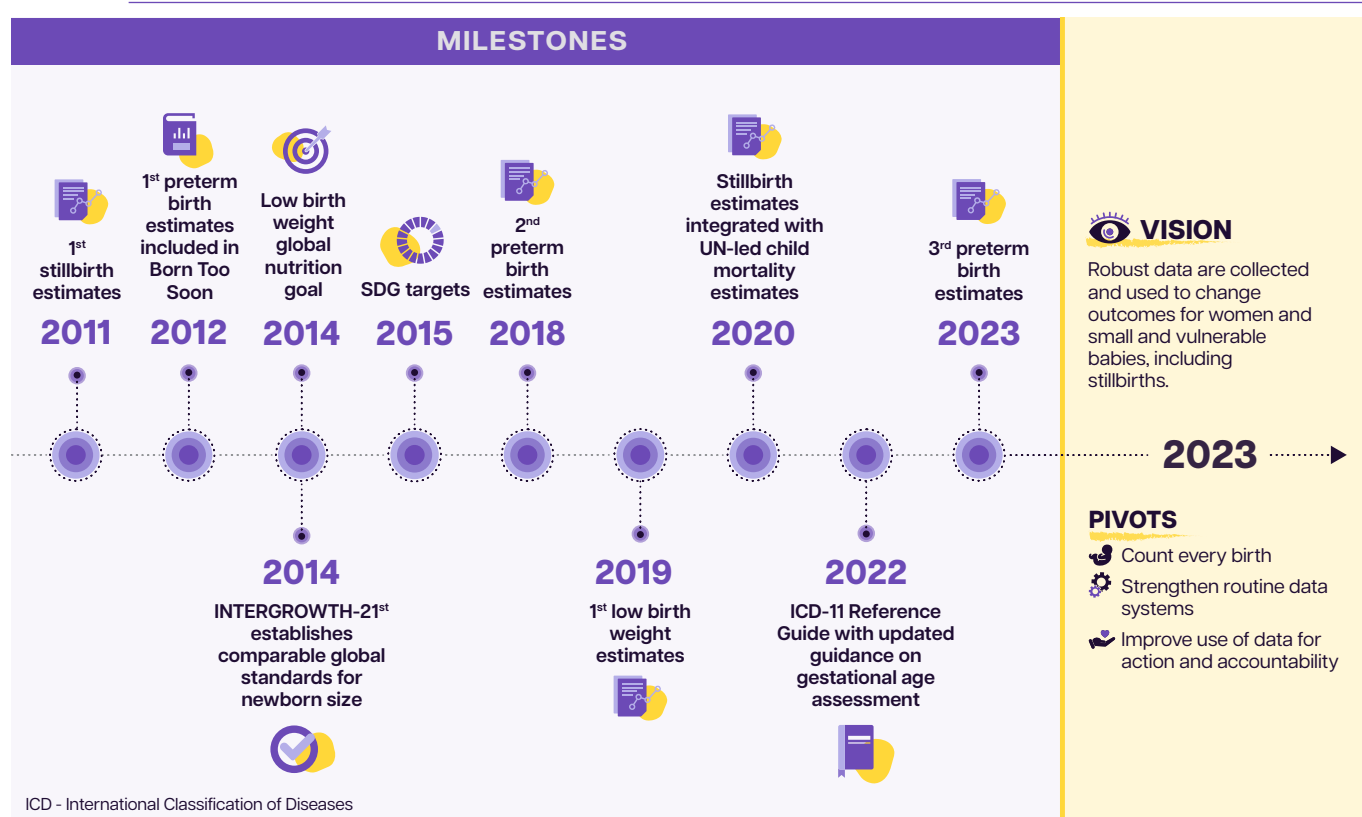
PROGRESS

Preterm birth trends in rates and numbers, 2010–2020

Preterm birth affects families in every country, on every continent. The past decade has seen mixed progress on collecting and acting on preterm birth data (Figure 2.1). Policy attention to a healthy

start has increased, and the first global goal for neonatal survival was included in the SDGs, with a linked target for stillbirths (see Chapter 1). The number of countries collecting data on preterm has stagnated over the last decade; however, early ultrasound dating and innovations in gestational age assessment have improved measurement, and some countries have strengthened their routine health information systems to better capture preterm birth rates.

FIGURE 2.1 Data for preterm birth: timeline of progress over the past decade and vision for the next decade



Despite some technological advances, recent estimates by WHO and the United Nations Children's Fund (UNICEF) show no measurable progress in reducing preterm birth rates globally. Preterm birth rates were 9.9% in 2020, compared to 9.8% in 2010 (1). There was also no measurable change in preterm birth rates in the highest-burden regions¹ (Southern Asia: 13.3% in 2010 and 13.2% in 2020, and sub-Saharan Africa: 10.1% in both 2010 and 2020). National-level preterm birth rates also changed little between 2010 (5.8%–16.5%) and 2020 (4.1%–16.2%).

Among countries with robust time series data, the 10 countries which reduced their preterm birth rates fastest were: Czechia, Austria, Brunei Darussalam, Singapore, Spain, the Netherlands,



Antenatal care at the National Centre for Mother and Children in Bayangol district, Mongolia.
© WHO/Yoshi Shimizu

¹ The SDG regions are used in this report, unless otherwise stated.

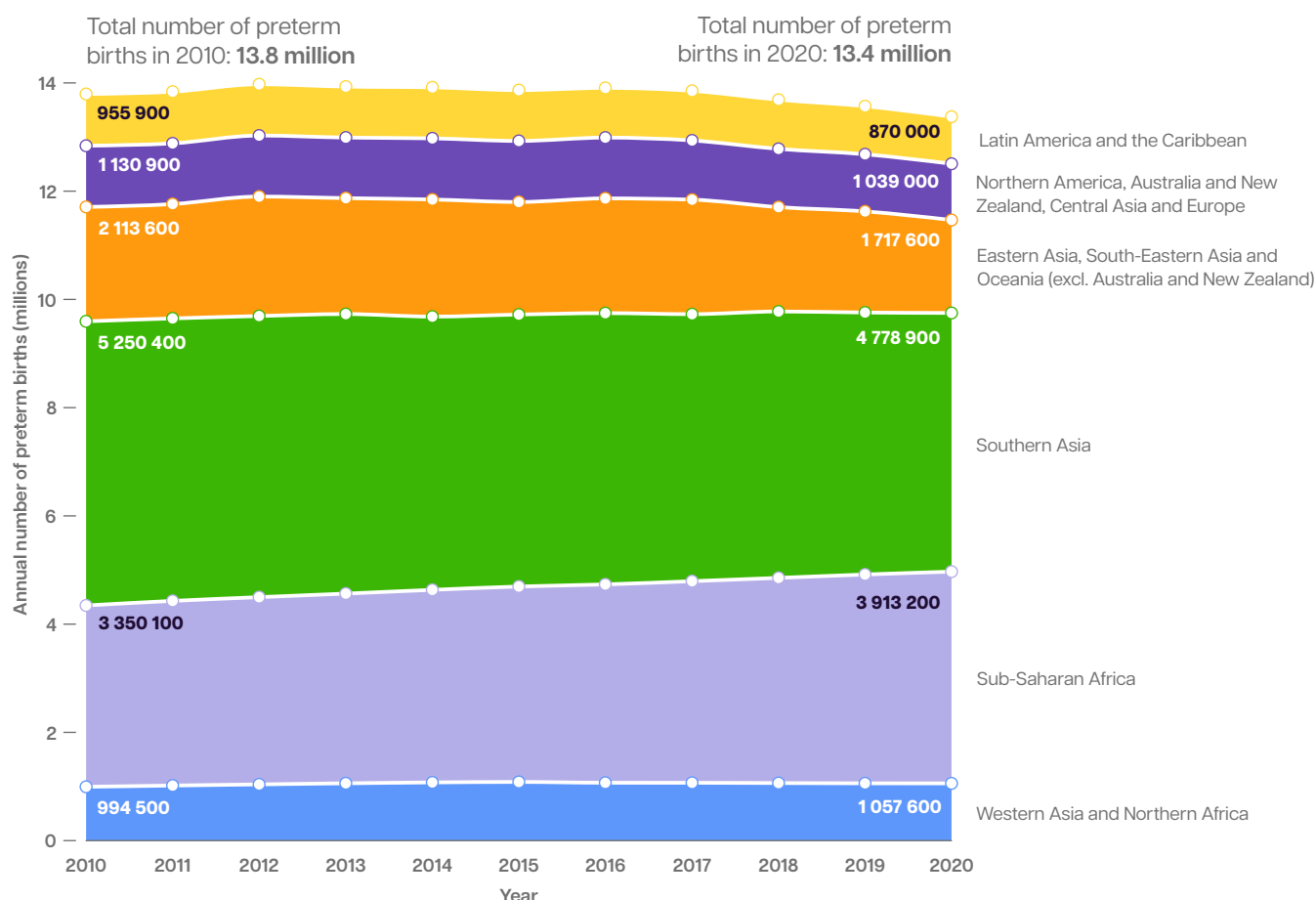
Denmark, Hungary, Brazil and Sweden. All these countries reduced their preterm birth rates by more than 5% between 2010 and 2020, but it is important to note that this equates to an annual average reduction of only about 0.5% per year. In 13 countries (Poland, Iceland, Croatia, United Kingdom of Great Britain and Northern Ireland, Bulgaria, Armenia, Bahrain, Ireland, Chile, Georgia, Colombia, the Republic of Korea and North Macedonia) the preterm rates *increased* by more than 5% in this period, although some of these increases may relate to improved data quality. In 52 other countries the preterm birth rate showed no measurable change (absolute percentage increase <1%).

The absolute number of babies born preterm decreased slightly from 13.8 million in 2010 to 13.4 million in 2020, primarily due to fewer births globally

and in many regions (Figure 2.2) (1). However, in sub-Saharan Africa the number of babies born preterm increased, with 563 000 more babies born preterm in 2020 than in 2010. This relates to increases in the birth cohort in sub-Saharan Africa, as well as to the lack of reduction in preterm birth rates (1).

The impacts of COVID-19 on preterm birth rates were both direct, with severe infection in pregnancy being a risk factor for higher preterm rates, and indirect, with other factors (such as reduced risk of other infections and lower stress) possibly reducing rates (Box 2.1). Importantly, lockdown policies may also have increased both stillbirth rates and neonatal deaths among vulnerable newborns, but the data are not yet conclusive.

FIGURE 2.2 Trends in annual number of preterm births by SDG region, 2010–2020



Data from WHO and UNICEF preterm birth estimates, Ohuma et al. (1).
Source: Lawn et al. (12)

BOX 2.1 Has COVID-19 affected preterm birth rates?

The COVID-19 pandemic has produced both direct and indirect effects on preterm birth outcomes. Recent evidence suggests that maternal COVID-19 infection may directly affect the fetus through pathways of viral transmission from mother to baby, poorer placental functioning and reduced maternal capacity due to systemic disease. These pathophysiological pathways due to COVID-19 are suspected to have contributed to an increased risk of preterm birth and a greater need for neonatal intensive care (2).

However, the full impact of COVID-19 is still unclear. Studies, predominately in high-income countries, have found that the COVID-19 pandemic did not affect preterm birth rates, and in some contexts preterm birth rates were even reduced, although this may be associated with an increased risk of stillbirth (3, 4). Other studies, including in both high- and low-income countries, found that mothers infected with COVID-19 have a higher rate of preterm birth, including medically indicated preterm delivery, than mothers not infected with COVID-19 (5).

Preterm rates and numbers in 2020

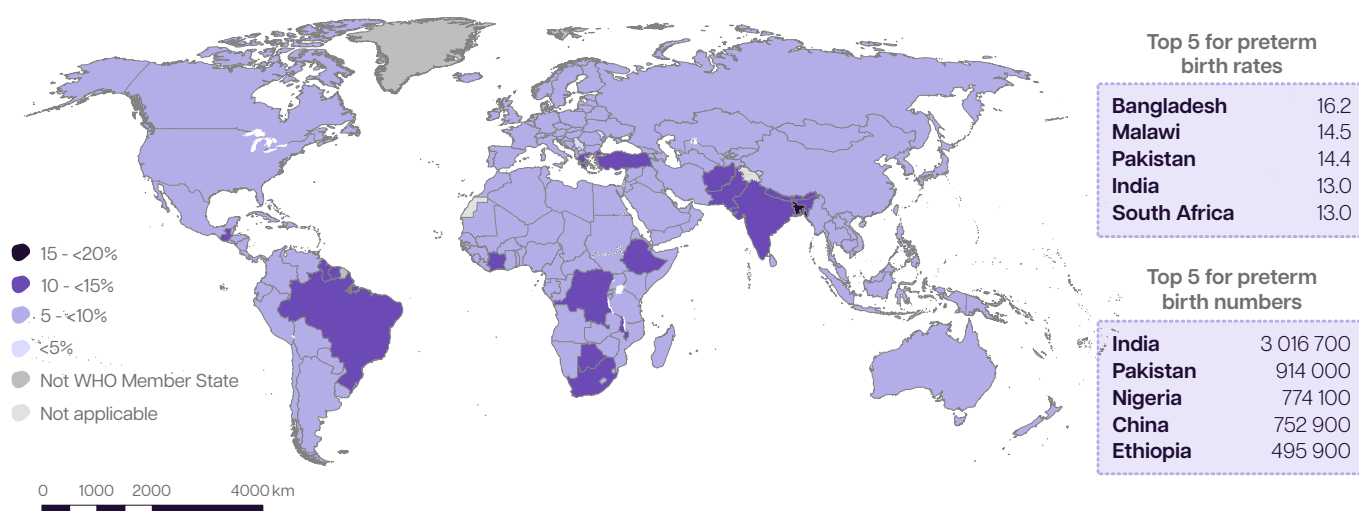
In 2020, an estimated 13.4 million live births were preterm, with 1 in 10 babies “born too soon” (9.9% of all live births) (1).

Preterm birth rates vary between regions, the highest occurring in Southern Asia, where 13.2% of babies were born preterm in 2020, compared to fewer than 8% of births in Eastern Asia, South-Eastern Asia, Northern America, Europe, Australia and New Zealand. However, sizeable national variations occur within regions. In Latin America, for example, preterm birth rates for countries with good data ranged from 5.8% in Nicaragua to 12.8% in Suriname.

There is also variation at national level. According to global estimates, Bangladesh has the highest

preterm birth rate (16.2%), followed by Malawi (14.5%) and Pakistan (14.4%). Although the highest rates are predominantly in low- and middle-income contexts (Figure 2.3), rates of 10% or higher persist in some high-income countries, such as Greece (11.6%) and the United States of America (10.0%). The countries with the lowest preterm rates were Serbia (4.1%) and Moldova (5.0%).

Almost half (45%) of all preterm births in 2020 occurred in just five countries: India, Pakistan, Nigeria, China and Ethiopia (Figure 2.3). India had the highest number of preterm births in 2020 (3.02 million, accounting for more than 23% of all preterm births worldwide) with Pakistan, Nigeria and China each having more than three quarters of a million preterm babies in 2020. The high numbers of preterm births in these countries reflect not only their high numbers of total births, but also higher preterm birth rates.

FIGURE 2.3 Estimated national preterm birth rates and numbers in 2020

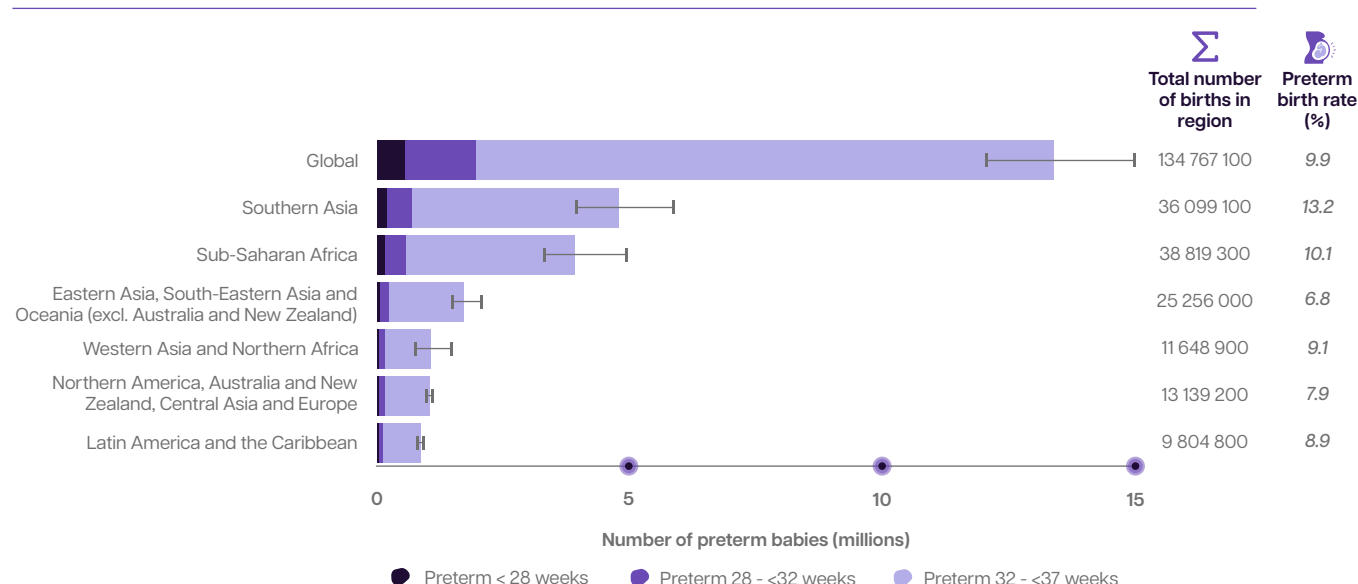
Source: UNICEF and WHO preterm estimates. Ohuma et al. (1)

Estimates are developed for international comparison and countries may decide to use their own national statistics for national planning and other purposes.

At the regional level, the largest incidence of preterm birth remains in Southern Asia, where 4.8 million babies were born preterm in 2020, including more than 700 000 at <32 weeks, with the highest

risks of mortality and long-term consequences (Figure 2.4). Sub-Saharan Africa accounted for 3.9 million preterm births, almost 600 000 of them at <32 weeks.

FIGURE 2.4 Preterm birth by gestational age and region in 2020



Preterm birth in numbers and rates



13.4 million babies were born preterm in 2020 (9.9% of all live births).



National preterm birth rates vary from **4–16%**. Southern Asia has the highest rates and numbers of preterm birth.



Almost **900 000 neonatal deaths** were due to direct complications of preterm birth.



85% of preterm births occur between 32 and 37 weeks of gestation where survival is usually possible without neonatal intensive care.

Source: WHO and UNICEF preterm estimates. Ohuma et al. (1)

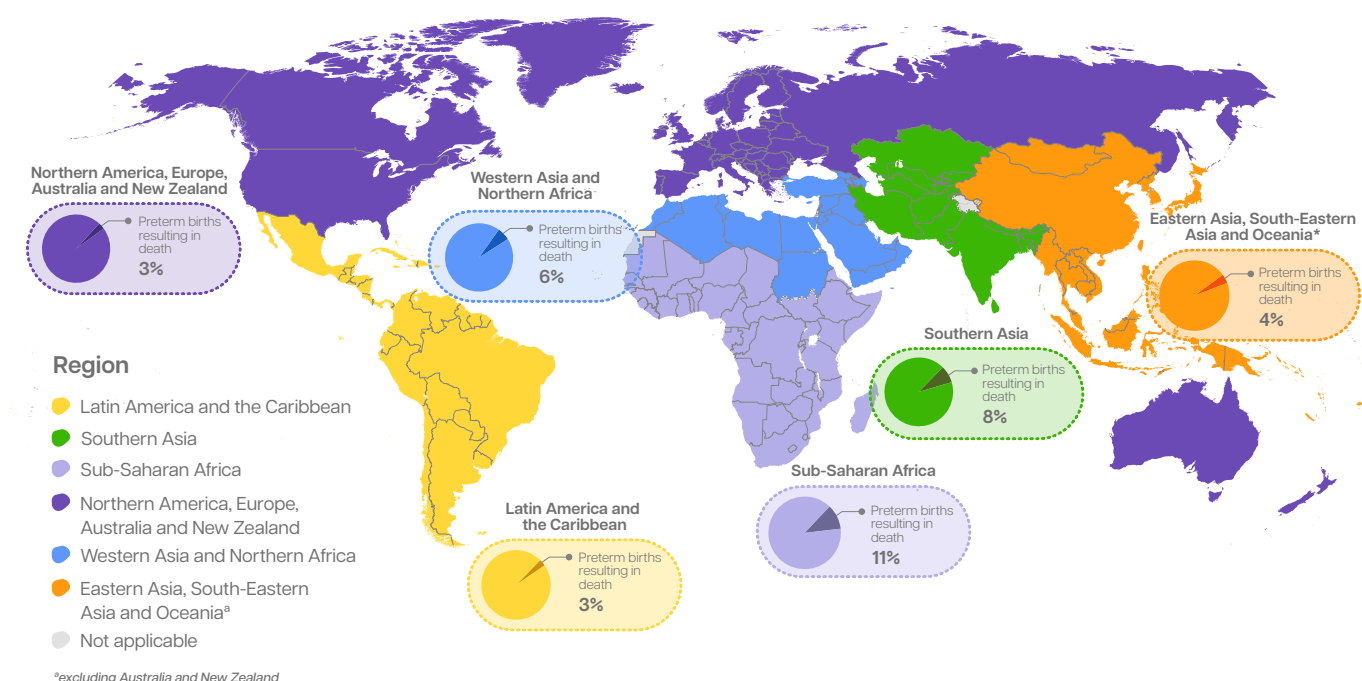
In 2020, nearly 1.2 million preterm newborns are estimated to have been born in the 10 most fragile countries affected by humanitarian crises (Afghanistan, Chad, Central African Republic, Democratic Republic of the Congo, Myanmar, Somalia, South Sudan, Sudan, Syria and Yemen) (6). Many women and preterm babies in these settings face increased challenges in accessing care, especially higher-level care.

Deaths and lifelong impacts for survivors of preterm birth

Neonatal conditions remain the fifth leading cause of death globally (after ischaemic heart disease, stroke, chronic obstructive pulmonary disease and lower respiratory tract infections) and the leading cause of loss of human capital (DALYS). Preterm birth is an important contributor to overall neonatal conditions (7).

This high burden of DALYs is due primarily to deaths at an early age. Preterm birth complications are the leading cause of child mortality (8). Almost a million children (0.9 million) were estimate to have died due to direct complications of preterm birth in 2019, and over a third of all neonatal deaths worldwide are estimated to be due to direct complications of preterm birth (8). These numbers reflect continued stagnation in the reduction of child deaths due to prematurity (8).

Inequalities in care between and within countries result in unacceptably large survival gaps for babies born preterm. Higher-resourced settings have near-universal survival for those born over 28 weeks' gestation, compared to much higher mortality among babies, even up to 32 weeks' gestation, in places where access to care is limited. Disparities in preterm survival also vary widely across regions (Figure 2.5).

FIGURE 2.5 Regional variation in the proportion of preterm births resulting in neonatal death in 2020

The darker shading in each pie chart indicates the proportion of preterm births that result in death in the first 28 days of life, by region. Data sources: Preterm birth numbers by country and region from Ohuma et al. (1). Mortality estimates generated by applying country-specific 2019 preterm cause-specific neonatal death proportions from Perrin et al. (2) to 2020 country-specific live birth estimates from World Population Prospects (<https://population.un.org/wpp/>) (9).

Preterm birth is also associated with long-term detriments to respiratory and cardiac systems, and especially with neurodevelopmental impacts on survivors. These range from major disabilities, such as diplegia, especially for those most preterm, to less severe outcomes. Importantly, new research shows that being born even a few weeks preterm can result in learning and behavioural spectrum disorders; since most preterm babies are born at between 32 and 36.9 weeks, this is a more frequent outcome. Indeed, even those born at between 37 and 39.9 weeks have a slightly elevated risk of adverse neurodevelopmental outcomes.

It is important to recognize that many of these disabilities are preventable and are a sensitive marker of quality of care. A crucial example is blindness or visual impairment due to retinopathy of prematurity, which has been increasingly reported over the last decade, especially in Latin America and South-Eastern Asia, often in newborns who were only moderately preterm. Improving safe oxygen use (avoiding saturations above 95%) and scaling up screening and treatment are crucial to avoid a repeat of the epidemic of blindness seen in the United States in the 1960s.

These outcomes seriously affect not only the individuals born too soon, but also their caregivers, communities, health systems and wider society.

PROGRAMMATIC IMPLICATIONS FROM THE DATA

This toll of preterm birth is an enormous burden and has not reduced for several decades. Affecting all countries, it should feature more prominently on the global health agenda. Evidence shows that this burden can be reduced. If countries are to achieve SDG 3.2 to end preventable neonatal deaths, and also transform human capital through the whole life-course, urgent action is needed both to prevent preterm birth and to improve the quality of care for those born preterm. Although stillbirths are often left out of this equation, most stillbirths are born preterm, and greater investment in primary prevention of preterm births could help to reduce the 1.9 million stillbirths every year.

Track 1: Preventing preterm birth, using and improving data

Despite little progress having been made in reducing preterm births at global and regional levels, progress has been seen in a few, predominantly higher-income, countries. Reducing preterm births in all settings will require addressing the drivers of preterm birth, which may be context-specific.

Table 2.1 provides an overview of known risk factors in both spontaneous and provider-initiated preterm births. In settings with high caesarean section rates it is crucial to consider the incentives for this and to increase knowledge about the risks to women

and their babies due to non-medically indicated caesarean section. For spontaneous preterm birth, many of these interventions can be delivered through high-quality antenatal care. Some of these programmatic approaches are detailed in Chapter 4. However, intersectoral interventions targeting whole populations, such as reducing smoking and obesity and improving air quality, are also important for reducing preterm birth, as outlined in Chapter 6.

Encouragingly, some countries are improving data on preterm birth, incorporating these data in national systems and using this information to track progress and inform programmes (Box 2.2).

TABLE 2.1 Preterm birth risk factors and prevention strategies

Type	Risk factors	Examples	Prevention strategies ^b
Spontaneous preterm birth ^c	Age at pregnancy and pregnancy spacing	Adolescent pregnancy, advanced maternal age, short inter-pregnancy interval	Preconception care, including access to family planning from adolescence, after birth and throughout reproductive years
	Multiple pregnancies	Increased rates of twin and higher-order pregnancies with assisted reproduction	Introduce and monitor policies for best practice in assisted reproduction
	Infection	Urinary tract infections, asymptomatic bacteriuria, malaria, HIV, syphilis, chorioamnionitis, bacterial vaginosis	Sexual health programmes aimed at prevention and treatment of infections prior to and during pregnancy Intermittent preventive treatment of malaria (context-specific), antenatal screening for lower genital tract infections and asymptomatic bacteriuria
	Underlying chronic medical conditions	Diabetes, hypertension, anaemia, asthma, thyroid disease, HIV	Maximize preconception control for pre-existing conditions, as well as screening and prompt management during pregnancy
	Nutritional	Undernutrition, micronutrient deficiencies	Assess and treat low nutritional status prior to conception and in early pregnancy Consider supplementation (e.g. iron folate and zinc supplementation) for pregnant women without systemic illness
	Lifestyle and work-related	Smoking, excess alcohol consumption, recreational drug use, excess physical work and activity	Adopt laws and rights-based approaches to protect pregnant women, and ensure maternity leave Behavioural and community public health interventions targeting pregnant women and women of reproductive age, e.g. pharmacological interventions for smoking cessation
	Environmental	Exposure to indoor and ambient air pollution, heat stress	Public health measures, antenatal counselling, avoidance of air pollution and excessive heat where possible

Type	Risk factors	Examples	Prevention strategies ^b
Spontaneous preterm birth^c	Maternal psychological health	Depression, violence against women	Antenatal screening where capacity to provide a supportive response is available
	Genetic and other	Genetic risk (e.g. family history), cervical incompetence, intrauterine growth restriction, congenital abnormality	Individual-specific interventions, e.g. cervical cerclage for women with singleton pregnancy and high risk of preterm birth
Provider-initiated preterm birth	Induction or caesarean birth for maternal indication	Common indications include: pre-eclampsia/eclampsia, placental abnormalities (e.g. placenta accrete) and pre-existing maternal conditions	Not applicable
	Induction or caesarean birth for fetal indication	Common indications include severe fetal growth restriction	Not applicable
	Induction or caesarean birth without medical indication	Non-medically indicated, due to physician or patient preferences or incentives	Programmes and policies to reduce the practice of non-medically initiated preterm birth Midwifery-led continuity models of care have proved effective

^b Updated from Blencowe et al. (10) and Medley et al. (11).

^c Includes preterm birth following preterm prelabour rupture of membranes.

BOX 2.2 Country snapshot

Electronic health information system improves availability of preterm birth rate data in Mozambique

Despite resource constraints, Mozambique has achieved improvements in its health information system by developing a web-based national monitoring and evaluation system (DHIS2-SISMA) in partnership with the Ministry of Health of Mozambique and Jembi-MOASIS¹. Since 2016, Mozambique has used this system to generate national data on preterm birth and low-birth-weight statistics, demonstrating the country's ability to make data available despite its economic and health system limitations. Currently, the system is used primarily by hospitals in the National Health Service, and less by the private sector. Data sharing across the whole health system is increasingly important to ensure that data are comprehensive, and to enable tracking of subnational trends (11). Further investments are needed to increase the representativeness and quality of these data.

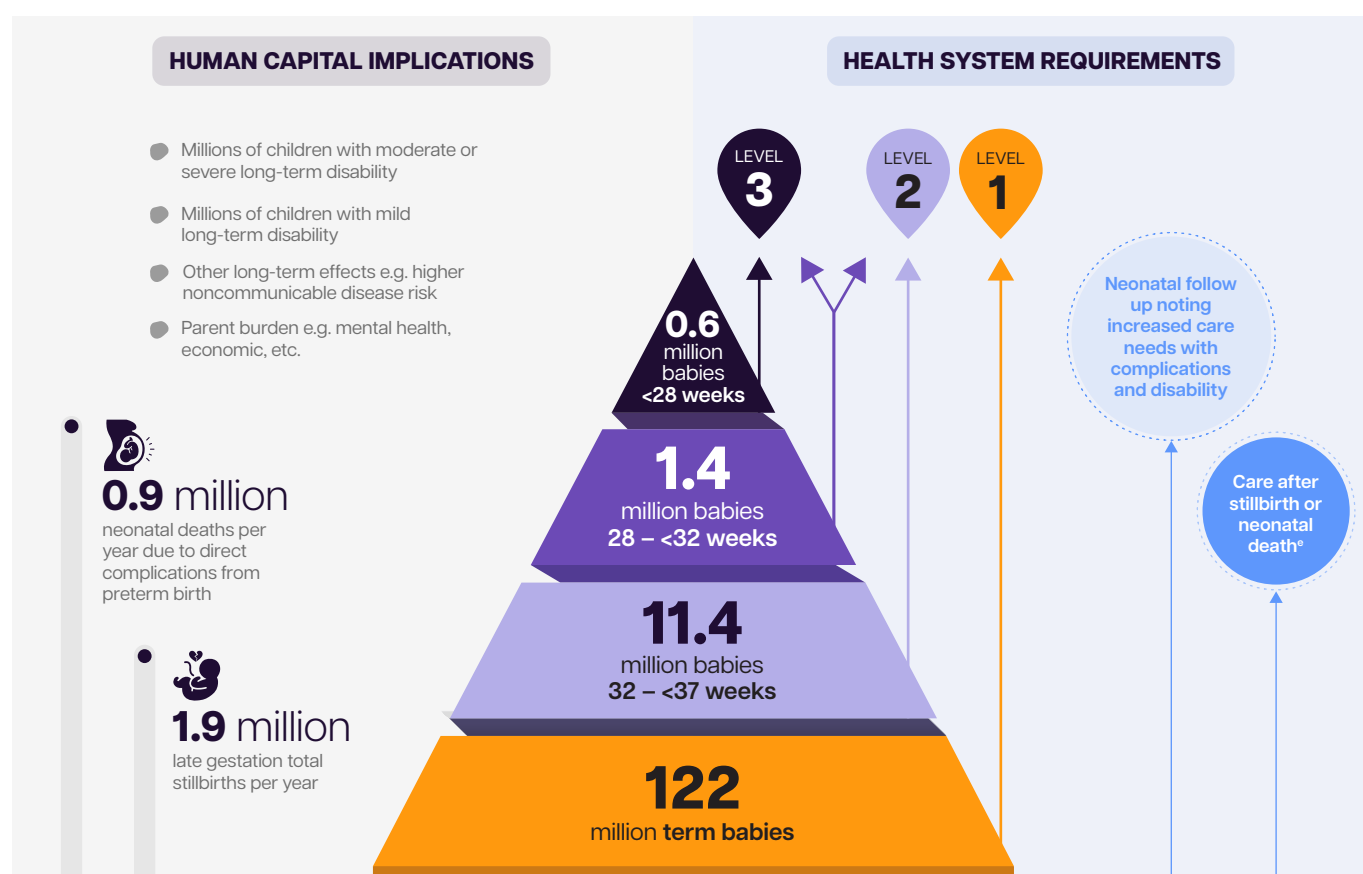
¹ A South African non-profit organization, funded by the United States of America, that builds local capacity by developing information systems in low-income countries.

Track 2: Caring for preterm babies across the life-course, using and improving data

Some countries have made notable progress over the past decade in improving care for small and sick newborns (see Chapter 5). Accurate data on gestational age allow preterm babies to be categorized into subgroups, which is essential

to enable countries to assess and plan for the level of care needed, since gestational age is a predictor of the risks of mortality and long-term disability. All babies, regardless of gestational age, require essential newborn care, and most babies born preterm require additional support or special newborn care, with a smaller number, including those born at <28 weeks, requiring intensive care (Figure 2.6).

FIGURE 2.6 13.4 million preterm births in 2020: human capital implications and health system requirements



Around three quarters of stillbirths are preterm in high- and upper-middle-income settings (12).

* In addition to newborn care, health systems need to be designed to provide care after a stillbirth or death in this high-risk population and to cater throughout the care continuum for the increased health-care needs associated with preterm birth. See Chapter 5 for details.

Adapted from Lawn et al. (12)



A midwife does a check-up on a preterm baby in the United Republic of Tanzania. © UNICEF/UN0270666/van oorsouw

Many settings lack systems for routine follow-up of at-risk newborns, have gaps in care, and lack adequate information about the short-, medium- and long-term impacts of preterm birth on human capital. Chapter 5 provides more details on health-care services for preterm newborns, integrated within care for all small and sick newborns, as well as at-risk neonatal follow-up.

Track 3: Including stillbirths in counting, accountability and action

Preterm birth data currently report only the rate of live births. However, this practice overlooks a major part of the burden: a large proportion of stillbirths are among babies born before 37 weeks' gestation (Box 2.3). In order to end preventable deaths, data are required on both live and stillborn babies.

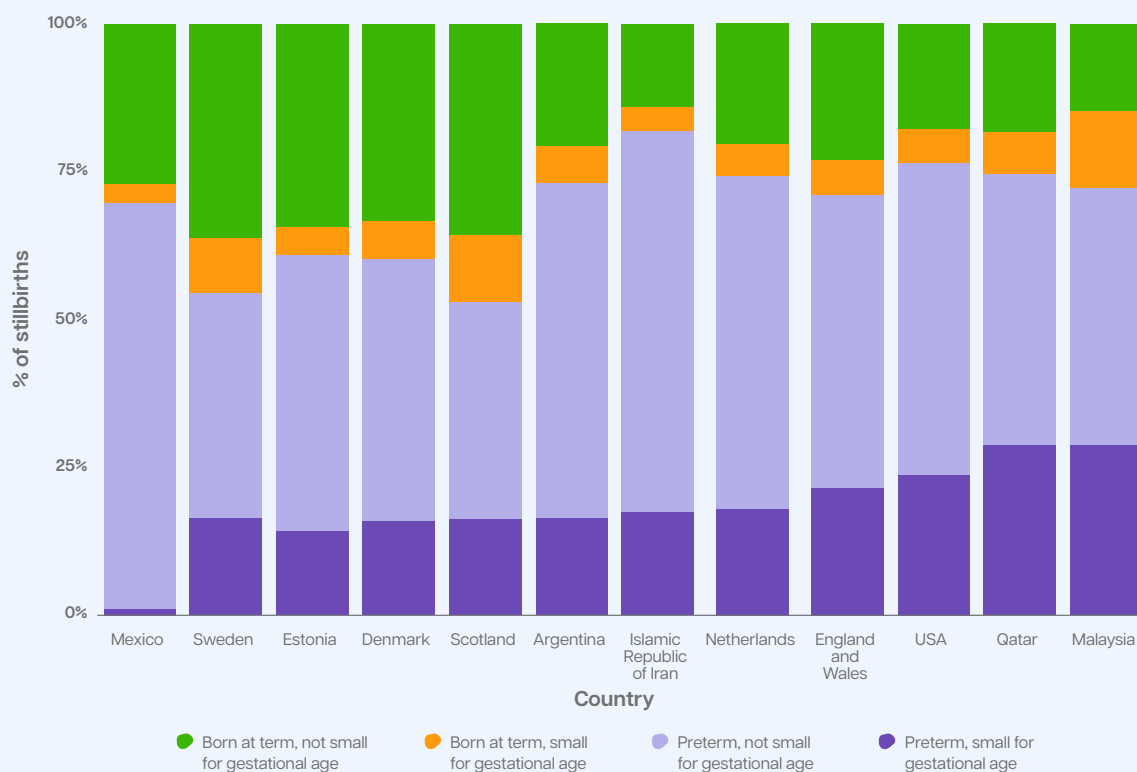
Stillbirth is an important global health issue: 2021 saw an estimated 1.9 million late-gestation stillbirths (at 28 or more weeks) worldwide. Stillbirth and preterm birth are associated with similar vulnerability pathways, whereby preterm labour can result in stillbirth and, conversely, in utero fetal death may result in preterm labour.

To monitor and track progress for the world's most vulnerable babies it is essential to include and count stillbirths alongside live-born preterm babies and the 0.9 million associated neonatal deaths. Omitting those born still distorts the quantification of the total burden of those "born too soon", especially in comparisons between different settings and when assessing trends over time. For example, with better obstetric monitoring, more deliveries to prevent stillbirth could increase the rates of preterm births among live births. Interventions to address preterm birth (e.g. due to infections or pre-eclampsia) may also reduce stillbirths, but the full impact of such interventions will only be measurable by recording stillbirths.

BOX 2.3 Out of the shadows: stillbirths count alongside preterm births

Analyses of 12 upper-middle- and high-income countries (0.6 million stillbirths \geq 22 weeks' gestation) showed that around 74% of stillbirths in these settings were preterm (12). However, stillbirths are not included in preterm burden estimates, which reflect live births only. Excluding stillbirth data from research and reporting is a serious omission that fails to acknowledge the major impact of this loss on women and families.

Four types of vulnerable newborns among stillbirths



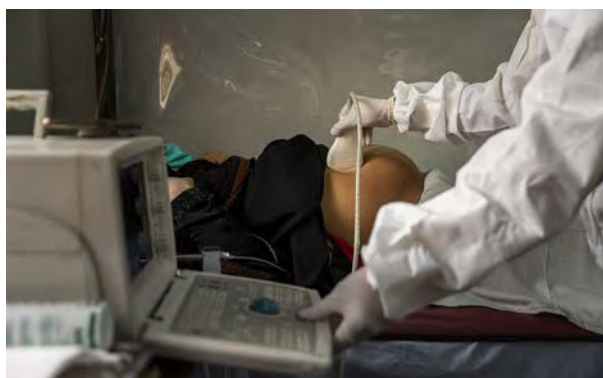
Source: Lawn et al. (12)

PIVOTS

Data are needed to track progress and to inform action. Gaps in routine data availability, quality and reporting in many low- and middle-income countries (LMICs) currently limit the evidence available on preterm births. This limitation can be overcome by improving data collection at the individual level for every baby, strengthening data systems to capture this information and ensuring that the data are made available.

Pivot 1: Count every baby and improve measurement of gestational age and birth weight

Improving data on preterm birth requires counting every baby everywhere, whether live or stillborn, and recording their gestational age and birth weight. The WHO minimum perinatal dataset for every baby includes gestational age, sex and birth weight, as well as any caesarean section. It is essential that these data are collected for every birth, and are of good quality, in order to inform future action to prevent preterm births.



A gynaecologist conducts an ultrasound in Pakistan.
© WHO/Blink media – Saiyna Bashir

Gaps in gestational age measurement are commonly cited as barriers for preterm birth data. However, substantial advances over the last decade make the availability of accurate gestational age measurement possible in most countries. Antenatal care coverage has increased and ultrasound is more often available and at lower cost. While first trimester pregnancy ultrasound is still considered the gold standard for pregnancy dating, there is now evidence that sonography up to 22–24 weeks provides acceptable accuracy (13, 14). Recent ultrasound innovations may also increase the accuracy of gestational age assessment for pregnancies >24 weeks. In view of these advances, all countries should strive to invest in improving the accuracy of gestational age determination in the first trimester, use these data for better individual care and collate them in routine data systems.

Birth weight is a long-standing measure for assessing babies. Although data on weight have been routinely collected for decades, the widespread introduction of digital scales over the last decade enables greater accuracy.

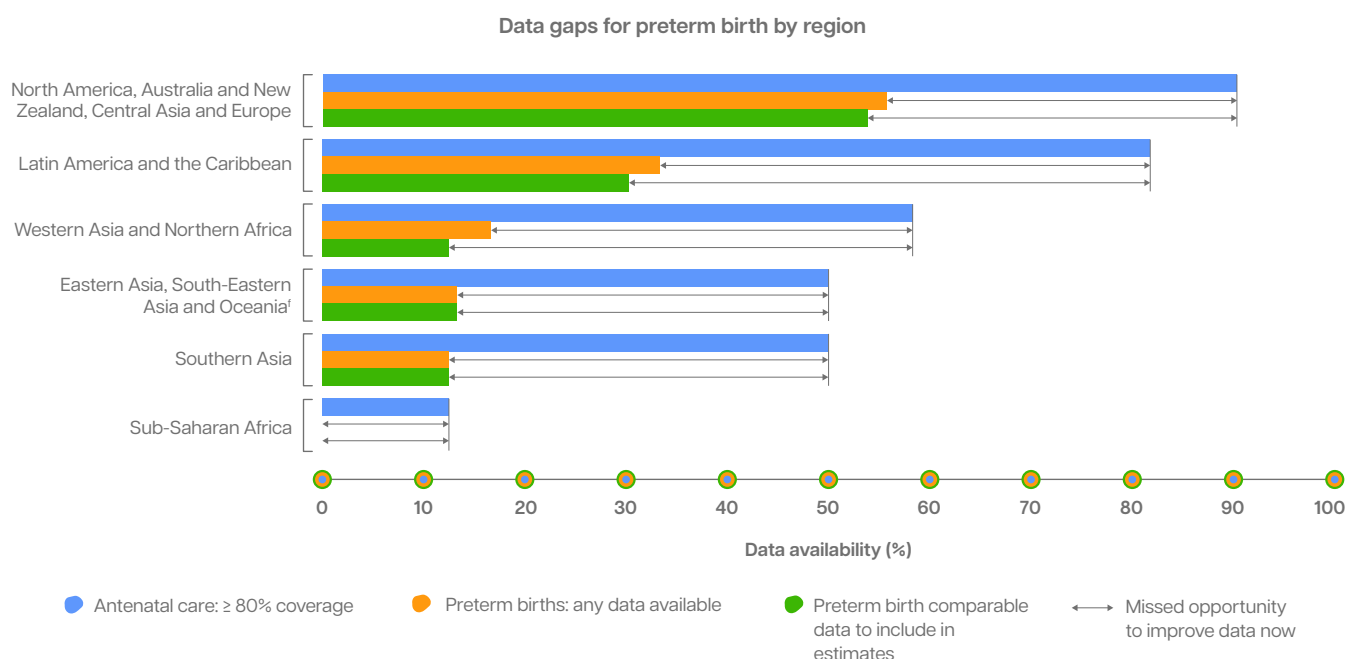
Routine assessment of size for gestational age is also now possible, given the improvements in measurement of gestational age and birth weight over the past decade, coupled with the release of the INTERGROWTH-21st growth standards (15). Pivoting to including size-for-gestational-age assessment for every baby will facilitate more granular classification of risks for vulnerable newborns, for example by newborn type, combining size-for-gestational-age with gestational age. This information will improve individual clinical care, enable better assessment of long-term outcomes and help drive accountability for progress towards global nutrition targets and relevant SDGs (12).

Pivot 2: Strengthen routine data systems for tracking progress of small babies, including follow-up care

Despite the increasing rates of births in health facilities over the past decade (now around 80% worldwide) and investments in health information systems, opportunities have been missed to improve preterm birth data. Recording gestational age information in labour wards for all facility births, and collating aggregate data through health information systems, would enable the tracking of progress at national and subnational levels. Only 33% of countries and areas (64 out of 195) routinely collected national preterm birth data of sufficient quality to be included in the latest round of global, regional and national preterm birth estimates for 2010–2020; however, 81% (158) have useable low-birth-weight data, partly due to this being measured in surveys. Gaps in routinely collected data on preterm birth are most marked in Southern Asia, South-Eastern Asia and sub-Saharan Africa which, on average, also have the highest rates and absolute numbers of preterm births (Figure 2.7).



Mahlet is a midwife in rural Ethiopia.
© World Vision Canada

FIGURE 2.7 Missed opportunities to improve capture of national administrative data on preterm birth, by SDG region, 2010–2020

[†] Excluding Australia and New Zealand

Figure represents gaps for 194 WHO Member States and the occupied Palestinian territory, including east Jerusalem.

≥80% coverage of four antenatal visits was used as a proxy for early antenatal attendance and accurate gestational assessment.

Adapted from Lawn et al. (12)

Reliable preterm birth data are achievable in countries that have both high rates of births in health facilities and robust health information data systems. Improving routine data systems in these countries requires attention and adequate investment. In countries with weak routine data systems and fewer births in health facilities, and in settings affected by conflict or other humanitarian crises, innovative strategies are needed to collect and use data on preterm birth.

While the first step towards overcoming data gaps for preterm birth is to ensure that every baby, live- or stillborn, is counted and recorded in relevant data systems, it is also necessary to improve data quality to maximize comparability. Over the last decade, tools have been developed to assess the quality of data on newborns within routine health information systems (16, 17).

Most routine health information systems record only aggregate data in their electronic data systems. Over the next decade, increasing national coverage of electronic-based individual-level data will be an important step. Individual-level data are crucial for individualized care and quality improvement on maternity wards and newborn care wards. When setting up such a dataset it is important to start small and focus on high capture and data quality, expanding the variables later. Having a standard dataset, for example for

neonatal inpatient care, can address programmatic quality issues, such as hypothermia at admission for inborn and outborn babies, and by weight group. In settings with more robust data collection systems, individual-level data with unique identifiers can enable linkages to track short- and long-term outcomes following preterm birth and other vulnerable newborn types across populations, in order to reduce gaps in follow-up care (12). Such electronic cohorts also enable long-term human capital outcomes to be tracked across the life-course, including health, education, welfare and economic outcomes (18). Currently there are very few such studies in LMICs.

Individual-level data facilitate equity analyses. Disaggregated data can be used to identify the geographical and other population groups with the worst outcomes, enabling resources to be allocated to the populations in greatest need.

Improved data are also needed to understand the drivers of preterm birth in different settings. A first step towards this is to collect information for every baby on whether birth was spontaneous or provider-initiated, using more standard definitions and applying this data to inform interventions, such as reducing non-medically indicated caesarean sections (19).

Pivot 3: Improve the use of data for action and accountability

The final pivot for data on preterm birth and other small babies is to ensure that these data are used to drive accountability for action. This requires data, not only on preterm birth rates and outcomes, but also on what works and how to address key risk factors and improve coverage of high-quality care for preterm babies at all levels of the health system. Data need to be accessible to a range of

stakeholders, including governments and ministries of health, and public health policy planners and implementers. Importantly, they also need to enable families and civil society to engage actively in accountability processes. A range of formats is likely to be required, such as annual health reports, maternity reports, dashboards, open databases and lay summaries, such as March of Dimes' annual report of state-level preterm birth rates across the United States of America (Box 2.4).

BOX 2.4 Country snapshot

Annual report on state-level preterm birth rates to drive change in the United States

Between 1980 and 2006, the USA experienced a 30% relative increase in preterm births. In response, March of Dimes, an organization advocating for maternal and newborn health in the USA since 1938, launched an annual "report card" to track preterm birth rates at the state level and across the nation, in order to inform stakeholders and to advocate for federal and state policy changes to improve maternal and newborn health. Published each November during Prematurity Awareness Month, the report grades each state according to a preterm birth goal of 8.1%, calculated using several interventions known to be effective in reducing preterm birth, including modifiable risk factors for providers, individuals and communities. Interventions include smoking cessation, reduction of teenage pregnancies and reduction of non-medically indicated caesarean births. Since 2019, the reports have included data on maternal risk factors, social drivers and relevant policies.

The 2022 Report Card gave the USA a grade of D+ for preterm birth, compared to a C- in 2021. Capturing a full year of data from the COVID-19 pandemic, the 2022 Report Card revealed that outcomes for both mothers and babies had worsened. The preterm birth rate increased by 4% in one year, to 10.5%: the worst rate since 2007. Black and Native American women were 62% more likely than White women to give birth preterm, and their babies were twice as likely to die as those of White women.

The report cards depend on standard definitions and consistent data to ensure their mutual comparability. Unfortunately, public health surveillance data required for policy and programmatic decisions are often inaccessible to public health researchers in the USA. Although privacy is a key consideration, transparency is possible if safeguards are employed. A core minimum dataset, collected across states and also worldwide, is required. Investments are needed to increase the interoperability of data, both among agencies and more widely, to enable accountability and action. Importantly, the availability of timely annual data, in combination with the power of parent groups, has helped to drive accountability, receiving major media attention and increasing the scope for faster change.

UNITED STATES

Key reading

- Lancet Small Vulnerable Newborn Series (<https://www.thelancet.com/series/small-vulnerable-newborns>).
- United Nations Children's Fund (online database). UNICEF Data (<https://data.unicef.org/>).
- World Health Organization (online database). World Health Organization Data (<https://platform.who.int/data/maternal-newborn-child-adolescent-ageing>).
- United Nations Children's Fund (online database). Never forgotten: the situation of stillbirth around the globe. UNICEF; 2023 (<https://data.unicef.org/resources/never-forgotten-stillbirth-estimates-report/>).

Behind every statistic is a story

Meet **Jalen**

from **the United States of America**



Gabriela and Jerome remembering their son, Jalen.

Gabriela and Jerome Foster from Nevada, USA were excited about welcoming their third child to the family. Gabriela had gotten pregnant just three months after the birth of their second daughter.

However, on 27 November 2012, Gabriela went into preterm labour, and their son, Jalen, was stillborn having died of a common bacteria known as group B streptococcus or GBS. "I was admitted to the hospital with a high fever, chills and labour back pain. I held on to hope but never imagined to hear, 'there is no heartbeat'."

"I never imagined hearing 'there is no heartbeat'."

A month earlier, Gabriela had gone to the hospital complaining of clear fluid leakage. The nurse told her that it was just a yeast infection and discharged her. "I was never seen by a doctor nor did the nurse run a culture to make sure it was a yeast infection. If they had done that, they would have found GBS."

The pathology report confirmed that the cause of death was GBS. Gabriela had been aware of GBS testing in pregnancy but hadn't understood why it was done and why it was so important. "There was nothing that I could have done. There is no support to families who experience prenatal onset of GBS."

Their traumatic experience made them realize the lack of resources for families that suffer a pregnancy or infant loss in their community. "When we lost our son, there was no number to call for support. We felt helpless, alone and lost."

They started a non-profit organization in honour of their son to help families following such a tragic loss. "We didn't want someone else to be in the same situation that we were in," said Jerome. "We both wanted to make a difference in the community and honour our son, so we started Jalen's Gift." Their organization works with local hospitals, doctors' offices and hospice care facilities in Las Vegas offering families a memorial care package, remembrance photography, financial assistance towards burial costs and grief support.

In the next decade, Gabriela and Jerome would like to see more awareness about GBS in pregnancy as well as support to parents, especially to fathers, after a stillbirth. Through their work, they see the need to support fathers just as much as mothers in bereavement support.



Memorial to Jalen.

"Don't exclude fathers. You know, the moment you're pregnant, we're pregnant together, and when it just stops, you feel helpless. We have to help women understand their husbands' experience. I am grieving too. I lost a child as well. I think that is part of shaping the support for men."

Learn more about their organization at www.jalensgift.org



Father embraces preterm newborn in Brazil.
© Gláucia Galvão

Chapter 3

Rights and respect: putting people at the centre of the response to preterm birth

KEY MESSAGES

Progress

Human rights law and global health processes have increasingly recognized that upholding the rights of and respecting women, babies, parents and families, and health-care providers is essential for good health and well-being, stronger health systems and societal progress.

The fundamental rights of women, babies and their families include, but are not limited to: access to high-quality care, including developmental care; informed consent; being together; not being detained; and not being discriminated against. These rights can only be realized by protecting the rights of those who deliver the care: the health-care providers.

Priorities

Ensuring that the rights and respect relating to preterm birth are upheld will require action across the continuum of care, across sectors, and with strong partnerships between the mother–baby dyad and health-care providers, as well as the families, communities and systems that support them.

- National-level action requires the adoption and monitoring of international and regional human rights instruments, with multisectoral collaboration and social mobilization where violations continue.
- Community action requires strengthening accountability mechanisms at all levels and partnering with those affected by preterm birth when planning policy processes and in the design, implementation and monitoring of care, particularly women, families and health-care providers.
- Facility-level action requires that health systems are designed to respect and protect the fundamental human rights of the people in them, both care seekers and care providers. Implementing respectful care relating to preterm birth will require structural and social changes, as well as stronger data systems.
- Individual-level action requires a focus on caring for the mother–baby dyad, as well as understanding the needs of health-care providers, both for themselves and to provide high-quality, respectful care to patients.

Pivots

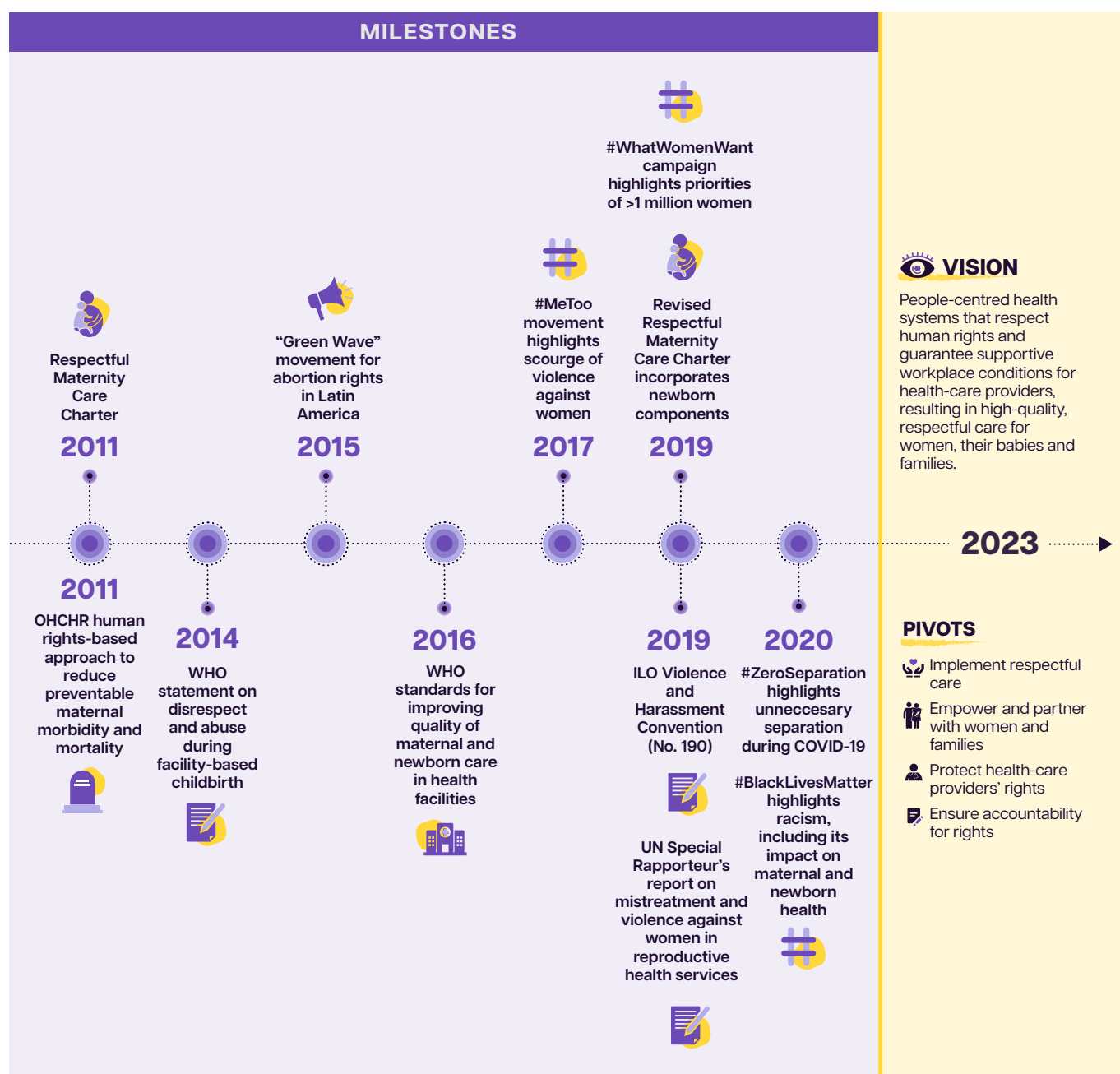
To operationalize respectful and rights-based care for preterm birth, four primary shifts are needed: scaling up respectful care; empowering and partnering with women and families; addressing the shortage of health-care providers and protecting their rights; and strengthening policy action and accountability.

PROGRESS

This chapter focuses on respecting and upholding the rights of women, babies, parents, families and health-care providers. Over the past century, human rights law and global health processes have increasingly recognized that the rights relating

to preterm birth are critical for good health and well-being, stronger health systems and societal progress (1). Since the publication of the 2012 *Born Too Soon* report, the global human rights landscape pertaining to preterm birth has seen major advances in policies, guidelines and action (Figure 3.1) (2, 3, 4, 5, 6, 7, 8).

FIGURE 3.1 Rights and respect: timeline of progress over the past decade and vision for the next decade



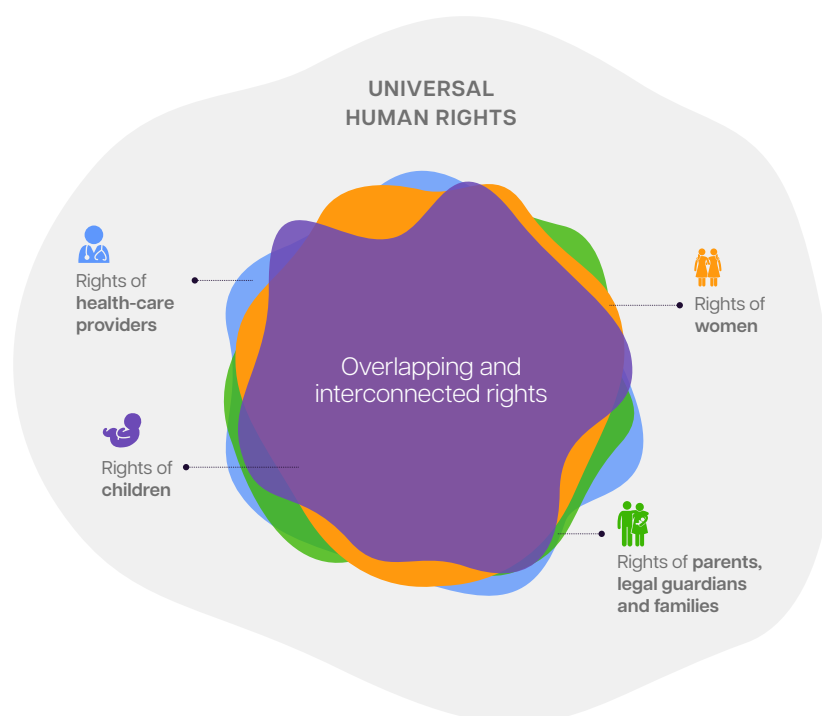
Human rights belong to all people, without discrimination. While the rights of women, children (including those born preterm), their parents and families, and health-care providers overlap, some specific rights are important to specific populations, or dependent on the local situation. These rights include access to high-quality care, including

developmental care, as well as informed consent, being together, absence of detainment and absence of discrimination. Beyond the health-care facility, important rights relevant to preterm births include the rights to social protection, maternity leave and childcare, as well as early identification and rehabilitation in cases of disability. Of course,

these rights cannot be realized without protecting the rights of health-care providers, including the rights to freedom of association (including unionization and collective bargaining), to decent working conditions and to fair pay. Figure 3.2

illustrates how the human rights of these groups intersect and overlap. The supplementary web files for this report provide illustrative examples of these rights (available at the end of this chapter).

FIGURE 3.2 The overlapping human rights of women, children, parents and families, and health-care providers



The SDGs and the linked *Global Strategy for Women's, Children's and Adolescents' Health* focus more strongly on rights than previous global goals and strategies (9). UN human rights treaty-monitoring bodies continue to articulate and explain the rights of women and children, and approaches to realizing these rights, such as measures to ensure access to birth registration (10, 11). More recent human rights treaties, such as the Convention on the Rights of Persons with Disabilities (2006), have further articulated rights relating to preterm birth (1). UN General Assembly resolutions on human rights have also made links with factors relevant to preterm birth, such as a healthy environment (12).

For the health workforce, in 2019, the International Labour Organization's Violence and Harassment Convention (No. 190) became the first international treaty to proclaim the right to work free from violence and harassment, including gender-based violence and harassment (5). Severe shortages and inequities remain in the global health workforce. For example, there is a global shortage of 900 000 midwifery positions (13). Initiatives such as the Midwives' Voices, Midwives' Demands campaign (2022), led by the White Ribbon Alliance, gave voice

to this cadre to demand better and more timely pay, and properly equipped workplaces (7).



© White Ribbon Alliance

Even with global advances, it can take decades before national policy changes, new legislation and human rights instruments take effect. However, some countries have made remarkable progress in the past decade. The UN has started to document

advances in addressing mistreatment of and violence against women in reproductive health services (11). Legal rulings upholding informed consent and the right to privacy by various regional and national courts, such as Mexico and the European Court of Human Rights, have bolstered these rights (14).

Social movements, such as Black Lives Matter and #MeToo, together with efforts for climate, reproductive and disability justice, have created space for new conversations, research and programmes, as policy-makers become more attentive to systems of oppression and to power-

related determinants of health, and activists and communities are further empowered to demand action. Some movements, such as “The Green Wave” in Latin America, have led directly to legal changes to protect reproductive rights (see Chapter 4). Campaigns such as What Women Want (6) have also shifted the health policy discourse and elevated women’s and parents’ voices (Box 3.1). Such social movements have prompted responses and action. For example, health-care professional associations have recognized and committed to respectful care by issuing statements and charters to guide members’ practice (Box 3.2) (15).

BOX 3.1 What Women Want: the power of participation

Launched in 2018, What Women Want is an unprecedented local-to-global advocacy campaign to improve the quality of reproductive and maternal health care for women and girls. The campaign, led



Woman participating in What Women Want campaign in Pakistan. © White Ribbon Alliance

by the White Ribbon Alliance and supported by 114 partners, asked 1.3 million women and girls in 24 countries to identify their top priority for their own reproductive and maternal health, listened carefully to their needs and aspirations, and acted by mobilizing women, communities and advocates to present demands to local and global decision-makers. The number one demand was for respect and dignity in health-care settings.

Listening to women and girls is a radical act. They know best what is needed for their health and well-being and that of their families and communities. Yet the views of women and girls are often met with disdain and

dismissal. Listening to women is a challenge to the power structures that often silence their voices and ignore their ambitions. To be listened to is to be valued.

The campaign mobilized more than US\$ 330 million in multigovernment health and social programmes, enabling major improvements in more than 40 000 health facilities and the hiring of more than 7000 additional health workers, and contributed to more than 40 health and gender policies. Worldwide, more than 500 million women and girls benefited from the courage of those who spoke out to demand their health and rights in this campaign. Social movements, such as the What Women Want campaign, pave the way towards increased rights and respect, including positive health and rights outcomes for women and their newborns who experience preterm birth.



Woman participating in What Women Want campaign in Nigeria. © White Ribbon Alliance

The trend towards respectful care has grown stronger worldwide over the past few decades, including respectful maternity care (RMC) and family-centred care (FCC) for babies, women and families. RMC is highly contextual and should be defined by the recipients of health-care services: women themselves. WHO defines RMC as “care provided to all women in a manner that upholds their rights and dignity, privacy and confidentiality, ensures freedom from harm and mistreatment,

and enables informed choice and continuous support during labour and childbirth” (16). Growing documentation of the mistreatment of women and health-care providers relating to maternity care has led to a greater focus on addressing the gaps in quality of care and the linked structural drivers (17, 18). In 2019, the Respectful Maternity Care Charter was updated to outline some of the fundamental rights of newborns, along with those of women, in health-care settings (Box 3.3) (3). WHO has also

acknowledged the importance of RMC in the past decade (4), incorporating positive experience of

care into new maternal and newborn health-related guidelines (19).

BOX 3.2 Health-care associations embrace women's demands for respect and dignity

Health-care settings, which should be safe spaces where women are listened to and provided with respectful, high-quality care, can instead be pervaded by disrespect and abuse. This can have direct negative consequences for women's health, as well as discouraging them from seeking care in the future for themselves and their babies.

In December 2022, recognizing the critical role of health-care professionals in responding to women's demands for respectful and dignified care, the Health-Care Professional Associations constituency of the Partnership for Maternal, Newborn & Child Health (PMNCH) issued a joint statement concerning the views expressed by more than 1.3 million women and girls in the What Women Want campaign (see Box 3.1) (15).

The statement acknowledged women's demands and the deeply rooted oppression that often underpins disrespect and abuse, including sexism, racism and colonialism, as well as structural barriers. The statement expressed the associations' unified commitment to address women's demands, and to introduce additional measures to provide all women, girls and gender-diverse people with high-quality and respectful care in every interaction, calling also on others to support these efforts. The associations committed to providing biannual updates on their ongoing work, including efforts to disseminate and promote it within their member organizations.

This interaction between civil society and health-care professional associations has been both constructive and instructive: it is a powerful example of the importance of amplifying women's voices, and of listening to and acting on their words.

BOX 3.3 Respectful Maternity Care Charter: the universal rights of women and newborns

- Everyone has the right to freedom from harm and ill-treatment.
- Everyone has the right to information, informed consent, and respect for their choices and preferences, including companion of choice during maternity care and refusal of medical procedures.
- Everyone has the right to privacy and confidentiality.
- Everyone is their own person from the moment of birth and has the right to be treated with dignity and respect.
- Everyone has the right to equality, freedom from discrimination and equitable care.
- Everyone has the right to health care and to the highest attainable level of health.
- Everyone has the right to liberty, autonomy, self-determination and freedom from arbitrary detention.
- Every child has the right to be with their parents or guardians.
- Everyone has the right to an identity and nationality from birth.
- Everyone has the right to adequate nutrition and clean water.



Midwives in India.

© UNICEF/UN0517364/Panjwani



Women in West Bengal advocating for improved quality, equity and dignity in reproductive, maternal and newborn health services.

© White Ribbon Alliance

FCC is defined as a “mutually beneficial partnership between health-care providers, patients and families in health-care planning, delivery and evaluation”. It includes basic human rights, such as dignity and respect, information sharing and participation (20). While the terminology of FCC has gained prominence in relation to preterm birth in recent decades, the concept is not new. In preterm care, FCC approaches consider the parents and family to be central to a child’s well-being, a paradigm shift in many neonatal units. Adopting FCC approaches in preterm care has proven benefits for babies and parents in both low- and high-income settings (21, 22), and is recommended in the new WHO guidelines on the care of preterm and low-birth-weight babies (19). The policy of “zero separation” of the mother–baby dyad (especially important given the enduring legacy of restrictive policies implemented during the COVID-19 pandemic) reflects core concepts of both FCC and RMC (8).

Global political, economic and health system trends have important consequences for rights and accountability relating to preterm birth. Some of these facilitate the recognition of rights, and others work against them. As described in Chapter 1, conflict, climate change, COVID-19 and the cost-of-living crisis have had devastating impacts, including on health systems. Respectful care for women and babies typically has not been front and centre in responses to these crises (23) and many countries offer only limited rights. In the COVID-19 pandemic, many women were deprived of their right to a birthing companion, and parents were deprived of their right to care for their babies (8, 23). While access to care remains poorest in the highest-burden settings, over-medicalization of maternity care has also resulted in unnecessary interventions,

including caesarean sections (see Chapter 4). Increasing calls to localize and decolonize public health and humanitarian assistance are echoed by calls for greater community input into decisions, attention to rights, and consideration of the full spectrum of sexual, reproductive, maternal and newborn health in service delivery (24).

PROGRAMMATIC PRIORITIES

Ensuring rights and respect in preterm birth prevention and care will require action across the continuum of care, across sectors, and with strong partnerships between the mother–baby dyad and health-care professionals, as well as the families, communities and systems that support them. Priority actions required at different levels will vary, but all must be rooted in human rights principles, including equity and non-discrimination, participation, transparency, empowerment, the best interests of the child, international cooperation and assistance, and accountability. Programmatic priorities needed at each level are highlighted below, according to the continuum of care, and drawing from evidence and country experiences (25, 26, 27, 28).

National level: laws, participation and accountability matter

States are responsible for adopting global human rights laws and legal frameworks relating to preterm birth, for implementing them, and for monitoring their application and violations. The adoption of international and regional human rights instruments by States is fundamental: it provides the legal basis for implementing policies and interventions, including on the right to health, family leave, breastfeeding and health-care workers’ rights. Critically, States need to provide financial protection for women and families, given the high costs of care relating to preterm birth, including through comprehensive universal health coverage (UHC) plans.



Citizen Hearing in Uganda.
© White Ribbon Alliance

The social, environmental and other determinants of maternal and newborn health, such as pollution and racism-related stress, also need to be addressed (see Chapter 6). States have a duty to actively monitor and document rights violations. Multisectoral collaboration and social mobilization are necessary where violations have become normalized due to drivers perceived to be unchangeable, such as stigma, discrimination, corruption and rigid professional hierarchies.

At the national level, community participation and community-driven efforts to interpret global guidance and to demand accountability for implementation are key. Those affected by preterm birth should participate actively in the formulation and adoption of relevant national and subnational

policies and practices, and there are inspiring country examples of how this can be done (Box 3.4). When parents and health-care professionals work together, combining their skills and experience, they can make meaningful progress that addresses inequalities and fosters respectful care. Accountability mechanisms that enable public conversations about preterm-related rights, such as citizen hearings at which citizens can publicly voice their concerns, should be adapted to context and implemented urgently. Advocacy days or months also provide opportunities to raise awareness and advance norms around rights and respect relating to preterm birth. Examples are World Prematurity Day (November 17), World Birth Defects Day (March 3) and Pregnancy and Infant Loss Remembrance Month (October).

BOX 3.4 Country snapshot

Maternity leave in Brazil

In 2020, the Brazilian Supreme Court upheld a claim for extended paid maternity leave in cases of childbirth followed by hospitalization, whether due to preterm birth or to any health condition that caused the mother or baby to be hospitalized after delivery. The case was the culmination of years of advocacy and dialogue with politicians and decision-makers. A nongovernmental organization, the Brazilian Parents of Preemies' Association, together with affected mothers, engaged with interministerial government bodies, including representatives of the Ministry of Health, the Ministry of Women, Family and Human Rights and the Ministry of Citizenship and Human Rights, and raised awareness of the struggles faced by the families of preterm babies in Brazil. The law now allows for extended maternity leave when a mother or baby remains in hospital for longer than 14 days. This favours bonding, increases the chances of breastfeeding, and ensures better mental and physical health for mothers and babies, in addition to enabling women to act more productively in the labour market. The law also benefits families of preterm babies, who are likely to have longer hospital stays after delivery than their full-term counterparts, increasing the stress and financial strain for their families.

Community level: empowerment and participation matter

There are multiple approaches to community-level engagement for rights and accountability. Social accountability programmes typically entail communities assessing the quality of care against an agreed standard, and then engaging in dialogue and collective action to negotiate improvements and accountability (29). Most accountability efforts to date have focused on accountability for clients of health services or their communities, as the ultimate rights-holders, with the State (usually the Ministry of Health) being the party responsible for delivering on the right to high-quality maternal and newborn health care, as the duty-bearer. For their part, States and those in charge of health systems can enable and institutionalize these discussions through participation and by establishing community advisory committees or hospital community boards. Likewise, health-care providers and communities can organize to

demand improvements in their working conditions and, by extension, their ability to provide respectful, accountable care.

Community scorecards are an example of a means of improving the accountability of government and community groups, as demonstrated in Ghana (Box 3.5). Community members identify specific improvements that health facilities can make to better serve families at high risk and those caring for a preterm baby. Communication campaigns for social and behavioural change can raise awareness of the needs and rights of preterm babies and their families (30).

BRAZIL

Women's support groups and peer support models, such as parent groups, reflect evidence-based strategies for improving health outcomes, preparedness after discharge and parents' mental health (31). Greater understanding of

different models in different contexts, especially in LMICs, can strengthen and sustain such programmes. Women and parents can partner in research projects and in health system redesign, contributing their unique expertise.

BOX 3.5 Country snapshot

Ghana's quality of care community scorecards

In 2017, Ghana Health Services developed and rolled out a system of scorecards relating to high-quality maternal and newborn health, with the aim of improving community accountability mechanisms. The scorecards align with national standards for high-quality maternal and newborn care, including a standard specifically concerning rights and respect. The inclusion of human rights provisions in the standards of care provides a mechanism to hold the health system to account. Community committees, comprised of volunteers from the local community, complete the scorecard collectively every quarter, rating health facilities on the perceived levels of respect and compassion provided in their care, and access to health insurance. The results are submitted to and reviewed by health facilities' quality improvement teams, who respond locally or request support from the regional health service. To ensure sustainability, the regional quality director is responsible for ensuring that scorecards are completed and responded to regularly. Every year, the Ghana Health Service publicly recognizes regions responding well to the scorecards at the national quality of care conference, as an incentive for other regions to strengthen their use of the scorecards. The use of community scorecards has increased accountability for and community engagement in the quality of maternal and newborn health services in Ghana, and is a strong model that could be replicated elsewhere.

Facility level: strong health-system readiness matters

The health system, including all levels of health facilities, plays a critical role in promoting respectful care and creating a supportive environment for women, babies, parents and health-care providers. Long-standing priorities for respectful care at facilities include privacy during childbirth, care for babies and their parents, and support for kangaroo mother care (KMC) and breastfeeding. Programmes must include the elimination of routine practices involving disrespect, such as breaking the mother–baby dyad or unnecessary caesarean sections, which can also exacerbate the prevalence of preterm birth (see Chapter 4). Over the past decade, multiple global guidance documents have been published to support health facilities in operationalizing a rights- and respect-based approach (26, 32, 33). Health-care providers need to assess treatment plans with parents and be guided by the best interests of the child, as provided by the Convention on the Rights of the Child (1).

Health facilities must also remove any policies and practices of detention for failure to provide payment relating to preterm birth, which are common but often undocumented. The threat of high care costs and the risk of detention discourage women from attending health facilities, reducing antenatal care and increasing the risk of maternal and newborn

death. Despite clearly violating human rights, this practice continues in many settings, such as in Nigeria (34), highlighting the urgency and critical importance of implementing equity-enhancing UHC policies.



Partnership with women and parents of preterm babies requires specific investments and efforts. For example, to keep the mother–baby dyad intact, health facilities require specific resources, such as beds for KMC, and can partner with parents, whose experiences are valuable for helping to design

these units. Parent–provider communication at the facility level is critical for preterm birth outcomes. Various FCC models seek to fulfil the human rights of children and their families: these may vary according to context (Box 3.6).

BOX 3.6 Country snapshot

Whole-of-community approach to caring for preterm babies in Uganda

Research in Eastern-Central Uganda by the Makerere University Centre of Excellence for Maternal Newborn and Child Health reveals the need for a “whole family” support culture for women with preterm babies who are admitted to hospital. Mothers are encouraged to play an active role in caring for their preterm babies, for example by checking their temperature, feeding them and providing skin-to-skin contact. However, care for preterm babies is not left only to parents: many relatives also provide logistical, emotional and financial support. Although it is still difficult for many other facilities, newborn care centres of excellence, such as Kiwoko Hospital, are making strides in improving the comfort of mothers in newborn care units, for instance by providing meals, guaranteeing privacy and providing laundry services and beds for mothers in the unit. Such family-centred care improves mother–baby bonding, results in earlier discharge, and decreases mothers’ anxiety by boosting their confidence in their ability to care for their baby. This excellent example of a whole-of-community approach to supporting women and preterm babies can inspire other facilities.

Respectful care also requires systems and facilities to respect the health workforce. Good leadership and management in health systems are critical to address the organizational issues preventing respectful care (25). Addressing these challenges will require transformational institutional leadership, strengthened supervision, improved accountability mechanisms and greater investments in the health workforce.

Health-care providers’ competency and workplaces matter

Health-care providers are at the front line of the provision of respectful care to women, babies and parents. As well as providing clinical care, they also prepare and support parents and families in caring for their preterm babies after discharge. Health-care providers require adequate and continuous education in the knowledge, attitudes and skills required to provide respectful care, not only to fulfil their role as caregiving partners, but also to be aware of their own rights. Special training relating to preterm birth may focus, for example, on: birthing companions; communication with affected parents and families to understand their preferences; and presentation of care options in informed and non-judgemental ways. Health-care providers need professional development, good supervision and enabling environments that respect their rights. They may also need emotional and psychological support to cope with adverse outcomes, such as preterm birth and stillbirth.



Class of midwives in India.
© White Ribbon Alliance

Many health-care providers struggle to respect and fulfil the rights of their patients because their own rights are not respected (32). Health-care providers, especially midwives, are often overworked, underpaid and under-resourced with the tools (space, equipment, training) necessary to provide respectful care. Most providers of preterm birth care, notably midwives and nurses, are women and may also suffer from harmful gendered power relations in the workplace (18). Intentional efforts are needed to tackle the gender power relations that prevent respectful care (35). Understanding the needs of health-care providers, both for themselves and to provide high-quality, respectful care to patients, is vital for improving the care of preterm babies and their families. *The State of the World's*

Midwifery 2021 clearly outlines programmatic priorities for maternity care with an integrated human-rights focus: more approaches like this are needed (13).

The mother–baby dyad: respectful, high-quality care and participation matter

Respecting and supporting the mother–baby dyad helps to fulfil the rights of both, and usually benefits both, physiologically and emotionally. However, respecting the birth mother’s rights, preferences or medical needs may occasionally require her absence from the newborn, and the child’s best interests may include active involvement by others (other parent or caregivers, and/or health-care professionals).



Mother with preterm baby in Armenia.
© WHO / Malin Bring

As described above, caring for the mother and baby as a dyad involves enabling evidence-based practices, such as skin-to-skin contact, KMC and breastfeeding (Chapter 5). At the individual level for mothers and babies, autonomy and influence over decisions regarding the pregnancy and birth are important. While fathers, partners or other caregivers can play a critical role in supporting the new mother and caring for the baby, women’s voices need to be heard at all levels of the health system. Contributions by fathers and partners to caregiving also have the benefit of helping them to bond with the preterm baby and to embrace their caregiver role (36). Parental involvement during inpatient neonatal intensive care is proven to benefit newborn outcomes, including weight gain and increased frequency of exclusive breastmilk feeding after discharge, as well as benefiting their parents (21, 37).

Mental health support for affected parents is another priority. This includes bereavement care in cases of death, and counselling when a preterm baby survives. Communication and counselling, effective provider–parental engagement and supportive work environments are founded in human rights, and also reduce parental stress and anxiety (28). Separation can lead to short- and long-term negative health and social consequences for parents, including depression and chronic stress disorder, and for decreased alertness in newborns; this in turn poses the risk of a myriad of long-lasting detriments to the child’s physical, social and cognitive development (38).

Women especially, but also other affected parents and families, need the knowledge, confidence and skills to advocate for respectful care, as well as security against retaliation for speaking out. Empowering women, particularly, is a priority to ensure that they can make effective decisions relating to their health and that of their preterm baby, and seek mental health services when needed.

Research and monitoring tools already exist to measure the level of respect for women in maternity care settings, and new tools are under development that incorporate questions about respectful care of the mother–baby dyad in the postnatal period (39). Interventions to improve the experience of families with babies in intensive care have been identified (40) but further research is needed on implementation, especially in low-resource settings.

PIVOTS

Rights-based approaches to preterm birth care, and in health care more broadly, have never been more acutely needed. Conflict, climate change, COVID-19 and the cost-of-living crisis have weakened health and political systems, placing women, babies, affected parents and families, and health-care providers at even greater risk. Multilevel, multisectoral and multistakeholder action is needed to address the systemic barriers preventing the realization of these rights by the most affected. While countries would greatly benefit from a wide range of interventions, four major shifts towards respectful and rights-based care in the coming decade are prioritized here.

Pivot 1: Scale up respectful care for women, babies, parents and families

Realizing respectful care by scaling up RMC and FCC will require whole systems to be reimagined and redesigned. Change must take place at all levels, including in: national policies that secure rights and the legal systems that uphold them; health system design and implementation; community empowerment and accountability; and the social norms and practices of individuals. Now that “experience of care” is firmly embedded in global policies and guidelines, national and subnational policies and resources are needed to enable its implementation. Financial protection, as part of UHC, needs to be in place for families affected by preterm birth, due to the potentially high costs of immediate and ongoing care and the threat of detention in facilities due to failure to pay.

Pivot 2: Empower and partner with women and families

Meaningful partnership and active participation are key human rights principles. Women and affected families have a central role to play in preterm birth prevention and care. Ensuring the protection of their rights will require action and accountability through mobilization via networks, digital technology, social media, social accountability and legal empowerment. Empowering and partnering with advocates, civil society organizations and community-based initiatives, such as women’s groups and affected parents’ groups, are necessary to prevent and care for preterm births in a way that is both effective and supportive of rights. Policy-makers and donors will benefit from exploring how to better partner with, equip and finance women’s groups and parents’ support groups, creating opportunities for them to raise their needs and concerns, and providing trauma-informed and respectful care. Involving women and families of preterm babies in all aspects of care, policy, and budgetary, administrative and judicial processes enables their needs to be met, ultimately raising the quality of care and fostering the implementation and sustainability of RMC and FCC.

Pivot 3: Protect health-care providers’ rights

Health-care providers and managers are responsible for delivering systems that function effectively, providing life-saving and harm-free health services while protecting the rights of both those seeking and those providing care. Core to this will be addressing the global health-care provider shortage across all cadres, and especially of midwives and nurses who are at the front line

of preterm birth prevention and care. Additionally, everyone working in health care must receive fair pay and enjoy safe and decent working environments. The elimination of workplace harassment and the protection of health workers’ rights are urgently needed, supported by clear mechanisms through which the State can be held accountable. Legal and social approaches must be used, with explicit reporting mechanisms and transparent implications for all actors at community, facility and national levels. For example, health-care providers must be able to raise issues, such as stock outs, without fear of repercussions.



Training on respectful maternity care for district medical officers, quality managers and nursing staff at Balurghat Super Specialty Hospital, West Bengal, India.

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Pivot 4: Strengthen inclusive, transparent and data-driven policy action and accountability

Strengthening accountability in the health system overall will improve not only care for women and babies but also health-care providers’ working conditions. Transparent and clear accountability mechanisms will be necessary at all levels: between providers, within facilities and throughout the health system. To achieve this, more and better data are needed to drive action to improve preterm birth outcomes, including qualitative and quantitative indices, benchmarks and tools. Standard indicators for RMC and FCC need to be agreed and data should be routinely collected, together with maternal and newborn health indicators, and embedded within national health information systems to inform strategies for improving outcomes.

Key reading

- Zampas C, Amin A, O'Hanlon L, Bjerregaard A, Mehrtash H, Khosla R, et al. Operationalizing a human rights-based approach to address mistreatment against women during childbirth. *Health Hum Rights*. 2020;22(1):251-64 (<https://pubmed.ncbi.nlm.nih.gov/32669805/>).
- Respectful Maternity Care Charter: Universal rights of mothers and newborns. Washington DC: White Ribbon Alliance; 2019 (https://whiteribbonalliance.org/wp-content/uploads/2022/05/WRA_RMC_Charter_FINAL.pdf).
- Human rights instruments (website). United Nations Human Rights Office of the High Commissioner (<https://www.ohchr.org/en/instruments-listings#tab-1>).
- Global Alliance for Newborn Care (website). European Foundation for the Care of Newborn Infants (<https://www.efcni.org/activities/projects/glance-global-alliance-for-newborn-care/>).

Behind every statistic is a story

Meet Santiago from Costa Rica



Pablo and Katherine
and their son Santiago.

Pablo Mendez and his wife Katherine were elated when she became pregnant with their first child. Like any first-time parents, they made a schedule of everything they would need to do to welcome the baby, including remodelling their house in Heredia City, Costa Rica.

However, in February 2020, at 25 weeks' gestation, Katherine went into preterm labour and was taken into surgery, where their son Santiago was born.

"We had made sure to tick all the boxes. We had not missed any clinics, we had all the tests and scans done and they showed that our baby was doing well. Suddenly there was fear and uncertainty, and everything was just too complex for us to handle."

Because of the uncertainty at the beginning of the COVID-19 pandemic, Pablo was not allowed into the operating theatre with his wife. Santiago was taken to the NICU. Visiting restrictions were put in place as the hospital tried to cope with COVID-19, and Pablo's access to both his wife and his son was extremely limited.

"I felt so powerless."

"I was not allowed to see my son. Only mothers and women could enter the area, no men were allowed in. And when my wife got an infection post-surgery, I was only allowed to see Santiago for 15 minutes, and I was not allowed to touch him. I felt so powerless."

Initially, doctors told Pablo that Santiago had blood on his brain that might cause some health issues. Weeks later, they learned he had cerebral paralysis. Katherine was able to hold her son when he was four weeks old. She provided skin-to-skin contact three times a day but could not breastfeed

Santiago until his feeding tubes were removed two months later. Pablo's first opportunity for physical contact with Santiago was six weeks after his birth.

"That happened by chance. The nurse was cleaning his incubator and she asked me to hold him while she did it. And you can imagine, Santiago was the size of my hand."

Santiago was discharged when he was 4 months old. He is unable to hold up his head or sit by himself. He is fed via a machine. He has also been diagnosed with West Syndrome: a severe infantile epileptic condition which causes seizures as well as cognitive and developmental impairments.



Santiago in the NICU.

"He is still the sweetest boy. He is starting to enjoy therapy and is becoming more aware of his environment. He has a couple of gastrointestinal and renal surgeries scheduled, but for now we are just trying to enjoy every moment, every milestone he makes. Something as simple as him laughing means so much to us, and we celebrate each laugh."

The change that Katherine and Pablo would most like to see in the next decade is partnership between medical practitioners and patients. Sometimes they felt "foolish" when asking questions or not listened to by health-care providers. They believe the partnership between themselves, all of the people in the hospitals, therapists, family and friends in caring for Santiago has been central to their progress.

SUPPLEMENTARY FILE 1: Key human rights conventions relevant to preterm birth and related rights**Global**

- Convention on the Rights of the Child (1989)
- Convention on Elimination of All Forms of Discrimination Against Women (1979)
- International Covenant on Civil and Political Rights (1966)
- International Covenant on Economic, Social and Cultural Rights (1966)
- Convention on the Rights of Persons with Disabilities (2006)
- Convention on the Elimination of All Forms of Racial Discrimination (1965)
- International Labour Organization conventions

Regional

- The African Charter on Human and People's Rights (1981)
- The African Charter on the Rights and Welfare of the Child (1990)
- The American Convention on Human Rights (1969)
- The Inter-American Convention on the Prevention, Punishment, and Eradication of Violence against Women (1994)
- The European Convention on Human Rights and Biomedicine (1997)

Illustrative articles relevant to preterm birth

Human right	Legal foundation	Text
Social protection	ICESCR	Art. 10: "Special protection should be accorded to mothers during a reasonable period before and after childbirth. During such period working mothers should be accorded paid leave or leave with adequate social security benefits"
Social protection	CEDAW	Art. 11: "maternity leave with pay or with comparable social benefits without loss of former employment, seniority or social allowances"; "provision of the necessary supporting social services to enable parents to combine family obligations with work responsibilities and participation in public life, in particular through promoting the establishment and development of a network of child-care facilities"
Social protection	CRC	Art. 26: "for every child the right to benefit from social security, including social insurance"
Health	ICESCR	Art. 12: "enjoyment of the highest attainable standard of physical and mental health"; "reduction of the stillbirth rate and of infant mortality and for the healthy development of the child"
Health	CEDAW	Art 12: "ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation"
Health	CRC	Art. 24: "enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health"; "diminish infant and child mortality"; "ensure the provision of necessary medical assistance and health care"; "ensure appropriate pre-natal and post-natal health care for mothers"
Health	CRPD	Art. 25: "persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability"; "Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children"
Family planning	CEDAW	Art. 10: "Access to specific educational information to help to ensure the health and well-being of families, including information and advice on family planning"
Equality and nondiscrimination	ICCPR	Art. 26: "equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status"
Equality and nondiscrimination	ICESCR	Art. 2: "without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status"
Equality and nondiscrimination	CRC	Art. 2: "without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status"

Human right	Legal foundation	Text
Equality and nondiscrimination	CRC	Art. 23: "right of the disabled child to special care"
Equality and nondiscrimination	CEDAW	Art. 12: "eliminate discrimination against women in the field of health care"
Equality and nondiscrimination	CRPD	Art. 5: "prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds" Art. 25: "ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation"
Information	ICCPR	Art. 19: "freedom to seek, receive and impart information"
Information	CRC	Art. 13: "freedom to seek, receive and impart information"
Information	CRC	Art. 5: "respect the responsibilities, rights and duties of parents ... members of the extended family or community ... legal guardians or other persons legally responsible for the child, to provide ... appropriate direction and guidance in the exercise by the child of the rights"
Informed consent	European Convention on Human Rights in Biomedicine	Art. 5: "An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it. This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks. The person concerned may freely withdraw consent at any time" Art. 6: "Where, according to law, a minor does not have the capacity to consent to an intervention, the intervention may only be carried out with the authorization of his or her representative or an authority or a person or body provided for by law"
Respect and dignity	ICCPR	Art. 17: "unlawful attacks on his honour and reputation"
Respect and dignity	CRC	Art. 16: "unlawful attacks on his or her honour and reputation"
Respect and dignity	CRC	Art. 23: "mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community"
Respect and dignity	African Charter on the Rights and Welfare of the Child	Art. 13: "Every child who is mentally or physically disabled shall have the right to special measures of protection in keeping with his physical and moral needs and under conditions which ensure his dignity, promote his self-reliance and active participation in the community"
Privacy	ICCPR	Art. 17: "arbitrary or unlawful interference with his privacy, family"
Privacy	CRC	Art. 12: "arbitrary or unlawful interference with his or her privacy, family"
Privacy	CRDP	Art. 22: "protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others"
Privacy	European Convention on Human Rights in Biomedicine	Art. 10: "Everyone has the right to respect for private life in relation to information about his or her health. Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed"
No separation	CRC	Art. 9: "a child shall not be separated from his or her parents against their will"
Nutrition	CEDAW	Art. 12: "States Parties shall ensure to women ... adequate nutrition during pregnancy and lactation"
Nutrition	CRC	Art. 24: "ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents"
Nutrition	CRPD	Art. 25: "Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability"
Best interests of the child	CRC	Art. 3: "In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration"
Decent work and fair pay	ICESCR	Art. 7: "Fair wages and equal remuneration for work of equal value without distinction of any kind, in particular women being guaranteed conditions of work not inferior to those enjoyed by men, with equal pay for equal work"; "Safe and healthy working conditions"
Freedom of association	ICCPR	Art. 22: "the right to freedom of association with others, including the right to form and join trade unions for the protection of his interests"
Freedom of association	ILO Convention No. 87	Freedom of Association and Protection of the Right to Organize
Collective bargaining	ILO Convention No. 98	Right to Organize and Collective Bargaining

Human right	Legal foundation	Text
Equal remuneration	ILO Convention No. 100	Equal Remuneration Convention
Discrimination in employment	ILO Convention No. 111	Discrimination (Employment and Occupation) Convention
Occupational safety	ILO Convention No. 155	Occupational Safety and Health Convention
Freedom from harassment	ILO Convention No. 190	Art. 4: "the right of everyone to a world of work free from violence and harassment"

Mapping of international and regional human rights and instruments pertaining to the rights of women,

newborns and health-care workers to demonstrate overlapping and intersecting rights

Human right	International human rights instruments					
Right to health	ICESCR	CEDAW	CRC	CRPD		
Right to equality and nondiscrimination	ICCPR	ICESCR	CEDAW	CRC	CRPD	ICERD
Right to social protection	ICESCR	CEDAW	CRC	CRPD	ICERD	
Right to information	ICCPR	CEDAW	CRC	CRPD		
Right to dignity and privacy	ICCPR	CRC	CRPD			
Right to food and nutrition	ICESCR	CEDAW	CRC	CRPD		
Right to decent work and fair pay	ICESCR	ICERD	CRPD	CEDAW	ILO Convention No. 100	ILO Convention No. 190
Right to freedom of association and to form a union	ICCPR	ICERD	CRPD	ILO Convention No. 87	ILO Convention No. 98	

Key:

CRC: Convention on the Rights of the Child (1989)

CEDAW: Convention on Elimination of All Forms of Discrimination Against Women (1979)

ICCPR: International Covenant on Civil and Political Rights (1966)

ICESCR: International Covenant on Economic, Social and Cultural Rights (1966)

CRPD: Convention on the Rights of Persons with Disabilities (2006)

ICERD: Convention on the Elimination of All Forms of Racial Discrimination (1965)

ILO: International Labour Organization Conventions

1. United Nations. Convention on the Rights of the Child, Resolution 44/25,. United Nations General Assembly (1989). Available from: <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child>
2. United Nations. Convention on the Elimination of All Forms of Discrimination against Women, General Assembly resolution 34/180 (1979). Available from: <https://www.ohchr.org/sites/default/files/Documents/ProfessionalInterest/cedaw.pdf>
3. United Nations. International Covenant on Civil and Political Rights, General Assembly resolution 2200A (XXI). (1966). Available from: <https://www.ohchr.org/sites/default/files/ccpr.pdf>
4. United Nations. International Covenant on Economic, Social and Cultural Rights, General Assembly resolution 2200A (XXI). (1966). Available from: <https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-economic-social-and-cultural-rights>
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7. International Labour Organization [Internet]. Conventions and Recommendations 2023 [cited 26 March 2023.]. Available from: <https://www.ilo.org/global/standards/introduction-to-international-labour-standards/conventions-and-recommendations/lang--en/index.htm>.



A woman, pregnant with her first child, was followed through her pregnancy by a team in Vanuatu.
© WHO/Valeria Fernandez

Chapter 4

Women's health and maternal health services: seizing missed opportunities to prevent and manage preterm birth

KEY MESSAGES

Progress

In the past decade, the coverage of health services for women has improved globally and focus has increased on quality and experience of care. However, unacceptable inequities in coverage and quality remain and are hindering progress towards the effective prevention and management of preterm birth, and on reducing the number of stillbirths.

Programmatic priorities

Women's access to a comprehensive set of high-quality, respectful services for sexual, reproductive and maternal health is fundamental to improving health outcomes, including the prevention and care of preterm birth, and to achieving UHC. Priorities for the next decade span the following four areas.

- Preconception care, including ensuring that all women and adolescent girls can determine the number and spacing of their children.
- Pregnancy: evidence-based, high-quality and respectful antenatal care to reduce the likelihood of preterm birth occurring and to improve maternal and newborn health outcomes more broadly.
- Childbirth: evidence-based, high-quality and respectful care around the time of childbirth. When preterm birth is imminent before 34 weeks' gestation and adequate childbirth and preterm newborn care is available, antenatal corticosteroids should be used to prevent newborn morbidity and mortality.
- Postnatal care: evidence-based, high-quality and respectful postnatal care to facilitate positive health outcomes for the woman, the newborn and the family. In the case of stillbirth or neonatal death, it is vital to ensure that women and their families are offered compassionate bereavement care.

Pivots

Emphasize that the government, civil society, the private sector and all development partners must join forces to ensure the effective integration of sexual, reproductive and maternal health services within UHC, as well as integrating action on the known modifiable risk factors for preterm birth.

Seize the opportunity of recent increases in *coverage* of women's sexual, reproductive and maternal health care to improve the *quality* of care before, during and after childbirth, provided by multidisciplinary teams of health-care providers in partnership with women.

Fully leverage existing tools to improve the prevention and management of preterm birth, including the appropriate use of antenatal corticosteroids.

Ensure that women and families receive respectful, person-centred care, and that women's and adolescents' voices are respected.

PROGRESS

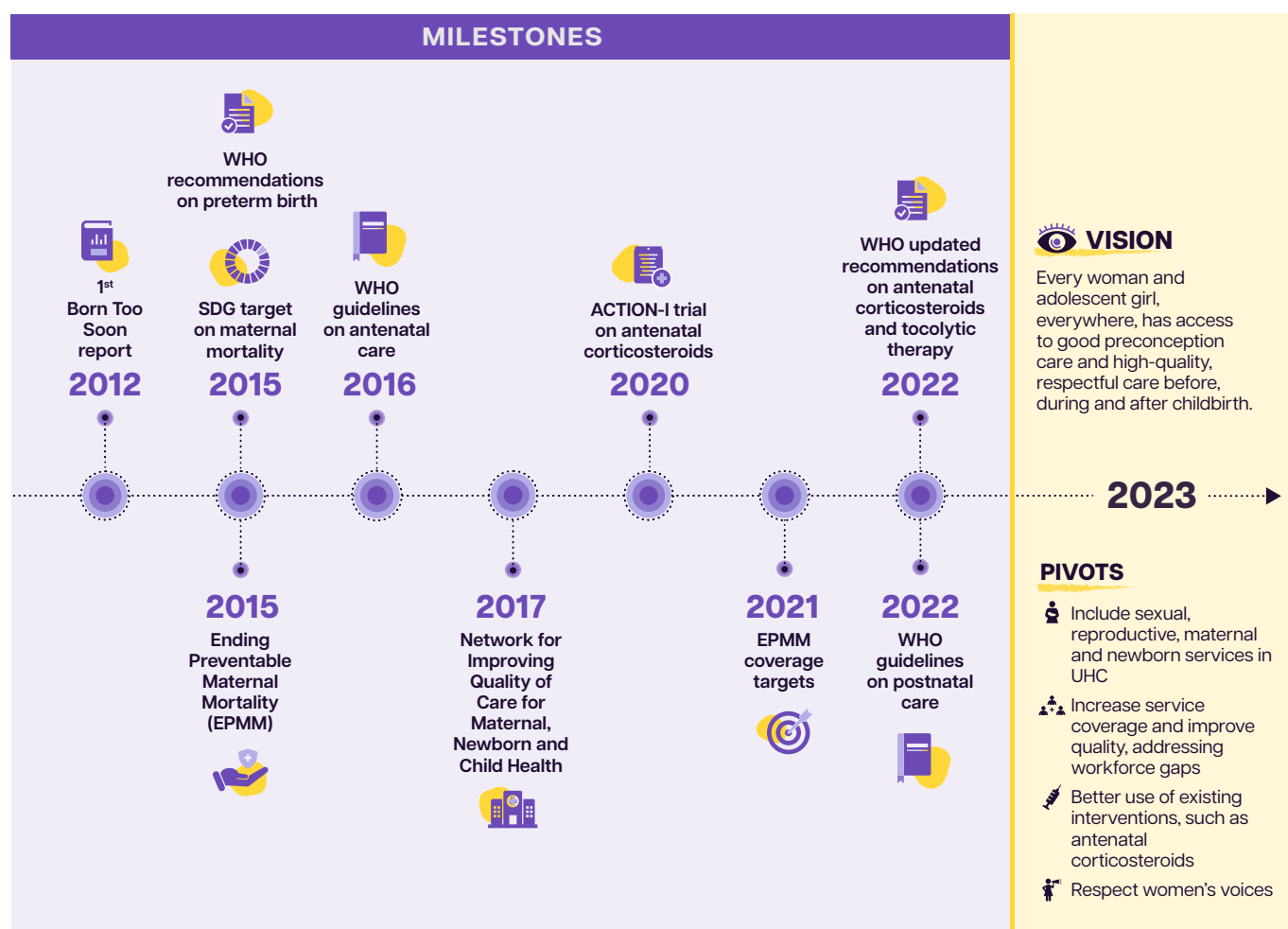
In the decade since the first *Born Too Soon* report was published, advances in women's and adolescents' health and human rights have been uneven, with significant progress on certain issues and in certain countries, and stagnation and rollbacks in others.

The latter years of the Millennium Development Goals saw increased investments in efforts to reduce maternal mortality and accelerating progress in many countries. New policy frameworks and technical guidelines were developed, including those relating to preterm birth prevention and management, bolstered by new data and evidence (Figure 4.1).



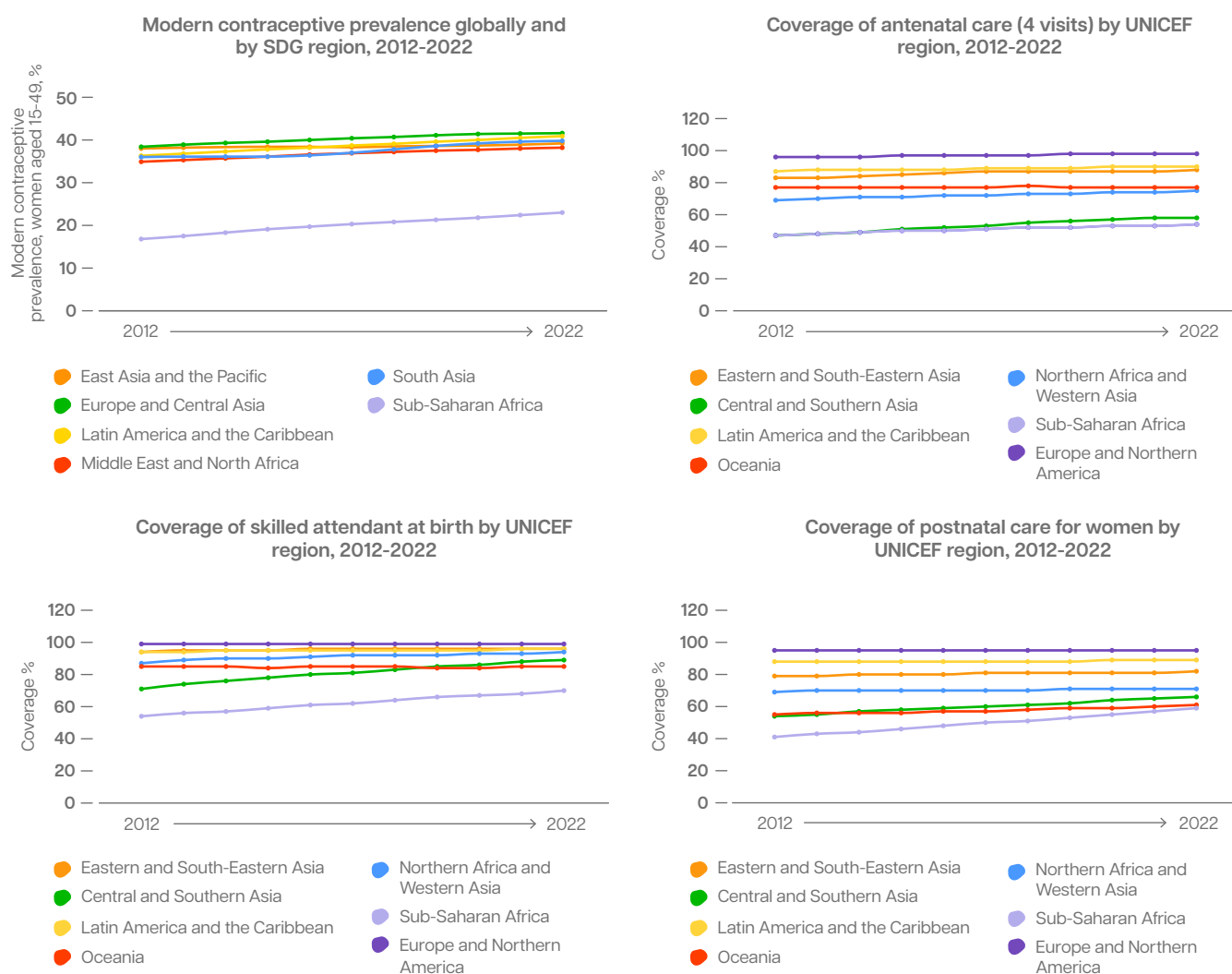
Maternity hospital in Malawi.
© White Ribbon Alliance

FIGURE 4.1 Women's sexual, reproductive and maternal health: timeline of progress over the past decade and vision for the next decade



There have been improvements in the coverage of sexual, reproductive and maternal health services in many countries across all income levels (1). Figure 4.2 shows progress in coverage of four important indicators: met need for family planning, antenatal

care (four visits), skilled attendant at birth and postnatal care. The adolescent fertility rate in LMICs has also reduced, from 52 per 1000 women aged 15-19 years in 2012, to 43 per 1000 women in 2020 (2).

FIGURE 4.2 Coverage of key sexual, reproductive and maternal health services, 2012–2022


Source: Family planning data courtesy of FP2030; data for antenatal care (4 visits), skilled attendant at birth, and postnatal care (women) courtesy of UNICEF.

The past decade has seen a greater focus on quality of care. For example, in 2017, 10 countries, supported by WHO, UNICEF and UNFPA, joined forces to establish the Network for Improving Quality of Care for Maternal, Newborn and Child Health, with the goals of halving maternal and newborn deaths and stillbirths in health facilities by 2022 and improving the care experiences of women and families in health facilities.

There has been a paradigm shift towards providing woman-centric health-care models that promote social autonomy and the empowerment of women. Emerging literature has highlighted the benefits of women's empowerment in improving access to vital services across the sexual, reproductive health (SRH) spectrum, before, during and after childbirth. Evidence shows that these approaches are key to the provision of respectful, high-quality care that delivers positive experiences for women before, during and after childbirth, and as such they are emphasized in multiple WHO guidelines (3, 4, 5).



Milo Health Centre, Kenya.
© White Ribbon Alliance

Despite a concerted pushback against SRHR in some countries, social movements have been engines of progress advancing access in others. As noted in Chapter 3, the “Green Wave” movement

which swept through Latin American countries from 2018 led to strict abortion laws being liberalized, which had previously been unthinkable (Box 4.1).

BOX 4.1 **The “Green Wave” in Latin America**

The “Green Wave” movement was the product of more than 20 years’ work by organizations from all walks of life, working on a multipronged strategy. Activists not only targeted the laws in their countries but also engaged with people in the streets, at schools and in the private sector to achieve the legal and social depenalization of abortion. The green bandanas worn by activists became a symbol of unity and a visual representation of mass mobilization across the region. In 2020, Argentina legalized abortion, followed by Colombia in 2022. In 2021, Ecuador introduced an exemption to the abortion ban for cases of rape, and in the same year, the Supreme Court of Mexico recognized a constitutional right to safe, legal and free abortion in early pregnancy, although access varies between states.

Despite these and other successes, the latest maternal mortality estimates are a stark reminder that improving women’s health and well-being is an urgent and unfinished task. While maternal deaths reduced significantly between 2000 and 2015, such gains have largely stalled, and in some cases even been reversed. In 2020, there were an estimated 287 000 maternal deaths worldwide, 95% of which occurred in LMICs. Between 2016 and 2020, only 31 countries achieved significant reductions in maternal mortality, whereas 133 saw progress stall and 17, mostly in Europe and the Americas, experienced an increase (6).

There are large inequities in both coverage and quality of health-care services. Significant discrepancies are seen between regions, for example, there is 98% coverage of antenatal care (four visits) in Northern America and Europe compared to 54% in sub-Saharan Africa. Inequalities within countries are equally shocking. For example, in Kenya births attended by skilled health personnel range from 35% in the lowest wealth quintile to 92% in the highest (7).

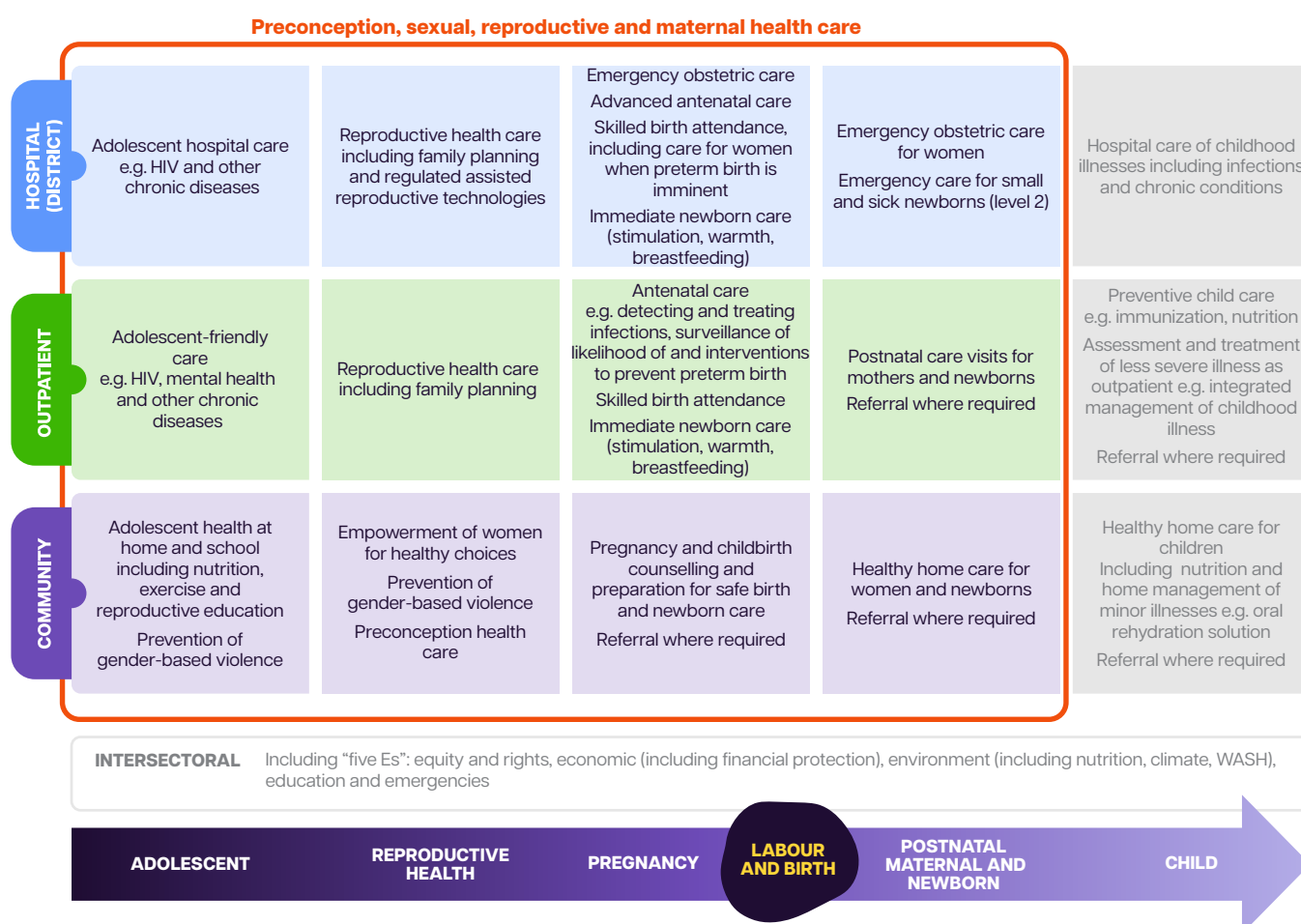
In many places, increased coverage of sexual, reproductive and maternal health services has not been accompanied by improvements in quality. This is clearly a missed opportunity for the prevention and management of preterm birth, and more broadly for the prevention of maternal and newborn morbidity, mortality and stillbirths. Women may be attending their four antenatal visits, but these visits may begin too late (after the first trimester) and appropriate screening for risk factors for preterm birth (and other maternal conditions) is far from universal. Women also continue to experience disrespect and abuse in many health-care settings, which can dissuade them from future use.

Challenges such as conflicts, disease outbreaks and climate change further threaten women’s and adolescents’ access to the high-quality health services that are essential for preventing and managing preterm birth. In nine countries facing severe humanitarian crises, maternal mortality ratios were more than double the world average (551 maternal deaths per 100 000 live births, compared to 223 globally) (6).

The evidence is clear: promoting equitable access to respectful and high-quality sexual, reproductive and maternal health services, including in resource-limited and fragile settings, is central to achieving meaningful reductions in preterm birth and preterm-associated morbidity and mortality. This chapter explores what needs to be done to bridge the substantial gap between current scientific knowledge and the often variable quality of health services for women and adolescents.

PROGRAMMATIC PRIORITIES

Embedded within the continuum of evidence-based sexual, reproductive and maternal health services is a group of interventions that can prevent preterm birth or mitigate its effects on a newborn (Figure 4.3). These well documented interventions (8, 9, 10) which are reflected in current clinical guidelines (3, 4, 5) are explored in detail below.

FIGURE 4.3 Continuum of care, with focus on health-care packages for adolescent girls and women


Preconception: a critical window for preterm birth prevention

Equitable access to high-quality SRH services is critical to ensure that every woman and adolescent girl is able to control whether and when to get pregnant. These services also bring a wide range of social, economic and educational benefits, and prevent many pregnancy-related health risks (11, 12).

Despite setbacks in some countries, other countries have made considerable advances in implementing programmes designed to increase access to SRH services. For example, countries across regions such as Chile, Ethiopia, Jamaica and the United Kingdom have successfully implemented strategies to reduce adolescent pregnancies, which have important knock-on effects for the prevention of preterm birth (Box 4.2) (13).



Group of pregnant women and their husbands receiving information on maternal and child health in Georgia.

© WHO/David Kharatishvili

BOX 4.2 Country snapshot**Reducing adolescent pregnancy in Chile**

Early pregnancies negatively affect adolescent girls' health and rights, and the health of their babies, with higher risks of preterm birth, low birth weight and severe neonatal conditions. Adolescent pregnancy also contributes to an intergenerational cycle of risk: recent evidence shows that women born preterm have a higher likelihood of future preterm delivery (14).

Responding to its high adolescent fertility rate, Chile adopted the regional Andean Plan for the Prevention of Adolescent Pregnancy, aiming to reduce the adolescent fertility rate by 10% by 2020. A multisectoral five-pronged strategy was implemented, involving training health workers, creating adolescent-friendly spaces in primary health centres, promoting a range of contraceptive methods, improving outreach and referrals and improving school retention and re-entry for pregnant adolescents and adolescent mothers. The strategy was supported by enabling laws and policies, intensive collaboration between key stakeholders, including research organizations, civil societies, and youth and women's advocates, and committing to sustain levels of human and financial resources across changing governments.

The outcome was impressive and can inspire others: the adolescent fertility rate for women aged 15-19 decreased from 55 births per 1000 in 2007 to 41 births per 1000 in 2018; births to adolescents aged under 19 reduced by 51% between 2000 and 2017; and there was a 30% increase in contraceptive use by adolescents at first sexual intercourse between 2007 and 2018 (15).

Infertility is an often overlooked element of SRH, despite recent WHO estimates suggesting that one in six adults worldwide experienced infertility in 2022 (16). Data from some higher-income countries, where age at first birth is increasing (advanced maternal age is a known risk factor for preterm birth), suggest that overuse of multi-embryo transfers for in vitro fertilization (IVF) are contributing to higher preterm birth rates (17, 18). Some countries have adopted a single embryo transfer policy, but there is great variation across and within countries. While not currently a large driver of preterm birth rates globally, this could become a more substantial contributor in the future as access to infertility treatments expands, unless countries adopt responsible IVF policies (19, 20).

Preventing preterm birth through high-quality antenatal care

High-quality antenatal care is vital to help women and adolescents have healthy pregnancies, to identify those at increased risk of preterm birth and to deliver effective interventions to mitigate and manage the risks. Box 4.3 describes the three levels of preterm birth prevention. Since 2016, WHO has recommended that pregnant women and adolescents everywhere should have a minimum of eight antenatal contacts (replacing the previous recommendation for four) (3). The first antenatal contact should be prior to 12 weeks' gestation, and all women should have a dating ultrasound prior to 24 weeks (21). The latter is particularly critical, as accurate gestational age estimation underpins the safe and timely use of preterm-related interventions.



BOX 4.3 Definitions of primary, secondary and tertiary prevention of preterm birth

Primary prevention: interventions that are directed at all women during pregnancy.

Secondary prevention: interventions directed at women identified as having a specific risk factor. This involves a thorough history, clinical examination, and often a predictive test to identify women more likely to give birth preterm, such as cervical length measurement using ultrasound, or fetal fibronectin testing. These higher-risk women can then be offered therapies, such as progesterone or cerclage.

Tertiary prevention: interventions made after preterm labour has commenced, primarily intended to improve the health of preterm newborns in early life.

Although coverage of antenatal care has increased over the past decade, there is an urgent need to ensure that these points of contact between a woman or adolescent girl and her health-care provider result in timely, evidence-based care.

Many interventions have been shown in systematic reviews to prevent preterm birth across the continuum of care for women. Some relate to optimizing maternal diet and nutrition, while others relate to treating infections. Some medications and supplements provided antenatally to prevent the occurrence of certain pregnancy complications also appear to have “downstream” benefits for preventing preterm birth. Research has also shown that some interventions previously thought to reduce preterm birth are in fact ineffective, including bedrest and activity restriction, avoidance of vaginal sex and vitamin D supplementation (22). While this evidence is being adopted into country and international guidelines, there is still a significant gap between knowledge and common practice.

How care is delivered during antenatal care visits is also important. Increasingly, the value of person-specific, women-centred antenatal care is being recognized, as is the need for tailored management of risk factors for preterm birth (23). For example, more frequent monitoring is warranted for women with a multiple pregnancy. Some pregnant women need support relating to gender-based violence, recreational drug use, healthy weight

or environmental pollution (24, 25, 26, 27, 28). Screening for mental health issues is also important during antenatal care visits. Common perinatal mental disorders (including depression, anxiety and somatic disorders) are a major cause of disability during and after pregnancy, affecting the quality of life of the woman or adolescent girl and her baby. Almost one in every five women in LMICs experiences one or more mental health issues during pregnancy or after childbirth (29). Mental health disorders can in turn affect the well-being of the baby throughout the life-course.

Different health system arrangements have also been shown to affect preterm birth rates. For example, a midwifery-led continuity of care model can reduce preterm birth. In this model, a woman receives antenatal, intrapartum and postnatal care from the same midwife. This is recommended by WHO in settings with well functioning midwifery programmes (Box 4.4). Group antenatal care, where women participate in pregnancy-related educational and peer support activities with other women, has been shown to increase continuation in antenatal care and coverage of some interventions (e.g. intermittent preventive treatment of malaria in pregnancy) that may decrease the risk of preterm birth. Some studies have found that group antenatal care might also help to prevent preterm birth. Further implementation research is needed to better understand its effectiveness and adaptation to different contexts and settings.

BOX 4.4 Country snapshot**Midwifery-led continuity of care: a promising model for addressing inequalities in the United Kingdom**

Lambeth is an area of south London with high inequalities and markedly higher maternal and perinatal mortality and morbidity risks than elsewhere in the city. In 2018, the Lambeth Early Action Partnership (LEAP) commissioned a midwifery continuity of care service for pregnant people living in areas with high levels of deprivation. Clients are given longer and more frequent appointments; the team is based in a local children's centre and benefits from well established referral pathways to wider sources of support for clients, including for infant feeding and in response to domestic abuse.

More than 600 LEAP babies have been born since the service began. Research findings have indicated reductions in preterm birth rates and caesarean births for clients using the LEAP midwifery-led continuity of care service, compared with clients who received traditional midwifery care (30). Feedback from clients is very positive, with 100% reporting that they trusted staff and felt that the staff understood their needs. These encouraging findings contribute to evidence about the impact of midwifery-led continuity of care on improving outcomes for mothers and babies, including the potential reduction of preterm births.

In 2022, the NHS England strategy to reduce inequalities included midwifery-led continuity of care for women from Black, Asian and other minority ethnic communities and from the most deprived groups. As of 2022, 58 teams are implementing this model of care across England, with more expected throughout 2023.

Care around the time of birth for women experiencing a preterm birth

As shown in Figure 4.2, women worldwide are increasingly giving birth in facilities. However, as with antenatal care, the coverage and quality of care around the time of childbirth (intrapartum care) varies around the world. Improving the quality of intrapartum care is critically important for reducing maternal and newborn deaths, and for preventing stillbirths, 40% of which happen during labour. The overwhelming majority of these stillbirths are preventable with the right interventions (31).

Most preterm births involve no known risk factors. When preterm labour or preterm prelabour rupture of the membranes (PPROM) does take place, women need tertiary preventive care (Box 4.3). The most critical element of this is a course of antenatal corticosteroid (ACS) injections, such as intramuscular dexamethasone or betamethasone. When given to women with a high likelihood of birth prior to 34 weeks' gestation, it speeds up fetal lung development, meaning a preterm baby can breathe more easily at birth (32).



A mother and baby who have participated in the LEAP programme.
© Lambeth Early Action Partnership

In the past decade, the safe and appropriate use of ACS in LMICs has been actively researched. ACS should be used in women prior to 34 weeks' gestation where preterm birth is considered imminent and no maternal infection is present (see Box 4.5) (33). However, it should only be used where adequate childbirth and preterm newborn care are available. Inappropriate use of ACS, particularly when a full-term baby is exposed, probably causes long-term harm and should therefore be avoided (34). In recent years, trials in high-resource settings suggest there may also be a role for ACS after 34 weeks' gestation; a WHO-led trial is currently exploring this issue in low-resource countries (35).



Skin-to-skin contact between mother and newborn in the Philippines. © WHO/Yoshi Shimizu

BOX 4.5 The safe and appropriate use of antenatal corticosteroids for preterm birth

The Antenatal Corticosteroids Trial, an implementation trial in six LMICs, found that efforts to scale up ACS in limited-resource settings could harm mothers and babies (36). This led WHO to conduct the Antenatal Corticosteroids for Improving Outcomes in Preterm Newborns (ACTION)-I trial to determine whether and how ACS could safely be used in low-resource countries (37). The trial found that a course of intramuscular dexamethasone reduced neonatal death and caused no maternal or newborn harm. In 2022, WHO confirmed its recommendation that ACS therapy be used for women at risk of preterm birth from 24 to 34 weeks of gestation when the following five criteria are met (38).

WHO ACS treatment criteria

1. Gestational age assessment can be accurately undertaken.
2. There is a high likelihood of preterm birth within seven days of starting therapy.
3. There is no clinical evidence of maternal infection.
4. Adequate childbirth care is available, including the capacity to recognize and safely manage preterm labour and birth.
5. The preterm newborn can receive adequate care, including resuscitation, kangaroo mother care, thermal care, feeding support, infection treatment and respiratory support, including continuous positive airway pressure as needed.

Tocolytic drugs can slow or arrest preterm labour, allowing more time both for ACS to work and to transfer the woman to a higher-level care facility (39). In a major change to its guidelines, in 2022 WHO recommended using nifedipine for tocolysis when spontaneous preterm labour is present (39). Tertiary prevention care should also include magnesium sulfate for women likely to give birth before 32 weeks' gestation, to prevent cerebral palsy. Also, when PPRM is present, administration of the antibiotic erythromycin can prolong pregnancy and prevent neonatal morbidities. Like full-term babies, preterm babies also benefit from delayed umbilical cord clamping after birth (40).

While administering ACS to women with a high risk of preterm birth is standard practice in high-income countries, its use in LMICs is suboptimal. Multicountry analyses have identified bottlenecks that can hinder the uptake of ACS, including inadequacies in leadership and governance, health service delivery, health financing, health information systems, essential medicine and technologies, community ownership and partnership (41, 42). However, there are encouraging examples of countries that are overcoming barriers to the appropriate use of ACS (Box 4.6).

BOX 4.6 Country snapshot**Improving uptake of ACS in Cambodia and the Philippines**

The first *Born Too Soon* report highlighted generally high rates of preterm birth in Cambodia (10.5%) and the Philippines (14.9%). In spite of their governments prioritizing the reduction of mortality from preterm birth, including the use of ACS in both countries' national guidelines, uptake remained low. A situational analysis was undertaken to identify the key barriers to the implementation of ACS in practice. Stockouts were rare and cost was not reported to be a barrier because mothers were not charged for the medication. However, data from both settings identified poor provider knowledge about implementing ACS effectively as a key challenge.

In collaboration with the Ministries of Health of Cambodia and the Philippines, a non-randomized study was conducted in 2013–2014. A standardized one-day technical training course on preterm birth and ACS use was delivered to clinical managers and skilled birth attendants in 12 facilities across Cambodia and the Philippines, followed by a monthly audit and feedback process. Monitoring and evaluation of this work identified that coverage of at least one dose of ACS (dexamethasone) increased from 35% at baseline to 86% at endline in Cambodia, and from 34% at baseline to 56% at endline in the Philippines, among women who gave birth at 24–36 weeks' gestation. This encouraging study shows that it is possible to rapidly overcome lack of provider knowledge, and thus to increase coverage of ACS for women at risk of preterm birth. Information about the key barriers in the specific subnational context is essential to inform action (43).



Skin-to-skin contact between parents and newborn babies after birth in the Philippines.
© WHO/Yoshi Shimizu

Caesarean section is an essential lifesaving surgical procedure and is performed when vaginal birth is not possible or when it poses a risk to the health of mother and baby. Many countries are experiencing rising rates of late preterm caesarean section and labour induction (17). The drivers are complex and include clinical practice and women's and families' personal and cultural preferences. However, there is evidence that inducing labour and performing caesarian sections without medical indications are widespread and are probably causing preterm births that could have been avoided (19).

Caesarean section rates worldwide have steadily increased over the past 30 years, and in some countries they account for more than half of births (e.g. Dominican Republic (58.1%), Brazil (55.7%), Cyprus (55.3%)). Worldwide, approximately one in five is now by caesarean section and this number is projected to increase to nearly 30% by 2030 (44). Even an emergency caesarean section can increase the risk of a preterm birth in a subsequent pregnancy. Increasing caesarian section rates are a worrying trend that will have consequences for preterm birth rates if not addressed appropriately.

Postnatal care for women following preterm birth

The postnatal period – the first six weeks after birth – is a critical time for newborn and maternal survival, and for supporting both the newborn's healthy development and the woman's mental and physical recovery and well-being. Worldwide, more than 3 in 10 women and newborns do not receive postnatal care in the first days after birth, when most maternal and newborn deaths occur.

In 2022, WHO published new guidelines on routine postnatal care for women and newborns (5), and updated its guidelines on the care of preterm and low-birth-weight infants (45). The guidelines emphasize the importance of good-quality, respectful postnatal care, with a minimum of four postnatal contacts, and the need to ensure that all women are provided with contraceptive information and services (5). Even with such support, women with preterm infants are at greater risk of postnatal depression, requiring additional care and support.

In cases of preterm birth, women and families should be involved in the routine care of their babies in health-care facilities, which has been shown to improve the experience of women and families, improve health outcomes for the baby (see Chapter 5) and decrease parental anxiety. Women and families of preterm infants describe the importance of being actively involved in their baby's care, needing emotional and logistical support and clear information, and valuing positive relationships with compassionate and respectful health-care providers (46). Parental leave and entitlements are necessary to address the special needs of mothers, fathers and other primary caregivers of preterm and other vulnerable newborns.

Every stillbirth and death of a newborn baby is a tragedy and has a devastating impact on bereaved parents and families, who have higher rates of depression and anxiety and often do not receive the care and support they need (47). Best practice guidelines recommend that parents should be offered the opportunity to see and hold a stillborn baby, and many studies suggest that parents can benefit from spending time with their stillborn baby in a supportive environment. However, these practices are often not followed, compounding the grief and trauma experienced by bereaved families. There are inspiring examples of bereavement care (Box 4.7) and such models need to be supported, funded and expanded at scale. Maternal death, while rarer, is catastrophic. Bereavement models and training for health-care professionals should include stillbirths and newborn and maternal deaths, addressing both the needs of families and the adverse consequences for health-care providers.

BOX 4.7 Country snapshot**Birth With Dignity in Uganda: improving bereavement care**

Birth With Dignity was founded in Uganda in 2017 by nurses who were burdened by both the high rates of maternal deaths and stillbirths in the country, and the lack of bereavement care for families. It was common practice across Uganda to keep the stillbirth diagnosis from the mother until after the birth and then to take the baby away immediately for burial.

Over the past six years, Birth With Dignity has trained hundreds of Ugandan nursing students, midwives and physicians on high-risk perinatal care to prevent maternal death, and on bereavement care. This includes educating mothers whose baby has died during labour on the grief process and the importance of seeing and holding their baby. The family is offered a photograph of the baby to keep, especially if the mother was unable to see her baby due to medical issues. Families have expressed gratitude for the care they received. Birth With Dignity has now established high-risk perinatal programmes at Mbale Regional Referral Hospital and at Nsambya Hospital in Kampala. The team also includes parents of stillborn babies who work to raise awareness across Uganda about stillbirth prevention and compassionate bereavement care.

UGANDA

What is needed to support improved service delivery?

The programmatic priorities listed above all rely on well functioning health systems, with maternal care integrated as a central element of UHC, including primary health care. The factors listed below are key to the successful and sustainable implementation of high-quality maternal health-care services.

Human resources

Ensuring the availability of adequate numbers of well trained, competent and motivated health-care providers is essential to redress quality of care deficiencies (48). The global shortage of health-care providers is particularly severe in LMICs (49). Many maternity services are understaffed, compromising patient safety and limiting the quality of care. Health-care providers also need high-quality pre- and in-service education and refresher training, managerial and clinical leadership, and a contemporary scope of practice that ensures they can deliver high-quality, evidence-based preterm care. They also need written, up-to-date clinical protocols to guide their preterm labour prevention and management decisions that are context-specific (38, 39, 50).

Maternity health-care providers highly value opportunities to improve their knowledge and skills in preterm management. Effective strategies include drills, simulation exercises, supportive supervision, on-the-job training and mentoring, as well as continuous quality improvement and multidisciplinary care models for managing preterm labour (51, 52). Where new care models are introduced, such as group antenatal care or continuity of care, health-care providers require orientation, a facilitative environment for care, and mentorship from experienced staff.

Infrastructure and commodities

Health-care providers must be able to work in an enabling and adequately resourced environment. The delivery of good-quality preterm care is unnecessarily restricted by stockouts of essential medicines or supplements, inadequate infrastructure, dysfunctional equipment and outdated restrictions on scope of practice, particularly for nurses and midwives. The quality of essential medicines, including ACS, may also be poor in some settings. These issues are best addressed through health system strengthening, including strong regulation.

Health information systems

Gestational age at birth is infrequently collected and reported in national registries in most LMICs. System-wide efforts to establish and improve birth registries are needed, including creating a culture of "good documentation", and using electronic systems to simplify data capture and reporting (Chapter 2).

Referral systems

Timely and appropriate referral is also required for women presenting in preterm labour to a lower-level health facility. They may need ACS and tocolysis before a rapid transfer to a higher-level centre where adequate preterm newborn care is available. However, many women face practical challenges, particularly in remote and rural settings (poor roads, few vehicles, high transportation costs and long distances) so some families are reluctant or unable to travel between facilities. Referral systems must also ensure that women and preterm newborns are reconnected to their primary and community health-care providers after discharge from higher-level care. Efforts must be made to strengthen and sustain these referral pathways, particularly in emergencies, to enable the continuation of service provision.



Medical transport, Mali.
© World Vision Canada

PIVOTS

Pivot 1: Emphasize that the government, civil society, the private sector and all development partners must join forces to ensure the effective integration of sexual, reproductive and maternal health services within UHC, as well as integrating action on the known modifiable risk factors for preterm birth

As countries define their UHC policies and programmes, there is a unique opportunity to ensure that these efforts include equitable, high-quality sexual, reproductive and maternal health services, grounded in evidence. These services, including interventions to prevent and manage preterm birth, are health-promotive, inexpensive and highly cost-effective. Access requires earmarked investment to reduce out-of-pocket expenditure, including for family planning and contraceptives, as critical components of essential care packages. Special efforts are needed to ensure the provision of contraception to underserved populations, and at key moments along the life-course, including during adolescence to prevent teenage pregnancies, and postpartum before hospital discharge.

There is also a need for broader public health education and communication on behavioural and lifestyle changes to prevent preterm birth, including smoking cessation, improved nutrition and physical activity.



Doctor speaking during a class on COVID-19 prevention integrated into family planning and maternal health in the Philippines.

© WHO/Rolox dela Pena

Pivot 2: Focus on improving the quality and experience of care for women and adolescents before, during and after childbirth

A major global shift in maternal and newborn health care over the past decade has been the move beyond focusing on coverage of essential interventions, and towards the broader goal of high-quality, respectful care before, during and after pregnancy. Across the continuum of care, opportunities must be seized to increase coverage and to improve the quality and the experience of care. Each contact with the health-care system is an opportunity to improve the prevention and management of preterm birth and, more broadly, to prevent maternal and newborn morbidity and mortality and stillbirths. A plethora of new global policies and guidelines on maternal health care have been developed over the past decade: there is now no time to lose in closing the implementation gap and translating the evidence and policies into action.



A midwife checks a pregnant woman in Uganda.
© White Ribbon Alliance

Pivot 3: Fully leverage existing tools to improve the management of preterm birth, including appropriate use of ACS

Women in preterm labour need timely, evidence-based interventions to improve the health outcomes for the preterm baby, particularly the use of ACS. Compared to a decade ago, there is now stronger evidence of the effectiveness of ACS and tocolytics; however, ACS and tocolytic coverage remain suboptimal in many LMICs. Greater political commitment and investment are needed to ensure that this evidence is prioritized and acted

upon. More research is needed to identify barriers to implementation, as well as greater sharing of country learnings on overcoming these barriers, in order to scale up the effective use of these commodities.

Pivot 4: Ensure that women and families receive respectful, person-centred care, and that women's voices are respected



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Positive care experiences are a vital dimension of care quality. This includes effective communication, respect, preservation of dignity, social and emotional support, and listening and responding to the concerns of women and families. Women and their partners may be learning about preterm birth for the first time in a stressful context, such as preterm labour. They need clear information about treatments, side-effects and prognoses for their baby and themselves, provided sensitively and respectfully. The need for respectfully delivered and clear information can be even greater in the postnatal period. Compassionate bereavement care for women and families who have experienced the death of a baby, whether stillborn or due to complications after birth, is urgently needed.

Beyond provider-client communications, women's and families' voices must be heard in broader conversations: they should be actively involved in developing the policies and services that affect them. Their voices are a powerful means of increasing social accountability for the delivery of equitable, accessible and high-quality services.

Key reading

- Ending preventable maternal mortality [website]. World Health Organization (<https://www.who.int/initiatives/ending-preventable-maternal-mortality>).
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- Medley N, Vogel J, Care A, Alfirevic Z. Interventions during pregnancy to prevent preterm birth: an overview of Cochrane systematic reviews. Cochrane Database of Systematic Reviews; 2018 (<https://pubmed.ncbi.nlm.nih.gov/30480756/>).
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Behind every statistic is a story

Meet Estelle

from Australia



Estelle at 7 years old.

Seven weeks into her pregnancy with her

fourth child, Australian mum Rachel Taufer suddenly started bleeding heavily. In tears, she called an ambulance, then curled herself into a fetal position on her living room floor, crying and praying as her three children, aged 5, 3 and 1, looked down at her.

In hospital, she learned that a subchorionic haematoma (blood clot) had formed between the placenta and the wall of the uterus. Despite taking bed rest her condition worsened, resulting in placenta previa and placenta accreta, and she was hospitalized at 21 weeks' gestation due to major bleeding.

Her hospital stay was traumatic, not only because she feared for both her own and her baby's lives, but also because of her experience of care there. "I knew which nurses would clean me up when I had a big bleed, and which nurses would throw a blanket over me and feel it was totally gross."

"They were all talking about me, but no one was talking to me."

Rachel's children visited her once a day. Her eldest started kindergarten while she was on bedrest in hospital. She says, "I went from being independent and active and very much involved in my children's lives to being a spectator on the sidelines, not even able to hold or lift them." Doubting that she would survive, Rachel and her husband Nathan made jewellery for her other children using her fingerprints.

Rachel felt stigmatized by some medical staff due to her history of anxiety; she believes this made them less willing to listen to her.

"One of the hardest things was not feeling heard, and the lack of communication, especially because

it was about something happening to my body, and medical professionals distrust a woman's knowledge about her own body. Two days before Estelle was born, I knew that something was not right, I was in absolute agony, and I said so, but nobody took me seriously until it got to a dire state and I became septic. They were all talking about me, but no one was talking to me."

At 26 weeks' gestation, Rachel went into preterm labour, suffering from sepsis. She was rushed into surgery where she gave birth to Estelle, who was in a critical condition and was taken to the NICU. Rachel's uterus, fallopian tubes and part of her bladder were removed. Rachel remained in hospital for a month after waking from an induced coma, and then stayed by her baby's side in NICU for three months.



Sister Amelia meeting Estelle.

Estelle, now seven years old, was discharged at 38 weeks' gestation. Despite a couple of hospital visits and stays, she is now happy, healthy and "a ray of sunshine, so resilient and always looking on the bright side". However, Rachel still suffers from PTSD relating to the experience of Estelle's birth. "The fear of losing a child never dissipates."

One change that Rachel would like to see in the next decade is better communication between medical staff and families. "Things like letting parents know next steps, keeping us informed, allowing us to make smaller decisions that can mean a lot, such as choosing a first outfit. And mental health care being offered for mom, dad and siblings."



Chapter 5

Care for small and sick newborns: high return on investment is possible now

KEY MESSAGES

Progress

Over the past decade, the world has reached significant policy milestones for newborn care, but gaps remain for programmatic action, especially for babies born too soon, too small, or who become sick.

Globally, the place where babies receive care has shifted, with 80% of births now occurring in health facilities.

An estimated 30 million small and sick newborns have life-threatening conditions that require inpatient care in hospitals each year, half of whom are preterm.

Programmatic priorities for inpatient newborn care

Quality improvement and availability of inpatient newborn care is urgently needed now to reach SDG target 3.2 (<12 deaths per 1000 live births) and Every Newborn Action Plan targets.

Most of the major causes of neonatal death can be prevented by adopting a health systems approach to the scaling up of SSNC in countries. This requires 10 core components: political commitment and leadership; financing; human resources; appropriate infrastructure; equipment and commodities; robust data systems and use of data for action; referral systems; linkage with high-quality maternal care; family and community involvement; and post-discharge follow-up systems.

Pivots

Prioritize more ambitious, committed investment in SSNC to ensure equitable universal access to high-quality, family-centred services, including in areas of conflict and for marginalized populations.

Accelerate implementation with widespread involvement and support from families, communities, professional societies, politicians and business communities.

Learn together, across countries, to bring critical innovations to high-burden populations faster.

Integrate newborn care into maternal, referral and follow-up systems to ensure that the newborns who survive also thrive.

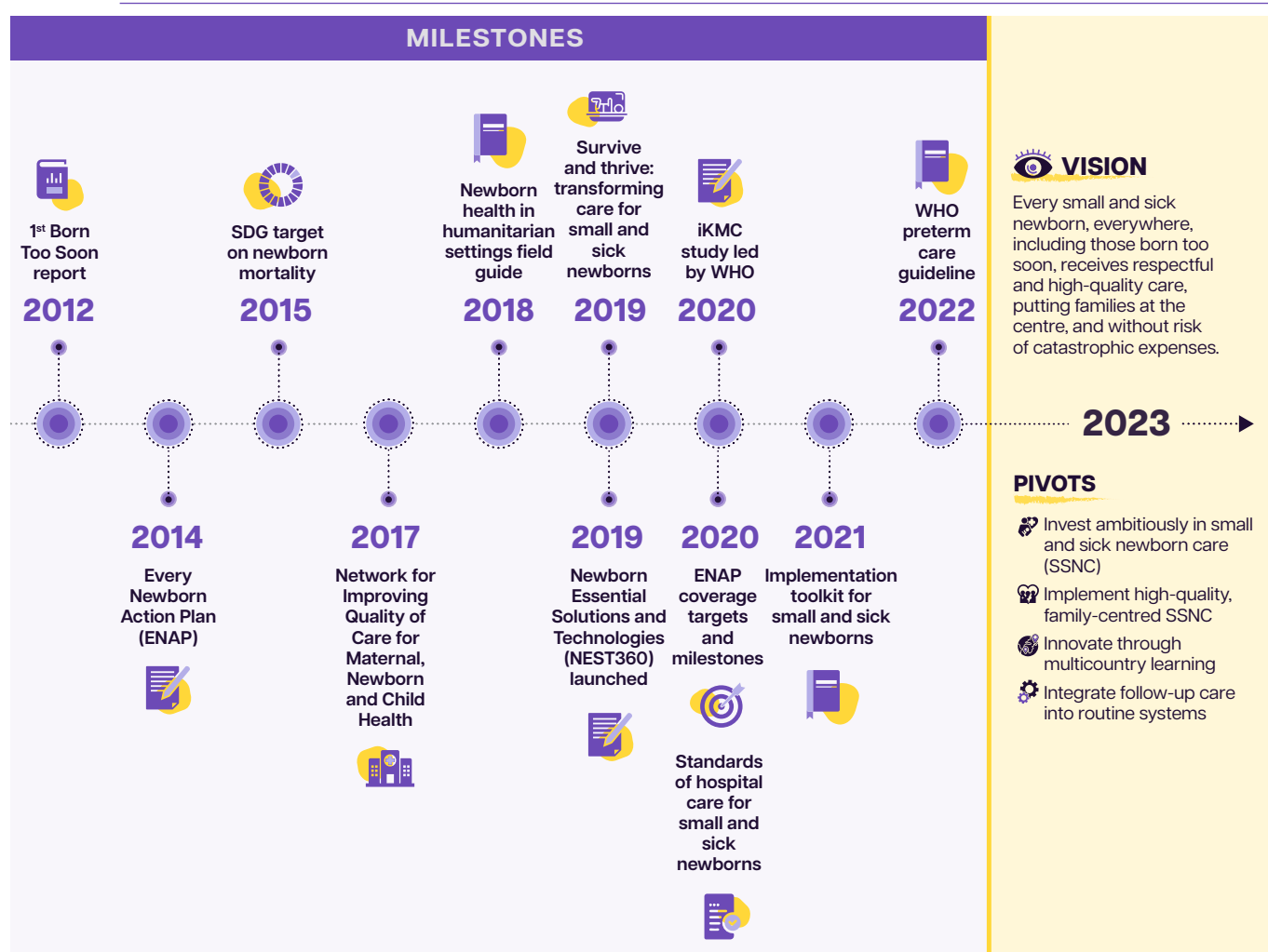
PROGRESS

This chapter focuses on the 30 million babies born each year who require hospital care to treat life-threatening conditions (1). Everything that happens to them in hospital matters, and can determine their survival, influence their brain development and affect their entire life-course.

The past decade: what has moved?

The world can be proud of progress achieved over the last decade, which has seen new attention and urgency to prevent newborn deaths, particularly among babies born preterm (2). Some key milestones are depicted in Figure 5.1, chief among them ENAP, adopted in 2014 by 194 countries (3). Subsequently, the SDGs and the *Global Strategy for Women, Children's and Adolescents' Health* were endorsed, both including the first ever targets for reducing newborn mortality to <12 deaths per 1000 live births (4).

FIGURE 5.1 Newborn health: timeline of progress over the past decade and vision for the next decade



Building on the ENAP momentum, the *Survive and thrive: transforming care for every small and sick newborn* report presented a call to action towards ensuring that every newborn has a chance to live a healthy and productive life (1). Importantly, it included the term “newborns born too small who become sick”, together with preterm newborns, as the population most vulnerable to death and long-term disability.

In 2020, ENAP coverage targets were updated to include specific targets for small and sick newborns (5). New UN standards and technical guidelines have been published, bringing together the latest evidence (6, 7).

And yet, despite progress and policy milestones, an estimated 2.3 million newborns died within their first 28 days of life in 2022 (8). This is 6400 newborn deaths each day, with preterm birth being

the leading driver of under-5 mortality (8). Almost all newborn deaths (98%) occur in LMICs, and 78% occur in sub-Saharan Africa and Asia. The “four Cs”

described in Chapter 1 further threaten hard-won gains and heighten risks for already vulnerable newborns (Box 5.1).

BOX 5.1 Caring for small and sick newborns in conflict settings

Nine of the 10 countries with the highest neonatal mortality rates are in conflict zones (9). The Bridging Research & Action in Conflict Settings for Health of Women & Children (BRANCH) Consortium is working to improve health care in conflict areas by improving evidence and guidance for effective action on women’s and children’s health. Members of the BRANCH Consortium played a lead role in a *Lancet* Series that highlighted the lack of comprehensive, high-quality data from conflict-affected areas, particularly on newborn care, which hampers the delivery of essential interventions (10).

Technical field guidelines on newborn care are available, but the implementation of evidence-informed context-specific interventions in conflict settings requires focus. The Inter-Agency Working Group on Reproductive Health in Crises published the *Newborn Health in Humanitarian Settings: Field Guide* in 2018. However, caring for small and sick babies remains a major challenge in conflict areas with weak health systems and few skilled health workers.

Health-sector interventions must recognize the contextual challenges and translate broad recommendations into pragmatic local solutions. This will usually require task sharing and reliance on community health workers and outreach workers, such as vaccinators and technicians. Engaging communities is also vital to ensure their involvement and secure humanitarian access (11). To address these challenges, the humanitarian system has developed innovative solutions, including the packaging of interventions and the use of more flexible modes of delivery, such as mobile clinics and community-based care. These solutions, if rigorously evaluated, could provide effective strategies for newborn care in conflict settings.

Data obtained from a tracking tool used to chart progress towards ENAP targets point to some key gaps that must be bridged to improve newborn survival (12). As of 2019, 78 of the 90 countries using the tool had developed a national newborn action plan, but only 45 had a national guideline/strategy for care of small and sick newborns, while just 6 included all four high-impact interventions (neonatal resuscitation, treatment of serious neonatal infection, KMC and ACS) in their national health management information system (12).

There is still a dearth of investment in newborn health, which accounts for just 10% of investment in reproductive, maternal, newborn and child health, despite 47% of under-5 child deaths occurring during the neonatal period (8, 13).

Although numerous evidence-based interventions are available to improve survival, geographical disparities in implementation coverage and quality persist. Innovations exist, but gaps in stable distribution and training, unreliable supply chains and lack of skilled workers present continuing barriers to roll-out. Care for newborns and their mothers is often siloed and there is an urgent need to better integrate newborn care into maternal, referral and follow-up services in order to realize a systems approach to care.



Newborn care unit in Chattisgarh, India.
© UNICEF/UN0517372/Panjwani

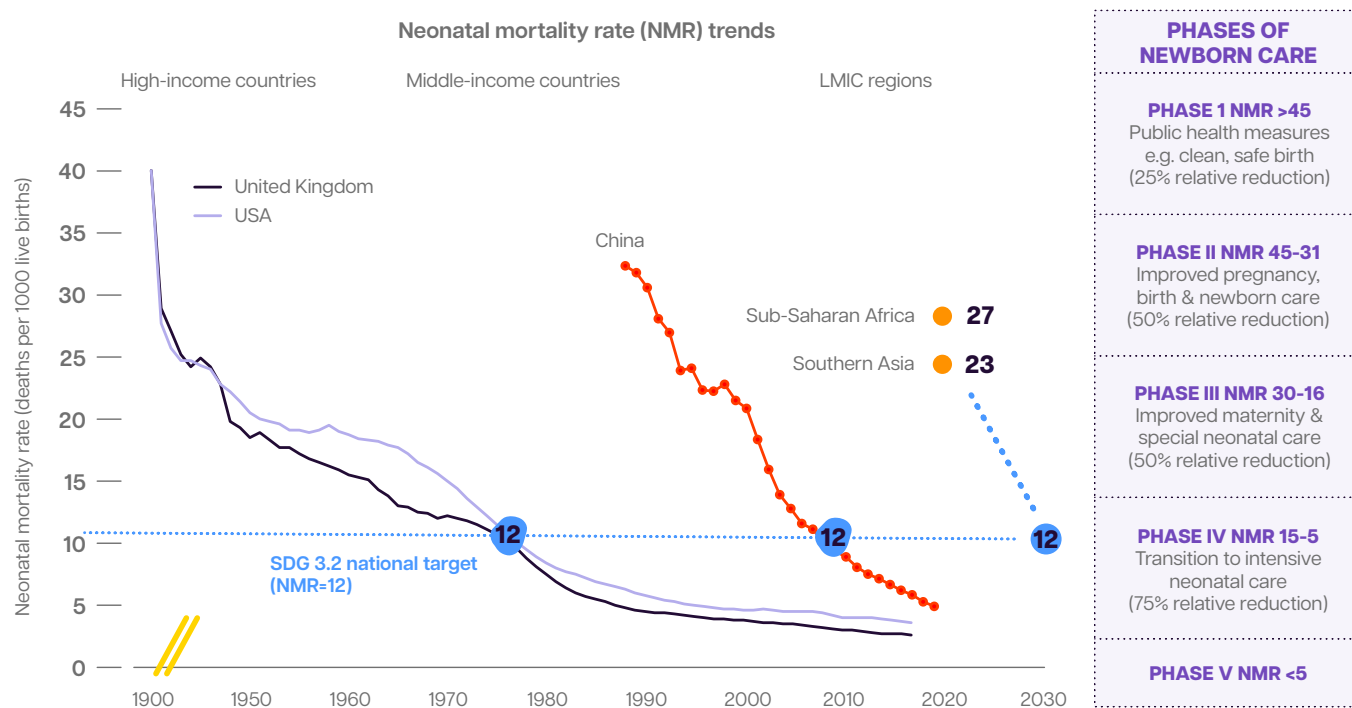
Poised for programmes

The world is at a poignant moment in time. To achieve the vision and goals set out in ENAP and the SDGs, greater focus and attention are needed to transform care for small and sick newborns. Despite significant advances in policies on newborn health, action to implement evidenced-based care provision has been slower. However, countries are now poised for programmatic action due to two substantial shifts in newborn care over the past decade.

The first is a shift in the “phases of care”. Historically, countries that have substantially reduced newborn deaths achieved declines in their neonatal mortality rate (NMR) over five phases (see Figure 5.2 for illustrative examples). Of 195 UN Member States, 92% are now in phase III or higher. The 48 countries

currently in phase III (with an NMR of 16–30 deaths per 1000 live births) must improve SSNC in order to advance to phase IV. Importantly, countries that invested in their nursing and midwifery workforces achieved sustained reductions in maternal and newborn mortality.

FIGURE 5.2 Historically informed neonatal mortality rate (NMR) reductions by phases of care



Adapted from Lawn et al. 2023 (14)

The second notable shift is the place of care. As noted in Chapter 4, facility-based births have increased over the last decade: 80% of the 135 million annual births worldwide now occur in a health facility (15). A baby’s chances of surviving and thriving are largely determined by the services available and delivered at the place of birth. The increased coverage of facility births therefore presents an important opportunity to improve quality, including access to skilled health workers and FCC. A growing global multistakeholder community of practice is sowing the seeds for faster implementation of SSNC (Box 5.2).

The next section sets out key programmatic priorities to leverage these opportunities and close the gaps to improve survival and long-term health outcomes. This includes strengthening health system resilience to enable sustained delivery of high-quality care for all admitted newborns, and integrating care for preterm babies with care for other small and sick newborns.

PROGRAMMATIC PRIORITIES

What inpatient care is needed for small and sick newborns?

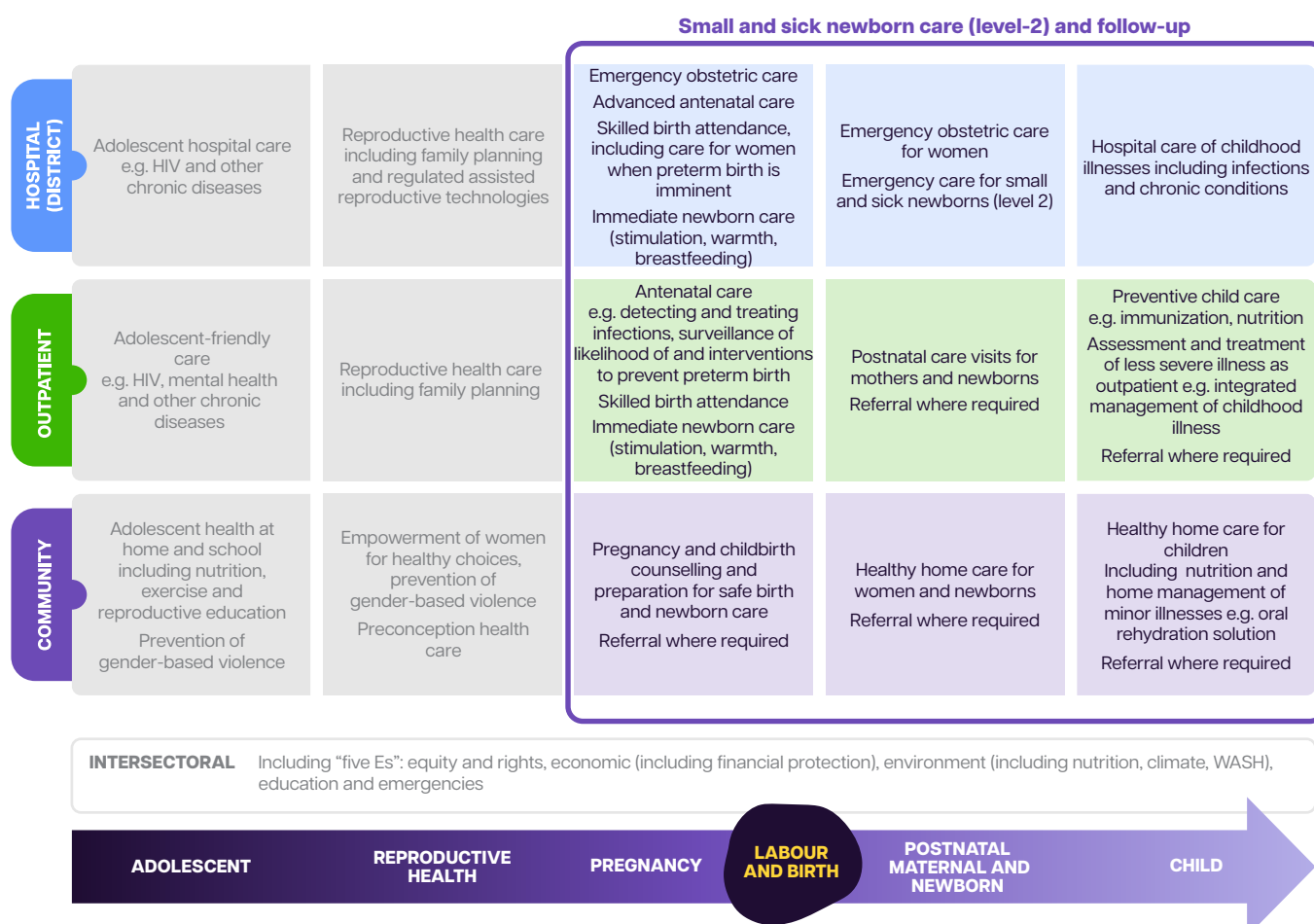
The simplest organization of inpatient newborn care has three levels, mirroring primary, secondary and tertiary care at the population level. These levels need to be interconnected by communication and referral systems, and to function within the continuum of care for maternal, newborn and child health (Figure 5.3). 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. Although this chapter focuses on level-2 care, health systems must be strengthened and transformed at every level. This must be accompanied by the transformation of social, economic and legal institutions.

BOX 5.2 Global network driving action to improve small and sick newborn care

The Care of the Small and Sick Newborn Community of Practice was established in 2022 to improve knowledge, implementation and practice relating to newborn care through cross-country learning, linked to ENAP. This global network has grown rapidly, spanning continents and including health-care professionals, parent groups, researchers and others. Relevant health-care professional organizations include:

- The International Paediatrics Association and the International Federation of Gynecology and Obstetrics, both of which supported the roll-out of ENAP and continue to support initiatives for high-quality newborn care globally.
- The African Neonatal Association, founded in 2022, comprised of neonatologists and paediatricians from more than 40 African countries. The group is especially mindful of equity, access, ethics, family-centredness and quality.
- The Council of International Neonatal Nursing, a longstanding champion for newborns, received funding to strengthen and support neonatal education in Africa and to facilitate the standardization of nursing programmes across countries.

FIGURE 5.3 Continuum of care, with packages focused on SSNC (level-2) and follow-up care



Standards of care and evidence based-interventions

Level 3: 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.

+ 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 infants).

Level 2: Special newborn care

Thermal care; comfort and pain management; kangaroo mother care (<2500 g irrespective of stability); 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.

Level 1: Essential newborn care

Immediate newborn care (thorough drying, skin-to-skin contact of newborn with mother, delayed cord clamping, hygienic cord care); neonatal resuscitation (when needed); early initiation of and support for exclusive breastfeeding; routine care (vitamin K, eye care, vaccinations, weighing, 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.

Sources: WHO/UNICEF *Survive and Thrive*, 2018 (1)
WHO, 2020 (6)

Level-2 care for small and sick newborns

Many countries are in phase III or a higher level of care provision (Figure 5.2) with an NMR of <30 deaths per 1000 live births, and with most births occurring in facilities. Countries with higher

mortality rates need to focus on public health approaches and social determinants of health, encouraging facility birth where possible. However, most countries need to improve facility-based level-2 SSNC.

Every district, or equivalent subnational planning unit, needs a facility providing level-2 SSNC, with families at the centre, follow-up care, and functioning referral services from and to level-1 and level-3 facilities. This requires, not a “one at a time” approach, but a government-led, systems approach to the implementation of care. WHO specifies various aspects of health systems that need improvement, and emphasizes that high-quality, family-centred inpatient care requires an adequate space, competent professionals in all areas, and equipment and supplies to deliver the care (16).

Developmentally supportive care

It is especially important to consider developmentally supportive care in facilities as it is often neglected (1). Globally, 13 million preterm newborns survive each year, 2.7% of them with moderate to severe impairments and 4.4% having mild neurodevelopmental impairments (1). To support healthy growth and well-being, preterm newborns require developmentally supportive care,



including the following interventions to optimize child development and human capital.

- Optimize nutrition: provide human milk; use cue-based, infant-guided feeding; involve parents in feeding to improve breastfeeding initiation and duration; initiate KMC (17).
- Safeguard sleep: cluster care; provide care to coincide with sleep and wake cycles; minimize noise and light (18).
- Manage pain and stress: recognize signs of stress and pause intervention when possible; use positioning and boundaries to provide containment (19).
- Position and interact: maintain head in midline with limbs and trunk flexed and tucked; handle with slow, gentle movements; talk gently; provide support during transfers.
- Protect skin: maintain humidity during skin maturation; monitor susceptible skin/mucosal areas for breakdown; target wireless monitoring systems; promote skin-to-skin contact and massage; initiate breastfeeding early; position correctly (20).



Palliative care and bereavement care

Mothers, fathers and families need information and support when a baby is stillborn or when a newborn dies. 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. Respectful, culturally

sensitive and compassionate bereavement care, including psychological and spiritual support after a newborn death or stillbirth, reduces negative emotional, psychological and social effects for parents and staff (21). Steps to create or preserve memories are important and should be culturally appropriate.

Which systems do we need to transform?

Most approaches to improving the care and survival of small and sick newborns have focused on single interventions. However, most small and sick newborns have more than one problem and therefore require multiple interventions. The delivery of the broad range of interventions outlined above depends on a functioning health system (with adequate infrastructure, financial and human resources and information systems to track progress) and effective, timely referral and follow-up care systems.



Referral systems

Health facilities providing care for newborns require functional referral systems to ensure smooth transitions between different levels of the health system. Inpatient care should be complemented by care outside of hospital, including transport systems and home-based care in the community. It is important to recognize that not all complications can be predicted before birth: even with high-quality antenatal and obstetric care, some newborns will require inpatient care unexpectedly. In these cases, the newborn's survival depends on effective referral and safe transport, with no separation of mother and newborn. Each facility should have a clear written policy describing their level of care, including admission and discharge policies, and a written referral plan to guide cases in which a higher or lower level of care is needed.

The policies should also emphasize the importance of returning every newborn and their family to their local facility as soon as appropriate.

Health-care systems to become more family-centred

Family engagement in inpatient care of newborns results in better health and development outcomes, improved patient and family experience, higher health worker satisfaction and better resource allocation. Maximizing contact with parents, especially mothers, promotes bonding, breastfeeding, cognitive development and shorter hospital stays. Without support for parental participation, unintentional harm can occur to both newborns and families. Active family involvement requires context-specific adaptation and flexibility, and parental support groups/networks play a crucial role in driving change (covered in more detail in Chapter 3).

Follow-up care systems

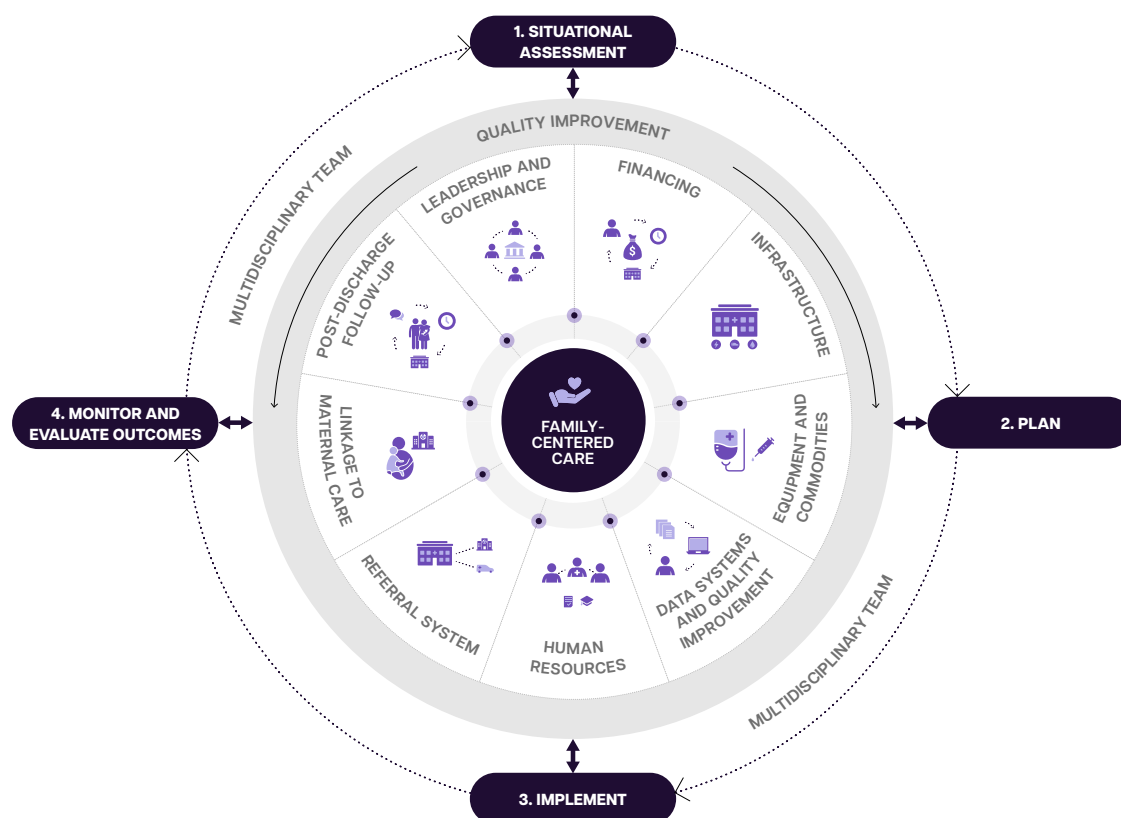
Discharge planning with parents is essential to ensure their competence and confidence to

provide essential nurturing care at home. It is necessary to think beyond mere survival to enable that babies thrive after discharge. Follow-up care from trained health-care workers is needed to monitor the baby's condition, support the family in KMC and nurturing care, and refer in the event of new danger signs or complications (including retinopathy of prematurity follow-up for small babies receiving oxygen therapy).

How to implement SSNC

Implementing SSNC involves four steps (Figure 5.4). Each step requires collaboration by a multidisciplinary team focused on each of the 10 WHO-UNICEF core components for scaling up care for small and sick newborns at the country level (seven of which are adapted from the WHO health system building blocks) (22). These components are compatible with components highlighted in the *Survive and Thrive* report, and with WHO people-centred care (1). Such teams require strong political leadership and commitment, for example from national ministries of health, but multistakeholder input is also needed.

FIGURE 5.4 Implementation of small and sick newborn care (with the baby and their family at the centre)



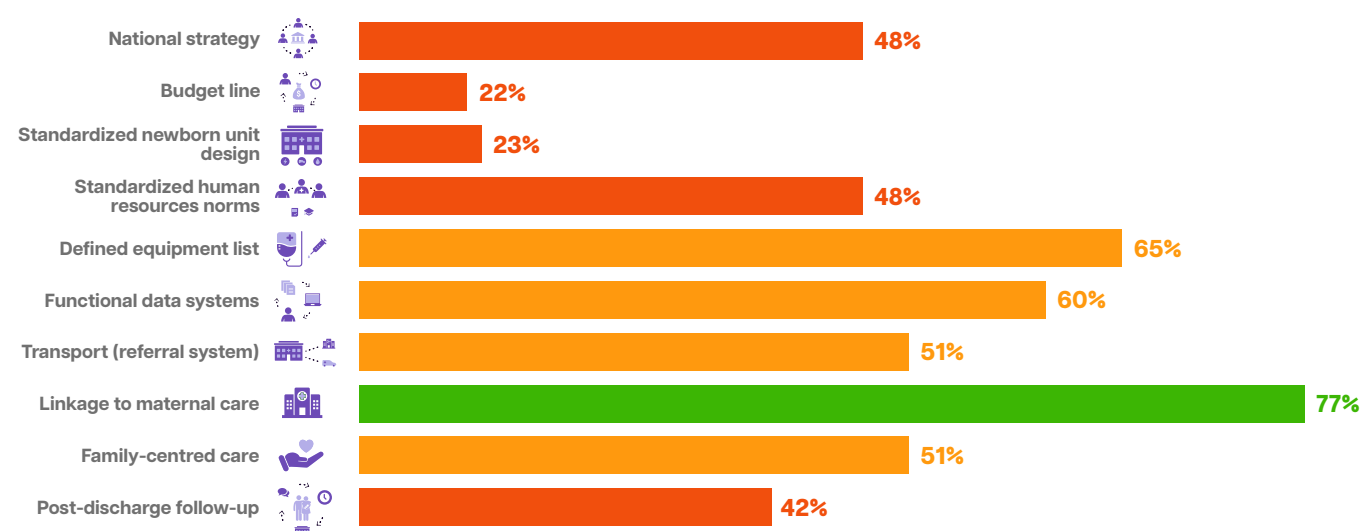
Four steps adapted from Knippenberg et al. (23). Wheel adapted from (24) and the WHO-UNICEF 10 core component model for small and sick newborn care scale-up (22).

Step 1: Situational assessment

In order to make informed decisions to improve the quality of newborn care, stakeholders need to know the state of SSNC at the national, subnational and district levels. Tracking coverage of ENAP target 4 requires capturing the number of districts providing level-2 newborn care. Health facility assessment data should also be collected for each

unit providing level-2 care, including about the availability of essential medicines, equipment and staff. Figure 5.5 depicts situational assessments of 106 countries according to the 10 core components for SSNC (22). The analysis should inform the planning of programmes aiming to improve inpatient care provision by addressing emerging gaps.

FIGURE 5.5 Status of the WHO/UNICEF 10 core component model for scaling up small and sick newborn care in 106 countries, based on reporting for ENAP/EPMM



Note: N=106 countries

Source: Joint ENAP-EPMM Country Progress Tracking, 2023. Data courtesy of UNICEF

Adapted from: Together for change: for every pregnant woman, every new mother, every newborn (2023) (25)

Step 2: Plan and budget

A phased implementation plan is an effective pathway for countries to reach every district, or equivalent subnational unit, with essential newborn care (level-1) and level-2 SSNC. The plan should be developed with input from key stakeholders, including national and subnational governments, health-care providers and community members, and should consider the unique needs and challenges of each district. The plan should include a quality improvement plan, closely involving implementers who provide daily care to newborns and their families.

Use data to drive investments. Data should be used to determine where investment is most needed, such as increasing the availability of essential medicines and supplies, strengthening the capacity of health workers, or improving the physical infrastructure of health facilities. Using data to inform investment decisions enables the allocation of resources in a targeted and effective manner to improve outcomes for small and sick

newborns. Using informed decisions to achieve effective resource allocation also strengthens the case for investment in newborn care (Box 5.3).



A nurse checks up on baby in the United Republic of Tanzania.
© UNICEF/UN0270630/van oorsouw

BOX 5.3 Country snapshot**Government-led change: a strong investment case for SSNC in the United Republic of Tanzania**

The United Republic of Tanzania has included SSNC targets in its National One Plan III, requiring additional investment. The Ministry of Health spearheaded a five-step investment case, adapted from the Global Financing Facility framework. First, national policy frameworks and guidelines were reviewed. Second, the potential impact of scaling up SSNC was estimated using the Lives Saved Tool for 2025 and 2030. Third, set-up and running costs were estimated using an activity-based-costing approach and the NEST360 Device Planning and Costing tool (available as a global public good). Fourth, return on investment was estimated. And fifth, potential financing opportunities were identified and targeted.

By 2025, in support of ENAP coverage target 4, the United Republic of Tanzania aims to have functional neonatal level-2 care units in 146 district hospitals and all 25 regional referral hospitals. At 85% coverage, estimated cumulative lives saved would be 36 600 by 2025, and 79 900 by 2030. The NMR was predicted to fall from 20 to 13 per 1000 live births, superseding the government target of 15 by 2025. However, this would miss SDG target 3.2 of fewer than 12. Set-up costs were estimated at either US\$ 112 million (scenario A: all neonatal units built new) or US\$ 65 million (scenario B: 50% neonatal units built new, 50% renovated/repurposed), driven by infrastructure. Running costs were estimated at US\$ 54 million (scenario A) or US\$ 25 million (scenario B), driven by the human resources gap. Even with all neonatal units built new (scenario A) this would be achievable with a 2.6% increase in government health expenditure.

The investment case in the United Republic of Tanzania is convincing, with a potential return on investment of US\$ 7-12 per US\$ 1 invested in SSNC. The government has committed additional resources and is mobilizing more. The five-step process and tools may be useful for other countries to adapt and further refine.

Adapted from Kamuyu et al. 2023 (26).

Step 3: Implement

To effectively implement high-quality care for small and sick newborns in hospital, several key ingredients are necessary.

Right place. It is essential that newborns are treated at the right level of care, which requires a functional and effective referral system. This is especially important in humanitarian settings, where access to care can be limited. The COVID-19 pandemic highlighted the opportunity for enhanced facility-based newborn care, as investments have been made in staff training, supply chain (including oxygen), data systems and transportation facilities.

Right devices, drugs and diagnostics. The right medical supplies and devices are a prerequisite for high-quality care for small and sick newborns. WHO has set standards for detecting and managing a number of clinical syndromes that require specialized medical supplies, devices and diagnostics (6). This includes ensuring that the right equipment and medications are available at the appropriate level of care, that these are in good working order, and that health-care workers are trained in their correct use. Low-cost products and technologies that positively affect survival rates are increasingly available, including those adapted

for low-resource settings (e.g. bubble continuous positive airway pressure (CPAP); point-of-care diagnostic tools, including bilirubinometers and haemoglobinometers). However, detection of neonatal sepsis, an important cause of neonatal mortality, is a major gap, especially in LMICs (27).

Right people. Strengthening the health workforce is crucial, and should include valuing systems, mentorship and opportunities to combat attrition. Policy-makers, implementers, managers, health-care workers, biomedical engineers and families all play important roles in improving the implementation of evidence-based interventions for level-2 SSNC (Box 5.4). Skilled health-care workers must be trained to provide high-quality, respectful care. A multidisciplinary team is essential, including biomedical engineers, clinicians, nurses, laboratory staff, procurement staff and managers, all working together to sustain high-quality SSNC at the institutional level. Data clerks are often overlooked, but also play a critical role in maintaining the quality of care. Many LMICs lack a skilled neonatal workforce: human resource strategies to improve newborn care in health facilities in LMICs urgently need to be adopted.

BOX 5.4 The right people are needed to provide small and sick newborn care

Mother. Empower the mother. COVID-19 exacerbated chronic separation policies in many neonatal units worldwide, where parents often feel more like visitors than parents. The ramifications of separation are multifold, affecting KMC, breastfeeding, family bonding and mental health (28).



Family and communities. Community care, especially with curative services, is a feasible and important component of the continuum of care for mothers and newborns, especially in hard-to-serve populations, such as those that are rural or post-conflict. Communities and families must be involved when implementing care for babies that are small and sick (1).



Health-care providers. As of 2020, there was a global shortage of 15 million health-care providers, primarily in LMICs where the burden of neonatal mortality is greatest (29). Chronic shortages of skilled providers, especially nurses and biomedical engineers, were exacerbated by the COVID-19 pandemic. Inexperience, rotation and attrition are common challenges faced by facilities across all income settings and need to be directly addressed.



Country governments and leaders. Strong leadership and governance are at the heart of the process. Government commitment is needed to develop national plans for newborn health, with a dedicated budget line. Collaboration and coordination are needed across governmental ministries, including health, education and transport, as these bodies share responsibilities within an integrated model of health service delivery.

CPAP, a non-invasive mode of ventilation used in preterm born neonates with respiratory distress syndrome, has been used since the early 1990s. It is known to decrease mortality by up to 50% if correctly implemented. Table 5.1 provides an

example of the people, place, devices and drugs needed to implement CPAP in low-resource settings, and Box 5.5 presents a case study of overcoming barriers to CPAP implementation in South Africa.

TABLE 5.1 The right place, device, drugs and people are needed to improve access to and use of CPAP in LMICs

Right place	Right device/drugs	Right people
<p>Space with oxygen and air supply; capacity to blend oxygen and air is critical to prevent retinopathy of prematurity</p> <p>Systems for transport and referral</p> <p>Strong essential care package, including resuscitation, thermal care, and infection prevention and control policy</p>	<p>Sell as a package of care, not a stand-alone intervention, to enable upstream factors in antenatal care to be addressed which could delay or prevent preterm labour and delivery</p> <p>Sustainability factors, to be included from the onset when the CPAP roll-out is planned, include:</p> <ul style="list-style-type: none"> • financing • oxygen and air supply • human resources • water and electricity <p>Steroids antenatally: new evidence shows that any steroid before delivery is better than none. Preterm labour protocols should be available and implemented appropriately and safely</p>	<p>Staff, including biomedical and maintenance, infection prevention and control</p> <p>Senior leadership buy-in is essential to allow ongoing financial support for consumables and equipment maintenance and repair</p> <p>Support to staff: once implemented at facility, provide outreach and support to brief staff, provide regular monitoring and evaluation, especially to discuss successes and failures of initiating CPAP</p>

BOX 5.5 Country snapshot**Overcoming barriers to CPAP implementation at scale in South Africa**

In 2003, a randomized control trial in South Africa among extremely low-birth-weight babies with respiratory distress syndrome found that the CPAP-treated group had significantly better 7-day and 28-day survival rates than the group not receiving CPAP (30).

In South Africa CPAP was well established in tertiary and regional hospitals. Pilot studies at district hospitals in Western Cape (2010) province showed that CPAP could be administered entirely by nurses, significantly reducing the need for intubation, ventilation and transfer to regional hospitals, with no significant change in mortality (31). In 2015, CPAP was included in the 15 interventions developed by PRICELESS SA (Priority Cost Effective Lessons for Systems Strengthening South Africa) that at scale would reach the SDG target of <12 newborn deaths per 1000 live births by 2030 (32). The Perinatal Problem Identification Programme recorded a 20% reduction in deaths due to respiratory distress syndrome in babies weighing >500 g in the five years, in part due to the use of CPAP outside of tertiary facilities (33, 34).

Successful implementation and roll-out depend on considerations, including addressing fear of failure, as not every baby survives, and the right patient is critical for success. Facility readiness for implementation must be assessed before implementing CPAP. A feedback loop, to debrief staff on the quality of CPAP and discuss early CPAP success and failures, is important for improving CPAP provision at facility level.

Step 4: Monitoring and evaluation for quality improvement

Monitoring and evaluation determine the effectiveness of an implementation plan and identify areas for improvement. This should include regular data reviews and input from health-care providers and community members, as well as sustained efforts to feed back data for local use. Utilizing data to increase care quality, linked with mentorship, can refine clinical care pathways and improve outcomes. Functional, robust information systems are needed in each unit providing level-2 care to enable use of high-quality data for action at the local level. Core metrics from ENAP for assessing the impact, progress and quality of SSNC delivered are detailed in Box 5.5 (35).



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BOX 5.6 Core metrics for assessing the impact, progress and quality of small and sick newborn care

Implementers and planners must focus on outcome indicators for impact, but other metrics are also important for assessing progress and quality.

- **Outcome indicators:** stillborn rate, neonatal mortality rate, low birth weight and preterm birth rate must be measured and compared to 2030 and other targets.
- **Coverage indicators:** percentage of facility births, percentage of districts with a level-2 SSNC unit, percentage of districts implementing KMC.
- **Service readiness indicators:** health facility assessments, scoring for infrastructure, human resources, etc.
- **Quality of care indicators:** use of KMC, use of CPAP, infection detection. It is also critical to address the lack of indicators for satisfaction and perceived quality of care by families.
- **Process indicators:** regularity of neonatal/perinatal audits, documented use of data for change.
- **Investment indicators:** governmental budget lines for child/newborn health, expenditure of official development assistance. Leaders need to know how much money is invested in newborn health, and whether it is being spent effectively.

To reach the SDG target of ending preventable deaths by 2030, countries must transform their measurement and reporting systems. Functional information systems are especially needed to enhance surveillance of infections and antimicrobial resistance associated with health care. Improved national and local surveillance is also needed to tailor empirical antibiotic recommendations and implement effective antimicrobial stewardship programmes, part of the *WHO Global Action Plan for Antimicrobial Resistance* (36).

PIVOTS

Pivot 1: Invest ambitiously in SSNC

Investment in SSNC is a critical need that requires bold action and collaboration from governments, investors and other stakeholders, and should include the following actions.

- Advocate for investment at global, regional and national levels to implement SSNC programmes in more than 80% of districts (or equivalent subnational planning unit) in order to reach ENAP coverage target 4 (5).
- Set ambitious targets, engage a wide audience and employ a results-oriented, practical approach to achieve better outcomes for newborns.
- Drive country-led investment efforts, highlighting the significant returns from investment in this area.
- Streamline insurance coverage for maternal and newborn care and integrate SSNC interventions into UHC schemes. This will



Health worker examines baby in Canada.
© WHO/Christine McNab

ensure equitable access to high-quality care for all newborns and provide financial protection for families. UHC is essential to ensure that all newborns have access to the care they need to survive and thrive, and to reduce health inequities.

- Transform care for newborns to improve human capital and drive economic development.

Pivot 2: Implement high-quality, family-centred SSNC

The need to implement high-quality SSNC is urgent and affects all stakeholders, including families, communities, health-care workers and governments.

- Provide family-centred care that is evidence-based, well organized, accessible and adequately resourced, and which prioritizes safety, efficiency, equity and timeliness.
- Integrate newborn care into existing maternal services, ensuring comprehensive and coordinated care for both mother and newborn.
- Ensure sufficient numbers of skilled health-care providers to provide care in facilities, at all hours, especially trained and motivated nurses, who can work in partnership with families.

Pivot 3: Innovate through multicountry learning

Over the next decade, attention must be paid to collaborative multicountry learning to develop and enhance the tools, technologies and innovations required for SSNC in all contexts (Table 5.2). This includes the following actions.

- Establish learning networks and foster knowledge exchange to move faster together and to protect progress on newborn survival achieved over the last decade.
- Explore low-cost technology options that are purposed for low-resource settings and resilient to climate shifts. Climate is a growing threat to health globally; small and sick newborns are particularly vulnerable.
- Develop cost-effective, robust devices, which requires implementation research and usability testing to establish feasibility in various contexts.
- Establish equitable partnerships between public and private organizations, communities and researchers to ensure that innovations reach those who need them most.



A health worker hands a preterm baby to his mother at a clinic in Iraq.
© UNICEF/UN0648656/Njiokiktjen

TABLE 5.2 Innovations required for progress in small and sick newborn care

10 core components for scaling up SSNC in countries ^a	Innovations required
Family-centred care	<ul style="list-style-type: none"> Maternal and newborn intensive care units Knowledge and buy-in regarding follow-up care Kangaroo mother care wards
Leadership and governance	<ul style="list-style-type: none"> District governance; monitoring and response units allowing district and subdistrict governance mechanisms
Financing	<ul style="list-style-type: none"> Country investment cases for SSNC
Human resources	<ul style="list-style-type: none"> Task-shifting implementation strategies SSNC education and training (WHO modules, COINN CoNP and competencies)
Infrastructure	<ul style="list-style-type: none"> Specialized and functional newborn units adapted for context
Medical supplies and devices, including equipment and commodities	<ul style="list-style-type: none"> Local manufacturers and procurement systems New antibiotics Lower-cost, robust CPAP equipment Innovative diagnostics: sepsis point-of-care tests Outbreak response triggers Simplified blood culture processes, suitable for low- and middle-income countries
Robust data systems	<ul style="list-style-type: none"> Integrate newborn and SSN data within DHIS Facility-level data dashboards Proposed methods for how best to capture SSN interventions for family-centred care
Referral systems	<ul style="list-style-type: none"> Integrate referral systems with electronic health records Use of telemedicine technologies Implement evidence-based and community-based referral systems Standardized referral protocols
Linkage with high-quality maternal care	<ul style="list-style-type: none"> Linked newborn-maternal records
Post-discharge follow-up system	<ul style="list-style-type: none"> Innovative ways to increase awareness and education for caregivers Use of telemedicine and mobile health technologies for communication

SSNC: small and sick newborn care; CPAP: continuous positive airway pressure; CoNP: community of nursing practice; COINN: Council of International Neonatal Nurses; DHIS: district health information system

^a Adapted from WHO-UNICEF's 10 core components for scaling up small and sick newborn care in countries (22).

Pivot 4: Integrate family-centred care and follow-up for developmental outcomes into systems

- Transform existing maternal and newborn health systems into family-centred systems to ensure that the needs of mothers and newborns are met. This includes providing comprehensive, culturally appropriate and accessible care, tailored to the specific needs of each family.
- Shift focus away from provider-centred care to prioritize family involvement; ensure that health-care providers are trained to provide family-centred care.

- Integrate follow-up for developmental outcomes into existing systems to ensure that all newborns have the opportunity to reach their full potential. This can include regular check-ups, developmental screenings and interventions to support healthy growth and development.
- Empower parents and prioritize financial protection for families of small and sick newborns requiring care.



Mother with her two sons, Pakistan.

© White Ribbon Alliance

Key reading

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Behind every statistic is a story

Meet Abhishek and Koresh

from **Nepal**



Anita and her sons Abhishek
and Koresh.

Anita Gurung, from Chitwan, Nepal, went into labour when she was seven months pregnant with twins. Her mother-in-law noticed that she had severe stomach pains and rushed her to hospital with her husband. They had not yet made any preparations for the babies, not expecting delivery to be so early.

Anita was worried and questioned whether the babies would survive. She had previously had a miscarriage, and feared a repetition of that loss. "At that time I was very worried and frightened for the babies: would they be fine or not?"

She gave birth to twin boys in October 2020. Baby Abhishek weighed 1250 grams while baby Koresh weighed only 950 grams at birth. Both were taken to the NICU at Bharatpur Hospital.

Anita felt well taken care of by the health-care providers. "They took good care of me and my babies. They wrapped my babies in clothes, washed and cleaned up all the blood, and put me into bed. I felt very good."

Five days after birth, Anita and Abhishek were transferred to the KMC Unit while Koresh remained in the NICU because he had developed pneumonia a few days after birth and required oxygen. With guidance and help from the nurses, Anita was eventually able to provide KMC and breastfeed both babies. "They told me to keep the baby next to my skin, on my chest, for some hours during the day, and I saw my first baby grow rapidly."

For Anita, the KMC unit was important for both her own hospital experience and the care she was able to provide to her babies. While in hospital she could see them frequently, and was guided on how to express breast milk. She was also taught about the importance of skin-to-skin contact between preterm babies and their parents. Anita says KMC helped both her babies to gain weight. By the time she and the babies were discharged two months after their birth, they weighed 1800 grams and 1700 grams respectively.

"I was told that if I kept my babies warm they would gain weight. One of the nurses visited frequently, and she cared for me and my babies a lot."

**“They took good care of
me and my babies.”**

Besides health care and attention, Anita also received clothes and blankets for her babies from hospital staff and her friends. "I was taken very good care of during my stay. Health workers used to come and see me and take care of my babies. They helped when I was not feeling well, and they played with the babies and helped me to produce and feed milk to my babies."



Chapter 6

Intersectoral action: integration for impact on preterm birth

KEY MESSAGES

Progress

The last decade has seen a growing focus on intersectoral interventions to improve health and well-being outcomes, notably in the SDGs and in efforts to mitigate the effects of the COVID-19 pandemic.

Intersectoral action has the potential to reduce the burden of preterm birth and thus to benefit mothers and babies, transform human capital and improve the health of future generations.

Programmatic priorities

Intersectoral determinants affect women and their vulnerable newborns throughout the life-cycle. Characterized as the “five Es”, all these determinants must urgently be addressed: equity and rights; economic; environment, including nutrition and climate; education and emergencies.

Pivots

Better measurement of and accountability for outcomes for vulnerable newborns, notably preterm, small for gestational age and stillbirths, in intersectoral programmes across the “five Es”.

Invest in achieving equity-focused, gender-transformative and rights-based policies and programmes across sectors, prioritizing:

- equitable and inclusive education, including comprehensive sexuality education;
- innovative financing schemes that protect and support families with preterm babies;
- environmentally adaptive systems that prioritize maternal and newborn health; and
- emergency response plans that ensure the continuation of maternal and newborn health services.

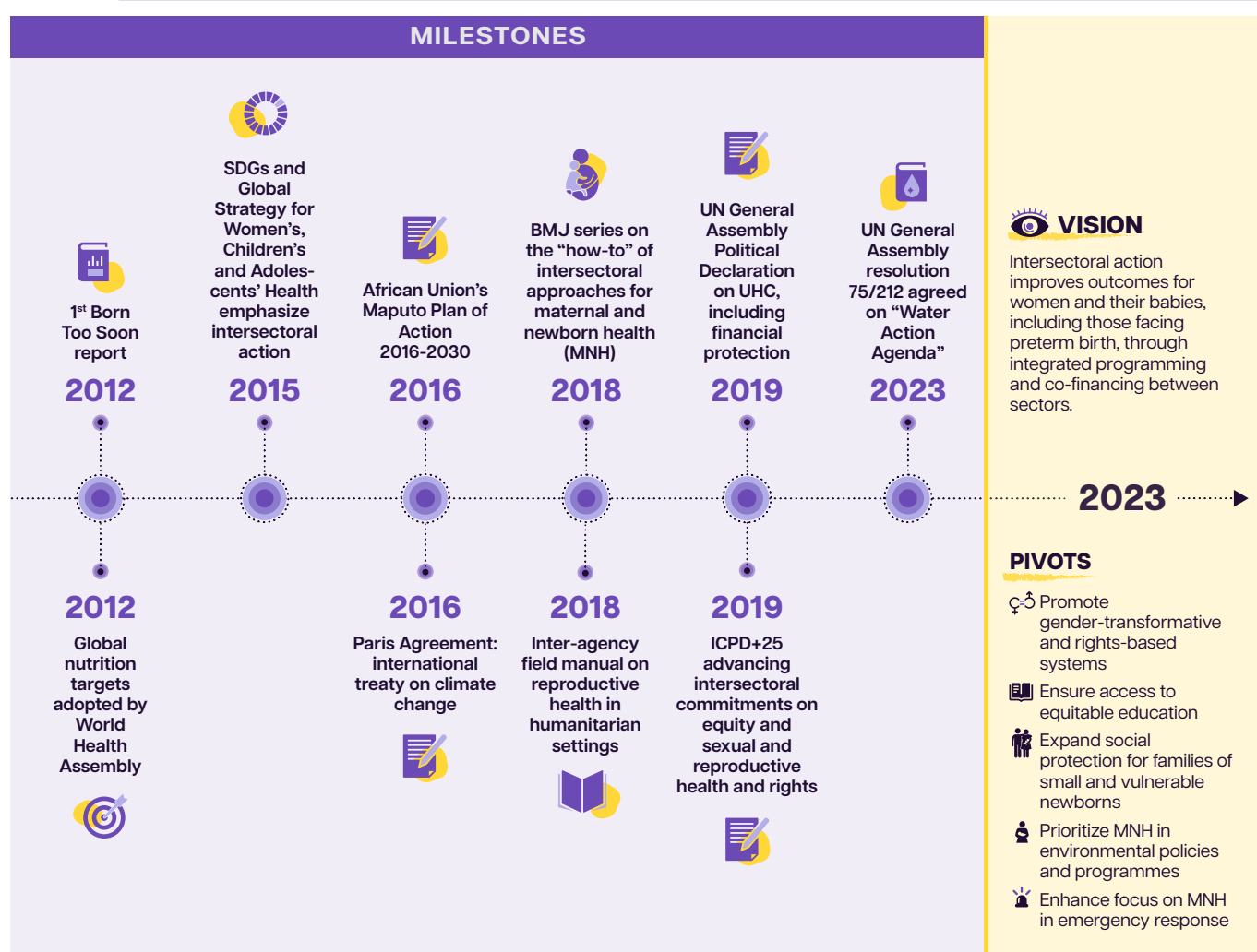
PROGRESS

The remarkable progress achieved for maternal and child survival in the past decades was not due to the health sector alone. Between 1990 and 2010, 50% of the global mortality reduction in children aged under 5 years was attributable to investments from outside of the health sector, for example in economic growth and education, especially of women (1). The importance of intersectoral approaches is emphasized in the 2030 Agenda for Sustainable Development and the *Global Strategy for Women's, Children's and Adolescents' Health*

(2016-2030), both launched in 2015. Figure 6.1 presents policy and implementation milestones relating to intersectoral action since the first *Born Too Soon* report in 2012.

In 2023, against the backdrop of the COVID-19 pandemic, the growing climate and cost-of-living crises, and the emergence of new and worsening conflicts (four Cs), it is widely accepted that intersectoral action is essential to achieve health-related goals, including those concerning preterm birth and small and vulnerable newborns.

FIGURE 6.1 Intersectoral action impacting on preterm birth: timeline of progress over the past decade and vision for the next decade



Preterm birth results in loss of human capital and poor outcomes across generations, significantly affecting health and skills, and hence national development. Women who were themselves born preterm have a 60% higher risk of delivering preterm babies than women born at term (2). These impacts provide a strong argument for decision-makers and advocates to support investments and policies to prevent preterm birth (3).

Since the first *Born Too Soon* report, the importance of intersectoral action has become clearer, notably highlighted in the SDGs, which have one health goal linked to 16 intersectoral goals. Shocks from the "four Cs" have significantly challenged the achievement of the SDG 3 targets on health and well-being, and threaten to reverse progress on the health-enhancing SDGs, including for education and gender equality (4).

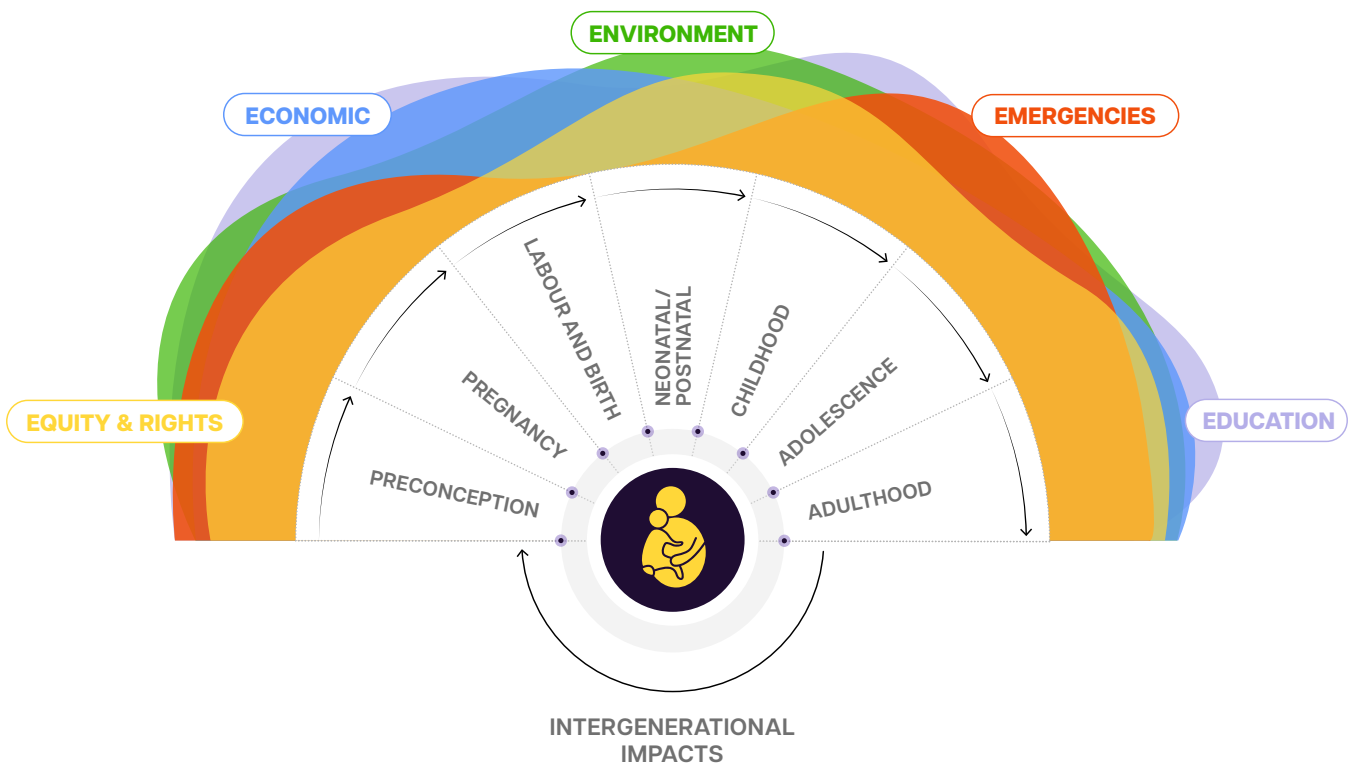
While health interventions are vital, intersectoral action is also crucial for managing complex public health issues, as underlined in the COVID-19 pandemic.

The same principle of intersectoral action holds true for the prevention of and care for preterm birth, because it is a complex public health issue. Over the last decade, evidence about *what* can be done, and country experiences of *how* it can be done, have also expanded. This chapter reviews this emerging knowledge, much of which draws on literature beyond preterm birth, and outlines priorities for more integrated action and better measurement in the decade ahead.

PROGRAMMATIC PRIORITIES

Building on the *Global Strategy for Women's, Children's and Adolescents' Health*, this section outlines the programmatic priorities relating to the five interconnected “Es” – the factors most profoundly affecting women at risk of preterm birth and small and vulnerable newborns: equity and rights, education, economics, the environment and emergencies (Figure 6.2).

FIGURE 6.2 The “5 Es” of intersectoral influence on preterm birth



1. Equity and rights

Women's lack of autonomy, agency and economic independence results in their marginalization and impairs health and economic growth outcomes. Specific examples, such as child marriage and female genital mutilation, translate into increases in neonatal mortality, stillbirths and long-term morbidity (5). Addressing gender-based discriminatory practices, such as excluding pregnant adolescent girls from services, is essential to improve the health of women and their newborns. Family planning is a key component of women's and girls' reproductive rights.

Gender-based violence is associated with higher rates of preterm birth (6, 7, 8). Teenage mothers are at particular risk: gender and age make adolescent girls doubly vulnerable to gender-based violence, which stems from intersectional systems of oppression, exclusion and discrimination (9). Another priority is to end early and forced marriage. The consequences of child marriage, including lack of education and unemployment, are lifelong, and propagate an intergenerational cycle of poorer health outcomes (10).

Racial discrimination is associated with higher rates of maternal mortality, preterm births and low birth weight. Rohingya refugees, facing social exclusion, were 60% more likely than Malaysian nationals

to give birth to a low-birth-weight baby (11). Programmes that address one point of inequality can also reduce others. Box 6.1 explains how one

state in the USA is using an intersectoral approach to tackle stark racial inequities in preterm birth rates.

BOX 6.1 Country snapshot

Addressing racial inequities in maternal and newborn health in New Jersey, United States of America

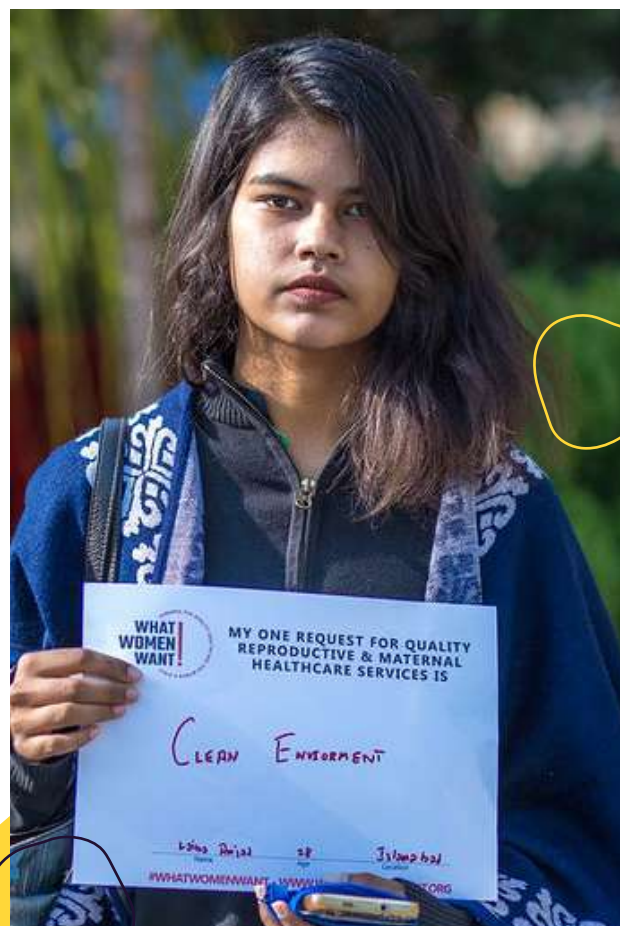
Between 2014 and 2016, in New Jersey, USA, Black women were seven times more likely than White women to die due to pregnancy-related causes. In 2018, Black non-Hispanic women experienced almost three times as much severe maternal morbidity as White non-Hispanic women. In 2017, the Black newborn mortality rate was more than three times that of the White newborn mortality rate. For Black infants, the top cause of death was prematurity and/or low birth weight. Overall, complications from preterm birth are the leading cause of newborn death in New Jersey, overrepresented by Black infant deaths (20%) and Hispanic infant deaths (29%) compared to White infant deaths (6%).

Recognizing these racial disparities and inequities, in 2018, New Jersey launched a year-long multistakeholder consultation process, culminating in the development of the Nurture NJ Strategic Plan. This intersectoral strategy (health, education, housing, business, government, justice, etc.) seeks to address historic failures. Since its launch, a variety of interventions have been introduced, including increased funding for family planning; an increase in the Earned Income Tax Credit; equal pay legislation; goal setting on reducing environmental hazards; the establishment of the New Jersey Maternal Data Center; increased college affordability; and investment in the community health workforce. The strategic plan has set the long-term goal of 100% of mothers and babies residing in high-needs areas to be nurtured in the context of a fully built maternal and infant health ecosystem throughout the 1090 days from three months before conception to the child's second birthday.

2. Education

Education is a cornerstone for increasing socioeconomic status and, in turn, a key predictor of the health of both women and their babies (12). Reduced educational attainment, defined as less than completion of high school, has consistently been shown to be associated with a 10-48% increase in preterm birth (3, 13), noting that educational attainment involves a series of intersecting inequities, including the challenge of teenage pregnancy. Babies born to adolescent mothers are more likely to be born too soon and to die in the perinatal period (14). For adolescents, lower levels of partner's education are also associated with adverse health outcomes for both mother and baby, as well as worse birthing experiences (15).

Access to education can also have an indirect positive effect on preterm birth rates. Increased access to education, particularly secondary education including comprehensive sexuality education for adolescent girls, has been shown to reduce early and forced child marriage and adolescent pregnancy. Box 6.2 highlights the approach taken in Zambia to reduce adolescent pregnancy.



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BOX 6.2 Country snapshot

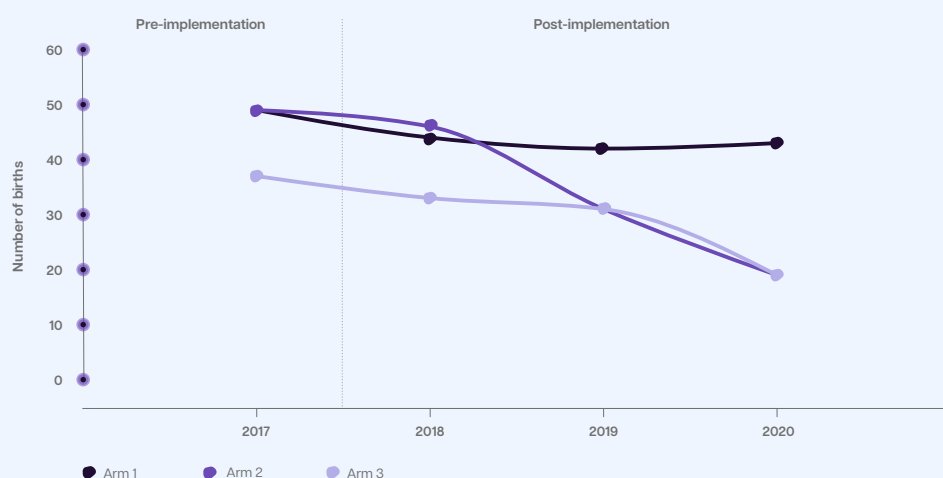
Reducing adolescent pregnancy through comprehensive sexuality education in Zambia

Concerned by high rates of early and unintended pregnancies, Zambia's Ministries of General Education and Health collaborated with the Population Council, United Nations Population Fund (UNFPA) and United Nations Educational, Scientific and Cultural Organization (UNESCO) to develop and test a model linking comprehensive sexuality education programmes in schools with access to receptive adolescent sexual and reproductive health services at health-care facilities. The project significantly increased students' exposure to both.

Program participants were divided into three arms: Arm 1 - the control group which received continuation of existing routine comprehensive sexuality education services and current structure of school-health facility linkages; Arm 2 - which received the continuation of services in addition to the utilization of trained nurses to provide information on adolescent sexual and reproductive health with a mechanism for referral where additional care was required; and Arm 3 – which received continuation of services in Arm 1 in addition to provider facilitation of periodic comprehensive discussions with adolescents on SRH services and periodic visits to SRH services at health facilities when needed.

Since the programme's inception, adolescent pregnancies have significantly declined among a population of 5571 girls aged 12 to 24. In the control group (Arm 1) 2.7% of the participants became pregnant, compared to 0.7% in the group who received school-based services and referrals (Arm 2) and 1.3% who received health services outside of school (Arm 3).

In the future, it will be important for such programmes to include preterm birth and stillbirths as outcome indicators, in order to better document impact.



Reduction in number of births after implementing comprehensive sexuality education

Babies born too soon or too small are at risk of neurodevelopmental delays, but when cared for in a nurturing environment and with the right supportive care, these vulnerable newborns are more likely not only to survive but also to thrive. However, too many newborns are deprived of their right to receive nurturing care, including inpatient hospital care (16). Greater attention to ensuring consistent delivery of nurturing care for all newborns – especially the most vulnerable – is essential.

3. Economic

The interrelationship between poverty and health, and the impact of poor health on economic

development, are well established (17). Stark disparities in neonatal outcomes occur across income levels within countries. For example, in the United Kingdom, babies born to mothers living in areas with the lowest income levels are twice as likely to be stillborn than those of mothers living in the highest-income areas. Babies born in the lowest-income areas also have a 73% higher risk of neonatal death than those in the highest-income areas (18).

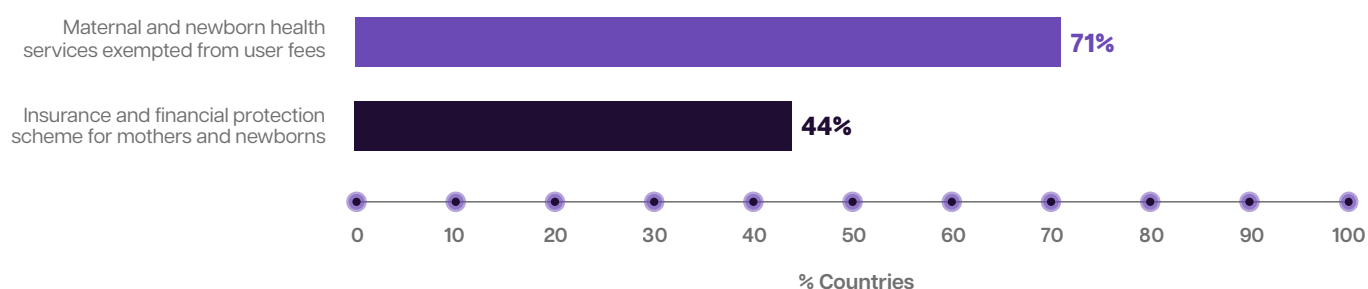
Out-of-pocket payments (OOPs), which are common in countries of all income levels, can put the greatest pressure on the poorest, and catastrophic health spending can push vulnerable families into poverty (19). Macroeconomic

ZAMBIA

uncertainties, compounded by rising costs of living and increased inflation, put considerable financial pressure on vulnerable families. For families of preterm and other sick newborns, OOPs may be required for a baby's hospital stay and treatment, as well as indirect costs such as travel and accommodation for family members. OOPs tend to have the greatest impact on poor and marginalized groups. They are a fundamental impediment to care for small and vulnerable newborns, including

preterm babies. Of the 106 countries surveyed in 2022 using the ENAP-EPMM Tracking Tool, 59 do not have an insurance scheme that covers all pregnant women and mothers (Figure 6.3) (20). Despite fiscal constraints, this is a particularly important moment for countries to invest in UHC, prioritizing extending coverage to the most vulnerable, so that they are able to access health services according to need, rather than their ability to pay.

FIGURE 6.3 Financial protection for maternal and newborn health services, 2022



Data source: ENAP-EPMM tracking tool data. Courtesy of UNICEF

Social protection measures are also vital for the families of preterm babies. The 2022 WHO recommendations for the care of preterm or low-birth-weight infants cited family involvement as key to improving routine preterm care, but some families cannot fulfil these essential roles without social protection. However, as of 2022, very few LMICs have specific policies for families with preterm babies. Only two countries (Canada and

Germany), both high-income, reported providing families with additional financial support (“parental allowance”) for their preterm babies. Parental leave and entitlements are necessary to address the special needs of mothers, fathers and other primary caregivers of babies born too soon or too small (21). Box 6.3 highlights an intersectoral approach to social protection and nutrition for pregnant and breastfeeding mothers.

BOX 6.3 Country snapshot

Addressing the nutritional needs of pregnant and breastfeeding mothers in Pakistan through social protection programming

The World Food Programme's Fill the Nutrient Gap (FNG) analysis aims to improve understanding of the drivers of malnutrition in local contexts by identifying bottlenecks, opportunities and enabling factors linked to food insecurity and malnutrition across the food system. It is carried out for the general population of a region or country, as well as for nutritionally vulnerable groups, such as young children, pregnant and lactating women, adolescent girls and older people. Adolescent girls were identified as a key intervention group because one in five adolescent girls is malnourished, and babies of mothers aged under 20 years were more likely to be small at birth than babies of mothers aged over 20 years.

In Pakistan, the FNG analysis enabled the government to identify options that combined approaches, for example, cash transfers with nutrition-specific interventions. A social protection package targeting pregnant and breastfeeding women during the six months after delivery and children aged up to 24 months was enhanced with a nutrition-sensitive conditional transfer component. The combined services included: quarterly antenatal care visits; immunization; growth monitoring and nutrition education; specialized nutritious foods for women during pregnancy and lactation and for children aged 6 to 23 months; and a small cash transfer to encourage the uptake of services. This intersectoral coordination has enabled the available funds to be used more effectively, increasing the positive impacts achieved.

4. Environment

Evidence is increasing of the impact of environmental factors on preterm birth and linked perinatal outcomes, such as stillbirth (22).

Climate change

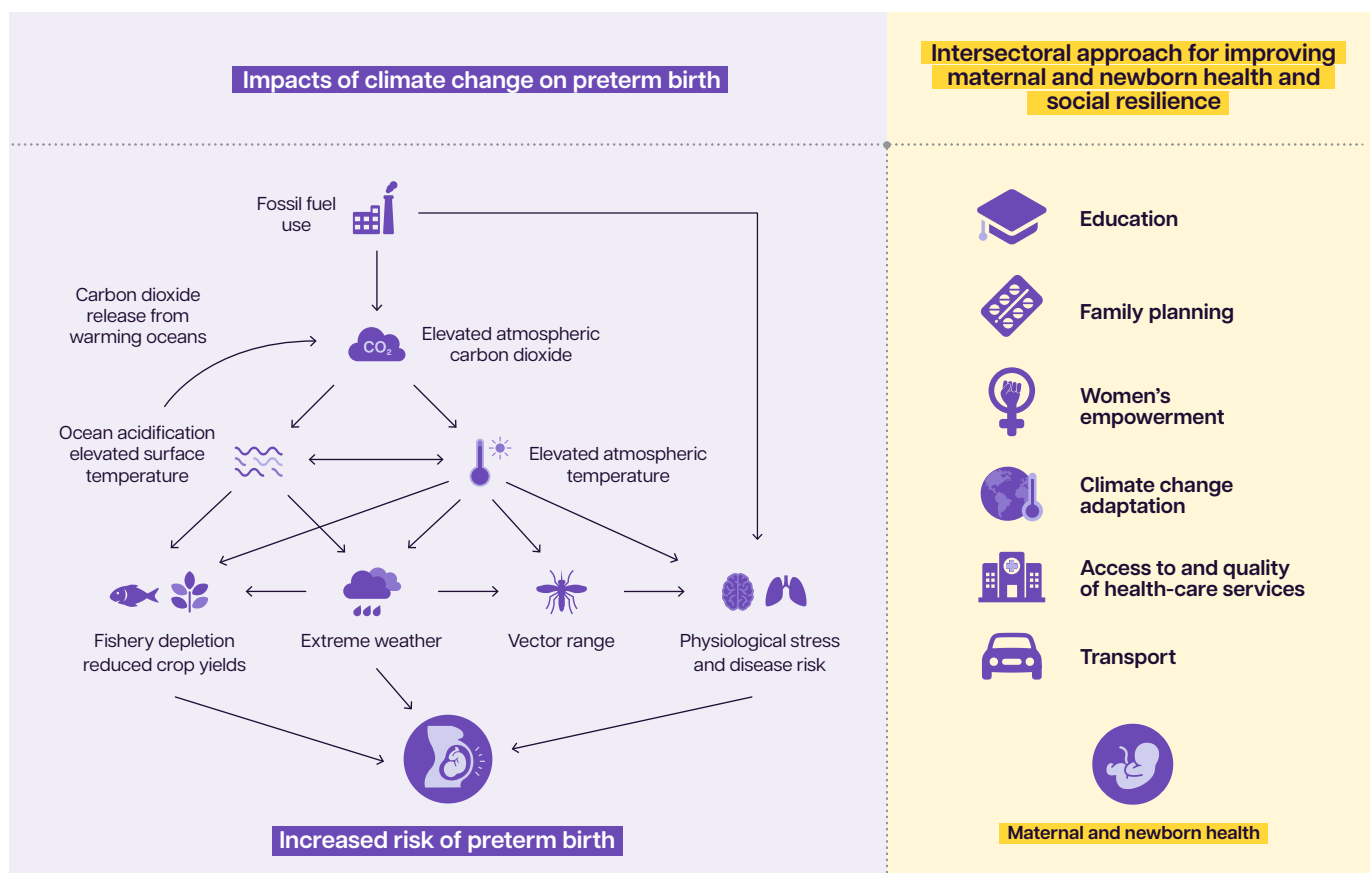
Climate change has harmful impacts during the perinatal period (23). It increases the risk of preterm birth by direct pathways, such as: air pollution caused by burning fossil fuels (increases risk by 52% in asthmatic mothers (23)); extreme heat exposure (increases risk by 16% (24)) and other extreme weather events, such as drought (25). Although the impacts of climate change are being felt in all areas of the world, the people most affected have contributed least to the crisis. For example, globally, 91% of deaths of preterm babies related to air pollution occur in LMICs, while high-income countries make the greatest contribution to



© White Ribbon Alliance

climate change (26). Recent estimates suggest that household air pollution was an attributable factor for 15.6% of all low-birth-weight babies and 35.7% of all preterm births, notably in low-income countries (27). Figure 6.4 provides an overview of the impact of climate change on women and newborns, and key areas where intervention is needed to reduce that impact.

FIGURE 6.4 Impacts of climate change on maternal and newborn health



Climate impact



Air pollution increases the risk of preterm birth in asthmatic mothers by 52%



Globally, household air pollution contributes to an estimated **15.6% of all low-birth-weight babies and 35.7% of preterm babies**



Extreme heat exposure increases the risk of preterm birth by 16%



A woman is interviewed in front of WASH facilities in Malawi.
© White Ribbon Alliance

Despite the growing body of evidence linking the effects of climate change with maternal and newborn health, its impact remains politically underappreciated. An analysis of 50 national and international climate policy documents (28) showed that only 12% referred to maternal health. An analysis of 19 national adaptation plans (29) showed that only 37% (7) referred to pregnancy and infancy, and then primarily in reference to the general context. Pregnancy and newborn health are often prioritized below other health concerns, and

environmental impacts on maternal and newborn health have rarely drawn the attention or resources of policy-makers and implementers.

Water, sanitation and hygiene (WASH)

Safe drinking water is a human right, yet in 2020, only one in four people globally had access to this in their homes (30). Lack of access to clean drinking water and poor sanitation negatively affect the health of women and babies. For example, exposure to *Listeria monocytogenes* bacteria in water, for which the infection rate is more than 17 times higher in pregnant women, is associated with miscarriage and preterm birth. Drinking unsafe water, such as groundwater contaminated with arsenic or fluoride, has also been linked to higher rates of miscarriage and stillbirth (31).

Lack of sanitation facilities also affects women and newborns negatively, yet almost half the world's population do not have access to safely managed sanitation. Studies in India found that women who practise open defecation, as well as those without a place to wash their hands, are likely to experience poorer pregnancy outcomes than those with such access (32). Culturally sensitive programmes that improve women's access to clean and safe water and toilet facilities, as discussed in Box 6.4, are an important component of an intersectoral response to preterm birth.

BOX 6.4 Addressing the maternal and newborn health needs of indigenous communities in South America

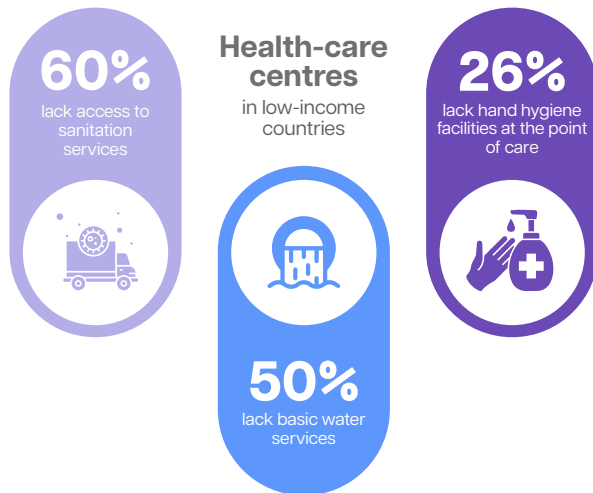
The Chaco Project, coordinated by the Pan American Health Organization and supported by Brazil, is being implemented in the Gran Chaco, a sparsely populated area of the Rio de la Plata basin divided between eastern Bolivia, western Paraguay, northern Argentina and Brazil. The programme seeks to strengthen health services for indigenous women and children and to reduce maternal, neonatal and child mortality. The project aims to provide health services to 400 000 people, 30% of whom belong to indigenous communities who are more likely to experience poor maternal and newborn health outcomes and to face barriers in accessing health services.

The project employs an intercultural approach to health care, prioritizing intersectoral interventions to ensure access to safe water and nutrition, and to respond to emergencies such as droughts and floods. Care for mothers and children was improved through: training personnel; working with indigenous midwives; knowledge exchange between countries; the introduction of perinatal technologies; and improved care of children with diarrhoea and pneumonia. Between 2017 and 2019, the project installed safe water systems in two hospitals, 17 rural communities and 18 indigenous communities. A nutritional health programme was implemented in Paraguay, and school health promotion programmes were developed in Argentina.

By addressing some of the intersecting inequalities experienced by indigenous women and children, the Chaco Project also addresses the intersectoral enablers of women's and children's health. Moving forward, including preterm birth and related outcomes in the monitoring and evaluation of such intersectoral projects will be vital to deepen the evidence base to inform future action.

Infections acquired in health-care facilities present a serious risk to women and newborns. Figure 6.6 outlines the current gaps in WASH services in health-care facilities in low-income countries. Correct handwashing with clean water, and access to hygienic toilets for health-care providers, women and their families, are key components of infection prevention.

FIGURE 6.5 WASH in health-care centres in low-income countries



Globally, women and girls comprise the majority (60%) of people with chronic malnutrition, and nearly 30% of women of reproductive age (15-49 years) suffer from iron deficiency anaemia (34). In the 12 countries hardest hit by the current food and nutrition crisis, the number of acutely malnourished pregnant and breastfeeding adolescent girls and women increased by 25% between 2020 and 2022 (35). Nutritional deficiencies, particularly iron deficiency anaemia, can lead to preterm delivery and low birth weight. Nutritional deficiencies can also lead to decreased iron in the baby and impaired child development.

Preterm birth is one of two underlying causes of low birth weight (small-for-gestational age being the other) (36). Low-birth-weight newborns are more likely to become children who are stunted or wasted, and to experience developmental delays, and more likely to become undernourished adolescents, and then undernourished adults (37). A vicious cycle of malnutrition and undernutrition passes from mother to child (37). Low-birth-weight newborns are also more likely to have adult-onset chronic diseases, such as hypertension and diabetes (38). Poor nutritional status produces negative effects throughout the life-course and across generations.

Nutrition

The nutrition of mothers directly affects the nutrition of their newborns. There is a significant correlation between undernourished mothers and low-birth-weight newborns. Conversely, maternal obesity is associated with an increased risk of preterm birth (33).

Breastfeeding is a high-impact practice for all newborns and especially important for those that are preterm and vulnerable, with extra support needed to enable exclusive and optimal feeding for six months. Intersectoral action is crucial, including parental leave and greater policy momentum to address social determinants and inappropriate marketing practices (39). Box 6.5 presents an example of intersectoral support for breastfeeding and good practices to mitigate the impact of marketing breast milk substitutes.



BOX 6.5 Country snapshot

BURKINA FASO

Intersectoral approach to support breastfeeding in Burkina Faso

Breastfeeding is not the sole responsibility of women: it is incumbent on all of society to provide an environment that is conducive to and supportive of breastfeeding. This requires action across areas beyond the health system, including education, employment and gender roles. In LMICs overall, fewer than one in two women initiates breastfeeding within an hour of birth, and more than one third of babies experience prelacteal feeds, i.e. foods other than breastmilk, during the first three days after delivery. The reasons that women do not breastfeed are many and complex, but they include the often aggressive marketing of commercial milk formula as a substitute for breastmilk.

Recognizing the challenge, in 2012, Burkina Faso adopted the National Infant and Young Child Feeding Scale Up Plan (2012-2025). This works to standardize messaging about infant nutrition and health at community level, including the education of traditional leaders, while facilitating the creation of support groups for mothers and promoting good feeding practices. In 2021, Burkina Faso updated a national decree on marketing and practices related to breastmilk substitutes to address the exploitative practices used by the formula milk industry in the region. The decree demonstrated the government's commitment to regulating the marketing of breastmilk substitutes and to implementing the International Code of Marketing of Breast-Milk Substitutes and related World Health Assembly guidance (40, 41).

The *Lancet's* Small Vulnerable Newborn series estimated the potential impact of eight innovative nutritional interventions, notably omega-3 fatty acid supplements, zinc supplements (or higher doses of zinc in multiple micronutrient supplements) and calcium supplements. If further research confirms their efficacy then these could provide substantial additional benefits (42).

5. Emergencies

It is important to address the broad spectrum of emergencies that affect maternal and newborn health. These include: conflicts; environmental disasters, including extreme weather events made more likely and more severe by human-caused climate change; and pandemics and epidemics. Other fragile situations can result from severe economic crises. Many countries experience more than one of these emergencies concurrently, compounding vulnerabilities.

Recurring conflict or political instability have devastating consequences for the health of women and newborns. Countries with protracted or sudden emergencies requiring international humanitarian assistance (measured as those with humanitarian response plans) experience 58% of global maternal deaths, 48% of newborn deaths and 47% of stillbirths (43).

In addition, risk factors for preterm birth are likely to increase substantially in humanitarian settings: examples include exposure to gender-based violence, infectious diseases, disrupted access to care, unsanitary and unstable conditions, and overcrowding. In addition, with increasing displacement, access to care is further hindered by language, literacy, cultural and financial barriers, in addition to ethnic and gender disparities.

Capacity to deliver the specialized and highly technical care needed for small and vulnerable newborns is often limited in humanitarian settings where health systems are already fragile and under-resourced (see Box 6.6). Among respondents to a 2018 survey of Global Health



A mother breastfeeds her preterm baby in Ethiopia. © WHO/Blink Media - Hilina Abebe

Cluster partner agencies, fewer than half (47%) reported having the technical capacity to provide essential newborn care during a response,

including care of low-birth-weight and preterm babies.



A mother and her daughter walk home with a container of water in Kenya. © WHO/Billy Miaron

BOX 6.6 Country snapshot

Impact of emergencies on preterm birth and small and vulnerable newborns in Yemen

Yemen is experiencing a political, economic and humanitarian crisis. After nearly a decade of conflict, Yemen is on the brink of socioeconomic collapse, and is currently ranked as the most fragile country in the world. Conflict has caused massive internal displacement. Repeated climate shocks and the breakdown of WASH services have greatly increased the risk of communicable disease spread, including cholera, measles and diphtheria.

A 2017-2018 retrospective study of admissions to NICUs in north-west Yemen found that approximately one in three newborns was admitted due to complications from preterm birth, and that more than two in three neonatal deaths were due to complications from preterm birth (44). Preterm newborns bear a significant burden of morbidity and mortality in Yemen, as in other humanitarian settings where accessing early and specialized neonatal care is difficult.

YEMEN

Key components of intersectoral action for addressing preterm birth

Table 6.1 provides an overview of evidence-based interventions that can serve as the key components of an intersectoral response to the prevention of and care for preterm births. These interventions should be implemented in an integrated manner, ensuring that sectors work together to deliver for the women and newborns. Intersectoral approaches are needed to effect complex interventions, and dedicated efforts and resources are needed to support implementation.



Women saving money for emergencies during pregnancy and childbirth in a women's group meeting. © White Ribbon Alliance

TABLE 6.1 Components of an intersectoral approach to address preterm birth across the life-course

	Risk factors for preterm birth	Interventions (general)	Interventions (with evidence specific to preterm birth)
Equity and rights	Gender-based violence Child marriage Female genital mutilation (FGM)	Laws, policies and programmes to address harmful gender practices such as early and forced marriage, FGM and gender-based violence Gender-transformative laws, policies and programmes that advance gender equality and women's bodily autonomy and agency Policies and laws that support increased women's representation and leadership at all levels of government and decision-making	Prevent child marriage and FGM Reduce intimate partner violence, including by promoting positive masculinity
Education	Reduced educational attainment, especially of girls and women	Laws, policies and programmes that support the advancement of girls' education and counter harmful gender and social norms Transformative comprehensive sexuality education programmes that promote gender equality and prevent early and unintended pregnancy	Social protection to enable girls to remain in school beyond primary education Implementation of nurturing care to support neurological development, especially for at-risk newborns
Economic	Out-of-pocket payments, poor access to high-quality care, lack of financial or social protection	Cash transfer programmes that cover nutrition, housing, education and access to high-quality health care Policies that promote sustainable and equity-enhancing financial incentives Investments in systems-level interventions addressing the underlying causes of preterm birth and low-birth-weight babies, including gender empowerment and education, programmes addressing adolescent SRHR, and prevention of child marriage and teenage pregnancy Increased resources for better health system performance and targeted social protection measures to improve financial risk protection for families of preterm and low-birth-weight babies	Parental leave and entitlements that address the special needs of mothers, fathers and other primary caregivers of preterm or low-birth-weight babies User-fee alleviation and subsidization of essential care Universal child health benefit, e.g. cash transfers for new mothers and families
Environment	Climate threats, lack of WASH, and unmet nutritional needs, including suboptimal breastfeeding	Climate-resilient and environmentally sustainable health systems that support uninterrupted delivery of maternal, newborn and child health-care services Laws and regulations to protect communities from exposure to pollutants known to be harmful to human health, including reproductive health Improved implementation of existing WASH strategies and frameworks, such as the WHO strategy on WASH and the Every Newborn Action Plan Implementation of gender-responsive national nutrition plans	Resources and services for pregnant and postnatal women living in areas affected by climate change Integration of maternal and perinatal care into climate mitigation and adaptation plans Implementation of nutritional guidance, including exclusive breastfeeding Promoting positive masculinity (sharing responsibility of household chores) to reduce exposure to pollutants
Emergencies	Humanitarian and natural disasters, conflicts	Increased financial and human resources to implement best practices for integrating maternal and newborn health services in these settings, as well as capacity building and infrastructure investments Implementation of gender-responsive emergency response plans that ensure maternal and newborn health services	Implementing existing guidance on delivering life-saving maternal and newborn care during responses; maintaining routine maternal and newborn health services during disease outbreaks; supporting self-care interventions; and capturing core indicators relating to preterm birth and low-birth-weight babies Expansion of women's access to social protection programmes, especially in emergencies where women struggle to obtain adequate nutrition

PIVOTS

Women and vulnerable newborns are at risk from siloed approaches. Government and multipartner efforts are needed to overcome the fragmentation between sectors. Given the major potential gains for human capital, studies of intersectoral interventions are urgently needed. These should measure perinatal outcomes, notably stillbirth and preterm birth, as well as maternal and child outcomes. The following pivots are vital to prevent preterm births, protect small and vulnerable newborns and their families and ensure greater accountability.

Pivot 1: Equity through gender-transformative and rights-based policies and programmes across sectors

Policies and frameworks should promote SRHR and women's bodily autonomy and agency, specifically addressing harmful gender and social norms, such as child marriage and FGM.

Pivot 2: Education that is inclusive through the life-cycle

A life-cycle approach is required to facilitate a healthy start and early childhood development and to support the retention of adolescent girls in secondary education, ensuring access to comprehensive sexuality education to transform gender and social norms.

Pivot 3: Economic investments that are smarter with co-financing across sectors

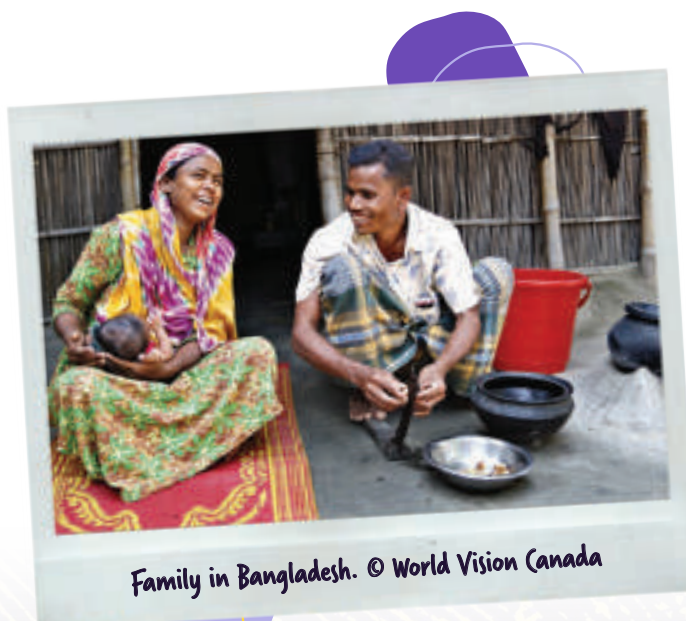
Invest in financing for comprehensive care coverage for women and babies, ensuring that maternal and newborn care are included in UHC and insurance schemes, avoiding or minimizing OOPs, and providing extra support for families of small and vulnerable newborns. Cross-sectoral co-financing schemes, with pooled budgets, are needed.

Pivot 4: Environmentally adaptive systems

Use an intersectional lens when considering the populations most vulnerable to environmental factors. Bearing the greatest burden and highest risks, the specific needs and vulnerabilities of women, children and newborns must be taken into account when building and strengthening systems to provide nutrition, WASH, clean air and climate adaptation responses. Improving access to safe water and clean air, ending hunger, addressing malnutrition across the life-course, and considering women, newborns and children in climate adaptation and mitigation strategies and policies should be prioritized.

Pivot 5: Emergency preparedness and response

Strengthen the intersectoral coordination and resilience of national emergency management systems capable of responding to any emergency, whether of conflict, climate or pandemic. Response plans must be adaptive and responsive to the needs of vulnerable populations, and specifically provide for maternal and newborn services, including the prevention of and care for preterm birth. Pooled funds should also be used to secure resources for essential prevention of preterm birth and care for small and vulnerable newborns.



Key reading

- Partnership for Maternal, Newborn and Child Health, World Health Organization, the World Bank Group, Alliance for Health Policy and Systems Research. Success factors for women's and children's health: Policy and programme highlights from 10 fast-track countries. Geneva: World Health Organization; 2014 (<https://apps.who.int/iris/handle/10665/178624>).
- The 2023 Lancet Series on breastfeeding (<https://www.thelancet.com/series/Breastfeeding-2023>).
- The Lancet Countdown on health and climate change (<https://www.thelancet.com/countdown-health-climate>).
- Lancet Series on women's and children's health in conflict settings (<https://www.thelancet.com/series/conflict-health>).

Behind every statistic is a story

Meet

Ainsley
from Kenya



Ashley and her daughter Ainsley.

When 17-year-old Ashley Toto found out that she was pregnant, she felt “lost”.

She knew about different contraceptive options, but used only a condom with her boyfriend because she feared the side effects of other contraceptive measures. “People say that contraceptives have so many side effects. I have heard of women bleeding for many days when using family planning. So I have always been scared to try them.”

After unintentionally becoming pregnant, Ashley left boarding school and moved to Kibera, Nairobi in Kenya. “It was so hard being in school while pregnant. People kept talking about me. So I decided to leave school. I also lost most of my friends. They did not want to associate with me.”

She went first to her elder brother, but he asked her to move out and go to their parents in rural Kenya. “He could not house me while I was pregnant. I knew that if I went to my rural home I would never go back to school again, but I had already registered to take the national exams.”

A well-wisher took her in, and she started braiding people’s hair to make at least a little money for her upkeep. But at 28 weeks’ gestation, following abdominal pains, she was referred to Mbagathi Hospital in Nairobi, where complications were diagnosed. “They did not explain much. I did not even understand what complications they were talking about. I thought maybe I was going to die so I just followed the instructions I was given, which were to stay in hospital.”

Ashley gave birth to her baby girl, Ainsley, at 30 weeks. “She was so tiny; I did not know what to do with her.” Discharged after two weeks, Ashley and Ainsley have had to return to hospital numerous times for Ainsley. “She has difficulty breathing and a simple flu really puts her down.”

Ashley says it has been a tough journey taking care of her baby and herself. Six weeks after her baby was born, she sat for her secondary school national exams, while juggling her responsibilities as a new mother.

“I thank God I finished the exams, although I did not get the grades I had hoped for. But that is beyond me now. I need to focus on my baby’s survival.”

“Don’t write off a girl, just because she got pregnant early.”

Ainsley is now 6 months old and doing well. To take care of her, Ashley does menial jobs, including doing people’s laundry and plaiting their hair.

In the next decade, Ashley would like to see more support given to teenaged and young mothers. “Don’t write off a girl, just because she got pregnant early. It is depressing and stressful, but it is not the end of life.”



Rumbidzwai Chinyama, born at 26 weeks, 900g.
© Alexander Stevenson, African Neonatal Association

Chapter 7

Decade of change: to 2030 and beyond

Investment will bring returns for every family, in every country

Every two seconds, a baby is born too soon.

For the **baby** this can mean death, or survival with a lifelong disability that limits their opportunities and potential. Some babies born too soon go on to live healthy lives, free of disability, but the risks of death or disability are higher for preterm babies than for those born at full term.

For the **mother** preterm birth can entail stress and heartbreak, and devastating practical consequences, including for employment. It can also lead to mental health issues, including post-traumatic stress disorder.

For the **family** life is turned upside down. This can cause family tensions, with one parent in hospital caring for one child and one at home caring for others. It can entail a heavy financial burden or even bankruptcy.

For the **health system** it means more costs, especially if the baby is extremely preterm, and may involve specialized hospital care for weeks or even months. Health-care professionals have the strain of caring for vulnerable babies and witnessing death, which can weigh heavily while the professionals may lack appropriate support.

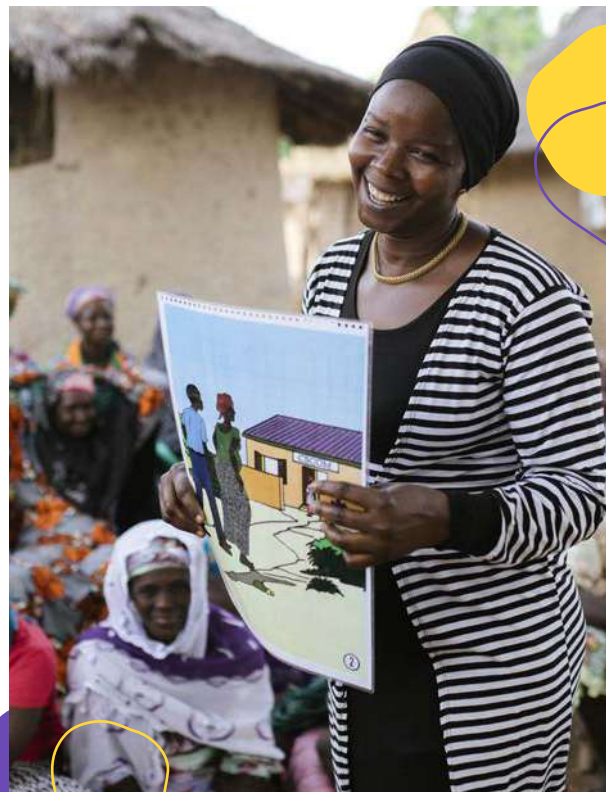
For **countries** these vulnerable newborns represent an enormous loss of human capital and economic growth. The time around and immediately following birth is arguably the most sensitive of all. Failure to provide the right care reverberates not only across the life-course but across generations, with staggering human and economic costs.

This societal impact is not limited to poorer countries. Global and regional rates of preterm birth are high and have not changed in the last decade. Middle- and high-income countries are also affected. For example, Brazil and the USA both have high rates and very high numbers of preterm births, with recent increases. Meanwhile, in all countries, rich or poor, inequities dictate the chances of a baby surviving and thriving. For instance, in the USA, babies born to Black and Native American

women are 62% more likely to be born preterm, and twice as likely to die, as the babies of white women (1).

Yet, despite the challenges of the past decade, there are inspiring examples of progress across the world. Lessons can be learned from these and applied to achieve progress in all regions and all settings, powered by a people-centred movement that engages families and communities to inspire action. That action is needed now if countries are to meet the SDG targets by 2030, and if families and countries are to realize their potential across generations. The cost of inaction, in terms of human capital, is simply too great.

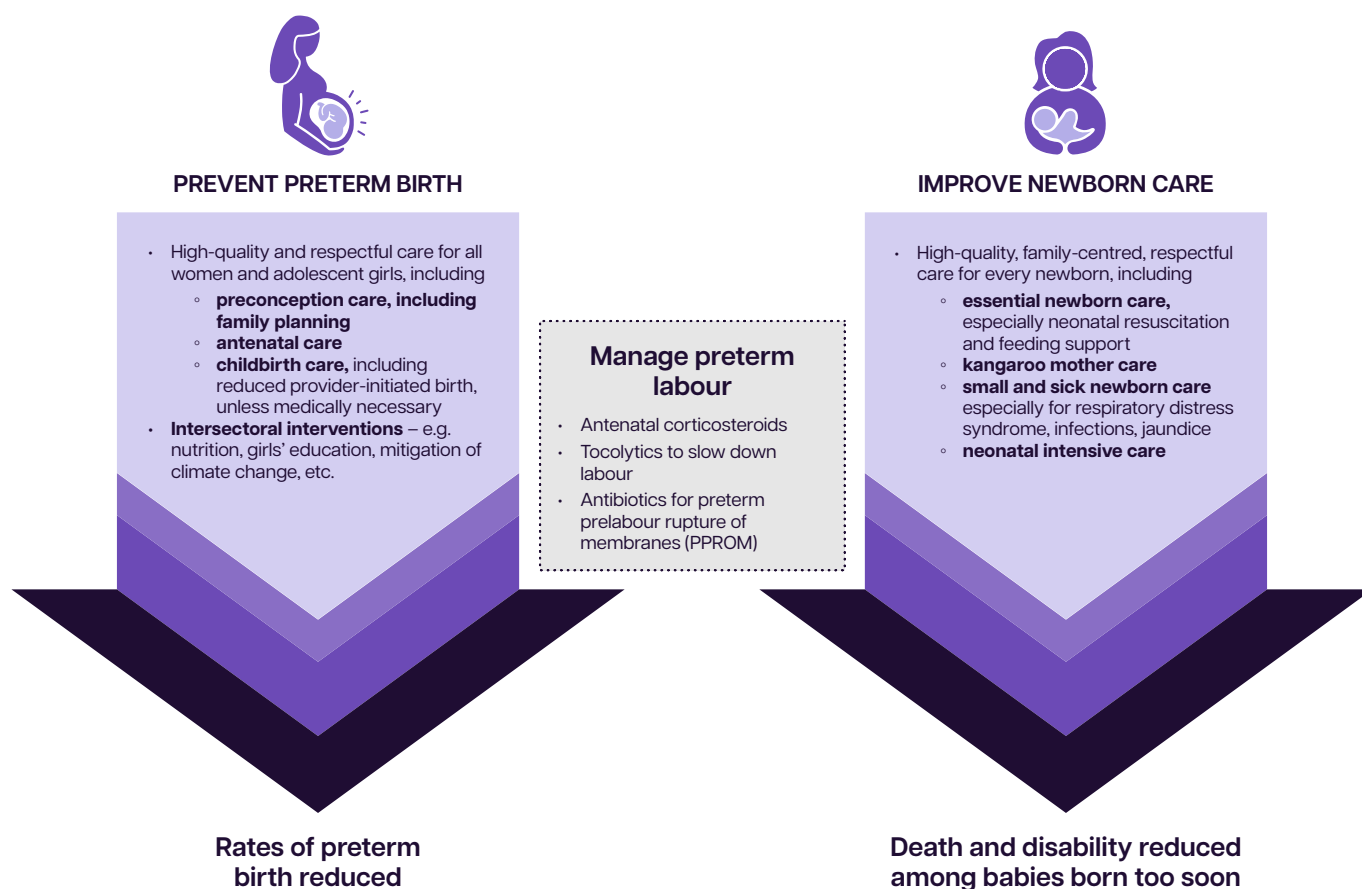
This report's call to action focuses on two priority tracks (Figure 7.1) followed by four key actions. Together we can enable rapid change to reduce the burden of preterm birth in the coming decade and optimize high-quality maternal and newborn care.



Health educator in Mali.
© World Vision Canada

Two priority tracks

FIGURE 7.1 Twin tracks to reduce the burden of preterm birth and unlock human capital



Pregnant woman getting her belly measured by a doctor, Romania.
© WHO/Malin Bring

Track 1: Prevent preterm birth through upholding women's rights and ensuring access to respectful, high-quality health care

There has been little, if any, progress in preventing preterm births over the last decade. That progress must be accelerated. This means acting more decisively on the known risk factors for preterm birth, and investing more strategically in research to better understand the preterm births that have no known risk factors.

Respecting, protecting and fulfilling rights related to sexual and reproductive health is vital, as is closing gaps in coverage and quality care across the continuum of care, with strong investments in obstetric care, including midwifery services. This must include a stronger focus on family planning, with explicit efforts to reach adolescents. Better leverage is needed of existing tools to prevent and manage preterm birth, including the appropriate use of ACS (Chapter 4).

Track 2: Provide respectful, high-quality care for small and vulnerable newborns

There are huge inequities in the survival chances of preterm babies around the world. Of those who receive high-quality care, even if born at 28 weeks of gestation (born three months too soon) more than 95% will survive without disability. However, of those born in settings without such care fewer than 5% will survive (2). Yet change is possible. For example, the 10 countries making the most rapid progress in newborn survival have dramatically reduced their neonatal mortality rates in the last decade by investing in SSNC (3). Countries can only reach the SDG target of a neonatal mortality of <12 per 1000 live births if they have high coverage of SSNC, including CPAP for preterm babies needing respiratory support (Chapter 5).

Given recent evidence-based innovations that also empower families, such as KMC, faster progress could be made in all LMICs. Local action is essential in order to bring improved newborn care units to every district of every country. This requires the right space, the right people (e.g. neonatal nurses), the right devices and the right data to monitor and improve care.

In both tracks, women, babies and their families must be at the centre so as to fulfil their rights to care that is respectful and of high quality, and which meaningfully engages them in care and decision-making. The investment required along these two tracks is not small, but the returns are huge.



A health worker uses equipment to treat preterm babies and babies with birth defects in Kyrgyzstan.
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Preterm baby in an neonatal intensive care unit in Kyrgyzstan. © UNICEF/UN055277/Lister

Collective action

To achieve this change together, this report calls for the following four actions.

Action 1: INVEST

Many countries need to increase their progress by two or three times if they are to meet the SDG targets for maternal and newborn survival, and the Global Strategy target for stillbirth prevention. In particular, they must invest in high-quality, respectful care for women before, during and after birth, and in SSNC. This must include:

- UHC schemes, covering priority maternal and newborn health interventions and financial protection; and
- primary health-care systems to ensure that every district hospital can provide emergency obstetric care and SSNC.

It is crucial to include both maternal and newborn care services in plans for UHC. Families must not be obliged to pay for services, which pushes them into poverty, disincentivizes them from using health services, and can even result in mothers and babies being held in facilities until they can pay. The *Lancet* Nigeria Commission found that more than 80% of Nigeria's total health expenditure was out-of-pocket: the highest rate in the world. It is estimated that public financing of essential interventions in Nigeria could reduce inequalities and provide health and financial benefits to all households (4). If well targeted, it would particularly benefit households in less developed areas, such as those in rural regions and in the lowest-income districts and states. Nigeria is far from alone.

The response to COVID-19 has provided opportunities for learning, and for leveraging investments in, for example, infection prevention and oxygen systems, both of which are critical for addressing the burden of preterm birth.

Money committed to maternal and newborn health is an effective *investment*, not simply an *expenditure*. Despite negative macroeconomic conditions (influenced by, among other factors, the COVID-19 pandemic) investment in preterm birth and high-impact interventions produces substantial returns. In South Asia, scaling up an evidence-based package of interventions to save the lives of newborns, including small and vulnerable newborns, has been calculated to return US\$ 2-17 for every US\$ 1 invested (5). In the United Republic of Tanzania, a conservative investment case for SSNC showed similar promise, with a similar potential return on investment (6). Globally, breastfeeding is one of the most cost-effective interventions in the whole spectrum of women's, children's and adolescents' health care, returning US\$ 35 for each US\$ 1 invested in its promotion and protection (7).

Yes, some of the systems-wide change that is required, for example building NICUs and training medical staff, means spending money. But it produces big returns, not only financial, but in human capital across the whole life-course.

It is not just *more* investment but *smarter* investment that is required. Better facilities must be built, rather than continually refurbishing inadequate ones. Through such smart investments, China is now reducing neonatal mortality by 8.8% per year (8, 9).

Through smart investment in HIV prevention and tobacco control, the world has achieved remarkable results and saved millions of lives. Babies born too soon are not only just as important but are greater in number. One reason why governments have not acted on their behalf is that the women and babies affected do not grab headlines. They must now receive the attention and support they deserve.

More and better targeted investment is urgently needed. Investment must come from domestic resources as well as donors. Between 2010 and 2019, there was less investment in maternal than in child health, very much less for newborns, and almost no mention of stillbirths (10). National investments are larger than donor inputs, but harder to track. Unless investments can be tracked, accountability is undermined.

Action 2: IMPLEMENT in partnership with women and families

Adopting the right policies is necessary but not sufficient. Many countries have adopted targets and national policies but are not implementing them. Local action is essential for national and global change, as highlighted in the *Together for Change* report (11).

Achieving impact requires systemic change in every district of every country. Reaching every district with the high-impact package of level-2 SSNC with CPAP is an important strategy. Rushing to add too early items that are more expensive and complex to deliver could make it harder to deliver essential services at scale, and could even increase inequalities.

Service quality is as vital as service coverage. Governments must ensure equitable access for women and adolescent girls to high-quality SRH services, including family planning, and care before, during and after childbirth. Coverage must be increased and the quality of services improved. Whole systems must be changed, including infrastructure and human resources. And implementation must follow the tenets of respectful and family-centred care, with women and families participating as equal partners and key agents of lasting change.

Much has been achieved, but much remains to be done: not just listening to women and parents but partnering fully with them. Their meaningful involvement is required at all levels of health care: from individual facilities to national and subnational policies and programmes, and on global platforms for maternal and newborn health more broadly.



Action 3: INTEGRATE

The activities of other sectors matter for preterm birth. Chapter 6 identified five intersectoral domains affecting maternal and newborn health, especially for the most vulnerable: equity and rights; environment; economic; education; and emergencies. In particular, the climate emergency poses a major but underappreciated threat to newborns and pregnant women. Intersectoral interventions can act as powerful “health enhancers”, contributing to the health of mothers and babies. For example, girls’ education enhances health-service utilization, while WASH and nutritional interventions have important impacts on maternal and newborn outcomes, and social protection is critical to address inequities.

Emergency response plans must also meet the needs of the most vulnerable and must include the prevention of preterm birth and care for preterm babies as part of maternal and newborn services.

It is essential to push for collaboration, break down siloes and insist that perinatal outcomes, notably stillbirth and preterm birth, are measured and recorded in research and programmes in these key sectors. This would greatly expand understanding of the impact of intersectoral interventions on reducing the burden of preterm birth, and would bolster the case for greater investment in these areas.

Action 4: INNOVATE

Innovative and creative approaches must be employed, with new ways of working and collaborating across society. Technical innovations and system changes play a critical role in high-quality maternal and newborn health care. Locally led innovation is crucial to close gaps between innovation and implementation, and is enabled by multicountry learning networks.

Smarter research is also needed, matched to burden and possible impact. New analyses of global research funding over the last decade show that funding of US\$ 577 million per year is directed towards neonatal outcomes, yet there is almost no mention in that research of stillbirths. Less than 7% of the global total is spent in LMICs, despite these countries accounting for 98% of the burden, although encouragingly a few middle-income countries, notably Brazil, China and South Africa, are investing more in these research topics in their own countries. There is also a predominance of spending on basic laboratory research. Most research investments are targeted at preclinical or observational studies, with implementation research receiving less than 3% (12). Implementation

research, linking evidence on the health of women and newborns with practice, is likely to yield higher impact in the immediate term. Research funders aiming for impact in health outcomes, rather than just in academic papers, could be held accountable for investing smarter, given the large potential to reduce the burden, especially by funding locally led research on implementation where the burden is highest.

Our vision for change: top-down and bottom-up for greater momentum

National actors must work with global partners to prioritize action, advocate and invest. Only by acting together can stakeholders ensure that every woman and adolescent girl has access to high-quality, respectful care, and that every baby, everywhere “has a chance to be born alive, at the right time, and the right size” (13).

To achieve these aims and build momentum, pressure is needed, not just from the top down (from governments and donors) but also from the bottom up: from families and communities, including health-care providers and civil society. Stakeholders must champion change together, amplifying the call and holding leaders to account.



Pregnant woman in Zimbabwe.
© White Ribbon Alliance

Such collaborations can and must shift social norms. It is unacceptable simply to expect that babies born too soon are destined to die or to live with disabilities. Leaders, parliamentarians, decision-makers and even heads of state must act on behalf of their most vulnerable citizens and drive this social change. To that end, complacency is the enemy. Putting babies born too soon high on the global health agenda requires constant advocacy from all parties to build momentum and fuel progress.

Leadership is crucial at all levels. Countries across the world have shown that strong leadership can achieve powerful results.

The world can take inspiration from Wayde Van Niekerk, an Olympic gold medal winner from South Africa. When Wayde was born in July 1992, 11 weeks early, he weighed just one kilogram. He immediately required a blood transfusion and was fighting infection. During his first hours and days his survival was in doubt, and doctors assumed that, even if he lived, he would have lifelong disabilities. He spent several weeks in an incubator. But with the expertise of his doctors and nurses, and the love and support of his mother and wider family, Wayde not only survived, but thrived.

Wayde's story may sound exceptional. It shouldn't be. Because keeping women and babies healthy, and caring for small and vulnerable newborns, not only prevents human suffering but leads to long-lasting benefits for individuals, communities, societies and economies. Protecting human rights and investing in human capital yields benefits for everyone, including future generations: for every family, everywhere.



A mother practising kangaroo mother care, India.
© Gates Archive

Behind every statistic is a story

Meet Chinyere from Nigeria



Chinyere Ezeaka teaching a medical team to operate CPAP machine and oxygen splitter devices.

In many African families elder siblings are responsible for looking after younger ones at home. That was the case in Professor Chinyere Ezeaka's childhood home: as an elder child, she spent much time taking care of her younger siblings. She says that that role of caregiver influenced her career choice: paediatrics beckoned.

"As a young girl I kept wondering how doctors 'spoke' to these tiny humans. How could doctors know when and where babies are unwell, when the babies cannot talk? That fascinated me."

Professor Ezeaka is the head of the Neonatology-Perinatology Unit at the Lagos University Teaching Hospital, Nigeria and a founding member and past National President of the Nigerian Society of Neonatal Medicine. For more than 20 years she has championed newborn health, and is actively involved in advocacy, teaching, clinical practice and research.

"When I started, most activities were centred solely on maternal and child health with the newborns falling in between the cracks. There was no discussion of newborns as a unique, separate entity that needed attention on their own, away from infants and older children." But she realized that, unless newborn deaths were reduced, "as a country, a continent, and even globally, it would not be possible to achieve significant reduction in under-5 mortalities."

Over the last two decades, Professor Ezeaka has seen a shift in newborn health care, with more focus on reducing deaths from preventable causes, including preterm births. Partnership has been a key ingredient to success.

"There has been a lot of synergy and momentum in countries; one group cannot do it alone. There have been collaborations between governments, development partners, neonatologists and many other stakeholders to work on national protocols and policies to benefit newborns and their families at all levels of care."

Professor Ezeaka is optimistic that change can be achieved in sub-Saharan Africa. "Targets have been set for newborn health, and many countries are expediting actions to meet those targets with committed leadership and partnerships."

“There has been a lot of synergy and momentum in countries.

In the next decade, she wants to see greater emphasis on quality care for the small and sick newborn. She wants "more investments in technology and innovations, equipment and machines. Many of these newborns are dying because they don't have access to evidence-based interventions that should be available to all."

Professor Ezeaka has had many opportunities to work outside Nigeria but she remains dedicated to remaining in Nigeria to strive and advocate for all our vulnerable newborns who are "tomorrow's future."

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CHAPTER 7

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