



REVIEW

A landscape analysis of the key global stakeholders working on interventions around preterm birth that improve neonatal mortality and morbidity. [version 1; peer review: awaiting peer review]

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Abstract

Background

Over a decade after the landmark 'Born too Soon' report, preterm birth remains a leading cause of under-five mortality. Addressing its global burden is key to meeting United Nations Sustainable Development Goal 3; to end preventable deaths of newborns and children by 2030. We conducted a landscape analysis to explore the types of organisations addressing preterm birth, highlight the scope of interventions and initiatives, and identify gaps and opportunities for shared learning.

Methods

We combined google searches with citation searching, and opinion of experts in child health, to identify the major global stakeholders working to improve outcomes of preterm birth, with evidence of activity since 2012. We conducted a thematic analysis and narrative synthesis of key stakeholder websites to categorise their functions and priorities, and the types of interventions they were implementing.

Results

A total of 38 key organisations and 28 interventions were derived from the searches. Organisations were thematically grouped into knowledge sharing (n = 15), knowledge production (n = 12), funders (n = 6), legislation and advocacy (n = 15), implementer (n = 14) and network organisations (n = 11). Interventions covered a wide scope of functions including education (n = 11), research (n = 10), resources (n = 7), legislation (n = 2), and health systems (n = 2) interventions. The majority of global stakeholders were funded from and headquartered within high-income settings.

Discussion

There is scope for significant learning across global stakeholders, in

particular to support carers in low-resource settings. Further opportunities for impact include a need for community-based initiatives and whole systems approach that address the long-term needs of preterm babies and their families, particularly in low- and middle-income countries (LMIC) settings. Greater knowledge production and funding from LMICs is needed to create contextually relevant resources and address implementation challenges.

Keywords

Preterm Birth, neonatal mortality, neonatal morbidity

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Introduction

It has been over a decade since the landmark report ‘Born too Soon; a global action report on Preterm Birth’¹ as launched by World Health Organisation (WHO) in response to Every Woman Every Child effort². The report was the first comprehensive review of the global burden of preterm birth, highlighting it as a leading cause of neonatal and under-five mortality. Annually, 15 million babies are born prematurely, with an estimated one million children dying each year as a result^{3,4}. There is significant regional variation in the incidence and survival following preterm birth, with sub-Saharan Africa and South Asia disproportionately affected⁵⁻⁷. Babies born preterm often have lifelong care needs as a result of complications including cerebral palsy, chronic cardiac, renal, and respiratory problems, a higher risk of developmental delay⁸ and future mental health problems⁹. These complications further impact quality of life, contribute to increased risk of premature adult death¹⁰, and place additional burdens on health systems.

Adopting a multi-stakeholder approach, the Born too Soon report outlined the importance of investment in research, interventions, and the implementation of strategies to reduce mortality associated with preterm birth¹. Despite the collective efforts of multiple organisations and initiatives focusing on preterm birth or more widely on neonatal care over the last decade^{11,12}, the incidence and mortality from preterm birth and its complications have remained largely unchanged¹³. Reducing the burden of preterm birth is key to achieving United Nations (UN) Sustainable Development Goal 3: ending preventable deaths of newborns and children under the age of five by 2030¹⁴, however, considerable work is still needed^{1,12}, requiring a coordinated, long-term approach¹⁵. While WHO provides recommendations on evidence-based interventions for the prevention and management of preterm birth, there is limited information about organisations that provide and support these interventions in those areas of the world most impacted by preterm birth^{11,15-18}.

We conducted a landscape analysis to explore the types of organisations involved in addressing the issue of preterm birth, and the interventions being implemented in this area, to provide a better understanding of what work is being done, to identify gaps and opportunities for learning between organisations, and to highlight the current efforts and progress of preterm birth initiatives since the Born too Soon report.

Methods

Definition of key stakeholders for landscape analysis

We defined a key stakeholder working on preterm birth to include platforms, collaborations, and networks who are working in preterm birth, including those involved in:

- a) Implementation of preterm birth programmes
- b) Providing knowledge-based resources to the global community to improve preterm care
- c) Delivering hospital and community-based care around the issue of preterm birth

d) Developing policy documents

e) Developing hospital guidelines for preterm birth

We excluded organisations that had been inactive for last 10 years without updating their website, those without a focus on preterm birth and its consequences, purely donor organisations, and individuals (rather than organisations) working in this field.

Information sources

We followed the landscape analysis methodology outlined by VanderZanden and colleagues¹⁹. We identified key global stakeholders working with a specified mandate to improve outcomes of preterm birth through three approaches; a) Google searches, supplemented with b) citation searching of relevant websites and c) guidance from expert informants.

We searched Google in the UK between January 2022 – February 2022, using predefined search terms (Table 1) to screen key stakeholders identified within the first five pages of the google search outcome. To provide a comprehensive overview of stakeholders, we included the first five pages, rather than the first three pages outlined by VanderZanden *et al.*¹⁹

In addition to the Google searches, we adopted a snowballing technique to identify further global stakeholders mentioned on an included organisation’s website and combined this with further citation searching of articles mentioned on identified websites. Finally, we approached key informants, who were leading international experts in child health, and provided information relating to organisations working in the field of preterm birth, to both verify and supplement those identified through the google and citation searches. Key informants were contacted both face-to-face and by email to provide their expert opinion on stakeholders working in this area. Following identification of the organisations involved in preterm birth, we extended our landscape analysis to search their websites and identify interventions they were employing in the field of preterm birth (Table 4).

Search strategy

Key search terms were derived by considering the population of interest (preterm babies) and types of organisations involved in preterm birth (Table 1). To generate a comprehensive list of key search terms for each of these areas for the google search, associated terms for ‘preterm baby’ and ‘organisation’ were derived using the corresponding Medical Subject Headings (MeSH) terms from PubMed (Table 1).

Table 1. Key search terms.

Key Term	Associated terms
Preterm baby	Preterm, preemie, premature
Organisation	Organisation, charity, Non-Governmental Organisation (NGO), support, platform, collaboration, network

We conducted a total of five google searches; to include the range of key terms (Table 2). For each search conducted, the first five pages of results were considered, to maximise the chance of obtaining all suitable organisations. We further searched for organisations working in low- and middle-income countries (LMICs). For each search, we looked at the results header and summary, and considered the types of interventions and initiatives of the identified organisations. An entity was included in the landscape analysis if it met the inclusion criteria (outlined above) and had not already been included from a previous search or recommendation.

Selection process

After conducting the google searches, citation searching of websites and information from key informants, duplicates were removed, and the remaining relevant sources were re-assessed for eligibility for the landscape analysis using the inclusion and exclusion criteria outlined above. Included sources were summarised in a PRISMA diagram (Figure 1)²⁰.

Data extraction

We captured the details of relevant websites, organisations and their interventions using a standardised data extraction tool designed to capture details about the organisation, its scope of practice, interventions, target groups and geographical reach. The data extraction tool consisted of headings within two excel spreadsheets to capture relevant data. These tables can be accessed from Supplementary Files 1 and 2 within the appendix. The data extraction was conducted by GM and then checked by other authors (SN & ME) for accuracy.

Key stakeholders were included in the data extraction if they met the following criteria:

1. Met the definition of key stakeholder working in the field of preterm birth as detailed above.
2. Active in the last 10 years at time of review (since 2022).
3. The description and relevant materials were in English.
4. Had an active website with contact information for leadership and description of participants.

Quality appraisal

We used the AACODS (authority, accuracy, coverage, objectivity, date, and significance) quality appraisal tool to assess the quality of the google searches and of any further identified grey literature sources²¹.

Data analysis

We analysed the data from the key stakeholder websites for emerging themes that described the functions and priorities of each stakeholder and conducted a narrative synthesis of findings²². In addition, we analysed data from each included website to identify the categories for interventions being implemented by the key stakeholders, using a classification for intervention functions. Interventions with the aim of improving preterm birth outcomes were categorised using guidance from Smith, Lassi, and colleagues^{23,24}, and included: research (including clinical trials), workforce interventions, clinical intervention implementation, resources, advocacy, guidelines, and training^{23,24}. After reviewing all relevant websites and documents from organisations, we identified gaps for potential future work.

Patient and public involvement

Patients were not involved in this research.

Results

Summary of results

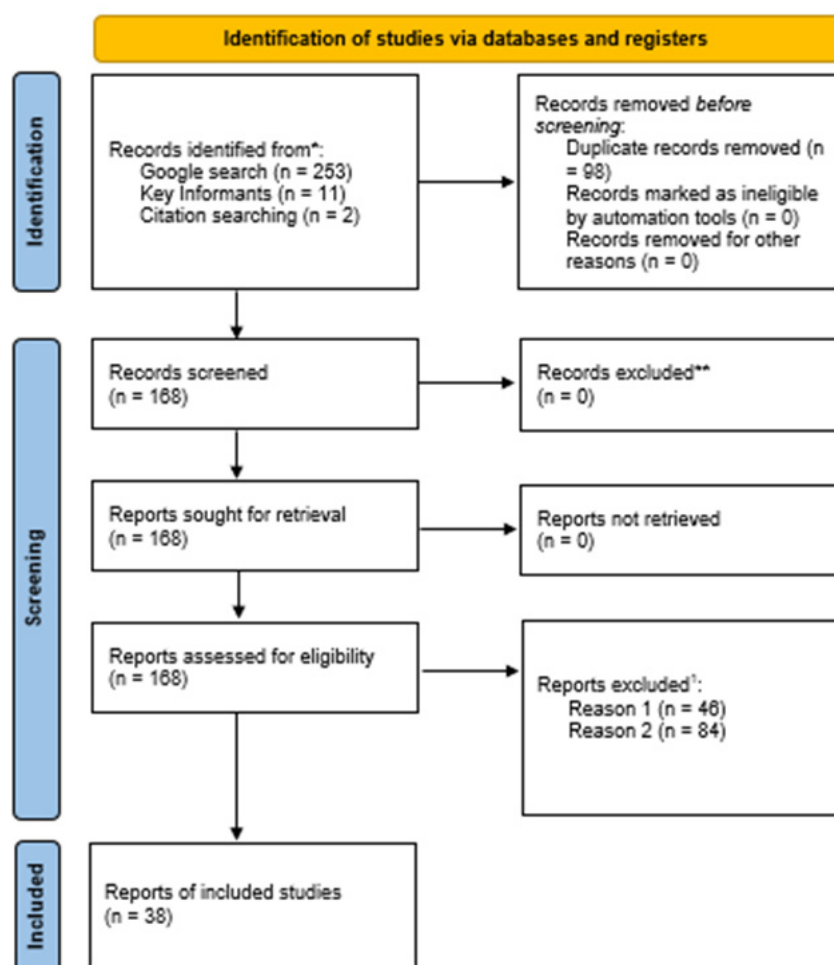
A total of 38 organisations were identified through the defined search strategy, implementing a total of 28 interventions. Most included organisations were obtained from the google search (n = 26). Two further organisations were obtained through citation searches of the organisations' websites. Five expert informants were contacted, of which three responded, and identified a further 11 key stakeholders organisations working on preterm birth, meeting the inclusion criteria of the study. Duplicate organisations were removed, yielding a total of 38 key stakeholders. The results are summarised in Figure 1.

The global landscape for preterm birth

Of the 38 organisations identified relevant to the field of preterm birth, the majority were from high income countries (HIC) (n = 23), followed by global organisations (n = 13); a limited number of organisations were located solely within LMICs

Table 2. key search terms used in google search.

Google search number	Set of key search terms inputted
1	Preterm birth, premature, preemie
2	Preterm birth, premature, preemie, organisation
3	Preterm birth, premature, preemie, organisation, NGO
4	Preterm birth, premature, preemie, organisation, LMIC
5	Preterm birth, premature, preemie, organisation, network



*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers).

**If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools.

† Reasons for exclusion:

Reason 1 – Journals

Reason 2 – No relevance

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372: n71. doi: 10.1136/bmj.n71

Figure 1. PRISMA diagram summarising the organisations included in Table 1. This figure has been tailored to our project and reproduced with permission from Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372: n71. doi: [10.1136/bmj.n71](https://doi.org/10.1136/bmj.n71).

(n = 2). All the listed global organisations working within LMICs had their main headquarters in high income countries.

The organisations intervening in HIC regions presented a greater proportion of initiatives that focused on parents and families as the target group (n = 17). In contrast, this was not evident for organisations working within LMICs. All organisations

working within LMICs included health workers as a key target group (n = 15). Researchers (n = 5) and policymakers (n = 9) were also a target for multiple organisations operating within LMIC regions, however, none (n = 0) focused on family and parent strategies in LMICs. Several organisations had more than one target group (n = 19), including family, health workers, policymakers, and researchers.

Organisations were both national and global in reach, and were categorised into the following emergent themes, which outlined if they were involved in preterm birth as a) knowledge sharing organisations, b) in knowledge production, if they had c) roles in funding, as and d) implementer, or if they worked as e) part of a network. Most organisations (n = 21) fell under more than one category in terms of their scope of work.

Knowledge sharing organisations. Knowledge sharing organisations (n = 15) either focused on empowering parents or providing health workers with the necessary and current information and skills. Initiatives to empower parents included informative videos such as ‘Small Wonders’ and Neonatal Intensive Care Unit (NICU) care packages^{25,26}. Another key aspect of the parent-led organisations was creating a community network for peer learning and accessible support from other parents and qualified healthcare professionals specific to preterm birth. Multiple organisations such as ‘Tommy’s’, ‘Best Beginnings’ and ‘Small and Mighty babies’ have created community networks for parents^{25,27,28}. Knowledge sharing within healthcare worker networks circulated research and guidelines, such as the ‘Healthy Baby Network’²⁹. Although not specific to preterm birth, the network provided extensive information and accessible regarding on this topic.

Knowledge production organisations. Knowledge production organisations (n = 12) focused on creating new research and innovations targeting preterm birth. Organisations such as ‘Bliss’ and ‘Borne’ liaised with researchers within university institutions to work on a range of preterm birth issues, such as management of preterm birth post labour and biomarkers in pregnancy^{30,31}. Half of the organisations listed as producing research were solely operated within HICs (n = 6).

Funder organisations. Funding provides financial support to preterm birth initiatives and enables collaboration between preterm birth organisations, that may co-produce research or implement change. There were a limited number of funder organisations identified from the search (n = 6). Closely linked with knowledge production and implementers, funder organisations enabled work to be conducted in this field, and had the power to decide areas of focus. For example, the Bill and Melinda Gates Foundation invested in research focusing on developing innovations and generating evidence to understand the burden of maternal and neonatal conditions³². Whereas March of Dimes had recently focused some of its funding on research relating to maternal health from a biomedical lens, including high-risk pregnancies, genetic factors, and their subsequent risk of preterm birth³³.

Legislation and advocacy organisations. Legislation and advocacy organisations (n = 15) either worked with policymakers to change legislation regarding preterm birth, and/or empowered parents and families through outlining their rights to improve their maternity experience. ‘Maternity Action’ advocated for parents’ rights and empowers families with legislative knowledge on their rights, such as during maternity and paternity leave and financial support³⁴. Other legislation and advocacy organisations aimed to influence policymakers to change legislation and highlight policies, such as ‘Bliss’ and ‘March of Dimes’^{30,33}. Further organisations aimed to highlight the

need to prioritise preterm birth initiatives and advocate for change, such as the ‘Partnership for Neonatal and Maternal Health’³⁵.

Implementer organisations. Implementer organisations (n = 14) provided tangible support towards the prevention and management of preterm birth within populations. Implementer organisations identified from the results, mainly focused on hospital-based care, and provided equipment, financial aid, and workforce opportunities. These organisations mainly focused on healthcare workers and policymakers as their target groups. Organisations that provide resources and implement, may be particularly important in low-resource settings. Half of the organisations that implemented preterm birth initiatives (n = 7), operated solely or partly within LMIC regions.

Network organisations. Network organisations (n = 11) produced a ‘space’ or a ‘system’ for individuals impacted by preterm birth to interact. For example, the Council of International Neonatal Nurses (COINN) aimed to provide a community of nurses who want to stay updated with guidelines and research³⁶. Network organisations may further provide opportunities for collaboration within neonatal health. Other network organisations focused on creating a community network for families to support and exchange knowledge.

Scope of preterm birth interventions

A total of 28 interventions were derived from the websites of organisations presented in Table 3. These interventions are summarised in Table 4 and categorised into education (n = 11), research (n = 10), resources (n = 7), legislation (n = 2), and health systems (n = 2) interventions. Four interventions were classified by more than one category.

Education-based interventions. Interventions focused on education (n = 11) provided information to the parents, families and/or healthcare workers, through training. Education & training directed to parents provided information on preterm birth, caring for a premature baby, signposting towards resources available both within the organisational websites and nationwide, and information on parents’ rights following the birth of a preterm baby. Furthermore, multiple educational interventions targeted at parents and families also had a community aspect, which enabled parents to receive verified individualised information from health professionals and the ability to share, discuss and build connections with peers in similar situations. For example, Tommy’s Pregnancy Hub app provided a space for parents to monitor their pregnancy and their baby’s progress, read relevant research and receive tailored midwife advice, and connect parents with similar experiences through sharing real-life stories. Education & training for families were accessible in different formats; in-person groups, apps, and online websites³⁷. Online websites providing educational resources, such as the ‘Raising Children Network’, ‘Healthy Children, Very Well Family’ and ‘What to Expect’, have capacity for global reach^{13,38–40}. These sites provide relevant information and are accessible in LMICs, however may not contain context specific information.

Research-based interventions. All research-based interventions identified by this landscape review were led or funded by

Table 3. summary of global organisations working on preterm birth.

Organisation	Category: Funder, legislation and advocacy, implementer, network, knowledge production, knowledge sharing	Target groups: Family, health workers, policymakers, researchers	Geographic areas: Global, regional e.g., Asia, national e.g., India
Action ⁴¹	Legislation and advocacy, knowledge sharing	Health workers	National (UK)
Best Beginnings ²⁵	Knowledge sharing, legislation and advocacy, network	Family, policy makers	National (UK)
Bill and Melinda Gates Foundation ³²	Funder	Researchers, health workers, policymakers	Global
Bliss ³⁰	Legislation and advocacy, knowledge production	Family, policymakers, health workers	National (UK)
Borne ³¹	Knowledge production	Researchers, health workers	National (UK)
Brave Beginnings ⁴²	Implementer	Health workers	National (USA)
Canadian Premature Foundation (CPBF) ⁴³	Knowledge sharing	Family	National (Canada)
Council of International Neonatal Nurses (COINN) ³⁶	Legislation and advocacy, network	Health workers	Global
DIYA India Foundation ⁴⁴	Implementer	Health workers	National (India)
EKAM Foundation ⁴⁵	Implementer	Health workers, policymakers	National (India)
European Foundation for the care of Newborn Infants (EFCNI) ⁴⁶	Legislation and advocacy, network, knowledge production	Policymakers, health workers	Regional (Europe)
Every Preemie ⁴⁷	Implementer	Health workers, family	Global
GLANCE - Global Alliance for Newborn Care ⁴⁸	Network, legislation and advocacy, implementer	Researchers, health workers, policymakers	Global
Global Alliance to Prevent Prematurity and Still Birth (GAPPR - GAPPS) ³⁸	Implementer, knowledge production, legislation and advocacy, network	Researchers, health workers, policymakers	Global
Graham's Foundation ²⁶	Implementer, knowledge sharing	Family	National (USA)
Healthy Children ⁴⁹	Knowledge sharing	Family	National (USA)
Healthy Newborn Network ²⁹	Knowledge sharing, legislation and advocacy, network	Health workers, policymakers, researchers	Global
Ickle Pickles ⁵⁰	Implementer	Health workers	National (UK)
JHPIEGO ⁵¹	Implementer, knowledge production	Researchers, health workers	Global
March of Dimes ³³	Funder, legislation and advocacy, knowledge production	Health workers, family, policymakers	National (USA)
Maternal Health Task Force ⁵²	Knowledge sharing, network	Health workers	Global
Maternity Action ³⁴	Legislation and advocacy	Policymakers	National (UK)
Maternity Matters Dorset ⁵³	Knowledge sharing	Family	National (UK)

Organisation	Category: Funder, legislation and advocacy, implementer, network, knowledge production, knowledge sharing	Target groups: Family, health workers, policymakers, researchers	Geographic areas: Global, regional e.g., Asia, national e.g., India
Miracle Babies ⁵⁴	Implementer, knowledge sharing	Family, health workers	National (USA)
National Childbirth Trust ⁵⁵	Knowledge sharing	Family	National (UK)
Partnership for Maternal and Neonatal Health ³⁵	Legislation and advocacy, knowledge production, network	Health workers	Global
PATH ⁵⁶	Funder, knowledge production	Health workers, policymakers	Global (Africa, Asia, USA)
Pregnancy Birth Baby ⁵⁷	Knowledge sharing	Family	National (Australia)
Raising Children Network ⁵⁸	Knowledge sharing	Family	National (Australia)
RECAP Preterm ³⁹	Knowledge production	Researchers, health workers	Regional (Europe)
Save the Children ⁵⁹	Implementer, legislation, and advocacy	Policymakers, health workers	Global
Small and Mighty Babies ²⁸	Network, implementer	Family	Regional (UK and UAE)
The Warren Centre ⁶⁰	Implementer, knowledge sharing, legislation and advocacy	Family	National (US)
Tommy's ²⁷	Funder, knowledge production, implementer, network	Family, health workers	National (UK)
United Nations Children's Fund (UNICEF) ⁶¹	Funder, knowledge production, legislation and advocacy	Health workers, policymakers, family	Global
Very Well Family ⁶²	Knowledge sharing	Family	National (USA)
What to Expect ⁴⁰	Knowledge sharing	Family	National (USA)
World Health Organisation (WHO) ¹³	Funder, Knowledge production, legislation, and advocacy	Health workers, policymakers	Global

Table 4. Summary of the interventions being developed or implemented by organisations listed in Table 3.

Organisation	Name of intervention and brief description	Type of intervention (research, legislation, education, health systems, resource)	Target group (family, health workers, policymakers, researchers, hospital management)	Geographic areas (global, regional, national)
Best Beginnings ²⁵	Small Wonders Twelve bite-size films following families and their journey in neonatal units.	Education	Family	National - UK
Best Beginnings ⁶³	Baby Buddy App An app that supports parents and caregivers with knowledge and an interactive community.	Education	Family	National - UK
Bliss ⁶⁴	The Parental Bereavement Bill Bliss aims to influence the Parental Bereavement Bill by extending the entitlement to self-employed and unemployed parents.	Legislation	Policymakers	National - UK
Bliss ⁶⁴	Parental Leave Bliss calls for the government for increased parental leave for parents of premature and sick babies.	Legislation	Policymakers	National - UK
Bliss ⁶⁵	FEED1 Research to investigate if more mature babies (30 - 33 weeks) can be safely fully fed from first day.	Research	Researchers, health workers	National - UK
Bliss ⁶⁵	CASSAVA Research to investigate the best delivery method for preterm babies.	Research	Researchers, health workers	National - UK
Bliss ⁶⁵	Surfon Research investigates whether giving surfactant early to late preterm and early term infants with respiratory distress reduces number of days babies need to stay in hospital.	Research	Researchers, health workers	National - UK
Bliss ⁶⁵	OPTI-PREM Research investigates the best type of neonatal unit for babies at each week of gestation	Research	Researchers, health workers	National - UK
Bliss ⁶⁵	CuBS Research investigates whether schedule based, or cue based is a better approach for feeding.	Research	Researchers, health workers	National - UK
Bliss ⁶⁵	ToSCin Research investigates when the best time is for stoma closure (following bowel surgery) to ensure the baby grows strong.	Research	Researchers, health workers	National - UK
Borne ⁶⁶	Borne's Uterine Mapping Project (BUMP) Research studies biological interactions in cells and tissues to understand normal vs dysfunctional labour in order to prevent preterm birth.	Research	Researchers, health workers	National - UK
Diya India Foundation ⁴⁴	Embrace Warmers Equipment Installing Embrace Warmers to reduce mortality in premature babies due to hypothermia.	Resource	Health workers, hospital management	National - India
Graham's Foundation ⁶⁷	Premie Parent Care Packages Provides information and resources for NICU.	Education	Family	National - USA
Healthy New-born Network ²⁹	Resources Collection of resources filtered by keyword, type, issue, and country for healthcare professionals.	Resource, Education	Researchers, health workers	Global

Organisation	Name of intervention and brief description	Type of intervention (research, legislation, education, health systems, resource)	Target group (family, health workers, policymakers, researchers, hospital management)	Geographic areas (global, regional, national)
Ickle Pickles ⁵⁰	NICU equipment Funds equipment for NICUs: incubators, ventilators, breast pumps, feeding chairs and tiny baby nest.	Resource	Health workers, hospital management	National - UK
March of Dimes ³³	Educational Resources Educational resources for parents on pregnancy, baby, complications, and loss, with further tools and resources.	Resource, Education	Family	National - USA
Miracle Babies ⁶⁸	Transportation from homes to NICU Free transportation from homes to NICU, CTICU and CHD families known as Miracle Babies Shuttle.	Resource	Family	National - USA
Tommy's ⁶⁹	Secondary data analysis on effectiveness of corticosteroids Research investigates the effects of unnecessary use of corticosteroids on women at risk of pre-term birth.	Research	Researchers, health workers	National - UK
Tommy's ⁷⁰	EQUIPTT study Testing the QUIPP app that calculates the risk of premature birth.	Research	Researchers, health workers	National - UK
Tommy's ³⁷	Pregnancy Hub Provides information for parents on pregnancy, giving birth, after birth and premature birth.	Education	Family	National - UK
Healthy Children ³⁸	Knowledge Online educational resources for parents and families on pregnancy, labour, and parenting.	Education	Family	Global
Raising Children Network ³⁹	Knowledge Online educational resources for parents and families on pregnancy, labour, and parenting.	Education	Family	Global
Very Well Family ⁶²	Knowledge Online educational resources for parents and families on pregnancy, labour, and parenting.	Education	Family	Global
What to Expect ⁴⁰	Knowledge Online educational resources for parents and families on pregnancy, labour, and parenting.	Education	Family	Global
WHO ⁷¹	Every New-Born Action Plan (ENAP) Multiple recommended interventions for different member states to reach ENAP aims.	Health systems	Policymakers, health workers, hospital management	Global
WHO ⁷²	Management of pregnancy and mothers with preterm labour/ risk of preterm birth Updated guidelines for management of pregnancy and mothers with preterm labour or risk of preterm birth, and care of preterm babies.	Resource, health systems	Health workers	Global
WHO ^{73,74}	WHO ACTION and clinical trials WHO clinical trials -Implementation research to scale up Kangaroo Mothercare in India and Ethiopia. ACTION (Antenatal Corticosteroids for Improving Outcomes New-borns) trials aims to assess 'how steroid injections can be used safely and effectively for women and preterm new-borns in LMICs'	Research	Researchers, health workers, hospital management	Global – 6 countries
WHO ⁷⁵	Survive and Thrive Provides resources and recommended techniques such as antenatal steroid injections and 'kangaroo mother care'.	Resource, education	Researchers, health workers, hospital management	Global

organisations within HICs ($n = 10$). Multiple research projects focused on postnatal interventions for preterm babies, aiming to reduce the risk of mortality and morbidity ($n = 6$). This included research investigating the best feeding method for preterm babies, use of surfactant, and implementing Kangaroo mother care in LMIC settings^{65,73,74}. Borne's Uterine Mapping Project (BUMP), focused on pre-term birth biomarkers to further understand how preterm birth can be identified early and prevented⁷³. Globally, fewer interventions focused on researching the long-term effects of preterm birth and its long-term management ($n = 1$). Research on European Children and Adults born Preterm (RECAP) preterm had an ongoing cohort study to understand how preterm birth impacts later childhood and adulthood³⁹. The Warren Centre provided 'Early Childhood Interventions' to children with developmental delays and disabilities⁶⁰ and aid the transition from home to school, thus supporting children with a range of conditions resulting from preterm birth. Interventions relating to long-term support for preterm-born children were limited to HICs.

Resource-based interventions. Resource-based interventions ($n = 7$) provided tangible goods for families, hospitals, and their communities. Types of resources included equipment, financial aid, and educational materials. Multiple interventions provided financial aid to either hospitals, communities, or parents. Miracle Babies, based in California, USA, supported parents of preterm babies through three initiatives: 'Transportation Assistance Program', 'Miracle Hours' and 'Miracle Babies (MB) bags'⁶⁸. The transportation programme offered a free shuttle bus service for parents with preterm newborns to and from the NICU and specialist care facilities. The 'MB bag' provided resources needed for baby and the parents within the NICU. The Graham's foundation also provided a similar care package for parents⁶⁷. These resource-based interventions may particularly benefit those from lower socioeconomic backgrounds who may not have financial ability to travel daily to NICU facilities or to purchase resources needed for their preterm infants. Resource-based interventions also included provision of NICU equipment, goods, or extra workforce to aid completion of tasks on NICU. For example, Ickle Pickles supplied local communities in the UK with NICU-related equipment, which in turn, provided financial relief to NICUs, and improved patient experience for both families and health workers⁵⁰. Further initiatives included the Ekam foundation in India, who provided medical resources and workforce for eye screening in new-borns to detect Retinopathy of prematurity (ROP)⁴⁵.

Legislation-based interventions. In the UK, multiple changes in policy are currently underway. Bliss advocates for the Parental Bereavement Bill and the Parental Leave Bill⁶⁴. The Parental Bereavement Bill entitles parents to paid leave from work if their child or baby dies, Bliss would like this bill to be extended to unemployed and self-employed parents. Bliss advocated for the Parental Leave Bill to be changed and extended for parents with a new-born in neonatal care.

Health system interventions. Health system interventions were scarce ($n = 2$), with very few interventions focusing on

implementing systems-level change through widescale training, workforce, or organisational change. The systems-level approach interventions were conducted by the global organisation, WHO; and included action plans and guidelines that influenced management and care of preterm babies at a health systems-level^{71,72,75}.

We conducted critical appraisal of the included websites and materials using the AACODS²¹ (authority, accuracy, coverage, objectivity, date, and significance) quality appraisal tool. Most organisations' websites met these criteria to a sufficient standard for inclusion in the landscape analysis, however, there was some variability in quality of the websites of organisations with regards to the AACODS checklist. Authority refers to reputability and whether the organisation was a leading stakeholder within the field. Most websites included in the analysis, were created and managed by reputable organisations and have authority within the field of newborn health and preterm birth. However, multiple websites lacked detailed reference lists, which limits the validity of the information provided within their websites. Some organisations, such as the Healthy Newborn Network²⁹ and WHO¹³ referenced research articles. Regarding accuracy and coverage, most websites had a focus on preterm birth, or a dedicated subsection for preterm birth. Organisations' websites included in the landscape analysis detailed past and ongoing projects, their mission statement, and their focus within the realm of preterm birth. Some organisation's websites focused solely on preterm birth initiatives, whilst others had broader reach to include newborn and maternal health. Objectivity refers to bias and whether the argument is balanced. Organisations included in the landscape analysis, presented evidence within their websites about the burden of preterm birth, and of their ongoing work and research, however not all websites contained the explicit dates of when the website page was published or last updated, which might limit the objectivity and reliability of the website. All the included websites and organisations had significance in the field of preterm birth.

Discussion

In this landscape analysis of key stakeholders involved in preterm birth, we identified 38 key organisations working to improve morbidity and mortality of preterm birth globally. These organisations were mainly headquartered in HIC settings with a global reach, and worked across the fields of knowledge-sharing, knowledge-producing, funding, advocacy and legislation, implementation, and formation of networks. Our study further highlighted the wide range of activities and interventions being conducted by these organisations from digital health platforms to research into biomarkers to predict preterm birth. Most organisations in our review focused on one particular aspect of preterm birth, rather than taking a whole systems view of the issue.

Our results highlighted a paucity of community-focused interventions impacting morbidity and mortality outcomes of preterm birth in LMIC settings. A high proportion of organisations in HICs focused on interventions directly communicating and working with parents and families experiencing preterm

birth. These parent and family initiatives focused on empowering and providing community networks to offer knowledge and support, through mobile apps and social media means^{25,27}. These were identified as key gaps and potential area of focus for preterm birth organisations within LMIC contexts, particularly given the reach of digital and mobile technologies globally. A previous review analysing preterm birth preventative community groups found a mixed outcome on effectiveness, but highlighted sharing knowledge and use of social media may be particularly useful⁷⁶. Peer and professional knowledge and support provided through apps such as those developed by Tommy's and Best Beginnings accessible from home, may have a positive impact^{25,27}. Through these apps, parents can communicate with NICU staff and other parents that have premature babies can create a community that can provide the needed psychosocial support⁷⁷.

Another significant finding from the data is that power and influence on funding for preterm birth initiatives remains in the global north. A high proportion ($n = 23$) of organisations had their major global headquarters based in HIC regions, including global organisations with LMIC impact such as WHO and Program for Appropriate Technology in Health (PATH)^{13,56}, although, WHO does have regional and country offices in LMICs. Physical location of global headquarters in HIC regions may influence funding decisions and impact the scope and availability of interventions in LMIC contexts and may further limit knowledge production specific to LMIC contexts. Prolonged support and funding are dedicated to some preterm baby organisations based in HICs, such as March of Dimes, Every Premie and European Foundation for the care of Newborn Infants (EFCNI), such models of sustainable funding for preterm birth initiatives were not evident in LMIC regions from our search^{33,46,47}.

Long-term needs of children born preterm

The results of our study highlighted there are few organisations and initiatives dedicated to the long-term needs of children born prematurely. These findings are supported by previous studies regarding education and healthcare systems, despite evidence indicating premature birth can have long term neurological, developmental, and pulmonary consequences⁸⁻¹⁰. In the UK, it was highlighted that there is a significant knowledge gap amongst educational staff relating to the impact of preterm birth in school children⁷⁸, with staff feeling unequipped to manage and support their needs. This may have further detrimental effects on the child's learning and represents a potential public health concern⁷⁸. A qualitative study to explore healthcare workers' understanding of adults born prematurely and their experiences interacting with health systems, found that many were unaware of the individual being born prematurely, and the increased risk of associated diseases⁷⁹. Further research and education is needed to communicate the long-term effects and management of preterm birth globally, especially within LMIC context, where the burden of preterm birth falls.

Policy-level interventions have been implemented in Northern Ireland, allowing greater flexibility for preterm born

children when starting school⁸⁰. The government bill allows preterm children to delay their school start to the next school year, as most would have been 'Young for Year' if born at term⁸⁰. Further advocacy relating to parental leave and school policies may be beneficial to preterm born children and their families in other global contexts.

Research led and funding with LMICs

As noted in our results, research into preterm birth primarily takes place in HICs, and funding is held by HIC organisations. These findings are supported by previous studies, that global health research is controlled by the HIC-led organisations, with roots of colonialism and setting the research agenda within LMIC settings⁸¹, resulting in power imbalances^{82,83}. Financial resources are a form of power within the global health field and influence investment and funding of interventions, for example, the USA is still the largest donor in development assistance in health, but also the largest bilateral donors for reproductive, maternal, newborn and child health funding too with \$5.8 billion in 2017, followed by the UK^{84,85}. Our results highlight the need for context-specific research and funding based in LMIC settings, to produce knowledge and interventions specific to LMIC countries. For instance, risk factors for preterm birth may vary between LMICs and HICs, however, as most of the research early identification of preterm birth is conducted in HIC settings^{30,33}, and findings may not be transferrable to LMIC settings, where there are differences in biological, social, and environmental factors impacting preterm birth. Furthermore, greater knowledge production from LMICs will allow emphasise the importance of bi-directional learning between HIC and LMICs and south-to-south learning.

Systems-level approach

A systems-level approach in healthcare acknowledges that multiple components interact to influence an outcome^{81,86}. Complex interventions in healthcare require multidisciplinary teams with the common goal of reducing preterm birth mortality and morbidity. This includes key stakeholders within healthcare, research, policymaking, educational institutions, and public health. The results of our review demonstrated a lack of interventions with whole-systems approach related to preterm birth. Health systems strengthening through an evidence-based approach to the prevention and management of preterm birth may improve quality of care, and address implementation challenges in global settings⁸⁷.

Limitations

There are limited methodological papers to guide the conduct of a landscape analysis. We followed the guidance available, whilst ensuring our methods were replicable and transparent. Our study was further limited as searches were conducted in the UK in the English language. Thus, our search engine may be biased to producing results relevant to UK, and results may appear differently if a similar search was conducted in LMICs. This may skew the results from the searches and disproportionately represent organisations and interventions dedicated to preterm birth HICs. To counteract this effect, we did ensure that the invited key informants were from the global community,

and aware of the global landscape for preterm birth. There may, however, also be other successful community-based preterm birth organisations without an online presence missed in our search and by our key informant. Lastly, searches were carried out in January–February 2022, and reflect the landscape for preterm birth at that time. We have, however minimised these limitations by presenting the methods and discussion in a transparent and reproducible way.

Conclusion

This landscape analysis has highlighted the key organisations and intervention categories with the aim of reducing morbidity and mortality in preterm birth. Addressing global morbidity and mortality rates due to preterm birth may require further focus on a systems-level approach, nurturing community-based initiatives, and inspiring locally driven change to focus on the needs and families of preterm babies in low-resource settings globally. There is a need for further LMIC-led and funded research. As reducing mortality and morbidity outcomes for preterm babies is key to achieving the aim of SDG 3 in reducing preventable under-five deaths, further support is required by national governments to acknowledge preterm birth as part of the public health agenda, providing long-term funding and legislative change in this field.

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Data availability

Underlying data

All data underlying the results are available as part of the article and no additional source data are required.

Reporting guidelines

Zenodo: PRISMA reporting checklist and flow chart. DOI [10.5281/zenodo.7672266](https://doi.org/10.5281/zenodo.7672266)

Zenodo: Supplementary File 1 (data extraction of organisations) and Supplementary File 2 (data extraction of interventions) DOI [10.5281/zenodo.7714185](https://doi.org/10.5281/zenodo.7714185)

Data are available under the terms of the Creative Commons Zero “No rights reserved” data waiver (CC0 1.0 Public domain dedication).

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