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Shubha Setty
Ghislain Franck Houndjahoue
Monika S. Patil
Sonia Bandeira
Abhishek Makkar
Mariya Mukhtar-Yola
Anna Sedney
Michele Barrila-Yetman
Helga Naburi
Modupeola Akinola

Assessing data collection systems in African Neonatal Association-affiliated newborn units: Implementation barriers, sustainability, and opportunities for improvement

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Shubha Setty (✉)
2220 N Druid Hills Rd NE, Atlanta, GA 30329,
Email: ssetty@emory.edu

Ghislain Franck Houndjahoue
Centre Hospitalier Universitaire Pédiatrique de Bangui, RCA

Monika S. Patil
Baylor College of Medicine, Texas Children's Hospital, Houston, TX, USA

Sonia Bandeira
African Neonatal Association, Kigali, Rwanda

Abhishek Makkar
Children's Health-Dallas, Dallas, TX, USA

Mariya Mukhtar-Yola
National Hospital Abuja, Nigeria

Anna Sedney
Nemours Children's Hospital, Orlando, FL, USA

Michele Barrila-Yetman
Children's Healthcare of Philadelphia,
Philadelphia, PA, USA

Helga Naburi
Muhimbili University of Health and Allied Sciences, Dar es Salaam Tanzania

Modupeola Akinola
Brenner Children's Hospital, Winston-Salem, NC, USA

Abstract: Globally, the under-five mortality rate has decreased, though reductions in newborn mortality have not improved to the same degree. Data collection systems have been widely shown in the literature to improve newborn care and subsequently mortality outcomes, often through facilitating quality improvement (QI) initiatives. The African Neonatal Association (ANA) has partnered with the Children's Hospitals Neonatal Consortium (CHNC) to support their mission of improving outcomes for newborns and their families in Africa through the development of an Africa-focused data network. To support this initiative, a survey was disseminated to ANA-affiliated newborn care facilities to establish a baseline assessment of newborn-specific data systems, identify barriers and limitations, evaluate the use of databases for QI initiatives, and assess educational needs. Survey respondents identified that despite high utilization of data collection systems for monitoring newborn outcomes and QI initiatives, key barriers to sustainability and effectiveness of these databases included insufficient staffing, inadequate funding, and high clinical workloads. There is ongoing collaborative development of a virtual QI workshop between CHNC and ANA members to support newborn healthcare providers in LMIC settings given unanimous QI education interest from survey respondents.

Keywords: Data collection, Quality Improvement, Newborns/ Neonates

Introduction

Over the past decade, the under-five mortality rate has decreased globally, however, reductions in newborn mortality have lagged. The proportion of newborn mortality has increased and now comprises nearly half of all the deaths in children under age five globally.[1] The distribution of newborn mortality remains inequitable with the highest burdens remaining in low- and middle-income countries (LMIC).[1] Among the top twenty countries with the highest burden of newborn mortality, seventeen are in Sub-Saharan Africa.[2,3]

Improving the quality of newborn care is a widely recognized strategy endorsed by the World Health Organization to improve outcomes for small and sick newborns in health facilities.[4] Data collection systems and databases facilitate QI initiatives, which have been widely shown in the literature to improve newborn care and subsequently mortality outcomes. High-quality new born data systems also provide the infrastructure necessary for benchmarking, implementation of quality improvement initiatives, clinical research, and evaluation of health system performance.[5,6,7] Currently, most countries in Sub-Saharan Africa do not have standard databases for electronic records for newborns born in health facilities, and data collected for health ministry reporting is limited to basic information.[8,9] There are several studies published which have shown successful implementation of individual newborn databases and improved newborn outcomes in some Sub-Saharan countries[10,11,12], however, no studies report on standard data collection systems across the continent or even specific African regions. Furthermore, little is known about the barriers to implementation, long-term sustainability, or the extent to which existing newborn databases are used to support quality improvement and research.

The ANA was established in 2021 and is comprised of African neonatologists and pediatricians working in newborn care in Africa. One of their core missions is to improve outcomes for newborns and their families in Africa through improving the quality of newborn care. [13] The ANA has partnered with the Vermont Oxford Network (VON) to develop the African Neonatal Network (ANN) as a standardized database to support QI and research.[14] The CHNC is a collaboration of Level IV neonatal intensive care units (NICU) across the United States of America (USA) that also seeks to improve care and outcomes for newborns through sharing of data, information, and ideas to support research and QI initiatives.[15] The CHNC has recently partnered with ANA to support their efforts, including the development of the ANN. Establishing a baseline understanding of existing neonatal data systems is essential for guiding implementation strategies, prioritizing resource allocation, and ensuring that the ANN addresses the diverse needs and infrastructure of neonatal units across Africa. To support this initiative, a survey was disseminated to ANA-affiliated neonatal care facilities to establish a baseline assessment of newborn-specific data systems, identify barriers and limitations, evaluate the use of databases for QI, and assess focused educational needs.

Methods

A multidisciplinary, multi-lingual, and geographically representative team was intentionally assembled, comprising of African and US neonatologists, pediatricians, researchers, and data collectors from ANA and CHNC. Linguistic representation included individuals from Francophone, Lusophone, and Anglophone African countries.

Across-sectional survey was co-designed on the topics of facility demographics, current data collection and QI efforts, barriers to data collection, strategies to overcome barriers, and focused educational needs using a combination of multiple choice and free text responses in Research Electronic Data Capture (RedCAP). The survey was administered electronically by email and messaging applications, such as WhatsApp (WhatsApp LLC, Melo Park, California, USA), to all registered ANA members in three languages (French, Portuguese, English) from January to March 2024.Translations were performed by native speaking medical providers and translation services at Emory University in Atlanta, Georgia, USA. Reminder emails and messages on WhatsApp were sent out every two weeks starting in February 2024 to encourage survey completion.

The project team compiled the results in Microsoft Excel and analyzed using descriptive statistics. Quantitative variables were described as a mean with standard deviation and categorical variables were described with frequencies and percentages. Free text responses were reviewed and grouped into common themes.

Ethical Considerations

Non-human subjects research determination was obtained from the Emory University Institutional Review Board. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation and with the Helsinki Declaration of 1975, as revised in 2013.

Results

Forty surveys were fully completed and analyzed. The completed surveys represented 26 African countries (Table 1), which was 70% of the 37 ANA-represented countries at the time of the survey (Figure 1). Most of the surveys were completed in French (53%), followed by English (40%) and Portuguese (7%). Most participating facilities were described as referral centers (85%). Table 2 shows the facility demographics of the newborn units surveyed.

Regarding the current state of databases and data collection, 24 individual respondents (60%) described having a neonatal specific database, with half using a mixed electronic and paper format (50%) (Table 3). The most common uses of the databases were monitoring outcomes and metrics (96%), data collection (92%), and QI initiatives (79%).The most common QI initiatives cited were those addressing hand hygiene (27%), early and late onset sepsis (20%), and hypothermia (19%) (Table 3).

Fig 1: African Neonatal Association Countries in 2024

Table 1: Countries Represented in Completed Surveys

Country	Number of Surveys Completed
Tanzania	2
Somaliland	1
Ethiopia	2
South Africa	1
Mozambique	2
Senegal	4
Chad	3
Benin	1
Nigeria	2
Mali	3
Zimbabwe	1
Togo	1
Uganda	1
Central African Republic	2
Ghana	1
Kenya	1
Cote d'Ivoire	1
Namibia	1
Cameroon	1
Somalia	1
Gabon	1
Comore	1
Zambia	1
Gambia	1
Madagascar	3
Guinea-Bissau	1
Total	40

Table 2: African Neonatal Association Facility Demographics

Facility Demographics	Number (%)
Neonatal Facility Type	
Neonatal Intensive Care Unit	30 (75%)
Special Care Nursery	5 (13%)
Other	5 (13%)
Hospital/Clinic Category	
Referral	34 (85%)
District	4 (10%)
Other	2 (5%)
Hospital/Clinic Characterization	
Federal/Public Institution	34 (85%)
Private Institution	4 (10%)
Faith-based Institution	2 (5%)
Other	0 (0%)
Average Neonatal Census per Month	
0 - 10 neonates	1 (3%)
11 - 30 neonates	6 (15%)
31 - 50 neonates	9 (23%)
51 - 100 neonates	10 (25%)
100+ neonates	14 (35%)
Number of Neonatal Beds	
0 - 10 beds	5 (13%)
11 - 30 beds	14 (35%)
31 - 50 beds	16 (40%)
50+ beds	5 (13%)
Presence of a Kangaroo Care Unit	
Yes	35 (88%)
No	5 (13%)
Number of Beds in the Kangaroo Care Unit	
0 - 10 beds	30 (75%)
11 - 30 beds	5 (13%)
31 - 50 beds	0 (0%)
50+ beds	0 (0%)
Medical Supervision of Neonatal Care (choose all that apply)	
Neonatologist	23
Pediatrician	29
Medical Officer	19
Nurse Practitioner	17
Physician Assistant	1
Other	7

Table 3: Current data collection and QI efforts

Current data collection and quality improvement efforts	Number (%)
Current Neonatal Specific Database	
Yes	24 (60%)
No	16 (40%)
Current Use of Database (choose all that apply)	
Data Collection	22
Monitoring outcomes and metrics	23
Quality improvement initiatives	19
Research	18
Other	0
Database Format (choose all that apply)	
Electronic	7
Paper	5
Electronic, Paper	12
Other	0
Electronic Database Format (choose all that apply)	
REDCap	2
Microsoft Excel	15
Other	3
Data Collector (choose all that apply)	
Physician	12
Medical trainee	5
Nurse	7
Advanced practitioner (i.e. nurse practitioner or physician assistant)	11
Clerk	12
Other	6
Special Funding for Data Collection	
Yes	4 (17%)
No	20 (83%)
Data Audit	
Yes	11 (46%)
No	13 (54%)
Current QI Initiatives	
Yes	30 (75%)
No	10 (25%)
Current QI Topics (choose all that apply)	
Hand hygiene	27
Hypothermia	19
Hypoglycemia	15
Early and late onset sepsis	20
Jaundice	18
Hypoxic-ischemic encephalopathy	19
Other	10
Current Research Initiatives	
Yes	26 (65%)
No	14 (35%)
Staff Members with Specific Training in QI or Data Collection and Analysis	
Yes	15 (38%)
No	25 (62%)
Type of Specific Training (choose all that apply)	
Institute for Healthcare Improvement online course	7
Course through an academic institution or hospital	8
Other	5
Presence of an Institutional or Regional Review Board	
Yes	21 (53%)
No	19 (47%)

The most common obstacles to data collection in all facilities surveyed were lack of staff (75%), funding (70%), and collection materials, such as forms, electronics, and applications (63%). Challenges to sustainability of data collection and database maintenance in all facilities primarily involved lack of assigned personnel for data collection (73%), insufficient funding (68%), and high clinical workload (63%) (Table 4).

All 40 respondents (100%) reported interest in gaining QI skills and 38 respondents (95%) were interested in gaining data collections skills (Table 5).

Table 4: Obstacles and Challenges

Obstacles and Challenges to Data Collection	Numbers (%)
Obstacles Encountered (choose all that apply)	
Lack of funding	28
Lack of time	12
Lack of staff	30
Lack of knowledge	14
Lack of forms/devices/apps	25
Not an institutional or personal priority	11
Other	4
Challenges to Sustainability of Data Collection and Database Management (choose all that apply)	
Lack of data storage, security, and privacy	17
Lack of assigned personnel for data collection	29
Lack of funding	27
Competing priorities	19
High clinical work load	25
Competing quality improvement and research projects	5
Other	2

Table 5: Education Interest

Interest in Education	Number (%)
Interest in Gaining QI Skills	
Yes	40 (100%)
No	0 (0%)
Interest in Gaining Data Collection Skills	
Yes	38 (95%)
No	2 (5%)
Interest in Establishing a Database for Those Without	
Yes	32 (80%)
No	1 (3%)
Not applicable, already have a database	7 (18%)

Discussion

Our survey provides an important assessment of newborn-specific data systems among newborn care facilities affiliated with the ANA, highlighting both progress and ongoing gaps in newborn data capacity across Africa.

The continued inequitable high newborn mortality rates in LMICs remains a global challenge. The strengthening

and capacity building of data collection systems and databases that facilitate QI initiatives and research has been put forth as an integral part of the solution for improving newborn mortality outcomes, especially in these high burden regions.

The survey conducted highlights a robust engagement in newborn database usage with 60% of respondents maintaining newborn-specific databases. This reflects a promising trend, although there remains room for improvement. Comparable evidence from the IMPULSE study conducted across four African countries reported higher availability of key newborn data, ranging from 64% to 100%, particularly for indicators such as newborn mortality, birth outcomes, and stillbirths.[16]

The comparatively encouraging results observed in our study may be partly explained by the high proportion of participating facilities being referral centers, often affiliated with university hospitals. These settings are more likely to host research activities and have better integration with national health information systems, which can incentivize the establishment and use of structured databases.

However, access to and use of newborn databases must extend beyond referral facilities to include primary and secondary care facilities with the goal of improving newborn outcomes. In line with Every Woman Every Newborn Everywhere, robust and standardized data systems are essential to inform QI efforts, support decision-making, and monitor progress at all levels of care.[17]

Recent African initiatives demonstrate the feasibility of implementing standardized newborn datasets to support QI. The Newborn Essential Solutions and Technologies (NEST360) Alliance developed the Neonatal Inpatient Dataset (NID), a standardized patient-level dataset for small and sick newborns that captures key clinical information and supports facility-level QI efforts across several African countries. The NID provides an important example of how structured newborn data systems can be integrated into clinical care processes to generate actionable information for improving newborn outcomes.[18]

Despite high utilization for monitoring outcomes and QI initiatives, respondents identified key barriers to sustainability and effectiveness of these databases to include insufficient staffing, inadequate funding, and high clinical workloads. Addressing these barriers is critical for enhancing the sustainability and efficacy of data collection efforts in newborn care. In this regard, stronger engagement from Ministries of Health and national policy makers is urgently needed to invest in dedicated, well-trained human resources for data management and use (Fig 2).

Fig 2: Survey reported strategies to overcome obstacles to data collection and database management

Furthermore, newborn-specific databases should complement existing health information systems. While platforms such as District Health Information Software 2 (DHIS2) have strengthened national reporting, they often lack the patient-level clinical detail needed for newborn QI and research.[19] Initiatives such as NEST360 and the ANN can bridge this gap by providing standardized newborn data while aligning with national reporting priorities.

Additionally, it is important to recognize that priority actions will vary across and within countries, depending on the specific constraints identified at different levels of the health system. This need for context-specific approaches has been similarly highlighted by findings from the IMPULSE Phase 1 study, which underscored the significant heterogeneity in data availability and system performance across settings.[16] Therefore, successful implementation will require a balance between standardized core datasets and adaptable approaches that allow facilities to address locally relevant priorities.[20]

While these findings provide important insights into the current landscape of newborn data collection systems across ANA-affiliated facilities, several limitations should be considered when interpreting the results. Survey responses were self-reported and may be subject to reporting bias. Participating facilities were predominantly referral and university-affiliated centers, which may limit generalizability to smaller or rural newborn units. Additionally, facilities with established databases may have been more likely to participate, introducing potential selection bias. As a cross-sectional survey, this study could not evaluate causal relationships between database implementation and newborn outcomes.

Finally, survey respondents showed near unanimous interest in QI and data collection education. There is ongoing collaborative development of a virtual QI workshop between CHNC and ANA members to support newborn healthcare providers in LMIC settings to

support this educational interest.

Conclusion

This co-designed cross-sectional survey provided a baseline assessment of newborn-specific data systems, identified key barriers and limitations, evaluated the use of databases for QI, and assessed focused educational needs across ANA-affiliated newborn care facilities, thereby informing the development of the ANN and educational QI workshops.

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Author Contributions

Dr. Setty: concept, design, literature search, data acquisition, data analysis, manuscript preparation, manuscript editing, and manuscript review
Dr. Houndjahoue: concept, design, literature search, data acquisition, data analysis, manuscript preparation, manuscript editing, and manuscript review
Dr. Patil: design, literature search, manuscript preparation, manuscript editing, and manuscript review
Dr. Bandeira: design, literature search, manuscript preparation, manuscript editing, and manuscript review
Dr. Makkar: design, literature search, manuscript preparation, manuscript editing and manuscript review
Dr. Mukhtar-Yola: design, manuscript editing, and manuscript review
Dr. Sedney: design, data analysis, manuscript editing, and manuscript review
Ms. Barrila-Yetman: design, manuscript editing, and manuscript review
Dr. Naburi: manuscript editing and manuscript review
Dr. Akinola: concept, design, manuscript preparation, , and manuscript review

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