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ORIGINAL ARTICLE

Empowering newborn screening programs in African countries through establishment of an international collaborative effort

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Abstract

In an effort to explore new knowledge and to develop meaningful collaborations for improving child health, the *First Pan African Workshop on Newborn Screening* was convened in June 2019 in Rabat, Morocco. Participants included an informal network of newborn screening stakeholders from across Africa and global experts in newborn screening and sickle cell disease. Over 150 attendees, representing 20 countries, were present including 11 African countries. The agenda focused on newborn screening rationale, techniques, system development, implementation barriers, ongoing research, and collaborations both globally and across Africa. We provide an overview of the workshop and a description of the newborn screening activities in the 11 African countries represented at the workshop, with a focus on sickle cell disease.

Keywords Newborn screening · Sickle cell disease · Pan-African · Rabat declaration · Public health

Abbreviations

ACMG	American College of Medical Genetics and Genomics
AfroSickleNet	Africa Sickle Cell Research Network
AMDNNPH	Moroccan Society for Newborn Screening and Handicap Prevention
APHL	Association of Public Health Laboratories (U.S.)

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App	Mobile application (telephone, etc.)
BCG	Bacillus Calmette–Guérin
CCP	Comprehensive care program
CDC	Centers for Disease Control and Prevention (U.S.)
CH	Congenital hypothyroidism
CNRST	National Center for Scientific and Technological Research (Morocco)
EID	Early infant diagnosis
GAVI	Global Alliance for Vaccines and Immunization
H3Africa	Human Heredity and Health in Africa
Hb	Hemoglobin
HIV	Human immunodeficiency virus
HPLC	High performance liquid chromatography
IAEA	International Atomic Energy Agency
IEF	Isoelectric focusing
IMR	Infant mortality rate (under 1 year)
ISNS	International Society for Neonatal Screening
MDG	Millennium development goal
MENA	Middle East North Africa
MoH	Ministry of Health
NBS	Newborn screening
NIH	National Institutes of Health (U.S.)
NNSGRC	National Newborn Screening and Global Resource Center (U.S.)
SCA	Sickle cell anemia (SCD-SS)
SCD	Sickle cell disease (group of diseases associated with Hb S)
SCDIC	Sickle cell disease implementation consortium
SCD-SC	Sickle cell disease SC
SCT	Sickle cell trait (sickle gene carrier, AS)
SDG	Sustainable Development Goal
SCCAN	Sickle Cell Carers Awareness Network
UN	United Nations
U5MR	Under 5-year mortality rate
UNICEF	United Nations International Children's Emergency Fund (now called the UN Children's Fund)
US3	Uganda Sickle Surveillance Study
WHO	World Health Organization

Introduction

Newborn screening (NBS) has existed in many developed countries since the early 1960s and currently reaches about one-third of the world's newborn population. Of those newborns that are screened, many residing in countries with low- and middle-income economies only receive screening for a single condition while those in countries with higher-income economies may be screened for over 50 conditions (Therrell et al. 2015b). There is limited organized NBS within the African continent with NBS programs currently in place primarily along the northern coast. While NBS for congenital hypothyroidism (CH) is generally considered to be the most consequential screened condition globally, the impact and incidence of sickle cell diseases (SCD) throughout sub-Saharan Africa make this group of disorders the most vital for NBS in a significant portion of the continent.

Each year, approximately 400,000 babies are born with SCD worldwide and more than 75% of these births occur in sub-Saharan Africa (Piel et al. 2013a) where it is estimated that 50 to 90% of affected infants will die before their 5th birthday (Grosse et al. 2011). Fortunately, early diagnosis of SCD coupled with comprehensive care has been demonstrated to be effective in improving newborn survival and related health outcomes (Chaturvedi and DeBaun 2016; Streetly et al. 2018; Shook and Ware 2018). The World Health Organization (WHO) and the United Nations (UN) have each designated SCD as a global health problem (World Health Organization 2006; United Nations 2008). In 2010, the 63rd World Health Assembly urged member states to address the concerns of limited resources dedicated to prevention and management of birth defects by raising awareness of all relevant stakeholders about the importance of NBS programs and their role in identifying infants born with congenital birth defects (World Health Organization 2011). Subsequently, the WHO African Region developed a strategy for addressing SCD in Africa (WHO Regional Committee for Africa 2010). While critical to improving survival, NBS implementation is particularly challenging in low-income, high-burden settings such as those in much of Africa (Kato et al. 2018).

Table 1 provides a listing of African countries based on the UN Secretariat's most recent report (United Nations 2019) and summarizes national data that inform some of the issues affecting NBS implementation. In addition to the latest population statistics (United Nations 2019), the fertility statistics and rankings (U.S. Census Bureau 2020), birth and mortality statistics (UNICEF 2019), and estimated percentages of sickle cell anemia (SCA) and sickle cell trait (SCT) (Piel et al. 2013b) are provided. The latter data, while difficult to obtain because of a scarcity of published reports, are particularly informative in terms of burden of SCD.

Africa is the world's second largest continent and also the second most populous with a population exceeding 1.3 billion. The sub-Saharan African population is expected to increase by 1.1 billion between 2019 and 2050, which is more than half of the expected world population growth. Population trends globally are driven by trends in fertility, so it is not surprising that 40 of the top 50 countries with the highest fertility rates (average number of children born to women 15–44 years of age), are African countries (Table 1) (U.S. Census Bureau 2020). Unfortunately, fertility rates and poverty are closely linked, and they compound the significant economic burdens associated with delivery of health care

Table 1 African countries with selected demographic data

Country	Population[a] mid-year 2019 (× 1000)	Fertility rate[b] 2019 (world rank)	Births[c] 2018 (× 1000)	Infant[c] mortality rate (under 1)		Infant[c] mortality rate (under 5)		Estimated[d] Hb AS% in population	Estimated[d] Hb SS% in population
				1990	2018	1990	2018		
Sub-Saharan Africa									
Eastern Africa									
Burundi	11,531	5.6 (6)	437	105	41	174	58	8.59	0.31
Comoros	851	4.2 (31)	27	88	51	125	67	4.48	0.10
Djibouti	974	2.8 (64)	21	92	50	118	59	0.01	0.00
Eritrea	3497	4.0 (33)	105	94	31	153	42	0.43	0.01
Ethiopia	112,079	4.0 (34)	3537	120	39	202	55	0.44	0.01
Kenya	52,574	3.8 (40)	1479	68	31	107	41	6.54	0.30
Madagascar	26,969	4.1 (32)	860	97	38	159	54	9.94	0.49
Malawi	18,092	4.5 (24)	621	139	35	239	50	6.79	0.24
Mauritius	1270	1.4 (175)	13	20	14	23	16	0.00	0.00
Mayotte	266	3.7 (42)	–	–	–	–	–	6.89	0.19
Mozambique	30,366	5.1 (11)	1110	161	54	241	73	5.01	0.19
Réunion	889	2.3 (91)	n/a	n/a	n/a	n/a	n/a	0.04	0.00
Rwanda	12,627	3.8 (39)	391	94	27	154	35	5.48	0.14
Seychelles	97,739	2.3 (93)	2	14	12	17	14	–	–
Somalia	15,443	6.1 (2)	629	108	77	179	122	0.30	< 0.01
South Sudan	11,062	4.7 (18)	387	150	64	254	99	–	–
Tanzania[e], United Republic of	58,005	4.9 (12)	2071	101	38	166	53	11.04	0.60
Uganda	44,270	5.5 (7)	1627	109	34	185	46	12.79	0.68
Zambia	17,861	4.9 (13)	629	111	40	186	58	14.41	0.92
Zimbabwe	14,645	3.6 (44)	443	52	34	80	46	0.45	0.13
Middle Africa									
Angola	31,825	5.6 (5)	1257	132	52	223	77	14.84	1.10
Cameroon	25,876	4.6 (20)	893	85	51	137	76	15.77	0.99
Central African Republic	4745	4.8 (16)	166	117	84	180	116	11.78	0.63
Chad	15,947	5.8 (4)	654	112	71	212	119	8.72	0.41
Congo, Democratic Republic of	78,736	6.0 (n/a)	3468	119	68	186	88	17.15	1.34
Congo, Republic of	5381	4.6 (22)	173	59	36	90	50	17.51	1.20
Equatorial Guinea	1356	4.6 (23)	44	121	63	179	85	20.34	1.55

Table 1 (continued)

Country	Population[a] mid-year 2019 (× 1000)	Fertility rate[b] 2019 (world rank)	Births[c] 2018 (× 1000)	Infant[c] mortality rate (under 1)		Infant[c] mortality rate (under 5)		Estimated[d] Hb AS% in population	Estimated[d] Hb SS% in population
				1990	2018	1990	2018		
Gabon	2173	3.7 (43)	67	60	33	93	45	23.05	2.13
Sao Tome and Principe	215	4.4 (n/a)	7	67	26	108	31	15.47	0.83
Southern Africa									
Botswana	2304	2.7 (66)	56	39	30	51	36	0.66	0.01
Eswatini (Swaziland)	1148	3.0 (n/a)	30	54	43	71	54	1.16	0.01
Lesotho	2125	3.2 (55)	56	72	66	90	81	0.07	0.00
Namibia	2495	3.3 (49)	70	50	29	74	40	2.04	0.05
South Africa	58,558	2.4 (82)	1184	46	28	59	34	0.48	0.01
Western Africa									
Benin	11,801	4.9 (14)	417	106	61	175	93	18.18	0.14
Burkina Faso	20,321	5.2 (10)	751	99	49	199	76	10.32	0.45
Cabo Verde	550	2.2 (89)	11	47	17	61	19	6.12	0.18
Côte d'Ivoire	25,717	4.8 (15)	898	105	59	155	81	10.42	0.50
Gambia	2348	5.3 (9)	88	82	39	167	58	13.40	0.65
Ghana	30,418	3.9 (37)	876	80	35	127	48	13.86	0.74
Guinea	12,771	4.7 (17)	453	139	65	236	101	18.28	1.35
Guinea Bissau	1921	4.5 (n/a)	66	132	54	223	81	8.14	0.31
Liberia	4938	4.5 (25)	160	175	53	262	71	8.57	0.36
Mali	19,658	5.9 (3)	795	120	62	230	98	9.35	0.45
Mauritania	4526	4.6 (21)	148	71	52	117	76	8.65	0.39
Niger	23,311	7.2 (1)	1037	133	48	329	84	11.97	0.66
Nigeria	200,964	5.4 (8)	7433	125	76	211	120	18.28	1.37
Senegal	16,296	4.6 (19)	548	71	32	139	44	11.48	0.55
Saint Helena[f]	6	–	–	–	–	–	–	–	–
Sierra Leone	7813	4.3 (29)	256	156	78	263	105	18.56	1.33
Togo	8.082	4.4 (28)	262	90	47	145	70	16.22	1.04
Northern Africa									
Algeria	43,053	2.7 (67)	1023	42	20	50	23	1.54	0.03
Egypt	100,388	3.2 (53)	2591	63	18	86	21	2.54	0.06
Libya	6777	2.2 (95)	126	35	10	42	12	4.24	0.13
Morocco	37,054	2.4 (79)	682	62	19	79	22	0.54	0.01

Table 1 (continued)

Country	Population[a] mid-year 2019 (× 1000)	Fertility rate[b] 2019 (world rank)	Births[c] 2018 (× 1000)	Infant[c] mortality rate (under 1)		Infant[c] mortality rate (under 5)		Estimated[d] Hb AS% in population	Estimated[d] Hb SS% in population
				1990	2018	1990	2018		
Sudan	42,813	4.4 (26)	1347	82	42	132	60	7.13	0.33
Tunisia	11,695	2.1 (98)	203	43	15	55	17	2.58	0.05

[a] United Nations, Department of Economic and Social Affairs, Population Division (2019). World Population Prospects 2019: Data Booklet (ST/ESA/SER.A/424). Available at: https://population.un.org/wpp/Publications/Files/WPP2019_DataBooklet.pdf (accessed Dec. 1, 2019)

[b] World population review fertility rate. Available at: http://worldpopulationreview.com/countries/total-fertility-rate/ (accessed Dec. 1, 2019)

[c] UNICEF, The State of the World's Children 2019 Statistical Tables. Available at: https://data.unicef.org/resources/dataset/sowc-2019-statistical-tables/ (accessed Dec. 1, 2019)

[d] Piel FB et al. 2013b (aee Supplementary Appendix, Table 4. Hb AS = sickle cell trait; Hb SS = sickle cell anemia

[e] Includes Zanzibar

[f] Includes Ascension and Tristan da Cunha Islands

generally. Thus, although NBS is cost-effective as a health program, its sustainable implementation in Africa is difficult.

As a public health priority, NBS has been shown to increase in importance when the infant mortality rate (IMR—less than 1 year) and the U5MR decrease, particularly in countries with low- and middle-income economies (Therrell et al. 2015b). Data illustrating the progress made since 1990 in decreasing both IMR and U5MR in African countries are given in Table 1. The extremely high incidence of SCD, particularly in sub-Saharan Africa, combined with the positive impact of early detection and treatment of SCD on both IMR and U5MR, and the ability for SCD to be detected through NBS, health policy makers in Africa have a unique and growing opportunity to endorse and prioritize funding for this critical health intervention program.

The first meaningful projects to develop and implement NBS programs for SCD began in 1993 in Kumasi, Ghana (Ohene-Frempong et al. 2008) and Cotonou, Benin (Rahimy et al. 2009). A few years later, the International Atomic Energy Agency (IAEA) provided NBS training and start-up funding in a number of African countries emphasizing radioimmunochemical screening methods for CH (Solanki 2007). Unfortunately, implementation of any kind of sustainable NBS at the time was met with only limited success (Solanki 2007; Tshilolo et al. 2008). Renewed interest in NBS and the possibility of international NBS collaborations with African countries surfaced in 2006 when a visiting U.S. National Institutes of Health (NIH) delegation identified NBS as an emerging health priority across the Middle East/North Africa (MENA) region (Krotoski et al. 2009). At that time, the annual number of deaths among children under the age of five had dropped below 10 million to 9.7 million representing a 60% drop since 1960 (UNICEF 2008). NBS was seen as a means of continuing this decrease in order to help meet the Millennium Development Goal (MDG) of a two-thirds reduction in U5MR globally by 2015.

In November 2006, the Morocco Ministry of Health (MoH) partnered with the NIH to convene the first MENA regional NBS conference in Marrakech, Morocco, entitled *Strengthening Newborn Screening in the Middle East and North Africa*. This meeting brought together NBS stakeholders from 18 MENA countries and technical experts from 11 countries in Europe, North America, and the Asia Pacific (Krotoski et al. 2009). A primary meeting outcome was the 2006 *Marrakech Declaration*, which outlined the needs and plans for NBS programs in MENA. A second MENA meeting followed in Cairo, Egypt, with a third in Doha, Qatar. Each of the three MENA meetings was limited in focus to Middle East and North African NBS activities, excluding the rest of the African continent.

Also, in 2008, the UN General Assembly recognized SCD as a global public health concern as a result of the morbidity and mortality caused by the disease and the resulting

significant social and economic impact that results (United Nations 2008). Since then, recognition of the need for, and value of, NBS for SCD across various African countries has increased and has continued to be documented including reports supporting its technical feasibility (Tshilolo et al. 2009; Kafando et al. 2009; Burnham-Marusich et al. 2016; Tubman et al. 2016; Chindima et al. 2018; Kiyaga et al. 2018; Tshilolo et al. 2019), health impact (McGann et al. 2013; Makani et al. 2015; Green et al. 2016; Tshilolo et al. 2019), and cost effectiveness (McGann et al. 2015; Kuznik et al. 2016). Efforts to speed the time to obtain screening results and reduce screening costs through point-of-care NBS technology have also been ongoing (McGann and Hoppe 2017). A lack of health workers trained in genetics, with an understanding of NBS and SCD and capable of providing family support and counseling, has been recognized and actions are underway in Ghana to provide a counseling training model useful in a community-based setting (Treadwell et al. 2015; Anie et al. 2016). Other collaborations between developing African NBS programs and established NBS programs have been reported including both screening (Tubman et al. 2016) and clinical/research (McGann et al. 2017; Smart et al. 2018; Tshilolo 2019).

In an effort to share the results of these and other NBS activities in Africa, to explore new knowledge, and to develop meaningful collaborations for improving child health, the *First Pan African Workshop on Newborn Screening* was convened in June 2019. Meeting organization focused on shared experiences between an informal network of NBS stakeholders across Africa and NBS global experts. The agenda was intended to facilitate NBS program implementation and foster research and other collaborations both within Africa and globally. This report provides an overview of the workshop and describes the progress of NBS implementation across Africa and local actions undertaken to increase NBS activities on the continent.

Method (workshop description)

The *First Pan African Workshop on Newborn Screening* was held in Rabat, Morocco, June 12–14, 2019. Meeting organization was a collaboration between the National Center for Scientific and Technological Research (CNRST-Rabat, Morocco), the Moroccan Society for Newborn Screening and Handicap Prevention (AMDNNPH), and the American College of Medical Genetics and Genomics (ACMG-Bethesda, Maryland USA). Input was also provided by the Sickle Cell Foundation of Ghana, the International Society for Neonatal Screening (ISNS), the U.S. National Newborn Screening Resource and Global Resource Center (NNSGRC), the U.S. Association for Public Health Laboratories (APHL), the Genetic Alliance, and Save Babies Through Screening Foundation and some international commercial sponsors.

A network linking NBS activities within Africa does not currently exist. In order to organize the workshop, a contact list was developed with input from commercial vendors, international NBS experts, known NBS project leaders in Africa, and public health officials in Morocco focusing on NBS. Particular attention was paid to SCD interests and activities as a focal point for workshop discussions and information exchange. Email contact and a meeting website formed the basis for workshop invitations. Limited travel funding was available.

While emphasis was on participation from within the African continent, participants included over 150 attendees from 20 countries including 11 African nations: Morocco, Angola, Benin, Democratic Republic of Congo, Ghana, Malawi, Mali, Nigeria, Sierra Leone, Tanzania, and Uganda. To ensure current information exchange, expert technical advice, and multi-disciplinary input into NBS system development, international experts and leading public health officials from Europe, North America, and the Asia-Pacific were included as faculty. Focus was given to NBS for SCD, because of its importance on the continent.

The workshop format included a pre-meeting discussion on NBS registries and data usage followed by a 2-day symposium focused on other NBS infrastructure and policy considerations, education/communication (consumers, professionals, and policy makers), clinical research, and future directions (including screening for critical congenital heart disease). Participants were allowed time to report on individual country experiences within Africa and discuss their implementation challenges to a sustainable national NBS system. The goals of the Rabat workshop were to:

1. Provide information on the importance of data collection and use in policy development, including discussions on creating useful and usable case registries in low-income economic settings.
2. Review the current status of NBS internationally, illustrating successful NBS system development strategies in low- and middle-income economies.
3. Share information about local, regional, and national NBS activities and related projects across Africa.
4. Consider ways in which consumers (parents) and professionals, including policy makers, could be better educated about, and involved in, developing sustainable NBS in their unique environments.
5. Learn about expanded NBS possibilities, particularly point-of-care testing for critical congenital heart disease.
6. Explore and develop collaborations and related actions needed in order to expand NBS system development across the continent.
7. Share the outcomes of the workshop with other African countries through a published report and its widespread

dissemination, including a meaningful declaration by those present that encourages development and support of NBS by national health ministries.

Results

The workshop program included lectures by various experts and sessions devoted to updates and information exchange. Participants were encouraged to share national data and information on NBS along with other related activities. Emphasis was given to comprehensive healthcare for SCD because of the high prevalence and burden of SCD in most sub-Saharan African countries (see Table 1). The following summaries provide an overview of the workshop.

Pre-meeting discussion—data and registries

As NBS programs expand, screening test results and case-specific data also increase. As a result, the efficient capture of screening and other case-specific data are critical for effective patient tracking and program evaluation. Both the NNSGRC and APHL have considerable experience in collecting and managing national data, particularly as it relates to program evaluation (Therrell and Hannon 2006; Yusuf et al. 2019). The ACMG and NIH have complementary experience in defining meaningful and common data elements useful for patient follow-up and case registries (Lloyd-Puryear et al. 2019). Representatives from each organization participated in a program of lectures and discussions that emphasized the importance of planning for data capture, data management, and data analysis before initiating a NBS program. The collection and use of SCD data in the US (Ojodu et al. 2014; Therrell et al. 2015a) were discussed along with possible collaborations with the Sickle Cell Disease Implementation Consortium (SCDIC), a NIH project supporting multi-component interventions to address the delivery of quality care for SCD and to develop a longitudinal registry of patients with SCD (DiMartino et al. 2018). Participants saw examples of why collection and analysis of program data are important and how case registries can be effectively used as a long-term follow-up tool (Hinton et al. 2011). Discussions focused on how to (1) define the purpose of a registry (research, patient tracking, or quality assurance) to aid in determining registry data elements; (2) identify and convene stakeholders (patients, parents and families, clinicians, specialists, public health professionals, and researchers); and (3) identify and define common data elements.

Country reports—listed alphabetically

In 2008, despite the SCD burden in Africa and the advantages associated with NBS with SCD management, the Republics of Benin and Ghana were the only two countries in Africa with comprehensive SCD NBS programs (Rahimy et al. 2009). The same is generally true today although there is increased interest and activity aimed at NBS implementation in a number of African countries. The following country reports update the status of NBS screening in the 11 African countries represented.

Angola (Republic of Angola) In 2005, a SCD clinic was established at the National Children's Hospital in the capital city of Luanda with approximately 1000 new patients seen annually. In 2011, a partnership between the Angola MoH, Chevron Corporation and Baylor College of Medicine led to the launch of an NBS program focused on capacity building and local management. A 2013 report from this project indicated that 36,453 infants were screened. The screening results showed 21.03% with SCT, 1.51% with SCA, and 0.019% with sickle cell disease SC (SCD-SC) (McGann et al. 2013). A majority of affected infants (54.3%) were successfully contacted and brought to clinical care. Compliance in the newborn clinic was excellent (96.6%). The calculated first-year mortality rate for babies with SCA compared favorably to Angola's national IMR. This NBS program has now expanded to 11 centers in Luanda and 11 centers in northern Cabinda province, and has tested over 300,000 newborn dried blood spot samples. A cost-effective analysis in 2015 (McGann et al. 2015) found the NBS program to be cost-effective; however, the downstream medical costs, including acute care, were not included in the report. Despite this success, SCD NBS is still not present in the 16 other provinces outside of Luanda/Cabinda.

Benin (Republic of Benin) A SCD NBS program has existed for 26 years in Benin's largest city, Cotonou (Rahimy et al. 2009). The pilot strategy implemented was a targeted approach based on identification and active information and education of pregnant at-risk-women. 'At-risk' was defined as being a carrier of either hemoglobin (Hb) S or Hb C, which was determined by traditional hemoglobin screening during their pregnancy. Women considered 'at-risk' were offered voluntary enrollment into the NBS and follow-up programs. During the initial period, NBS was requested by 79.3% of the educated at-risk-women, of whom 81% requested the result of the test. Eighty-five percent of eligible SCD babies were effectively enrolled into a SCD comprehensive care program (CCP), which included intensive socio-medical intervention tailored to local constraints in order to overcome barriers to health care and to ameliorate the disease course. In the fourth year of the program, more at-risk-mothers became aware of its existence and brought their children for testing. Enrollment also was allowed for children diagnosed as a result of acute pain events and led to early diagnosis of SCD in many toddlers. Initial data analysis indicated a reduction in both morbidity and mortality and satisfactory physical growth among

most patients. The under-five mortality rate reported was 15.5 per 1000 in the series of children studied with SCD, which was 10 times lower than the overall under-five mortality rate at the time. About 80% of enrolled children were regularly followed after 5 years.

Democratic Republic of Congo (DRC)] A pilot SCD NBS program was initiated in the area around Kinshasa in 2006 (Tshilolo et al. 2009). Interestingly, aside from Hb S, the program found an absence of variant hemoglobins and also showed that the SCT frequency was similar across all provinces in the country. More recently, a comprehensive newborn and early screening program was implemented by collecting dried blood spots from newborns and children under 5 years of age from maternity and primary healthcare centers. The program was focused on raising awareness, early case identification, early access to adequate preventative care, and training of medical professionals. Almost 150,000 infants were screened over a 10-year period. The screening program has also identified other hemoglobinopathies, including alpha thalassemia. Data indicate that children with SCD are living longer as a result of NBS (because of early penicillin prophylaxis) and early vaccinations. The most pressing need identified is treatment for older children with SCD, which includes access to therapies such as hydroxyurea (Tshilolo et al. 2019).

Ghana (Republic of Ghana) NBS for SCD began in Ghana in 1993, funded by a research grant from the NIH in collaboration with Ghana's MoH and other institutions in Ghana (Ohene-Frempong et al. 2008). In 2010, the NBS project was adopted by the Government of Ghana to scale it to a national program. Newborns are now screened using a heelstick at the place of delivery or at the first well-baby visit at 40 facilities in Kumasi and Accra plus two rural sites. A central NBS laboratory performs testing with isoelectric focusing (IEF). Screen positive babies are tracked by telephone or home visit and referred to a sickle cell clinic. At the clinic, the diagnosis is confirmed, the infant is placed on penicillin prophylaxis, and comprehensive management is initiated. All data have been managed since program inception using a national registry. By the end of December 2018, the program had screened 498,618 babies of which 8511 (1.71%) had been diagnosed with SCD. Case findings include 4385 children with SCA, 4040 with SCD-SC, and 86 with SCD S-beta thalassemia. More than 6750 of the babies with SCD have been referred for medical management to the Kumasi Centre for SCD at Komfo Anokye Teaching Hospital.

Of particular interest in Ghana has been creation of a mobile application (App), which is used to enhance program efficiency. Screening site information and the baby's demographic data are entered directly into the App by screening nurses and these data are submitted electronically to the screening laboratory. When the newborn's blood specimen arrives at the laboratory, the demographic data are integrated with the screening test results and reported back to the screening site immediately after testing. In this way, nurses are able to start tracking babies immediately resulting in more efficient follow-up and faster time to treatment. Data from the App are used to generate and send weekly and monthly reports on screening site performance via email. The NBS program also has established a SCD genetic counseling training and certification program for health workers (Treadwell et al. 2015; Anie et al. 2016) and a similar program for non-health workers (e.g., teachers) is planned. Both the mobile App and the counseling program are models adaptable to other African NBS programs.

Malawi (Republic of Malawi) Based on gross national income, Malawi is the second poorest country in Africa, only exceeding Burundi (Malawi GNI per capita 1962–2019). A recent decrease in the U5MR has been observed primarily due to decreases in infectious diseases secondary to vaccines and other interventions (Table 1). The decreasing infectious disease burden should result in an increased contribution of non-communicable diseases to infant morbidity and mortality. However, SCD has not yet been realized as an important contributor to the IMR mortality rate in Malawi and no NBS program currently exists. A surveillance study on the prevalence and distribution of sickle cell trait (SCT) and SCD in the central region districts of Malawi has been conducted in partnership with the Malawi MoH, the University of North Carolina's Project Malawi, and Cincinnati Children's Hospital. Using newborn dried blood spots, 10,000 samples were obtained and tested for hemoglobinopathies using IEF to confirm hemoglobin prevalences. Partnerships with the Malawi MoH's human immunodeficiency virus (HIV), early infant diagnosis (EID), and immunization programs allowed for more efficient use of logistics. Approximately 7% of samples showed SCT. Most infants identified with SCD were found and referred to a SCD CCP. Future challenges include capacity building for health care provider education and laboratory training.

Mali (Republic of Mali) A pilot study in 2010–2012 considered the value of screening babies for SCD and other hemoglobinopathies born to mothers with a positive Emmel screen during pregnancy (Diallo et al. 2018). Study results disproved the value of this manner of targeted NBS since the Emmel screen shows only the presence of Hb S in adults and does not detect Hb C or other hemoglobins. Aside from this study, no information on other NBS has been reported. Among other maternal and child health issues, both a high IMR and high U5MR currently exist in Mali (see Table 1).

Morocco (Kingdom of Morocco) As previously noted, the Morocco MoH hosted the first MENA regional NBS conference in Marrakech in 2006. Emphasis at this meeting was on

screening for CH because of its increased importance in the north and northeast of Africa where SCD is less of a problem. Interest in NBS for CH in Morocco has now resulted in its inclusion in the Morocco MoH national action plan (Plan Santé 2025) to improve the continuum of health care throughout the kingdom (Morocco Ministry of Health 2018). As NBS infrastructure develops, expansion over time to include other conditions such as SCD is a natural program progression. While NBS has been a consideration as genetics and genomic medicine progresses within the country, its development has been slow due to complexities within the healthcare system and the lack of trained genetics personnel (Belhassan et al. 2016). This *First Pan African Workshop on Newborn Screening* is a continuing effort to formalize sustainable NBS in Morocco and to examine the potential for adding SCD to any screening panel under consideration.

NBS and identification of couples at risk for a child with SCD are considered a first step in decreasing the adverse effects of hemoglobinopathies. Epidemiologic studies have identified the highest incidence of SCD in the Northwestern region of Morocco. A study of SCD patients from 2011 to 2015 found that SCA was much more prevalent than SCD-SC (81.25% vs. 2.08%) (Hafiani et al. 2017). Implementation of NBS and development of a national action plan to improve the quality of SCD management were identified and recommended as ways to improve disease outcomes.

A pilot NBS α-thalassemia study in 2015–2016 included 1658 newborns and showed, in addition to other hemoglobinopathies, an estimated prevalence of 0.96% for α-thalassemia with six different alleles identified (Laghmich et al. 2019a). The heterogeneity of the different α-globin alleles reflects the anthropological history of the country as a migration crossroads between Europe and sub-Saharan Africa and helps to explain the variability of α-thalassemia severity across Morocco. This study also suggested development of a nationwide screening strategy.

Consanguinity is integral to the social life of Morocco and is estimated to occur in 34% of all marriages, lower than most other countries in the region. A 2016–2018 study of consanguinity in the hemoglobinopathy population found, however, that consanguinity in the parents of hemoglobinopathy patients was much higher (50.25%) than in the normal population. This study also documented that, while high, this is a 14.22% decrease from the previous generation, presumably due to improving genetic information and education (Laghmich et al. 2019b).

Nigeria (Federal Republic of Nigeria) Although a cord blood screening pilot was initiated in Nigeria in 1986 (Kulkarni and Jekeme 1986), the first serious NBS pilot for SCD began with a study of 644 babies in one hospital in Benin City in 2000 (Odunvbun et al. 2008). Laboratory testing was done in collaboration with the research laboratory at the National University of Benin. NBS was accepted by 99.7% of the mothers to whom it was offered and the prevalence rate for SCD was found to be 3% (2.8% SCA, 0.2% Hb SC). Study recommendations included the addition of NBS to the ongoing Bacillus Calmette–Guérin (BCG) immunization program.

Since that time, a number of NBS projects have been conducted in Nigeria. In 2010–2011, a study of 10,001 infants and children aged 5 and younger in the north and northwest districts of Nigeria was conducted to consider the use of high performance liquid chromatography (HPLC) for NBS. Similar to other studies, the prevalence of SCD was high (2.69%). The presence of beta-thalassemia in the population was also confirmed in this study (Inusa et al. 2015).

In 2012, six government-sponsored MDG SCD Centers were established for NBS (one in each zone of the country) and equipped with HPLC systems for NBS. The high cost of reagents was a major deterrent to their successful operation (Nnodu 2014); however, linking to the country's immunization program reduced some of the NBS costs. Additionally, use of point-of-care NBS technology has been piloted, particularly in Gwagwalada Area Council, Abuja (Nwegbu et al. 2017; Nnodu et al. 2019). Since NBS is new, parents often do not believe their infants, who appear quite healthy at birth, have SCD. This underscores the need for more education on NBS to improve public awareness for the population and health care providers.

In 2017, a retrospective 4-year review of the records of the screening laboratory in a tertiary care facility in Anambra State in Southeast Nigeria examined the experiences of NBS with IEF and sought to determine the local prevalence of SCD (Ejiofor et al. 2018). A total of 4961 babies during 2013–2017 were evaluated. SCT was detected in 24.3% of the samples, but only 0.32% was found to have SCA, much lower than in other studies. The study leaders suggested several possibilities for this lower rate including higher literacy in the region, increased sickle carrier screening and couple's counseling, and religious influences.

Sierra Leone (Republic of Sierra Leone) Despite tremendous health issues created by the Ebola virus epidemic in 2013–2016, newborn, child, and adolescent health remain as a government priority and a strategic plan for preventing and controlling anemia 2018–2025 is in place (Sierra Leone Ministry of Health and Sanitation 2018). NBS for SCD is specifically noted one of the ways to substantially reduce both the IMR and the U5MR. In 2017, the first specialty clinic for SCD was established in collaboration with the University of Cincinnati (U.S.), Jericho Road Community Health Center (a U.S. federally qualified healthcare center), and Sickle Cell Carers Awareness Network (SCCAN—a local patients' advocacy group). A NBS pilot was begun in January 2018 using a point-of-care screening device. Newborns testing positive are enrolled in an Under Five Wellness Program where they

receive free treatment. Data are being gathered in a 2-year project which will be used to persuade the government of the value of NBS (International Society of Nurses in Genetics 2019).

Tanzania (United Republic of Tanzania) The U5MR in Tanzania decreased by 57% between 1980 and 2011 providing an opportunity to revise health policies to continue this trend. Tanzania has the 4th highest prevalence of SCD in the world, but it lacks a national NBS program. Health policy considerations have identified NBS (including penicillin prophylaxis) and pneumococcal vaccinations as the best way to reduce mortality from SCD in Tanzania (Makani et al. 2011; Makani et al. 2015). In 2009, an initial pilot study for NBS was conducted at Muhimbili National Hospital in Dar es Salaam. Of 2053 screened, approximately 13% had SCT and approximately 0.6% had SCA. Highest incidences were among patients with parents from the Coastal Regions or Lake Zone and lowest incidences among patients with parents from the Northern Region (Rwezaula et al. 2015). Another more recent NBS pilot in 2015–2016 from Muhimbili University of Health and Allied Sciences reported on 3981 newborns. Thirty-one babies were identified with SCD (0.8%), of which 28 (90.3%) were subsequently enrolled in a SCD CCP (Nkya et al. 2019). A larger unpublished study has now been completed in the northern Lake Zone, which includes over one-third of the population. This surveillance study was conducted in partnership with Bugando Medical Centre and Cincinnati Children's Hospital, which equipped the lab, trained the staff, and provided study oversight. Over 17,000 dried blood spots, collected in the U.S. Centers for Disease Control and Prevention (CDC)-sponsored HIV EID program, were screened using IEF. The SCT prevalence observed was > 20%, with the prevalence approaching 30% in some districts. The prevalence of SCD was > 1.2%. This project also looked at co-morbidity with HIV and malaria.

Uganda (Republic of Uganda) A recently completed nationwide surveillance study in Uganda, in collaboration with the HIV EID program, showed prevalences of 13.3% and 0.7% for SCT and SCD, respectively, higher in the central and northern regions and lower in the southwest (Ndeezi et al. 2016; Kiyaga et al. 2018). There is a high early mortality rate with 80% of SCD patients not living to see their 5th birthday. Before the Uganda Sickle Surveillance Study (US3), challenges included (1) limited data regarding the SCD burden; (2) lack of knowledge about SCD among healthcare workers and the public; (3) failure to recognize SCD as a non-communicable disease; (4) lack of a national strategy related to SCD, including no NBS and lack of access to care; and (5) associating SCD with witchcraft and curses. Following completion of the surveillance study, the MoH and its partners initiated prospective NBS in some of the high burden districts. This targeted NBS, which ran from 2015 to 2018, tested 163,334 babies and found a prevalence of SCT of 15.5% and SCD of 1.3%. The slight increased prevalences were attributed to targeting the high burden districts. Study partners included the Uganda MoH, Makerere University, the Uganda Central Public Health Laboratories, Cincinnati Children's Hospital, and the HIV EID program (Kiyaga et al. 2019). Cincinnati Children's Hospital equipped the lab, trained the staff and provided study oversight. This study confirmed that SCD is a major public health concern with an estimate of 16,695 SCD births per year. As part of the education efforts, teams of local physicians and public health experts were trained and community awareness campaigns were launched. Educational efforts included cultural leaders, politicians (resulting in an oral presentation of a statement to parliament), and traditional healers, who had previously claimed to heal SCD. Programs for the engagement of religious leaders were also initiated that emphasized pre-marital testing and counseling.

Other topics discussed

NBS has been defined as a six-part system that includes education, screening, short-term follow-up, diagnosis, management, and evaluation (long-term follow-up) (Therrell 2001). Education is particularly important when programs and ideas are new and in relatively low literacy settings. A number of studies in various settings in Africa have demonstrated the lack of knowledge about NBS and the specific diseases screened, not only among parents (Obed et al. 2017; Aderotoye-Oni et al. 2018) but also among health professionals (Adegoke et al. 2018). Family advocacy experts from the US discussed not only the need for parent and professional education, but also the need for parent involvement in policy- and decision-making activities related to NBS (Evans et al. 2018; Forman et al. 2013). Parental involvement becomes even more critical as patients detected by screening are considered for enrollment in research studies. Since June 2010, there has been increasing interest in African research projects that would enhance the ability to apply genomic and epidemiologic approaches to determinants of chronic and infectious diseases in Africa. The Human Heredity and Health in Africa (H3Africa) initiative has funded a number of different studies that have directly impacted the possible implementation of NBS for SCD (H3Africa Consortium et al. 2014; Wonkam et al. 2015). In low literacy settings, such as much of Africa, educating and involving parents in the decision-making processes related to research participation are challenging and may require innovative approaches (Bukini et al. 2019; Dennis-Antwi et al. 2018; Ojewunmi et al. 2019).

In 2009, WHO "recommended that a policy of universal neonatal screening be adopted in all countries and communities with available rehabilitation services and that the policy be

extended to other countries and communities as rehabilitation services are established" [World Health Organization 2009]. While traditional NBS refers to tests from heelstick blood placed on a special absorbent paper, dried, and submitted to a laboratory for screening tests, other types of NBS at the point-of-care also exist. In Africa, as NBS is becoming more widespread, there is growing interest NBS for critical congenital heart disease (CCHD) using pulse oximetry point-of-care testing (Glidewell et al. 2019). Workshop participants were given the opportunity to learn more about the importance of screening and to observe the specific screening techniques with a hands-on demonstration from screening experts that emphasized lessons learned from those already screening (Oster et al. 2016).

Conclusion

Ten primary challenges to implementing sustainable NBS in low- and middle-income countries previously have been identified: planning, leadership, education, medical, technical, and logistical support; policy development, administration, evaluation, and sustainability (Padilla et al. 2010; Therrell and Padilla 2014). Additionally, a model for regional NBS collaboration in a low- and middle-income economy adaptable to Africa has been described (Padilla et al. 2012) along with details for establishing a NBS system and assessing its component parts for quality improvement (Therrell and Padilla 2005; Therrell et al. 2010). The NBS working group of the Africa Sickle Cell Research Network (AfroSickleNet) has recently reviewed current NBS projects in sub-Saharan Africa and published a comprehensive report on challenges to implementing widespread NBS (Hsu et al. 2018). In Nigeria, steps have already been taken to systematically evaluate the process steps to successful NBS implementation (Inusa et al. 2018) and this may serve as a model for other African countries.

As reflected in the country summaries, NBS programs across Africa vary in their scope, history, and success. Some programs have been established for many years and some are only in their infancy. NBS sustainability requires integration of all system components within local (jurisdictional) geographic, economic and political constraints, and as such, relies on local MoH endorsement and support (McCabe et al. 2002; Therrell et al. 2015b). Several participating countries noted their successful sharing of resources with ongoing immunization programs or HIV early intervention programs as the key to NBS program implementation. Building NBS systems provides opportunities for infrastructure development that can allow NBS to expand to include not only SCD and other hemoglobinopathies, but also other screenable congenital conditions. Some countries are already including future NBS expansion once a sustainable infrastructure is in place (Yarhere et al. 2019). Reliable cost estimates are also essential to MoH policy considerations. A 2016 comprehensive study predicts high cost effectiveness in 24 of the 47 sub-Saharan African countries studied and probable cost effectiveness in 10 others. In that study, NBS for SCD was found to be generally cost effective when the prevalence of SCD exceeded 0.2–0.3%, although cost effectiveness was also possible to achieve in some situations where the incidence was lower (Kuznik et al. 2016).

The prevalence of SCD across sub-Saharan Africa is the highest in the world and yet there are only a few organized NBS efforts ongoing with comprehensive healthcare still developing. Workshop participants acknowledged the importance of partnerships with more established programs both for NBS implementation and research. Participants also recognized the importance of the *First Global Congress on Sickle Cell Disease* (Ghana in 2010) (Odame et al. 2011), in drawing attention to the problems of SCD in Africa and around the world. They supported the ideas recently put forth by the U.S. March of Dimes and others regarding pathways for NBS progress (Hsu et al. 2018; Howson et al. 2018). As an acknowledgment of the commitment of participants and faculty to continue moving forward to implement sustainable NBS for SCD and other conditions in Africa, participants concluded the meeting by agreeing to the *2019 Rabat Declaration on Newborn Screening* in commitment to their solidarity of purpose (see Appendix 1).

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Conflict of interest The authors declare that they have no conflict of interest.

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Appendix 1 2019 Rabat Declaration on Newborn Screening

Preamble

The *First Pan African Newborn Screening Workshop* occurred in Rabat, Morocco, June 12–14, 2019 and included attendees from 11 African nations: Morocco, Angola, Benin, Democratic Republic of Congo, Ghana, Malawi, Mali, Nigeria, Sierra Leone, Tanzania, and Uganda in addition to countries in Europe, North America, and Asia/Pacific. International experts from around the world and in the region provided the human resources necessary to accomplish the meeting's goal of exploring new knowledge and developing meaningful collaborations for improving child health by implementing sustainable newborn screening programs throughout Africa.

Early identification can be facilitated by screening newborns shortly after birth for congenital or genetic disorders that can result in major disabilities, when not managed early. In addition to benefits for the child and family, there are also significant benefits to society when early treatment can lead to productive individuals with a meaningful life whose long-term disability is not a lingering burden to families and society. Sickle cell disease (SCD) is a group of conditions, common in Africa, for which early identification and interventions lead to significantly improved health outcomes. The high prevalence of undiagnosed non-communicable diseases, including SCD, invariably contributes to excess mortality in children less than 5 years of age (Wastenedge et al. 2018). Each year, approximately 400,000 babies worldwide are born with SCD (Weatherall 2011), with more than 75% in sub-Saharan Africa, where it is estimated that 50 to 90% die before their 5th birthday (Grosse et al. 2011). The World Health Organization (WHO) and United Nations have designated SCD as a global public health problem. In addition to SCD, other important conditions to be considered by countries developing newborn screening programs include congenital hypothyroidism, phenylketonuria and the thalassemias.

In order to begin to address ways in which newborn screening for SCD and other congenital or genetic disorders may be established, we have sought to identify challenges to implementation of sustainable newborn screening programs and the ways in which our collective engagement can further our efforts to improve child health across the African continent. With regard to these issues, Workshop participants formulated the *2019 Rabat Declaration on Newborn Screening*.

Declaration

Recognizing that newborn screening programs must function within local public health systems governed by political and societal realities in a given context;

Recognizing that there may be a need for substantial adaptations tailored to the local realities in order to accomplish the ultimate goals of early identification, treatment and enrollment into comprehensive care;

Recognizing that sub-Saharan Africa accounts for over 75% of the global SCD burden, and appreciating that a newborn screening panel can include many different congenital conditions,

- We hereby affirm that hemoglobinopathy screening should be the major focus of newborn screening programs within sub-Saharan Africa;

- All countries should endeavor to establish a NBS program within the context of their national health care system.

We have identified the following activities to promote sustainable newborn screening across Africa:

- Engagement with Ministries of Health to boost awareness of need for newborn screening; to request endorsement of newborn screening; and to ensure alignment with country goals;
- Engagement with global health organizations—e.g., WHO and Gavi (the Vaccine Alliance) to establish collaboration opportunities for sharing resources;
- Engagement with manufacturers of diagnostic equipment and supplies to collaborate with countries to promote and lower costs for newborn screening;
- Engagement with pharmaceutical companies regarding treatment options for affected babies and children, especially low-cost antibiotics, and generic hydroxyurea for SCD;
- Exploration of different screening methodology options, such as point-of-care diagnostic technologies to lower cost and program efficiency;
- Establishment of and prioritizing a minimum list of common conditions to screen infants in Africa in the short term with SCD as the focus;
- Establishment of country-based and community-based associations working on newborn screening;
- Training of healthcare workers (doctors, nurses, health educators, genetic counselors, etc.) and public health laboratorians about newborn screening and genetics;
- Public education about newborn screening and SCD, in particular;
- Partnership with international maternal and child health, community-based, affected-family and public health organizations that have resources to assist;
- Continued presentation and publication of pilot screening results;
- Inclusion and education of community members and families as stakeholders in decision-making processes.
- Setting up data management systems within the newborn screening programs that can enable evidence-based decision making and longitudinal tracking of SCD patients.

The successful introduction and expansion of newborn screening in Africa will require careful planning and advocacy. Some pilot programs exist with variable approaches, but sustainability requires support from country Ministries of Health (MoH). Helpful partnerships with key stakeholders are needed, including affiliations with other programs of MoH (e.g., maternal and child health, immunization, health education, etc.). In addition, developing collaborative partnerships with other countries for laboratory and clinical support could be utilized.

We have identified the following general challenges to implementing newborn screening for sickle cell diseases (SCD) and other conditions (thalassemias) in Africa:

- Lack of comprehensive national newborn screening programs;
- Lack of newborn screening policies and guidelines;
- Lack of well-trained health workers;
- Lack of the necessary laboratory infrastructure and associated systems, such as sample transport and laboratory information management systems, to enable testing and dissemination of results;
- Lack of stable, consistent and sufficient funding.

We recognize the need for establishing collaborations and networks to facilitate the development of sustainable newborn screening programs in all countries.

In order to develop such a collaborative network in Africa, and to move newborn screening forward in our respective countries, we pledge to:

- Participate in increased communication efforts across the continent including a regional website, biennial regional meetings and annual meetings to share resources and assess each country's progress;
- Develop smaller focused topic groups to address important issues (e.g., training, clinical standards of care);
- Establish a national advisory committee (including representatives of advocacy groups and affected-family organizations) for newborn screening planning;
- Work with the MoH to gain national support and to address other important issues (e.g., finances, integration with other MoH programs);
- Ensure standardization of data through the encouragement of the implementation of the common data elements for newborns to facilitate sharing and exchange of data within the continent as well as with the rest of the world;
- Seek opportunities to train the next generation of health care and public health professionals in new technologies as applied to newborn screening (e.g., molecular genetic methods);
- Work with affected families and MoH to develop, provide and continually assess templates for culturally-sensitive, multi-media educational materials, and requisite well-trained health educators.

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