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## Building capacity for birth defects surveillance in Africa: Implementation of an intermediate birth defects surveillance workshop

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### Abstract

Each year around the world, it is estimated that 300,000 neonates are born with a neural tube defect. Many countries, however, are still lacking comprehensive birth defects surveillance registries. Comprehensive birth defects surveillance systems can help countries understand the magnitude and distribution of the problem. These systems can also provide information about biological, contextual, social and environmental determinants of birth defects. This information in turn can be used to identify effective and implementable solutions, and to evaluate prevention and management strategies to improve quality performance. This paper summarizes the development and implementation of an online pre-course training and in-person surveillance workshop conducted between 2014 December and 2015 March for representatives from six African countries. Feedback given by participants provided valuable lessons learned that can be applied to subsequent trainings and workshops.

### Background

The World Health Organization (WHO) estimates that approximately 3.2 million birth defect-related disabilities and an estimated 276,000 newborn deaths occur every year [1].

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Among the most common and severe [1] of these birth defects are neural tube defects (NTD), a group of serious birth defects of the brain and spine. Each year around the world, it is estimated that 300,000 neonates are born with an NTD [2]. For those who survive, there is often the need for lifelong medical care and intervention. There is evidence showing that consuming folic acid prior to, and during the early stages of pregnancy, can prevent the occurrence and reoccurrence of the majority of NTDs [3–5]. Nonetheless, an important proportion of the world's industrially milled wheat and maize flour and rice remains unfortified [6]. Further, in some settings, public health programs with daily or intermittent provision of supplements containing folic acid for women of reproductive age remain challenging to implement or sustain [7].

Many countries are seeing the results of successful interventions aimed at decreasing infant mortality due to diarrheal and infectious diseases. As a result, however, under-5 mortality due to birth defects is becoming increasingly more visible [8]. In September 2000, leaders from around the world drafted the United Nations Millennium Development Goals (MDG) in an effort to improve health outcomes [9]. MDG 4 aimed to reduce the under-5 child mortality rate by two-thirds by 2015. Moreover, in May 2010, the 63rd World Health Assembly passed a resolution on birth defects calling upon countries “*to prevent birth defects wherever possible, to implement screening programmes, and to provide ongoing support and care to children with birth defects and their families*” [10]. More recently, the United Nations post-2015 Sustainable Development Goal 3 calls for countries to “*Ensure healthy lives and promote well-being for all at all ages*” [11]. Together, these calls to action have provided countries with a goal that must incorporate specific attention to the impact and prevention of birth defects.

According to a recent report released by the World Bank, the highest rates of child mortality occur in the sub-Saharan Africa region [12]. Further, birth defects prevalence in the African region ranges from 5.2 to 75.4 per 10,000 births [13]. Although the majority (94%) of severe birth defects occur in low- and middle-income settings and in settings often associated with poor maternal nutrition and/or exposure to infection and teratogens [1], there remains a paucity of data in these countries [2, 13]. A systematic review of published global NTD data from January 1990 through July 2014 found that only about 40% of the 194 WHO Member States had any published NTD prevalence data [13]. Among these, the percent reporting within each region was as follows: African (8/47; 17%), Eastern Mediterranean (12/21; 57%), European (26/53; 49%), Americas (15/35; 43%), South-East Asian (4/11; 36%) and Western Pacific (9/27; 33%). The majority of the data was from surveillance or registry systems only in the American and European regions [13]. This highlights the need for sustainable birth defects surveillance systems that can provide countries with an accurate estimate of the burden of birth defects, and that can be used to advocate for prevention and care and to also evaluate the impact of the actions taken. Comprehensive birth defects surveillance systems can help countries understand the magnitude and distribution of the problem. These systems can also provide information about biological, contextual, social and environmental determinants of birth defects. This information in turn can be used to identify effective and implementable solutions, and to evaluate prevention and management strategies to improve quality performance.

## Program description

In 2010, the U.S. Centers for Disease Control and Prevention (CDC)'s National Center on Birth Defects and Developmental Disabilities (NCBDDD) launched a global initiative to reduce morbidity and mortality due to folate-sensitive NTDs. This initiative, known as Birth Defects COUNT (Countries and Organizations United for Neural Tube Defects Prevention), is currently focused on two regions, South-East Asia and East Africa, and includes three main objectives to advance and support NTD prevention efforts: science, partnerships, and public health policy.

The science objective addresses the importance of building and strengthening public health capacity for birth defects surveillance and epidemiology. As part of this work, the authors of this manuscript formed a partner group to develop training tools to help meet this need. Over the past few years, we have conducted birth defects surveillance workshops for medical officials and health care professionals from multiple countries within the African region. These basic-level workshops have focused on increasing awareness of the importance of birth defects surveillance, the need for establishing a comprehensive program to collect accurate and timely data, and the utilization of these data to plan for, implement and evaluate birth defects prevention programs, and the need to improve quality of life for those affected by birth defects through early detection and referral to services.

As a next step, we carried out an intermediate level workshop targeted to health professionals in African countries. First, we developed and disseminated a needs assessment tool to 30 participants of previous basic-level workshops from 12 African countries: Ethiopia, Morocco, Tanzania, Kenya, Nigeria, Malawi, Mozambique, Rwanda, Uganda, Madagascar, South Africa and Togo. The goal of the assessment was to identify countries that needed to establish birth defects surveillance, to assess the feasibility of implementing a program within a short time frame, and to determine what respondents perceived as the immediate next steps in this process. We selected representatives from countries that were actively moving forward with the development of a birth defects surveillance program to participate in this regional intermediate workshop. We conducted the workshop between 2014 December and 2015 March for representatives from six African countries: Kenya, Malawi, Nigeria, Uganda, Rwanda and Tanzania.

The workshop consisted of several components: an online pre-course training; the development, submission, and review of a draft protocol and standard operating procedures (SOP); attendance at an in-person surveillance workshop; evaluation of the online pre-course training and in-person surveillance workshop; and one year of follow up and technical assistance provided by the partner group. The primary aims of this workshop were to help participants develop, revise and/or refine country protocols for birth defects surveillance, and to provide a forum for discussion about how to address anticipated challenges to implementing the surveillance systems. Upon completion of the workshop, the participants were expected to begin the birth defects surveillance implementation process in their countries of work.

### Online pre-course training

We developed a curriculum for a 7-week online pre-course training, which included weekly recorded lectures with associated knowledge tests, and a forum for discussing issues and questions about birth defects and birth defects surveillance. The training was hosted on a web platform and access to the site was provided to participants at registration.

The lectures included instruction on the classification of birth defects, and detailed presentations on specific birth defects and risk factors. A review of the primary training tools used to conduct the surveillance workshop – the *WHO/CDC/ICBDSR Birth defects surveillance: A manual for programme managers* [14], *WHO/CDC/ICBDSR Birth defects surveillance: Atlas of selected congenital anomalies* [15], and *WHO/CDC/ICBDSR Birth defects surveillance training: Facilitator's guide* [16] – was also conducted. At the end of each lecture, there was a link to a knowledge test. These knowledge tests were used to assess to what extent the participants understood the lectures and could apply their knowledge to simple scenarios. Participants had three opportunities to take each knowledge test to improve their knowledge and demonstrate understanding and mastery of the content.

### Protocols

Prior to attending the workshop, each participating country was required to submit drafts of their existing birth defects surveillance protocol and SOP. Staff from the partner group reviewed each protocol and provided detailed feedback to participants for revision. The participants were asked to bring drafts of their protocols and SOPs to the workshop for further review and discussion.

### In-person surveillance workshop

The in-person surveillance workshop was held in a lecture hall at Arusha Lutheran Medical Centre, in Arusha, Tanzania on 2015 March 2–6 (Appendix A). During the workshop, several topics were reviewed and expanded, including the topics presented in the online pre-course training. Specific attention was devoted to issues of data quality, analysis, and interpretation. Participants also learned how to use a data collection template, and how to classify and code birth defects. Importantly, extensive time was allotted for country representatives to develop and refine their program's protocol, and to participate in small and large group discussions about anticipated challenges and opportunities for utilizing data to launch prevention efforts. Finally, participants had the opportunity to go on a site visit, guided by the hospital's surgeon, to the hospital's clinic for children with disabilities, which included several children with spina bifida (an NTD).

### Follow-up and technical assistance

One of the goals of bringing teams from different countries to the workshop was to help foster program networks. At the workshop, the participants began the discussion about developing a network to provide one another with support and guidance as they move forward with the implementation of their protocols in their home countries. The network has continued to be active via email after the end of the workshop.

Following the in-person surveillance workshop, all six countries submitted revised protocols for review and feedback. We have committed to providing one year of technical assistance to each country, including giving guidance for improving protocols, assisting workshop participants in addressing emerging challenges to implementation, and providing overall support. It is anticipated that three countries will be ready to implement their protocols by the end of 2015.

## Evaluation

Participants were asked to evaluate the online pre-course training and the in-person surveillance workshop. These evaluations provided lessons learned and areas for improvement for future workshops.

### Feedback, online pre-course training

Most participants indicated that the online pre-course training (referred to as the online pre-course platform by participants) was a useful component that “helped provide context in advance of the workshop”. They described the videos as “interactive” and “educational”.

- “This (the videos) was a really useful component of the online pre-course platform.”
- “The videos in the online pre-course platform were excellent. They were very interactive and did a great job of describing the characteristics of various birth defects.”

They also indicated that the online pre-course training increased their knowledge and understanding of “the importance of surveillance and the principles of setting up a system”, “the epidemiology of birth defects, especially from a global perspective”, and “the characteristics of various birth defects”. Finally, the online pre-course training was helpful because it “ensured all participants came to the workshop with a similar background on birth defects and birth defects surveillance”.

- “The online pre-course platform made the workshop easier to follow because I had time to get to know the material in advance.”
- “The online pre-course platform was a helpful addition to the workshop. It provided baseline information about birth defects surveillance which helped provide context in advance of the workshop training.”

### In-person surveillance workshop

Participants also evaluated the in-person surveillance workshop. Comments were very positive on all aspects of the workshop. Participants found the small group work, the open discussions, and the questions-and-answer discussion time to be the most enjoyable and helpful aspects of the workshop.

- “I really enjoyed the small group work on the protocol and preconception health. The workshop did a great job addressing issues that affect Africa’s birth defects surveillance efforts.”

- “I most enjoyed the open discussion on important issues, such as preconception care, prevention measures, planning for data collection, and coding birth defects. The Q&A time was also helpful in learning more about these topics.”
- “The interactive nature of the workshop was very enjoyable and allowed for collaboration among the participants.”

Participants also appreciated the expertise of the facilitators, and the amount of planning that went into the preparation and execution of the course.

- “The facilitators were a vast source of knowledge and experience and I really enjoyed learning from them.”
- “The facilitators had great breadth and depth of knowledge on the topics covered.”
- “The workshop was well planned and the facilitators were full of excellent information. This experience will be useful as we set up birth defects surveillance systems in our countries.”

The “simple language” of the course was also crucial to some participants’ understanding of the material, as was the ability to present the information in a way that was relevant to participants from a variety of African countries. Participants found the workshop to be very useful in setting up birth defects surveillance systems in their countries.

- “The workshop had a multinational approach and helped address issues about integrating the material in-country which was very helpful.”
- “This experience will be useful as we set up birth defects surveillance systems in our countries.”
- “I also enjoyed the focused discussion on country-specific protocols.”

### Improvement

The participants also provided feedback on how the course could be improved. One particular challenge noted was the need for additional time to complete the online pre-course training. The modules were extensive and required focused and lengthy attention by the participants, who were also employed full-time. Not only was this taxing on the participants’ time, but also required consistent electricity and internet access, which was a challenge for some participants.

- “Give people more time since we have to find extra time for the modules.”
- “Increase the (open) period of the modules. One week per modules was not enough because in remote areas internet is not reliable.”

As part of the online pre-course training, the participants could post questions in an open forum. However, some participants did not feel comfortable posting questions to a forum that could be viewed by other participants. Perhaps for this, or other reasons, the question forum was not often used.

- “Questions and Answers infrequently used.”
- “The forum appeared inactive.”

Internet connectivity was another challenge of the online pre-course training. Many participants noted that they had difficulty participating in some parts of the pre-course, particularly viewing videos.

- “Videos where internet is a problem are not useful.”
- “Videos were not opening adequately.”
- “Navigating from one page to another took a long time.”

Challenges for the in-person component of the workshop dealt mostly with a perceived lack of time. Participants wanted additional days for the workshop, more time for discussion, more time with faculty, and additional time to conduct site visits to referral and treatment centers for individuals with birth defects.

- “More exercise and small group discussion.”
- “To visit one of the hospitals treating complications related to birth defects and see how they manage patients.”
- “Timetable should include practical sessions at least one day to visit (the hospital) to see actual babies and coding.”

One participant noted difficulty integrating some of the services provided by the treatment center that was visited into those in his/her home country where the facilities are not currently equipped to provide the same level of care.

## Lessons learned

Although the lessons learned we describe in this section refer to those we can apply to future birth defects surveillance workshops, we also feel these lessons can be relevant to others seeking to develop and implement workshops on a variety of topics.

The following list provides the primary lessons learned from this birth defects surveillance workshop:

- *Provide an online pre-course training to maximize the time available for the in-person surveillance workshop.* Earlier workshops that did not utilize an online pre-course training had to devote at least one full day to background information to ensure that all participants were starting the workshop with the same baseline level of knowledge about birth defects and surveillance. By utilizing an online pre-course training, this background information would be provided prior to the in-person surveillance workshop, and allow longer time for learning and understanding. The in-person surveillance workshop would build on this common foundation with a focus on more practical activities related to the design and implementation of the surveillance systems. Further, the use of forums in the online pre-course training allowed for the trainees and faculty to virtually meet each other before the in-person surveillance workshop, giving them a sense of common purpose.

- *Engage groups that are already committed to the development of a birth defects surveillance program and have local support to launch a program.* In our experience, securing support for a surveillance program in-country can take a large amount of time and effort. This groundwork should be laid in each participating country before attending the workshop. The focus of an intermediate workshop, then, is not on how to secure support, but rather on addressing practical implementation issues – what do countries need to move toward implementation of a protocol quickly and effectively?; what are some areas of confusion that still exist and how can workshop facilitators help participants work through these?; how have other countries addressed these issues?
- *Have a workshop that is local and that engages teams rather than individuals from each project or site.* Five of the six participating countries sent a team rather than a single individual. Each team member provided support to one another in developing the protocol, revising the draft prior to attending the workshop, and continuing with revisions following the workshop. Having a team also helped to ensure that there was more than one person trained in birth defects surveillance who was responsible for carrying out the implementation of the protocol. In this way, if one staff member left the organization or was placed in another role, there were others who had been trained and were knowledgeable who could follow through with the work.
- *Make the workshop practical and interactive.* We minimized lectures and prioritized small group discussions and practical exercises. However, the success of this approach depends heavily on participants coming to the workshop with a solid background gained through the online pre-course training.
- *Commit to a set amount of time after the workshop during which to provide technical assistance.* This is critical to ensure that the participants follow through on the implementation of their protocols.
- *Develop an evaluation tool for obtaining more informative feedback.* While evaluations generally yielded positive comments from participants, it would have been helpful to design evaluation questions that help workshop staff better understand the practical tools participants might find useful in their everyday work (e.g., quality control, coding, classification, analysis, reporting).

## Next steps

We used the feedback from the workshop participants to make revisions to the online pre-course training. For example, we are developing new content for additional videos that can be used in upcoming workshops in other regions. Further, we are seeking to address poor connectivity issues that impact a participant's ability to view or download a presentation. For instance, we plan to develop scripted slides to make available to participants in PDF form.

As participant countries finalize their protocols, we are committed to providing them with technical expertise during the piloting and implementation of these six distinct surveillance



systems, and will assist these countries in developing meaningful evaluation criteria and sustainability plans. Additionally, we will support the efforts of participants toward the development of an alliance for birth defects in order to identify and support creative ways for these countries to share ideas, determine best practices, and provide a forum for dissemination of findings. Overall, the online pre-course training and in-person surveillance workshop described were very successful in providing participants with additional information and support to move forward in the implementation of a birth defects surveillance program. We fully expect the countries to implement their surveillance protocols, which will provide them with the data necessary to not only have a more accurate measure of the burden of birth defects, but also to advocate for increased resources for birth defects prevention and care programs in their countries.

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### Malawi

Chancy Banda, Ntcheu District Hospital; Dr. George Bello, Community Health Sciences Unit, Ministry of Health; Brenda Chirwa, Bwaila Hospital; Ellen Mpanganaji Thom, WHO- Malawi

### Nigeria

Dr. Amos Olufemi Adeleye, Department of Neurological Surgery University College Hospital, Ibadan; Olubunmi Remilekun Lawal, President of Neural Tube Defect and Hydrocephalus Foundation in Abuja

### Rwanda

Dr. Jean Jacques Irakiza, Kibagabaga Hospital

### Tanzania

Dr. Henry Chinyuka, Ulanga District Hospital; Dr. John Gwakisa, Morogoro District Hospital; Dr. Hamisi Kimaro Shabani, Muhimbili Orthopedic Institute; Dr. Rogat Kishimba, Field Epidemiology and Laboratory Training Program, Ministry of Health; Nailijileji Laizer, Lutheran Hospital in Arusha; Dr. Catherine Mlelwa Mungongo, Lutheran Hospital in Arusha; Golda Orega, Lutheran Hospital in Arusha; Dr. Mwanakulya Simfukwe, Morogoro District Hospital

### Uganda

Dr. Linda Barlow, Makerere University-Johns Hopkins University Research Collaboration Center; Ayoub Kakande, Makerere University-Johns Hopkins University Research Collaboration Center; Joyce Matovu, Makerere University-Johns Hopkins University Research Collaboration Center; Dr. Daniel Mwanja Mumphe, Makerere University-Johns Hopkins University Research Collaboration Center; Dr. Jolly Nankunda, Mulago Hospital

## Appendix A: Agenda, Intermediate congenital anomalies surveillance workshop, Arusha, Tanzania, 2–6 March 2015

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<b>Day 1</b>	<b>Core content on birth defects</b>
8:30	Opening remarks
8:45	Presentation of the course
9:00	Short review of the on-line pre-course
10:30	Break
11:00	Trainees presentation: Background of their surveillance program (15 minutes for each group)
14:00	Lunch
15:00	ALMC spina bifida presentation
15:30	Small group activity: program coverage, case inclusion, age of inclusion, case ascertainment, case and denominator finding
<b>Day 2</b>	<b>Developing the program protocol</b>
8:15	Visit to the Hospital and spina bifida clinic
9:15	Summarize key points and clarify issues of the previous days
9:30	Trainees presentation of the Day 1 small group activity (10 minutes for each group)
9:40	Questions/Answers session
9:50	Introduction of PreSurv software suite
10:30	Break
11:00	Promoting quality control and quality improvement
11:30	Small group activity: developing protocols data collection method and standard operation procedures
12:45	Group picture- World Birth Defects Day
13:00	Lunch
14:00	Small group activities: Continuation of developing protocols
15:30	Break
16:00	How to use PreSurv software suite
<b>Day 3</b>	<b>Program in Action</b>
8:00	Summarize key points and clarify issues of the previous days
8:15	Questions/Answers session on previous day presentation and activities
9:30	Birth defects experience at Arusha Lutheran Medical Centre
10:30	Coding and classification exercises
11:00	Continuation of coding and classification exercises
13:00	Lunch
14:00	Data analysis and elements of interpretation
<b>Day 4</b>	<b>Program in Action, and Risks and Prevention</b>
8:00	Summarize key points and clarify issues of the previous days
8:15	Prevention of birth defects and other adverse pregnancy outcomes: general principles
9:00	Fortification in Africa: challenges, barriers and opportunities
9:45	Preconception care

10:30	Break
11:00	Small group activity: opportunities to implement prevention
13:00	Lunch
14:00	Small group activity: finalizing surveillance program protocols
<b>Day 5 <i>Revisiting Protocol and Next Steps</i></b>	
8:00	Summarize key points and clarify issues of the previous days
8:15	International Federation of Spina Bifida and Hydrocephalus
8:45	Program presentations of revised surveillance program protocols and discussion
10:30	Break
11:00	Continuation of country presentations
13:00	Lunch
14:00	Quiz on main concepts discussed during the week
15:00	Feedback on course, next steps, call to action, conclusions

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