Design Support for a Zika Pregnancy Registry in the Caribbean Region

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Background

The recent Zika virus outbreak in the Americas has had a range of previously unanticipated negative impacts on the health of pregnant women and infants born to mothers who acquired the infection during pregnancy. Health systems have needed to adapt to address prevention and management of these effects, including regarding surveillance. Both routine surveillance systems and pregnancy registries can serve as important public health tools to monitor the ongoing impact on affected populations, including infants born to women who were pregnant during periods of suspected and confirmed infection. A strong surveillance system can also serve as an early detection system for potential future epidemics. Many countries impacted by the Zika epidemic do not have established surveillance systems that routinely monitor adverse pregnancy and infant outcomes. At the request of the United States Agency for International Development (USAID), the Maternal and Child Survival Program (MCSP) Zika Response Team provided technical support to the Caribbean Public Health Agency (CARPHA) during their initial discussions around design of a pregnancy registry as part of MCSP's activities in the Eastern and Southern Caribbean. It is anticipated that MCSP's support for registry development will facilitate readiness for future outbreaks in this highly susceptible region that does not otherwise have a regional system to collect exposure and outcome data relevant to Zika infection in pregnancy.

MCSP's Approach to Technical Support

Workshop to Review Potential Approaches to Overall Registry Design

In March 2018, MCSP and CARPHA co-facilitated a meeting to review potential approaches to design a pregnancy registry. Meeting attendees included representatives from CARPHA, MCSP, Trinidad Ministry of Health (MOH), USAID, and the US Centers for Disease Control and Prevention (CDC). The overall goal of the first meeting was to discuss the feasibility, design, and potential implementation of a Zika pregnancy registry for the Caribbean region. Specific objectives of the meeting were as follows:

- Discuss potential approaches to designing a CARPHA-led pregnancy registry for use in the Caribbean region, particularly in the context of the recent outbreak of Zika virus infection in the Americas.
- Discuss operational parameters for implementing a registry in Trinidad.
- Identify actionable next steps and initiate plans for a second meeting focused on relevant data collection and management.

Given CARPHA's current goals and resources, the group recommended that CARPHA establish a pregnancy registry that retrospectively describes key characteristics of the recent epidemic based on available data. These data will serve as the foundation for the registry, after which new cases, if they occur, could be added prospectively. The Pan American Health Organization/World Health Organization Perinatal Information System (SIP) and District Health Information Software 2 (DHIS2), both of which the Trinidad MOH currently uses, appear to be natural starting points for building the type of registry desired by CARPHA. Those systems contain the majority of data of interest from Trinidad on both suspected and laboratory-confirmed cases of Zika virus infection in pregnancy. Meeting participants recommended that CARPHA and Trinidad MOH work together to review the data elements currently present in SIP, compare those elements

with other Zika pregnancy registries (i.e., CDC), and define the data elements that would be preferred for inclusion in a registry. The scope of the data should be specific enough to be able to describe key epidemiologic and clinical details, but limited enough in quantity so as not to overburden health systems (especially frontline health workers) being requested to complete and submit/process case report forms. During the meeting, CARPHA clarified that they would be interested in rolling out a pregnancy registry in Trinidad, Jamaica, and one other country, potentially one of the smaller islands. Participants agreed that CARPHA should liaise with Jamaica and the third country (once identified) to understand ongoing data collection activities in these countries as they relate to Zika surveillance and pregnancy/infant outcomes in general. CARPHA representatives agreed to evaluate whether SIP or a similar system can be used to collect the same type of data in these countries to submit to the CARPHA registry.

Workshop to Review Approaches to Registry Design within the Jamaican Context

After the first workshop, CARPHA, USAID, and MCSP worked with colleagues in Jamaica to hold a second workshop to discuss Jamaica's potential involvement in a Caribbean region Zika pregnancy registry. Attendees included CARPHA, Jamaica MOH, USAID, MCSP, the ASSIST Project, and UNICEF. The specific workshop objectives included the following:

- Discuss potential approaches to the design of a CARPHA-led pregnancy registry for use in the Caribbean region, particularly in the context of the recent outbreak of Zika virus infection in the Americas.
- Review current processes in Jamaica for recording cases of pregnant women and infants exposed to Zika virus.
- Review the epidemiology of the Zika virus outbreak in Jamaica.
- Discuss operational parameters for implementation of a national and regional Zika pregnancy registry.

Several recommendations emerged from the workshop discussions. The group recommended that Jamaica participate in a CARPHA-led Caribbean region Zika pregnancy registry that retrospectively describes key characteristics of the recent epidemic based on data that are currently available, and new cases, if they occur, could be added prospectively. The Jamaica MOH expressed interest in joining Trinidad on the registry, and CARPHA agreed to explore the addition of a third country. The group agreed that CARPHA, the Jamaica MOH, and the Trinidad MOH should work together to review the current data elements in the Jamaica Zika Case Investigation form and subforms (Jamaica does not use SIP) and in the SIP used by Trinidad public sector facilities, compare those elements with other Zika registries (i.e., CDC), and define the data elements that would be feasible and preferred for inclusion in a registry. Similar to the recommendation made at the first meeting, the scope of the data should be specific enough to be able to describe key epidemiologic and clinical details, but limited enough in quantity so as not to overburden health workers and routine data collection systems. Jamaica MOH participants agreed to share the Zika investigation forms with CARPHA and other meeting participants. Participants decided that CARPHA would draft a list of recommended data elements to include in a database and share this list with both Jamaica and Trinidad MOHs to determine if the respective ministries would agree to share this information. After completing the above recommendations, CARPHA would consider a follow-up meeting to discuss the operational and logistical issues involved in implementing the proposed registry.

Follow-up Activities to Workshops

After the second workshop, MCSP continued to provide virtual support to CARPHA to discuss the development of a database and proposed variables to include in the registry. MCSP continued to advise a streamlined and practical approach to include registry variables, to facilitate data quality, and to facilitate stakeholder buy-in. CARPHA hired a consultant to create the database, based on CDC Zika pregnancy registry elements as a starting point, and agreed to reach out to MCSP if further support was needed.

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