A conversation with Dr. Alan Lopez on November 18, 2013 about health information systems

Participants

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Note: These notes were compiled by GiveWell and give an overview of the major points made by Dr. Lopez.

Summary

GiveWell spoke to Alan Lopez about strengthening health information systems. Topics discussed included the history of the Health Metrics Network, the major barriers to improving vital registration systems (i.e. systems that track births, deaths and causes of death), the growing momentum around the vital registration agenda, and funding priorities for surveillance systems.

History of health information systems

The World Health Organization (WHO) has traditionally been responsible for health information systems, but it has generally put few resources into the area, emphasizing disease control efforts instead. Calls for more attention to health information systems arise occasionally, because data from those systems are critical to inform health policy.

Health information systems are relatively underfunded compared to health interventions (such as immunization and malaria control).

History of the Health Metrics Network (HMN)

The Health Metrics Network (HMN) was established in 2005 as a partnership between international organizations, donors, academic institutions and countries. Its goal was to strengthen health information systems (HIS). The Gates Foundation seeded it with a roughly \$50 million grant and the World Health Organization (WHO) hosted it.

Under the leadership of Dr. Carla Abou-Zahr, the HMN initially worked on developing frameworks, standards and assessment tools for health information systems. In particular, it published the "Framework and Standards for Country Health Information Systems" and "Assessing the National Health Information

System: An Assessment Tool," which laid a strong foundation for work in the area. The HMN did not at this point focus on country interventions.

When leadership changed, HMN's strategy shifted towards direct grants to countries and investments in information technology (IT). In a handful of "Wave 1" countries, HMN made substantial grants towards improving IT infrastructure. In Dr. Lopez's opinion, this technology was not appropriate for the countries in which it was implemented. Dr. Lopez also believes HMN did not follow up with countries to an appropriate extent after providing grants nor did it provide sufficient guidance on how best to use these grants. Some of this funding may still be in a bank somewhere because countries did not know how to use the funds.

In 2009 and 2010, Dr. Richard Horton, the editor-in-chief of the Lancet, chaired the board of HMN and Dr. Lopez chaired the board in 2011 and 2012. They sought to focus HMN on strengthening civil registration systems and vital statistics. During this period, HMN built substantial momentum in several regions for the vital registration agenda.

In June of 2013, funding for HMN from the Gates Foundation ceased. HMN did not succeed in raising additional funds, and so had to shut down. Dr. Lopez speculates that the Gates Foundation withdrew because it tends to fund technology and innovation, rather than infrastructure projects, like health system and health information system reform. That focus along with the initial riskiness of the investment, an impression of a lack of leadership in the field, and a period in which HMN did not effectively use its resources might have also led them not to renew funding. In addition, there was some unease both within and outside of WHO about the hosting arrangements for HMN; it was often not clear to countries and partners where the boundaries were between WHO and HMN, in part because of similar mandates in HIS strengthening.

The AusAID-funded HIS Knowledge Hub

In 2008, the Australian Development Assistance Program (AusAID) reached out to academia to strengthen the evidence and knowledge base for Australian development assistance, which was likely to increase substantially. Dr. Lopez, then Head of the School of Population Health at the University of Queensland, received a \$11 million grant over 5 years from AusAID in 2008 to improve the knowledge base for strengthening health information systems in the Asia-Pacific region. The purpose of grant was to assist the Australian development program by stimulating and informing policy dialogue in the region, and was otherwise unrestricted. Dr. Lopez used this money to establish a Health Information Systems Knowledge Hub (HISHub) at the University of Queensland, which aimed to advance knowledge and develop country-level expertise in the strengthening of health information systems, particularly vital registration systems. The Knowledge Hub worked closely with the HMN, and also with WHO, producing jointly branded guides and assessment tools as well as promoting and disseminating those products to countries through the HMN

and WHO. The Knowledge Hub also developed its own framework for assessing the functioning of civil registration systems relying heavily on the framework developed by HMN for health information systems.

In June of 2013, AusAID funding for the Knowledge Hubs initiative ceased. The new government has yet to make a decision about future funding for initiatives such as Knowledge Hubs to help strengthen CRVS systems in the region, but initial expectations are that the new government does not support foreign aid to the same extent as the previous one.

Momentum for vital registration

The last 4 years of work by the HMN and the Knowledge Hub has built momentum for the vital registration (VR) agenda. Indications of the increased interest in this work include:

- The United Nations Economic and Social Commission for Asia and the Pacific have worked on strengthening VR in Asia and the Pacific.
- Thailand has set up a number of consortia on VR.
- The Economic Commission for Africa has started to apply Knowledge Hub tools in partnership with the African Development Bank and the African Union. They have a consortium focused on vital registration led by Pali Lehohla.
- Claudia Stein at the WHO European Office is leading efforts on the vital registration agenda in the Central Asian republics.
- Tim Evans at the World Bank has expressed interest in the vital registration agenda.
- The Regional director of the WHO, Eastern Mediterranean Office has made vital registration strengthening one of his priorities..

Barriers to a functioning vital registration system

Lack of leadership, organization and sustained focus are the primary barriers to improving vital registration systems. In each country, stakeholders, including the census bureau, medical associations, and the department of statistics, must be convened in order to discuss specific problems limiting the quality of vital registration data and work towards solutions to address those problems.

These stakeholders also often require guidance on how to assess the strengths and weaknesses of their systems and, in particular, how to apply the HIS Hub (see www.uq.edu.au/hishub) assessments and tools. Dr. Lopez suggested reading the working papers published by the Knowledge Hub describing successes in Sri Lanka and the Philippines to better understand the scope of the interventions.

Many countries lack the capacity to look at datasets critically, diagnose quality issues, and then design solutions. There need to be individuals tasked with the job of detecting data quality issues and coordinating solutions (for example, noticing that a data set says that there were a number of pregnancy deaths in males and then coordinating with the medical school to more accurately assign the cause on death certificates). Small, targeted investments can make big differences to data quality.

Funding priorities for surveillance systems

Dr. Lopez would like to see additional investment in improving the following types of data (in order of priority):

- 1. Vital registration: How many die and of what? The focus here should be on improving completeness of death registration and on the accuracy of cause of death assignment.
- 2. Chronic disease risk factors: Surveillance of risk factors, such as tobacco, alcohol, fasting plasma glucose, blood pressure and physical activity. A lot of research exists on how to effectively design these systems. Countries would conduct nationally representative surveys every 3-5 years giving data by age, sex and sub-district. A funder could also consider surveillance of injuries.
- 3. Effective coverage: How well are health systems delivering cost-effective interventions that tackle the top causes of burden of disease? For instance, a country could run periodic surveys that take blood samples from children to measure antibody presence from a national immunization program to more precisely estimate the coverage of proven vaccines in the population. This may require a separate survey program or could potentially be added onto an existing survey program. It could also incorporate data from routine information systems, such as data systems in hospitals. This data exists, but many countries don't use it because they worry about the quality of the data and don't know how to improve those data sources.
- 4. Nonfatal illness: Surveillance of nonfatal illness, particularly diseases that cause a large burden, such a musculoskeletal diseases and mental health. The problem for these systems is not necessarily a lack of funding, but designing these surveys to be comparable and useful for Global Burden of Disease assessments.

Other actors

Other actors in health information systems include:

- UNICEF and Plan International work on improving birth registration.
- Ties Boerma is responsible for health information systems for the World Health Organization.
- Sam Notzen at the CDC has a small team working on vital registration.

- PARIS21 and the Busan Partnership for Effective Development are interested in improving statistics systems generally. They don't a particular interest in vital registration.
- The Global Fund sets aside 5-10% of its grants for evaluation.

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