

New Initiative Addresses Issues Concerning In-Country Data

A new initiative aims to publish stories and promote discussions that will help improve the ways in which in-country data is collected, interpreted and used in situations such as national strategic planning and concept note development for the Global Fund to Fights AIDS, Tuberculosis and Malaria.

The "Where There Is No Data" initiative was established by a group of researchers and consultants. Currently, the initiative is hosting a website, a Facebook page and a twitter feed.

The Global Fund has said that under the new funding model (NFM), it wants to fund applications that make a clear case based on sound analysis of the epidemiology of AIDS, TB and malaria in a given context, and of the gaps in the current response to these diseases.

The organisers of the initiative say that although standards in the collection of epidemiological and programmatic data have improved a great deal in recent years, community organisations and groups representing key populations – such as men who have sex with men, transgender individuals, sex workers, and people who inject drugs – know that in most countries there are still considerable gaps in information.

"The studies that exist may be small, or focused on specific locations, and may not always adhere to the highest standards," said Matthew Greenall, one of the founders of Where There Is No Data. "As a result, decision makers, many of whom are represented on country coordinating mechanisms, are quick to write off what data there is."

Mr Greenall told GFO that in some countries, decision makers are so averse to working with these key populations that they may not even accept good quality data. At the same time, he says, although the Global Fund has set out clear principles to enable community organisations and key populations to

participate actively in the development, implementation and monitoring of Global Fund grants, these groups often struggle to participate effectively.

"While they can eloquently describe the challenges they face in terms of stigma, violence, criminalisation and discrimination in access to services," Mr Greenall said, "they are often less well equipped to participate in decisions that are based on epidemiology, attributable risk and cost effectiveness, as they must be under the NFM."

The Where There Is No Data <u>website</u> will publish regular stories describing real-life examples of how research on challenging topics can be conducted; advice on methods; discussions of how research challenges have been overcome; and explanations of the different types of data and research used for developing and evaluating health programmes. The first few posts on the website addressed the challenges faced by marginalised populations in HIV programmes.

Mr Greenall said that anyone is welcome to submit articles to be posted on the website. "This is how we hope to get most of the content," he said.

The <u>Facebook page</u> will feature relevant news stories, provide notifications of new content on the website, and provide a forum for discussions and requests for advice. The <u>Twitter feed</u> (@wtinodata) will be used to let followers know about new content on the website and Facebook page.

To start with, information on Where There Is No Data will be published in English, but users can initiate discussions in other languages on the Facebook page. People who are interested in receiving content and updates by email can subscribe to a list; instructions are on the site. Also on the site are a description of the organisers and a method for contacting the initiative.

Read More