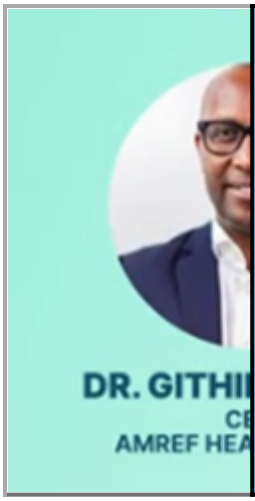
Power lies in Communities, Pay Attention to Non Tropical Diseases – Notes from the Field @77th World Health Assembly Sidelines

PANEL DISCUSSION

Global Goals, Local Gains: how can institutions empower communities?

Hosted by Sara Jerving, Senior Reporter, Devex, which organized the panel discussion, framing the key question as “Localization in the health space requires a transfer of power. Is it happening? And how to get it done at a grander scale?”

Two panelists, namely, Dr Githinji Gitahi, CEO, Amref Health, Africa and Dr Angela Chaudhuri, Chief Catalyst, Swasti, India challenged the very title of the session. Their views and those of the third panelist, Petro Terblanche, CEO, Afrigen Biologics in their own words are detailed below. Jerving acknowledged concerns about the session title and stated that titles of session in future would be handled with care.



“Empowerment is not a single point of activity, it’sa concept that recognizes that those facing themost challenges also know the solutions to those challenges.”
– Dr Githinji Gitahi, CEO, Amref Health, Africa

“The title of this meeting is ‘How can Institutions Empower Communities?’ but the power lies in the communities. You can’t empower communities. As per Cambridge, it means “license”, “to allow”. It’s almost as if “empower” means we are giving the community a license or authority to do something, which is actually not true. Though, there is a different interpretation of enabling people – Oxford also mentions empower as making people stronger and more confident, in claiming proposed rights. We only work with communities because they allow us to. How do you actually create structures and tools for communities to realize their power? To get them agency to exercise that power, it’s not ‘to empower them’.”

“It is communities that hand over the mandate to governments to operate on their behalf. And then the government creates an environment for NGOs, public sector to operate to help communities to exercise their power. Without information, without systems, without structures, they may not be able to use their agency. And our role is to support and strengthen them, to give them the knowledge and the means about their rights and demand for them. For instance, World Menstruation Day. In Kenya, a law was passed and we inform the girls in communities that they can ask for menstrual hygiene products.”

“Institutions see themselves as acting on behalf of communities but that is never possible. What we do is we take the community voice and amplify it. However, the communities should lead what we do. It’s not about creating a legal structure for registration, but how close to the community is the decision of how to use that money. Who has the power to decide the priorities of the community? As an organization, we, too, began with the traditional model where we started flying people in and out. A shift to a mindset to give up power makes us feel vulnerable. For instance, why is the launch of the African Vaccine Manufacturing Accelerator scheduled to take place in Paris, France and not Africa? I call upon the community, and we are all community, what are we going to do about it?”

“We assume that what is published is knowledge. We have already decided the structures so unless it’s published in Lancet or BMJ, it doesn’t matter. But communities have knowledge. Doing it ourselves doesn’t mean doing it alone. What the funders bring to the table also matters. So, we’re saying respect the community knowledge, respect the community systems and how they use them and not expect them to have the same system, but how do we rejig them and better use the community knowledge?”

“Need to foster a research and development environment end-to-end, not just product, but process, epidemiology surveillance, evidence-based policy development. – Petro Terblanche, CEO, Afrigen Biologics.	

“As a research and technology organization, a private company, we have a commitment not only to understand how to engage with communities but also to give back to communities.”

“Local manufacturing, regionalization is being spoken of as key. We talk of Low-Income Countries very easily but Low Middle-Income Countries is a very broad term. Africa, for instance, has 55 nations, which comprise both LIC and MIC and 1.4 billion people. Africa imports 70% meds and 95% of critical diagnostics and medical devices and 99% of the vaccines we need. So, how do you empower a continent to have health security and to supply their own people? It requires an ecosystem from the last mile in reforming healthcare. And there are 700 million women on the continent. 4 million of them mothers. Imagine if we could train them in basic healthcare!

Then there is the regulatory system. How do we ensure that the products that go to our people are safe and effective? Following that is logistics and supply chain, how do we get these products to our people? How do we empower and build capacity not only for full finish but for drug substance and drug manufacturing on the continent? It’s the political leadership who must provide an enabling policy environment that will incentivize local manufacturing, skills development, financial support. And then Gavi’s African Vaccine Manufacturing Accelerator (AVMA) instrument, one of many other innovative mechanisms come in.”

“Africa has a burden of Chronic Diseases, Non-Communicable and Communicable. We need to prioritize products that address neglected diseases on the continent. It is this ecosystem as a whole that needs to be put in place for health security and preparedness for the next pandemic. But we need to also look at socio-economic development. The poorest people live in Africa, how do we provide them jobs?”

“How does the WHO Messenger RNA Technology Transfer Hub (mRNA TT Program) Program contribute to that? We’re building capacity and capabilities for a future-relevant technology. The mRNA TT Program is not only for vaccines and therapeutics but also for other environmental concerns, crop protection. We’re building a platform and also building it in a system, which is an Open Access system. We will share that

knowledge and technology with 5 other partners in Africa and 10 other partners in LIC and MIC. The platform is built, the process is completed. In September, we will undertake the full package transfer. In next 2 years, it will be initiated and completed."

"Vaccine hesitancy, we must understand what the fears of the communities are, and not assume that we need to educate them about vaccines. Freedom of knowledge and understanding is a two-way conversation. Also need to address the disinformation on social media. The scientific community and public-private partnerships do not engage with communities at all levels as partners on the route to health. We need to fix this in a collective, partnership model."

"The WHO Civil Society Commission is the first time the WHO is engaging directly with civil society and not just member states choosing to work with civil society."
– Dr Angela Chaudhuri, Chief Catalyst, Swasti, India, and member, WHO Civil Society Steering Committee.

"Communities are not homogenous, but disparate, defined by their work, who they are, their gender, where they live, all of that. They cannot be boxed. So, in rooms like these, how do we hear their voices? Institutions are also community institutions like Self-Help Groups (SHGs) who empower the communities so we hear their voices. But they're the most poorly invested institutions. Proximate leadership is both the most powerful and the most powerless. And the most under-invested. They are the ones who must design what the problem is, the system they're working in and thence the systems of systems to arrive at a solution that is implemented and monitored together with them."

"The WHO Civil Society Commission is to value and engage with civil society in an all-institution manner. Working Groups are in place. The plan is to have a Civil Society Strategy and we are inviting civil society to be part of the Commission and Working Groups. We already have 200 civil society groups globally."

PANEL DISCUSSION

From the Margins to the Mainstream – Ending the Neglect of Non-Tropical Diseases

The session was chaired by Sara Jerving, Senior Reporter, Devex, which organized the panel discussion. Noting that treatment for Non-Tropical Diseases (NTDs) is often underfunded because NTDs are overlooked, Jerving threw open the session to a panel comprising Thoko Elphick-Pooley, Executive

Director, Uniting to Combat NTDs, Dr Monique Wasunna, Drugs for Neglected Diseases Initiative (DNDI), Africa, Ambassador, Drugs for Neglected Diseases Initiative and Adam Weiss, Guinea Worm Eradication Program, The Carter Center. We bring all they said in their own words.

"Togo was able to harness the community health workers (CHWs) who are really the engine for NTD elimination, and it is to be noted that it is largely women CHWs who drive this disease elimination, many of them going door-to-door."
– Thoko Elphick-Pooley, Executive Director, Uniting to Combat NTDs

"Togo is the first country in the world to eliminate four entities [dracunculiasis (Guinea worm disease), elephantiasis (lymphatic filariasis), human African trypanosomiasis (sleeping sickness) and trachoma]. Eradication is possible when the country's political leadership embeds it in every action. And also has funding. For instance, the eradication of elephantiasis was made possible by support from the Global Fund. If you have the will, you'll find a way to fund that work. Togo is a tiny country, I am told, so, it was possible, but then what about Mali? It's a huge, complex country. Yet, it eliminated trachoma, one of the infectious diseases responsible for blindness in the world. And this is due to over 20 years of dedicated work from the partner here [The Carter Center was one of four partners supporting Mali's Ministry of Health]. It's because of commitment and dedication and keeping on going against all the odds. Partners who do not give up."

"The latest reports show that 1/3rd of African countries are in debt distress. Interest payments are more already than investments in health and education. European elections may see the rise of the far right, which will mean funding for development is just not going to be a priority. A replenishment traffic jam was reported by Devex recently. It's a concerning picture that we may not be able to meet everything we need. This affects 1.65 billion people on the planet. Diseases that are hardwired in the SDGs, with serious targets to reduce by 90 per cent for an intervention against an entity. By that benchmark of 2015 based on 2010 figures, by 2030, that 1.65 billion should reduce to 200 million. We are nowhere near. Biggest potential source of financing for us has to come from grant financing countries and for countries needing financing for NTDs, it will be the International Development Association (IDA) – the World Bank. Countries can't take loans. So, we're fully encouraging a fully replenished IDA21. And they need to create a flagship initiative for elimination of NTDs."

“We have to embed access right from when research is being developed. Pregnant and childbearing aged women have to also be considered but have often been excluded from trials.”
– Dr Monique Wasunha, DNID, Africa

“Drugs for Neglected Diseases Initiative was founded in 2003 to fill the research and development gap for NTDs that existed. The then ineffective, toxic, not easy to use treatment was frustrating doctors and those with the diseases. Research infrastructure, capacity building for conducting trials was needed, ethics protocols had to be strengthened. The initial strategy was to see if we could reduce the duration of a registered treatment, or combine with others, then explore the possibility of replication for other entities. Later, there was a long-term strategy of treatment from scratch.”

“There are also other aspects for the safety profile. Is it oral or injectable drug? What is its interaction with other drugs? The WHO passes it, then it is also designated as being for first line or second line treatment. Ministry of Health has to say they want the treatment after looking at data and then their guidelines need to be changed at the policy level to allow usage. It has to be part of the Essential Medicines list. This in turn also means regulatory approval and training of the field doctors on its use. Governments need to take responsibility for protecting their citizens and have to put in the money for procurement and not rely only on donors etc. We need commitment across the board – civil society, partners, researchers, academia, specialists in the area etc. We cannot advance policy change without working closely with the governments.”

“For pandemic preparedness, how to ensure those without cell phones, electricity, basic infrastructure have access to wherewithal and knowledge of what some of these diseases look like, the symptoms? What is the structure and system for reporting that information?”
– Adam Weiss, Director, Guinea Worm Eradication Program, The Carter Center.

“We have worked in deworming in Africa, Middle East and Asia, and it’s possible because of trust and relationships. Respecting sovereignty of member states and that of local community over their own challenges and problems, as opposed to helicoptering people in and solving other people’s problems is key. We need to be active listeners. Partnerships are easy to build when there are people with drive, commitment and passion. Like Makoy Yibi who’d walk through swamps for days, climb mountains, and be in very insecure environments while working for the Guinea Worm Eradication Program, Ministry of Health, South Sudan.”

“Mutual sharing of tools, knowledge and understanding with each other; what communities bring to bear, what individuals bring to bear. What’s needed is developing diagnostics locally and delivery with less supply chain management issues.

“Capacity to respond is where a multi-surveillance system could be very helpful but still has to deliver treatment and care at the end of that road as opposed to just detecting the disease. Community health workers need to be trained and equipped over time from a multi-disease platform. Training has to be chipped in also by other departments like fisheries, livestock, environment with some of the technical inputs. So, the education system needs to be built and designed for addressing community needs in very diverse contexts.”

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