A Different Kind of Army

A call to place community leadership at the center of the Ebola response

International Rescue Committee | NOVEMBER 2014

INTERNATIONAL RESCUE COMMITTEE

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Executive summary

The deadliest outbreak of Ebola will only be stopped when communities are fully incorporated as leaders and partners in the international response.

Foreign militaries have been deployed to help stop the deadliest, longest and most widespread Ebola outbreak ever recorded. But the global response has yet to fully enlist another kind of army needed to win this war — the very communities in West Africa that are being affected. The epidemic will only be stopped when communities are fully incorporated as leaders and partners in the response effort.

Global responders and governments must continue to scale up action, but scaling up will not be enough. In this Call to Action, we describe how the global response can be improved by describing the difference between community empowerment and mere consultation. We highlight three cases in which community leadership led to reductions in Ebola transmission, and provide recommendations on how community leadership can become a central element of the Ebola response scale-up.

The Ebola response will be most effective when it draws from two key sources of knowledge. The public health practitioners leading the global response have important knowledge about Ebola transmission and treatment. Less widely recognized, however, is the fact that communities in the affected areas hold essential knowledge of their own: knowledge about how to implement infection prevention measures in the unique context of their villages and neighborhoods.

For example, members of communities are best placed to mediate traditional West African values of hospitality with basic approaches to infection control; to care for the sick without touching them; and to provide proper respect to the deceased without risking infection. Community-led infection prevention can, if widely adopted and practiced in conjunction with treatment, help bring this outbreak to an end. Community leadership can help to ensure that distrust and misinformation is overcome; that individuals take basic precautions; that sick people are referred for treatment; that people who have been exposed are identified; and that victims are buried safely.

Community-led infection prevention has been limited thus far for several reasons. Ebola control measures challenge deeply established community practices, particularly those around burial. Second, community members often do not trust those who are communicating prevention measures. Finally, communities have only been given a limited role by governments and international responders. We need to scale up our actions, but we also need to act differently.

Fostering widespread community leadership for a rapidly spreading disease is a formidable challenge. But there is good news. Some individuals and communities have already taken the lead. In this document, we describe the actions of leaders in three very different contexts and explore what made them so effective.

Global responders seeking to stop the epidemic must understand what individuals and groups are already accomplishing. We must find the thousands of groups and individuals who know how to connect with communities and support them. Community leadership must be at the heart of the global response.

Recommendations

The governments of Liberia and Sierra Leone, and the other governments and agencies supporting them, need to scale up a comprehensive set of Ebola control interventions. These interventions include case identification and contact tracing, the aggregation and analysis of surveillance data, lab testing, treatment for Ebola, safe and dignified burials of Ebola victims, and treatment for other common diseases. Most of these efforts will be only be fully effective if communities are actively engaged and, in many cases, take the lead. The following recommendations outline how this can be achieved:

- **Communities must be involved in key decisions.** They should especially take the lead in prevention activities that involve essential community practices. These activities may include case identification, contact tracing, burials, and any form of quarantine or treatment that happens in the community. Specifically, communities need to make the decisions about what actions are undertaken within their boundaries, and how those actions are put in place.
- **National and international responders must listen to communities.** Individuals with relevant skills and experience must be in key posts in the national and international response structures. These people should include anthropologists, community organizers, and others with the knowledge and background to listen to and work with communities. Government officials and outside experts should also consider living closer to affected communities to build trust, promote collaboration, improve efficiency and show solidarity. Global responders need to understand decision-making processes and investigate channels of communication with communities, including village health teams, local or national organizations and community leaders. Local decision-makers must build relationships upon trust and respect in order to establish effective partnerships in

LEFT: A woman walks by a mural for infection prevention in Liberia, October 2014.

which communities develop solutions and critically review solutions designed by others. Communities must be able to voice their concerns and recommendations. Where response efforts are unsuccessful, outside organizations must immediately consult communities to identify flaws and solutions.

- **Listening should be accompanied with rapid action.** National and international response structures should be set up to provide rapid, flexible support to community action. Communities are more likely to trust and work collaboratively with outside partners if they see that dialogue brings results. Any funding mechanism should be transparent and set up to make small grants quickly and in a variety of locations. Logistical support from outside responders to communities should be based on community needs and provided through community structures. It is essential that services provided to support community-led measures — for example, dispatching ambulances to respond to Ebola cases identified by communities — be of the scale, efficiency and quality necessary to maintain community trust.
- **The same principles of community leadership should be applied to Ebola preparedness and surveillance work in surrounding countries.** Communities in those countries, particularly those closest to Guinea, Liberia, or Sierra Leone, should be full partners in the effort to prevent Ebola from crossing further borders.

The IRC's Ebola Reponse

The International Rescue Committee (IRC) is leading a large-scale response to the Ebola epidemic in the most affected regions of Sierra Leone and Liberia. The IRC is involved in all major areas of Ebola control and mitigation, including case identification, lab testing, treatment of Ebola patients, contact tracing, burial, infection control, data management, coordination, and support for primary health care clinics.

The IRC is supporting these interventions at both clinic and community levels. The IRC has more than 500 staff members in the region and is supporting 455 clinics that serve more than 2.3 million people. The IRC has worked in Sierra Leone since 1999 and in Liberia since 1996. Prior to the outbreak, the IRC was providing medical services and helping to rebuild both countries' war-damaged health care systems, with a particular emphasis on community participation. It also offers programs in education, child protection and gender-based violence prevention and support.

Why does Ebola continue to spread?

The current outbreak in West Africa is the largest, longest and most complex Ebola epidemic in the nearly four-decade history of the disease. To stop it, we must understand why.

The current Ebola epidemic in West Africa is the largest, longest and most complex in the nearly four-decade history of the disease. The first known case in the current outbreak was that of a two year-old boy in Guinea who died from the disease in December 2013. By October 27, 2014, more than 13,000 cases and nearly 5,000 deaths had been reported, with the actual number estimated to be much higher.[1] The number of cases, as well as the numbers of deaths caused by the disease, exceed all past outbreaks combined, and infection rates continue to grow exponentially.[2] The epidemic has brought the economy to a standstill in affected countries and shuttered hospitals and schools.

The situation could get worse. The U.S. Centers for Disease Control and Prevention (CDC) predicts that, without additional interventions or changes in community behavior, Liberia and Sierra Leone could have as many as 1.4 million cases by January 20, 2015.[3] A few related cases have appeared in Spain, the United States and Mali.

The statistics convey the severity of the situation, but they do not capture the profound psychological impact of the outbreak. "We even prefer war to this Ebola war," said one man in Liberia, referring to the country's brutal 14-year civil conflict. "Because if you hear that war is coming to the area, you can run. But with this Ebola, you don't know who is who."

Understanding the challenges

It is critical to understand how the outbreak continues to grow at an unprecedented pace despite increasing resources allocated to contain it.

There are two general explanations for the accelerating spread of the epidemic. One is that key services needed to contain it, including case identification, contact tracing, and treatment, are not being implemented at sufficient scale and quality. For example, more Ebola treatment units are being set up to safely support infection control and provide care, but the number of beds appears to be increasing at a smaller rate than the epidemic itself.

As of October 22, 2014, the World Health Organization (WHO) reported that the 1,126 treatment beds in the three most affected countries only met 25 percent of the estimated need. Contact tracing systems have also struggled to keep up with the pace of the disease. The issue of scale is further exacerbated by the spread of the epidemic in densely packed urban neighborhoods, where isolation is harder to achieve, and contact tracing is particularly challenging.

The second key driver of the epidemic is a disconnect between public health authorities, both national and international, and the people whose actions ultimately control the outbreak: community members. The explanations for, and solutions to, this second issue remain insufficiently discussed and addressed.

From the start of the epidemic in December 2013, communities refrained from declaring cases and fully collaborating with authorities. One of the primary reasons was a lack of trust in national and international public health authorities. This mistrust has complex roots in Liberia and Sierra Leone's colonial past and in both countries' civil wars. A study of the current Ebola outbreak found that people in Liberia, who were still traumatized by their experiences with war, were more distrustful of government messages about Ebola prevention.[4] This distrust was exacerbated when actions, like quarantine, were taken by outside authorities without consulting with communities.

Not all of this disconnect between responders and communities can be attributed to a lack of trust. Ebola is a frightening disease, as witnessed by the current reaction in Europe and the United States. The disease's latent period, its horrific symptoms, and the fact that patients are treated in closed facilities by people entirely covered by protective suits, are deeply disquieting to patients. Due to these various factors, the disease has regularly generated fear, panic, and alternate non-scientific explanations through its history. In previous Ebola outbreaks, communities grappled with widespread rumors and perceptions that government or NGO healthcare workers started the disease. It was also a common belief that healthcare workers aimed to capitalize on the outbreak.[5]

Finally, it is an unfortunate fact that many of the precautions needed to prevent the spread of Ebola conflict with deeply-rooted West African cultural practices, particularly those related to burial. The difficulty of tackling Ebola transmission in poor and densely populated neighborhoods, which lack access to basic services, only adds to these complex challenges.

How to stop the spread of Ebola and Ebola-related deaths

ACTION	GOAL
Prevention of contact	Stop transmission
Ensure quality health care	• Stop transmission, particularly to healthcare workers • Improve survival for non-Ebola patients • Identify Ebola cases
Find individuals with Ebola	• Improve survival for Ebola patients • Stop transmission
Monitor people who had contact with Ebola patients	• Identify Ebola cases • Stop transmission
Lab confirmation	• Improve survival for Ebola patients • Stop transmission • Improve survival for non-Ebola patients
Isolation and treatment	• Improve survival for Ebola patients • Stop transmission
Safe burials	Stop transmission

Communities can bring value and results to every aspect of Ebola response.
We have highlighted components where community involvement is particularly critical.

These factors are also linked with each other. Changing cultural norms is difficult under any circumstances but especially so when institutions advocating for the changes do not have the trust of communities.[6] The starting point for any planning and action must be an understanding of the distrust of authority, the trauma of war, the inherently frightening nature of Ebola, and cultural priorities. The relative importance of each factor varies from community to community, but they have one common point: they are best addressed by restoring a sense of control to communities and individuals alike.

> "We even prefer war to this Ebola war. Because if you hear that war is coming to the area, you can run. But with this Ebola, you don't know who is who."
>
> —MAN FROM LIBERIA

Communities in control

If this epidemic is to be stopped, community engagement must not be limited or undervalued. Community leadership must be placed at the heart of the global response.

What is a Community?

The definition of a "community" varies from one context to another. It can be a village, a group of villages, a neighborhood or a particular group within a neighborhood. Communities exist where ongoing and permanent relationships, or collective visions or goals, bind a group together.

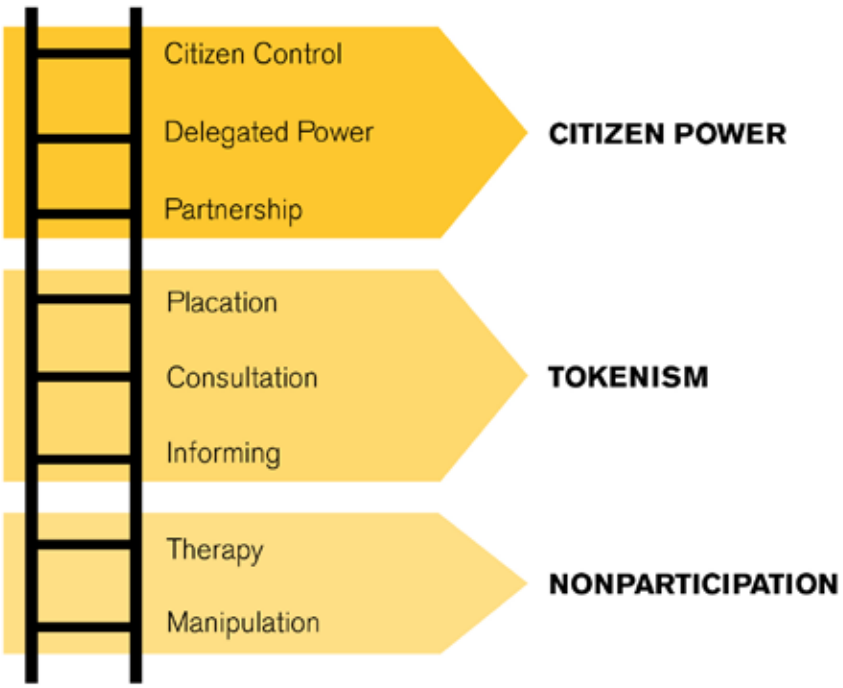
Community health has become a cornerstone of global public health. Many public health schools have community health departments, and many ministries of health in Africa have community health units. There is agreement that policy makers and health workers must focus on communities, since that is where the majority of infection prevention measures must take place.

Many policies, however, have put communities in limited roles to implement models designed by others. Community members employed by organizations often deliver messages developed far from the communities they serve. Messages have not always been tested for their acceptability or effectiveness. More recently, community health workers have been trained to provide treatments for common illnesses, but often under careful supervision and under instruction to follow procedures.

Arnstein's ladder of public participation (*see below*) demonstrates that these types of approaches fall in the middle of the scale and short of community empowerment. The ladder illustrates the range of potential for incorporating communities in response efforts. We must understand the crucial distinction in terms of approach, activities and outcomes between tokenism and citizen power.

The International Association for Public Participation has developed another scale (*see p.7*) that is helpful in distinguishing between different levels of community engagement.[7] The scale classifies community action from ones in which the communities are passive, such as being informed about actions taken by others, to ones in which they are most active, including collaboration between equals. The scale culminates with communities taking the lead in determining priorities, and

Arnstein's ladder of public participation



Levels of community engagement

The International Association for Public Participation

deciding how those priorities can be implemented. The general trend in global community health has been a rise from the lower end of the scale towards the middle.

By both measures, the global Ebola response is positioned in the middle of the scales, offering opportunities for improvement. A number of strategy documents developed by U.N. agencies and international nongovernmental organizations reference community engagement.

Examples include:

- The WHO Ebola Response Roadmap, which lists among its priority actions the inclusion of community health workers in the response effort and community engagement in "complementary approaches."
- A community health worker training manual that prescribes specific actions to stop the transmission of Ebola, and instructs community health workers to "give correct information and mobilize community leaders."
- A community response strategy focusing on training community health workers, distributing kits, establishing community isolation centers, and "partnering with politicians, community, religious, and opinion leaders."
- A document describing Ebola care units, to be run by community members.
- A "community-based Ebola response strategy," developed by an organization not operating in the affected region, focusing on mass deployment and training of community health workers, and dissemination of standard Ebola messages.
- A document developed by the IRC early in the response, which outlines how the already-existing practice of home care for Ebola patients can be made more safe.

These documents show a laudable attention to community response. However, they also illustrate areas to be improved:

- Candidates for mobilization are limited to community health workers, though others may be better placed to mobilize communities to take action. Several of the documents assume that the government or other implementers will train community health workers, who in turn will get community leaders and other individuals to act.
- Plans do not recognize the prevalent distrust of communities and community leaders toward the government, U.N. agencies and some nongovernmental organizations.
- Plans describe the incorporation of community leaders but do not detail how effective leaders will be identified or how a trusted relationship will be built.
- Timelines are not appropriate for the urgency of the situation. One of the documents, for example, outlines a six-month roll-out period, which is too long for an epidemic that is growing exponentially.

Collectively, these documents represent the state of community involvement in the global response strategy: there is widespread recognition that community involvement is important, but a limited or incomplete view of how to engage with communities in affected areas.

We believe that communities must be empowered to contain the epidemic and that these efforts can be strengthened by involving the right people in the strategizing process.

The next section outlines examples of those people and what they have achieved.

Where community leadership is working

Individuals and groups in Liberia and Sierra Leone show what can be achieved when communities are in control, and why support for this type must be scaled up.

Community leaders are using their credibility, understanding of context, and innovative mindset to develop solutions that can change the trajectory of this crisis.

These three cases illustrate what can be achieved when communities are in control, and why support for this type of community leadership must be urgently scaled up.

We must support these leaders, and help them expand their efforts, just as we are supporting the scale-up of other elements of Ebola response. We will succeed only when we look for solutions in the right places — the villages and neighborhoods of West Africa.

A native son returns

Liberia has been hit harder than any other country in the outbreak, recording more than half of the total deaths recorded in West Africa.[8] Inside Liberia, Lofa County was one of the first and most severely affected parts of the country. Of all suspected, probable and confirmed cases of Ebola in the country, one-fifth were in Lofa County.[9]

Though Lofa County was the epicenter of the outbreak, it has seen a reduction of the number of cases as well as the number of infections among community health workers. The average number of cases reported per week fell from 20.9 on August 16, to 4.4 on September 20, 2014.[10] In the Foya Case Management Center, located in Lofa County, the number of cases declined from 139 in mid-August to nine cases on October 9.[11]

Alpha Tamba, a physician's assistant who grew up and works in the county, exemplifies the community leadership that has helped to curb the spread of Ebola in Lofa. Tamba works with Pentecostal Mission Unlimited (PMU)-Liberia, a partner of the IRC. But it is as a native son that he has been able to protect seven villages from Ebola.

In May 2014, Tamba volunteered to educate villages about Ebola and Ebola prevention. He initially encountered hostility from different communities that accused him of spreading myths about Ebola to garner money from the government. On one occasion, he was beaten and barely escaped with his life.

"We knew this was serious and dangerous," he said. "I worried about whether my village was treating health workers like this as well. I knew I had to go visit my village."

OPPOSITE PAGE: Alpha Tamba in Lofa County, where he worked with communities to prevent infection.

Tamba returned to his village, Gbandu, near the border with Sierra Leone and Guinea — close to epicenter of the West African Ebola outbreak. To his surprise, he was greeted not with hostility, but joy and relief. Villagers had been waiting for someone trustworthy and informed to talk to. They immediately organized a village meeting. A group of young men threatened Tamba, but community elders quickly intervened.

"This is our brother," they told the young men. "This is your brother. You must listen to him. He would not lie to us, and he would not join any group to do evil to us."

Speaking in the local language, Tamba explained facts about Ebola. He told them that the rumors they had been hearing were false and that Ebola was real, and that they could die. He explained that they were not powerless but could stop Ebola with measures like avoiding direct contact. Only a month before, Liberia's Minister of Health had visited the region and people had walked out on him, disbelieving. Now the same people listened to Tamba.

"You sent me out to study," he told them. "Now I'm coming back with the knowledge that you sent me for."

Tamba's relatives and neighbors thanked him for easing their anxiety and confusion. He left and came back with chlorine and five buckets, some of which he had received from his employer and the nearest hospital, and some purchased with his own money.

Tamba then posed a critical question.

"I've played my part, but I won't always be around. You can't rely on me alone to save you from Ebola. Now that you believe that this disease exists, what can you do to prevent bringing this disease to our town?" he asked.

The village's groups met separately: women, elders, young men. Each group decided on an action they would take: women would not allow anyone go to Guinea for trade. Elders restricted outsiders, other than health workers, from visiting the village. The young men, who had threatened Tamba before his initial presentation, announced that they would stop attending social activities and bars in nearby towns until the outbreak had passed. They also offered to provide security for the village.

At the request of the village elders, Tamba visited seven nearby villages. Again, he was welcomed. At the time of Tamba's visit,

there were hundreds of Ebola cases in the surrounding area, including more than 100 in one village alone. As of mid-October, only three cases had been recorded since his visit. Tamba's own village has yet to see a single case. Tamba's initiative, his credibility, and his ability to ask a simple question: "What are you going to do?" has saved lives.

Learning to bury their own

Kenema District is close to the border of Liberia and Guinea and was the initial hotspot of the Ebola outbreak in Sierra Leone. But between July and September 2014, the district saw a dramatic decrease in the number of newly confirmed cases.

The IRC has had an active presence in Kenema for 15 years, working in health facilities and in communities throughout the district. As the Ebola outbreak grew, it became clear that practices involving death, burials and care for the ill were largely responsible for the spread of the disease. Contact with the bodies of deceased Ebola victims is a key source of exposure in new cases. Where the source of contact was known, funerals were the source of infection for between 70 and 80 percent of the Ebola cases in Sierra Leone, according to the CDC.

Since communities were best positioned to take into account their practices, beliefs and concerns, the IRC shared a questionnaire with chiefs, religious leaders, and women and youth leaders. The questionnaire focused on two issues: What strategies did the leaders think would work best? And how would they like to be involved?

The IRC received an overwhelming response, which included details of actions they had already adopted. They described successes in getting family members to call an ambulance for suspected cases.

Community leaders also asked for specific assistance, such as protective equipment for relatives to use until ambulances arrived. The infection control measures undertaken, and requests for support, varied from place to place. Some chiefs wanted to provide a separate place in the community to keep individuals under the care of community members until ambulances arrived. A few suggested that the government place an ambulance near the chief's headquarters to speed up arrival times.

"We actually want to ensure they eat, wash and ease themselves (use toilet) with our care and support," a leader responded. "Helping the sick is the right thing to do as they cannot do it for themselves. It is very cruel to abandon a family or community member."

Many of the responses detailed the difficulty of reconciling Ebola control measures with traditional customs, particularly burials.

"We do not like it that way at all," a leader said. "It has not been our culture and tradition to do so, and it is very painful."

Changing such behavior has proven to be an intense challenge in both Sierra Leone and Liberia. Despite these challenges, community leaders in Kenema expressed a willingness to make the necessary changes and a desire to instruct their communities on how to make the changes themselves.

Community members expressed particular concern about the treatment of the deceased by external teams. They described burial teams who worked in hasty and disrespectful ways and, in one instance, arrived drunk. In response, community leaders suggested an alternative to outside burial teams: they requested that trusted community members receive training on how to conduct safe burials. This would also allow them to ensure proper respect to the deceased.

"We really want them to allow us to bury our dead people," a community leader said. "If it is not safe the way we have been doing it because of Ebola now, then let them teach us and tell us all the things we should do to make it safe for us to do it ourselves. But at least let us not see strangers burying our people and more so dropping our dead relatives hastily into a hole."

This work of training community members, and willingness to redevelop protocol, has led to vastly increased collaboration by the families of people who had died — a development that has the potential to save many lives.

Pushing Ebola back, street by street

Dr. Mosoka Fallah is implementing what he calls a community-based initiative to stop the Ebola virus. He is working in Montserrado County, which includes Liberia's capital city, Monrovia. Nearly half of the total deaths in Liberia have occurred in Monrovia and greater Montserrado County.

Dr. Fallah grew up in the densely-packed urban neighborhoods of Monrovia, and he knows them well. He returned to Liberia in January 2013 after completing a doctorate in immunology and a master's degree in public health in the United States. In Monrovia, he launched a flagship training program in public health for mid-level health workers of the Ministry of Health and Social Welfare through a USAID grant that was implemented by Indiana University. Working alongside friends,

LEFT: Dr. Mosoka Fallah discusses his Ebola response plan. RIGHT: Teams in charge of burying the bodies of suspected Ebola victims. The teams are made up of Liberian health workers organized by Global Communities, one of the IRC's partner organizations in Liberia.

he was also starting a non-profit Refuge Place International clinic. As he was in the process of graduating the first batch of public health technicians in March 2014, he was quickly confronted with the spread of Ebola. Fortunately, he had the trust of senior officials at the Ministry of Health and of neighborhood groups.

Dr. Fallah quickly came to realize that there was a disconnect between the residents of Monrovia and health authorities. Many individuals did not believe official information about Ebola, and many people did not believe that the disease existed. As a consequence, many individuals were not referring suspected cases of Ebola for treatment or notifying authorities of the disease's spread.

Dr. Fallah initially began working on a small scale in West Point, the biggest slum in Liberia. He started by convincing households to refer cases to health authorities. He realized the widespread nature of the problem, and that his approach needed to be dramatically scaled up. He developed a model that began with community meetings and training in surveillance and culminates in an Ebola response plan that is designed and implemented by the community itself.

He recruited a team of 18 medical students to help him. He joined forces with community groups that had already established their own Ebola response networks in urban slums. With the support of IRC partner Action Against Hunger (ACF), Dr. Fallah was able to reach more than 170 communities in Montserrado County. In one neighborhood alone, his team uncovered 34 hidden Ebola deaths, which then allowed for more effective contact tracing and containment. In all of the communities where Dr. Fallah works, people have organized task forces that collect daily information on new cases and deaths. They also report on visitors who are moving in and out of the community.

Dr. Fallah is ready to expand his initiative. The resources he needs are modest — more staff, a vehicle, smartphones to transmit information more effectively and rain gear for his staff. In the meantime, some of the communities he is working with have already begun to help neighboring communities organize.

Dr. Fallah's achievements are based on his understanding of community members and the mutual respect they have for each other. He is succeeding because he approaches communities as allies who will bring know-how to the fight against Ebola.

The methods of Dr. Fallah and his allies are key to curtailing the outbreak in Monrovia. If one man can be so effective using the approach of working with communities, it stands to be seen what can be accomplished with an army of people and communities using the same approach.

"It cannot be done from behind a laptop or with a written policy," he said, about stopping the outbreak of Ebola. "It is about getting your hands dirty.

End notes

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We are grateful to Alpha Tamba, Mosoka Fallah and the community leaders of Kenema, Sierra Leone for sharing their stories, and most of all for the lives they have saved, and are continuing to save.

The International Rescue Committee (IRC) responds to the world's worst humanitarian crises and helps people to survive and rebuild their lives. Founded in 1933 at the request of Albert Einstein, the IRC offers lifesaving care and life-changing assistance to refugees forced to flee from war, persecution or natural disaster. At work today in over 40 countries and 22 U.S. cities, we restore safety, dignity and hope to millions who are uprooted and struggling to endure. The IRC leads the way from harm to home.

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