



**World Health
Organization**

Building the legacy of Ebola

**Survivors, health systems, and a blueprint for
research and development**



**Report
to donors**

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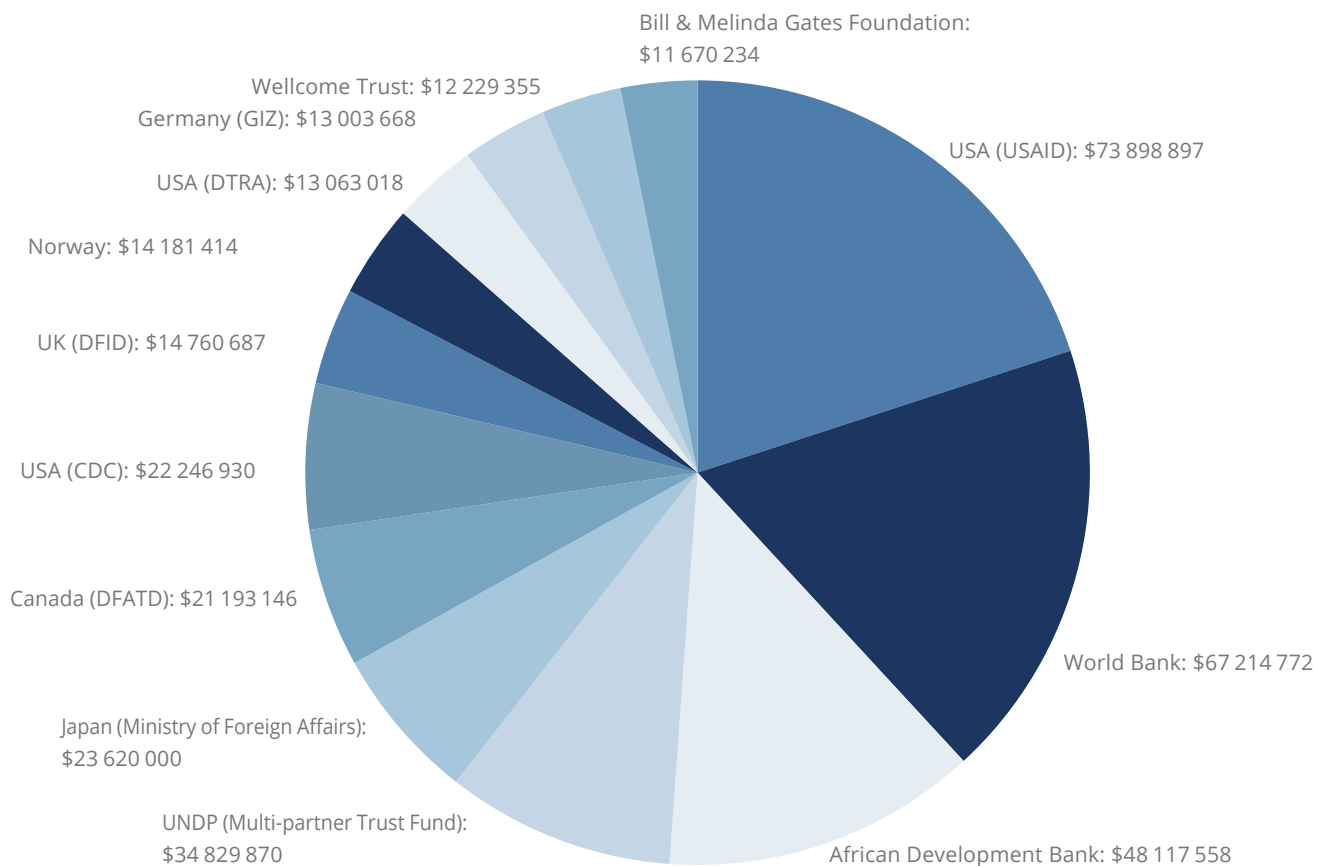
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Introduction

More than 11 000 people died from Ebola virus disease (EVD) in Guinea, Liberia and Sierra Leone during the 2014–15 West Africa epidemic: many times more than the total infected during all previous outbreaks of the disease combined. But that terrible death toll is only half of the story. The unprecedented scale of the outbreak resulted in an unprecedented number of survivors, many of whom still need help to deal with the lasting physical and psychosocial consequences of their infection. This new, complex and often marginalised patient population placed a significant additional burden on the shattered health systems of Guinea, Liberia, and Sierra Leone—systems that urgently needed to be rebuilt. The severity of the outbreak also opened the eyes of the world to our collective vulnerability to emerging and re-emerging infectious diseases, and the need for coordinated global action to ensure that we are better prepared for the next outbreak—forearmed with the vaccines, therapeutics and diagnostics that were absent during the height of the EVD epidemic.

Previous reports to donors have detailed WHO's leading role in the international response that, by the end of 2015, had successfully brought an end to human-to-human transmission directly linked to the original outbreak. This report describes the work done by WHO from January 2015 up to the end of December 2016 to address the long-term issues of survivor care, health-systems strengthening and research. This work would not otherwise have been possible without the foresight and commitment of donors (see below) who, having contributed generously to the WHO-led response to the outbreak, recognised the importance of dealing with its consequences.

Top donors (>\$US 10 000 000) to WHO's Ebola response



The WHO EVD Survivor Programme

Although outbreaks of EVD have previously been documented in Central Africa, very little is known about the long-term effects of the disease in people who have recovered from acute infection. Anecdotal reports and case studies of the clinical problems experienced by survivors began to surface early on during the West Africa epidemic, but most of these early reports described the experiences of health workers who had been medically evacuated, many by WHO, after contracting EVD whilst caring for patients, and who had been treated in countries with advanced health facilities. Although these reports yielded important insights, it was unclear how representative they were of the wider survivor population. It was not until early 2015, after the peak of the epidemic, that researchers were able to start to systemically build up a picture of some of the lasting effects experienced by the general survivor populations in Guinea, Liberia, and Sierra Leone.

In August 2015 WHO convened the first workshop on EVD survivors in Freetown, Sierra Leone, to bring together survivors, national policy makers, clinicians, researchers, and operational partners. The aim of the workshop was to review the available evidence about the difficulties faces by survivors, and at the same time plot a course ahead to ensure that survivors and their contacts received the care they need to cope with the lasting effects of infection and protect themselves from any possible risk of reinfection. It was immediately clear that there were many challenges. All available data pointed to the existence of a post-Ebola syndrome, with a large proportion of survivors experiencing joint pain, headache, muscle pain, sleeplessness, depression, and eye problems such as blurred vision, uveitis, conjunctivitis and vision loss. There was also increasing evidence that the virus persisted for longer in parts of the body that were protected from an intense immune response, such as the testes in men, the inside of the eye, placenta and fetus, and the central nervous systems. Gaining a better understanding of how long the virus persisted in parts of the body was identified as a particularly high priority in the context of managing the residual risk of reinfection, particularly reinfection through contact with the semen of male survivors.

Another important question was how best to determine the size of the survivor population itself. Due to the under reporting of cases in the community, and the varying proportion of suspected cases that were likely to have been confirmed but were never tested, taking all confirmed, probable, and suspected cases into account gives the most reliable estimate. By multiplying this total by 1 minus the case fatality rate, we get an estimated total survivor population of approximately 10 000 (table 1), most of whom are located throughout Liberia and Sierra Leone.

The data and testimony presented at the August meeting made it clear that coordinated action was urgently needed to inform survivors and their close contacts to protect them from the risk of infection, and on the other hand tackle the social stigma and isolation endured by many survivors, and ensure that that their clinical needs were understood and addressed. Attendees agreed that WHO should lead the development of Interim Guidelines for Clinical Care for Survivors of Ebola Virus Disease, and establish a survivor programme led from WHO headquarters in Geneva to coordinate work in two main areas:

- 1) Ensuring the provision of best clinical care for the common problems suffered by EVD survivors
- 2) The assessment and management of the residual risk of transmission and re-ignition of outbreaks. Most importantly the risk linked to the persistence of Ebola virus in the semen of male EVD survivors.

Below and right | Engaging with communities and religious leaders is a key part of the SA-Ceint programme in Guinea, helping to erode the stigma associated with having survived infection with EVD. These images show WHO staff meeting members of the general community: teams were not permitted to take photographs of survivors owing to the marginalisation that many still face.



Table 1 Estimated total number of survivors and male survivors

| Country | Case fatality rate | Confirmed, probable, and suspected cases | Total survivors | Total male survivors |
|--------------|--------------------|--|-----------------|----------------------|
| Guinea | 62% | 3805 | 1446 | 723 |
| Liberia | 66% | 10 084 | 3429 | 1714 |
| Sierra Leone | 69% | 14 124 | 4378 | 2189 |
| Total | | 28 013 | 9253 | 4626 |

The WHO EVD Survivor Programme was launched in November 2015, with a small technical team in headquarters and a dedicated Country Office focal point in each of the affected countries to coordinate activities tailored to their respective national contexts. In collaboration with a number of key partners including US CDC and Médecins Sans Frontières (MSF), in January 2016 the team published the first iteration of the [WHO Interim Guidance on Clinical Care for Survivors of Ebola Virus Disease](#), which was subsequently translated to French and updated in June 2016. In September 2016 the role of the team in headquarters transferred to the WHO Regional Office for Africa, with Country Office focal points continuing to provide assistance to national efforts to promote the health and welfare of survivors.

Guinea

In Guinea, of 1268 registered survivors in the country's database, 1078 (85%) had been found alive by the end of August 2016. The WHO Country Office has worked closely with the Ministry of Health National Coordination Cell for the Fight against Ebola to implement the Guinean survivor programme: Surveillance Active en Ceinture (SA-Ceint). The programme is based on active disease surveillance of the families and close contacts of survivors, and is implemented by a dedicated team of survivors who report suspicious health events in survivors and their contacts to a district-level SA-Ceint team on a weekly basis. The approach stemmed from a need to minimise the risk associated with virus transmission from a survivor, which was suspected to be the cause of several small-scale flare-ups of transmission in areas of Guinea that had previously been free of EVD transmission for some time.

The programme is scheduled to run until the end of 2017 and is complemented by survivor clinics run by international non-governmental organizations (NGOs) such as MSF and Alima, as well as by the national health system, although, because specialized referral capacities are mostly concentrated in the capital, most complex cases are referred to Conakry. The WHO Country Office survivor focal point in Guinea will continue to work with the country's MoH to address the main areas of need for survivors, which include a lack of essential medicines and equipment for survivor care, and the limited availability of specialists outside the capital, particularly in the areas of eye care and mental health.

Liberia

There are 1558 survivors registered in Liberia: a number at the lower end of WHO's estimate of the number of survivors in the country. The WHO Country Office is continuing to work to support the ministry of health, which has developed a 5-year implementation framework to integrate survivor care into the national health system as part of wide-ranging health-system strengthening.

WHO has supported the Liberian Ministry of Health to adapt clinical care guidance for survivors to the national context (published in March 2016). WHO also helped the ministry to convene two national workshops designed to disseminate guidance to key facilities throughout the country, and to forge connections and build a network of clinicians who provide clinical care to EVD survivors as part of governmental and non-governmental programmes. In parallel, the Men's Health Screening Program has been run since 2015 to test the semen and monitor the general health of male survivors. The program is run collaboratively between the Liberian MoH, US CDC and WHO, and has been crucial in helping to characterise the residual risk of reinfection potentially posed by the semen of male survivors.

In the longer term WHO will continue to support the Liberian MoH to continue to identify and register EVD survivors, and ensure access to routine and specialized care, essential medicines and referral capacity.

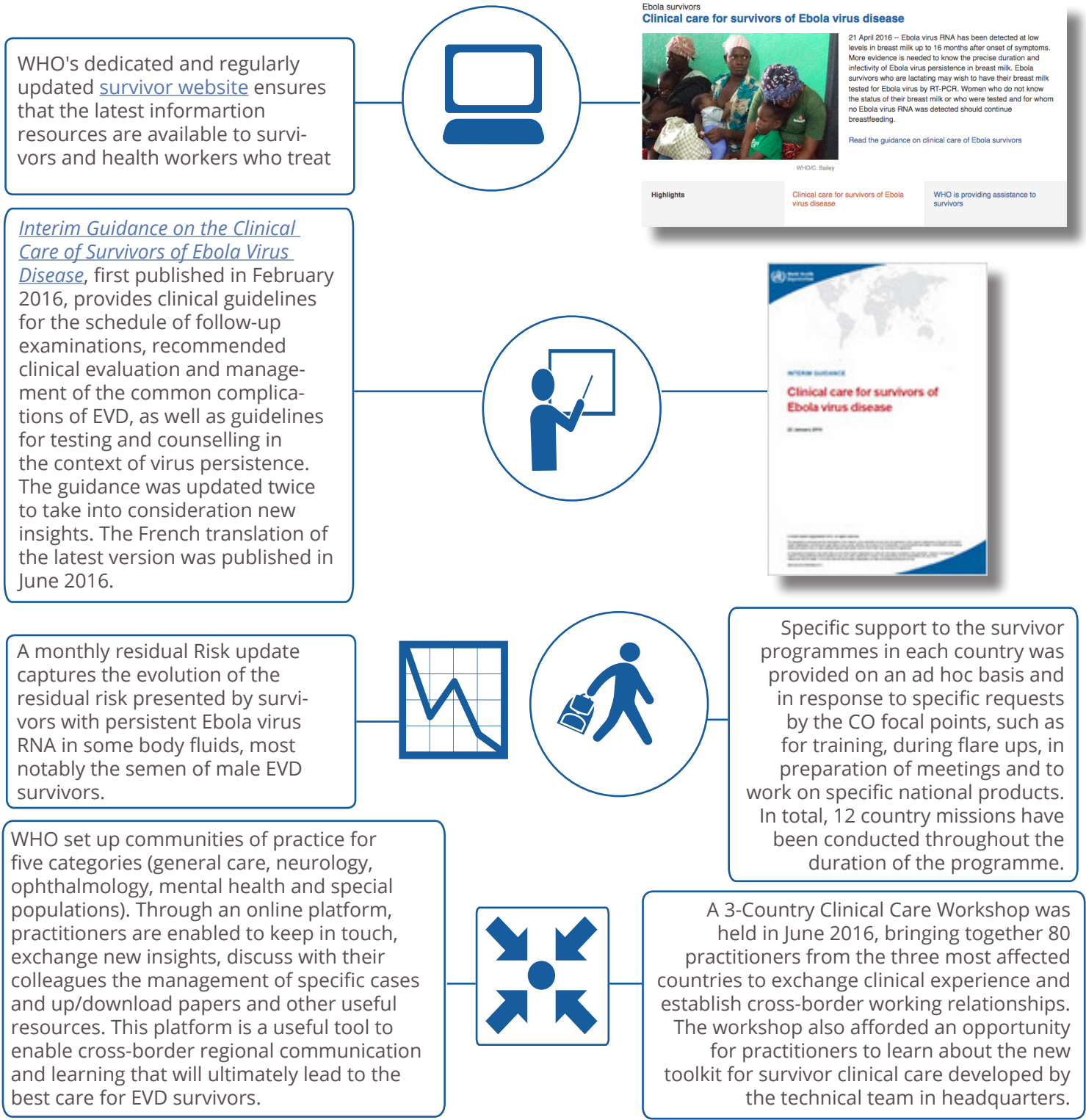
Sierra Leone

Almost 3500 survivors are registered by the Ministry of Social Welfare, Gender and Children's Affairs (MSWGC) in Sierra Leone, compared with an estimate of 5000 by WHO. The WHO Country Office has worked as part of a consortium that includes the MSWGC, the Ministry of Health and Sanitation, and other international and national partners to roll out the Comprehensive Programme for EVD Survivors (CPES). The programme has created a nationwide, coordinated network of survivor care centred on survivor advocates who are focal points for the survivor community, help to direct survivors to appropriate clinical care, and report events potentially related to Ebola virus persistence. Each health facility in the country has a member of staff who has been trained to examine survivors, provide necessary care for common conditions, and to refer them to specialist services if needed. A system of procurement of essential drugs has been established to ensure that the main medications needed to treat survivors are available. In addition to CPES, the government also runs the Project SHIELD testing programme to screen the semen of male survivors, helping to ensure that they and their close contacts understand the potential risks of reinfection.

WHO continues to work with relevant partners in Sierra Leone tackle remaining challenges including shortages of equipment and subspecialty capacity to treat survivors who require specialised treatment.

WHO EVD survivor programme: key outputs

Between November 2015 and the end of September 2016 the WHO EVD Survivor Programme worked fast to establish a solid foundation of guidance, tools, networks and programmes upon which the future of survivor care in Guinea, Liberia, and Sierra Leone can be built.



Strengthening health systems

The fragility of the health systems of Guinea, Liberia, and Sierra Leone, was one of the primary drivers of transmission in the early stages of the West Africa Ebola outbreak. As the outbreak spread, these health systems collapsed completely, with dire consequences. Over 10 000 additional deaths from HIV/AIDS, malaria and tuberculosis are estimated to have occurred, whilst routine immunization programmes for measles and other preventable diseases were interrupted. As a result, the national governments of Guinea, Liberia and Sierra Leone developed plans not only to rebuild their health systems in the wake of the outbreak, but to ensure that they would be prepared to detect and respond to any future outbreak of infectious disease.

Throughout 2016 a small team based in headquarters and the Regional Office for Africa worked across Guinea, Liberia and Sierra Leone to link service delivery with health promotion and social determinants, building resilience through community engagement. WHO has also supported each of the three Ebola-affected countries in their efforts to reform district health management teams (DMHTs), convening a technical workshop in April 2016 to rethink leadership and management capacity strengthening within the context of resilient sub-national health systems. Representatives from the Ebola-affected countries developed roadmaps which are now being translated into operational planning.

Guinea

In Guinea, WHO has supported national efforts to standardize quality service delivery throughout the health system, and address training gaps in the use of personal protective equipment (PPE) in order to better protect health workers from infection in any future outbreak.

In addition to developing triage guidance for the national context, WHO also implemented training and supervision of infection prevention and control (IPC) activities in 12 prefectural hospitals and 52 health centres between April and July 2016. Over the same period 600 resident students from the Faculty of Medicine, Pharmacy and Dentistry of Gamal Abdel Nasser University of Conakry were also trained in basic Infection Prevention and Control, ensuring that the future generation of clinicians are better prepared for any future epidemic.

Universal health coverage and quality

February 2016 | The Kobe Workshop on Resilience and Quality Universal Health Coverage was convened by WHO in Kobe, to bring together partners from the three-Ebola affected countries to develop consensus on the linkages between recovery, resilience and quality universal health coverage, based on the experiences of participants.

March 2016 | Through the generous donation of the Japanese Ministry of Foreign Affairs, WHO initiated a twinning partnership for improvement initiative between Nagasaki University, Japan and Tellewoyan Memorial Hospital in Lofa County, Liberia .

June 2016 | WHO hosted the Lead & Deputy Lead of the Liberia MOH in Geneva, Switzerland, to discuss operationalization of the national health quality strategy and facilitate sharing of best practices and key lessons learned on the successful application of quality of care strategies.

October 2016 | Following a scoping visit to sensitize the government and partners on the TPI initiative, WHO initiated a quality and safety in-depth situational assessment to identify bottlenecks, barriers and drivers for instituting quality improvement as a critical component of service delivery systems in Tellewoyan, Liberia.

November 2016 | WHO convened an action planning workshop in Geneva with representatives from Liberia and Japan to take forward recommendations of the situational assessment conducted in Oct 2016, and developed a sustainable plan of action between Tellewoyan Hospital and Nagasaki University.

Liberia

In Liberia, WHO has been working with the Liberian Ministry of Health to implement its plans to embed quality improvement approaches into routine service delivery, and institutionalize quality of care and patient safety as a fundamental element of its health system. Having collaborated with the Liberian government and other partners to develop 28 IPC and Water, Sanitation and Hygiene (WASH) indicators throughout 2016, in 2017 WHO will support the implementation and monitoring of evidence-based IPC guidelines in the field. WHO will also continue to support the development of the Liberian National Health Quality Strategy, continue to provide technical assistance for a twinning partnership between Liberia and Japan.

Sierra Leone

WHO continues to support the Ministry of Health and Sanitation (MOHS) to strengthen capacity to prepare for and respond to public health events. Key milestones achieved throughout 2016 include the creation of public health emergency management committees (PHEMC) at the national and district level, the development of hazard-specific preparedness and response plans (EVD, cholera, flood and Zika virus), the development and validation of operational guidelines for rapid-response teams (RRTs), RRT training modules, and the training of RRT members (12 at national and 156 at district level). In January 2016 rapid-response teams dealt swiftly with a flare-up of EVD caused the re-emergence of persistent virus. WHO continues to maintain institutional readiness to respond within 6 hours to any new outbreak.

WHO has continued to support the MOHS to implement Integrated Disease Surveillance and Response (IDSR) and the International Health Regulations (IHR) 2005 within the Presidential 10 – 24 months post Ebola recovery plan. IDSR roll out has been helped by the maintenance by WHO of 13 district field offices, each with at least nine staff (five technical and four in administrative or support roles) who supported the District Health Management Teams (DHMTs) in the transition from Ebola response to the restoration of essential health services, IPC strengthening, community engagement and management capacity building. In addition to the capacity building and technical support offered by the district teams, the operational capabilities of the WHO field offices have been a stabilizing factor in ensuring a prompt response to disease alerts, and the provision of technical support for immunization.

Moving the needle: vaccine development in an emergency

When the Ebola outbreak began, there were no approved vaccines, medicines or diagnostics for the disease. From the outset WHO played a leading role in coordinating the research and development of new treatments, diagnostics, and vaccines, working closely with governments, academia, and industry to accelerate development of key new technologies. As a result there are now 13 separate diagnostic tests approved by WHO for emergency use. However, the development of a safe, effective vaccine against Ebola has been, in the history of vaccine development, a completely unprecedented achievement, compressing what would ordinarily take over 10 years into under two. The VSV-EBOV vaccine shows what can be achieved when regulators, academics, industry, governments and international institutions align to achieve a research and development goal.

As well as providing a vaccine for use in the response, the experience of bringing the world together in a coordinated research and development effort has enabled WHO to help spearhead a global movement to ensure that the world is able to act quickly the next time there is a major disease outbreak. The lessons learned from Ebola have already informed the response to the Zika virus in early 2016, with research integrated into the Strategic Response Framework for Zika. The research and development blueprint (see over) sets out a clear roadmap for the development of systems to govern and coordinate the rapid activation of research activities during an emergency. And WHO is committed to playing an active role in the [Coalition for Epidemic Preparedness Innovations](#) (CEPI), which was officially launched at the World Economic Forum in January 2017. As well as developing vaccines against known infectious diseases, CEPI also hopes to shorten the time it takes to invest in facilities and partnerships to enable the development of new vaccines against new, sudden-onset infectious disease threats.

Research and development

The West Africa Ebola epidemic saw the large-scale mobilization of governments, academia, industry and other institutions across the globe in an effort to learn more about Ebola and develop the medical technologies needed to save lives. Many of those efforts brought results. Post-Ebo-Gui study of EVD survivors in Guinea, PREVAIL III natural history research study in Liberia, and the Viral Persistence Study in Sierra Leone have shed light on the lasting effects experienced by survivors. The VSV-EBOV vaccine was shown to be highly effective, and played a pivotal role in the latter stages of the epidemic. However, Ebola also exposed serious shortcomings in the way the global scientific and research and development community organises itself during an epidemic.

WHO has convened the [R&D Blueprint](#) coalition to produce a global strategy and preparedness plan that allows the rapid activation of R&D activities during epidemics. Its aim is to fast-track the availability of effective tests, vaccines and medicines that can be used to save lives and avert large scale crises. With WHO as convener, the broad global coalition of experts who have contributed to the Blueprint come from diverse medical, scientific and regulatory backgrounds. WHO Member States welcomed the development of the Blueprint at the World Health Assembly in May 2016.

The road ahead

Building our capacity to respond effectively to new global disease threats is crucial to achieving the Sustainable Development Goals. Ebola showed how an uncontained epidemic can set back decades of progress in health and economic development. WHO will continue to work to ensure that the legacy of Ebola is stronger, more resilient health systems in Guinea, Liberia, and Sierra Leone, and a stronger, more resilient mechanism of global preparedness, detection, and response are developed.

To that end, the creation of the WHO Health Emergencies Programme (WHE) in 2016 has been at the heart of a broader process of WHO reform. Since May 2016, when Member States mandated the creation of the new programme at the World Health Assembly, the WHE has made rapid progress towards building the operational capacities and capabilities that will enable WHO to respond more effectively to outbreaks and emergencies. WHO now has an established structure and Standard Operating Procedures (SOPs) for the WHE programme, has ensured consistent use of the new Incident Management System to coordinate responses to emergencies, and at the same time, has continued to provide technical and normative support for our Member States.

WHO's responses to recent crises—including the humanitarian crisis in northeastern Nigeria, outbreaks of yellow fever in Angola and the Democratic Republic of the Congo, and Zika virus in several regions—have shown that WHO is moving in the right direction, and that the Organization continues to learn and refine how it works. But there is much still to do. To deliver for populations affected by health emergencies we must continue to strengthen WHO's core capacity, particularly in areas related to providing direct help to affected populations. Building this sustainable capacity will take time and investment, but as the Ebola outbreak showed, there are potentially enormous returns to be gained from averting even a single uncontrolled epidemic.