Momentum is clearly building to deliver on the global promise to improve access to health for the underserved. Partnerships across sectors are galvanizing to accelerate responses to noncommunicable diseases (NCDs), universal health coverage (UHC), and health worker shortages worldwide. From UN declarations, creative public-private partnerships, engaged local health systems and nongovernmental organizations, and activated networks of people living with NCDs, their health workers, care teams and families - it is clear that the field of global health is mobilized to reach our goals.

As a collaborator in this response, we believe that progress can be leveraged when we listen to our partners and distill key lessons from their views and the results achieved. In our work together, we have found four crucial elements that lead to improved patient outcomes for NCDs in underserved communities:

- Being creative to improve healthcare worker capacity;
- Engaging communities in care delivery;
- Focusing on sustainability and scale in every phase of implementation; and
- Ensuring continuous improvement through examination of results and lessons learned.

Thank you to our partners for their openness to new ideas, trust in sharing perspectives, and most importantly, their dedication to ensuring health access for the underserved. Their invaluable insights and lessons will undoubtedly spark bold efforts across many others who aim to improve healthcare for underserved populations globally.

The pace of change in global health is exciting as the landscape evolves with each new partner, perspective and opportunity. We look forward to continuing in this journey with countless others who bring new ideas to solve the problems of improved health for the underserved.

Paurvi Bhatt
Vice President, Medtronic Philanthropy
President, Medtronic Foundation
This report highlights the learnings across Medtronic Foundation’s Global Health portfolio, bringing together lessons in the following areas:

CAPACITY BUILDING
HEALTHCARE WORKER CAPACITY

COMMUNITY ENGAGEMENT
LINKAGES TO COMMUNITY-BASED SERVICES

COMMITMENT
SUSTAINING AND SCALING PROGRAMS
Introduction

ACKNOWLEDGEMENTS

Medtronic Foundation is focused on improving health access and outcomes for the underserved.

In building a successful future for global health, Medtronic Foundation sought to learn from the past through the lens of partners’ evidence and expertise. Medtronic Foundation’s partners reflected on the best practices that have led to their success in improving noncommunicable disease care and strengthening health systems. Medtronic Foundation deeply appreciates these partners’ passion for and commitment to improving health for underserved populations and extends a special thanks to partners who shared their insights and stories for this report. The report that follows highlights these learnings across Medtronic Foundation’s Global Health portfolio, bringing together lessons in health systems strengthening and capacity building for the health workforce, community engagement to improve patient empowerment and self-care, and commitments to sustaining programs which we hope will serve as a guide for implementers and funders interested in building the future of healthcare in low resource settings.

MEDTRONIC FOUNDATION GLOBAL HEALTH INVESTMENTS

Medtronic Foundation’s Global Health work is focused on improving health outcomes for underserved populations around the world through scalable and sustainable models.

Noncommunicable diseases (NCDs), including cardiovascular disease, diabetes, and other chronic conditions, are the leading cause of death and disability worldwide and are on the rise in low- and middle-income countries. Medtronic Foundation has prioritized investments to address NCDs, given the particular burden they have on underserved populations worldwide.

Medtronic Foundation’s partnerships are focused on chronic disease management programs, supporting successful models of care for acute conditions, and empowering patients and frontline healthcare workers to ensure their experiences are represented in the larger global dialogue about healthcare. Medtronic Foundation operated three multi-country, multi-stakeholder, multi-year Signature Global Health programs focused in these areas. In addition, Medtronic Foundation partners with organizations to pilot innovative ideas to improve healthcare delivery through a variety of one-year opportunity grants. Across all Medtronic Foundation’s partnerships, the Foundation seeks ways to elevate the experiences of patients and of front-line healthcare workers, which are often missing in global conversations about healthcare.
Executive Summary

Partner best practices are highlighted through the three domains of capacity building, community engagement, and commitment to sustaining and scaling programs. Medtronic Foundation’s partner stories highlight snapshots of successful approaches to program implementation and recommend lessons learned for future implementation. A summary of these recommendations is included directly below, with the full domains following in the body of the report.

Best practices for healthcare worker capacity building, community engagement and self-care, and commitments to sustaining programs

CAPACITY BUILDING – HEALTHCARE WORKER CAPACITY

- Tailor clinical guidelines to specific healthcare worker roles to help providers better understand their contribution to noncommunicable disease (NCD) care, both as individuals and as part of the broader system.
- Create interactive, team-based training models to build relationships and strengthen communication across otherwise separate players in the healthcare system.
- Ensure trainings include feedback mechanisms for all team members to understand the shared goals, strategies, current performance metrics, and best practices and areas of improvement.
- Individualize training to healthcare workers’ knowledge and practice gaps through competency-based assessments and clear feedback loops.
- National Community Healthcare Worker programs should focus not only on increasing access to essential health services, but also on the quality of healthcare delivery.
- Create ongoing opportunities post-training for real-time feedback and mentoring.
- Pair trainings with continued in-person and remote mentorship to reinforce and improve skills.
- Use the patient experience to inform trainings and help providers problem-solve and improve care holistically.
- Engage stakeholders to ensure capacity building investments address local surgical needs, challenges, and opportunities.
COMMUNITY ENGAGEMENT – LINKAGES TO COMMUNITY-BASED SERVICES

- Translate health advice into action by having CHWs offer support in locations where patients routinely make choices about healthy living.
- CHWs and CPs can provide anecdotal evidence of patients activated and empowered to self-management, but systematically measuring patient empowerment remains challenging.
- Improve patient linkages to clinical care and health management by providing resources that go beyond the traditional medical approach, like food prescriptions.
- Use community resources creatively to meet patients in their homes, overcome barriers to care, and address patient needs.
- Integrate community organizations as part of the healthcare team to more effectively address patients’ social needs.
- Allocate sufficient project staff and time for community-based services, as these project activities compete with staff capacity needed for noncommunicable disease (NCD) screening, diagnosing, and treatment.
- Especially in decentralized, rural settings, identify and engage a broad network of local community-based organizations to build the foundation for accessible programming and help overcome transportation barriers for patients.
- Understand barriers faced by underserved population (example: food insecurity) and foster partnerships with other sectors to overcome these barriers paired with tailored educational interventions.

COMMITMENT – SUSTAINING AND SCALING PROGRAMS

- Identify ways to demonstrate value to decision-makers throughout implementation.
- Align programming with core government priorities to lay the groundwork for future uptake.
- Identify the conditions that demonstrate political willingness for project implementation.
- Cultivate government champions who can make the case for ongoing investment in proven programming.
- Closely monitor national health policies to understand how sub-regional differences affect policy implementation.
- Count and demonstrate the burden of disease to gain the attention of policy-makers, especially critical for rare and “invisible” diseases, such as congenital heart disease.
- Use insights from people living with noncommunicable diseases (NCDs) to improve programming, raise awareness, and advocate for change.
- Embed respectful and authentic engagement of people living with NCDs into existing decision-making structures and systems to strengthen the NCD response.
- Scale up by embedding new norms of engagement with PLWNCDs across all levels of the health system.
Capacity building – Healthcare worker capacity

The growing disease burden of NCDs has stretched the capacity of health systems globally as countries balance the demands of both infectious and noncommunicable diseases at a population level.

In this context, providers need trainings and tools that are responsive to the NCD burden and focused on improving skills and knowledge, which can translate into improved patient outcomes. In support of strengthening healthcare worker capacity, Medtronic Foundation has partnered with implementing organizations, whose stories are featured below, to strengthen healthcare worker competence and confidence in disease awareness and treatment, chronic condition management, and acute, emergency response for time-critical events, and provide ongoing mentorship and performance improvement with the goal of improving NCD care for underserved patients globally.
In its mission to improve acute stroke care and clinical outcomes, Duke Clinical Research Institute (DCRI) relied on their proven and promising model of systems implementation where a key component of training and education is used to simplify complex guidelines into a streamlined playbook and use training to build provider relationships that improve patient care and outcomes.

Through work on treating acute heart attacks and sudden cardiac arrest dating back to 2003, DCRI had learned the power of simplifying and streamlining clinical guidelines into playbooks. For its IMPROVE Stroke program, DCRI transferred the model to stroke care, creating a playbook from the American Heart Association/ American Stroke Association guidelines, expert opinion, and consensus best practices that allowed the full spectrum of healthcare workers - from 911 staff to EMS to hospital staff - to understand their individual role in a patient’s experience of acute stroke. In addition to being team-based, the playbooks are living documents, adjusted and improved by the full range of providers using them regularly through meetings and online document hosting, allowing changes to be shared in real-time.¹

Through education about the playbook and interactive updates, healthcare providers are moving beyond didactic education to tailor and customize their learning and build cross-organizational relationships that encourage communication and support better stroke care.

**Recommendations**

- Tailor clinical guidelines to specific healthcare worker roles to help providers better understand their contribution to care, both as individuals and as part of the broader system.
- Create interactive, team-based training models to build relationships and strengthen communication across otherwise separate players in the healthcare system.
- Ensure trainings include feedback mechanisms for all team members to understand the shared goals, strategies, current performance metrics, and best practices and areas of improvement.

¹ The above data on DCRI programming is sourced from internal program reports and correspondence.
BUILD TRAININGS TO IMPROVE DIAGNOSTIC SKILLS THROUGH AN INDIVIDUALIZED APPROACH

Last Mile Health (LMH), an NGO focused on professionalizing the community healthcare worker (CHW) role in Liberia, believes healthcare worker trainings and assessments should be focused on real-world clinical practice and diagnostic skill building. LMH partners with the Ministry of Health to evaluate healthcare worker competency and performance through a correct diagnosis and treatment audit creating several clinical scenarios and assessing the correct treatment rates for core disease areas. CHW performance is then aggregated and analyzed at a national level to guide subsequent trainings and used by managers to support improvement at an individual level. In areas where performance is lower, new digital trainings have been rolled out to improve clinical performance and patient outcomes.

LMH is expanding this approach through their online Community Health Academy, which uses a similar structure of coursework, including videos, animations, quizzes, and score cards to track and build CHW skills, and targeted feedback from CHW supervisors based on performance. By building a training approach focused on demonstrating diagnostic and treatment skills and embedding a data-driven feedback loop, LMH ensures that training is goes beyond improving healthcare worker knowledge and translates into better care for patients. Over 2,000 CHWs in Liberia are currently using this platform with plans to expand to over 15,000 CHWs by 2021.²

Recommendations

- Individualize training to healthcare workers’ knowledge and practice gaps through competency-based assessments and clear feedback loops.

- National Community Healthcare Worker programs should focus not only on increasing access to essential health services, but also on the quality of healthcare delivery.

² The above data on Last Mile Health programming is sourced from internal program reports and correspondence.
**IMPROVE CARE THROUGH A RELATIONSHIP AND PATIENT-CENTERED APPROACH TO CAPACITY BUILDING**

Jhpiego partners with facilities in Kisumu, Kenya, to build skilled, component surgical teams through hands-on learning and ongoing mentorship on safe cesarean birth and pregnancy-related laparotomies for medical and clinical officers and their surgical teams. This style of mentorship builds skills and confidence in decision making, ensuring non-specialists are valued contributors to the care team. Jhpiego’s clinical trainings pair three days of didactic and simulation-based learning around safe surgery best practices and checklists with two days of hands-on practice and mentorship at the surgical team’s facility site and ongoing mentor visits. During these ongoing visits, mentors conduct direct surgical observations and simulate drills to increase teams’ comfort using the WHO surgical safety checklist. This on-the-job mentoring allows the surgical teams to practice and be coached in their daily environment, using the resources available and addressing challenges inherent to their local facilities. The surgical teams substantially increased their adherence to the WHO surgical safety checklist, which can be used as a proxy for patient safety, from 0% to 84%.³

“Some [teams] would have a patient in their operating theater and be texting one of the specialists in the capital, asking them about a particular situation, and they’ll get an immediate response.”

ALENA TROXEL
JHPIEGO

Mentors also help the surgical teams see their work through the eyes of their patients via a tool that guides the surgical teams through a patient’s experience of surgery, starting from when a patient reaches the hospital gate to the procedure itself to recovery and discharge. Through this process, surgical teams identify ways to improve the patient journey while eliminating redundancies and inefficiencies in the system.

This approach to skills building has forged strong relationships and ongoing communication between mentors and surgical teams. Some surgical teams independently created WhatsApp groups between trainees and mentors after the trainings to get real-time feedback on clinical cases.

By taking training beyond the classroom, providers build relationships and communication channels, which are critical for a well-performing surgical team, and implement system improvements based on the patient experience.

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**Recommendations**

- Create ongoing opportunities post-training for real-time feedback and mentoring.
- Pair trainings with continued in-person and remote mentorship to reinforce and improve skills.
- Use the patient experience to inform trainings and help providers problem-solve and improve care holistically.
- Engage stakeholders to ensure capacity building investments address local surgical needs, challenges, and opportunities.

³ The above data on Jhpiego programming is sourced from internal program reports and correspondence.
**ORGANIZATION:** Case Western Reserve University  
**PROGRAM:** RHD Action  
**GRANT PERIOD:** 2013 - 2018  
**DISEASE AREA:** Rheumatic heart disease

**CHALLENGE:** In the last decade there has been increasing interest in developing cardiovascular care capacity in Uganda, along with other chronic non-communicable diseases. In 2011, Makerere University began developing a cardiovascular workforce initiative in partnership with Case Western Reserve University (Case Western) and the Uganda Heart Institute (UHI). Through this partnership, it became clear that the Ugandan health workforce needed additional support to address both the detection and treatment of rheumatic heart disease (RHD), especially given that RHD affects over 1 million children in Sub-Saharan Africa.

**AIM:** Case Western, along with the RHD Action-Uganda team, worked to create a sustainable, national RHD care infrastructure by delivering trainings that leveraged existing HIV/AIDS resources and incorporated access to technology, with the goal of future uptake of training infrastructure by the Government of Uganda.

**ACTION:** As requested by Ugandan providers and in order to address the lack of healthcare professionals trained in RHD, healthcare worker training was a core priority of RHD Action Uganda. Case Western trained over 200 healthcare providers in RHD detection and both basic and advanced level treatments. They used community-based courses targeted to local providers and teachers, week-long intensive apprenticeships for regional providers, and yearlong trainings for Ugandan interventional cardiologists abroad. To strengthen local surgical skills for RHD, Case Western also facilitated the exchange of two Ugandan cardiologists to Brazil, facilitated by an RHD Action staff doctor, for two weeks of intensive training. This training structure guarantees competency at every point along the RHD care cascade, ensuring that Ugandans are diagnosed in a timely manner and have consistent access to support and both basic and advanced level treatment.

**RESULTS:** Four additional regional “centers of excellence” have greatly improved both retention of patients and treatment adherence, with 91% penicillin adherence for patients retained in care. Additionally, mortality among people living with RHD decreased by one-third after the program started compared to the four years prior to the formation of RHD Action. These centers have also facilitated echo screenings for over 13,000 children for latent RHD. Due to the success of the trainings and new reputation as a center for excellence in RHD treatment, the UHI of Kampala was given semi-autonomous status. This granted UHI independent financial management, allowing them to offer benefits, salaries, and entitlements to retain highly skilled and specialized heart surgeons and secure the long-term sustainability of Ugandan-led advanced RHD cases.

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* The above data on Case Western Reserve University and RHD Action programming is sourced from internal program reports and correspondence.
Community engagement – Linkages to community-based services

Improving health requires a commitment to addressing factors that stretch far beyond the medical to encompass the “conditions in which people are born, grow, work, live and age”\(^7\), known as the social determinants of health.

These factors affect life outside the clinic, influencing patients’ choices and outcomes in their homes and communities. Medtronic Foundation is committed to supporting patients holistically, acknowledging the breadth of factors that influence patients’ outcomes and creating linkages between the community and the clinic that promote health. The stories that follow highlight partner organization best practices in support of this aim.

BUILD AUTHENTIC COMMUNITY ENGAGEMENT

Pillsbury United Communities (PUC) links clinical and community resources for hypertension and diabetes management to reduce significant disparities in the control of these conditions among underserved populations. Their work on improving management of hypertension and diabetes is connected to the larger HealthRise program supported by Medtronic Foundation. PUC connected clinicians, pharmacists, care coordinators, and diabetes educators based at clinics to community paramedics (CPs) and community healthcare workers (CHWs) who provide culturally and linguistically appropriate primary care services to patients in their homes and community.

With the goal of providing comprehensive support for individuals with diabetes and hypertension, PUC expanded its CHW program to an unusual new space – a wellness center within a grocery store. North Market, a full-service community grocery store built in an urban food desert, provides the community with affordable, quality food as well as programming focused on nutrition, fitness, and healthy living. The CHW, who is located within the wellness center, serves as a touchpoint, linking patients with multiple services in one location and turning clinical advice into action.⁸

Recommendations

- Translate health advice into action by having CHWs offer support in locations where patients routinely make choices about healthy living.
- CHWs and CPs can provide anecdotal evidence of patients activated and empowered to self-management, but systematically measuring patient empowerment remains challenging.

FOOD AS MEDICINE FOR CHRONIC CONDITIONS

Second Harvest Heartland, a food bank working to end hunger through community partnerships, addresses the social determinants of health through a food as medicine approach, providing food prescriptions to individuals living with diabetes and hypertension in Minnesota. Stepping outside the traditional role for a food bank, Second Harvest Heartland works on an individual level to link patients with community resources to ensure clinic partners are aware of the full range of patients’ health needs.

Second Harvest Heartland operates like a bridge between clinical support for diabetes and hypertension management and patient resources at a community level. Food prescriptions are provided in the clinics as an incentive for patients to continue engaging with the health system. Early research results from the FOODRx program indicate improved hypertension and diabetes outcomes and resulted in long term cost savings to the system.⁹

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⁸ The above data on Pillsbury United Communities programming is sourced from internal program reports and correspondence.
⁹ The above data on Second Harvest Heartland programming is sourced from internal program reports and correspondence.
Recommendations

- Improve patient linkages to clinical care and health management by providing resources that go beyond the traditional medical approach, like food prescriptions.
- Use community resources creatively to meet patients in their homes, overcome barriers to care, and address patient needs.
- Integrate community organizations as part of the healthcare team to more effectively address patients’ social needs.

CREATE COMMUNITY SUPPORT NETWORKS IN LOW RESOURCE SETTINGS

Building on its model for screening, diagnosing, and managing diabetes, hypertension, and elevated cholesterol, Project HOPE, a HealthRise partner in the Northern Cape province of South Africa, approached NCD programming holistically by providing community-based support services for individuals living with these chronic conditions. Ninety-four support groups were initiated during the project, including five-step groups to empower patients, village saving and loans groups to provide patients with financial support and stability, and gardening groups to tackle food insecurity and grow nutritious vegetables for a healthy diet. Ultimately, these patient groups were designed to promote patient self-care, treatment adherence, and a healthy lifestyle. Project HOPE’s implementation in the Northern Cape uncovered important learnings about the complexity of building comprehensive NCD support services in poor, rural settings with high rates of unemployment and food insecurity. Recommendations for organizations seeking to address the social determinants of health in similar settings are outlined below.  

Recommendations

- Allocate dedicated project staff and time for community-based services, as these project activities compete with staff capacity needed for NCD screening, diagnosing, and treatment.
- Especially in decentralized, rural settings, identify and engage a broad network of local community-based organizations to build the foundation for accessible programming and help overcome transportation barriers for patients.
- Understand barriers faced by underserved population (example: food insecurity) and foster partnerships with other sectors to overcome these barriers paired with tailored educational interventions.

10 The above data on Project Hope programming is sourced from internal program reports and correspondence.
CHALLENGE: For many immigrant women, navigating the complex New York City healthcare system is incredibly difficult, with multiple barriers preventing them from accessing healthcare or gaining the information needed to manage their health conditions.

AIM: Grameen PrimaCare works through its Grameen Promotoras program to provide basic health screenings and peer group meetings for health promotion in the South Bronx. Their goal is to help their participants increase their health knowledge, increase participation in primary prevention activities, and to improve their overall health and quality of life.

ACTION: Grameen Promotoras capitalized on an existing weekly microloan meeting run by Grameen America to offer additional counseling on health topics to attendees. The peer group meeting topics were designed through continuous collaboration between Grameen’s Promotoras (community healthcare workers), Grameen’s staff physician, and the meeting participants. Importantly, the community healthcare workers as well as the staff physician are both of the community they are serving.

Additionally, the Promotoras connect the participants to health and social services such as cancer screenings and food banks. Employing and training program staff from the community of interest creates an inherent understanding of the specific, community level barriers to health and allowing providers and participants to “speak the same language”, improving trust in both the health knowledge provided and to the referred institutions. Group participants themselves also play a strong role in motivating others to take care of their health. “A lot of our women have never had eye exams. If we can get one person as part of these groups to make the trip to go get the eye exam and get the glasses, then when she comes back and shows off her new glasses, that will encourage them to do it as well. If you can get some of your participants to have successes with their appointments, that also drives other women to follow up.” Greg Mann, Grameen Primacare

RESULTS: Grameen Promotoras increased access to healthcare services and improved participant knowledge and related health behaviors. Over the course of 8 months from September 2017 - May 2018, Promotoras discussed 36 health topics during meetings and referred 376 women to health services including dental, cancer and vision screenings, primary care providers, and food pantries. Based on survey results, 41% of women who attended these meetings experienced an increase in health literacy. Additionally, they noted an increase in average daily consumption of fruit from 2.0 to 2.6 servings, an increase in average daily consumption of vegetables from 2.9 to 3.4 servings, and a 16% increase in having a primary care physician. The vast majority of participants were either very satisfied (77%) or satisfied (20%) with the program, and 90% of participants reported having learned a lot about how to take better care of their health. The above results show improvements that were not observed in the control group.  

“
We serve immigrant women, so our medical doctor is from the community...When she arrived in this country...she likes to tell the story about how she was cleaning houses. We’ve been effective because of her and her background. She knows the community so well.”

GREG MANN, GRAMEEN PRIMACARE

11 The above data on Grameen PrimaCare programming is sourced from internal program reports and correspondence.

RESULTS BY THE NUMBERS

- 41% increase in health literacy
- 0.6+ increase in average daily servings of fruit
- 16% increase in having a primary care physician
Commitment – Sustainability and scale

Sustainability and program scale are critical goals that often underpin funders’ and implementers’ approaches to global health programming, vetting program models and allocating resources effectively in service of scale.

Given the growing burden of NCDs globally and limited private and public resources, implementers and funders alike are focused on building quality programs to last. Medtronic Foundation partners have codified several key tenants for scaling and sustaining programs and driving long term change. Their learnings and insights are outlined below.
ALIGN PROGRAMMING AND GOVERNMENT PRIORITIES FOR SUSTAINABILITY

The HealthRise initiative relied on a global set of partners to pilot promising interventions to improve diabetes and hypertension care and outcomes. While pilots are a common approach to building evidence for novel public health programming, many struggle to identify follow-on funding to sustain and scale proven approaches. To ensure sustainability was built in from the start, partners engaged government and private partners to expand and extend programming beyond the pilot phase.

In Brazil, HealthRise pilots were led by HealthRise Teófilo Otoni (HRTO), comprised of a partnership of several universities, and HealthRise Vitória da Conquista (HRVC), a collaborative, university-based partnership. HealthRise Brazil was built in the public health system, in partnership with the municipal Secretary of Health, which would allow it to stay even without additional extra funding. While the two pilots used different implementation models, they both focused on improving diabetes and hypertension screening, management, treatment, data collection and use, and education of health providers and patients. The subsequent of the HealthRise pilots was driven by two primary factors. First, HealthRise Brazil was intentionally built within the public health system to ensure its continuity; the Ministry of Health used funding available within private hospitals to direct support to continuing the HealthRise pilots. Secondly, HealthRise programming was at an inflection point where project results and program learnings were emerging after a year and a half of implementation. The Minister of Health recognized this as an important moment where the pilots’ results could provide insights for other chronic disease management initiatives and prioritized their continuation. As a result, while the HealthRise pilots concluded in 2018, the government committed to fund the next phase of both pilots through the partnership of Albert Einstein Hospital, with the goal of using phase two data to inform and support routine diabetes and hypertension care management for primary health providers.

In India, HealthRise partners responded to a request from the government of Himachal Pradesh state to develop and implement an electronic Health Card to collect information on individual NCD risk factors during household visits. HealthRise partners built and tested the eHealth Card, adding on a module about follow-up care to complete the continuum of care for patients. Subsequently, the government has committed to adopting the eHealth Card, including hosting and maintaining the application through an IT agency partnership and providing relevant staff training.12

### Recommendations

- Identify ways to demonstrate value to decision-makers throughout implementation.
- Align programming with core government priorities to lay the groundwork for future uptake.

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12 The above data on HealthRise Brazil and India programming is sourced from internal program reports and correspondence.
IDENTIFY POLITICAL READINESS AND ENGAGING PROJECT CHAMPIONS FOR LONGER-TERM INVESTMENT

Children’s HeartLink expands access to care for pediatric congenital heart disease (CHD) by strengthening screening and referral systems and enhancing surgical capacity for CHD in Kerala, India. In partnership with Amrita Institute of Medical Sciences (AIMS), a Children’s HeartLink Center of Excellence for referrals and training, and the Government of Kerala, the project has trained over 800 healthcare workers on prenatal and newborn screening. The Government of Kerala allocated $3 million in their current budget for congenital heart disease treatment, equipment, and provider trainings, and most importantly, created Hridyam, a unique registration system to manage the detection, referral treatment and quality outcomes for CHD, the first of its kind in a LMIC.

Children’s HeartLink attributed their programmatic achievements and subsequent government investment to several core factors. First, Children’s HeartLink chose Kerala as the site of their pilot initially due to state’s epidemiological and political readiness to address pediatric congenital heart disease (PCHD). PCHD was a growing contributor to infant and under five mortality in Kerala and state government had crafted specific goals to address related mortality, creating an environment ready for Children’s HeartLink’s interventions. Secondly, Children’s HeartLink was working with a strong government champion at the state level and an experienced local training partner and surgical treatment center of excellence in the form of AIMS, which resulted in an ideal setting for both implementation and subsequent government investment.13

“Sometimes a region may be ready on a population-level but they may not have a government champion. We were lucky to have a government champion who understood that and wanted to work on it.”

BISTRA ZHELEVA
CHILDREN’S HEARTLINK

Recommendations

- Identify the conditions that demonstrate political willingness for project implementation.
- Cultivate government champions who can make the case for ongoing investment in proven programming.
- Closely monitor national health policies to understand how sub-regional differences affect policy implementation.
- Count and demonstrate the burden of disease to gain the attention of policy-makers, especially critical for rare and “invisible” diseases, such as CHD.

13 The above data on Children’s HeartLink programming is sourced from internal program reports and correspondence.
DRIVE CHANGE AND CONTINUED INVESTMENT IN NCDs THROUGH MEANINGFUL INVOLVEMENT OF PEOPLE LIVING WITH NCDs

The valuable contributions of people living with NCDs (PLWNCDS) have been underutilized, with PLWNCDS often having minimal roles in NCD related decision-making, policy-setting, and approaches to strengthening treatment, care, and support services. The perspectives of people with lived experiences are central to building a strong narrative on NCD prevention and control globally and ensuring people-centered policymaking and programming.

To address this gap, the NCD Alliance launched Our Views, Our Voices, an initiative by the NCD Alliance (NCDA) and PLWNCDS dedicated to promoting the meaningful involvement of PLWNCDS in the NCD response and combating stigma and discrimination. Our Views, Our Voices has reached almost 2,000 PLWNCDS around the world whose inputs have built the “Advocacy Agenda of People Living with NCDs” which serves as a compass for action for the NCD community.\textsuperscript{14} NCDA now supports the development of country-specific advocacy agendas, informed by the priorities and recommendations of PLWNCDS to act as a tool for national NCD responses, ensure a human rights and social justice approach to NCDs, and institutionalize meaningful involvement of PLWNCDS across sectors.

NCDA also developed a report, “\textit{Meaningfully Involving People living with NCDs: What is being done and why it matters}”, in partnership with PLWNCDS from thirteen countries, to define meaningful involvement, offer a framework for multisectoral involvement, and outline the skills people living with NCDs need to engage in advocacy and advisory roles.\textsuperscript{15} This report harnesses the expertise of PLWNCDS and shares case studies intended to illustrate how civil society, governments, and the health sector can begin their own meaningful involvement strategies, ultimately leading to measurable outcomes.

Recommendations

- Use insights from people living with NCDs to improve programming, raise awareness, and advocate for change.
- Embed respectful and authentic engagement of people living with NCDs into existing decision-making structures and systems to strengthen the NCD response.
- Scale up by embedding new norms of engagement with PLWNCDS across all levels of the health system.


RHD PROGRAM: US HeartRescue
GRANT PERIOD: 2011-2021
DISEASE AREA: Cardiac arrest
CHALLENGE: More than half a million people in the United States experience cardiac arrest annually, leading to preventable death and disability. Following a cardiac arrest, immediate treatment is essential for increasing the likelihood of survival with good neurologic and functional outcomes; however, many states lack the technical expertise and infrastructure to consistently achieve a fast and proficient response.

AIM: The goal of US HeartRescue is to implement effective community-based programs across the United States to measure and improve care for cardiac arrest. Engaging a range of clinical and non-clinical stakeholders, US HeartRescue aims to build state-level networks with the knowledge and experience to create an ever-improving response to cardiac arrest.

ACTION: US HeartRescue has three key components that support sustainability and scale. First, the focus on engagement at the state level can leverage policy and legislative authority to ensure cardiac arrest is a long-term priority. The successes of these early adopter states have been well documented and has encouraged further states to implement the model. Secondly, US HeartRescue provides seed dollars and initial human resources which are then matched by in-kind donations from participating states, bolstering local ownership and investment. Finally, US HeartRescue has operationalized lifesaving programs and protocols to allow for adaptable, cost-effective program adoption of core interventions, enabling each state to tailor its program priorities and investments.

Illinois is a prime example of HeartRescue’s ability to build local buy-in, forge regional partnerships, and tailor core programming to state needs. The Illinois HeartRescue team (ILHR) prioritized ensuring equity for out-of-hospital cardiac arrest by identifying and eliminating urban disparities in cardiac arrest care. Through partnerships with public health, fire, hospital, government, sports, and nonprofit organizations, ILHR implemented core programming focused on measuring and improving cardiac arrest response, providing resources for healthcare professional and EMS, and conducting bystander trainings at schools, hospitals, health associations, cultural centers, and major league sporting events.

RESULT: US HeartRescue has made important progress in Illinois and beyond; in five years, Illinois HeartRescue has improved overall cardiac arrest survival from 2% to 10%, and survival after bystander intervention has increased from 25% in 2013 to 42% in 2017, exceeding the national average.

From six original partner states, US HeartRescue has expanded to cover 18 states, home to nearly 90 million people, each with programs specifically tailored to their unique context. States have reported increases in the number of individuals trained to perform CPR, improved response times, and increased survival rates.

“Where they [Illinois] used to save a handful of lives every year, they’re now saving upwards of 100 or more lives. They’ve really made some remarkable progress that translates into public health impacts.”

TOM REA, UNIVERSITY OF WASHINGTON

16 The above data on US HeartRescue programming is sourced from internal program reports and correspondence.