Technology for Health and Disability: making ODK 2.0 accessible

Proposal Status: Awarded--Pending Funding

Executive Summary

Data is a cornerstone of health and development programs, whether it is used to evaluate the impact of programs to eradicate malaria, help local NGOs effectively measure and implement immunization programs on the ground, or adopt the best response during humanitarian crises. Today, there are one billion people with disabilities (PWDs) worldwide, constituting one of the most marginalized and vulnerable groups in every country around the globe. The dearth of data on PWDs and the health issues they face contributes to their invisibility in statistics, policies, and international programs. It is urgent that PWDs and the organizations that serve them are empowered with an operational and accessible data collection tool.

The Open Data Kit (ODK) platform has enabled numerous health organizations to implement mobile data collection and management activities in a reliable and cost effective manner, and the new ODK 2.0 offers even more capabilities to the sector. We will augment it further in close partnership with the University of Washington, health NGOs, and organizations serving people with disabilities. Through this project, we will offer to the global health community an enhanced, sustainable version of the platform that is also more accessible to PWDs and their organizations, thereby expanding the usability, impact, and user base of this crucial resource.

Background Information

Most health NGOs, even the largest ones, have limited technical and financial capacity and cannot design, build, and support efficient tools for field data collection and analysis, let alone meet the critical need for security and privacy. That is why the ODK platform has been so critical for the health sector globally: it provides an efficient and reliable tool for field data collection on mainstream devices. The next generation, ODK 2.0, offers superior capabilities to the health and social sector, such as support for elegant and advanced UIs, the ability to sync information in two directions so that an app user can access information added by other users, and improved server-side management capacity. However, applications on the platform still need to address fundamental accessibility for people with disabilities, such as audio-only navigation and multimodal interfaces.

Today, more than one billion people, 15% of the world's population, live with disabilities of various types and degrees, 80% of whom live in low-income countries (source: World report on disability, WHO and the World Bank, 2011). This estimate is likely to rise with an aging population. PWDs are one of the most marginalized and vulnerable groups in every country and are disproportionately affected by health problems. The WHO highlighted in its report widespread evidence of barriers, including inadequate policies and standards, prejudice, lack of services, and problems with service delivery. The report shows that PWDs are between two and three times more likely to be denied healthcare, and to report being treated badly in healthcare settings.

The Sustainable Development Goals (SDGs) have extensively prioritized the needs of people with disabilities. It will be difficult to attain them without including PWDs. Major funders such as DFID and Ford are also beginning to condition grants based on inclusive policies. This is an issue that is increasingly difficult to ignore, but has suffered from an extreme lack of in-depth, actionable data.

Lack of consultation and involvement of PWDs and lack of data and evidence are major barriers cited by the WHO report. The acute absence of data on their rights and condition, despite the level of abuse they are subject to globally, contributes to their invisibility in health programs and human rights debates. There are no accessible data collection tools that Disabled Persons' Organizations (DPOs) can use to collect data on the struggles PWDs face and on their needs. We want to fix this situation, and we think that ODK is the best platform to leverage to do so.

Digital Health Technologies

This project builds upon ODK 2.0 and the Android operating system. ODK 2.0 is the latest version of the Open Data Kit, an open source suite of tools that allows organizations to build mobile data collection solutions. ODK 2.0 is managed by researchers at the University of Washington, and is used to create Android-based mobile data collection tools for a range of organizations. The openness of the platform allows for those in the mobile data community to both develop tools for themselves and, where applicable, commit code back to the core ODK 2.0 platform. The Android operating system, on which the ODK 2.0 app runs, is an appealing platform for digital health organizations as Android is the most widely used smartphone platform in the developing world, with over 85% market share worldwide (Gartner, February 2018).

Project Description

We have already made significant contributions ODK 2.0 back-end code, through a project with the Skoll Foundation and Fundación Paraguaya, resulting in a more streamlined and usable platform for NGOs. Now we want to use our expertise regarding accessible technology for PWDs to continue augmenting ODK 2.0, so that it better serves the health community in emerging countries and so that it becomes a powerful tool for DPOs and PWDs. By making the ODK platform accessible to DPOs and the PWDs that they serve, we will empower them to advocate for PWDs' rights and implement more and better health programs for PWDs. DPOs will, for instance, be able to give PWDs the ability to privately answer questions about their healthcare experience or to anonymously report being denied health care.

Making the ODK 2.0 platform more accessible will not only open it up to a large and important new user audience that should not be left out, it will also benefit the health community as a whole. It will greatly improve its usability for all, making it easier for field teams to survey aging populations, or populations with low literacy levels.

Depending on available resources, we propose to implement the following activities. For the sake of clarity, we are presenting these in two phases, and we are attaching a budget for both phases. It is possible, however, for us to just implement Phase 1 under this award if necessary.

Use Cases

There are two core use cases for the health of people with disabilities. First, imagine a person with a disability working in health care who is part of a team either:

- collecting information
- managing care through a data collection process
- distributing medical supplies such as vaccines
- providing medical information

This person needs to be able to access the digital tools required for their job, including tools built upon ODK 2.0. In order to do this, these tools have to have accessibility features. Organizations that serve people with disabilities are frequently also staffed by people with disabilities, so building accessibly into the mobile data collection tools will have an amplified impact on the health outcomes of people with disabilities as it empowers the organizations that serve them. Even beyond health workers with recognized disabilities, incorporating accessibility is a good design practice as it allows for enhanced usability for "situational accessibility" – i.e. when accessibility can help due to situational elements such as harsh lighting, where screen readers can be helpful even for sighted users.

The second use case is where a person with a disability is accessing health care. This person may need to fill out a medical form describing symptoms or simply providing background information. As more of these forms move to digital platforms, accessibility features are crucial to make health care accessible to all. A variation on this use case is for surveys on quality of care that a person with a disability receives. We are seeing more data being collected about services for people with disabilities in other sectors like employment and education, and the capacity to allow people to provide personal information privately and independently in a healthcare setting is crucial to moving the field forward.

Activities

Phase 1 – Need Finding and Iterative Development

- Actively engage with health organizations, NGOs, and our consortium of partners to do user research on ODK 2.0 accessibility challenges for PWDs/DPOs.
- Iteratively develop enhancements, additional features, and development guidelines, and test them with key partners before integration into the main ODK 2.0 code.

Phase 2 – Need Finding, Iterative Development, and Implementation with Key Partners

Following completion of Phase 1 activities:

- Identify key partners to implement the enhanced features developed.
- Implement and deploy the enhanced ODK 2.0 platform with partners on the ground to get more detailed feedback, inform the development roadmap, and trigger the adoption of ODK 2.0 in the disability community.

Deliverables, Workplan, and Schedule

The activities described above will be implemented on the following workplan/schedule. Quarters refer to the project implementation quarters based on project start date.

Activities	Q1	Q2	Q3	Q4
User research	X			
Iterative development	X	X	X	X
Testing with partners		X	X	
Integration with main ODK 2.0 code		X	X	
Implementation partner identification and outreach		X	X	
Deployment with partners			X	X
Feedback and next steps				X

These activities will result in the following deliverables:

- Accessibility enhancements to ODK 2.0;
- Integration of enhancements with main ODK 2.0 code;
- Implementation of ODK 2.0 enhancements with on the ground global health implementation partners.

Consortium Team

Benetech, the lead organization

Benetech harnesses the power of Silicon Valley technology to drive positive, sustainable social impact. With an entrepreneurial team drawn from successful startups, major technology companies, and innovative social sector organizations, we are leaders in creating nonprofit software solutions that empower NGOs and communities in need. Our track record speaks for itself:

- Our work in Global Literacy has made Benetech a leader in accessibility. Bookshare , the world's largest library of accessible reading materials, has provided over 11 million books to 500,000+ readers, empowering PWDs to succeed in education and the workforce worldwide. Our DIAGRAM Center explores the advanced accessibility needs of people with a broad spectrum of disabilities.
- Benetech has been a trusted partner to the disability movement for over twenty-five years: we are serving on three national disability-related advisory committees, we played a major role in the creation and adoption of the Marrakesh Treaty, and we were a key part of advocacy for the Convention on the Rights of PWDs.
- We have been developing open source software to support the social sector for decades. We launched world-changing open source products, addressing needs in education for PWDs, human rights, poverty, and the environment. We also run Code Alliance, a social enterprise that connects Silicon Valley developers with open source software for good projects such as Medic Mobile and Samasta Health Foundation.
- During a project with Fundación Paraguaya in 2016, we enhanced the ODK 2.0 back end and built our data collection tools on top of it. Our software suite based on the latest ODK 2.0 platform included the ability to build extensible Android data collection apps quickly with features such as visual survey capability and mapping, as well as a back-end administrative system that allowed organizations to manage multiple teams collecting different kinds of data. The ODK development leadership approved our enhancements and incorporated them back into the main ODK code.
- Our flagship Martus information management platform is a leader in secure human rights data collection, assisting defenders in 50+ countries to document human rights violations.
- We already work at the intersection of data collection and accessibility, having recently partnered with Internews on the Department of State-funded USABLE program to identify PWDs' unique needs and inputs on digital security technologies.

Anh Bui, VP of Benetech Labs (anhb@benetech.org) will be Benetech's project lead. She will be the point of contact for our consortium and this proposal.

University of Washington, the lead ODK organization

The University of Washington will have a major advisory role at every step of this project as our main goal is to contribute useful and meaningful code back to the ODK 2.0 platform.

Organizations and NGOs that serve and advocate for PWDs

Benetech has been working with and for PWDs for decades. We can count on a solid list of partners to participate. These may include such organizations as Disability Rights Fund, the Leonard Cheshire Disability, Inclusion International, and/or Sightsavers. We will also leverage learning from a related project where we are engaging with a global and local disabled persons organization on mobile data and interface needs of youth with disabilities. DPOs address health challenges of PWDs in developing countries in many ways, including advocacy and direct delivery of health services.

We stand behind the motto of PWDs and DPOs: "Nothing about us without us." Those organizations know best how to implement data collection in different regions of the world for different types of disabilities, and what features ODK 2.0 should offer to serve them adequately. That is why we will rely on those partners to provide insights both during the need finding and the development phases.

Other health organizations who want to partner

We are looking forward to hearing from other health organizations that are currently using ODK 2.0 or are planning to do so, in order to

broaden and strengthen our consortium team.

Community Feedback

Benetech will engage with both health NGO partners and organizations who serve people with disabilities in other sectors to solicit feedback from the community. This fits into a wider initiative at Benetech focused on data around the rights of PWDs in areas outside of health (including employment and education). Our work gives us access to a large community that is deeply involved in the delivery of services to PWDs, and will provide valuable insights into effective health delivery. With this community, as well as other key voices we will identify specifically for this project, Benetech will actively solicit feedback through a range of communication channels.

Self Assessment on the Global Good Maturity Model

The following linked tool shows Benetech's self-assessment on the Global Good Maturity Model. We have also uploaded an excel version of this model.

https://goo.gl/vhvBmS