Crowd-Mapping for Inclusion: *Increasing access to HIV/AIDS awareness, prevention and services for people with disabilities in Uganda*

Q: What did you learn in your pilot? What were the outcomes?

Our team is amazed how much you can learn in just two short weeks, major take-aways and improvements include:
1. a shift from categorizing people with HIV/AIDs & Disabilities as passive recipients/participants to active contributors/team members;
2. a transition away from traditional academic research practices (read, hypothesize, recruit, conduct) to a simpler, person centered (ask, listen, act) model;
3. increased focus on reciprocal exchange of information between the project team both in and outside of Uganda with other stakeholders, policy teams and decision makers;
4. flexible approaches to the resource mapping component of the project based on human, technical and fiscal capacity;
5. the acknowledgment that we still have work to do to develop/implement the technology.

We've detailed the above here, as well as in our revised user experience map (attached).

1. Early iterations of the #CrowdMappingU project referred to the people with disabilities in our project as "participants". After additional conversation with the team at The National Union of Disabled Persons of Uganda (NUDIPU) we recognized that those collecting and sharing data on HIV/AIDS services and resources were not simply passive participants or numbers on a spread sheet- they are the heart of this work and deserve to be referred to, treated and compensated as team members.

2. We've also transitioned away from the traditional research methodologies in our initial approach to the project design. Prior to the improvement phase of our project, the majority of the information we had collected and used to draft our design came from research publications. As a team comprised of academics and self-proclaimed "data-geeks" we are accustomed to conducting comprehensive literature reviews that guide research question development. Only then, do we typically have the opportunity to dig deeper, asking questions and making connections with individuals and project beneficiaries.

Applying principles of human centered design not only allowed for participant engagement early on- but also, demanded it. We have been able to revise our project using an "Ask, Listen, Act" model. This enables us to give context to the publications we initially relied, while also providing an avenue for us to fill in the gaps as viewed through the eyes of our team in Uganda, as opposed to those determined by the research team in the US.

3. Our initial project design centered on collecting data on HIV/AIDs services for mapping and communication to development actors. With the critical insight from NUDIPU we recognized that by implementing mobile data collection we have the ability to timely share information with people with disabilities, development actors and, with additional proto-typing and partnerships, we can also provide real-time information to the ministry of health

and related partners on supply-levels and access to medication etc. (see #5 for additional information).

4. Human Centered Design preaches the importance of flexibility. This has been a critical component for us as we work to ensure that the information we collect is stored and mapped in a way that is accessible and valuable to a variety of stakeholders. We initially planned to piggy-back on AidData's DREAMS project (collecting and mapping data on HIV/AIDs in Uganda and Zambia), however; we recently learned that they have decided to focus solely on Zambia for now. Rather than view this as a project barrier, we have shifted our approach to consider alternative options and partnerships including early communications with the team at Humanitarian Open Street Mapping and consultations with technology providers regarding mobile app development. While the collaboration and involvement with AidData may have shifted, our relationship with them is ongoing and we are lucky to still consider them partners and resources for data-management, sharing and analysis.

5. Throughout the iterations of this project we have often had the urge to say "okay, we've got it, let's stop there"- but the more research we do on the principles and approaches of design thinking and human centered design- and the more people we talk to about this project- the more we recognize that there is potential to use technology in a way that has not been used before. For example, the earliest drafts of the design focused on using the same or similar SMS technology as that used by Unicef's U-Report. However, after considering the accessibility challenges of using an existing service we have begun to explore other avenues; including expanding beyond SMS to a mobile application approach. While we recognize that this shift will likely be more timely and costly, the long-term benefits in Uganda and potential to implement this program across the globe- and/or with multiple beneficiary groups- far exceeds initial expectations. Our hope is that by thoughtfully considering the technology now, we will create a user experience that justifies the cost-benefit.

Q: What is the demand for this data and what are their needs? With the objective of improving outcomes for PWDs, do you anticipate needed to push them to use the data and how?

The demand for this data is multi-level:
1. One of the biggest issues around HIV/AIDs and people with disabilities is the misconception that they are not a high-risk group. This is false. Their disability increases vulnerability for contracting the virus and reduces the likelihood that they will have adequate, timely access to supports and services. By simply focusing on this population we help to bring attention to the need for targeted programs.

2. There are multiple stakeholder groups positively impacted by this project: people with disabilities seeking resources/treatment, NGOs/DPOs supporting HIV/AIDs and overall physical/health wellbeing, development actors that require data/evidence to provide financing/funding; Ugandan policy makers acting on behalf of people with disabilities and the HIV/AIDs community as a whole. As a result of this project ALL of these groups will have access to new information, and most importantly- the data will have been sourced directly from the population, which has historically been very difficult because of stigma and access.

3. Initial conversations with our team in Uganda don't anticipate any challenges recruiting team members with disabilities and HIV/AIDs for this project. Previous efforts to share knowledge and information have been somewhat successful- but are often stalled by (1) access to information; (2) issues with confidentiality/stigma; (3) providers who lack education/knowledge of disability; and, (4) lack of infrastructure and planning for future initiatives. All of which we have considered and factored into the planning of #CrowdMappingU

Q: Does data seem to drive decision making in Uganda or are there other more dominant factors?

According to our team's research, decision makers in Uganda are very open to the idea of data or evidence-based policy making. With Uganda being one of the designated Fast-Track countries globally that can make a significant contribution to ending AIDS as a public health threat by 2030 (UNAIDS, 2017); there is a national and global call for action. Specific calls for multi-sector interventions found in the National HIV and AIDS Priority Action Plan 2015-2016/2017-2018 (2015), and related publications all point to the need for data-driven decision making.

More specifically:

- HIV/AIDs funding in Uganda is primarily donor funded. The most recent National AIDs spending assessment report (2012) shows that the government of Uganda contributed 12%, development partners contributed 68% and the balance of 20% was financed from private sources including out of pocket (2014). This shows the need for development support which is closely tied with data, monitoring and outcomes.

- UNDIPU has recently increased their presence in national meetings and events on the issue-including representation on steering committees; raising issues specifically for people with disabilities

- In 2014, the Ugandan government initiated its first multi-donor geocoding exercise to map its "Public Management Information System" (over 800 development projects); a collaboration with our partner AidData. The government's hope was to "visualize who's funding what and where in their country to inform national development planning, improve coordination between development partners, and strengthen civil society interventions" (AidData, 2014). Additionally, UNICEF's U-report, a contributing influence for this project, which focused on collecting data and information primarily from youth in Uganda saw their population grow to 89,000 users in less than a year; which gained interest from government and media, garnering increased engagement by members of parliament.

Q: Will the data be open source and/or linked with national databases?

For this project to have the desired impact it is imperative that all data collected be available on open-sourced platforms. Clear, consistent monitoring and reporting is a critical component of #CrowdMappingU. The goal is to collect, share and disseminate data widely to multiple audiences and stakeholder groups. Our partner, AidData currently tracks and reports $40 trillion in funding for development, with the goal of allowing donors and

governments to maximize the impact of their investments; allowing citizens to hold their leaders accountable and providing transparent, accessible data for all. We are lucky to have their expertise to help guide our data reporting.

Q: What led you to focus on HIV resources in particular?

In short, need and access were the catalysts for focusing this project on HIV/AIDs. The majority of work undertaken by our research team is focused on the inclusion of populations that are the most marginalized. With several years of combined research on disability in development we are incredibly knowledgeable about the unique challenges faced by people with disabilities in the developing world. We also know that when you combine disability with HIV/AIDs, vulnerability increases, and access to services and supports decreases.

Previous work in Uganda undertaken by AidData and existing relationships with our team members at UNDIPU helped us to focus in on HIV/AIDs. This is a population that consistently encounters barriers to social and economic inclusion and for who targeted interventions have been absent. Additionally, by focusing our project on participatory data collection via technology, we are confident that we can have an immediate, long-lasting impact that is rooted in respect for privacy and preservation of self-esteem and builds on goals of increasing access and improving outcomes.

Q: How have donors/government fed into this initiative's design? What insights do you have into their decision making which led you to create this solution? What alternatives did you consider?

It is critical to undertake this project in a climate where there is need and buy-in. Having researched Uganda's approach to both disability and HIV/AIDs services, we were inspired by the appearance of progress and collaboration in both areas. Examples include:

- The above referenced reliance on donor funding for HIV/AIDs plays a role in securing government support. To be blatant, the nation simply cannot afford to eradicate or treat the HIV/AIDs in-country without development support;
- Increased presence of UNDIPU members/leadership in national and global conversations about HIV/AIDs shows a willingness to interact with individuals with disabilities and, points towards recognition that this population has unique, complex needs that cannot be met with traditional approaches;
- The limited pool of literature and publications available on the intersectionality of disability and HIV/AIDs (with specific mention of Uganda) highlight some positive instances of government supported or funded good-practices including: the existence of disability tailored services offered by non-governmental AND government facilities; participant reporting of improved physical access in government healthcare facilities via ramps/modifications and efforts to improve infrastructure and make resources more accessible and available using large print or pictures (2016). This was not the case in Zambia or Ghana, which were also included in the referenced study.

In terms of alternatives, we wanted to stay away from traditional interventions that focus on capacity building or knowledge sharing through avenues such as community based training or awareness building campaigns. Our partners at UNDIPU concluded similar efforts this past December with mixed results. Barriers such as access and stigma were not effectively managed via those methods; however, community participation has improved which will support recruitment of team members for our proposed project. Additionally, it was important for us to design a project that did not require government funding or approval but- that will ultimately provide those policy makers with tangible, actionable information. As development actors and experts we have seen the benefits of piloting new approaches in small communities and using the results and learning to garner additional interest and support.

Q: To what extent have people with disabilities contributed to project design? How will it meet their needs?

While the Open IDEO application process has been managed and facilitated by our team members from the University of Massachusetts Boston, our partners at UNDIPU have been essential to the design, improvements and resulting revised project. The feedback loops included consistent exchange of information back and forth between US-based and Ugandan team members. During this process our team at UNDIPU went out into the community to share our idea and to garner feedback. This is where we got the idea to use the technology not only to share resources, but also to report critical information on medication shortages, lack of providers or barriers to access instantly with health policy decision makers and/or NGOs/DPOs/CBOs providing care and support. This helped us to transform our project from a simple data collection/mapping research study to an interactive tool for change.

Additionally, as previously mentioned, the person-centered approach helped our team to move beyond focusing on the issue in terms of data and numbers (as in the literature) to instead direct our attention towards finding solutions that have immediate impact. This is a far cry from other development or social justice research that tends to be more longitudinal and time intensive.

This project will meet the needs of people with disabilities and HIV/AIDs in Uganda by:

- giving them the power, presence and tools to advocate for critical health services and equity;
- providing decision and policy makers with real-life accounts of the experiences of people with disabilities struggling to access HIV/AIDs services, supports and treatment;
- removing barriers to access information through the use of accessible technology;
- decreasing challenges of stigma and confidentiality by providing mobile resources delivered directly to the individual, eliminating the need to disclose disability or HIV status to non-essential contacts; and,
- building the capacity of our team members in Uganda by providing and training them to use technology, collect and share data and report progress and problems to support staff.

Q: Practically speaking, how does participating in the survey translate to amplified voice for disabled people?

One of the main drivers of this project has been the goal of filling a gap in participant driven data collection; by engaging our partners in Uganda not as participants, but as action researchers, who are integral members of the team and contribute to the design, implementation and reporting we ensure that their voices are among the loudest of those working to find solutions to the HIV/AIDs epidemic.

Disability is a complex, crosscutting issue that unfortunately, is often categorized by silence, shame and stigma. With ongoing support, passion for innovation and commitment to social change, #CrowdMappingU will use technology to break down barriers and improve outcomes; giving those without a voice (the deaf and hard of hearing) a voice - while helping to spread a vision of health equity (for the sighted and those with visual impairments) and opening doors for those (people with physical disabilities) who have typically been locked out of decision making.

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Questions or Feedback?
Ashley.Coates001@umb.edu

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