



MATRIRAKSHA

Digital Data Collection for
Maternal and Perinatal Healthcare
in Rural Nepal

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FOREWORD

At the start of this capstone project, improving maternal and neonatal health care in Nepal over the course of just one semester seemed like a daunting task. We are not health care professionals and none of us were from or had even been to Nepal. Who were we to think we could help fix problems on the other side of the world? However, weeks into the project, as we were discussing the affordances of paper, the tensions among values related to dignity, shame, access and transparency, and how poor usability can easily introduce additional burdens, it suddenly felt like we actually had a grip on what to do. Over the semester, we started to understand that these discussions did not just happen simply because this project was particularly suited to reflecting the concepts so often discussed within South Hall, rather, it was our way of thinking about and seeing the world that had changed. Where before coming to the School of Information we saw technology as providing business opportunities and easy fixes, we now see complex sociotechnical systems weaving together individual and collective perspectives, values, and goals. Beyond teaching us invaluable lessons about the reality of health care conditions in developing countries such as Nepal and the value of understanding the context during the design process, this project helped us realize that we recognize the role of the responsible information professional.

*On my honor, I will try:
To serve people and society,
to create technology for important
human needs,
and to abide by the I School pledge.*

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We extend our special thanks to **Megan O'Connor** for being a significant pillar in the project. Megan, your help allowed us to better understand Nepal's health care system - thank you for joining us during the field research portion! Without the data you helped us gather, this paper would certainly be a lot shorter!

We would also like to express our sincere gratitude to **Professor Jenna Burrell** for her invaluable guidance, suggestions and unparalleled support throughout this Capstone project, while serving as a constant source of motivation during this journey. We really enjoyed discussing the meaning and conveyance of time across cultures and learning more about a Western pregnancy preparation regimen.

Lastly, without the support and funding of the **Center for Technology, Society and Policy**, this project would not have happened. We are extremely thankful for the leadership of Elaine Sedenberg and Daniel Griffin and their faith in us and our project.



CARINA SAUTER



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INTRODUCTION

FACING REALITY

We had moved to the roof of the Mahadevsthan health post since the inside of this Nepali health facility was too cramped to accommodate our research team's meeting with One Heart World-Wide (OHW) field workers and the district's nine Female Community Health Volunteers (FCHV). Once atop the health post, we immediately noticed, only a few feet away from the gathered crowd of FCHVs, a woman laying on a dusty mat, buried under a pile of thick blankets; her black hair glistened with sweat under the hot afternoon sun as she moaned from the discomfort of the heat and increasing labor pains. We would later learn that the woman about to give birth was actually the sister of a FCHV and they had made the hours-long walk to the health post days earlier at the first signs of

labor. Fortunately, the woman and her family understood that delivery at a health facility was the safest choice for both the mother and child - yet this decision for women across Nepal can be impossible due to the uncertain timing of delivery, the long distances over steep terrain to reach often ill-equipped health facilities, and the lack of access to emergency services. These barriers ultimately lead to many Nepali women delivering their children at home without the help of a skilled birth attendant. On this roof, seeing how rural maternal health care is realized in the best of cases, we were confronted by the reality of the challenges that our partner, OHW, addresses each day so that more women, like the FCHVs sister, can access quality and safe health services.

"One Heart World-Wide (OHW) is a 501(c)(3) organization with over 15 years of experience implementing maternal and neonatal mortality prevention programs in areas where women often die alone at home giving birth. Our aim is to improve access to, and utilization of healthcare services to reduce the risk of maternal and neonatal mortality in the most remote, rural areas. We believe

that all women and newborns can receive the quality healthcare services they deserve during pregnancy and childbirth, anytime and anywhere."

- OHW in their own words

Since the impact of distance, infrastructure, education, and culture also affects the timeliness and quality of the information

to understand how these families can be helped, OHW wanted us to uncover how the information flows from these communities could be improved through the use of technology. Over the next four months, we discovered with our partner, One Heart World-Wide, multiple ways in which they could improve the speed and quality

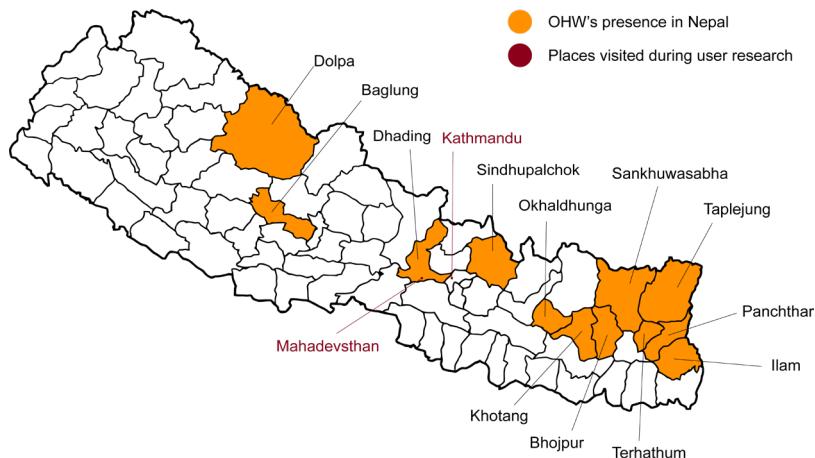
of information for their leadership, the government, and, ultimately, the families of rural Nepal.

Our initial discussions with the operations and development directors of One Heart World-Wide began in the end of November 2017. They had learned that students from UC Berkeley's School of Information specialized in addressing complex challenges regarding the collection, storage, analysis, and visualization of information. Through our conversations, our team learned that OHW had three (albeit connected) main desires for their Monitoring, Evaluation, and Learning (MEL) program for their maternal health programs.

First, they wanted to improve the speed & quality of information collected from rural communities in Nepal, with emphasis on their current mHealth SMS-based pilot and the reporting on deaths of pregnant women and newborns.

Second, they wanted to have a centralized datastore of collected information that could be accessed by staff members across Nepal and in the United States.

Lastly, OHW wanted a way to visualize and learn from the



1 One Heart Worldwide. Retrieved from <https://www.oneheartworld-wide.org/>

information, possibly using various dashboards with versions for internal and public users.

With OHW, we agreed to focus on rural community-based information collection while also considering how that data would be stored. Our thinking was that the usefulness of inaccurate or untimely data would be limited no matter how great the data architecture or visualization tools were. This agreement between OHW and our MIMS final project team came with one major caveat: our team must spend time in Nepal learning about OHW's programs and processes, the country's healthcare system, and the environment in general. We felt that offering any solution without our team members having experienced the specific context, even the short time of the nine days we ended up spending in country, would have been counter to the values and ethics engendered through our education at the UC Berkeley School of Information. Fortunately, with the generous support of the Center for Technology, Society, and Policy, we were able to meet this condition and fulfill the following goals:

Main Goals:

- Identify operational challenges, through user research, for OHW and its staff, volunteers, and partners to collect, aggregate, and store data.
- Propose improvements for OHW's current or proposed data collection and storage processes, potentially including human resources, technological resources, and braided communication planning.
- Offer concrete findings to improve information flows that would enable OHW to better monitor program effectiveness and serve their communities.

Our team collaborated with both OHW US and Nepal staff to produce an itinerary that would help us gain understanding and empathy for system stakeholders in the single week they would be on the ground in Nepal. Using the "follow the thing" mode of construction for multi-sited ethnographic work,² our strategy was to learn from a sample of users, managers, and beneficiaries that would allow us to "follow the data" from collection and aggregation to processing and sharing while observing the context of its users. Their goal was to answer the following questions:

Key Questions:

- What are the current obstacles and challenges to OHW's community-focused data collection?
- How might operational challenges best be addressed through

a combination of changes in system architecture, business processes, and communication methods? What are the realistic constraints for data collection that may not be overcome?

- How can OHW and other stakeholders feasibly implement and maintain our proposed information collection service in accordance with their long-term goals?

Splitting their time in Kathmandu and the district of Dhading over a week in January, our team's two user researchers - Steve Trush and Megan O'Connor (a Master of Public Health student at George Washington University) - conducted a series of semi-structured interviews with government officials including the Director for Health Management Information Systems, a Government Statistician at a District Health Office, and the workers at a rural Health Post. They also interviewed members of OHW, including the Program Director, the Monitoring & Evaluation (M&E) Director, the leader of an OHW District office, and their mHealth Engineer. They conducted a focus group with nine Female Community Health Volunteers and also observed, learned, and collected training material from the OHW staff throughout their time spent together.

Beyond the work in Nepal, we collected data about OHW's business processes, needs, and context through 6 phone conversations with the Director of Development and the Director of Operations (responsible for monitoring, evaluation, and learning). We also conducted a phone interview with members of MedicMobile, a leading technology development firm building mHealth solutions in Nepal.



Image 1 - Mahadevsthan Health Post in Dhading District

² Marcus, G. (1995). Ethnography In/Of the World System: The Emergence of Multi-Sited Ethnography. *Annual Review Of Anthropology*, 24(1), 95-117. doi:10.1146/annurev.anthro.24.1.95

PART ONE: USER RESEARCH

NEPAL'S MATERNAL & NEONATAL HEALTHCARE

Before exploring our findings and recommendations, one must understand the context of OHW's operations. The third United Nations Sustainable Development Goal (SDG) is to "ensure healthy lives and promote wellbeing for all at all ages" by the year 2030.³ To achieve this goal, Nepal is required to make significant reductions in both the country's maternal mortality rate (from 281 to 70 deaths per 100,000 live births)⁴ and its neonatal mortality rate (from 21 to 12 deaths per 1,000 live births).^{5,6} Due to lack of last mile healthcare availability, limited infrastructure, and prevailing social norms, rural Nepal experiences higher maternal and neonatal mortality, particularly from preventable causes of death associated with lack of health facility access and education.⁷ Over the last thirty years in rural Nepal, most solutions to these problems have centered on two entities - the rural Health Post and the Female Community Health Volunteer.

Health Posts

Reducing the mortality rates has been recognized as being dependent upon increasing the number of women who access care at government health facilities before the birth of a child (antenatal care or "ANC" visits) and for the delivery.^{8,9} The WHO recommends that pregnant women have at least four ANC visits with a Skilled Birth Attendant, with their first visit before their fourth month of pregnancy and follow-on visits at six, eight and nine months¹⁰. In the rural parts of the country, these facilities

take the form of health posts, government-run offices with a smaller number of staff and services than hospitals and clinics in the built-up areas. In Mahadevsthan, we visited one health post, a single story building with 5 to 6 rooms run by a staff of 6 workers. The staff at the Mahedevestan filled three roles that we were told were typical of most health posts in Nepal. The Skilled Birth Attendant (SBA; also called Educated Nurse Midwife) specializes in maternal and pediatric healthcare. A Health Post administrator (or "Health Post in Charge") manages operations within the clinic including reporting. Lastly, a Paramedic treats injuries and illnesses. The three staff members we met were all women, each college-educated, and could understand some English.



Image 2 - User Researchers, Health Post Staff and the OHW M&E Director

3 Health - United Nations Sustainable Development. Retrieved from <https://www.un.org/sustainabledevelopment/health>

4 Nepal Demographic and Health Survey. (2006). Retrieved from <https://dhsprogram.com/pubs/pdf/FR191/FR191.pdf>

5 Nepal Demographic and Health Survey. (2016). Retrieved from <https://www.dhsprogram.com/pubs/pdf/fr336/fr336.pdf>

6 Alkema, L., Chou, D., Hogan, D., Zhang, S., Moller, A., & Gemmill, A. et al. (2016). Global, regional, and national levels and trends in maternal mortality between 1990 and 2015, with scenario-based projections to 2030: a systematic analysis by the UN Maternal Mortality Estimation Inter-Agency Group. *The Lancet*, 387(10017), 462-474. doi: 10.1016/s0140-6736(15)00838-7

7 Khatri, R., Dangi, T., Gautam, R., Shrestha, K., & Homer, C. (2017). Barriers to utilization of childbirth services of a rural birthing center in Nepal: A qualitative study. *PLOS ONE*, 12(5). doi: 10.1371/journal.pone.0177602

8 Lincetto, O., Mothebesoane-Anoh, S., Gomez, P., & Munjanja, S. Antenatal Care. Retrieved from http://www.who.int/pmnch/media/publications/aonsectionIII_2.pdf

9 Maternal mortality. Retrieved from <http://www.who.int/news-room/fact-sheets/detail/maternal-mortality>

10 Nepal | Urban health profile. Retrieved from http://www.who.int/kobe_centre/measuring/urbanheart/nepal.pdf

Digital Infrastructure at Health Posts

About 10% of Nepal's population do not have cellular coverage, mainly due to rural areas' lack of cell towers, limited access to electricity, and winding mountain valleys shortening the reach of the few towers that exist.¹¹ People believe that telecommunication providers have little incentive to connect rural populations away from main roads as the return on investment is low: given the terrain, each new cell tower would only serve a small number of customers. The health post administrator that we met would generally keep her smartphone in the one corner of her house where she had coverage, but might bring it to the health post to simply listen to music or play games. This was in stark contrast to urban areas, specifically Kathmandu and Dhading Besi, and along the main highways, where we found cell phone service to be ubiquitous and reliable. We were able to communicate regularly using voice and data in those cities. Internet connectivity at health posts was said to be virtually non-existent although there was mention of satellite networks used within the area. While internet penetration has grown to 63% across Nepal (largely due to penetration of mobile devices and cellular data coverage), internet use, like mobile coverage, is more likely for urban populations.¹² However, in all cases, the reliability of the connection was impacted by intermittent power supply. Grid power would occasionally fail and only some locations have backup generators. Health posts without generator backups may have solar panels installed (one of One Heart World-Wide's initiatives).

Travel to Health Posts

Merely reaching the health posts for medical care from more remote villages is not without its challenges. Vehicle travel to rural health posts is constrained by the quality of the roads, with 4 wheel drive-equipped vehicles or off-road motorcycles needed to traverse the unmaintained dirt roads. Some communities are unreachable by vehicle and are separated by bridges and paths between steep valleys requiring walking along dirt roads. Walking was described by the Female Community Health Volunteers as their and their patients' main mode of conveyance. Pointing to a hill located far away to the east of the Mahadevthan health post, one FCHV described walking 7 hours each way to reach the health facility for their monthly meetings to share information about the pregnancies in their wards. Given sparse digital connectivity, rural populations depended upon walking and in-person interactions to exchange this information as well as medical equipments and medicine.

The lack of physical infrastructure also reduced the frequency that OHW field staff, generally based in the administrative center

of the supported district, could reach each health post. Even along main roads within and from Kathmandu, traffic presented the greatest obstacle to the OHW staff for reaching their field sites. The few highways lead from Kathmandu funnel into single lane roads that wind their way out of the Kathmandu Valley. Staff lamented that traffic jams caused their hired vehicles or buses to sit at a complete stop for several hours while an unknown situation further along the road was resolved. In our lone trip back to Kathmandu from Dhading Besi, we experienced one of these unexplained traffic jams; we were told we were lucky to only have been sitting immobile for an hour.

The OHW staff described the use of mail and couriers as a cumbersome network to move information or goods to the health posts as well. The government's postal service was described as having limited reach outside of Kathmandu and larger towns, and was known for losing mail. Instead of an official postal service, we were told small deliveries were enabled through informal courier arrangements: if an organization or community member had a friend, family member or employee travelling in a direction, packages could be carried by those facilitators to be handed off to recipients at a mutually convenient spot closer to their ultimate destination. Otherwise, paid private couriers would be hired, although these services might also only deliver materials to locations within a short distance from main roads.

Connection to the Community

The staff of the Health Post may not actually be from the surrounding area. Rural assignments are seen as a duty to the people of the country and the government may place a staff member at a post on the opposite side of the country for two or three years. The staff may also request transfers to other posts (or more urban health facilities) or may be involuntarily reassigned by the government. The staff members will certainly live within the community, but their primary connection and ability to conduct outreach to the mothers and children within the community is through the FCHVs.

Female Community Health Volunteer Program

In 1988, the Nepalese government created a program where female volunteers - officially titled Female Community Health Volunteers or FCHVs - would facilitate the delivery of maternal health education and services within their local communities.¹³ As

11 Shah, R. (2015). Assessing the opportunity to improve energy access: Ncell in Nepal. Retrieved from <https://www.gsma.com/mobilefordevelopment/wp-content/uploads/2015/10/NCell-report-October-2015.pdf>

12 Koirala, B. (2018). According to NTA, the internet penetration in Nepal has reached 63%. Retrieved from <https://www.gadgetbytenepal.com/internet-penetration-nepal/>

13 Khatri, R., Mishra, S., & Khanal, V. (2017). Female Community Health Volunteers in Community-Based Health Programs of Nepal: Future Perspective. Retrieved from <https://www.frontiersin.org/articles/10.3389/fpubh.2017.00181/full>

women in Nepal are less likely to seek health services or discuss health needs with men,¹⁴ the Ministry of Health believed that female volunteers would best be able to promote safe maternal health and family planning. FCHVs are selected from the married women, with at least one child, by the all-female “Mothers Group” of each village. The role of the FCHV is respected among the community owing to the direct impact of their support for local families, their relationships with service providers and NGOs, and the national recognition for their contributions for the lowering of maternal and neonatal mortality rates as the country strived to meet the Millennium Development Goals for 2015.

Each woman volunteers to serve their respective wards by providing primarily maternal healthcare education, outreach, and medication. Beyond meeting some personally, FCHVs were central to most conversations that we had during our time in Nepal, which somewhat reflected on their critical role in the government’s community outreach efforts, program delivery, and community-level data gathering.

All FCHVs are female, with observed ages from the mid-twenties to the mid-70’s. While reports have listed FCHV literacy as high as 83% for reading and writing Nepali, a common opinion among our interviewees was that older FCHVs tend to be illiterate, forgetful, and limited by diminished vision, hearing, and ability to walk.^{15,16} Indeed, to maintain a capable volunteer force, the Government of Nepal has begun offering long-serving FCHVs a 20,000 Rupee incentive to relinquish their role to other presumably younger, healthier, and more educated women. While this retirement incentive motivated some FCHVs to end their service, we also met FCHVs who said that recent initiatives to provide stipends and technology are more reason to keep volunteering: one long-serving FCHV stated that only recently has there been any compensation for their work, referring to initiatives that have provided travel stipends or even the “gifts” such as the OHW-provided mobile phones.

The progress attributed to the FCHVs and their position within their communities has led to the government and NGOs increasing their workload over time; two FCHVs stated that they felt overburdened by multiple programs of the government and NGOs that sought the FCHVs as an intermediary and community spokesperson. These programs even extend beyond delivering and monitoring healthcare to things like improving agricultural techniques. This opinion was shared by leaders within OHW who told us that they did not want to further increase the workload

of the FCHVs, who serve an average of about 7 hours a week.¹⁷ Despite the progress attributed to the FCHVs, these volunteers were said to be seen by the government as “the old way”; their success had plateaued and, for Nepal to reach the Sustainable Development Goals, more educated community health workers would need to take over much of their work. Thus, we were told that the government is not looking to expand the numbers of volunteers in the FCHV program despite the increasing responsibilities given to those aging volunteers.

FCHVs are seen as OHW’s main connection to the women in the rural communities. The FCHVs represent the last-mile for both OHW’s and the government’s connections to rural Nepal and are the first to learn of a pregnancy, the illness of an expectant mother, and the death of a newborn.

The role of NGOs in Nepal's Health Care System

Government-led programs like the FCHV program typically involve some partnership with non-governmental organizations like One Health World-Wide. OHW strengthens government-provided health services by reducing the barriers to mothers’ health facility access. They do so by improving the equipment and facilities at the health posts, training Skilled Birth Attendants and FCHVs to deliver services and educate local communities, and more effectively reminding mothers to attend antenatal care visits using technology.

Nepal's Health Management Information System

The FCHVs are not only the last mile for health services, they are also the main source for maternal and neonatal health information from outside of health facilities. Whenever a notable event, such as a pregnancy, birth, or maternal / neonatal death occurs within a community, the FCHVs are supposed to maintain this information on paper ledgers. Due to a lack of incentive, relatively high illiteracy rates, and only rudimentary training to capture medical information accurately, the FCHV constitutes a shaky first step of the information’s journey from within those off-road mountain valleys towards Kathmandu as part of Nepal’s

14 Houston, R., Acharya, B., Poudel, D., Pradhan, S., Singh, S., & Manandhar, M. et al. (2012). Early Initiation of Community-based Programmes in Nepal: A Historic Reflection. Retrieved from <http://nfhp.jsi.com/Docs/EarlyInitiationofCommunity-basedProgrammesinNepal-Ahistoricreflection.pdf>

15 An Analytical Report on National Survey of Female Community Health Volunteers of Nepal. (2007). Retrieved from <https://www.medbox.org/an-analytical-report-on-national-survey-of-female-community-health-volunteers-of-nepal/>

16 Female Community Health Volunteers in Nepal: What We Know and Steps Going Forward. (2016). Retrieved from https://www.advancingpartners.org/sites/default/files/sites/default/files/resources/nepal_apc_slidedoc_19july2016final_.pptx.pdf

17 Female Community Health Volunteers in Nepal: What We Know and Steps Going Forward. (2016). Retrieved from https://www.advancingpartners.org/sites/default/files/sites/default/files/resources/nepal_apc_slidedoc_19july2016final_.pptx.pdf

Health Management Information System.

Like almost every government, the government of Nepal gathers information about the health of its residents to measure the effectiveness of ongoing interventions¹⁸. This information also provides a basis for resource allocation. In respect to maternal and neonatal health, the value of the government's programs (and that of organizations like One Heart World-Wide) are largely assessed through impact indicators - like the aforementioned Maternal Mortality Rate and Neonatal Mortality Rate - and outcome indicators - such as rate of in-facility births and antenatal care visits. The single official system for capturing those metrics in Nepal is referred to as the Health Ministry Information System (usually called "H-M-I-S" when discussed in English). The HMIS reporting system integrates both paper and digital reporting of aggregate monthly totals from 6,600 health facilities (public, private, and NGO) across the country.

Paper-Based Reporting

Paper plays a major role in the HMIS. Each health facility is expected to maintain a series of 51 paper registers that collect individual information ranging from facility visitor logs to services provided to each patient. All medical data on individuals is stored on paper registers; electronic reporting is only for monthly aggregate rollups with the specific exceptions for HIV/AIDS, leprosy, and leishmaniasis ("kalazar"); furthermore, we were told that, by law, the government does not allow sharing of patient identification data.

Mr. Khanal, a government official in charge of the HMIS, told us that over 1,000 health facilities were not submitting paper reports but were able to submit aggregate data using

A photograph of a yellow monthly rollup report for the Health Management Information System. The form is titled "Health Management Information System Monthly Rollup Report". It includes sections for "Health Facility Type", "Health Facility Details", "Number of Births", "Number of Deaths", "Total Patients Attended", and "Total Patients Seen". A large grid for "Diagnosis/Other Services" is present, with columns for "Day", "Category", "Type", "Number", and "Persons". The form is signed at the bottom by "Signature" and "Name of Hospital".

Image 3 - A monthly rollup report

18 Nepal Demographic and Health Survey. (2016). Retrieved from <https://dhsprogram.com/pubs/pdf/SR243/SR243.pdf>

19 DHIS 2 Overview. Retrieved from <https://www.dhis2.org/overview>

20 Partnership in the Health Sector Program of Nepal. (2017). Retrieved from <http://nhsp.org.np/wp-content/uploads/2017/02/7.External-Development-Partners-Working-in-the-Health-Sector.pdf>

21 There are 14 Disbursement Linked Indicators (DLIs) with yearly targets and value attached to it ([funded by] World Bank, DFID and GAVI). These partners will disburse millions provided that yearly targets are met. If certain targets are unmet each year, the country of Nepal would risk losing money to provide services.

a web interface and a government-provided computer. This information is stored on an online, centralized instance of the DHIS2 (District Health Information System) platform, an open-source information system used for recording, analyzing, and sharing health information in over 60 countries.¹⁹

For the 5,600 or so facilities without DHIS2 access, an administrator at each health facility, at smaller health posts referred to as the "Health Post in Charge" submits a paper version of a monthly rollup to their respective District Health Office ("DHO") [Nepal is currently organized into 75 districts]. This handoff typically occurs at an in-person monthly meeting between the DHO and the administrator; each district may facilitate this meeting differently, possibly having meetings with a large portion of administrators simultaneously or quick individual exchanges of the reports. The statisticians at the DHO, reported to be each internet-connected, will enter each health facilities' information into the DHIS2.

HMIS Vision for 2020

Currently, only 600 health facilities have at least 1 human resource specialists trained to use the DHIS2 digital interface, with 1000 expected by July 2018. Mr. Khanal's vision is that, by 2020, all 6,600 facilities across the country would be able to report aggregated data using the online system, thus meaning each health facility in the country would have a computer, internet connection, and a trained DHIS2 user by July 2020.

The government's plan for every health facility in Nepal to submit their information to DHIS2 by the end of 2020 depends upon the success of the current initiative of the Ministry of Information and Communications connecting every health facility (and public school) to the internet by the end of 2019. It was unclear how many facilities already had an internet connection as of January 2018, but Mr. Khanal was confident that this goal would be achieved, "even if it's only 90, 95 percent complete" by July 2020. He mentioned how the government had regular meetings with project stakeholders to ensure completion; stakeholders from all levels of government, NGO partners, and the World Bank are all motivated to achieve the plan since the HMIS supports the government's ability to show Disbursement Linked Indicators.^{20,21}



Image 4 - Steve and Health Post Staff going through the 51 paper registers



Image 5 - FCHV register where information about pregnancies is tracked



Image 6 - User Researchers Steve Trush and Megan O'Connor with the Nepalese OHW senior staff

Changes in Government Structure

Beyond the ambitious scaling of the online information system (including connectivity, equipment, maintenance, and training) to over 5,000 facilities, the future reporting flows of the HMIS were described with great uncertainty given Nepal's transition to a federal structure. By the end of the 2018 fiscal year, the 75 districts will dissolve and the country will be reorganized into 753 palikas (or municipalities).^{22,23} An elected office at each palika will govern the wards and manage between 1 to 42 health facilities. While the administration, resourcing, and training for each health facility will be managed by the 753 palikas with some input at the national level, each health facility is expected to report their monthly totals directly to the government in Kathmandu via the online platform. However, government officials could not describe how the HMIS would function from the time when the country's federalization occurs to when a health facility is capable of reporting data using the web. Government offices at the palika level may not have internet connections or trained officials to collect the necessary data. Mr. Khanal alluded to being ready to enact multiple plans depending on what the ministers in the government decided; he recommended that they create a "bureau" at the minister-level to decide what the final plan should be. Regardless of how the government eventually implements a new online system, OHW staff felt that the federal restructuring alone would inevitably create chaos for HMIS reporting.

One Heart World-Wide's Reporting Needs

The impact of One Heart World-Wide's (and similar organizations') programs is largely determined and communicated through the reporting of their program outputs (number of birthing centers upgraded or SBAs & FCHVs trained) and outcome indicators, from in-facility births and antenatal care (ANC) visits to maternal and neonatal deaths. These metrics are regularly reported to stakeholders and donors in the form of annual and quarterly reports. However, this

- 22 Ghimire, B. (2017). New local level units come into existence. Retrieved from <http://kathmandupost.ekantipur.com/news/2017-03-11/new-local-level-units-come-into-existence.html>
- 23 New 744 local units replace VDCs and Municipalities - People's Review. (2017). Retrieved from <http://peoplesreview.com.np/2017/03/16/3891/>

information is often also needed for ad-hoc meetings and grant proposals.

Beyond the information that OHW receives from the government's HMIS, either through yearly official publications or unofficially via the District Health Offices, OHW uses other modes of data collection to provide a more complete picture of maternal health in rural Nepal.

Private Surveys

OHW will hire private surveyors to collect indicators at beginning and end of their initiatives in a District. Little concerns about the quality of this work were shared; instead, this mode's main limitations are the cost and time it takes for the surveyors to gather the information from the community. Since the information is seen as thorough (beyond meeting with health facility staff and FCHVS, the surveyors are said to incorporate the reportings of teachers and other community leaders into their reported numbers) and the source of the data can be attributed to a professional third party, OHW will publish the gathered statistics in their public reports in addition to the HMIS data (ie, not as a replacement).

mHealth Reporting

OHW has also explored the use of mobile technologies to gather information about their target population. Through a partnership with the technology provider MedicMobile, OHW has piloted an SMS-based reporting system with feature phones in Baglung and Dhading districts. During the pilot, once an FCHV learns of a pregnancy in her ward, the FCHV is told to use the provided feature phone and register the woman using a series of brevity codes. This information is relayed through a server in Kathmandu that sends notifications of the registration to OHW and the FCHV's local health facility. OHW can further view this information via a web portal created by MedicMobile. FCHVs will then receive reminder messages when a pregnant woman should visit the health facility for one of four antenatal care visits or deliver her baby. These reminders were intended to promote positive behavioral change by preventing forgetfulness and creating greater impetus for ANC visits and delivery in health facilities. FCHVs are also expected to send messages if there are any complications with the pregnancy (referred to as "Danger Signs"), if the pregnant woman dies, or if the pregnancy is aborted for any reason. OHW has also asked that FCHVs report the death of any woman aged 15 to 49 years old so that OHW can later determine if the death was, in fact, pregnancy-related.

Benefits of mHealth

OHW staff members spoke to the benefits of using mHealth beyond the intended positive behavioral impact still under



Image 7 - page from mHealth training manual

evaluation. They described how MedicMobile's system allowed them to see data in "real time" meaning, to them, that they are able to view the data as soon as the FCHV can successfully send out the text message. The Dhading staff leader credited mHealth for helping them to quickly learn about a death in December 2017; this saved time to plan and get approval for another employee to visit the FCHV and family to learn about the cause of death within weeks (including a customary mourning period discussed later) rather than months.

Sustainability of mHealth

We sought multiple perspectives on the intent to scale mHealth or transition the program to the government. We asked the HMIS Director if the government would want to integrate mHealth data into their data collection process. He saw no reason to incorporate another data source, stating "there is not 2 or 3 presidents, there is not 2 or 3 prime ministers - there can only be 1 president" implying that there should be only one data collection system used by the government. He felt that if health programs within the government needed to collect other data, they could request a change to the monthly rollup by the HMIS; if the NGOs wanted to use other data sources in addition to HMIS, they were free to do so. Our conversations with MedicMobile described a different picture, with the regional director stating that they had received approval to integrate mHealth data from up to 25 districts into the HMIS DHIS2 system. However, they did not know exactly what form this would take until plans are finalized by the end of the year.

Whether there is government motivation in adopting the technology or not, the cost of deploying a system that does not

capture large numbers of maternal health events factors heavily into OHW's future plans for mHealth. OHW employees described concern with not only the cost of providing feature phones and training to thousands of FCHVs, but also worried about the cost of replacing or fixing phones over time as warranties expired with no clear plan for the Nepalese government to pick up the tab.

Death Monitoring

In the weeks before our visit, OHW had started a "death monitoring" program within Dhading and six other districts. The plan was to interview families of deceased pregnant women, recent mothers, and newborns to find out information about cause of death. This information would then be shared within the organization and the DHO to recognize patterns of causes of death and then plan potential preventative interventions. One of the Dhading staff members had just returned from her first family visit for a deceased woman who had delivered a child in the last 42 days. The staff member's visit involved a 5 hour bus trip to the health facility, followed by a 30 minute walk with the ward's FCHV to the family home for an interview (referred to as a shorter version of a "verbal autopsy"). OHW will give the FCHV a small stipend, meant to cover travel expenses, which is viewed as an incentive for FCHVs to report deaths. It took approximately one month from notification (which, in this case, was via the mHealth platform) to verify the death and report the data to OHW in Kathmandu.

Maternal and Perinatal Death Surveillance and Response

The WHO, UNICEF, and the Nepal Government launched a similar program in five districts (Dhading is the only district to overlap with OHW's death monitoring program); this program was referred to as "MPDSR" (Maternal and Perinatal Death Surveillance and Response).²⁴ As described by the staff of OHW, MPDSR's main focus was on maternal deaths - not perinatal deaths - and had so far only been gathering information about the deaths (Surveillance) and had not planned any interventions (Response). We asked the OHW district staff whether the workers of the MPDSR would also visit the family of the deceased woman in North Dhading. Apologetically, a staff member said that the DHO would send an official with a medical professional to interview the family within the next two weeks; OHW would try to coordinate visits in the future to minimize the number of times the family needed to be interviewed.

When asked about future plans to work with this MPDSR effort, the M&E team leader said that OHW saw their reporting as much less detailed & invasive, quicker to perform, and more focused on perinatal deaths (cause of perinatal deaths are not included in HMIS, while the system has some limited information about maternal cause of death). When asked if OHW could gain access to the information collected by MPDSR, OHW senior

management appeared reluctant to investigate this possibility claiming that it is possible that the MPDSR pilot is not sustainable and that access to the information likely depends on financial involvement in the project.

Internal Reporting of Activities

Within the organization, OHW field staff across 12 districts need to submit monthly rollups and event reports for their program activities; these reports are necessary to show stakeholders what work is actually being done by OHW. Output indicators (such as the number of live births in facilities with OHW's improvements) are also included if the data is available. Rollups in Microsoft Excel spreadsheets and narrative reports in Microsoft Word are submitted via email at least monthly to OHW's Kathmandu office. In Kathmandu, the two-person M&E team consolidates each of these rollups into a master report by copying, pasting, and merging sheets, a process that reportedly takes a few days to accomplish. The M&E director may then analyze the data using Excel and SPSS to identify trends in outputs between the various field offices. The monthly reports, along with any findings from the M&E team, are sent to OHW's senior management in both Nepal and the United States. Reports are usually not disseminated back among the other field offices unless some important lesson or notable event is deemed worth sending to each of the field staff.

Challenges for OHW's Monitoring and Evaluation

One Heart World-Wide depends on timely, accurate information to effectively allocate resources, prioritize programs and initiatives and communicate progress to their stakeholders to justify further funding. Given the difficult terrain and limited infrastructure in rural Nepal, one might imagine the difficulties that exist to collect and share information, but, through our research, we realized the wide-ranging complexity of factors that affect the timeliness and quality of information.

Challenges to Timeliness

Delays in receiving information can impact how quickly OHW can respond to stakeholder requests, meet deadlines for various proposals, coordinate interventions, or complete administrative tasks. There are several reasons why OHW may not learn of a pregnancy, delivery, or death as quickly as their available communication methods might allow.

Delay for Official Statistics

In its current configuration, the HMIS is viewed by members of One Heart World-Wide as an inefficient system that gathers

²⁴ Nepal | building on MPDRs to implement MPDSR. Retrieved from <http://mdsr-action.net/updates/nepal-building-on-mpdrs-to-implement-mdsr/>



Image 8 - A monkey oversees the cremation sites at one of Kathmandu's major temple complexes.

inaccurate data. While OHW needs these government metrics to measure and plan their programs, staff members stated that, unless they are able to convince government officials to share unofficial data with them earlier, they would need to wait upwards of six months after the end of the fiscal year for the government to release the official numbers for the preceding year. The decision not to share unofficial data was seen as a way to prevent partners from causing panic based on erroneous data; an example provided by a DHO Statistician detailed that over 100 cases of dengue fever reported in his district were actually due to a health post administrator writing the number in the wrong column of the monthly report. The government's concern was that NGOs across the world could have taken the incorrect information at face value and started to draft unnecessary countermeasures.

Data Entry Delays at the District Level

Maintaining good relationships with the government officials at the District Health Offices is key for OHW to obtain more timely unofficial data (typically emailed to OHW's district field staff in spreadsheet format). Still, additional time delays can happen at the DHO level; a member of OHW's Dhading office told us they recently had to wait over 3 months for information because of a backlog that was due to the DHO not having enough people to manually enter the paper reports into DHIS2.

Hindu Perceptions around Death

Hindu followers in Nepal, who make up 81% percentage of the population,²⁵ will hold a 13-day mourning period as a

customary practice following a family member's death. During this period, families and neighbors are unlikely to share news of a death. Authorities will therefore only hear about a death in the case that it occurs in a health facility. Further, the FCHVs were also said to be unlikely to share word of the death during this period once they learned of one; OHW staff members stated they felt FCHVs wait to report out of concern that government officials or NGOs would contact them or the family for more information about the death, violating the privacy of the family's mourning.

Delays for Death Reporting

While mHealth may be useful for the FCHV to immediately notify OHW of the death, obstacles to timely death monitoring still exist. If the FCHVs do not inform OHW, OHW must wait to review HMIS data to determine whether a death had occurred and work backwards to the source of that report. Asked whether there was a role for the Health Post to notify OHW, the OHW M&E director stated that the health facilities have been told to contact OHW, but any reporting requirements "other than the HMIS are not taken seriously... it doesn't always happen." Finally, logistical matters, including planning, receiving approvals, and traveling, can create delays; OHW field offices, with two to four staff members, are small and deaths happen with enough frequency to cause backlogs.

Internal Delays

As OHW does not use any data-sharing platform other than email, their primary internal organization of M&E information

25 National Population and Housing Census. (2011). Retrieved from <http://cbs.gov.np/image/data/Population/National%20Report/National%20Report.pdf>



Image 9 - OHW data tracking of health facilities

is viewed as difficult to manage by the M&E director. He laughs about his constant copy and pasting as we observed him spending minutes searching through his inbox just to find suitable examples of the completed internal reports. While it was said that reports are generally submitted on time, ensuring data is correct or that the correct Excel template was used can add days to getting information that may be needed to respond to partners' questions, to meet deadlines for grant proposals, or begin planning on future interventions. Time to circle back to field staff is compounded by the time difference between the United States and Nepal and the busy schedules of field workers who may spend their day without connectivity.

Challenges to Data Quality

Concerns about inaccuracies in the data, both due to errors and underreporting, were relayed to us at every level, save for the director of the HMIS and the FCHVs - the end recipient and the first line of data collection. Of course, quality issues such as errors can also increase time spent trying to obtain more accurate information.

Data Transfer Errors

Interviewees mentioned data errors at each step in the system: data may be inaccurate or missing from the individual registers,

a mistake could be made when aggregating the total services provided, when transcribing those totals to the monthly report, or when the numbers are entered into the web interface. Beyond errors, OHW staff members felt that certain metrics, particularly neonatal deaths, were also underreported in the HMIS.

Underreporting

By comparing the results of their private surveys with the government's HMIS, OHW has assessed that certain metrics are underreported in the official statistics. OHW's M&E leader flipped through the latest annual book of official statistics, pointing out districts that had recorded no neonatal deaths for last year, exclaiming "this has to be underreported" since there was no way districts of these sizes could have zero deaths. Possible factors for this underreporting are rooted in Nepalese culture as well as the current health management information system workflow.

Gaps in Monthly Reports

If a death occurs during childbirth outside of a health facility, the responsible FCHV is supposed to capture this information on her paper register or, in case she is illiterate, simply remember it. The information should then be shared with the Health

Post at the next monthly meeting between the Health Post administrator and the FCHVs of that area. However, no updates about events that happened before the previous meeting are included in the monthly rollups. Therefore, if a mourning period for a death overlaps with the end of the previous month, the FCHV forgets an event happened in the last month, or the FCHV does not find out about a death from the community until after the next monthly meeting, that information will not be captured by the HMIS. One health post administrator told us there is no reason to fix the previous months' reports if they learned of something that was not originally included. Essentially, the Health Posts in Charge felt that they would be doing extra work that the DHO is not asking them to do.

FCHV Shame

Although some FCHVs mentioned forgetfulness and illiteracy as being issues for them, OHW field staff suggested that shame also played a role in underreporting. FCHVs find their work important, telling us that the position gives them a way to "protect the children", "contribute to [their] village", and "get to know and make their peers comfortable". Two OHW staff members told us that they think the FCHVs feel personal responsibility for a death, especially for babies. An OHW staff member related to being careful when asking for more information about a death as they did not want to make the FCHV feel like they were "being interrogated" to find fault.

Community Shame

FCHVs said that pregnancies may go unreported because the community member might not share the information with them. During our focus group, they mentioned two causes: shyness and shame. Some pregnant women avoided telling the FCHVs they were pregnant because those women were ashamed that they could not remember when their last menstrual period occurred while others were ashamed to be pregnant if they already had multiple children since they might be seen as a burden on the community. After asking the FCHVs how they determined that the women were pregnant, the group left while two women moved their hands up and down in front of imagined pregnant bellies.

FCHV Resourcing

As described previously, FCHVs serve a critical function as the government's and multiple NGO's "eyes and ears" into the communities. Since FCHVs will rely upon word of mouth and face-to-face interactions to provide their services, FCHVs must walk and meet with women across the community. For FCHVs assigned to large wards with high populations, the volunteers may not have capacity to help each of the women in their ward. One OHW staff member, in a survey about pregnancies

monitored by FCHVs, relayed that some FCHVs described having too big of an area to cover and too many people to serve as reasons for inability to report about more pregnancies.

Underreporting of mHealth

One Heart World-Wide's mHealth Engineer, (self-described as OHW's "only engineer") responsible for managing the OHW's deployment of MedicMobile's system, explained how the pilot in Dhading showed how mHealth also suffered from significant underreporting. For example, FCHVs in 19 of 45 Village Development Committees had registered under 50% of the expected pregnancies projected, via historical averages from previous government reporting, for those areas. After his analysis of registration rates, he interviewed the district's FCHVs to build a list of reasons that highlighted technical challenges with using the SMS-based system: FCHVs could not use the phones due to age-related vision problems, illiteracy, or no cell phone coverage. During our meeting in Mahadevestan, only 3 of 9 FCHVs said they were able to use the mHealth system. One older FCHV, who had joined the program from its inception, held up the mHealth mobile phone and said "I don't know how to use it... I need one of my family members to answer the phone for me." Another stated that she didn't have network coverage, but that she still treated the phone "like a gift." Of the 3 that did use the phone, the cell network coverage was described as inconsistent, that they would typically hope there was a place to send and receive messages on the way to and from visiting patients. OHW's engineer further described times when the technology failed, showing us a timeline on the web portal that displayed weeks of low numbers of registrations, blaming the MedicMobile system for "data loss."

Misleading Data

The reporting of one significant metric - the number of women who have completed four ANC visits - depends upon adherence to a schedule that may not be appropriate given the tracking of time in rural communities. A woman is considered as "4 ANC Visit Complete" only if their first visit to a health facility is prior to their fourth month of pregnancy and successive visits occur during months six, eight and nine, but, since those targets are calculated from the woman's last menstrual period date, meeting those goals can be difficult when a woman or FCHV may be guessing at the date of the last menstruation. Not only did some FCHVs mention possibly finding out about a pregnancy once they noticed that a woman is visibly pregnant, health post staff further described how many women struggled to recall their last menstrual period. Save for certain traditional Hindu followers that practice chapaudi (a segregation of women from families during menstruation),²⁶ they said that women

26 Stacke, S. (2017). The Risky Lives of Women Sent Into Exile—For Menstruating. Retrieved from <https://www.nationalgeographic.com/photography/proof/2017/03/menstruation-rituals-nepal/>

rarely remember their menstrual cycles by day of month; instead, women may describe their last menstruation period by broader time markers such as seasons, either by weather ("rainy season") or agricultural process (ie, planting of a certain grain). Given these uncertainties in time tracking, a woman may not even visit the health post until their fifth month and a delivery could occur much earlier or later than expected. We were also told that rural populations do use calendars of months and dates (typically following the Bikram Sambat calendar), but use or understanding could vary depending on education and literacy.

Technological Hope for the Future

Before we even arrived in Nepal and initiated the design process, we learned that OHW had initial plans for reducing the impact of these challenges to timeliness and quality, particularly through the use of information technology. OHW discussed potential data collection by Skilled Birth Attendants using web interfaces or spreadsheets on iPads, setting up a centralized database on Amazon Web Services so staff members could share data, and using customized websites displaying interactive maps of data. Beyond platforms, access to "real time data" was frequently discussed as a goal; in Nepal, we learned of a current pilot where OHW was using an SMS-based platform for Health Post medicine inventory management so that health facility administrators and DHOs would immediately receive notifications when stocks were low.

We did not observe or hear any resistance to the adoption of technology. Instead, OHW members related they would be receptive to solutions that would not increase the amount of effort for the FCHV or Health Post staff, would be cost effective, would help to "strengthen the government," and, as the OHW's Director of Operations told us, "well, it would have to work!"

Limitations

We recognize several limitations during this phase that likely influenced the quality of our work and results.

Limited In-situ Observation

We know one week in Nepal would not allow us to gain the deepest understanding of the system's context. Since our time in Nepal was limited, data was mainly collected through semi-structured interviews, limiting our ability to decrease distance between the researcher and the reality of OHW's operations and their beneficiaries' challenges.²⁷

27 Lofland, J., & Lofland, L. (2006). Analyzing social settings. Belmont, CA: Wadsworth/Thomson Learning

28 Charmaz, K. (2014). Constructing grounded theory. Sage, 214

Language Barriers

Our inability to understand Nepali inhibited our ability to observe without the translation help of OHW's staff members. Additionally, when we would ask questions to any person that did not understand Nepali, an OHW staff member would instead deliver the question and relay the answer back to us.

Lack of Theoretical Saturation²⁸

Finally, due to our lack of time in Nepal, we were only able to visit one district field site and a single health post. We do not assume that the challenges facing the health post's staff would extend to every other health facility; our plan allowed us to gather information on each stage of information flow, while not seeking a broad diversity of experience at any single level of information collection. Instead, we used interviews and analysis of staff reports to learn second-hand information about the operations of other districts, recognizing its limitations and seeking feedback from OHW regarding possible claims and assumptions we made.

After conducting the primary user research and building our understanding of the overall system architecture, we engaged in a design process that focused on visualizing the existing system through the perspective of the multiple agents involved.

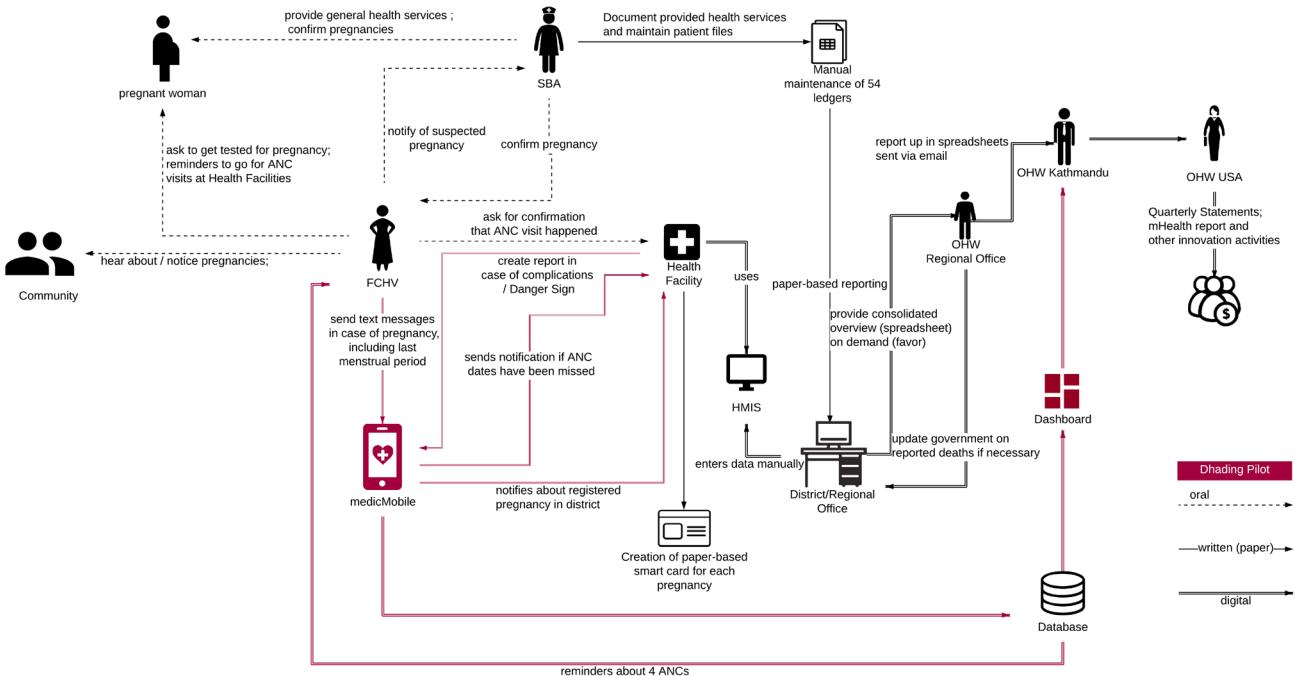
PART TWO: DESIGN PROCESS

UNDERSTANDING THE EXISTING SYSTEM

Based on our time in Nepal and our calls with OHW, we began by drawing out the existing structure of the maternal and neonatal health management system in Nepal, which includes the different government entities, OHW and mHealth. Visualizing these connections helped us obtain insights into the relationships between them and their role in the current system, and clarified the information flows from the FCHVs all the way to the government HMIS systems and OHW leadership. More importantly, this helped us to understand the different routes

of information flow and how the technological and logistical limitations, such as maintaining paper records in 51 registers at the health facility level or not being able to rectify the reports sent to the DHO at the end of each month, can affect the speed of information availability and reliability of the information obtained from these sources. Overall, this exercise served to provide a reference system, that needed to be improvised by means of the consideration of the existing bottlenecks and limitations of the entities and channels throughout our project.

Pregnancy Information Flow



Personas

Personas represent the archetype users who interact, or would interact, with the system we are designing. Having personas can help us in understanding the user, their current situation and how the system we are trying to enhance would improve their overall experience and help them overcome the shortcomings of the existing system. We built personas for the FCHVs, Health Post Staff, Government HMIS Management, mHealth and OHW Senior Management. This allowed us to evaluate their role in the system and associate them with a typical user profile, helping us to craft a mental image of each of the user types and take them into consideration while building out the system. Our persona development could only stretch as far as our available data, though, and due to our limited data collection in Nepal, we needed to be conscientious of creating shallow stereotypes for each role.

Empathy Maps

Empathy maps help us to understand the viewpoints of the system/product from the lens of each person involved and provide a better understanding of what the person sees, hears, thinks and feels or says and does. By capturing the gain and pain points, empathy maps allow us to understand friction within the existing system and begin to consider how changes would be perceived by its users. This exercise of creating empathy maps drew out that potential enhancements that could benefit everyone involved, at large, might cause negative reactions from certain user roles. For instance, a reporting system that lessens an FCHV's role may benefit the quality and speed of information, but this could leave the FCHVs feeling disregarded, unrecognized, and less motivated to provide services to their community. Furthermore, this exercise particularly connected our understanding of the existing system to what users may need if there are any enhancements or changes to the system. For example, digitizing the paper registers at the health post level would not only mean having the right infrastructure in place but also entail educating the health post staff to use these systems in an effective manner.

Rose, Thorn and Bud

Using the Rose, Thorn and Bud exercise, we analyzed the positive, negative and future potential aspects of the system from the perspectives of FCHVs, the Health Post staff, OHW district staff, OHW Nepal-based managers and OHW senior leadership. This provided the advantage of articulating the keys strengths and weaknesses of the existing setup and explicitly framing the problems that could potentially be addressed. Ideally, since this exercise provides us the opportunity to individually diverge as we each interpret as "roses", "thorns", and "buds", we would have involved the participation of our client given our team's narrow perspective of the users. Due to logistical constraints, this was not possible. However, once we narrowed the problems we could potentially address along with potential solutions, these were communicated to OHW for their feedback. By this time, we felt that we had a clear understanding of the problems that OHW would be willing and able to address.

FCHV

Female Community Health Volunteer



Opportunities:

- Well-Trusted & Respected in Community
- Credited with health indicator improvement over 2 decades
- Work hard for no pay
- Experience educating the community

Challenges:

- Significant Illiteracy Rate
- Significant Digital Illiteracy
- Age-related maladies for hearing, sight, memory, mobility
- Difficult to hold accountable
- Feel overburdened by NGOs
- Barriers due to distance, geography, and population

A day in the life of modern health workers in Nepal

Shreya is the administrator at a health post in Mahadevsthan. Shreya keeps the health post running and keeps track of patients, services, and equipment. She writes down this information in 51 paper registers as required by the Nepal Ministry of Health. Shreya records whenever a patient visits the health post. She also meets with FCHVs who tell her information like pregnancies or deaths that happen in their wards. Sometimes they forget the details - they are supposed to write the information in their registers, but some do not know how to read or write.



At the end of each month, Shreya combs through the 51 registers and sums up the total activities - visits, births, treatments, deaths - that happened during the month. She counts them up one by one and then writes the totals on a monthly report form. She tries her best not to make any mistakes while counting and copying to the other form, but it can be difficult with all of the cells and forms to complete.

She'll make the several hour trip to the palika administration center once a month and give the designated government statistics officer the report. Sometimes, the form will be checked for errors - looking to see if the numbers make sense; other times it won't be checked.

Shreya returns to work at the health post the next day. She doesn't usually hear from the palika about the information in the reports unless there is a glaring issue - one time she accidentally listed that there were dozens of dengue fever incidents and someone called her - turns out she wrote a number in the wrong column.

Sanjeep is a staff worker who works for One Heart World-wide. He implements OHW's programs from upgrading birthing centers, training SBAs how to use ultrasound machines, and educates FCHVs on ways to prevent newborn hypothermia in the wards. He also needs to keep track of all OHW activities and a list of impact indicators to help monitor program effectiveness. Since the federalization of Nepal, he must work with a dozen separate palika administration centers when he used to just build a relationship with the single district health office.

Sanjeep must visit each of the Palika centers to build a relationship with the government administrators - sometimes, they're willing to share the collected data from the Health Posts with him after they enter the information into a spreadsheet on their computer or directly into DHIS2. Handkeying the data can take weeks or months, luckily the centers with internet access might be able to email him the data....

Once Sanjeep has data from each of the respective Palikas, he must copy the data into a Google Sheet for the rest of the M & E team to see the information. He tries his best not to make mistakes when copying and pasting - the wait to get the data has already been weeks or months without needing to wait longer for corrections.

Sanjeep will try to visit Shreya's Health Post once every other month to check in on the status of current projects, collect data, and conduct retraining for solar power backups, the ultrasound machines, or infant warmers. He has a busy schedule though and while he'd like to visit every health post in his section at least once a month, it really depends on the number of current initiatives, the weather & road conditions, and whether he can get all of his paperwork finished!



Problems Identified

The process of diverging to conduct individual research and converging to communicate and consolidate our findings through these exercises helped us identify and realize the following problems, and use them as the basis for our ideation process:

- How might we increase the number of community-based neonatal and maternal deaths reported in the HMIS?
- How might we decrease the time for OHW to learn causes of death?
- How might we improve the quality and consistency of pregnancy-related data capture across different stages?
- How might we decrease the time it takes to transfer data from the health posts to OHW?
- How might we decrease the chance of transcription errors and data loss when transferring from paper to digital systems for all users?
- How might we make OHW's internal organizational data sharing more efficient?

Improved Information Flow Concepts

Once we understood potential problems within the existing system, we then created improved information flows to achieve the intended goals and needs of the users. We diverged as a team and individually created versions of potential, ideal future information flow diagrams. This exercise built upon our understanding of the system and also each of our individual ideas on how to overcome the problems prevalent in the system. Thus, our ideas ranged from using word of mouth to having a phone tip line/IVR system for more immediate reporting of maternal and neonatal deaths, or having rectification mechanisms for physical updation of monthly records to maintaining a central database for record maintenance and differential accesses. The exercise served as a milestone in our project life cycle since we combined the previous design exercises and conceptualized our expectations from an improved system.

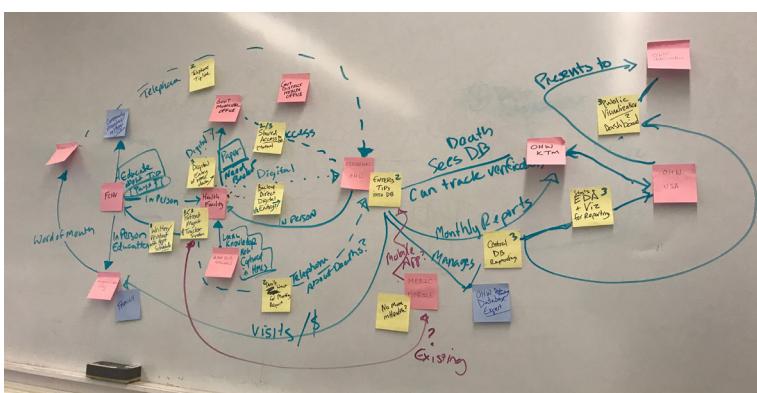


Image 10 - New information flow concepts created during a design sprint

Health Post Staff

Skilled Birth Attendants, Health Post administrator, Paramedic



Opportunities:

- Have been managing & training FCHVs successfully for decades
- Educated and Skilled
- Have and use smartphones
- Government Employee – could be fired (ie. there is accountability)
- Willing to work rurally in challenging conditions

Challenges:

- May have limited connectivity (no internet or cell service at some HFs)
- Manages 51 paper registries for all data
- Submit reports only 1x a month
- No follow-up with patients – no direct communication
- Does not correct previous months' reports unless asked to by DHO
- Does not report community-based information if not given by the FCHV

Need Assessment Matrix

Need assessment matrices provide a grid-based approach to ranking the proposed solutions against potential modifications.

This can further assist in:

- Understanding what the strong points of our proposed system through highly ranked components.
- Assessing the low ranked components and brainstorming how the experience may potentially be improved for the entities involved.

We started by first identifying the expressed and desired user needs based on our conversation with the stakeholders and dividing them into 11 categories:

- **Timeliness** - reduce the time for OHW to learn of a maternal or neonatal death
- **Efficiency** - reduce the work to receive information from OHW field staff
- **Quality** - improve the accuracy of the reported data
- **Respect for the Community** - respect the time of the FCHV and the health worker
- **Functionality** - consolidates all reported data in a central location
- **Reliability** - works even with intermittent internet, power, or cell coverage
- **Learning** - enables OHW to view trends in deaths by location and cause
- **Cost** - is feasible for OHW's budget
- **Simplicity** - is easy to manage by OHW
- **Desired Impact** - helps OHW to reduce neonatal and maternal deaths
- **Flexibility** - will keep working before and after uncertain government transition

Based on the perceived importance of each need, we assigned a weight to each of the individual needs based on their expected importance in the system. This was followed by creating a Need Assessment Matrix for each of the proposed information flows that ranked them against the enlisted needs, thus clearly highlighting the components that the information flows addressed well and the ones they could potentially improve upon. It also allowed us to pick the strong points from each proposed information flow and shape them towards our proposed solutions for OHW. The information flow that proved better from a timeliness and efficiency perspective and focused on centralizing the storage and maintenance of information was shaped into the idea for centralized data sharing. The information flow focusing on quality and respect for the community as well as accurate reporting of maternal and neonatal deaths evolved into the proposed solution for death reporting. This exercise was extremely useful for the project

and built upon the information flow diagrams developed in the previous exercise.

Outputs

"Low-level Prototypes"

As we moved towards formative stages in our work, we used diagrams showing information flows to function as low-level prototypes for user feedback. As we were not building an application or web portal, but instead designing a larger system showing how users would share information among each other, these process diagrams seemed most helpful to serve as our "prototypes." These, in conjunction with the brainstorming methodologies (discussed below) assisted us in building a barebone structure for multiple constituents while encapsulating the information gathered from the brainstorming sessions. Some examples of prototypes we built include the SMS system and the ANC visit reminder system.

Idea Proposals and Concept Notes

Our analysis and iterative refinement process allowed us to come up with three main proposals for OHW that, if implemented, would certainly help in improving the maternal health care system in Nepal. We presented these idea proposals to OHW in the form of detailed presentations and subsequently in the form of concept notes, which are detailed abstractions of what the ideas are, why they are important, how they would add value to the system, who would benefit from the solution and how to implement them in the system.

About Our Process

Brainstorming Methodologies

Given the diversity of backgrounds for each of the project members, we realized the importance of active discussions and brainstorming early on in the project lifecycle. This helped us in assessing and evaluating the critical components and potential solutions for these components based on multiple viewpoints that were driven by the expertise and individual social, cultural and technological experiences. The brainstorming activities ranged from discussing possible solutions to the specific elementary components of the system at the most granular level (deciding on whether to propose an IVR based or operator based tip line, for instance) to whiteboarding the thoughts for different major subsystems. An example of a brainstorming and whiteboarding session for the ANC Management system is as shown here.

Such brainstorming activities served as the overarching method for the various design process components and effectively

allowed us to put the ideas on the board and critique, combine or refine them through active participation and collaboration.

Participatory Design

A key component of our design process was the participatory design. We ensured that we actively involved the stakeholders (OHW) and the project advisor (Jenna Burrell) along multiple short iteration cycles (discussed below) of the design process, so as to incorporate feedback-loop as an essential component of our project lifecycle. This was achieved through numerous calls, presentations, document sharing and feedback sessions/documentation with OHW US and in-person meetings with the advisor on a routine basis, which enabled us to iteratively build a solution that actively incorporated the feedback, reservations in implementing specific aspects of the solution and dynamic requirement changes from OHW, along with the experiential guidance from the advisor while minimizing any communication barriers. This allowed us to be virtually on the field while still working across the world and combining the perspective of people who would be affected by the system and those who had already faced similar issues while designing information systems for the emerging societies.

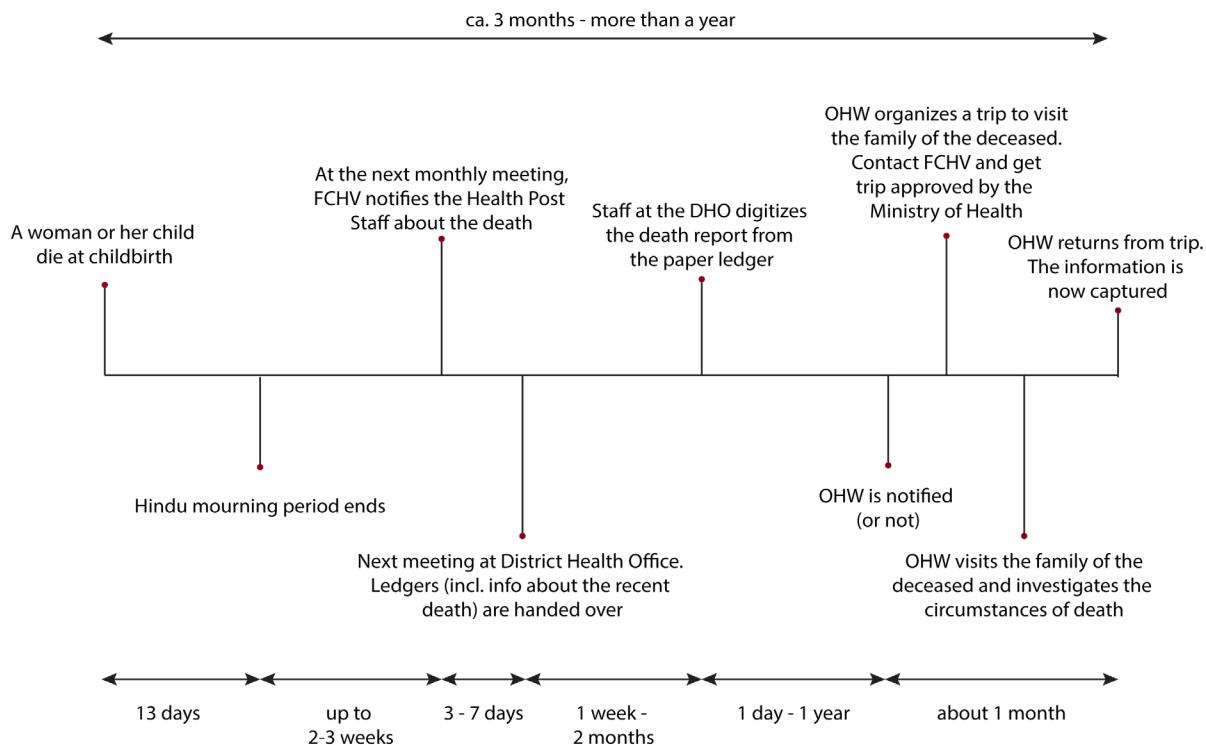
Short Iteration Cycles

We divided the project into short iterations of 10-14 days. Each iteration cycle involved working on clearly laid out goals for the iteration and presenting/sharing the progress of the iteration with both OHW and the advisor to seek their feedback and suggestions on refining the work for the iteration, deciding on the next steps and using the insights to drive the work on the goals of the next iteration. The iteration cycles served two big advantages: constant review of work that allowed for the incorporation of evolutionary ideas into the project as we went along and backtracking if we were deviating from the desired goals or if something could be done in a better way.

Insights Throughout the Design Process

Our greatest surprise was the uncertainty around the government transition. We had not expected that the District Health Office would be the main facilitator for the government's data collection system, but we also did not expect that the government's plans to replace the DHO would be both unclear and undeveloped. While DHOs might continue to serve the same functions unofficially until each palika has administrative capability, the restructuring of the government increases the

Current death reporting timeline



burden upon organizations like OHW with goals to increase government capacity. Beyond the resourcing needed for OHW field staff to interface with a far greater number of administrative offices, any investment in technology must be flexible to account for this uncertain reporting flows and management.

The quality or timeliness of the data decreased at each step of the “journey”

It was clear from our trip that what OHW had originally asked for - “real-time data” - would not be achievable given the many factors discussed. Quickly, we saw that no technology would provide near-instant knowledge of deaths and pregnancies in the community to OHW, but considered that improvements at various points of the information flow might improve the quality and timeliness of certain types of data. Additionally, we found that OHW’s and their stakeholders’ needs did not require all data to have the same degree of timeliness; as with the mHealth platform, a limited number of indicators could be shared via one technology while lower-prioritized data could use slower communication modes. Thus, we found ourselves replacing the goal of “real-time data” with a concept of “right-time data,” where data could be used as soon as feasible according to the needs of the user.

mHealth technology could be useful, but would not solve underreporting problems alone

The underreporting via the mHealth platform witnessed by OHW seemed unavoidable once we considered the combination of contributing factors, however, the push reminders could still be able to provide benefit to some users. Should the FCHVs capable of receiving these notifications be denied this benefit only since the technology was not suitable for compiling a complete data picture for organizations in Kathmandu? Instead, we wondered if it would be feasible to reinforce mHealth with multiple other communication methods (word of mouth, paper, texts, phone calls, emails, web portals) similar to Densmore’s concept of a braided communications channel where Ugandan health service providers used “one or more communicative channels ... to reinforce one another, through redundancy or complementary affordances, thereby creating a more appropriate, braided channel of communications.”²⁹

Paper offered multiple affordances in the HMIS

From our time at the School of Information, we learned to be sensitive to the affordances of using paper-based information systems and how they can be, for some contexts, the more appropriate means for organizing information than newer digital technologies.³⁰ With the government’s HMIS, we saw how paper provided the system resilience at minimal cost - no one mentioned registers suddenly disappearing or breaking, instead, logs and registers could be carried by thousands of FCHVs across the country. Beyond paper being the failsafe for the HMIS, it also prevented individual patient data from being shared easily (this can be good for security as privacy regulation may be lax or bad for sending information to another health post if a patient moves). As such, we felt we should not discount the involvement of paper in our solutions, at least considering methods for automating the digitization process.³¹

OHW’s efforts should support the government’s technological ambitions

The government’s plan to provide digital HMIS capabilities to every health facility by 2020 reminded us of the techno-enthusiasm of other large deployments of technologies in low-resource contexts that failed to meet the needs of those populations.³² From those deployments, we find that, beyond the sustainable design of the technology itself, system designers must also account for necessary training, maintenance, upgrades, repairs, replacements, and the logistics to support those needs. Since designers should not be expected to anticipate every requirement to accommodate system failures,³³ we wondered how OHW’s search for technological improvements might further the government’s efforts to connect Nepal’s health posts by uncovering best practices for system resilience. Presumably, OHW could “strengthen the government” by learning how failures would emerge and be addressed through smaller scale deployments of computers and online portals.

29 Densmore, M., Bellows, B., Chuang, J., & Brewer, E. (2013). The evolving braid: how an organization in Uganda achieved reliable communications. Proceedings Of The Sixth International Conference On Information And Communication Technologies And Development: Full Papers, 1, 257-266.

30 Sellen, A., & Harper, R. (2003). The myth of the paperless office (pp. 107-137). Cambridge (Massachusetts): MIT Press.

31 Chen, K., Kannan, A., Yano, Y., Hellerstein, J., & Parikh, T. (2012). Shreddr: pipelined paper digitization for low-resource organizations. Proceedings Of The 2nd ACM Symposium On Computing For Development, ACM.

32 Ames, M. (2015). Charismatic technology. Proceedings Of The Fifth Decennial Aarhus Conference On Critical Alternatives, 109-120.

33 Rosner, D., & Ames, M. (2014). Designing for repair?: infrastructures and materialities of breakdown. Proceedings Of The 17th ACM Conference On Computer Supported Cooperative Work & Social Computing, ACM, 319-331.

Limitations

We recognize several limitations during this project may have influenced the quality of our work and results.

Limited client participation

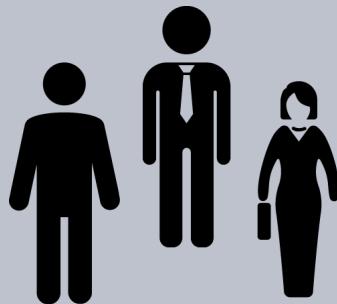
As stated above, we had intended on using participatory design processes to develop appropriate designs to address OHW's needs. We quickly learned that, as a small organization with staff members spread across the United States and Nepal, OHW would be able to offer limited time to participate in our design exercises. We attempted to mitigate these concerns by communicating stages of our design process and seeking feedback whenever possible and, by using collaborative documents over GoogleDocs, we facilitated asynchronous debate of proposed concepts. The feedback over iterations that we received was very helpful.

No access to non-OHW users after the initial research

As we expected, our design process generated many unanswered questions about the behaviors and perceptions of users and beneficiaries. We especially found ourselves wanting to understand how community members would react to some of our proposed changes and learn how other organizations' field staff work through similar conditions. We sought answers from One Heart World-Wide, researchers and other experts with experience in Nepal, and consulted previous literature on rural conditions, FCHVs, and health care within the country. By substituting additional user research with these proxies, we needed to emphasize getting feedback on our concepts from OHW as early as possible and communicate the assumptions that we had made.

OHW Staff

Regional & National Office NGO employees



Opportunities:

- Proficient with administrative work on computers, using internet, and sending email
- Staff is generally college-educated - most with advanced degrees
- Familiarity with Microsoft Office tools
- Very dedicated and enjoy working for OHW

Challenges:

- Lots of spreadsheets/excel/word docs
- Time consuming (copy and pasting)
- Data handling mistakes
- Burdensome to districts staff
- Reporting formats may be outdated
- Communication lag (timezone differences)

PART THREE: PROPOSED IDEAS

Building on our research and subsequent discussion and analysis, the team reimagined the information flows in the system. In an ideal world, what information would be available to which actors and at which time?

The systems that collect and share pregnancy and neonatal healthcare information depend upon the resilience and dedication of the people involved. From foot-travel over long distances to attend meetings, to transcribing pages and pages of monthly reports, to communicating across languages and timezones, the effort taken by the sharers of information cannot go unnoticed, yet when we learned about the points of the system where data was lost or delayed, we considered how data loss or delays, poor technological implementations, and the lack of proper coordination created additional burdens on those same people. While we wondered if any single technological advancement or process reconfiguration could revolutionize monitoring and evaluation for Nepal, system interdependencies led us to consider a targeted piecemeal approach to reducing inefficiencies and increasing data quality. Beyond meeting the needs listed previously, the most critical factors that guided this approach were the following:

- One Heart World-wide must have the ability to implement and influence the solution.
- The solution should not depend upon the transitioning District Health Office or palika offices.
- The solution could be scaled and sustained by the government in the future.

We thus recommend a 3-fold approach to achieve the goal of creating an improved healthcare information system in Nepal. We flattened the internal communication system through a centralized data sharing mechanism that takes into account the varying levels of technical literacy, suggested accesses and appropriate connections to the presentation layers in the form of dashboards or reports. Next, we broadened our coverage for death reporting by involving the community members as active agents in the death reporting pipeline and incentivizing them to be a part of this process. Finally, with the data sharing system and adequate mechanisms for death reporting in place, we refined the antenatal care reminder systems that harnessed the strengths of the existing system, while incorporating the advantages of cellular connectivity and network consolidation.

Internal Data Sharing

	faster access to relevant information
	better communication and knowledge sharing
	better data quality and insights for more effective decision-making

Death Reporting

	faster access to relevant information
	better data quality and insights for more effective decision-making
	relieves FCHV from the burden of reporting

Pregnancy Management

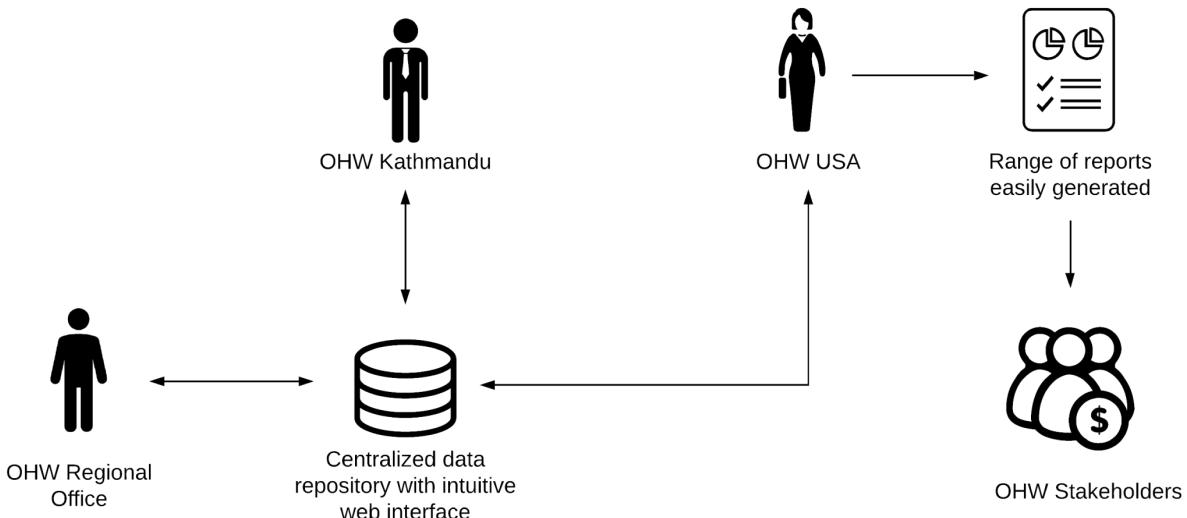
	increases effectiveness of existing programs
	makes it easier for FCHVs and expectant mothers to keep track of scheduled ANC visits
	easy data sharing with the government

INTERNAL DATA SHARING

Key idea:

A centralized reporting system between all OHW offices nationally in Kathmandu and in the US to enhance their ability to communicate and collaborate.

-  faster access to relevant information
-  better communication and knowledge sharing
-  better data quality and insights for more effective decision-making



The first idea the team proposed is a centralized reporting system between all OHW offices, nationally in Kathmandu and in the US to enhance their ability to communicate and collaborate. While aspects of the Government's HMIS may be beyond OHW's ability to influence, OHW has control over their own internal communications and could decrease the burden on staff, decrease the time for OHW leadership to receive accurate reports, increase the time available to learn and make decisions by all members, while creating greater opportunities for internal sharing of knowledge and ideas.

Identified Problem

There is currently a lot of work involved in requesting and sending information back and forth between OHW field offices, OHW Kathmandu, and their United States-based leadership. Time zone differences further exacerbate the amount of time to request, send, and receive information via email. Apart from wasting resources to generate one-off information requests and reports, there is also a high risk for miscommunication on information needs, and a lack of transparency of available

information. This makes communication and collaboration between OHW offices slow and tedious and, importantly, can be at the expense of time spent delivering programs.

Proposed Solution

Much of the pain of requesting and sending information between employees could be alleviated with a centralized reporting system. Built upon a shared database, a centralized reporting system means that OHW offices across the world can get instant access to relevant internal information. A dashboard view capability and an easy way to extract reports that can be shared with interested stakeholders could speed up current workflows by days.

Beyond data sharing within OHW and its stakeholders, the Nepalese government officials could be granted access to some preconfigured views of central data repositories as well. This would enable OHW to further walk the path toward eventual transfer of knowledge, information, and activities to the Nepalese government.

In a centralized system, data with a temporal or spatial

relationship can be more easily compared, reducing the time to identify and correct errors. It also reduces the risk of human error introduced through copy and pasting or spreadsheet mismanagement.

Overall, a data sharing platform could help make data more easily found, shared, and visualized.

Limitations

While centralized data sharing has several potential benefits, it faces some limitations as well. A first one is an increased technological complexity, putting an additional burden on the user. Depending on the choice of implementation, significant upfront development, configuration, maintenance, and training might be necessary, requiring resources that OHW cannot easily make available.

Introducing a centralized system will also not improve the quality or accuracy of the data entered into the system. This solution relies on having enough clean data to be usable, however, the potential time advantages for identifying inaccurate data can allow managers to seek corrected information quicker.

In addition, the design of such a system requires making formerly implicit choices more explicit. While sending emails with hand-curated information scattered around in the body and attachments might be messier, it allows for more bespoke communication. It also provides the sender the ability to give additional context to ensure the recipient interprets the data as intended. When everybody has direct access to the data, some of that relevant context might not be provided anymore, potentially leading to a misinterpretation of facts and ultimately

wrong decisions.

A centralized system also requires internet connectivity to sync and share data, but since lack of connectivity is only an issue for OHW staff during field visits and intermittent connection losses in the office, this limitation can be addressed by offline syncing functionality possible on OHW's computers.

Pending Questions

Central data sharing relies on introducing a centralized database, which is no small feat. OHW needs to assess its needs and make design decisions across a wide range of areas to ensure that the system has the capability to work as desired.

In addition, the rollout of such a new solution requires meticulous planning, coordination, and development. A usable interface for data entry must be created. Users need to be trained to use that system. Beyond upfront implementation needs, both the interface and the database must be routinely configured and maintained. Given that OHW generally transitions its local programs to the control of the Nepalese government after a three year period, the ease of transfer has to be a consideration as well.

Result

Despite the considerable effort that needs to be put into setting up and managing a central data sharing platform, OHW agreed that the solution would be a worthy investment for them.

We analyzed multiple options, including database types (SQL, NoSQL), front ends user interfaces (DHIS2, Google, or custom-built solutions), storage providers and hosts (Google, Amazon,

KEY CONSIDERATIONS FOR DATABASE IMPLEMENTATION DECISION

Data & Scale	<ul style="list-style-type: none">• What is the amount of data to be stored on a daily/weekly/monthly/annual basis?• How much historical data needs to be maintained?
Access	<ul style="list-style-type: none">• How many users would need access to the database and what kind of access should they have?• What is the learning curve for the database and its operations for those who would be using it?
Security & Resilience	<ul style="list-style-type: none">• What are the intended security considerations for the data?• How robust, failure-proof should the database be?
Interaction & Functionality	<ul style="list-style-type: none">• What kind of user interface and visualizations does the database support?
Maintenance	<ul style="list-style-type: none">• Can it be hosted on a physical computer/server or does it need a cloud storage solution?• Who would maintain the database and ensure it is up and running when needed?
Financing	<ul style="list-style-type: none">• How much are we able to invest up-front and on a periodic basis?

Dropbox), and even third party data managers like BAO Systems and Zoho. Each option was evaluated for its capability, cost, reliability, ease of use, training requirements, and maintenance.

Some of the considered solutions



Given OHW's limited resources and relatively small scale of data collection, the team proposed using G-Suite (including Google Sheets, Docs, Forms, and Drive) as the most suitable platform to implement a centralized database. These applications could encourage reporting using smartphones and also allow for offline use. The benefits of minimal development time, cost, and maintenance outweighed more customizable solutions involving custom user interfaces and cloud-hosted relational databases. This proposal resonated with OHW because it further validated some work they had previously done to migrate their data into Google Sheets. As of April 2018, the transition for OHW to G-Suite document management was underway.

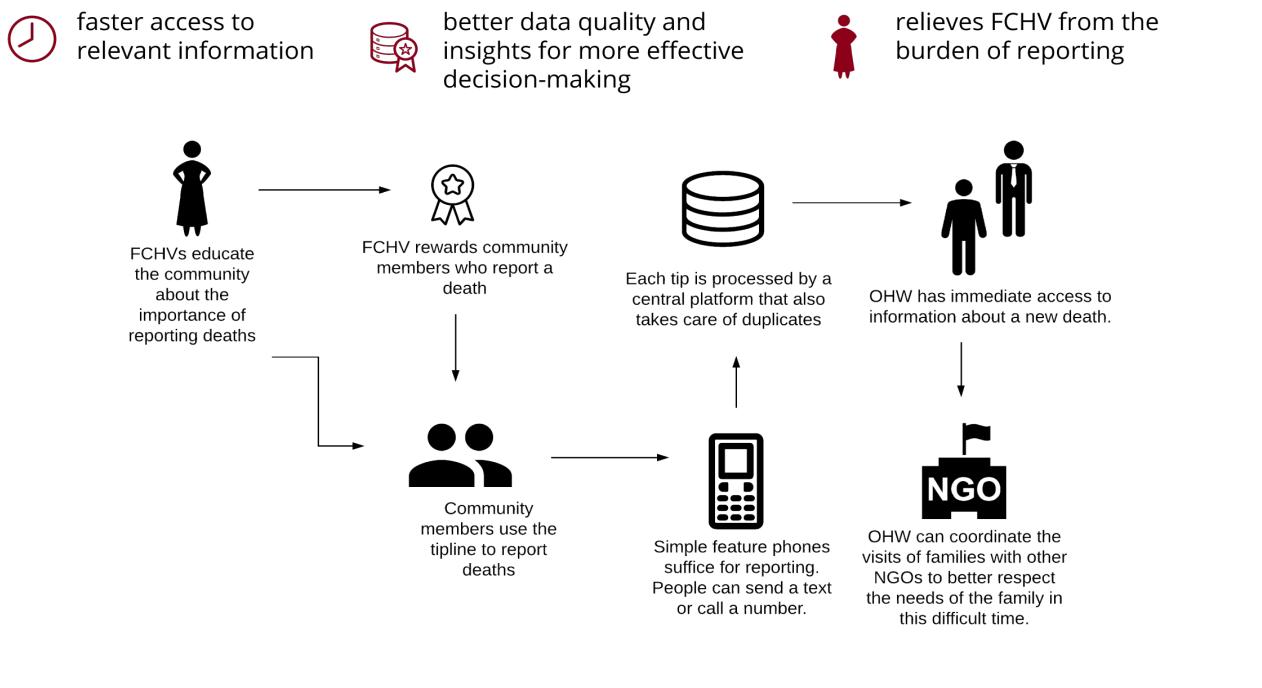
Reflection

We were surprised to end up recommending essentially Google Sheets to a client who had initial visions of a database deployment on Amazon Web Services. As designers, the solution's perceived simplicity betrays that it is, what we found, to be the best solution for the given context at the present time. A simple shared document store doesn't necessarily add an additional channel for data to flow, but we found that it should make the existing channels of communication much stronger through more efficient management of those flows. It is possible that more complex and extensible solutions are in OHW's future, but transitioning to G-Suite applications allows OHW to learn how centralized data management might fail to meet their needs without investing in more costlier solutions.

DEATH REPORTING

Key idea:

Engage the community to share responsibility for informing OHW of maternal and neonatal deaths by establishing a mobile tipline.



The second team proposal revolves around community engagement to share responsibility for informing OHW of maternal and neonatal deaths. Of the health-related information that OHW relies upon, knowledge of the circumstances around the death of a newborn, pregnant woman, or new mother, are especially important. By leveraging the information access of other community members beyond the FCHV, OHW will be able to build a clearer and timelier picture of local deaths and the reason behind them.

Identified Problem

Due to cultural factors around mourning and shame, limited resources of the volunteer force, and delays in the reporting chain, it can take up to two months for district staff to learn about a death, if at all.

Once a death has been reported, OHW field workers then travel to where the death occurred to gather more information on the cause of death. Given the relative inaccessibility of many of the more rural areas in Nepal, these journeys often take up a day or more one way. In addition, since other organizations or

the government will be interested in learning about the cause of death, a family could be interviewed about a very painful event multiple times, further incentivizing other families and communities not to report their deaths.

The problem that OHW faces in regards to death reports is therefore two-fold. Not only do they not get information in a timely manner, there is also estimated to be a considerable number of unreported deaths, making an accurate assessment of the effectiveness of their programs very difficult.

Proposed Solution

For OHW to be able to collect better information on maternal and neonatal deaths, the team envisioned involving other community members in sharing information about the causes of death. This idea stemmed from the private surveys conducted to gain better estimates of mortality in Nepal; those researchers will reach out to teachers and other community leaders to learn about deaths that may have been overlooked in the HMIS. One form of enlisting greater community involvement was via a community death tipline. Essentially, the idea is for OHW field staff to set up a SMS and/or phone tipline

that allows all community members with access to a phone to report a death. To give people in the community a reason to do so, a small incentive, from money, food, or recognition, could be provided to those reporting a so far unreported death.

This proposed solution would take the burden of reporting from the FCHVs and immediate family by opening it up to others. Multiple community members, including those with daily routines that take them towards areas of cellular coverage, might report on the same death, increasing the number of "eyes and ears" in the community. OHW may learn of deaths before the end of the customary mourning period but would not investigate until the mourning period is over.

Previously, where FCHVs might not remember to report deaths and may not be able to learn about all incidents in a densely populated area, their involvement could entail educating the community about the importance of death reporting, managing the disbursement of incentives, and still coordinate the OHW death investigation. An FCHV may feel pride for bringing recognition to peers in her community and would likely also exert social pressure on friends and relatives more able to use mobile technologies.

The solution leverages already existing infrastructure, minimizing the necessary investment in mobile technology to make it happen, and tiplines (with supporting campaigns) could be targeted for communities where underreporting may be more problematic.

Aside from proposing a death tipline, the team also recommended coordinating investigations on the cause of death among the Nepalese government and multiple NGOs interested in the accurate and timely collection of this information to lessen the burden on the families during this traumatic time.

Limitations

We understand that this solution has various limitations. Death is an important aspect of people around the world and any solution in this space needs to be very carefully crafted to respect the local religious traditions. Unless the death occurred in a health facility, our user research revealed limited ways to get detailed information about a death before the end of the thirteen day mourning period. However, OHW does not need the information so urgently to risk offending cultural norms as it is believed that immediate collection of information once the mourning period is over should be acceptable.

Providing a financial incentive to report a death can also be problematic. Enabling community members to gain from another family's misfortune could be perceived as inappropriate and received very negatively. Additionally, OHW

stated that financial incentives from the government can be challenging to obtain and sustain; even getting travel stipends from the government for FCHVs was a difficult process. We, instead, proposed exploring other incentive structures to include food, comfort items, certificates, or public recognition.

Pending Questions

Some of the questions we did not get to address in our proposal included the concrete technical implementation of this service, the end-to-end journey of its users, and the types of incentive provided to community members.

In addition, we would want to learn how coordination on death investigations between the Nepalese government and interested NGOs could transpire. Currently, these programs only overlap in Dhading district and the future plans for the WHO-led MPDSR are unknown to us.

Result

OHW leadership in the US thought that our concept for community-based death reporting was an interesting and novel idea. Given the potential sensitivities around death and the challenges in obtaining government incentives, however, OHW decided to develop this idea further with local staff in Nepal to better understand how such a solution would be received by the population. Given OHW's enthusiasm for our next proposal, we have collaborated with them to develop that concept instead and collectively have not explored this option further.

Reflection

Through this solution, we found how client participation can enable the designer to develop more appropriate solutions before embarking down the wrong path. The feedback from OHW about the previous difficulty they had with financial incentive programs allowed us to consider the possibility of non-monetary incentives. The questions whether those incentives would work in the community were largely unanswered after analysis of our data and were even beyond the immediate knowledge of OHW leadership without conducting additional research. This is how the design process should work - proposing reasonable solutions that can be iteratively improved based on additional testing and user research. This concept explored how the coverage of collection can be increased to add redundancy to an information system - more people involved in this system means more words shared by more mouths and more opportunity for existing communication technologies to be used. In the concept of braided communications, we did not add additional channels but increased the strength of the existing strands.

PREGNANCY-RELATED TRACKING AND NOTIFICATIONS

Key idea:

Introduce an electronic system that helps health post staff keep track of pregnancies and reminds pregnant women and their FCHVs about upcoming ANC visits.



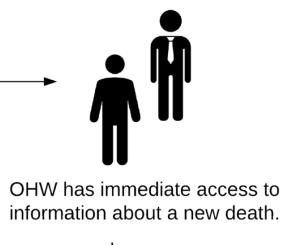
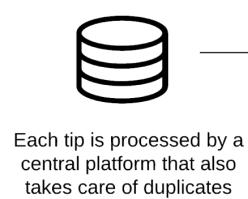
increases effectiveness of existing programs



makes it easier for FCHVs and expectant mothers to keep track of scheduled ANC visits



easy data sharing with the government



The third proposal is an electronic system used by the health post staff to improve case tracking and notification processes for expectant mothers, particularly for antenatal care (ANC) visits. A key aspect of the Nepalese government's and OHW's approach to improving maternal and neonatal health care is to understand when pregnant women need access to care. Women need to know when they should be at a health facility so they can plan their travels accordingly. The health organizations, on the other hand, need to better be able to monitor and evaluate pregnancies and ANC visits, and gain a better understanding on how often health facilities are accessed by expectant mothers.

Identified Problem

As discussed, information regarding pregnancies needs to flow in two directions (to the pregnant woman and to the managing health organizations). However, both of these channels currently have problems. Since programs to remind pregnant women to access health facilities (via written notes or SMS notifications) currently rely on the written records maintained by the FCHVs, these systems also depend on the literacy, digital access and availability of a single user - the FCHV. In the other direction, the HMIS system's reliance on paper reporting introduces two problems: first, the DHO (or palika administration offices, eventually) can become overburdened by the lack of efficient ways for digitization of the monthly rollups. Secondly, the logging of information in the 51 registers and the possibility of transcription errors raise the probability of pregnancies going unreported.

Proposed Solution

We took into considerations the limitations of the current system and proposed a system that allows for better, more efficient patient management. The tool is an electronic record management system with a user interface that will be run on appropriate hardware used by the health post staff. The intended solution aims to reduce the dependency on mHealth while maintaining a schedule of Antenatal Care visits for expecting mothers and generating context-appropriate calendars of appointments for both the patients and the FCHVs. Moreover, keeping in mind the future government initiatives for digital record maintenance wherein health workers are expected to use digital HMIS (DHIS2) in the future (2020), our solution focuses on introducing computers and maintaining electronic records at health posts, thus allowing for data to be synced more easily with the government and visiting OHW staff. This also translates to decreased reliance on FCHVs for schedule management since the additional responsibility for schedule management now falls on the health facility staff.

In the short term, the solution is offline and is intended to be used by Health Post employees who can enter visits into the tool and look up outstanding visits to help them coordinate with FCHVs in their monthly meetings. This helps them ensure all pregnant women in the district get the health care and attention they need to ensure a safe and healthy birth.

In the long-term, the tool would ideally replace the 51 paper ledgers currently maintained across all health posts in Nepal. While initial plans will be to deploy an offline system, we envision the eventual transition to an online tool that is centrally hosted.

Limitations

While the proposed solution serves to solve significant problems for the Nepal Government and OHW, it has a few limitations. Since the transition builds upon the idea of enabling health workers to use electronic patient management via computer or tablet, it calls for extensive training to ensure that the health workers understand electronic data management, including data entry, modification, security and sharing with government offices.

Obviously, the procurement and sustainable maintenance of any hardware devices can be a costly endeavor for the organization. Fortunately, the government is motivated to provide electronics to the health posts to achieve their 2020 goals - this can be an opportunity for OHW to coordinate the selection of suitable devices. The development, testing, and maintenance of the software also represents a resource-intensive process for OHW. While we envision lightweight applications that may range in

appearance and functionality from advanced Access/Excel forms to a scaled down version of DHIS2, the software must work reliably without much technical assistance.

At the same time, electronic data management and automated reminder system also means that the solution would have to protect against data loss, through regular data transfers to palika and OHW staff. Additionally, paper (printed) records could serve as backup, though that entails the maintenance of an additional medium.

Pending Questions

Some of the questions we did not get to address in our proposal included the selection of hardware for this system, such as whether to use laptops or tablets for data collection and sharing. Given the fact that both have their own pros and cons, the decision on which one to use for the ANC reminder system would depend on a lot of factors such as the cost, government influence, user familiarity with the hardware and interface, and ease of handling from the perspective of the SBAs. Another pending question relates to the nature of reminders and the form it takes: should they be in the form of simple text-based cards or vouchers given to the facilities, SBAs and patients, or simply paper slips given to the patients as informal reminders. Finally, given the multiple handoffs of information and the technical literacy of the users, we would like to better understand the encryption that should be implemented to address the encryption complexity-advancement tradeoff.

Result

We proposed an end-to-end solution in the form of a patient management system that provides ANC visit scheduling and reminders, taking into consideration both the technical limitations of the infrastructure (lack of internet access, for instance) and the digital literacy considerations of the people involved (limiting the duties of SBAs to simple data entry, storage and retrieval). OHW leadership decided that this idea and its implementation clearly met their needs and future goals, concurring that this system would nest within the government's plans and would be a promising concept for funding. OHW suggested possible refinements and wanted to explore multiple options which shaped the basis for proposals to fund program implementation. These are discussed in the following section.

PART FOUR: CONCEPT NOTES

To advance the third solution, OHW suggested that we collaborate with their staff, both in the US and in Nepal, on multiple concept notes that could be used to communicate the ideas to stakeholders and funders. These documents, drafted in Google Docs, resulted in a useful design exercise where our team and OHW's team could view ideas and respond to feedback immediately. We learned how OHW envisioned our initial proposal and we could address their concerns or raise additional questions as both teams described background, significance, methodology, timeline, benefits, limitations, collected indicators and tools, and budget. These documents are in progress as of this writing and shall remain as OHW's proprietary documents.

SMS-based Aggregate Reporting Tool

The first concept note we pursued with OHW consists of an SMS-based reporting system where skilled birth attendants would file the monthly roll-ups via cellphone. Text messages would include the reporting of maternal and neonatal information initially, but may scale to other indicators as necessary. Of course, this is a departure from our idea of individual patient management, yet it offers OHW access to monthly metrics immediately instead of waiting for off-line synchronization, and can be implemented quickly to serve as a stop-gap while the government is in transition. However, our concern with this idea is that it requires cellular coverage at the health post and doesn't move the health post closer to the government's goal of using a digital system. Further, the tool would create more work for the SBA - if only a small subset of indicators are reported, the government would certainly also require the usual paper report - without creating incentives for them to use the tool; there are no time-savings or value to be shared with the community other than a vague notion that a quick redundant reporting channel could result in more effective health interventions. Reporting of aggregate data would mean that patient reminders would also not be possible.

Electronic Medical Record System

The second concept note is more closely related to our initial concept where SBAs would use an offline system to log patient data, generate schedules for ANC visits and expected delivery dates, and be used to generate aggregate data for monthly rollups. As an intermediate step towards the government's intended goal of online reporting, we imagine this system being flexible to support multiple channels of communication, offline and online synchronization, and backend systems for SMS notifications to beneficiaries with cell phones and coverage. For instance, ANC visit reminders might be delivered to literate patients and FCHVs with mobile access, while a written card that depicts a calendar of seasons or agriculture could be provided for others. Beyond working out concerns for both resource-intensive hardware & software deployment and maintenance, we began to work out precisely how privacy and security might be maintained. Privacy of patients may be protected by only using unique identification numbers in the electronic record system matching personal information that is stored locally in paper registers. Security of data could be improved by encryption of data at-rest and in-transit.

Reflection

While other proposals had focused on strengthening individual communications channel by centralizing or democratizing data collection, this last proposal involves introducing new technology that could be a step towards realizing the government's ambitions to connect each health post. As information professionals, we realize that technology does not solve a problem on its own. Instead, positive impact on a population comprises of involving them in the iterative process of the technologies' design, development, deployment, and maintenance. We hope that we have included their perspective in the initial design work and see OHW as having an opportunity to involve the rural communities in successive stages earlier than what the government of Nepal may consider. We hope for a system that works for and counts the people on the margins: those less educated, those without access to technology, those who track time less accurately, those who walk everywhere.

What the future could look like

Following the recommendation of OHW, the Nepalese government has decided to provide each Health Post with the necessary hardware and equipment to directly manage its records on DHIS2 - the nationally used healthcare platform. Shreya is nervous about all the new things she will have to learn but also excited about the prospect of having such a powerful tool. It will allow her to keep track of everything in one place and make it easier for her to tell the women and FCHVs in her ward when the expectant mothers should return for their follow-up visits.

Shreya just received her **new laptop**. It has a preinstalled application called "Patient Manager". Sanjeev from OHW is at the Health Post today to give her and the SBA a class on how to enter a new patient into the system, how to update patient information, and generate a calendar of expected visits - Shreya is told in the Calendar view she could see which patients are expected to be seen in the next month, even organized by FCHV! Sanjeev also tells her about "Exporting" - the data is synced automatically to an external black box. Or if she has internet, it can be synced automatically to OHW's database. Shreya wished she had internet but she does not yet. Her palika leader told her the government has started the rollout but it is going to be another couple of months till her Health Post will be connected. Shreya is overwhelmed but Sanjeev reassures her that she will come to a longer training session in a month. She should try using the system and following along with a training manual in the meantime... but should also keep track using her traditional paper registers.



After a couple of months, Shreya uses the Patient Manager everyday. The training from Sanjeev and his frequent visits really helped her get up to speed. When a patient visits, she notes any indicators about the mother's and baby's health and updates the record. She notices that this patient was late for her visit so she reminds the woman to visit again in two weeks, writing the instructions on a pre-printed form, circling graphics to indicate the time to visit - there are boxes to fill in for each day between visits so that also illiterate women can keep track. Shreya is glad that she can view which women will need to be reminded to come in for ANC visits. She writes those names in the registers of the FCHVs during their monthly meeting at the health post later that week.



For the **monthly report**, she will bring the paper copy and also the little black box (she now knows it is actually called a USB stick) to the palika center. She doesn't know why she needs to bring both, but Sanjeev told her that the hard drive helps OHW and the government to get the information quicker. At the monthly meeting, the government statistician takes the harddrive and plugs it into their computer. The man tells Shreya that the data successfully copied and returns the harddrive back to her. He appears happier than before when he had to handkey in all of the paper reports.

Shreya is told by the government that she is being reassigned to a different HP in another palika. Goodbye Mahadevsthan! When she arrives at the new HP, she is surprised to see that they have "Patient Manager" as well! She also learns that they have an internet connection and that she doesn't need to worry about whether her hard drive gets broken because the patient information is being stored on another computer in Kathmandu.

This new HP also has a printer - Shreya is told that every week they print off the information that is stored in the Patient Manager so they have backup copies. This is important because now most of the indicators from the paper registers are now in the Patient Manager, not just maternal health data.

Shreya will still submit a paper report to the palika, but they usually have her information prior to the monthly meeting - the government officers will simply sync the information with the central patient management database.

The system also sends out text messages to the FCHVs and patients (if they opt in) to remind them about upcoming appointments. It's a whole different way of working!



CONCLUSION

Scope for Future Work

We are presently working with One Heart World-Wide to complete the concept notes for funding. We have provided them this report along with additional recommendations to improve the existing concepts. We have offered to assist them during their transition to G Suite applications. As the patient management tool comes to life, we are engaged with them regarding facilitating additional design and implementation work and are open to returning to Nepal for additional user testing to answer our pending questions.

Conclusion

We offer a plan that incorporates three proposals to address issues of quality and delays currently impacting One Heart World-Wide's Monitoring and Evaluation process. This plan is built upon the findings from our time in Nepal learning of the path that maternal health data travels from the community to OHW leadership. Yet, looking back over this report, we cannot help but consider "what could happen next?" especially since the stakes of this project are so high. Our ideas have the ability to affect life and death. In turn, just as we found discomfort in how easy one can simply define the under-resourced within the Global South in terms of their "challenges" and "limitations," we cannot merely submit this report without warning the reader of our own limitations. In this report, we have identified unanswered questions and methodological limitations, but, whether due to our definitions of words like "quality" and "timely" to the hundreds of decisions made during our design exercises, we have introduced assumptions, biases, and our primarily-Western values throughout this process. Some of these may have been avoidable; others are inherent to the role of the designer in this process. As students from the School of Information striving to be responsible professional technologists,³⁴ we hope you view this deliverable itself as a prototype meant to be tested, critiqued and challenged.

As for our ideas, we ask One Heart World-wide to view them as concepts to be improved through iteration and testing. Just as their Monitoring & Evaluation team works to evaluate the success of their current programs, the success of technological interventions must also be concretely defined and measured. While we are confident that our ideas represent an appropriate step towards better data management for OHW and the people of Nepal, the design process must continue via additional user research, concept testing, usability testing, development, deployment, and monitoring. Even though our future paths back to Nepal are uncertain, we want OHW to consider us as a continuing resource during this process. We hope to see future iterations come to life so that more Nepalese women and children are able to access the health services that they deserve.

³⁴ Perry, R. (2018). CTSP | A Pledge of Ethics for I School Graduates. Retrieved from <https://ctsp.berkeley.edu/an-ischool-pledge-of-ethics/>

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