Supporting the Logistics of Lab Sample Transportation with Mobile Technology

Developing a Sample Tracking Application for DHIS2 in Uganda

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Abstract

While mobile technology has massive potential in improving health-related data collection and management in developing countries, failure rates of such projects are high, and many projects fail to materialize beyond small-scale pilot projects.

In Uganda, effective *Disease Surveillance* and *Outbreak Response* is hindered by inadequate reporting and lack of timeliness in lab testing. This thesis examines how mobile-based technology can be utilized to support the logistics surrounding collection, handling and transportation of biological samples for laboratory testing in Uganda.

The study takes an interpretive and participatory approach to development and research, and begins by establishing design requirements for a logistics-supporting application based on the social and technological context of the system. Next, a high-fidelity prototype sample tracking application is developed, using an action research framework to iteratively identify problem areas in the application, plan- and execute actions, evaluate changes, and establish general findings.

Across multiple action research cycles, and using the prototype as a mediating artifact to facilitate participation and communication, emphasis has been placed on involving users, local stakeholders and decision-makers across all levels of the Ugandan health sector in the design and development of the system.

Evidence shows a mobile-based sample tracking application communicating directly with Uganda's DHIS2-based data warehouse, utilizing the convergence of technology offered in mobile devices, like camera and GPS, can provide stakeholders with timely and relevant data that would otherwise have been impossible to collect using traditional, paper-based reporting. However, successful implementation hinges on understanding - and accounting for - the socio-economic, political, infrastructural, and digital context the surrounds the system. This includes challenges like inadequate digital infrastructure and internet access, lacking general- and digital literacy among the workforce, fragmented health systems, ensuring long-term funding and continual development, and maintaining privacy of sensitive data. Additionally, the choice of development platform and underlying technology can influence both usability and ease of maintenance.

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Abbreviations

AFRO Word Health Organization Regional Office for Africa
ALIS African Laboratory Information System
API Application Programming Interface
AR Action Research
ARV Antiretroviral
CPHL Central Public Health Laboratories
DHIS2 District Health Information System 2
DHO District Health Officer
DSFP District Surveillance Focal Person
DS Disease Surveillance
DSFP Disease Surveillance Focal Person
eIDSR Electronic Integrated Disease Surveillance and Response
HC Health Clinic
HCI Human-Computer Interaction
HIS Health Information System
HISP Health Information System Programme
HMIS Health Management Information System
HMN Health Metrics Network
ICT Information and Communications Technology
ICT4D Information and Communications Technology for Development
IDI Infectious Diseases Institute
IDSR Integrated Disease Surveillance and Response
II Information Infrastructures
IP Implementation Partner
IS Information Systems
LIMS Laboratory Information Management System
MOH Ministry of Health
MSF Doctors Without Borders (Médecins Sans Frontiers)
ND Notifiable Disease
NGO Non-Governmental Organization
OR Outbreak Response
PHO Public Health Officer
PPE Personal Protective Equipment
QR code Quick Response code
UI User Interface
UID Unique Identifier
UiO University of Oslo
UNESCO United Nations Educational, Scientific and Cultural Organization
UNICEF United Nations International Children's Emergency Fund
UNHCR United Nations High Commissioner for Refugees
USAID United States Agency for International Development
VoIP Voice over Internet Protocol
WHO World Health Organization

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1 Introduction

1.1 Motivation

Uganda is a low-income country, where inadequate or unreliable physical and digital infrastructure, coupled with lacking human capacity and manpower in the health sector adversely affect implementation of ICT health initiatives (Kiberu et al., 2017). While mobile health technology has great potential to support timely and complete disease surveillance reporting (Brinkel et al, 2014), many so-called mHealth initiatives fail, due to lack of integration with existing Health Information Systems (HIS), proliferation of pilot studies not designed to scale up to national or regional use, and the physical, cultural and economic divide between developer and user (WHO, 2018a; Heeks, 2002).

Successful implementation of mHealth initiatives can happen through user participation in the design process, and by taking into consideration the technological, economic, and cultural context in which the system will be implemented (USAID, 2015).

During the course of this study, Uganda was faced with two major epidemic situations in the form of the 2018 DR Congo Ebola outbreak constantly threatening to cross the countries' porous shared border, and the 2020 COVID-19 pandemic, which caused a massive and total lockdown of the country. Coupled with a constant threat of outbreaks of potentially epidemic diseases like Cholera, Anthrax and Tuberculosis in the region, and the importance of rapid lab testing to contain potential outbreaks, improving logistics surrounding disease surveillance and outbreak response using mobile technology is an area of massive potential, and worthy of further exploration.

1.2 Context

This thesis is part of the Health Information Systems Programme (HISP), seeking to strengthen Health Information Systems (HIS) in developing countries.

Research was conducted intermittently over a period of two and a half years, while I lived part-time in Kampala, Uganda. Although this research is conducted by me alone, I was supported by local DHIS2 implementation partner HISP Uganda, with whom I worked closely throughout the period.

While the central theme of *logistics* remained constant throughout my research, my initial work on *Antiretroviral (ARV) commodity ordering* was discontinued due to Ministry of Health restrictions on my access to work on the ARV logistics management system. This prompted a change of research question and a change of domain from ARV to *Integrated Disease Surveillance and Response* (IDSR) and Outbreak Response.

During the course of this research, I developed a prototype IDSR sample tracking application with barcode scanning functionality for use in DHIS2. This application prototype, referred to as the *eIDSR Sample Tracker application prototype* throughout the thesis, was a DHIS2-compatible WebApp, developed with HTML5 technology. The application was intended to provide stakeholders tasked with collecting and transporting biological samples with an efficient,

mobile-based solution to fill out the underlying DHIS2 Tracker-based *eIDSR Tracker Capture Specimen Handling form*, developed by HISP Uganda.

1.3 Research question

The purpose of this thesis is to investigate how mobile technology can aid the logistics surrounding IDSR in Uganda, taking the local context in terms of needs, prerequisites, and human- and infrastructural capacity into consideration, while supporting integration with existing systems and structures. The research question is as follows:

> *How can mobile technology be implemented to support collection and transportation of biological samples in Uganda?*

The process of answering the research question is to (1) establish design requirements through understanding both the existing Health Information System structure in place in Uganda, as well as the cultural, political, socio-economic and infrastructural context in which this system would be implemented; (2) develop a working prototype, both for feedback and testing, and as a solid foundation for future development; and (3) identify problem areas and challenges, and the implication these would have for continued development of the application.

1.4 Overview

Chapter 2: Research context provides an overview of Uganda, including infrastructure, economic conditions and the health situation. The chapter also presents a brief background on DHIS2.

Chapter 3: Methodology presents the philosophical foundation this research is conducted, as well as the methods and methodologies employed.

Chapter 4: Theoretical background gives an overview of the literature and theoretical background through which my research will be analyzed.

Chapter 5: System Development introduces the prototype DHIS2 web application I developed as part of my research, explaining the use case and detailing the major milestones of the iterative development process.

Chapter 6*: Technical Specifications for the Prototype Application* elaborates on the technical implementation of the prototype application.

Chapter 7: Empirical findings presents the findings and data from my field trips and supplementary research.

Chapter 8: Discussion puts the empirical findings from chapter 7 into the context of the literature presented in chapter 4 and the research question for this thesis.

Chapter 9: Conclusions and future work summarizes the answers to the research question and reflects on possible future work.

2 Research context

The research presented in this thesis is mostly conducted in Uganda, and the aim of this chapter is to present relevant background information pertaining to my research, as well as the cultural, political and technological context that this study, and the associated system development, has been conducted in. A brief overview of Uganda is provided, including an elaboration on the Ugandan health situation and health infrastructure, before covering the HISP network that this study is a part of, and the DHIS2 platform that is central to my research.

2.1 Overview of Uganda

The Republic of Uganda is Situated on the north shore of Lake Victoria in East Central Africa, bordered by Kenya, Tanzania, Rwanda, South Sudan, and D.R. Congo (Central Intelligence Agency, 2020). Uganda is a low-income country (World Bank, 2020a), facing challenges from unchecked population growth, poor infrastructure, endemic corruption, human rights violations, underdeveloped democratic institutions and high mortality and morbidity due to communicable diseases like Malaria, HIV/ADIS and Tuberculosis (Central Intelligence Agency, 2020; WHO, 2018b).

A former protectorate of the United Kingdom, the country has a history of civil war, violence and unrest following its independence in 1962, notably including dictator Idi Amin's eight years as president from 1971 to 1979. During Amin's reign, Uganda suffered massive human rights violations, and an estimated 300.000 political opponents were killed during this period (Central Intelligence Agency, 2020). Subsequent guerilla wars and human rights violations under during Milton Obote's second reign from 1980 to 1985 claimed another 100.000 lives (ibid.). Current Ugandan president Yoweri Museveni came to power in 1986, and his reign has marked a period of relative stability and economic growth (World Bank, 2020a), although human rights concerns have been raised by non-governmental organizations (NGOs) like Amnesty International and Human Rights Watch, citing, among other issues, restricted freedom of expression, association and assembly, intimidation and obstruction of Civil Society, and human rights violations against homosexuals (Amnesty International, 2018; Human Rights Watch, 2018; Human Rights Watch, 2012). Additionally, Uganda struggles with endemic corruption and is currently ranked at 137th place out of 180 countries on Transparency International's Corruptions Perceptions Index (Transparency International, 2019).

Uganda has a population of around 43 million (World Bank, 2020b; Central Intelligence Agency, 2020), although exact figures varies from source to source. With a population growth rate of 3.18% and a median age of 15.9, Uganda's population is both among the world's youngest and fastest growing (Central Intelligence Agency, 2020; World Bank, 2020a). The population in Uganda is expected to reach 100 million by 2050 (ibid.). This explosive growth strains Uganda's ability to provide employment, education, health care and housing for its growing population, and reflects Uganda's fertility rates of 5,8 children per woman, among the highest in the world (Central Intelligence Agency, 2020).

Quality of education in Uganda is poor, and the school system in Uganda is inferior to their regional counterparts (World Bank, 2020a). Uganda has a literacy rate of 76.5%, significantly higher for men (82.6%) than for women (70.8%) (UNESCO, 2020). English is the official

language of Uganda and is taught in schools, although at least 44 languages are spoken throughout the country (Ethnologue, 2020).

21.4% of the Ugandan population lived below the poverty line as of 2017 (Central Intelligence Agency, 2020). 70% of the Ugandan population is employed in agriculture, mainly on a subsistence basis, and the agricultural sector has been instrumental in reducing poverty in Uganda, halving the number of households living in poverty from 1992 to 2013 (World Bank, 2020a). The Northern region of Uganda is the poorest in the country, in part due to the influx of refugees in the area (ibid.), with 33% of the population below the poverty line (UNHCR, 2020c).

Uganda has the largest population of refugees in Africa, hosting 1,42 million refugees and asylum-seekers, mainly from South Sudan and DR Congo (UNHCR, 2020a). The number of refugees has tripled since mid-2016, and continues to grow, with around 10,000 new refugees arriving every month until March 2020, when the Uganda temporarily closed all border entry points in response to the covid19 pandemic (UNHCR, 2020a; UNHCR, 2020b; UNHCR, 2020d). Described by Amnesty International as one of the most progressive refugee hosting models in the world, these refugees are given small pieces of land in the hopes of making them self-sufficient and not reliant on aid within five years of arriving in Uganda, and are given access to primary education, social services and healthcare by the Ugandan government (Amnesty International, 2017; World Bank, 2020a). The large number of refugees concentrated in the Northern region of Uganda puts pressure on local resources and service provision, including health services (UNHCR, 2020c).

2.2 Infrastructure in Uganda

While energy and road infrastructure make up a considerable portion of Ugandan government spending, the insufficient infrastructure in the country continues to hamper productivity and growth (Central Intelligence Agency, 2020). The African Development Bank (2018) ranks Uganda as 27th out of 54 countries in their 2018 Composite Africa Infrastructure Development Index, combining indicators for electricity, transport, ICT, and water and sanitation.

Only 3.2 percent of Uganda's 145,000-kilometer road network is paved, mainly the major national roads from Kampala to other big cities in the country (Uganda Ministry of Works and Transport, 2018). The largest current infrastructure projects are financed by loans and investments from other nations, most notably China (Mayers & Barungi, 2019).

Uganda has one of the lowest electrification rates in Africa, estimated at 20%, with 34 million people living without electricity (Central Intelligence Agency, 2020). The electricity grid is unstable, and power blackouts are frequent (Kiberu et al., 2017).

Internet penetration in Uganda is at 45.9% and is steadily growing (Central Intelligence Agency, 2020). 4G or 3G is available in the majority of the country, although many rural areas still have inadequate or missing coverage, and internet connectivity throughout the country can be slow and unresponsive (Kiberu et al., 2017).

2.3 Health situation in Uganda

Over 50% of morbidity and mortality in Uganda stems from communicable diseases, with Malaria, HIV/AIDS and Tuberculosis listed as leading causes of illness and death, alongside various respiratory, diarrheal, epidemic-prone, and vaccine-preventable diseases (WHO, 2018b). Uganda has an adult HIV prevalence of 5.7%, eleventh highest in the world, with 1,400,000 people living with HIV as of 2018 (Central Intelligence Agency, 2020; UNAIDS, 2020). From 2010 to 2018, AIDS-related deaths declined from 56,000 deaths to 23,000, and the number of new HIV infections have dropped from 92,000 to 53,000 (UNAIDS, 2020).

Proximity to Ebola-affected areas in DR Congo, and the influx of refugees from this region, puts Uganda at risk for Ebola outbreaks (WHO, 2019). Multiple Ebola cases has been registered in Uganda over the course of the ongoing 2018 DR Congo Ebola outbreak, although infections have been contained, in part due to UNHCR screening of people arriving at the Ugandan border (ibid.).

Undernutrition and stunting affect a third of Ugandans aged five and younger, and under-five mortality rate is at 53 per 1000 live births (WHO, 2018b). Life expectancy at birth is at 68.2 years (Central Intelligence Agency, 2020).

WHO (2018b) lists lack of resources to recruit, deploy, motivate and retain human resources in the heath sector as a major challenge affecting the Ugandan health system, alongside issues like lack of quality of the health care services delivered; insufficient timeliness, completeness, quality and reliability of health information; and frequent stock-outs of essential medicines and medical supplies. Health status is closely linked to underlying socio-economic, gender and geographical disparities, and the level of health care is typically lower in rural communities (ibid.).

2.4 Health Infrastructure in Uganda

Uganda's health system is highly reliant on external support, with the government share of health expenditures well below WHO recommendations (WHO, 2018b). Uganda has 6937 health facilities, according to the latest official report (Uganda Ministry of Health, 2018). Divided into an eight tier system, these facilities ranges from simple community based health services (tier 1) to the two National Referral Hospitals of Mulago and Butabika (tier 8), depending on the services provided and the target population covered (see figure 1: Service Delivery by Level of Health Facility). The Ugandan Government owns 45% of these facilities, while 40% are owned by *Private For Profit* organizations, and the remaining 15% are operated by *Private Not For Profit* organizations (Uganda Ministry of Health, 2018).

Tier	*Level*	*Quantity*	*Target population*	*Services Provided*
1	Clinic (HC I)	1,572	1,000	Community based preventive and Promotive Health Services. Village Health community or similar status
2	Health Centre II (HC II)	3,365	5,000	Preventive, Promotive and Outpatient Curative Health Services, outreach care, and emergency
3	Health Centre III (HC III)	1,574	20,000	Preventive, Promotive, Outpatient Curative, Maternity, inpatient Health Services and Laboratory services
4	Health Centre IV (HC IV)	222	100,000	Preventive, Promotive Outpatient Curative, Maternity, inpatient Health Services, Emergency surgery and Blood transfusion and Laboratory services
5	General Hospital	163	500,000	In addition to services offered at HC IV, other general services will be provided. It will also provide in service training, consultation and research to community based
6	Referral Hospital	3	1,000,000	In addition to services offered at the general hospital each hospital will offer a package of specialized services and training
7	Regional Referral Hospital	13	2,000,000	In addition to services offered at the general hospital, specialist services will be offered, such as psychiatry, Ear, Nose and Throat (ENT), Ophthalmology, dentistry, intensive care, radiology, pathology, higher level surgical
8	National Referral Hospital	2	10,000,000	These provide comprehensive specialist services. In addition, they are involved in teaching and research

Table 1: Service Delivery by Level of Health Facility (Uganda Ministry of Health, 2018; ibid., 2017; ibid., 2012)

2.5 Health Information Systems Programme (HISP) and the District Health Information System 2 (DHIS2)

Established in 1994 in South Africa as a collaborative research project between the University of Oslo (UiO) and the University of the Western Cape, HISP is now a global network working with governments, NGOs and private companies to implement sustainable, integrated health information systems through open standards (HISP, 2020; Braa & Sahay, 2012a). The HISP approach to development is rooted in the Scandinavian *participatory design* research tradition, striving for user participation and empowerment, and the concept of *information for action*, as opposed to a traditional data-based design and development of HIS (Braa & Sahay, 2012b).

Coordinated from UiO, the HISP network currently has teams located in 33 countries, including Uganda. Developing, governing, and implementing the open-source DHIS2 software is the core focus of the HISP community.

DHIS2 is the second iteration of the *District Health Information System*, a free, open-source, web-based HMIS platform currently in use in over 100 countries (DHIS2, 2020). DHIS2 supports collection, processing and analysis of data, management of facilities, registers, and indicators, as well as tools for presentation and communication (UiO, 2014).

In 2011, Uganda adopted DHIS2 at national- and district level, successfully increasing timeliness and completeness of reporting (Kiberu et al., 2014). Implementation and development are supported by local HISP implementation partner *HISP Uganda*.

3 Methodology

The purpose of this chapter is to present the research approach, methodology and methods used in this research. The chapter begins with establishing the underlying philosophical foundation, then presents the methodologies and methods employed, before moving on to how data has been gathered and analyzed.

3.1 Philosophical Foundation

In selecting a research approach, the methodologies and methods will be guided by the philosophical assumptions about reality and knowledge. In the IS literature there are three dominant such assumptions: *positivist*, *critical* or *interpretive* (Myers, 1997).

Positivist social science is associated with quantifiable measurements and empirical data, and assert that "reality is objectively given and can be described by measurable properties which are independent of the observer" (ibid.), and knowledge "is best attained if a social scientist adopts a value-free position and does not let biases interfere with his or her analysis" (Klein & Myers, 1999). Positivists strive to avoid intervention with their area of research, remaining as objective as possible (Orlikowski & Baroudi, 1991).

Critical research is an interventionist and emancipatory approach to research, aiming to challenge, expose and critique deep-seated structural contradictions within social systems (ibid., p. 5). Focusing on conflicts and oppositions in society, critical research strives to help eliminate causes of alienation and domination in contemporary society (Myers, 1999).

Interpretive research operates on an underlying assumption that our knowledge of reality is a social construction that the researcher is a part of, and thus it follows that there is no *objective* reality that the researcher can discover and convey to others (Walsham 1993, p. 5). Rather, interpretive researchers attempt to understand phenomena within a cultural and contextual situation, through the meanings and interpretations people assign to them (Orlikowski & Baroudi, 1991).

This research subscribes to the philosophical assumption that "access to reality (given or socially constructed) is only through social constructions such as language, consciousness and shared meanings" (Myers, 1997), placing it within the *interpretive paradigm*. This has informed both the methodology and the execution of this research.

A key element of my research would be the process of understanding Uganda's health system and the relevant actors and stakeholders involved in that system. Through accessing the subjective answers and interpretations of a multitude of relevant stakeholders, I could form what Geertz (1973) calls my "own constructions of other people's constructions of what they and their compatriots are up to" (p. 9).

Walsham (2006) argues for the importance of gaining and maintaining "good access to appropriate organizations for their fieldwork" (p. 322). Over the course of two and a half years of living in Uganda, I was immersed not just in Ugandan culture, norms, and language, but I was also immersed into local DHIS2 implementation partner HISP Uganda, working part-time from their office during this period. I would attend office meetings, engage in the social life in the office and even advice or assist HISP employees in their development work. In turn, HISP

Uganda was invaluable for my research in arranging field visits, giving me access to appropriate stakeholders, and providing feedback and data on my work.

Walsham (2006) asserts that this kind of high involvement "is good for in-depth access to people, issues, and data" and "positive benefits can often be gained because the field participants see the researcher as trying to make a valid contribution to the field site itself, rather than taking the data away and writing it up solely for the literature" (p. 321)

3.2 Research methodology

3.2.1 Action research

The methodological framework chosen for this research is primarily *action research* (AR). Fundamentally, AR works by introducing changes to a complex social process, and observing the effects of these changes (Baskerville, 1999). AR has been described as "an interventionist approach to the acquisition of scientific knowledge" (Baskerville and Wood-Harper, 1996, p. 169) and defined as aiming "[...] to contribute *both* to the practical concerns of people in an immediate problematic situation and to the goals of social science by joint collaboration within a mutually acceptable ethical framework" (Rapoport, 1970, p. 499), advocating a kind of action research that "seeks to optimize the realization of both the practical affairs of man and the intellectual interest of the social science community" (p. 510).

This dual goal of both practicality and science is what "distinguishes [action research] from applied social science, where the goal is simply to apply social scientific knowledge but not to add to the body of knowledge" (Myers, 1997). Baskerville and Wood-Harper (1996) agrees that "Action research merges research and praxis thus producing exceedingly relevant research findings." (p. 169)

Because action researchers participate in the phenomena under study, action research is intrinsically interpretive and qualitative (Baskerville, 1999).

AR can be visualized as a cyclical process consisting of five distinct phases: diagnosing, action planning, action taking, evaluating, and specifying learning (Figure 3-1) (Susman & Evered 1978, p. 588)

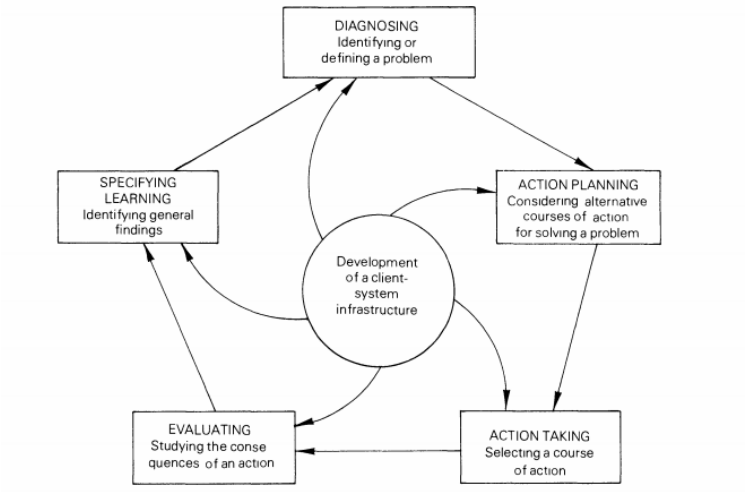

Figure 3-1: "Action Research Cycle" from Susman & Evered, 1978, p. 588

The number of cycles carried out will vary from project to project, but all five phases are necessary for a comprehensive definition of AR (ibid.) The first phase, *diagnosing*, refers to the holistic identification of problems or issues within an organization which is the cause for a desire for change, leading to a subjective working hypothesis. Next, researchers and practitioners collaborate on *action planning*, specifying actions that will improve on the issues identified in the diagnosing phase. The next phase, *action taking*, focuses on implementing the planned actions, before *evaluating* whether the change was successful. The final step of *specifying learning* refers to the process of extracting scientific knowledge from action research, whether the actions performed were successful or not (Baskerville & Wood-Harper, 1996, p. 5).

3.2.2 Interaction design

Interaction design refers to "designing interactive products to support people in their everyday and working lives" (Preece et al., 2015, p. 36), and has been used as an umbrella term covering "interface design, software design, user-centered design, product design, web design, experience design, and interactive system design" (ibid.). The four main activities for interaction design are "establishing requirements for the user experience, designing alternatives that meet those requirements, prototyping the alternative designs so that they can be communicated and assessed, and evaluating what is being built throughout the process and the user experience it offers." (ibid., p.465) Interaction design shares many attributes with action research, including an iterative solution-based workflow and working with community-based partners (Hayes, 2011), and the four steps outline above roughly correspond to the first four steps of the action research cycle (see Figure 3-1).

Winograd (1997) compares interaction design to the job of an architect, as opposed to other, more engineering-focused types of software development, concerning itself with the user experience and interactions than the technical aspect, and argues that an interaction designer should avoid seeing the machinery, and instead see the people using it.

While my research falls under the action research methodology, I incorporated some aspects of interaction design when developing an application prototype as a major part of my research. During the software development part of my work on this research, I had to assume the role of an interaction designer, alongside the roles of a researcher and programmer, to develop a user interface and -experience for the prototype that facilitates it's intended functionality and utilization.

In order to successfully evaluate the user experience and usability of the prototype application, I drew upon the concept of the widely cited *Heuristic Evaluation* (Nielsen, 1994), with which I could evaluate whether the user interface conform to a set of heuristic principles. These ten principles are:

1. **Visibility of system status**: Give users appropriate feedback at all times, regarding both system status, and the acknowledgement of the user's interactions with the system.
2. M**atch between system and the real world**: Have the system speak the users' language, and follow real-world conventions, making the system more intuitive.
3. **User control and freedom**: Support undo and redo, and allowing users to cancel a process or correct mistakes.

4. **Consistency and standards**: Have the application follow platform and industry conventions, and strive for consistency across terms and symbols internally.
5. **Error prevention:** Eliminate errors-prone conditions, and design the application to prevent errors from happening in the first place.
6. **Recognition rather than recall**: Don't force the user to remember information from one part of the process to another. Display visible or easily retrievable instructions to the user when appropriate.
7. **Flexibility and efficiency of use**: Cater to all experience levels by including *accelerators* for experienced users, like keyboard shortcuts or macros.
8. **Aesthetic and minimalist design:** Aim for a high "signal to noise" ratio by only displaying relevant information, and removing elements that are purely decorative.
9. **Help users recognize, diagnose, and recover from errors**: Give error messages whenever errors have occurred, communicate the nature of the error in plain language, and suggest a solution.
10. **Help and documentation**: Provide help and documentation focused on the user's task and easy to navigate. Give contextual help showing concrete steps.

I also incorporated the distinction between *effectiveness*, *efficiency*, and *satisfaction* in evaluating the usability of the prototype application interface, as described in Frøkjær et al (2000). *Effectiveness* is the "accuracy and completeness with which users achieve certain goals" (ibid., p. 345), relating to the quality of the solution and the number and severity of errors encountered. E*fficiency* is the "relation between (1) the accuracy and completeness with which users achieve certain goals and (2) the resources expended in achieving them" (ibid., p. 345), relating to the time spent completing a task or learning how to use the system. S*atisfaction* is "users' comfort with and positive attitudes towards the use of the system" (ibid., p. 345).

While the relationship between effectiveness, efficiency, and satisfaction are interlocking, and high scores in one dimension correlates to higher scores in the other dimensions (Jeng, 2005), but the correlations are not strong enough to use only one dimension as an indicator of overall usability (Frøkjær et al., 2000).

3.2.3 Ethnography

Ethnographic studies are a form of social and cultural anthropology, where the researcher spends a significant amount of time in the field immersing themselves in the lives of the people they study (Myers, 1999).

Ethnography allows the researcher to "gain an in-depth understanding of the people, the organization, and the broader context within which they work" (ibid., p. 5), but is time-consuming and usually focused on a single culture or organization (ibid.).

By spending a lot of time immersed in Ugandan culture and working with the HISP Uganda team in their Kampala office over a period of two years, my research took on certain elements of ethnographic research, particularly through *participant observation*.

3.3 Data collection

3.3.1 Goals

Arriving in Uganda before a problem statement had been landed upon, I had planned the data collection part of my research to be split into two parts, an explorative, open-minded first phase where I was to establish my working relationship with HISP Uganda, and absorb as much information as possible on the subject matter, followed by a more focused and narrowed second part, where I working towards a particular target using action research methodology.

This first part would mean both establishing a "client-system infrastructure or research environment" (Baskerville, 1997, p.2-3) and an extended first diagnosing-phase of the action research cyclical process (Figure 3-1), and should result in the identification of a problem from which I can move on to the action planning phase of action research, beginning the iterative process.

While the general area of enquiry was intended to be ARV medicine ordering and logistics, this project fell through for political reasons after about six months of research, forcing me to reevaluate my area of research. Fortunately, the establishment of the client-system infrastructure and the general understanding of the Ugandan health system were still relevant to other areas of research, although detailed information regarding ARV logistics were largely irrelevant outside the original context. After discussions and meetings with HISP Uganda, the research area of *Integrated Disease Surveillance and Response* (IDSR) was chosen, prompting a return to the action research diagnosing phase.

3.3.2 Field Work

Data collection happened in interspaced periods from October 2017 to November 2019, while I was part-time situated in Uganda. Over the course of two years, I conducted a total of nine field visits to various locations in Uganda, including 18 health facilities of various types and sizes, and conducting interviews with more than 30 participants.

A total of four field visits were conducted in relation to the original research domain of ARV logistics management. Although the details of ARV commodity ordering were largely irrelevant to my final IDSR-related research, the fieldwork was instrumental in my understanding of the Ugandan health sector in general. Furthermore, one of the field visits conducted during this period was linked to DHIS2 Tracker, which proved as relevant to my IDSR-related study as it would have been to ARV-related research.

A further five field visits were conducted directly linked to the main topic of IDSR in Uganda and Rwanda, gradually narrowing the field of inquiry from open-ended information-gathering, to diagnosing problems and evaluating implemented actions.

Most of my field trips were arranged in cooperation with HISP Uganda, drawing upon their extensive network of contacts and their access to relevant stakeholders and facilities.

The table below presents a list of my field visits, including dates and location. In addition to these field visits, I was working with HISP Uganda from their offices in Kampala for months at a time during my research, arguably comprising the single most comprehensive field work of my research.

Dates	*Field work*	*Location*	*Health Facilities visited*
October 31st to November 2nd 2017	Training Seminar on Web-based ARV and TB Medicine Ordering	Mbale District, Uganda	
November 9th to 10th 2017	ARV QO Visits with Clinton Health Access Initiative	Wakiso District, Uganda	Namayumba HCIV, Nabweru HCIII, Kira HCIII, Nsangi HCIII
November 27th to December 2nd 2017	DHIS2 Tracker Academy	Kampala, Uganda	
January 19th 2018	Participation in ARV Commodity Ordering at Mubende District Office	Mubende District, Uganda	Mubende District Health Headquarters
June 11th 2018	Demonstration of Rwanda DHIS2 IDSR system by HISP Rwanda	Kigali, Rwanda	
June 12th to 14th 2018	Understanding Uganda's Disease Surveillance infrastructure	West Nile District, Uganda	Arua Regional Referral Hospital, UNHCR Arua Office, Arua District Health Office, Koboko Hospital, Koboko Mission HCIII
November 28th to 29th 2018	Understanding Uganda's Disease Surveillance infrastructure, and testing prototype application	Hoima District, Uganda	Hoima Regional Referral Hospital, UNHCR screening station at lake albert, WHO makeshift cholera hospital, Kyehoro HCIII
November 12th to 15th 2019	Usability Testing of prototype and Interviews + Observations related to Uganda's Disease Surveillance Infrastructure	West Nile District, Uganda	Arua Regional Referral Hospital, Kuluva Hospital, River Oli HCIV, Arua Regional Veterinary Laboratory
November 19th 2019	Interviews and observations at Uganda Central Public Health Laboratories	Kampala, Uganda	Uganda CPHL

Table 2: List of field visits conducted

3.3.3 Participants

The participants in the study were intended to represent a broad spectrum of stakeholders involved in the relevant processes. In an attempt to cover the enormous patchwork of actors involved in the Ugandan health sector, my participants involved stakeholders as diverse as doctors, nurses, logistics workers, transportation workers, laboratory personnel, district hospital administration workers, statistical personnel, HISP representatives in both Uganda and Rwanda, representatives from various NGOs, embassy personnel and system developers working on similar implementations as my research.

Although my fieldwork was conducted in multiple locations across Uganda, two of the most comprehensive and ambitious field visits were performed in the West Nile region in northwestern Uganda. This area was part of an IDSR pilot project for HISP Uganda, affording me greater access to facilities and stakeholders than would have been possible elsewhere. West Nile is also interesting from a health services perspective, due to the vast number of refugees arriving from Democratic Republic of Congo and South Sudan, and the proximity to the ongoing Ebola outbreak.

Before a given field visit, I would submit to HISP Uganda a list of occupations and stakeholders I would like to interview and observe. This list would be based on our current understanding of the process I wished to study. Invariably, when in the field, we would find that some planned interview subjects were not available, and other opportunities presented themselves. Because of this, I was always prepared to perform ad-hoc interviews with unplanned stakeholders when in the field, based on the opportunities that would arise.

3.3.4 Triangulation

Triangulation in a social science context can be defined as "the combination of methodologies in the study of the same phenomenon" (Denzin, 1978, p. 291), referring to the process of using multiple methods or sources of data in qualitative research to cross-validate findings and data. Studies that use only one method of data collection are vulnerable to weaknesses linked to that particular method (Patton, 1999), and corroborating findings across data sets can reduce the impact of biases that may exist in a single study (Bowen, 2009). While triangulation is ideal, it is also expensive and time-consuming, and requires training in multiple methods, affecting the amount of practical use of triangulation (Patton, 1999).

Patton (1999) identifies four types of triangulation within qualitative research: examining data consistency across multiple methods (*methods triangulation*), examining data consistency within the same method (*triangulation of sources*), using multiple analysts to review the same data (*analyst triangulation*) and using multiple theories or perspectives to analyze the same data (*theory perspective triangulation*).

In this thesis, *triangulation of sources* has been used by gathering similar data at multiple locations and from multiple participants. *Methodological triangulation* has been employed by applying different data gathering techniques, like interviews, observations, and document analysis.

3.4 Data Collection Methods

3.4.1 Interviews

Interviews can be considered the primary source of data in interpretive research, and the best method of accessing participant interpretations (Walsham, 1995). Depending on the level of control an interviewer imposes on a conversation, interview styles can range from highly *structured* questionnaire-style interviews, through *semi-structured* interviews with broad parameters, to *unstructured*, conversation-like interviews (Preece et al., 2015, p. 332; Crang & Cook, 2007, p. 60).

The interviews conducted in my research were generally of the semi-structured variant, with a set of predefined questions prepared before a field visit. These interview sheets were meant to guide the interviews, but rather allowing the conversation to take different directions should interesting or unforeseen topics arise. In addition to this, a significant number of my interviews during field trips were opportunistic and ad-hoc in nature, due to the uncertainties of meeting the intended subjects when in the field, as well as opportunities to interview unplanned stakeholders presenting themselves.

Most of my interviews were conducted without recording the conversation on a recording device, as I found the process of listening back to hour long interviews in full, of little help to extract the interpretations of the participant. Instead, I followed the advice of making "rough but extensive notes during interviews, and writing them up in full as soon as possible after the interview" (Walsham, 1995, p. 78), generally writing up the interview the same afternoon or evening, often in my hotel room. Where I on a couple of occasions combined note taking with tape recording, I still endeavored to write up the interview as soon as possible after conducting the field work, to make sure my memories of the situation were still fresh.

Below is a table of interviews conducted as part of this project, and the location where the interview took place. Despite a lot of valuable data coming from conversations with HISP Uganda employees in the office, I have omitted these conversations from this list. Both because I do not consider these to be interviews so much as part of the process of gaining access to the HISP Uganda organization and understanding the structures, as well as the lack of written documentation on these conversations.

Interview participants	*Location*
Biostatistician	Mbale District
Implementation partner, Clinton Health Access Initiative	Mbale District
Store manager at a HCIV	Wakiso District
Nurse at a HCIV	Wakiso District
Store Manager at a HCIII	Wakiso District
Acting Store Manager at a HCIII	Wakiso District
Store Manager at a HCIII	Wakiso District
Biostatistician	Kampala
Biostatistician	Mubende District
Project Officer, Mildmay (IP)	Mubende District
Head of HISP Rwanda	HISP Rwanda offices, Kigali
System developer, HISP Rwanda	HISP Rwanda offices, Kigali
District Surveillance Focal Person	Arua Regional Referral Hospital, West Nile
Regional Surveillance Officer and Lab Mentor, IDI; Laboratory Specialist, IDI; Regional Project Coordinator, IDI	West Nile, by telephone
Public Health Officer, UNHCR	West Nile District
District Health Officer	West Nile District
Clinical Officer, Doctors Without Borders (MSF)	West Nile District
Lab Manager and District Lab Focal Person	West Nile District
Hub Coordinator	Hoima District
Nurse	Hoima District
Norwegian Embassy employee responsible for covering the Ebola situation in Uganda	Kampala
System developer, formerly of CPHL	HISP Uganda offices, Kampala
Hub Rider	West Nile District
Hub Rider	West Nile District
Hub Coordinator at Regional Referral Hospital	West Nile District
Head Nurse at hospital	West Nile District
Veterinary Officer, IDI	West Nile District
Sample Reception Officer, CPHL	Kampala
Lab Officer, CPHL	Kampala
Head of HISP Uganda	HISP Uganda offices, Kampala

Table 3: List of interview participants

3.4.2 Observations

While interviews are the primary source of data gathering in most interpretive research (Walsham, 1995), there are good reasons to supplement interviews with observations to help fill in details (Preece et al., 2015). Research subjects are not always able to describe their behavior with accuracy, or may omit cultural assumptions or customs that are taken for granted (Marks & Yardley, 2004).

Observations varies in the degree of researcher participation, from insider to outsider on a spectrum (Preece et al., 2015, p. 360). Outsider, or *structured observation* is commonly linked with quantitative research, where the researcher attempts to remain as neutral and uninvolved as possible, while insider, or *participant observation*, is generally associated with ethnographic studies, where the researcher is an active participant in the phenomenon studied (Marks & Yardley, 2004).

In my research, working with HISP Uganda from their office in Kampala over a period of two years yielded large amounts of participant observation data. As a naturalized part of the office environment, I was part of staff meetings and discussions, and spent time cooperating with various HISP staff members, helping them where I could assist with my knowledge, and eliciting their help and feedback on my project.

I also recorded a lot of observational data that would fall somewhere between the two extremes on the participation spectrum. After conducting interviews with participants at a field visit location, I would often ask to observe the routines of stakeholders as they carried out their related tasks. In some cases, this would take the form of a demonstration, where I would ask a participant to perform a given task with me present in the room. On other occasions, I was allowed to be present during relevant tasks and activities performed in places like health clinics or offices. While my lack of expertise or skill did not allow me to fully participate as a member in the activities observed, my presence in the environment and interaction with participants still placed these observations on the insider part of the spectrum (Preece et al., 2015, p. 361).

Figure 3-2: Observing the monthly ARV Commodity Ordering process at Mubende District Office

3.4.3 Prototyping

As a major part of my research, I developed a prototype DHIS2-compatible web application where I would iteratively add and change functionality during the action taking phase of the action research cycle.

By using a prototype, my intention was to provide an artifact for users and decision makers to interact with, leading to shared understanding, and improving user-designer communications, as well as building my own design expertise in developing this kind of application (Baskerville, 1999). Prototyping is well-suited to a participatory design approach to system development, allowing the users to give input and feedback to the developer, which in turn could lead to a greater sense of ownership with the system (Braa & Sahay, 2012a).

The prototype was a *high-fidelity prototype*, with complete functionality and having the look and feel of a final product (Preece et al., 2015, p. 545). While developing a *high-fidelity prototype* was time-consuming and complex compared to a *low-fidelity prototype* of the same product, and a simpler, less complete prototype might have been equally effective in gathering user feedback (ibid.), developing a working version of the application allowed me to gather data on the technical implementation of the system, and testing the viability of various developmental solutions. This was especially important as my prototype ended up including some functionality like barcode scanning that is not natively supported by DHIS2, meaning the prototype was not just a tool to elicit feedback from potential users and stakeholders, but also a technical proof of concept.

Chapter 5: System Development details the development and iterations of the prototype in detail.

3.4.4 Document analysis

Document analysis refers to the procedure of reviewing and evaluating various relevant documents, ranging from background papers, books and survey data to newspaper articles, brochures and event programs for the purpose of gaining understanding and empirical knowledge (Bowen, 2009).

As part of my research, I have reviewed relevant studies and literature, as outlined in Chapter 4. Additionally, analysis of relevant documents took place continually and contemporaneously with other parts of my research. Particularly, statistics and data from NGOs like WHO, UNHCR and MSF, as well as Ugandan news media and government reports helped contextualize the setting in which I was conducting my research.

3.5 Data analysis

Data analysis can often be an ongoing process, happening simultaneously with conducting research (Walsham & Sahay, 1999). This is doubly true for action research, where data analysis intrinsically happens as part of the action research cycle (Baskerville & Wood-Harper, 1996).

Walsham (2006) argues that "the researcher's best tool for analysis is his or her own mind, supplemented by the minds of others when work and ideas are exposed to them" (p. 325), and much of my analysis happened through either discussions with my HISP Uganda colleagues – preferably those who accompanied me on the field trip - or through rigorous report writing in the days following a field visit, as outlined below.

3.5.1 Field journal

Throughout my field visits and interviews, I kept a field journal where I recorded my observations and interview answers, combined with stream-of-consciousness notes made on the fly on interactions, environments, incidents, and my mindset and thoughts. After a day of field work, I expanded upon the notes made during the day, by writing down my immediate reflections and elaborating on paragraphs where I could only jot down brief notes during the field work, making sure I did this as soon as possible after finishing the field work while my memory was still fresh. (Crang & Cook, 2007, p54)

This practice roughly follows the guidelines presented in *Practicing Human Geography* (Cloke et al., 2004, p. 200-204), where six layers of description is suggested when making notes: (1) locating an ethnographic setting, (2) describing the physical space of that setting, (3) describing other's interactions within that setting, (4) your participation in interactions in that setting, (5) reflections on the research process, and (6) self-reflection provoked by the research.

While all of these six layers were present in my notes, they were all intermingled in a stream-of-consciousness style, where I would mix English and Norwegian (often in the same sentence), and important observations would be scribbled down alongside descriptions of the environment or my concurrent reflections, feelings, impressions, questions and hunches, as suggested by M.D. Myers in *Investigating Information Systems with Ethnographic Research* (1999, p. 9).

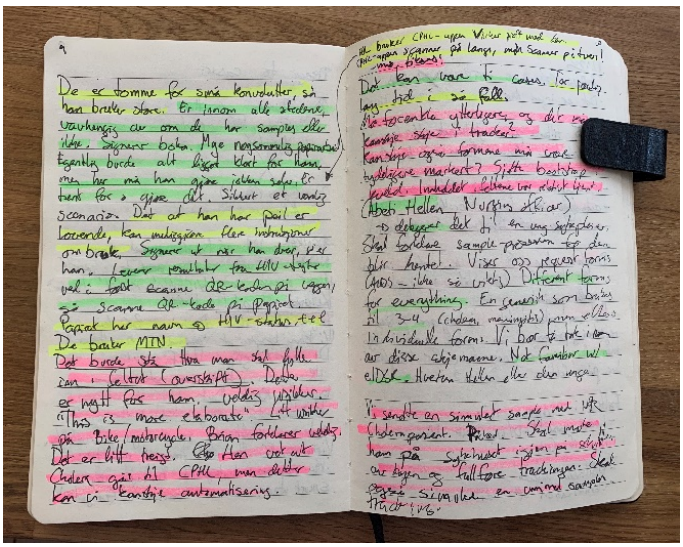

Figure 3-3: Page spread from my field journal

Baskerville & Wood-Harper (1996) points out that such detailed diaries can lead to problems for data analysis, "considering the volume and unstructured nature of data" (p. 9). To help make sense of the patchwork of notes, I would use different colored highlighter pens to separate the multiple types of information contained in the dense notes, later allowing me to quickly find the types of information I was looking for. I would also use these notes as the basis for writing structured reports in the days following a field visit (see section 3.5.2). I made sure to photograph the pages of the journal with my cell phone, and backing them up to the cloud, to avoid losing all my notes should the book itself be misplaced.

3.5.2 Reports

In *Writing Up Qualitative research* (2009), H. F. Wolcott asserts that "writing is thinking" (p. 19), and recommends researchers to start writing as soon as possible when conducting research, adding "writing is not only a great way to discover what we are thinking, it is also a way to uncover lacunae in our knowledge or our thinking."

Taking this to heart, and to further refine and process the observations and data from the field visits, I wrote detailed reports based on the notes from my field journal. This work was usually

undertaken within a couple of weeks of the field work, making sure the visit was still fresh in my mind, but allowing me to reflect on the data and attempt to put it in a larger context. These reports were not intended to replace my field journal notes as a source of data, but rather as a complement to them, forcing me to academically structure and analyze my observations, thinking about my finds in a new way. Where the reports are filtered and analyzed versions of the data, the field journal notes are contemporaneous with the events recorded, and represents a wholly separate set of data: my impressions during the research and after each interview, as described by Walsham (2006).

These reports would vary in length, depending on the scope and duration if the field work, but would usually tally between 5 and 20 pages, divided into chapters on procedure, methods, execution, findings, analysis, conclusions, and way forward. See the appendix section on page 97 for a sample report from my first field visit to West Nile.

The reports would be sent to both my supervisor in Oslo, and relevant staff members at HISP both to elicit feedback and to document my progress. They would also provide the basis for writing about my field work and empirical findings in this thesis.

4 Theoretical background and relevant literature

As my research question is “How can mobile technology be implemented to support collection and transportation of biological samples in Uganda?”, I present in this chapter literature relevant to understand the context surrounding the development of digital technology for health initiatives in developing countries in general, and Uganda specifically.

First, the concept of social informatics and Information Infrastructures are introduced, to establish Health Information Systems as socio-technological systems. Then, the concept of HIS is elaborated on, including literature on data collection for data warehouses, and the concept of integration, before presenting the concepts of Disease Surveillance and IDSR, which this study is based around. Finally, this chapter discusses the status, utilization, and challenges for digital technology for health in developing countries, and present the underlying prerequisites for successful implementation of such initiatives.

4.1 Social informatics

Designing, developing, and implementing information systems is not done in a vacuum, but is reliant on the social and technological context to which the system belongs. Kling (2000) argues that specific information technologies should be analyzed as a socio-technological system: a complex, interdependent system comprising the people, hardware, software, techniques, support resources and information structures involved, and the interrelations between these components. Understanding information systems as social systems is particularly relevant for understanding HIS in developing countries, where the “complex web of social, political, institutional and cultural relations [arises from] the involvement of technologies and various actors” (Braa & Sahay, 2012a, p. 12).

In ICT development, understanding the social context surrounding the system, and the users it is intended for, will help inform which features to include and trade-offs to make (Kling, 2000). One set of literature that emphasizes the socio-technical nature of information systems is that of Information Infrastructures.

4.2 Information Infrastructures

Information Infrastructures (II) is defined as "a shared, open (and unbounded), heterogeneous and evolving socio-technical system (which we call installed base) consisting of a set of IT capabilities and their user, operations and design communities." (Hanseth & Lyytinen, 2010, p. 4). Hanseth (2000) equates IIs to traditional infrastructures, i.e. the foundation or sub-structure for other systems, designed to enable a wide range of activities (p. 56).

A form of socio-technological network, IIs are defined by being a single, irreducible system used not just by one group of users, but *shared* by a larger community consisting of multiple, separate user groups, interacting with the system in different ways (ibid.).

IIs consists of several sub-infrastructures that are interdependent of each other, called the *installed base*, with which new components must be interoperable (ibid.). Thus, IIs are never built or designed from scratch or replaced wholesale, but components are added to- or replaced in the existing infrastructure. By allowing the integration of new components in unexpected

ways and contexts by users, IIs display and inherent and unbounded openness, which leads to IIs evolving over time, sometimes in unpredictable directions (Hanseth and Lyytinen, 2010).

4.3 Health Information Systems

Health Information Systems (HIS) is a broad term, covering the multitude of systems used for health data, including systems for such varied issues as logistics, patient records, and disease-specific systems, but also the infrastructure used to support these systems, like computers and handheld devices (Braa & Sahay, 2012a).

WHO defines HIS as one of the six essential building blocks needed to improve health outcomes in developing countries, stating that "a well functioning health information system is one that ensures the production, analysis, dissemination and use of reliable and timely health information by decision-makers at different levels of the health system, both on a regular basis and in emergencies." (WHO, 2007, p. 18)

However, one of the biggest issues undermining the development of effective HIS in developing countries, is the fractured and uncoordinated implementation of systems (Sæbø et al., 2011). National health systems in low- og middle income countries are typically comprised of a myriad of separate systems, each maintaining their own reporting systems (Braa et al., 2007). These systems are generally uncoordinated, vertical, and oblivious of what data is already being reported through other programs (Braa & Sahay, 2012a). With each programme or initiative within the health sector developing their own solutions custom-made for their data and reporting needs, there can be significant overlaps, inconsistencies, and redundancies in the reporting forms, negatively affecting both data quality and the efficiency of reporting (Sæbø et al., 2011). This has resulted in a broad, global consensus to strengthen HIS (Braa & Sahay, 2012a).

WHO's now defunct Health Metrics Network (HMN) was among the initiatives working towards strengthening HIS in developing countries. In their 2008 document *Framework and Standards for Country Health Information Systems* HMN states that there is a "broad consensus that improved health outcomes cannot be achieved without strengthening health systems (including health information systems) as a whole, rather than focusing on discrete, disease-focused components. (2008, p. 9)

HMNs stated goal is to "increase the availability, accessibility, quality and use of health information vital for decision-making at country and global levels" (ibid., p. 1), and argues that many developing countries find themselves in a vicious cycle where fragmented and fragile HIS fail to produce the data and information required by decision makers, leading to further decline in credibility, funding and, ultimately, data quality (ibid.).

4.3.1 Integration of Health Information Systems

The term integration in a HIS context can be ambivalent and broad, but Braa and Sahay defines it is the "process of joining distinct systems in such a way, that they appear as being whole in a particular perspective" (2012a, p. 60). In other words, integration does not necessarily entail the merging of multiple systems into one single, big system, but rather using the user's needs, the purpose of the HIS and the organizational perspectives as a basis for better efficiency and co-ordination in organizations (ibid.). Thus, more than just a technical term, *integration* also covers

the alignment organizational and political actors, and the interplay between these actors and the systems themselves (Sæbø et al., 2011).

Interoperability, on the other hand, is understood as one of the potential means to achieve integration, referring to "the ability of a system to use and share information or functionality, of another system by adhering to common standards" (ibid., p. 59).

According to Braa and Sahay (2012a), common standards are fundamental to both integration and interoperability, and the process of standardization can be understood as a continual, evolving, technical-institutional process, and separate standards into three levels: syntactic-technical, data-semantic, and organizational-political. The *syntactic-technical level* refers compatibility needed for data transfer, both between digital systems, and in the process of digitizing paper-based forms, through shared grammar or protocol. The *data-semantic level* is the meaning or shared understanding of the data and how it is calculated and utilized. Finally, the *organizational-political level* refers to the collaborative, social and political structures on which the system is dependent on and part of, as well as the transformation of these structures and supporting routines.

Elaborating on the social aspect of integration, Chilundo & Arnestad (2004) claim that integration is not primarily a technical issue, but rather a "complex and politically charged activity where multiple institutional influences and different, possibly competing, rationalities need to be aligned" (p. 7). Working with integration in HIS can involve multiple actors, including local, national, and international organizations and authorities, all with potentially differing or non-overlapping interests (ibid.). Successful integration processes must recognize and deal with the tensions and inherent differences between actors (ibid.).

One of the measures proposed by the Health Metrics Network (2008) to facilitate integration of HIS is the creation of a national *Integrated Data Repository*, where health data from multiple interoperable subsystems is collected and stored in a standardized and consistent manner. This data, collected from all levels, can then be aggregated and filtered, to suit the data needs of the various administrative levels of the health sector. According to HMN, a data repository should also include a simple and responsive toolset for accessing and combining data in meaningful and relevant ways for stakeholders.

The sentiment of creating a *data repository* is echoed by Braa and Sahay (2012a). Preferring the term *data warehouse*, Braa and Sahay advocates a less centralized approach, where each administrative level has their own database tailored to their specific data needs. The data in the *national data warehouse*, will be a subset of the data used throughout the *district data warehouses*.

4.3.2 Data collection

Reliable and timely information is needed throughout all levels of a country's health sector to inform decision making and ensure impactful resource allocation (Sæbø et al., 2011). However, while data collection might make sense at higher administrative levels of health care, reporting

and registration work is often done by local, point of care health workers, making it a burdensome workload on top of patient care, and relegating the registration process to a secondary concern (Chilundo & Arnestad, 2004). Furthermore, at lower administrative levels, registration work is sometimes regarded merely an institutional and bureaucratic process, where the data gathered is not utilized by anyone, further undermining the value attached to registration and reporting (ibid.).

Data quality can be improved by creating an "information culture" in the health sector, where decision-makers understand and appreciate the importance of quality information to aid them in their work, directly linking their data collection to tangible outcomes (Lippeveld & Sauerborn, 2000). Better data quality will in turn lead to better data utilization (Braa & Sahay, 2012a). All data collected should be used for decision-making and action, as "information is not an end in itself, but a means to better decisions in policy design, health planning, management, monitoring, and evaluation of programmes and services including patient care" (Sauerborn, 2000, p. 33).

The types of data and information needed, changes according to the administrative level of the user, with the granular, single-case information needed at patient care level giving way to aggregated and statistical data at the higher administrative levels (Braa & Sahay, 2012a). Determining each level's *essential data set* is key to providing relevant and needed data, rather than data that could potentially be important in the future (ibid.). By focusing on must-know information rather than nice-to-know, well-chosen data elements can be re-used in multiple settings and for multiple purposes (Braa et al. 2007). Creating an essential data set is based on two key principles: limiting the reporting requirements for health care workers, and integrating the reporting requirements of various programmes (Shaw, 2005).

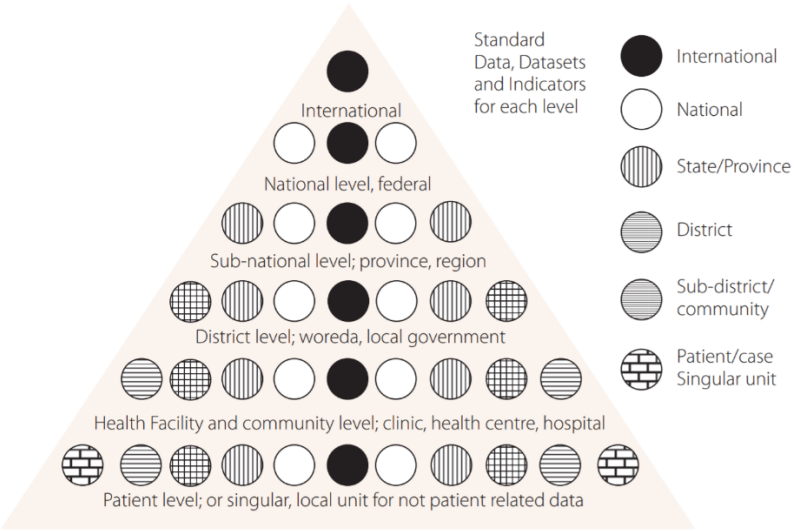

Figure 4-1: "Hierarchy of Standards" from Braa & Sahay, 2012a

Shaw (2005) recommends a top-down process of establishing and developing the essential data sets, with each administrative level determining which indicators they need to be able to manage their services efficiently, allowing each level within the health sector to develop their own data set, while still acknowledging the data needs of higher administrative levels. Figure 4-1 illustrates

the data needed at different levels of administration, as data is reported upwards in the system. Most data originate from operational health workers and –facilities, at the bottom of the pyramid in this model, and is filtered so the administrative level above receives only their essential data set (Heywood & Rohde, 2001). Temptations to transmit all available information upwards to the next level should be resisted (Shaw 2005). The essential data sets should be reviewed continually to make sure only relevant information is collected, to accommodate changes over time, and to keep the essential data set to a minimum (ibid., Heywood & Rohde, 2001).

By adhering to these principles, multiple health programmes can maintain their independence, and multiple local health clinics can collect data relevant to their actions, while at the same time being integrated through shard datasets, coordinated upward reporting and standardization of data and reporting (Braa & Sahay, 2012a).

4.4 Disease Surveillance

Public health surveillance is "the ongoing, systematic collection, analysis, interpretation, and dissemination of data about a health-related event" (Buehler et al., 2004) to monitor distribution and spread of illnesses. An important aspect of health surveillance is outbreak detection, i.e. identifying increased occurrences of infectious diseases (ibid.).

Timely detection of infectious public health threats is essential to reduce outbreak morbidity and mortality (Wagner et al., 2001). Accurate and complete information helps resource allocation and lets health officials take informed actions (Franco et al., 2006).

According to Buehler et al. (2004), early detection of outbreaks can be achieved in three ways: (1) timely and regulated reporting and communication on suspected cases throughout the health sector, (2) improved pattern recognition and predictive models lowering the threshold for investigation, and (3) monitoring health-related behaviors like emergency department visits, laboratory test volumes and even over-the-counter pharmaceutical sales and school- and work absence.

Developing countries generally face greater risks of epidemics, have environments that are conducive to disease transmission, often lack the capacity for timely outbreak detection, and have limited resources to respond to outbreaks (Nelesone et al., 2006). Infectious diseases, both endemic and epidemic-prone, is the most common cause of morbidity and mortality in Africa (Franco et al., 2006).

In 1998, the WHO Regional Office for Africa (AFRO) established the Integrated Disease Surveillance and Response (IDSR) strategy to integrate and strengthen disease surveillance systems across Africa. The original document detailed six actions to be undertaken to achieve these goals:

1. Building awareness among clinicians (physicians and nurses attending patients) regarding the use of case definitions and actions, specimen collection and timeliness of reporting.

2. Initiating case-based surveillance for selected diseases, including neonatal tetanus, hemorrhagic fever, yellow fever, and for diseases with highly effective intervention or large outbreak potential whose case load is relatively low.
3. Strengthening health personnel skills and practices regarding ail components of surveillance (particularly analysis and dissemination of surveillance data) at the district, intermediate and national levels through integrated in-service training and supervisory support.
4. Establishing or strengthening feedback loops at all levels.
5. Building the capacity of the laboratories and strengthening their involvement in supporting the disease surveillance system.
6. Monitoring of surveillance activities including timeliness and completeness of reporting. (WHO, 1998, p. 3)

As guiding principles, the IDSR Strategy Document (WHO, 1998) stresses the importance of *data collection for action*, i.e. only collecting data that will aid public health decision making and action. The system, including reporting tools and procedures, should be kept as *simple as possible*, to facilitate accurate and timely reporting. Furthermore, the system should be adaptable to changes, make information available to correct stakeholders and strive for integration between the various sub-systems (p. 4).

Employing ICT and mobile technology as a tool to help disease surveillance has great potential in supporting timely and complete data and reporting (Brinkel et al., 2014).

4.5 Digital Technologies for Health in Developing Countries

Digital and mobile technologies are spreading rapidly in Sub-Saharan Africa, with an estimated mobile phone subscriber penetration rate in 2018 of 44%, and 23% of the population using mobile internet on a regular basis (GSMA, 2019). The Health Metrics Network (2008) assert that digital technologies have the potential to drastically improve the amount, quality and timeliness of data collected. However, despite their proliferation today, there is still uncertainty around ICT contribution to development (Walsham, 2017; Marcolino et al., 2018). Thapa & Sæbø (2014) suggests the main reason for this lack of knowledge is the difficulty of isolating factors in the interplay between ICT and the surrounding the social, cultural, political and economic situation, and a 2018 systematic review of 371 studies on mobile health technology revealed low methodological quality within the field (Marcolino et al., 2018).

Mobile technology in health development, often referred to as *mHealth*, has the potential transform delivery of health services in developing countries due instantaneous nature of mobile technology and the availability of low-cost mobile devices (Marcolino et al., 2018; Hall et al., 2014). Furthermore, the convergence of technologies in mobile devices, like telephone services, SMS, internet browsing, VoIP, instant messaging services, Bluetooth, camera, and device-based apps, offers a lot of opportunities and flexibility for mHealth initiatives (Hall et al., 2014). mHealth tools can facilitate patient-provider communication, including with remote

populations or those "less inclined to engage with traditional health services" (Marcolino et al., 2018, p. 7). mHealth can also reduce error-rates associated with paper-based reporting, and save time during the data collection process (Mechael et al., 2010).

While the most common use of mHealth is data collection (Roess, 2017), Labrique et al. (2013) identifies twelve common mHealth application areas, benefiting from using one or more mobile technologies: (1) Client education and behavior change communication, (2) Sensors and point-of-care diagnostics, (3) Registries and vital events tracking, (4) Data collection and reporting, (5) Electronic health records, (6) Electronic decision support, (7) Provider-to-provider communication, (8) Provider work planning and scheduling, (9) Provider training and education, (10) Human resource management, (11) Supply chain management, and (12) Financial transactions and incentives.

Information Technology for Development (ICT4D) is an umbrella term for research on the use of ICTs in international development, including mHealth, covering multiple academic fields like Information Systems (IS), Human-Computer Interaction (HCI), geography, anthropology and development studies (Walsham, 2017).

The history of working with ICT4D is riddled with failures, over-promising and under-delivering, and abandoned or little-used projects (Heeks, 2010). Although the exact thresholds for failure can be subjective or vary from project to project, Heeks (2002) divides outcomes of ICT4D projects into three categories: *total failures*, *partial failures,* and *successes*.

The least subjective of the three outcomes, a *total failure* represents a system or project that is either never implemented, or implemented, but immediately abandoned. A *partial failure* means major goals are unattained, or the initiative has significant undesirable outcomes. Heeks argues partial failures in reaching goals are inherently subjective, and requires interaction with multiple stakeholder groups to identify, and that this form of sophisticated evaluation is often absent.

A partial failure means "major goals are unattained or [...] there are significant undesirable outcomes" (ibid., p. 101). A form of partial failure that is prolific in developing countries, is the *sustainability failure*, where systems that are implemented and successful, but then abandoned within a short timeframe (ibid.).

Finally, *success* means most - or all - stakeholders attain their major goals without significant undesirable outcomes (ibid.). According to Heeks, "only a minority [of ICT4D projects] fall into the success category" (ibid., p. 102). Like with partial failures, measuring a success requires a sophisticated and subjective approach to evaluation.

In a 2018 report on mHealth, WHO (2018a) notes that governments have found it difficult to implement successful mHealth solutions. An important factor contributing to this, is the tendency in the mHealth field towards smaller pilot projects that are not designed to continue or scale up after the study is completed (ibid., Agarwal et al., 2016). This phenomenon, sometimes referred to as "pilotitis", has led to widespread dissatisfaction among governments,

service providers and funding agencies towards small-scale mHealth intervention and pilot projects that are "successful in one context, but not 'rolled out' due to a variety of technical, practical, economic and often institutional and political barriers" (Franz-Vasdeki et al., 2015). Adding to this, perhaps as a result of the tendency towards pilot projects, many mHealth initiatives lack integration and interoperability with existing HIS (WHO, 2018a; Labrique et al., 2013).

These issues are also present in Uganda, where a 2017 literature review found most electronic health initiatives in the country were siloed proof-of-concepts, lacking sustainability (Kiberu et al., 2017).

While failures can provide interesting data for studies, the prevalence of failures within ICT4D projects is a very real and practical problem in developing countries, due to the comparatively limited availability of capital and skilled labor (Heeks, 2002). Initial costs for digital projects are typically higher than for non-technical interventions (Agarwal et al., 2016), and few cost-effectiveness analyses have focused on the costs "of misinformation transmitted, of addressing resulting problems, or of the diverse workforce required for implementation" (Roess, 2017).

A significant factor in ICT4D project failures can be attributed to the physical, cultural, and economic differences between designers and users (Heeks, 2002). This contextual disparity can manifest itself in incorrect assumptions – or lack of assumptions altogether – about the realities of the users and the environment. Heeks argues "the West", referring to industrial countries, is a state of mind as much as a physical location, which can lead to "Western-inspired designs within developing-country organizations" (p. 106). Mars and Scott (2010) asserts that there is a dichotomy between developing and industrial countries in terms of expectations and requirements of electronic health initiatives, leaving developing countries in danger of "adopting so-called international best practices, which may well be inappropriate for the developing world" (p. 243).

The USAID *mHealth Compendium* (2015) presents nine principles for successful implementation of mHealth projects, developed in consultation with organizations, including multiple UN initiatives, the World Bank and the World Food Programme, summarized below:

1. **Design with the user** by including all user groups in planning, development, and assessments, developing context-appropriate solutions informed by user needs and existing workflows, and develop systems in an incremental and iterative manner
2. **Understand the existing ecosystem** through aligning with existing technological and regulatory policies, and participation in networks and communities of like-minded practitioners.
3. **Design for scale** from the start of the project. Keep national and regional scales in mind, and make sure the system is replicable and customizable in other contexts.

4. **Build for sustainability** from the start of the project and plan for long-term financing. Engage local communities and developers, and work with the government to ensure integration into national strategies.
5. **Be data driven** and focus on outcomes rather than outputs. Leverage data as a by-product of user actions, and use real time data to inform decision makers.
6. **Use open standards, open data, open source, and open innovation**, investing in software as a public good, and exposing data and functionalities in a documented API.
7. **Reuse and improve** existing tools, platforms, and frameworks where possible, preferring interoperable solutions over siloed approaches.
8. **Address privacy and security**, and consider the context and need for personally identifying information.
9. **Be collaborative**, working across silos and disciplines to create coordination and integration. Document the work and process and publish material under a Creative Commons license.

These principles are echoed by Heerden et al. (2012), emphasizing the need for cooperation between the broader healthcare system, and adherence to international standards to ensure integration and interoperability.

There is also a significant call in the mHealth and ICT4D community for more and higher quality research, and to establish an evidence-base for cost-effectiveness and utility (ibid., Agarwal et al., 2016; Marcolino et al., 2018; Brinkel et al., 2014), as a strong evidence base could "reduce wasteful expenditure on programmes of showing little evidence of effectiveness and would instead promote best-practice models" (Heerden et al. 2012, p. 349).

4.6 Underlying infrastructure and prerequisites for ICT initiatives

Any digital initiative for development has a set for systemic prerequisites outside the scope of the initiative itself, including ICT infrastructure, ICT policies and an ICT literate workforce (Heeks, 2010).

The proliferation of ICT tools in the health sector amplifies the need for a skilled workforce that understands both health care and ICT, as well as the social ecosystems involved (Hersh et al., 2010). Challenges related to high staff turnover rates and insufficient numbers of trained personnel persists across Africa (Fall et al., 2019), including Uganda (Kiberu et al., 2017), where Isabalija et al. (2011) found lack of skilled staff and inadequate training to be major factors negatively affecting telemedicine system adoption. Davis et al. (1989) argues that adoption and successful implementation of a computer system is directly linked to the users' attitude towards the system, which is, in turn, influenced by the user's knowledge and skill, and the usability of the system.

Three levels of literacy affect a user's ability to properly utilize web technology: (1) basic literacy; (2) English language literacy, due to the prevalence of online content in English; and (3) digital

literacy, the competence to utilize digital devices and an understanding of the internet (Marcus et al., 2015). These skills are often lacking in developing countries, impeding internet- and digital adoption (ibid.). A study of the staff skill among health workers in South Africa tasked with reporting data for the national DHIS2 HIS, found that "64% of the respondents have poor numerical skills and limited statistical and data quality checking skills. […] Personnel appear to be reasonably motivated but there is considerable deficiency in their competency to interpret and use data." (Nicol et al., 2013, p. 778)

The lack of digitally literate workers in developing countries can be understood as a consequence of the *digital divide*, referring to "the gap between individuals, households, businesses and geographic areas at different socio-economic levels with regard to both their opportunities to access information and communication technologies and their use of the Internet for a wide variety of activities" (OECD, 2001, p. 5). Many factors can contribute to this divide, including poverty, affordability of devices, data- and telecommunication services, lack of digital literacy, lack of digital infrastructure and policy-related barriers (West, 2015). While the digital divide can be understood as a division between countries, this divide also exists *within* countries and communities, including between rich and poor, urban and rural, and men and women (Bukht & Heeks, 2018). Women in developing countries have marginalized digital participation compared to men, and the gender digital divide is especially significant in Africa (Antonio & Tuffley, 2014).

Besides human resources and capabilities, ICT and mHealth solutions require stable internet access to transmit and receive data, and consistent sources of electricity (Roess, 2017). This underlying infrastructure for digital access and connectivity is severely lacking in many developing countries (Bukht & Heeks, 2018). Particularly in rural areas, extensive telecommunications coverage throughout sparsely populated areas comes at a cost that may not be justified by the resulting use of said service (Barret & Slavova, 2011). Lack of stable power supply is a challenge both for ICT end users, who need to charge or power their devices, and for mobile operators, who will commonly need to supplement grid power with diesel generators to keep consistent service, driving up prices (Bukht & Heeks, 2018).

Enabling and active government involvement, as well as policies encouraging digital health initiatives, can contribute to effective implementation of digital health initiatives (Mechael et al., 2010; Kiberu et al., 2017). However, many developing countries face policy-related barriers to ICT usage, implementation, and literacy, including issues like telecommunication monopolies, tech sector taxes, lack of relevant or local language content, or governmental or civil censorship (West, 2015).

Developing ICT health systems in tandem with a support body from the MOH can increase the likelihood of the project addressing already identified needs, enhance standardization and integration, and incentivize policy changes for digital health initiatives (Mechael et al., 2010). Governments should work towards a cohesive national HIS strategy for new ICT4D and mHealth solutions, promoting interoperability and shared standards, while stopping funding to projects that lack interoperability (ibid.). Other proposed areas of government action include adoption

of a national personal ID system for patient identification, encouraging private sector to improve rural digital infrastructure to enable country-wide digital health coverage, and management of access control and privacy (ibid.).

In Uganda, consistent power outages, loss of internet connectivity and high telecommunication cost adversely affect implementation of health sector ICT solutions, and poor digital and physical infrastructure, as well as shortage of staff, is a burden on the health care system (Kiberu et al., 2017). Ugandan health sector human resources have low levels of computer literacy ICT-related skills, especially in rural areas (ibid.).

4.7 Conclusion

Of particular relevance for my thesis will be the findings from the literature that:

- Information systems can be understood as social systems, and Information Infrastructures provides a lens to understand them as such.
- HIS are never developed from scratch, but build on existing systems and practices.
- Lack of integration and interoperability between systems is a recurring problem which negatively affects data quality in HIS
- IDSR is dependent on timely and accurate data, and integrated solutions.
- ICT solutions for development have a high failure rate, some of which can be attributed to the physical and socio-economic distance between developer and user.
- Particularly mHeath initiatives are prone to explorative pilot studies that are never scaled up and rolled out.
- Failures in ICT projects in developing countries can be damaging due to the limited resources available.
- ICT projects in developing countries should be designed in collaboration with users, and should build on the existing infrastructure and ecosystem.
- Successful adoption of ICT software is aided user acceptance, which is in turn affected by user skill and system usability.
- Developing countries have inadequate access to skilled, motivated, and digitally literate personnel.
- Affordable and reliable access to fundamental ICT prerequisites like power and internet can be challenging, especially in rural areas of developing countries

5 System Development

For the sake of structure, I have divided the empirical material from my work in three chapters, each detailing a specific aspect of my research. This chapter details the development of the eIDSR Sample Tracker application prototype, detailing the major milestones of the iterative process. The next chapter, Technical Specifications for the Prototype Application, elaborates on the technical specifications of the application. Further and more detailed data from field work, and the testing and implementation process, is presented in chapter 7: Empirical findings.

Activities described in these chapters are intertwined and were carried out simultaneously, typically following a pattern of development, field testing, more development, more field testing. I have chosen to present development and implementation as two separate chapters for the sake of thematic structure, and to afford the reader an understanding of the prototype application before presenting the data this prototype generated. In the discussion chapter I will treat them as simultaneous activities, such as needed when investigating how the practices in the field influenced the development.

Based on my findings in Uganda, I developed an application for DHIS2 to help track biological samples as they are being transported for testing at a laboratory. This system was intended to run on low-spec Android devices and would communicate directly with Uganda's DHIS2 Tracker-based eIDSR programme, developed by HISP Uganda and used by the Ministry of Health (MOH) and the public health sector. eIDSR seeks to provide timely and relevant data on sample transportation and lab results, but without a mobile-based solution for registering data into eIDSR, reporting from Health Clinic level is hampered.

To understand the prototype application I developed, it is first necessary to understand the underlying DHIS2 Tracker platform and Uganda's eIDSR system with which it communicates. The process of enrolling patient cases and adding events to these cases is central to the eIDSR Sample Tracker prototype.

5.1 DHIS2 Tracker

Tracker is an extension of the DHIS2 platform for collecting, managing, and analyzing disaggregated data, like data on individual patents, cases, and events. By supporting the registration of all forms of case-based data, DHIS2 can be used for tracking women through antenatal and postnatal care, enrolling patients into health programmes, patient follow-up and appointments and tracking lab samples (DHIS2, 2020; Braa & Sahay, 2017). Through aggregation of individual data, Tracker can feed data into the main data warehouse in the same DHIS2 system.

The customizable nature of DHIS2 and Tracker allows users to set up their own Tracker Programs with stages through the main user interface, deciding what data to collect at each stage. HISP Uganda had set up such a program for *Integrated Disease Surveillance and Response* (IDSR), called *eIDSR*.

5.2 eIDSR

The eIDSR program consists of nine stages: *Perinatal Death Details, Contact Tracing, Final OutCome* (sic), *Case Monitoring, Lab Resulting, Maternal Death Details, Initial Diagnosis, Lab Request* and *Specimen Handling*. Each of these have a fillable form which upon completion adds an event to a patient/case object. Before adding an event, the case must first be enrolled in the system.

5.2.1 Enrolling a case

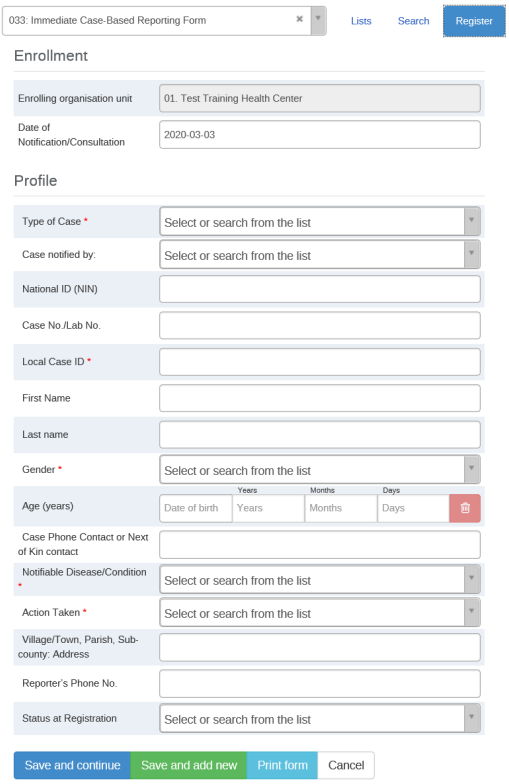

Figure 5-1: Form for enrolling patient/case in eIDSR

Enrolling a new patient in the eIDSR program requires registering a minimum of seven parameters on both the patient and the case. These are (1) the health center where the patient is enrolled, (2) the date of consultation, (3) whether the case is a human or an animal, (4) the local case ID number, (5) the gender of the patient, (6) the suspected disease, and (7) the action taken. A further ten optional fields, mostly related to identification and contact information, completes the form.

Notably, this form combines patient and case data in a single object, meaning each enrollment is both a patient and a health case in one. Once a patient case has been enrolled, a user can add events to this object, adding information like diagnosis, lab results, or sample transportation events.

5.2.2 The eIDSR Tracker Capture Specimen Handling Form

The *Specimen Handling* form serves as the foundation for the eIDSR Sample Tracker application prototype I developed as part of my research. Data collected by the application is sent to this form, to register a specimen tracking event.

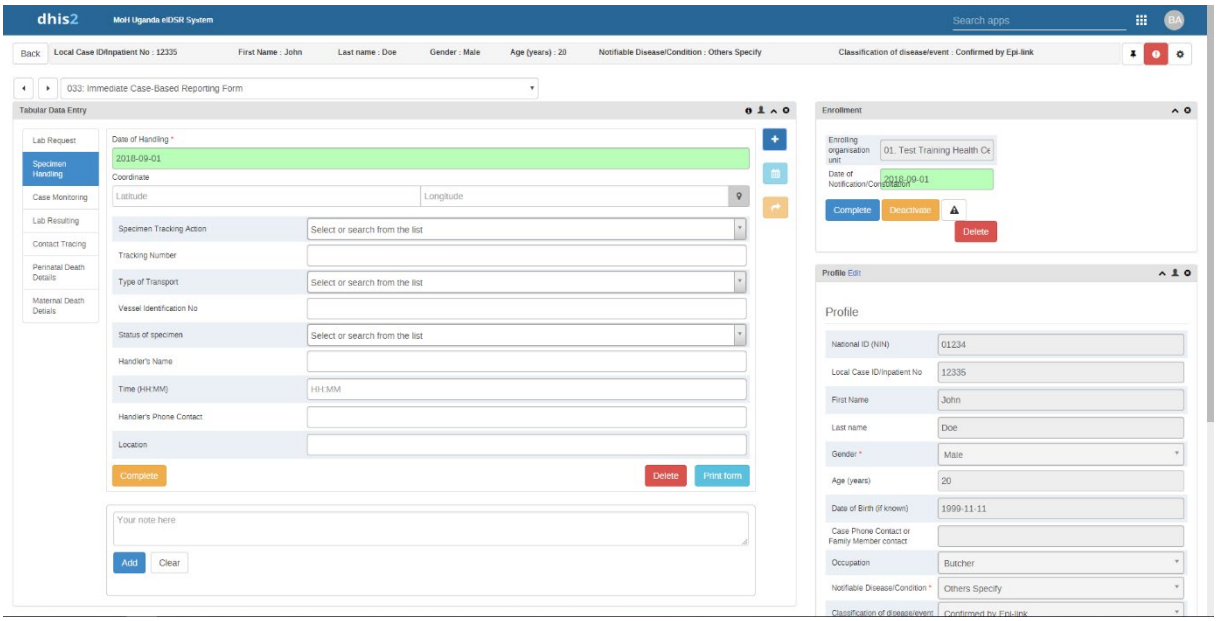

Figure 5-2: The eIDSR Tracker Capture Specimen Handling Form

Designed for tracking biological samples taken from patients with expected notifiable diseases as they are transported from testing site to laboratory, the form fields, as decided and implemented by HISP Uganda at the outset of my research, were as follows:

Date of handling: The current date when the registered event happened.

Coordinate: Coordinates in latitude and longitude of the event location.

Specimen Tracking Action: The current stage of transportation for the sample. Implemented as a dropdown menu with the following options:

Picked, Forwarded, Intransit (sic), Dispatched, Delivered, Received

Note the use of common Ugandan dialectic variant *picked* as a synonym for *picked up*.

Tracking Number: The barcode printed on the sample in numerical value.

Type of Transport: A dropdown menu with the following fields:

Air, Bicycle, Bus, Train, Car, Motorcycle

Vessel Identification No: The registration number for the vehicle transporting the sample, such as license plates, flight number or train reporting number.

Status of specimen: The condition of the specimen at the time of event registration. Implemented as a dropdown menu with the following options:

Bad Condition, Good Condition, Inadequate, Damaged, Lost

Inadequate means the sample size is too small for successful testing.

Handler's Name: The name of the person registering the event.

Time (HH:MM): The time when the event was registered.

Handler's Phone Contact: Phone number of the person registering the event.

Location: Current location in text form.

This structure provided the basis for my Android-compatible Prototype eIDSR Sample Tracker application, which was designed to offer an alternative and simpler way to fill out this form on an Android device in the field with minimal added workload for the stakeholder.

5.3 The Prototype eIDSR Sample Tracker Application

Effective Disease Surveillance is dependent on early detection of outbreaks (see section 4.4), but feedback from interview participants indicated that the logistics surrounding collection, transportation, testing and reporting on suspected notifiable diseases are inadequate (see section 7.3). While the eIDSR Tracker Capture program supports data on handling and transporting samples to improve awareness and accountability, when I started my study, there were no appropriate tools or mechanisms available to gather information on the transportation process, other than direct entry into the PC-based form fields of the eIDSR DHIS2 instance (Figure 5-2). With computers only scarcely available in health facilities, this meant timely and complete data on sample tracking was unfeasible.

The *eIDSR Sample Tracker application prototype* is intended provide stakeholders like Disease Surveillance Focal Persons, transportation workers, hub coordinators and lab personnel a way to quickly fill out the *eIDSR Tracker Capture Specimen Handling form* on an Android mobile device. By simplifying the process as much as possible, notably using barcode scanning to identify the sample, submitting information on a medical sample would hopefully prove to be an agreeable and a non-intrusive part of the sample handling routine for stakeholders.

5.3.1 Iterations

The prototype underwent major structural and flow-based changes as development progressed, adding more and more complexity to what was initially, a very linear workflow. The iterative process meant most individual changes of functionality and design were incremental, so documenting every iteration is not feasible within the scope of this thesis. However, there were some major milestones in development that I have divided into four broad stages, documented below. These milestones typically represent a major structural change to the flowchart representing the use case of the application.

5.3.2 First milestone - Initial use case and first functioning version

The ideal use case for the eIDSR Sample Tracker application can be summarized as follows: A stakeholder involved in the handling of a biological sample taken from a patient with a suspected notifiable disease uses his Android device to scan the barcode printed on the sample packaging. This gives the user a short form to fill out to detail the status of the sample. This data, together with automatically collected data like time, date, user, and location of scan is sent to the DHIS2 Tracker database as an event, providing other stakeholders with information on the sample.

The flowchart to the right (Figure 5-3) illustrates this basic use case, and was the initial workflow presented to and approved by HISP Uganda after the initial diagnosing step of the action research cycle. This version made no attempts to simplify the eIDSR registration form with which it communicated, beyond using the Android device camera to scan a barcode to identify the sample.

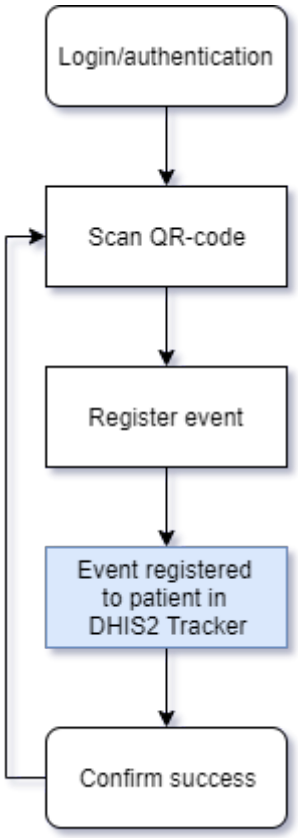

Figure 5-3: Original flowchart

At this point, I was working under the assumption that the samples were not priorly labeled with a bar code, and in collaboration with HISP Uganda, I was researching the practicality of issuing either QR code scanners or rolls of QR codes to health facilities. The use of QR codes over normal barcodes was preferred due to the ability to store much more information, including text. This would potentially allow the QR-code to contain essential, non-privacy breaching information on the sample, like *type of sample* and to which laboratory it is being transported. By doing this, even offline devices would be able to scan the label to display some key information on the sample. Developing and testing this version was technically successful, but revealed some structural and logistical issues that I addressed in the second major milestone version.

5.3.3 Second milestone

The second milestone in the development of the prototype application marked some departures from the original vision of storing information in QR-codes, and added a layer of complexity to allow barcodes to function as identification for specific specimens.

After some research, I concluded that printing QR-codes, although an enticing prospect, was not feasible at health facility level in Uganda, due to cost, maintenance, and digital infrastructure. Crucially, however, I learnt samples were already labeled with barcodes issued from Uganda's Central Public Health Laboratories (CPHL). While this meant abandoning the idea of storing key information on the sample in a QR-code, it solved the issue of distributing QR-codes to health facilities. This prompted the re-development of the scanning portion of the application, as the scanned object was now a numerical barcode rather than a QR code.

Barcodes come in a variety of formats and standards, each designed to fit a particular use case or industry sector (ISO, 2010). Obtaining a sample CPHL barcode for testing proved difficult and time-consuming, and development of the application had to commence without testing compatibility with CPHL's chosen barcode format. This meant the prototype application had to accept a wide variety of one-dimensional, numerical barcodes.

Furthermore, testing and interviews with HISP Uganda staff revealed that barcodes were not intrinsically tied to the specimen being transported in DHIS2. This meant the barcode had to be linked to a *patient Tracked Entity Instance* in DHIS2 before any events could be registered to the specimen.

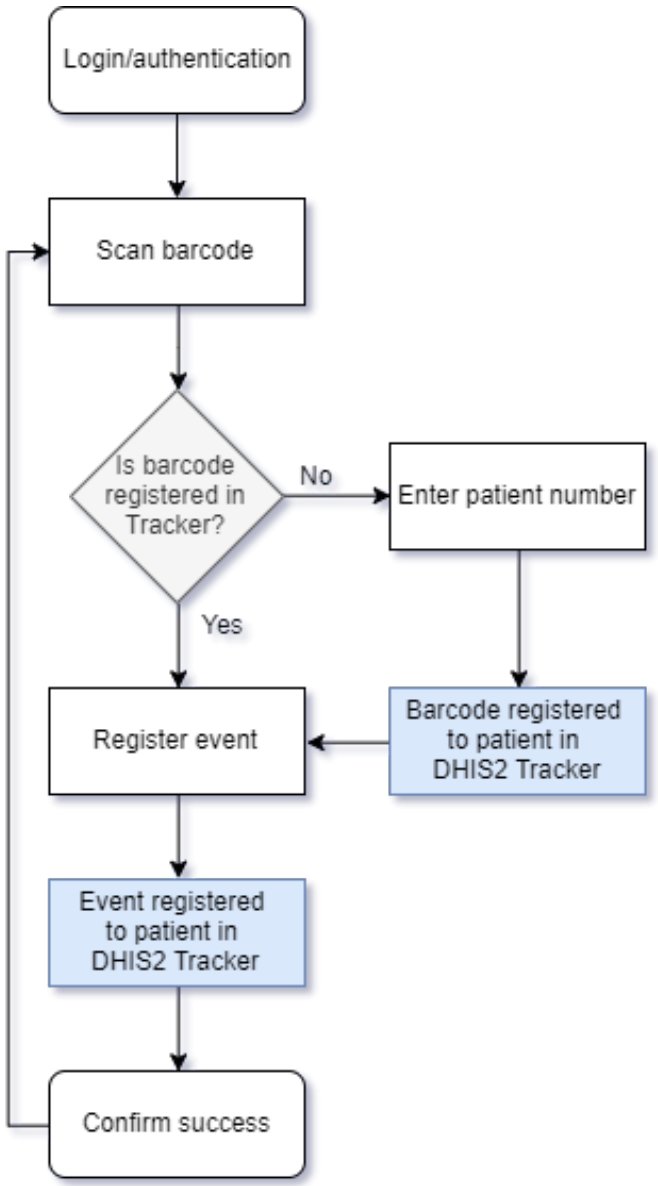

Figure 5-4: Second milestone flowchart

To solve this, a check was added after the scanning stage of the flowchart (Figure 5-4), where the scanned barcode is cross-referenced with all previously registered sample tracker events, looking for a match. If no such match is found, the user is required to enter the patient number, to link the sample to a patient. Once this link has been made, future scans of the same barcode will not require the user to enter a patient number, as these values are now coupled.

This version of the prototype application was tested in a field visit to Hoima district in western Uganda. During the planning stages of this field trip, I learnt that a similar application to my DHIS2-based tracking application was being developed by CPHL to track samples. This system would communicate with their LMIS, rather than DHIS2, and was being piloted in western Uganda, including Hoima.

Although I was initially given access by HISP Uganda to accompany CPHL on their pilot testing in Hoima, and potentially cooperate with them, this access was later revoked, citing the need for secrecy around my project to avoid shutdown of my project as a direct competitor to the CPHL system. This revelation of parallel development and subsequent need for secrecy had major implications for

my development, including limiting when and where I could conduct my research, and who I could interview and observe. It also meant that the purpose of my research would need to take into consideration the need to achieve interoperability or integration with the existing CPHL system, in addition to being integrated with Uganda's DHIS2-based eIDSR system.

5.3.4 Third milestone

The third milestone in the development of the prototype application saw changes in user experience and the addition of patient registration as a feature in the application.

Although hamstrung by the last-minute cancellation of working with CPHL and the sudden need for secrecy, the field trip to Hoima still yielded valuable data, informing future development of the application. Of note, I was able to test the application with genuine CPHL barcodes, confirming that the application supported the barcode format, and the application was technically able to register events as intended to specimens.

One of the finds that had further structural implications for the application, was the lack of patient registration in the DHIS2 system prior to collecting and transporting specimens. While the application included a system for linking a specimen to a patient, his functionality did not account for cases where the patient was not already registered in DHIS2, and according to my observations and multiple interview subjects in Hoima, this was the most common scenario. This meant the application would only be able to register events in a minority of real-world cases, prompting another major structural addition to the application flowchart.

The proposed solution was to allow the user to register a patient through the application when said patient is not already enrolled in Uganda's DHIS2 eIDSR system. Building upon the previous check for a registered barcode, upon entering a patient number that is not found in the DHIS2 eIDSR system, the user is prompted to register some details on the patient before moving on to register the specimen tracking event. This is done through a separate form, including only the strictly required fields needed to register a new patient as a *Tracked Entity Instance*.

In a real-world use case, this would generally mean that the first person to scan the sample for tracking will have to register the patient in the application before registering an event, while subsequent scans of the same sample will not require this input, and will move straight to the form for registering an event

Also based on finds from the Hoima field work, I started making rudimentary changes to usability. While user experience and stakeholder testing were intended to be the focus of future field work, it was clear from the limited user testing in Hoima that the application was perceived as complex, a problem that would only be amplified by adding patient registration to the application. Changes to the application were made to dynamically hide and show the fields needed based on previous input, reducing both clutter and required inputs for the user.

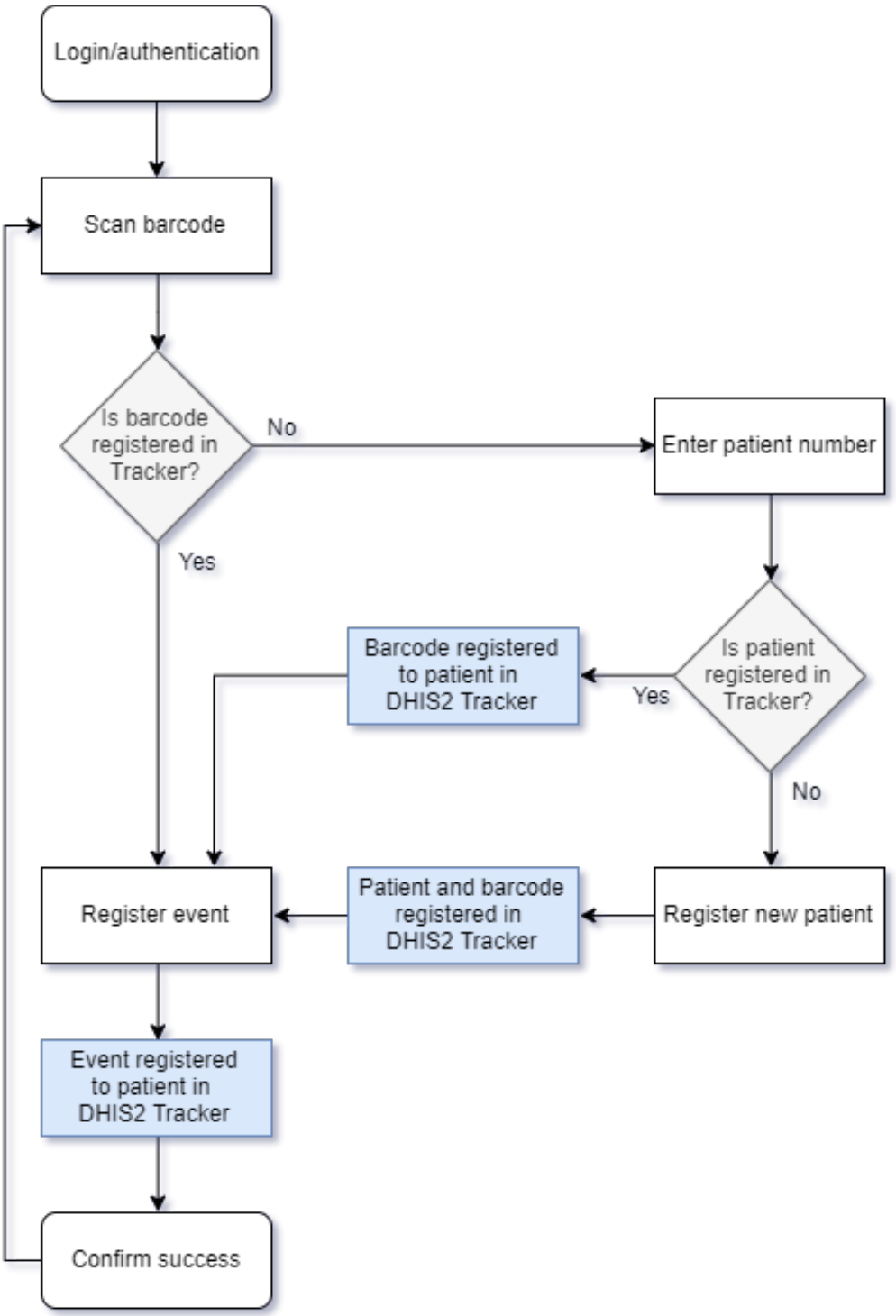

Figure 5-5: Third milestone flowchart

This version would be used in the most comprehensive field testing yet, travelling to West Nile District in Uganda to test with multiple actual stakeholders and simulating several instances of specimen collection. While far from Kampala, where I was based, West Nile district was chosen as the field of research for three main reasons. First, the district borders South Sudan and DR Congo, and has received more than a million refugees from these areas, making it a potential hotspot for outbreaks of epidemic diseases that eIDSR is intended to monitor. This includes the

threat of Ebola, as this research was conducted during the ongoing 2018 DR Congo Ebola outbreak, which has seen a limited number of cases in Uganda.

Secondly, West Nile was part of CPHL's pilot study for their sample tracking application, allowing us to understand the workflow and structure they have established. This insight could be invaluable in an attempt to integrate the two systems.

Finally, due to the status as a designated pilot area, HISP Uganda had greater autonomy to conduct research in the area, affording me more freedom in conducting research and interviews than in other districts in Uganda.

The version of the prototype application used in field testing in West Nile operated as follows (Figure 5-6 to Figure 5-14).

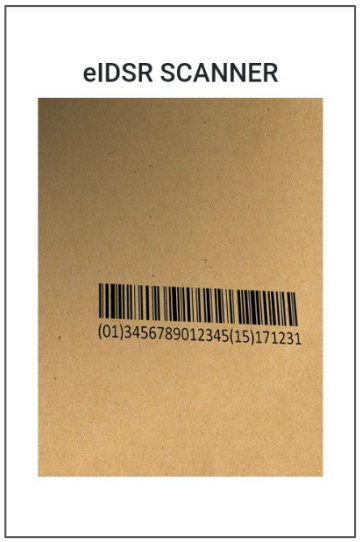

Figure 5-6: Scan view

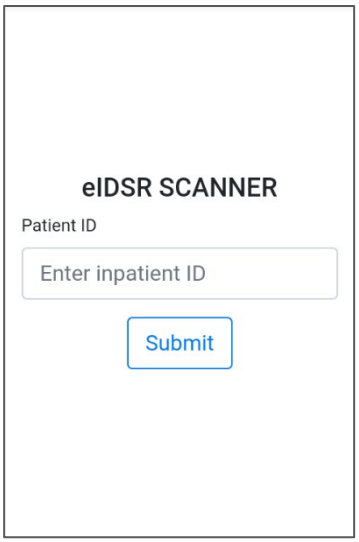

Figure 5-7: Patient ID-entry form

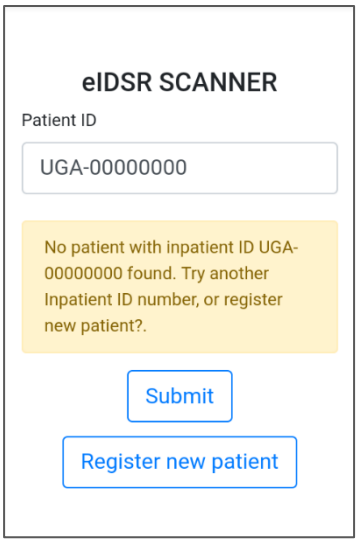

Figure 5-8: Patient ID-entry form with error message

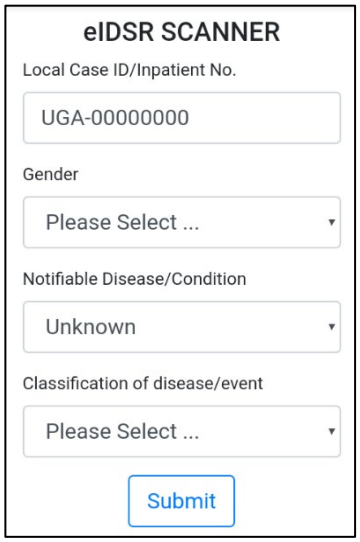

Figure 5-9: Patient registration form

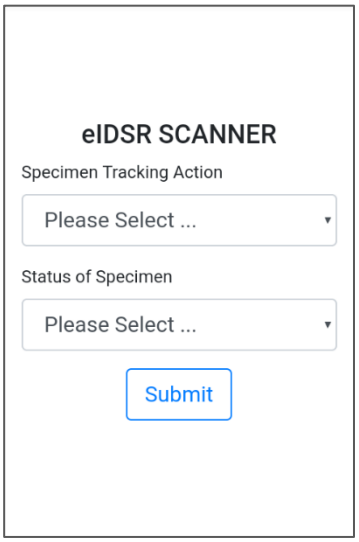

Figure 5-10: Event registration form

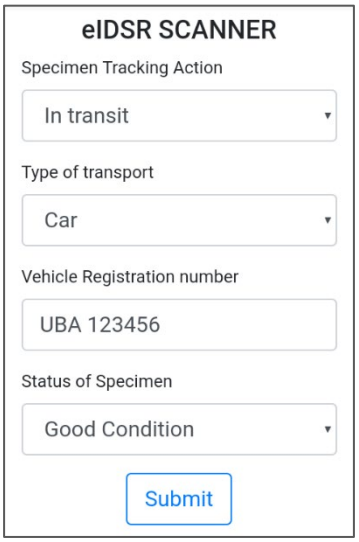

Figure 5-11: Event registration form with sample data

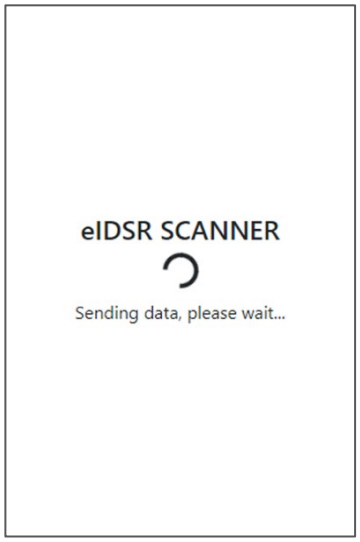

Figure 5-12: Loading spinner

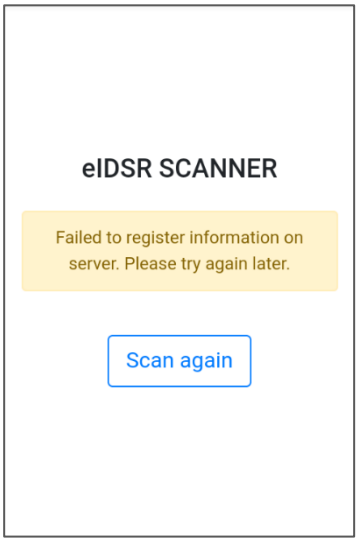

Figure 5-13: Connection error message

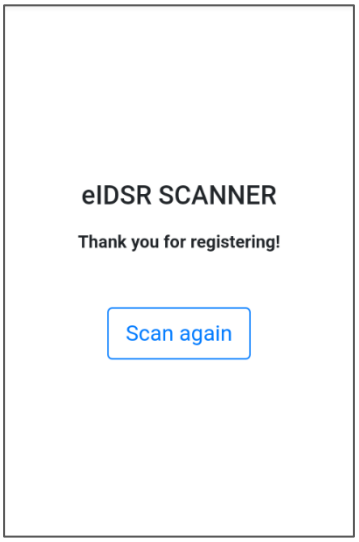

Figure 5-14: Success confirmation

The application takes the user straight to *scan view* (Figure 5-6), displaying video feed from the device's camera, preferring the rear camera if more than one is available.

Once the application recognizes and reads a barcode in the scan view, that barcode is cross-referenced with earlier registered barcodes. If this barcode has been scanned before, the user is taken directly to the *event registration form* (Figure 5-10). This represents the ideal workflow, which will usually be the case for all subsequent scans of any given barcode.

If this is the first time the barcode has been scanned, the application will prompt the user for the patient ID (Figure 5-7). If the patient ID entered exists in tracker, the user is taken to the *event registration form* (Figure 5-10).

If the patient ID is not recognized, an error message is displayed (Figure 5-8), asking the user to either try entering another patient ID, or registering a new patient. By clicking on the "Register new patient" button, the user is taken to the *patient registration form* (Figure 5-9). The editable field for Patient ID will by default contain the Patient ID that was entered in the *ID entry form* (Figure 5-7), under the assumption that the ID number is correct, but the patient has not yet been registered in the system. The form for registering a new patient contains the minimum needed fields for a patient to be registered, and once the user clicks submit and the patient is registered in Tracker, the user is taken to the *event registration form* (Figure 5-10).

After a link between barcode and patient ID has been established, either automatically by previous registration, or by user entry of patient ID or full patient registration, the *event registration form* (Figure 5-10) prompts the user for status and events. This entry is dynamic in that it responds to user input (Figure 5-11). If the user inputs "In transit" in the Specimen Tracking Action box, the user will also be asked to enter what type of transport is being used. If anything but "bicycle" is entered in this field, the user will be prompted vehicle registration number (car number plates, flight number and so on). See the section on *The eIDSR Tracker Capture Specimen Handling Form* above for a detailed description of the input fields.

Once the user has entered the desired information, they can click the submit button to post the data to the DHIS2 API, creating a new event in the eIDSR Tracker program with the entered data. Upon successful posting of an event in Tracker, the app displays a success message (Figure 5-14) and allows the user to go back to *scan view* (Figure 5-6) with a button labeled "Scan again".

The system will display a *loading spinner* while working on sending and receiving information (Figure 5-12). Errors reaching the server or posting data will prompt retries while displaying this spinner, but after a set amount of retries, the application will display an error (Figure 5-13).

5.3.5 Fourth milestone

The field testing in Hoima yielded massive amounts of data, both in terms of structure and usability. Particularly the user interface would undergo a major revamp following user feedback and observations, and solutions for handling cases where the device is offline or otherwise could not reach the server were proposed.

User testing with stakeholders in West Nile strongly indicated a need to simplify and streamline the user experience to account for relative lack of familiarity with concepts like web form fields. Furthermore, some fields confused the stakeholders, either in terms of where to press, or what information was being requested.

In coordination with HISP Uganda representatives, multiple form fields deemed superfluous were removed, many more had wordings changed, and some, where possible, had their input automated instead of prompting the user. The design was changed to better communicate where to press by giving contrast between form field and background with a (DHIS2 official) dark blue color scheme, and moving the form field captions *inside* the form itself.

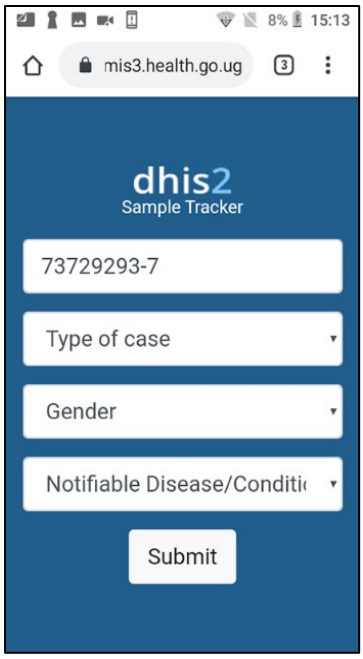

Figure 5-15: eIDSR Sample Tracker application prototype interface after implementing changes based on user feedback.

These changes were implemented in the prototype after the first day of user testing in West Nile, to gather feedback and data on the revamped design during the second day of user testing. This version tested much better with the stakeholders, but concerns remained over the amount of information needed to be registered and the additional workload this represented, especially when forced to register a patient before registering an event. Having multiple data input fields per page in the application, was also a source of confusion which future designs potentially would need to address. A detailed account of the user testing process, and the resulting changes to the prototype, can be found in section 7.5.

Additionally, while issues regarding reliance on the device being online had been on the agenda for future updates of the application, slow, spotty, or non-existent internet connection was found to be a major issue in the region, precipitating a structural change of the application to accommodate situations where the DHIS2 server cannot be reached without seriously impeding user workflow. Using the application in an offline environment means no checks with the server can be made regarding existing barcodes and patients. As proposed solution to this issue, when scanning a barcode to register an event when offline, the application can assume that neither the barcode nor the patient has been registered in the system, prompting the user for all possible required information. When the system is back online, this information is transmitted automatically to the DHIS2 server, disregarding the redundant information should it turn out that the barcode or patient has already been registered. This check for online status should be made at timed intervals, and data could be synced to the server automatically without user input. Prolonged periods of offline status could alert the user, in case the lack of internet is caused by issues that require human action, like lack of funds available in the subscription or mobile data turned off on the device. The proposed workflow is illustrated by Figure 5-16 below.

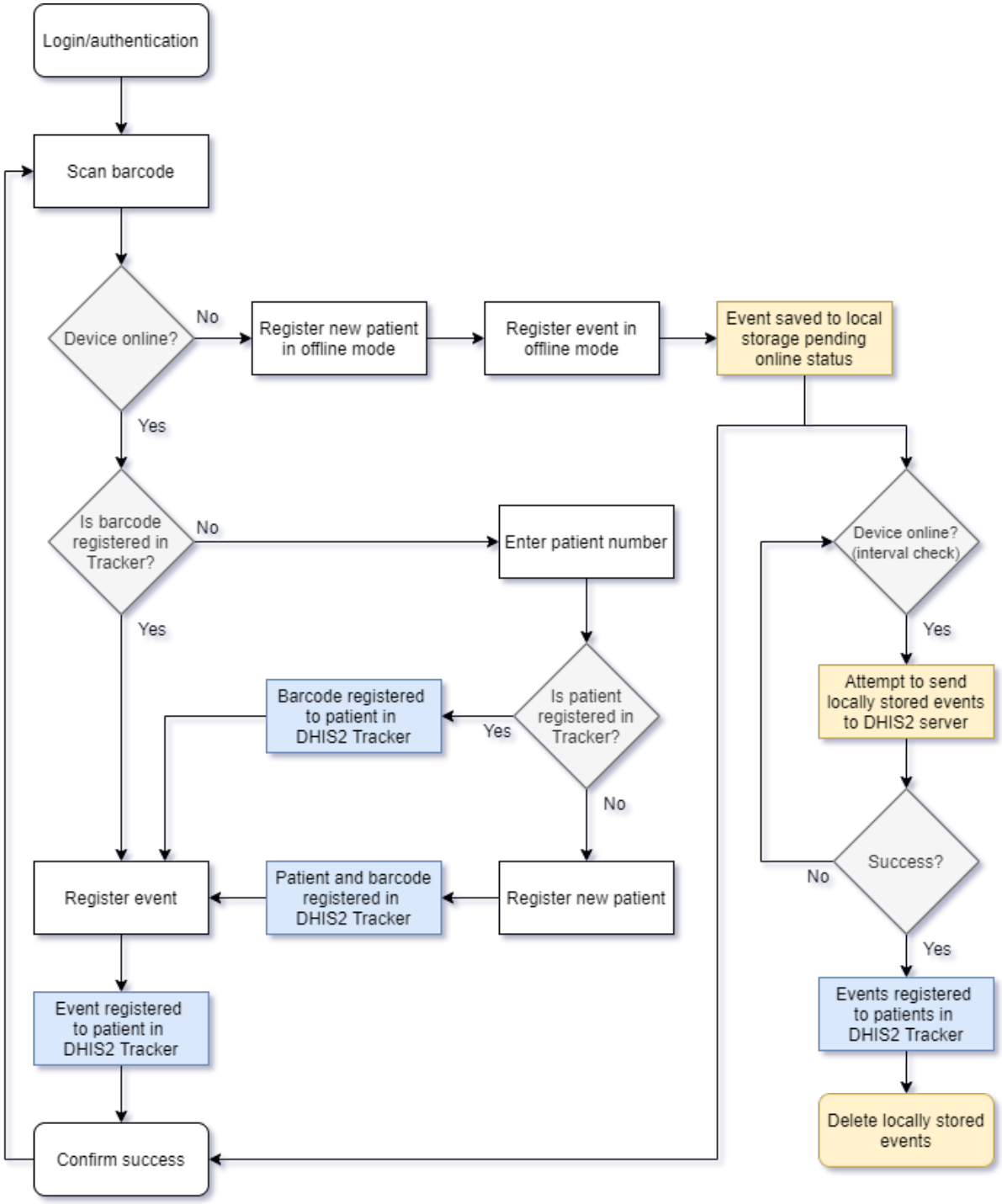

Figure 5-16: Fourth milestone flowchart

While the complexity of the application has expanded substantially from the initial workflow (Figure 5-3), the core user experience, as represented by the ideal workflow to the left side of Figure 5-16, remains largely unchanged on a conceptual level, keeping the complexity as low as possible for the user in most situations.

Details on my findings from the field trips as related to the application are presented in chapter 7: *Empirical findings*, including documentation on the CPHL tracking application, and the adjustments made to the eIDSR Sample Tracker application prototype after user testing. Discussions on possible future changes to this workflow and design, as well as reflections on usability, viability and integration potential can be found in chapter 8: *Discussion*. Further elaboration on the technical aspects of the prototype is presented in chapter 6: *Technical Specifications for the Prototype Application*.

6 Technical Specifications for the Prototype Application

While the finds and data generated by the cyclical AR process is the focus of this study, the technical implementation of the application is intrinsically linked to the functionality and utilization of the system, and certain observations and finds suggested modifications to the technical side of the system during the research process.

Therefore, the purpose of this chapter is to detail the technical approach to developing the eIDSR Sample Tracker application prototype, elaborating on choices of platforms and libraries, and giving brief technical insight into how the application communicates with the DHIS2 server. Chapter 8 will discuss the implications of these choices and what could potentially be gained by alternative solutions and platforms.

6.1 Platform and libraries

The DHIS2 dashboard supports importing and natively running HTML5-based applications that can interact with the DHIS2 API to send and receive information. By utilizing web technology, designers and developers can utilize a much larger toolset for building applications than what is natively available in DHIS2. In my case, scanning and interpreting barcodes was the core functionality of the application, which is not currently possible to do using only DHIS2.

As a DHIS2 WebApp, the prototype application is developed in HTML5, using JavaScript, JQuery and CSS. Additionally, the application utilizes the Bootstrap and ZXing-JS libraries to ease workflow and styling and provide core functionality for the application.

Bootstrap (https://getbootstrap.com/) is a popular CSS framework and front-end component library, providing tools for building responsive and mobile-friendly websites, and acts as a fundamental CSS stylesheet on which to base further CSS styling.

ZXing-JS (https://github.com/zxing-js/) is an open-source library for JavaScript for scanning and processing barcodes. After testing multiple alternatives, this library was picked for the prototype application due to its ease of implementation, small performance footprint and support for a wide range of barcode types.

Functions for capturing current time and date, searching Tracker for previous instances of barcodes and patient IDs, and posting events, patients and information in the eIDSR DHIS2 API were written in JavaScript and JQuery. The following information is automatically generated and stored by the application when a user starts a new scan process:

- Name of currently logged-in user, acquired from DHIS2 API
- Telephone number of the user, acquired from the DHIS2 API
- Current location in decimal coordinates, acquired from the device
- Current date and time, acquired from the device

Additionally, the application will store the value of a scanned barcode as a text string upon successfully scanning a barcode.

6.2 Barcode scanning

Several open source barcode scanning libraries were tested in the process of developing the prototype application. Particularly, an early change in use case from scanning QR-codes to barcodes, prompted a change of library from the QR-code-specific *jsQR* (https://github.com/cozmo/jsQR), and trialing multiple libraries to ensure compatibility with multiple barcode formats amidst uncertainties of what standard CPHL was using for their barcodes, resulting in the choice of ZXing-JS as scanning library.

With this library installed, the application is able to interpret barcodes appearing in the device camera video feed, saving the numeric barcode value as a variable. By transmitting this variable to the eIDSR API, the value can be used as an identifier, tying the barcode value to the specific sample.

6.3 Working with Tracker Web APIs

Central to the functionality of the application is communicating with the DHIS2 API to either read information or post new data. The specific structure of Uganda's eIDSR Tracker system, dictates what commands, keys, and logic to use to post and receive data from the API. This means the processes developed for my prototype application are specific to Uganda's eIDSR system, although it is likely possible to extrapolate and re-use much of the same logic for similar systems in other countries.

6.3.1 Finding the Patient ID that corresponds to a barcode

Because of the way the information is structured in the Ugandan eIDSR Tracker Capture module, after scanning a barcode, the application must perform a nested API search to find previous instances of the barcode, and if so, which patient ID it has been registered to.

The first step is to search through events and see if there is a Tracking Number that corresponds to the barcode that was scanned. The search looks like this:

/api/events/query?filter=PRTATrsmfjn:EQ:{barcode}&ouMode=ALL&programStage=vOc4kRUj4Ek

PRTATrsmfjn is the UID corresponding to the Tracking Number data element in Specimen Handling.

{barcode} is the number sequence from the barcode scan that initiated this process.

ouMode (organization unit mode) is set to *"ALL"* to search through all Ugandan health facilities, and *programStage* is set to *voc4kRUj4Ek*, which corresponds to "Specimen Handling". This

search produces a table of the registered event where the barcode was used, from which the application acquires the event ID.

This event ID is then used in a further search, to acquire the Tracked Entity Instance from the actual event data with the following search:

/api/events/{eventId}.json

From this json-file, the application acquires the UID for the Tracked Entity Instance, and finally uses this UID to search for the corresponding Patient ID by searching:

/api/trackedEntityInstances/{trackedEntityInstanceId}.json

From this file, the application can access the value of "Local Case ID/Inpatient No", providing the patient ID that the barcode was registered to.

6.3.2 Registering a new event

The purpose of the application is to register Specimen Handling events in Tracker in Uganda's eIDSR DHIS2 instance. This is done by collecting the necessary information from the forms filled in by the user, combining it with other collected information from the device, like name of user, time, date, and location, and posting the information as an object to the eIDSR DHIS2 API. This object is then posted to /api/events/.


```
▼<event storedBy="Anders" dueDate="2020-05-13T12:55:40.152" program="p55TSnIz83Z"
 href="https://hmis3.health.go.ug/eidsr/api/events/gN9FhATPmFy" event="gN9FhATPmFy"
 programStage="vOc4kRUj4Ek" orgUnit="AlBPuPILigI" trackedEntityInstance="VNNRZJobIa6"
 enrollment="nvYGvtoM9XQ" enrollmentStatus="ACTIVE" status="COMPLETED" orgUnitName="01. Test
 Training Health Center" eventDate="2020-05-13T00:00:00.000">
   <attributeCategoryOptions>xYerKDKCefk</attributeCategoryOptions>
   <optionSize>0</optionSize>
   <lastUpdated>2020-05-13T12:55:40.491</lastUpdated>
   <created>2020-05-13T12:55:40.153</created>
   <completedDate>2020-05-13T00:00:00.000</completedDate>
   <followup>false</followup>
   <deleted>false</deleted>
   <attributeOptionCombo>HllvX50cXC0</attributeOptionCombo>
   <completedBy>Anders</completedBy>
   <coordinate latitude="59.9457792" longitude="10.7905024"/>
  ▼<dataValues>
     <dataValue lastUpdated="2020-05-13T12:55:40.497" storedBy="Anders" created="2020-05-
     13T12:55:40.497" dataElement="pR3A73W6EuX" value="CPHL" providedElsewhere="false"/>
     <dataValue lastUpdated="2020-05-13T12:55:40.497" storedBy="Anders" created="2020-05-
     13T12:55:40.497" dataElement="xP8EQVyM2YQ" value="test-123" providedElsewhere="false"/>
     <dataValue lastUpdated="2020-05-13T12:55:40.497" storedBy="Anders" created="2020-05-
     13T12:55:40.497" dataElement="JEJFHDVFDYL" value="Intransit" providedElsewhere="false"/>
     <dataValue lastUpdated="2020-05-13T12:55:40.497" storedBy="Anders" created="2020-05-
     13T12:55:40.497" dataElement="Ncx6NncDL52" value="Good Condition" providedElsewhere="false"/>
     <dataValue lastUpdated="2020-05-13T12:55:40.497" storedBy="Anders" created="2020-05-
     13T12:55:40.497" dataElement="X8XQfXjJPFq" value="Car" providedElsewhere="false"/>
     <dataValue lastUpdated="2020-05-13T12:55:40.497" storedBy="Anders" created="2020-05-
     13T12:55:40.497" dataElement="QOaayYtyUdG" value="+256 774497228" providedElsewhere="false"/>
     <dataValue lastUpdated="2020-05-13T12:55:40.497" storedBy="Anders" created="2020-05-
     13T12:55:40.497" dataElement="SX1M9ctPN69" value="Anders Baggethun" providedElsewhere="false"/>
     <dataValue lastUpdated="2020-05-13T12:55:40.497" storedBy="Anders" created="2020-05-
     13T12:55:40.497" dataElement="PRTATrsmfjn" value="0051111407592" providedElsewhere="false"/>
     <dataValue lastUpdated="2020-05-13T12:55:40.497" storedBy="Anders" created="2020-05-
     13T12:55:40.496" dataElement="bFEm13S5DuJ" value="11:55" providedElsewhere="false"/>
   </dataValues>
 </event>
```


Figure 6-1: Simulated event registered to a simulated patient in the eIDSR DHIS2 API, through the eIDSR Sample Tracker application prototype

6.3.3 Registering a new patient

In cases where the patient has not yet been registered, the application will prompt the user to register the patient manually through the application. To minimize workload on the user, only the fields required by DHIS2 Tracker Capture for a new patient will be prompted. When the user presses Submit on the Register new Patient Form, the application packages the necessary information as an object and posts it /api/trackedEntityInstances/, creating a new patient Tracked Entity Instance, which an event can then be posted to.


```
▼<trackedEntityInstance created="2020-05-13T12:54:25.181" orgUnit="AlBPuPILigI"
 createdAtClient="2020-05-13T12:55:40.496" trackedEntityInstance="VNNRZJobIa6" lastUpdated="2020-
 05-13T12:55:40.496" trackedEntityType="MCPQUTHX1Ze" lastUpdatedAtClient="2020-05-13T12:55:40.496">
   <inactive>false</inactive>
   <deleted>false</deleted>
   <featureType>NONE</featureType>
  ▼<attributes>
     <attribute lastUpdated="2020-05-13T12:54:25.215" storedBy="Anders" displayName="Type of Case"
     created="2020-05-13T12:54:25.215" valueType="TEXT" attribute="hUvDUjcFmFB" value="Human"/>
     <attribute lastUpdated="2020-05-13T12:54:25.225" storedBy="Anders" displayName="Local Case ID"
     created="2020-05-13T12:54:25.225" valueType="TEXT" attribute="JgbTeRB321X" value="u1wu1we"/>
     <attribute lastUpdated="2020-05-13T12:54:25.236" storedBy="Anders" displayName="Notifiable
     Disease/Condition" created="2020-05-13T12:54:25.236" valueType="TEXT" attribute="rpkGPScBEus"
     value="DT141"/>
     <attribute lastUpdated="2020-05-13T12:54:25.242" storedBy="Anders" displayName="Action Taken"
     created="2020-05-13T12:54:25.242" valueType="TEXT" attribute="Rx2fEI9zDJ3" value="Specimen
     collected"/>
     <attribute lastUpdated="2020-05-13T12:54:25.230" storedBy="Anders" displayName="Gender"
     created="2020-05-13T12:54:25.230" valueType="TEXT" attribute="Rq4qM2wKYFL" value="Male"/>
   </attributes>
 </trackedEntityInstance>
```


Figure 6-2: Simulated patient registered to the eIDSR DHIS2 API, through the eIDSR Sample Tracker application prototype.

6.3.4 Changes to the underlying system

Since the eIDSR Sample Tracker application prototype is built to communicate directly with the DHIS2 eIDSR Tracker Capture application, sending data to the API by using UIDs, issues can arise from changes made to this underlying system. On several occasions during development, changes to the eIDSR form fields made by HISP Uganda meant the same changes had to be implemented in the eIDSR Sample Tracker application prototype to avoid compatibility issues. Ideas for how to implement a system to handle part of this maintenance work is presented in section 8.8.

7 Empirical findings

System development does not happen in a vacuum, and understanding the context in which a digital health initiative is developed is necessary for successful implementation (Heeks, 2002; Mars & Scott, 2010; USAID, 2015).

This chapter will start by introducing the infrastructural-, social-, and systemic context that a Ugandan mobile-based sample tracking application must take into consideration, before detailing the current CPHL-implemented sample tracking process. Finally, this chapter details the finds and observations from user testing of the eIDSR Sample Tracker application prototype, and the changes made to the application as part of that process.

7.1 Digital infrastructure

While wired internet is available in a few select locations in Uganda, mainly in Kampala, the de facto way of accessing internet in Uganda is through wireless mobile internet. Mobile WiFi hotspot routers, commonly referred to as MiFi, are ubiquitous, and widely used for internet access both privately and professionally. 4G and 3G coverage in the country is extensive, but incomplete, with coverage-, stability- and speed issues more common in rural or remote areas. Data is expensive, especially compared to local wages, with one GB of internet priced at about 10,000 Ugandan Shillings (approximately 25 Norwegian kroner or 2.6 US dollars), though varying based on expiry date and quantity. The Ugandan government introduced a social media tax in 2018 which is required for access to all types of social media, including Facebook and the widely used WhatsApp messaging service.

Only a minority of Ugandans have electricity in their homes. Power outages and -surges are common, and in wealthy communities, larger businesses, and institutions, grid power is commonly supplemented by private diesel generators, and fragile electronic equipment is protected by UPS boxes. Generators and fuel are expensive, prohibiting most private households from having backup power.

Most health facilities below hospital levels are either not connected to the internet at all, or have insufficient digital access. Most lower level health facilities have no digital devices, depending on paper-based solutions. One health facility I visited had a stationary computer that had not been used for months, due to lack of trained personnel and internet access. The District Health Focal Person at Arua Regional Referral Hospital did not have internet access at the time of our first field visit to the region, expressing ignorance as to why, but suggesting that the arrangement with an NGO partner for internet could have expired. Koboko Hospital had internet provided by IDI, but claimed they always ran out before the month was over, sometimes being offline for weeks at a time. Even when there is an internet connection it can be slow or unresponsive, especially during peak hours in the afternoon.

Because of the underdeveloped digital infrastructure, the general practice around health reporting in Uganda is still built around paper-based forms delivered from health facilities to

district hubs, where they are manually typed into a HIS. This process is a major source of errors. During my field work I witnessed errors, approximations, and guesswork, during both the paper reporting stage, and the digitization stage.

7.2 Personnel and human resources

Many health facilities reported understaffing, high staff turnover rate, inadequate renumeration, and lack of training as major issues affecting the quality of health care in Uganda. Employees at several health facilities regularly fail to appear at work, compounding the problem of understaffing, and leading to situations where tasks are often performed by overworked substitutes. Multiple health clinic staff members I talked to expressed frustration about the number of reporting forms they had to fill out with limited time available. Some admitted to either not understanding all the fields in the form, or making up rough numbers to speed up the form filling process. At nearly every facility I visited, arranged interview subjects failed to appear at work, a tendency my HISP Uganda colleagues were aware of and took precautions to make sure we had backup subjects.

Skill and proficiency varied a lot between health facilities, with a clear tendency of higher education and expertise at higher administrative levels. While most health sector employees I encountered in my field visits were trained, skilled and professional, at lower administrative levels, especially in rural areas, some employees displayed signs of poor literacy or numeracy, or insufficient work training. One particular employee in charge of ordering ARV medicine and equipment at a health clinic, struggled with basic arithmetic, leading to persistently erroneous orders. Multiple subjects made mistakes when filling in various forms. Most Ugandans have good commandment of the English language, although English language skills are generally a lot higher in urban areas than in rural areas. A small number of health workers I encountered had only a rudimentary understanding of English.

Digital literacy seemingly often depended on the education and training of the individual user, with a large number of health facility employees having very limited exposure to digital technology. Very few people had access to a computer outside of their working environment. Mobile phones are ubiquitous, but smart phones are a bit scarcer, reflecting their relative cost.

7.3 IDSR and Disease Surveillance

There was a broad consensus among the interview subjects that Uganda in general, and the West Nile region in particular, is not adequately prepared for disease outbreaks. The District Surveillance Focal Person (DSFP) for West Nile at the Arua Referral Hospital said the district lacks capacity for diagnosis, treatment, and investigation. Staff members at Infectious Diseases Institute (IDI) noted that response time on outbreaks is poor, and active surveillance and information sharing between stakeholders needs to improve. The Public Health Officer (PHO) at UNHCR in West Nile felt the NGOs in the area were reasonably well prepared for outbreaks, but explained that Uganda and West Nile lacks an existing health infrastructure to screen,

diagnose and treat the refugees in the area, and that there is a lack of coordination during outbreaks. This lack of preparedness and coordination was repeated by a Clinical Officer at Doctors Without Borders (MSF) in Arua, who also added that the district hospital does not have space or infrastructure for isolating contagious patients.

Reporting and diagnosing of Notifiable Diseases (ND) is inconsistent and unreliable, and often relies on NGOs to do active investigative work. The Public Health Officer at UNHCR stressed the need for ND symptoms to be picked up and reported earlier and more reliably. This sentiment is echoed by the IDI representatives I spoke to, claiming that the health facilities in the area severely underreport or fail to notice cases of ND symptoms. Health facility workers are instructed to report suspected cases of ND through sending a specifically formatted SMS to 6767.

The Clinical Officer at MSF listed lack of reporting on ND from health facilities as the biggest challenge facing DS/OR in the region, adding that several recent outbreaks have gone unnoticed until picked up by NGOs, including an ongoing anthrax outbreak that emerged more than a year ago, and a recent malaria epidemic. These were both discovered by partners (MSF and UNHCR respectively) through data analysis or investigation, but should have been picked up earlier.

Lack of commodities, especially Personal Protective Equipment (PPE), was repeated by nearly every interview subject as a major issue. The DHFP claimed they had only "hours" worth of PPE in case of an outbreak, the MSF representatives said there is very little commodities in stock in the region, while two Lab Managers at Koboko Hospital claimed they were systematically given too little PPE and commodities needed to gather samples, adding that this affected their ability to do collection and preliminary testing on biological samples in cases where a ND is suspected. The District Health Officer (DHO) in Arua noted that there was some initial stock of commodities available for a first response to an outbreak, but once these are depleted, they would often rely on partners for additional commodities as the MOH rarely delivered additional stock. The Public Health Officer at UNHCR concurred that the district does not have sufficient PPE. He explained that following protocol and taking the necessary precautions when handling suspected ND cases consumed a lot of commodities, exemplified with a recent tuberculosis patient who died exhibiting Ebola-like symptoms. The lab results for Ebola were eventually negative, but until this was confirmed, a lot of PPE was needed to secure against possible spread of infection.

Some confusion exists over the existence and validity of emergency response plans in the West Nile region. IDI and MDF believed no emergency preparedness plan existed, while UNHCR, the DSFP and the DHO and confirmed that it did, but they all expressed concerns that this plan did not automatically trigger additional funding or a concrete response from the government, thus rendering it largely useless. The UNHCR PHO noted that a plan without an accompanying budget cause inadequate response from the district authorities. The DSFP claimed the existing response plan required the MOH to respond to outbreaks, but this protocol was not followed. The UNHCR PHO in turn claimed that the MOH and the local government disagree on who is

responsible for handling outbreaks, with the MOH calling for the district to supervise the situation themselves, while the districts look to the MOH to take charge.

Both the District Health Officer and the District Surveillance Focal Person in Arua said they were rarely allocated additional funding, non-medicine commodities and resources from the MOH during outbreaks. The DHO estimated that he received the medicines he needed to handle outbreaks from the MOH about 70% of the time, and the rest of the time he relied on the various NGOs and partners.

According to the DHO, the biggest DS and OR challenge in the West Nile region is logistics. Large distances and poor infrastructure hinder effective transportation of personnel, commodities, and samples. The lab managers at Koboko Hospital confirmed that transportation of samples for testing in Kampala labs is an issue, and that they have used public transportation for sample transportation at least twice. They estimated that he processes of taking samples from a patient with ND symptoms, transporting them safely to a central lab in Kampala for testing and getting a result back could take anywhere from one to five days. The IDI representatives told me sample collection and testing take at least 72 hours at present, sometimes more. Noting that timeliness is important, both to preserve sample quality and to provide adequate outbreak response, they stated 24 hours as a target timeframe. The IDI representatives explained that dangerous samples are "triple packed" – three layers of packaging – for safety and transportation is done by a courier experienced in handling biological specimens.

7.4 Integration

The varying NGOs and partners operating in Uganda use their own Health Information Systems (HIS), most of which are not fully interoperable with the government HIS. UNHCR stated the governmental HIS did not support the granularity they needed for their work, and reported being happy with their own HIS, except the lack of integration with the governmental HIS, causing double registration. Similarly, MSF used their own ePol system, which was not integrated with the government HIS. Dataflow between them and the government happened through e-mails and written reports.

Uganda's Central Public Health Laboratories (CPHL), although governmental, recently implemented ALIS (African Laboratory Information System) as their Laboratory Information Management System (LIMS). ALIS is not natively interoperable with DHIS2, and efforts are currently underway to develop a system for brokering data between the two systems. At the time of my research, this effort was underdeveloped, and interoperability was limited.

DHIS2 is used by most public MOH-related health institutions, but data reporting into the system suffers from the lack of digital infrastructure in the vast majority of Ugandan health facilities. Reporting at facility level is generally conducted on paper, before being digitized centrally in each region.

7.4.1 The CPHL sample tracking application

Unbeknownst to me when I started developing the eIDSR Sample Tracker application prototype, there was a simultaneous development process happening where CPHL were developing their own mobile-based sample tracking solution. This process had begun roughly six months before I started my development, and HISP Uganda's wish for a DHIS2-native sample tracking application emerged from the difficulties of integrating the CPHL sample tracking application and data repository with their own DHIS2-based systems, covering their data requirements.

The CPHL system for tracking samples, and the associated routines and changes to workflow, has been implemented in the West Nile district. The application is based on scanning QR codes mounted on the walls at health facilities and then scanning barcodes on the packaging of the samples being registered, sending this data to CPHLs LMIS, ALIS.

This system has significant overlap with the eIDSR Sample Tracker application, although crucially, CPHL's application is not well integrated with Uganda's DHIS2 system. While efforts to exchange data between ALIS and DHIS2 is underway, a fundamental challenge in integration between the CPHL Sample Tracker and the DHIS2 eIDSR Sample Tracker Android applications, is the disparity in data intended to be collected, as well as the eIDSR requirement of tracked samples being linked to patients.

The CPHL application is only concerned with tracking the sample as it is transported from point of origin, via the district hub, to CPHL, requiring only location (through scanning the wall-mounted QR-code), scanning barcode on sample packaging, and type of sample. eIDSR, on the other hand, puts the sample into a larger context, requiring information on the patient before registering tracking events, and prompting the user for more details on the tracking events (see section 5.2). Because eIDSR requires sample events to be attached to a patent/case, the efforts made by the CPHL and HISP Uganda teams to send data captured by the CPHL application to DHIS2 are only successful if the case and patient is already registered in the system before a sample tracking event is registered, which is rarely the case.

The CPHL application is implemented and piloted in certain regions in Uganda, including the West Nile region, where I visited twice during my field work (see Table 2).

7.4.2 Observing the CPHL sample tracking process in Arua

In the pilot project in the West Nile region, the process of collecting and registering samples with the CPHL sample tracking application, before transporting them to CPHL in Kampala, worked like described below, based on my observations and interviews.

Arua Regional Referral Hospital employs 3 motorcycle riding Hub Riders who drives routes through the region, each visiting approximately 8-12 health facilities each day. Workdays for Hub Riders during my observations lasted around 10-11 hours. Hub Riders are not health personnel and have no medical background, but have been trained to handle medical samples.

These Hub Riders and other stakeholders in the region have been issued Android devices with MTN internet by CPHL.

Figure 7-1: A Hub Rider scans the wall-mounted QR-code at Kuluva Hospital

Upon reaching a facility, a Hub Rider will use the CPHL sample tracker app to scan a printed QR code mounted on the wall. This QR code contains a simple numerical value that works as a location ID, corresponding to the given facility. Following a successful scan, the application asks for the user to log in, identifying the user, and customizing the actions available based on his or her role. The Hub Rider will then pack any samples for collected in that facility in envelopes and apply a sticker with a CPHL barcode to the envelope. These barcodes are then scanned with the CPHL sample tracker application and classified according to sample type, marking these samples as collected in CPHLs Sample Tracker Dashboard. The Hub Rider then fills out some paperwork to confirm that he has collected the samples, and marks the envelopes with sample type and origin for his own reference. Aside from three or four diseases that share one generic form, each sample type has its own distinct paper form to fill out. Some of this work is supposed to be completed by health workers at the facility before the samples are collected, although the responsibility frequently falls to the Hub Riders. Finally, before the Hub Rider leaves the facility, he scans the facility QR-code once more to log out before he departs for the next location.

The number of samples to be collected from each facility varies from day to day, but according to the Hub Riders I spoke to, it is not unusual for larger health facilities to have upwards of ten samples for collection. Smaller facilities will usually have fewer or none at all. I followed the process on two subsequent days, and in both instances, the Hub Rider returned to the hub in the afternoon with around 30 samples, which I was told was a representative amount unless there is an epidemic outbreak, which will cause the number of samples to skyrocket, greatly increasing the workload.

The Hub Rider is also tasked with delivering paper-based lab results to the facilities on this route. These are registered at the facility by the Hub Riders scanning the QR code on the wall again, identifying his location, and then scanning a QR code printed om the result papers. The Hub Rider will then travel to the next health facility on his route by motorbike, following the same pattern at each stop. He is required to log into every health facility on the route, regardless of whether they have samples for collection or not.

The hub riders reported the occasional need to take long detours during their routes to find reliable internet connection when working in the more remote areas of the region, in order to send the data to the CPHL server.

At the end of the route, the Hub Rider returns to the Arua Regional Referral Hospital laboratory hub to deliver the samples collected. Here he will scan the lab QR code identifying his location, and then proceed to scan the barcode on all samples collected to mark them as "delivered to hub" in the system. In addition to this, there is some simple paperwork to fill out.

After a sample has been delivered, it must also be marked as *received* at the hub in the CPHL system. This is usually done by the resident Hub Coordinator, although other personnel sometimes fill in if the Hub Coordinator is preoccupied. I witnessed this a Hub Rider filling in for the Hub Coordinator for sample reception during one of the evenings where I was observing the sample tracking process. Because receiving requires special privileges in the application, the Hub Rider filling in for the Hub Coordinator when receiving the samples used the personal login details of the Hub Coordinator.

Receiving the samples means first scanning the wall mounted hub QR code, then scanning each sample while checking that the number and types of samples correspond to what had been delivered by the Hub Rider. After *receiving*, the Hub Coordinator – or the person filling in for him - will scan the samples one final time as he packages them in one or more batches, *referring* them to CPHL and marking the batches as ready to be collected and transported to Kampala. Transport happens on Wednesday and Friday early mornings, usually around 5.30. Dry samples will be packaged in envelopes, wet samples like blood plasma are packed in cold storage boxes. Most of the samples collected will be dry samples, as frequent power outages and budget constraints limits health facilities ability to refrigerate and store liquid samples.

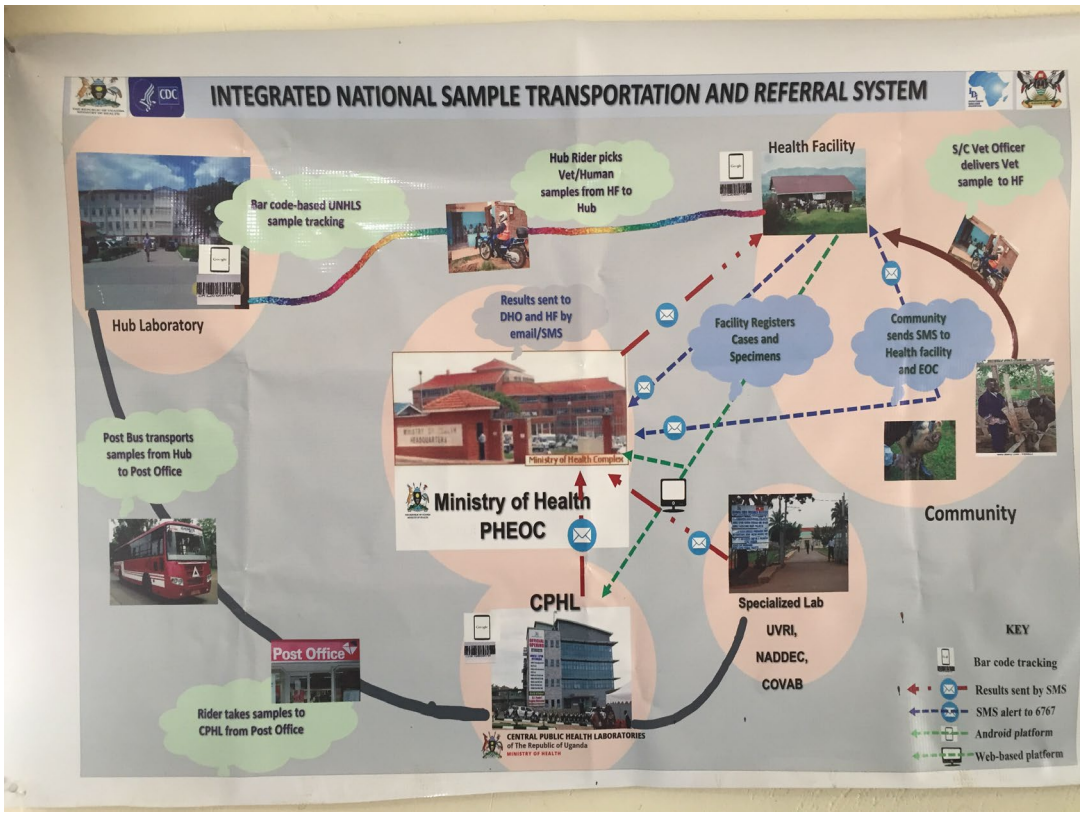

Figure 7-2: Chart in the Arua Regional Referral Hospital laboratory explaining how samples are collected and transported in the region

During my observations, the process of delivering, receiving, and referring samples was prolonged significantly by two factors: low bandwidth internet during peak internet usage hours in the late afternoon and poor light conditions due to fading daylight and inadequate interior lightning. Scanning each sample in the afternoon took a great deal of time because the light-sensitive cameras on lower-end Android devices like the ones used for the CPHL sample tracking application struggled to read the barcodes in low light conditions.

The barcodes on the samples are only used for tracking, and are discarded when the samples reach CPHL. The patient and sample are given multiple identification numbers that are subsequently used to link the lab results to the correct patient. The patient is given an *Inpatient Number* at the health facility he or she visited, as well as an *Outpatient Department Number*, the sample has a *lab number* that is used in the Lab Information Management System (LIMS), and an *Investigation Form Number*, which is the primary ID number used to link patient and sample. The patient is also registered with personal information like name, age, and address, to facilitate identification. Uganda's lack of national ID numbers or social security numbers means tracking the same patient across multiple unrelated health incidents is usually not achieved.

Samples delivered to the regional hub are subsequently packed collectively in batch envelopes, with a new bar code on the batch envelope now referring to all contained samples, rather than individual bar codes. This means registering this new batch bar code to all relevant events is necessary to allow tracking the samples from district hub to national laboratory.

Laboratory results are usually delivered by e-mail to the hub, from where they will inform the relevant health facility. In cases of confirmed cases of Notifiable Diseases, the local Disease Surveillance Focal Person and Uganda's Infectious Diseases Institute (IDI) will be alerted, who will coordinate with the District Health Office, Ministry of Health and NGOs to coordinate a response.

The Arua Regional Veterinary Laboratory employs Veterinary Officers whose job it is to collect samples from animals in the region if they receive reports of dead or sick animals. Some animal samples can be tested at his laboratory, others are sent to CPHL via the Arua Regional Referral Hospital Hub in the same way as samples collected from humans.

Before the CPHL sample tracking application pilot, samples from the region would be transported by the postal services. Postal workers had received training in handling potentially dangerous samples and transporting them to Kampala, usually by bus. This process was unreliable, and sometimes unsafe.

The Hub Riders and other stakeholders associated with sample collection and reporting, informed me that the CPHL application has suffered from a number of technical issues, and CPHL staff visited Arua the week before my last field trip to the region to troubleshoot. Although they were unable to clarify the exact nature of these issues, they seemed to be related to server communication issues or scanning failures. At higher administrative levels, the major recurring complaint about the CPHL sample tracking system was the lack of integration with Uganda's DHIS2-based data warehouses, leading to a lack of information on samples among non-CPHL stakeholders.

Figure 7-3: Demonstration of sample reception at CPHL, Kampala

All samples collected throughout Uganda that are not testable in local laboratories, are processed by CPHL in Kampala. Delivery of samples from all over the country happens every Wednesday and Friday. Barcodes are only attached to sample packages from areas where the CPHL pilot is ongoing, but where they are, the packages are scanned twice at arrival, marking them as delivered by transporter, and received by CPHL. This ends the tracking process, and further event relating to the samples are identified using date-based, lab-specific ID codes and the inpatient number of the patient, in addition to the name of the health facility of origin. Lab results are generally conveyed to regional hubs, who then distributes the results to the

appropriate health facilities. In cases where the results show positive for a Notifiable Disease, the relevant authorities are alerted, and containment procedures are initiated.

7.5 User testing of the eIDSR Sample Tracker Application Prototype

Uganda's eIDSR system demands more information on each sample and patient than the CPHL sample tracking application, meaning there are more form fields to be filled out in the prototype eIDSR Sample Tracker application than the CPHL app. eIDSR also requires a patient case to be registered in the DHIS2 system before events can be registered to a sample (see section 5.2.1), meaning the application will often prompt the Hub Rider for additional information on the patient before he can register the sample as collected. These additional steps confused our Hub Rider participants, who stated the CPHL application felt less complicated and time consuming to use.

The users were also confused by the design of the application. Using multiple drop-down boxes on a single page in order to group relevant information was unfamiliar to the users, and having the caption for the form field displayed above the drop down box itself made the users mistake the *caption* for a *button* they were supposed to press. This was exacerbated by the clean white-on-white design of the prototype application, further complicating what was a button to be pressed and what was simply text. The only standout feature on each page was the blue "submit"-button, which clearly labelled it as an actionable feature on each page. The users felt unsure of when to press "Submit", and frequently tried to push it before all information was entered in the form fields.

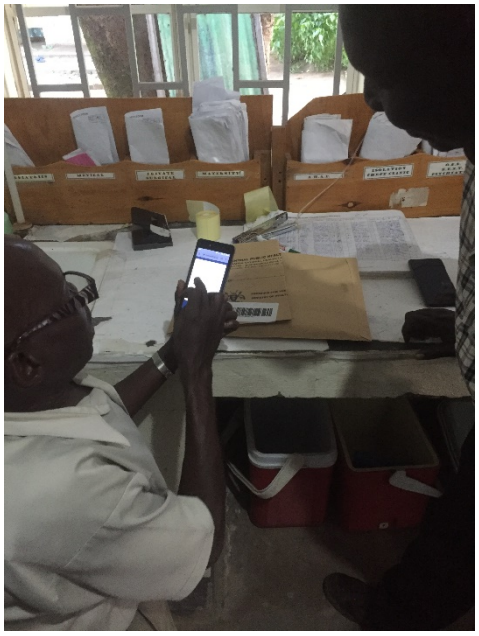

Figure 7-4: User testing the prototype eIDSR Sample Tracker application in the Arua Regional Referral Hospital Laboratory

The terminology of some of the fields were confusing to the Hub Riders and Hub Coordinator, with multiple readthroughs of all options required before settling on the one they felt was correct. Similarly, the field for "Type of Transport" lists multiple possible modes of transportation, including both "motorcycle" and "bicycle", which the Hub Rider treated as interchangeable terms. The colloquial term for motorcycle in Uganda is "boda boda". The "Condition" field lists multiple seemingly overlapping choices, including "bad condition", "damaged" and "inadequate", and the "Destination" field would always be "CPHL", since all samples are processed through them in Kampala.

The field for "Notifiable Disease/Condition" contains 74 options to choose from, resulting in a lot of scrolling to find the correct disease which delayed the process.

Furthermore, the participants repeatedly tried to scan the barcodes holding the device horizontally relative to the barcode. This was how the CPHL application was designed, and thus how they were trained to scan. The prototype eIDSR Sample Tracker application requires the phone to be held in a vertical position relative to a barcode to successfully scan, which the users had to be told after spending time unsuccessfully trying to scan from a horizontal position. Also, in the dim interior light after sunset, the Android devices sometimes struggled to capture the barcode with the camera, taking much longer than the near-instantaneous scans observed during daylight testing. This was true for both the eIDSR Sample Tracker application prototype and the CPHL application, meaning it is likely a consequence of light sensitivity of cameras on cheaper Android models, rather than the implementation of the software.

Both the Hub Riders and the Hub Coordinator sated that they would prefer a step-by-step system rather than multiple form fields grouped into one page.

In cases of slow internet connection, the prototype application spent a lot of time stuck on the loading screen while sending and receiving data, to the visible dismay of the users.

After identifying these problems on the first day of the second field trip to West Nile, I arranged a meeting with the two HISP representatives that accompanied me on my field work, and the Arua District Surveillance Focal Person in the afternoon in the Arua Referral Hospital premises, where we planned a series of changes to the prototype. These changes were then implemented during the evening, so they could be tested and evaluated the next day.

7.5.1 Interface modifications made during field work in West Nile

To improve workflow, limit mistakes and reduce the amount of time spent registering samples, the following changes were implemented to the prototype:

Changed the background color of the application to a medium dark blue, the same used in the DHIS2 design (#215e8c). Also changed the text color to white, and added a DHIS2 logo at the top of the page, replacing the somewhat unintelligible “eIDSR Scanner” headline. The color change was intended to improve clarity of what was background and what was user editable content.

Moved field captions from above the field to inside the field, making sure it was obvious were the user should click.

Changed the wording of the “Specimen Tracking Action” options to better correspond to the actual steps the sample goes through. The options in the revised version were as follows: “Picked from Health Facility”, “Delivered to hub”, “Received at hub”, “Picked from hub”, “In transit” and “Delivered to National Lab”. I chose to keep the Ugandan colloquialism “picked” as a synonym for collected in an effort to keep the options unambiguous for Ugandan users.

Removed “Destination” as a field in the application, and hardcoded the value sent to DHIS2 to “CPHL”. Since all samples pass through CPHL, this was superfluous to ask as a user input.

Removed “Damaged”, “Lost” and “Inadequate” from the “Status of Specimen” field, as these confused the Hub Riders and the Hub Coordinator, leaving only “Good Condition” and “Bad Condition” as options. “Damaged” is interchangeable with “Bad Condition”, “Inadequate” is only applicable for lab personnel, and since you cannot register a sample without scanning its barcode, “Lost” is redundant.

Removed “Classification of Disease/Event” field, and hardcoded the value to "Specimen collected", as this is the only scenario where this application will be used.

Removed the “Status of specimen” field entirely, hard coding it to “Good Condition” if the “Specimen Action” is set to “Picked from Facility” (collected), as status of the specimen before transportation has begun is redundant.

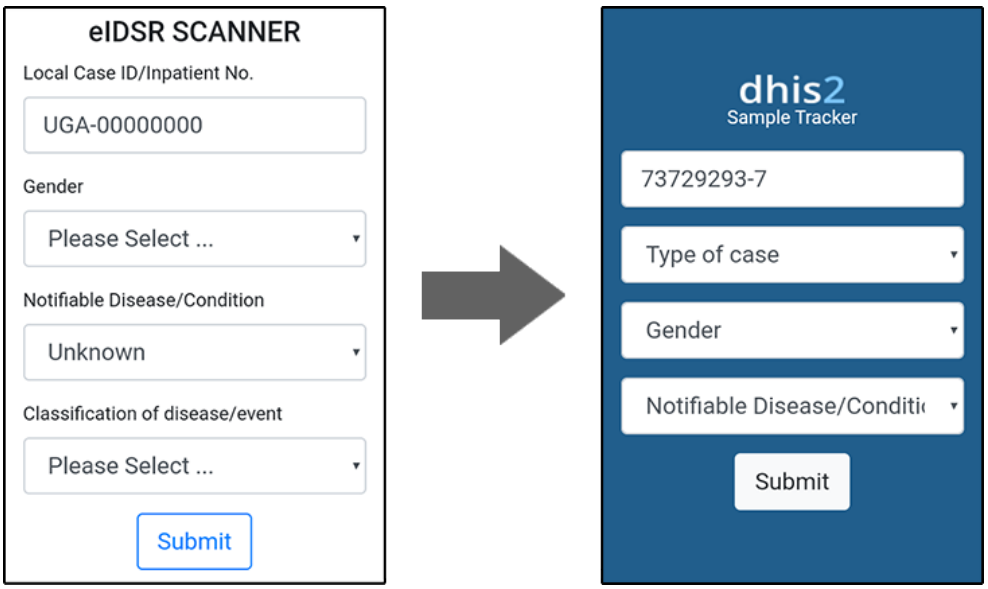

Figure 7-5: Example of design change following user testing

The updated application tested much better with the users and sped up the process of scanning and registering considerably. However, the participants expressed that they still felt the application was complex, due to the amount of information needed, and the application requiring multiple information inputs per page.

7.6 Further interface evaluation

By applying the concept of Nielsen’s (1994) Heuristic Evaluation to the interface, I identified several areas where the interface diverged from the set of heuristic principles, adding to the list of future additions to the interface. These principles, as described in section 3.2.2, and how they relate to the eIDSR Sample Tracker application prototype, are as follows:

1 - Visibility of system status: While the application would seamlessly move between offline and online mode, ideally leaving the user unconcerned about connection status for shorter periods of missing internet access, the application does not currently include a visual indicator on whether the DHIS2 server can be reached.

2 - Match between system and the real world: User feedback suggests that the efforts made to clarify language and inputs, as well as using instances of local colloquialisms like “picked”, have been at least moderately successful.

3 - User control and freedom: The application does not include a back-button allowing users to correct previously entered information, nor does it include a cancel button as an “emergency exit”.

4 - Consistency and standards: The application follows established external conventions for design and layout, and is internally consistent in terms of colors and symbols. The design has been brought more in line with established DHIS2 design through use of the DHIS2 blue color and the DHIS2 logo, although further work could be done in terms of aligning remaining elements like forms and fonts.

5 – Error prevention: A lot of effort has been put into designing an application that attempts to solve errors behind the scenes, including the proposed offline functionality, and repeated retries to communicate with the server on failure, hidden behind the loading spinner. Since many potential users of the application cannot be expected to have a high degree of digital competence, preventing errors is a strong prerequisite for this application.

6 – Recognition rather than recall: Users are not forced to memorize information from one page in the application to another.

7 – Flexibility and efficiency of use: The application does not offer any particular accelerators for expert users, nor does it offer tailoring the experience to specific users. This is partly due to the narrow and precise use case and workflow of the application, but the principle should still be kept in mind during proposed future development, especially if a redesign of the workflow is implemented to cater to users with lacking digital literacy, to still accommodate expert users.

8 – Aesthetic and minimalist design: The design of the application has been kept as clean and simple as possible through the design process, displaying only the relevant information to the user. This includes hiding redundant form fields based on input in other fields, like removing the field for vehicle registration number if the type of vehicle is a bike. Future additions to the application based on these heuristic principles could complicate the design through the inclusion of additional elements, necessitating continual consideration of this principle.

9 – Help users recognize, diagnose, and recover from errors: The most probable source of errors in the application, and indeed the only system errors encountered during fairly extensive testing of the application, comes from complications during the communication with the DHIS2 server, for instance due to a sudden loss of internet access, or DHIS2 server complications. While robust offline storage functionality should minimize the frequency of such errors, the application does still include error messages should these measures fail, although suggestions for recovery are limited to “try again later”.

10 – Help and documentation: While the interface should be intuitive enough to not warrant extensive documentation for the users, the application should provide some measure of in-app help or guidance for the user. This is not currently implemented in the application.

By compiling the findings from the field work with the missing or lacking elements from the heuristic evaluation, I compiled a list of intended changes to the user interface, that could be user tested in a future iteration of the application. These changes, alongside proposed technical and structural changes, are presented in section 8.10.

7.7 Policies and access to working on HIS-related projects

During my research, I encountered multiple instances of lack of access impeding my work, one of which would prove insurmountable to further progress on my thesis, prompting a revision of area of inquiry from Antiretroviral (ARV) commodity ordering to IDSR sample tracking.

My original work on ARV was aborted after more than six months of field work and preliminary development, when it was made clear to me from the MOH-hired developer working on the project, that I would not be allowed to do actual development on the DHIS2 ARV forms or have access to the MOH DHIS2 ARV instance. This, I was told, was because the DHIS2 ARV system was a MOH product, not a HISP Uganda product, although it remains unclear whether it was official MOH policy to deny access, or simply lack of interest from the MOH-hired developer to work with a foreign student.

Initial negotiations resulted in a permission to design a wireframe user interface (UI) for the ARV commodity ordering system that could then be handled over to the developers of the system. However, with no hands-on testing possibilities, no direct access to the DHIS2 ARV instance, and a perceived small chance of my suggested UI being implemented by the developers, this idea was discarded in favor of starting over with a project with which HISP Uganda had greater autonomy, eventually landing on IDSR and specimen tracking.

As detailed in section 5.3, my initial broad access to working on a sample tracking application for the eIDSR program was gradually eroded as complications arose around the development of a similar application by CPHL that I was not made aware of until my development process was well under way. For fears of my project being shut down, HISP Uganda asked me to keep a low profile on my development and research, avoiding unwanted attention. This placed a few restrictions on my work, notably limiting my field work to be conducted in western Uganda, where I could conduct field visits without explicit approval from the MOH due to HISP Uganda's involvement in the ongoing IDSR pilot studies in the area. I was eventually able to visit CPHL in Kampala to learn about sample reception, but I was not allowed to conduct user testing of the application outside West Nile district. Furthermore, HISP Uganda asked me to migrate my application between DHIS2 instances on multiple occasions, after the MOH started asking questions about why we were generating so much test data.

8 Discussion

In this chapter, the empirical findings from my field work and action research process, as presented in chapter 5, 6 and 7, and the literature presented in chapter 4 will be discussed in light of the research question "How can mobile technology be implemented to support collection and transportation of biological samples in Uganda?"

This chapter also includes reflections on the development process, the technical implementation and the approach, methodology and validity of my research.

8.1 Digital and Mobile Technology in Health-based Initiatives

While it is commonly agreed that mobile and digital technology has a lot of potential to improve data collection in developing countries (Health Metrics Network, 2008; Marcolino et al., 2018; Hall et al., 2014), there is both a lack of quality research on the subject (Walsham, 2017; Thapa & Sæbø, 2014; Heerden et al., 2012), and a high failure rate among mHealth and digital initiatives (WHO, 2018a; Heeks, 2002; Agarwal et al., 2016). To develop digital solutions that are successful, i.e. "in which most stakeholder groups attain their major goals and do not experience significant undesirable outcomes" (Heeks, 2002, p. 102), there are multiple pitfalls presented in the literature that should be avoided. These include lack of interoperability and integration with existing software and systems (WHO, 2018a; Labrique et al., 2013), designing with inadequate participation of local stakeholders (Heeks, 2002; Heerden et al., 2012), building systems without a clear plan for scaling up (WHO 2018a; Agarwal et al., 2016), and failing to understand and account for the technical, infrastructural, political and human context that surrounds the system (Roess, 2017; Mechael, 2010; Mars & Scott, 2010; Heeks, 2002).

Nine principles for successful implementation of mHealth projects are suggested in the *USAID mHealth Compendium* (2015), as presented in section 4.5. These are supported by organizations like UN and The World Bank, and echoes sentiments found throughout the literature on the subject. I will refer to these principles throughout this chapter, as well as other literature on the subject, as I discuss the various aspects of implementation of mobile health solutions in general, and a sample tracker application in Uganda specifically.

8.2 Integration

The socio-technological nature of a country's HIS, means these systems are not built from scratch, but continually evolve as components and sub-systems are added or replaced (Hanseth, 2000). HIS are a complex web of interdependent systems and structures (Braa & Sahay, 2012a), and lack of integration and interoperability between these components is frequently cited as a major impediment to HIS in developing countries, hindering effective collection, distribution, and utilization of data and information (WHO, 2018a). While Uganda's public health sector uses DHIS2 as its main HIS and data warehouse, multiple governmental- and non-governmental organizations have their own HIS tailored to their specific requirements. According to Kiberu et al. (2017), most digital health solutions in Uganda are siloed and donor funded.

Although integration does not necessitate the merging of multiple systems into a single, massive system, the various systems that coexist should strive for coordination and interoperability (Braa & Sahay, 2012a). The level of integration of various HIS in Uganda varies a lot, and many systems are not fully integrated with the Ugandan DHIS2-based HIS. Sharing of data between these systems is frequently done manually or through duplicate reporting. Many participants I spoke to called for increased interoperability and integration between the various HIS and data warehouses in use throughout the country and across organizations.

The lack of integration between CPHL's system for tracking samples and the national eIDSR DHIS2 instance limits MOH-employed stakeholders' access to sample tracking data, and this was brought up by multiple participants as a point of concern.

This dual implementation of systems for tracking medical samples is an example of fragmentation, i.e. lack of integration causing overlapping reporting, increased workload, and, ultimately, lower data quality (Braa & Sahay, 2012a). Chilundo and Arnestad (2004) describes integration as a highly political activity, where multiple actors with competing or differing interests must be aligned to achieve success. In the context of this study, this was reflected in the complexity of the situation regarding the CPHL Sample Tracking application, including the limitations it placed on the development of a DHIS2-native eIDSR Sample Tracker application (see section 7.7). The USAID (2015) principles for successful mHealth implementation state that reusing and improving existing tools, platforms, and frameworks is preferable to creating new, siloed solutions, and urge developers to work in collaboration across silos and disciplines to facilitate integration. Achieving integration in the systems used for sample tracking in Uganda requires not just a technical solution for integrated data flow, but an alignment between the organizational and political actors that are involved. Laying the groundwork for *organizational-political* collaboration is every bit as important as the *syntactic-technical* and *data-semantic* standardization that are fundamental to integration and interoperability (Braa & Sahay, 2012a).

The CPHL sample tracker system is completely separate from the DHIS2 eIDSR sample tracking system, developed independently and tailored to the specific requirements of CPHL. Although there are huge overlaps in data requirements between eIDSR and CHPL, there is only limited interoperability between the systems, leading to a fragmented and siloed approach. Where eIDSR stores data in Uganda's DHIS2 system, used by the government and Ministry of Health, the CPHL sample tracker application records data to their own HMIS called ALIS (African Laboratory Information System).

While attempts have been made by HISP Uganda and CPHL to support interoperability by transferring data from ALIS to DHIS2, these efforts have not been fully successful. One of the big blockers have been the intrinsic requirement in the eIDSR system of connecting data on samples to a *case* (section 5.2), which means eIDSR can only accept data on samples where the *patient case* has already been registered in the system. With only a minority of sample collection scenarios seeing a case registered *before* sample transportation begins, this method for exchanging data is not sufficient, leading to major data gaps in the eIDSR system.

For this reason, the functionality of creating new cases in DHIS2 Tracker through the eIDSR sample tracker application (see section 5.3.4) was lauded by developers and administration at HISP Uganda, as among the most significant innovation in the eIDSR Sample Tracker application prototype, offering a workaround to the problem of events needing to be registered to a patient case in eIDSR.

However, developing, maintaining, and forcing users to report the same data with two separate recording systems and storing the same data in two separate data repositories is not a satisfactory solution, representing a fragmented approach that generates redundant and overlapping reporting, and overburdens the users by requiring users to register samples in two separate applications. A single integrated application, providing data for all stakeholders through a single point of registration, would accordingly be preferable, and the only advisable solution to provide both CPHL and the MOH with adequate and timely data on sample transportation.

An integrated solution would likely entail a more elaborate registration process CPHL has implemented in their system, to fulfill the added data requirements of the Ugandan MOH. Where the CPHL application simply wants to track how many, and what kinds of samples are transported from health facilities to CPHL, the eIDSR Sample Tracker requires a lot of data to be entered on each patient/case and sample handling event. This intrinsic difference in utilization has ramifications for the design of the applications, necessitating a certain added level of complexity in the eIDSR application compared to its CPHL counterpart, which would have to carry over into an integrated version of the system.

However, as detailed in section 7.5, and discussed in detail in section 8.6 below, users found the eIDSR Sample Tracker application prototype to be more complex than the CPHL counterpart, which was partly down to the increased data demand of the eIDSR system, indicating that an integrated solution, while less resource demanding than two separate solutions, would still be a more complex and time-consuming solution than the current CPHL solution, unless MOH data sets are reduced.

8.3 Data Collection

The eIDSR Sample Tracker application prototype is a tool for data collection, intended to feed relevant data into the DHIS2-based data warehouse in Uganda. In one sense, the application can be understood as a digitized paper form – an easier and more immediate way to report data directly to the data warehouse, bypassing the need for time-consuming and error-prone manual entry of paper-based forms into a digital system. However, the convergence of technologies found in mobile devices offers possibilities beyond mere digitization of paper-based workflows (Hall et al., 2014; Labrique et al., 2013), especially in services dependent on timely data.

Real-time tracking of medical samples is not just *aided* by timely data, but wholly dependent on near-real time registration of data to be of any value for stakeholders, and to provide the intended information on sample location and delivery. Subscribing to the notion that

information is not an end in itself, but rather should be used for action (Sauerborn, 2000), the usefulness of the real-time tracking data portion of the information generated by a sample tracking application, diminishes after limited timeframe. Information on the location, type, transportation method, handling personnel, and status of a sample, which allows a laboratory and other stakeholders insight into what samples are expected at what time, is primarily useful during transportation. Secondary, less time-dependent usefulness of this information comes in the form of identifying bottlenecks in transportation, failures in transportation or handling, or other irregularities affecting timeliness and quality of transportation, which in turn can be used by decision makers to allocate resources and improve logistics. By scanning barcodes to automatically identify samples, allowing the capture of device location and other relevant data, and posting data directly to the DHIS2 data warehouse from anywhere, where data can be accessed and visualized in real-time, an Android-based sample tracking application enables usage of data through timeliness that would not be possible through analogue, paper-based reporting.

However, a fundamental problem for the eIDSR Tracker Capture Specimen Handling form is that it demands a lot of information from the user. This is a consequence of the intended function of the application; the eIDSR application intends to feed as much data as possible into a Data Warehouse, associating the event tracking data with various *program stages*, including patient details, lab results, case monitoring, and outbreak reports. The data requirements are mandated from the MOH, which means HISP Uganda, and by extension the development of the eIDSR Sample Tracker application prototype, must adhere to these requirements. There are, however, many non-essential, nice-to-have data input fields in the eIDSR Tracker (see section 5.2), which are not marked as mandatory. The early prototype versions of the eIDSR Sample Tracker application included many such non-mandatory fields to closely match the corresponding eIDSR Tracker Capture Specimen Handling Form, but these were removed after user testing demonstrated excessive time spent filling out these fields, as discussed in section 8.6 below. Through a combination of automatically filling in fields like location, time, date, name and phone number from the Android device, and limiting the options asked for in the forms to the ones marked as mandatory in the eIDSR tracker program, the time spent registering samples by participants was reduced. While this limited the number of fields to the MOH-mandated essential data set, the amount of information required is still substantial and time-consuming to register, especially if the user is required to register a patient in addition to a sample tracking event.

Because patient registration is a prerequisite for registering sample event data in the eIDSR Tracker Capture Specimen Handling Form (section 5.2), an eIDSR Sample Tracker application will by necessity add patient registration to the sample collection routine. As the first link in the sample collection chain, this task will regularly fall on the Hub Riders rather than health workers, raising privacy concerns, and further increasing the workload of staff members who are already tasked with working long hours. Hub Rider workdays in Arua varied in length depending on matters like route, weather, the number of samples to collect, internet connectivity and

traffic, but generally the Hub Riders would start early in the morning, and finish their round in the late afternoon or in the evening. During my field visit to West Nile district, I observed Hub Rider workdays lasting about 10-11 hours. Additional responsibilities and workload in the form of an expanded registration process for Hub Riders could result in requiring more employees to cover the same number of health facilities, increasing resource demand for the project.

In cases where the patient has not been registered in DHIS2 Tracker before the Hub Rider collects the samples, the user is tasked with filling out nine fields of information to complete registration of one single sample, in addition to scanning of the sample barcode: (1) Inpatient ID, (2) Type of Case (human or animal), (3) Gender, (4) Notifiable Disease/Condition, (5) Origin, (6) Specimen Tracking Action, (7) Type of Transport (if specimen is in transit), (8) Vehicle Registration Number (if specimen is in transit, and vehicle is any type but bicycle), and (9) status of specimen. The first five are for registering the patient, the last four for the Specimen Tracking. Multiply these nine questions by the 20-40 samples usually collected on a given day per Hub Rider, and it was clear that the eIDSR Sample Tracker application can significantly prolong the process of collecting samples from health facilities when compared to the CPHL tracker application, which only requires information on location (from wall-mounted QR code) and sample type.

Hub Riders are not trained medical personnel, but rather professional transporters or drivers, tasked with transporting medical samples from health facilities to the regional hub. This lack of medical training limits the information we can ask them to fill into a form regarding a patient. The eIDSR tracker patient registry form contains 20 fields, ranging from simple personalia like name and gender, to medical information like risk factors and symptoms. Keeping the required data on patients to a minimum, omitting fields that require medical expertise, is a prerequisite for using Hub Riders to register patient data.

In addition to the added workload, tasking Hub Riders with registering data on patients raises privacy and data security concerns, as filling out patient information means accessing patient records and sensitive information.

At lower administrative levels of the Ugandan health system, my observations indicated that patient confidentiality and privacy was frequently neglected and overlooked. Forms with patient names and health status were regularly lying around openly, or even used as examples by participants when explaining aspects of their work to me. In several health facilities, stacks of papers with lab results with names and corresponding HIV status were placed openly in areas where I conducted my interviews, or where the Hub Riders were gathering samples for transportation.

Indeed, the Hub Riders in West Nile district were already using forms which included sensitive information on patients to identify specimen types when they retrieved samples from health facilities. This lack of procedure around protecting private health information, means issues of patient privacy cannot be solved by a sample tracking application by itself, but steps should still

be taken to develop an application that address privacy of sensitive information during data collection, as recommended by the USAID mHealth Compendium (2015) and Heerden et al. (2012). Such steps could involve proper encryption of data when sending to the database, using the login credentials of in the application to limit access to patient data depending on user, and limiting the responsibilities of patient registration to appropriate personnel.

One possible solution to relieving Hub Riders of the patient registration burden and maintain a larger measure of privacy, could be to remove the mandatory status of most fields in the patient registration of the underlying eIDSR system, allowing the Hub Rider to register a patient with the inpatient number alone, creating an "empty" patient in DHIS2 tracker. To properly address privacy issues with this approach, health facilities would also need to provide the Hub Riders with inpatient IDs for the samples being collected, without other identifying information on patients. In conjunction with this, an alert system inside DHIS2 could be implemented, where stakeholders like the District Surveillance Focal Person and health workers tasked with registering patients, are prompted to fill in the remaining information on the patient once initial registration has been made by the Hub Rider.

The Arua District Surveillance Focal Person, was enthusiastic about a solution like this, adding that this would improve accountability and help place responsibility on the right stakeholders. Senior HISP Uganda members were more lukewarm to the idea, problematizing the practicality of sending notifications, and fearing the approach would lead to a proliferation of empty patient/case objects. In any event, such a solution would hinge on these alerts being responded to in a timely fashion, and that the information necessary to register these patients were available to the correct stakeholders after an empty patient had been created.

While outside the scope and control of the eIDSR application, performing continual evaluation of the MOH-defined essential data set for sample tracking to make sure all the data collected through the eIDSR programme is relevant and needed for decision-making and action, could help keep data collection manageable, and create a stronger link between data collection and tangible outcomes (Lippeveld & Sauberborn, 2000; Shaw, 2005; Braa & Sahay, 2012a).

8.4 Infrastructure

As detailed in section 4.6: *Underlying infrastructure and prerequisites for ICT initiatives*, having a solid digital infrastructure, including stable power and internet access is essential for delivery of ICT services. Throughout my field work in Uganda, I found issues related to online access to be a recurring issue negatively affecting the Ugandan health sector, limiting the potential of digital health initiatives.

These issued were generally caused by lacking or slow internet connectivity in the area, or device or data affordability issues, like the general data use during peak internet hours in West Nile slowing down sample registration to a crawl (see section 7.5), or the pre-paid internet allowance at a health facility running out weeks before their monthly refill (see section 7.1). Lack of stability and coverage in internet services in Uganda was also the cause of a major structural revision of

the eIDSR Sample Tracker application prototype, as detailed in section 5.3.5, and discussed in section 8.4.1 below. Furthermore, this lack of digital infrastructure affects digital literacy (West, 2015), discussed in section 8.5.

Inadequate digital access across Uganda means a majority of health-based reporting is done on paper forms, before being collected and manually entered into the data warehouse at a higher administrative level. This process is time-consuming and error-prone (Mechael, 2010), and improving digital infrastructure and -access to allow for direct, digital data entry at lower administrative levels could have a positive impact on data quality and timeliness.

While power blackouts and -surges across Uganda are frequent, especially in rural areas, concrete issues relating to Uganda's unstable power grid were less immediately recognizable on my field visits, but had implications for ease of using digital technology, like the need for costly UPS's and diesel generators to provide stable power for stationary computers and other sensitive digital equipment, and protect them from power surges. Bukht and Heeks (2018) also link the lack of stable power to higher prices and lower coverage for telecommunications services in rural areas, due to the added cost associated with the required diesel generator power.

The poor road network in rural Uganda was frequently brought up as a challenge for logistics by participants, affecting the timeliness of transportation, work hours, and increasing maintenance cost of vehicles.

As discussed in section 4.5, failure rates among mHealth and ICT4D projects are high, and most initiatives stagnate after an initial small-scale pilot study (Heeks, 2002; WHO, 2018a; Kiberu et al., 2017). Failure to account for the need to scale up the project after an initial pilot project, is commonly cited as a reason for failure (USAID, 2015; Franz-Vasdeki et al., 2015; Agarwal et al., 2016). Long-term successful digital health initiatives require adequate and relevant infrastructures in place, as well as resources for ongoing, operational costs like manpower, maintenance, telecommunications subscriptions, and training costs (Agarwal et al., 2016), all of which hinges on persistent donor or governmental support.

Unlike the CPHL application, the eIDSR Sample Tracker application prototype is built into the existing DHIS2 ecosystem in Uganda, integrating the data collection process with the country's data warehouse, thus building on part of the existing framework already in place, as recommended by the USAID mHealth Compendium (2015). However, while the CPHL application created obstacles for my research in the form of limiting my access to stakeholders and field work opportunities (section 7.7), the infrastructure, support structures and material put in place by CPHL for their sample tracking system corresponded with reasonable requirements for a fully functional and upscaled eIDSR Sample Tracker solution; a mobilization of resources way beyond the scope of this study. CPHL had already established routines for collecting and registering samples, recruited and trained personnel, and distributed Android devices and motorcycles to stakeholders.

This demonstrates how successful adoption of a mobile-based sample tracking system in a country, requires more than a robust software application and a solid infrastructural and human resource foundation. Many projects will have a set of specific preconditions in the form of specialized training, equipment, and routines, and failure to account for the long-term support and financing for these prerequisites during initial pilot projects is likely a contributing factor to the rate of sustainability failures in digital health initiatives documented by Heeks (2002) and WHO (2018a).

The infrastructure and put in place by CPHL for sample tracking could likely serve as a foundation for an integrated solution for sample tracking, serving both CPHL's ALIS data warehouse, and the MOH DHIS2 data warehouse, including using their QR code system for health facility identification.

8.4.1 Accounting for insufficient internet access

While the prototype application tested near-flawlessly when attempting to send and receive data to and from the MOH eIDSR DHIS2 instance during my field visits, multiple stakeholders and participants stressed the importance of accounting for loss of internet access.

With much of rural Uganda experiencing inadequate or unstable internet connections, developing robust offline functionality for the application is essential to assure timeliness and completeness of reporting. Taking this into account, a major and vital offline functionality overhaul of the eIDSR Sample Tracker application prototype is detailed in section 5.3.5 and visualized in Figure 5-16.

This solution would allow the user to scan and register tracking information on a sample even when no internet connection is available, by storing the information locally on the device until internet access is restored. The necessary tradeoff, is that the system then needs to assume that no prior information has been registered about the sample and the patient and case it belongs to, prompting the user for all potentially needed information, including information that might have been collected previously. While this represents a presumed increase of workload for the users, it is likely a reasonable compromise to make, provided my observations and participant feedback that mobile internet is available at most health clinics, is correct. Issues might still be compounded if the device remains offline for a significant period of time, which would slow down all reporting on samples due to the additional information required in offline mode.

Handling *slow* internet connection is a slightly different prospect from handling a *nonexistent* internet connection, in that lagging communication with the server directly affects the responsiveness of the application. I witnessed frustration among my participants as they were testing the application during peak internet hours in the afternoon in Arua, where internet speeds had slowed to a crawl, and the users had to wait for upwards of 20 seconds between filling out he various form pages in the application. The inclusion of a loading spinner (Figure 5-12) seemingly helped ensure the participants that the system had not stopped working, but steps should be taken to ensure waiting times are manageable.

One alternative is for the offline mode to be triggered not just by a lack of internet access, but also at a certain threshold when loading times are deemed too protracted. Keeping in mind that offline mode would frequently prompt the user for more information than in online mode, but loading times between form field pages would be eliminated, two approaches could conceivably be used for setting this threshold, either effectiveness or satisfaction, as distinguished in Frøkjær et al. (2000):

At what point does it take longer for the user to wait for server communication than it would if the application were in offline mode?

Or:

At what point does the user report being more frustrated by excessive loading times than by additional form fields to fill out in offline mode?

Although both alternatives have elements of quantitative research, in that they call for a value for a threshold, the first approach represents a measurement of the effectiveness of the application, and perhaps a positivistic approach to system design, while the second alternative represents accessing the perspective of the user, and is perhaps more relevant for this *interpretive study*.

Arguably, both effectiveness and satisfaction are relevant for the eIDSR Sample Tracker application prototype. An effective application means a smaller workload burden on the users, who, as discussed in section 7.4.2, were already working long hours to complete their tasks. Workload has been linked to correctness of reporting and data quality (Braa & Sahay, 2012a; Chilundo & Arnestad, 2004). Meanwhile, satisfaction is linked to system adoption rates (Davis et al., 1989). As described in Jeng (2005), there is a correlation between effectiveness and satisfaction, meaning these dimensions cannot be looked at in isolation.

During my field work, the participants were exposed to both (simulated) offline reporting, and (real) slowness of internet connection, with both situations leading to visible and expressed dissatisfaction. Interestingly, the object of dismay was different between the two situations, with the participants complaining about the application itself when faced with excessive reporting, but bemoaning the lacking digital infrastructure in the region when encountering long loading times due to slow internet connection, perhaps signaling some measure of acceptance of the perceived inevitability of poor digital infrastructure in the region.

8.5 Human capacity and digital literacy

HIS in developing countries should be regarded as socio-technical systems, where people, hardware, software, techniques, support resources and information structures form a complex and interdependent system, and understanding the social context surrounding the system is important for development (Kling, 2000).

While this social structure incorporates actors and social dynamics across a wide range of administrative levels and stakeholders, of particular relevance for my study, are the stakeholders tasked with reporting data on sample collection and transportation, who would be actively utilizing the eIDSR Sample Tracker application as part of their daily work routine. Understanding the skills and qualifications of these health workers, as well as their routines and current workflow, would be key to designing a mobile-based sample tracing system in Uganda.

As detailed in section 4.6, Marcus et al. (2015) argues basic literacy, English language literacy, and digital literacy affect a user's ability to properly utilize digital technology. My field visits in Uganda reveled massive variation in health worker competence and literacy levels, both general, English and digital, with a clear tendency of higher skill levels, education, and adequate training present in urban areas and higher administrative division, compared to lower administrative levels, especially in rural areas.

These observations are supported by Kiberu et al. (2017), stating that health workers in Uganda generally have "low levels of computer literacy and skills to use ICT equipment and systems, especially those in rural areas. […] There is also a shortage of qualified ICT personnel to manage and maintain technology equipment and to support health workers to use such equipment and systems, especially at lower health facilities." (p. 6); and the WHO (2018b) *Country Cooperation Strategy for Uganda*, stating a major challenge to the Ugandan health system are "the lack of resources to recruit, deploy, motivate and retain human resources for health, particularly in remote localities" (p. 1). According to UNESCO (2020), Uganda has a general literacy rate of 76.5% among the population aged 15 and older.

Fueled in part by poverty, lack of access to digital technology, affordability of telecommunications services and digital devices, lack of digital infrastructure, and policy-related barriers, the digital divide remains a challenge for implementation and sustainability of digital health solutions across Africa (West, 2015). The lack of both general and digital literacy, and the digital divide between "individuals, households, businesses and geographic areas at different socio-economic areas" (OECD, 2001, p. 5) should inform the design and implementation choices of digital solutions for health care in developing countries, as reflected in a call for participatory and user-centric design in the literature regarding ICT and mHealth in developing countries (Braa & Sahay, 2012a; USAID, 2015; Heerden, 2012). Heeks (2002), and Mars and Scott (2010) attributes a significant amount of ICT4D failures to the physical, cultural, and economic differences between developers and users, leading to designs that are not appropriate for the developing world.

Taking the digital divide and digital literacy into account means not only developing with a specific country in mind, but also specific user groups within that country. In my initial assumptions when developing the eIDSR Sample Tracker application prototype, I overestimated the ICT skill levels of the participants, due to earlier user testing with and feedback from HISP Uganda staff members, who represents a digitally literate segment of the Ugandan population. When referring to western-inspired designs in ICT4D as a cause of potentially damaging

assumptions, Heeks (2002) notes that "The West" in this context is as much a mindset as a physical location, that can exist among local members of developing country organizations.

This process, and the changes to interface design following the user testing is discussed in section 7.5.1. As revelatory and significant as user testing with actual, rural stakeholders was, even when testing with the Hub Riders and Hub Coordinators in West Nile district, the participants were presumably more digitally literate than the general population in the region, considering they had received training in a similar application by the Ugandan CPHL (see section 7.4.2).

Seeing as most mHealth pilot studies fail to materialize as upscaled, fully realized systems (WHO, 2018a; Kiberu et al., 2017), the USAID mHealth Compendium (2015) recommends *designing with the user* to develop appropriate solutions based on user needs and existing workflows, and *designing for scale* to make sure the system can be utilized in a wider context after an initial, smaller scale study. Arguably, part of a system's scalability would involve identifying not just the qualifications and training of the installed, pilot-stage user base, but also that of the *potential* user base, those who would utilize the system in a planned future, upscaled version. Understanding the wider competence and skills of the potential user base could provide important data to help estimating the amount and level of training needed to produce effective workers, and in turn the personnel expenses associated with introducing the system.

The shortage of qualified ICT-proficient personnel in sub-Saharan Africa (Kiberu et al., 2017; Nicol et al., 2013; Fall et al., 2019) means a more complex system, requiring high levels of digital literacy, has a much smaller pool of potential effective users in the workforce, inferring that digital systems should be kept as simple and easily maintainable as possible. Furthermore, as most health reporting in developing countries is performed by already-overburdened health workers (Chilundo & Arnestad, 2004), interface and application simplicity could reduce time demands when reporting, and training requirements for a workforce with high turnover rates and few resources available. Another positive side effect of designing for users who are at the very low end of the digital divide, is that it could promote work life inclusion across digital divide boundaries, potentially benefitting rural populations and women, who commonly have marginalized digital participation (Bukht & Heeks, 2018; Antonio & Tuffley, 2014).

8.6 User Interface

To inform the eIDSR Sample Tracker application design, I focused much of my research on interviewing, observing, and understanding the potential users and the context surrounding the system. During the latter stages of field work, with a high-functionality prototype at my disposal as a mediating artifact, user testing with actual stakeholders in their natural environment was performed to improve the application user experience and user interface. This resulted in a large number of changes, both structural and visual, as well as a compiled list of possible future changes to the system.

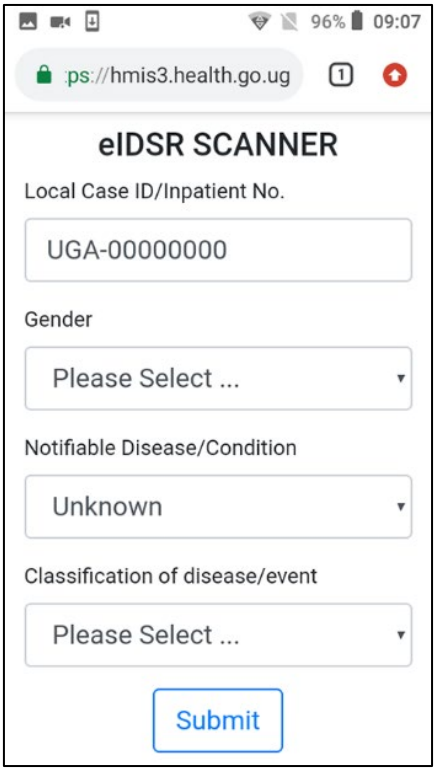

Figure 8-1: Form fields in user interface used for testing

When testing the application with stakeholders, participants struggled to understand how to fill in dropdown fields in a form, suggesting that this concept can be complicated to users with lacking digital literacy. The confusion was exacerbated by the prototype design also presenting multiple data entry input fields per page, and by having headers written above the fields, coupled with the white-on-white design making separating the fields from the background problematic for users not accustomed to digital forms. The blue submit button also drew attention, and the participants were inclined to press that button before filling in relevant information. Furthermore, some of the language confused the participants, as did some of the options. Participants generally felt the application was complex, and demanded a lot of input.

My original assumption during development that multiple dropdown forms per page were user friendly were based on three primary assumptions, which were now contested by my observations in the field: First, I considered the eIDSR Sample Tracker application prototype to be a form of digitization of a paper form, even if it did not directly replace an analogue counterpart. This led me to believe that multiple data entry fields per page, like you would see on a paper form, was preferable. Secondly, internal user testing and feedback at HISP Uganda suggested familiarity with the concept of dropdowns and digital form fields. Finally, the application was built on top of an existing structure in Uganda's eIDSR Tracker Capture form (see 5.2). While it represented a significant simplification of the myriad of fields and buttons in the Tracker application, it still clung to the basic design principles of fillable forms and dropdown menus.

These assumptions can be interpreted as a result of my cultural, economic, and physical distance from the intended users of the system, as described in Heeks (2002). Although I was living part-time in Uganda at the time of development, and was working closely with local stakeholders in HISP Uganda, the digital literacy among employees at HISP Uganda were high, especially in an Ugandan context, meaning feedback on usability from that environment represents stakeholders on the skilled side of the digital divide; users with high-level understanding of digital technology who are perhaps more accustomed to what Heeks (2002) described as western-inspired designs.

User testing the eIDSR Sample Tracker application prototype in a region where the CPHL application was already being piloted, afforded me a unique opportunity to learn from the implementation and utilization of that system, but the eIDSR application would invariably be compared to its CPHL counterpart rather than judged on its own merit. Habits formed by the

training and use of the CPHL application shaped how the participants understood and handled my prototype, which yielded some usability data that are more situational than universal. One such case was my observation that the participants would invariably turn the Android device sideways to a horizontal position when attempting to scan a barcode, even though the application was designed to be used when held vertically. This stemmed from a requirement in the CPHL application to hold the device sideways when scanning barcodes. Contrarily, the scanning library I had chosen for the eIDSR Sample Tracker application prototype only natively supported scanning in vertical position. While forced horizontal scanning was an artifact of the CPHL application, this observation nonetheless highlighted the need to support scanning unrestricted by direction to accommodate varying user expectations.

The perceived complexity and excess of required inputs was partly down to participants comparing the application directly with the CPHL application, which requires significantly less data input from the user.

To counteract some of the beforementioned issues, I developed a revised version of the prototype eIDSR Sample Tracker application for testing on the second day of field work in West Nile, as documented in section 7.5.1. The updated prototype application included fixes like new background color to distinguish fields from the background, improved wording in some form fields, form field captions moved into the field itself and multiple unnecessary fields removed and auto-filled by the application.

In total, these changes made during the field trip were intended to make the application easier to understand, more visually pleasing, less complex to use, and less time consuming by removing redundant data input. These changes tested much more positively with the participants, who expressed that this revised version was easier to understand, was quicker in use, and the language and inputs were more intelligible.

Observations and feedback still indicated that multiple data entry points per page was perceived as confusing and convoluted, and the amount of data required still felt excessive when compared to the CPHL application.

8.7 Development Platform

Working from the premise of using a mobile device to scan barcodes and register data on samples in DHIS2 Tracker, the choice of development platform was important to ensure compatibility with existing DHIS2 structure, while supporting key functionality like barcode scanning and direct access to the DHIS2 API. Since DHIS2 does not currently support scanning barcodes natively, the choice was made to develop the prototype using HTML5 technology.

My experience with using HTML5 was largely positive, with DHIS2 dashboards supporting importing HTML5-based applications as WebApps, which integrates the application into the existing DHIS2 instance. This allowed straightforward communication with the instance API, and ensured the application exists as part of the DHIS2 ecosystem.

Furthermore, with its support for importing open source libraries, low system requirements, universal standards and enormous developer user base around the world, using HTML5 to develop applications for DHIS2 provided a massive development toolset, and enabled technical solutions and interface designs that would not be possible using DHIS2 natively. Through JavaScript and jQuery, interacting with the DHIS2 API to send and receive data was effective, and CSS allowed quick and flexible visual prototyping, especially coupled with the Bootstrap CSS library. Support for frameworks like React and Angular further enhance the utility of using HTML5, by allowing responsive and component-based applications. JavaScript ranks as the most widely known programming language according to the *2020 HackerRank Developer Skills Report* (2020), and the ubiquity of web development proficiency can be beneficial for future maintenance of the system.

However, one major drawback to using HTML5 technology in mobile application development for DHIS2 is the lack of an Android dashboard application that can natively run WebApps within its own framework. Instead, HTML5 applications needs to be run through a normal web browser by entering the URL of the DHIS2 instance, logging in, and then accessing the application from there. This process is both tedious and time consuming, and represents a potential problem when facing users with uncertain levels of digital literacy.

During user testing, I circumvented this problem by creating a shortcut to the URL of the application on the DHIS2 instance on the Android device desktop, and allowing the user to go straight to the eIDSR Sample Tracker application, rather than manually finding it in the DHIS2 instance dashboard website, simulating the look and utility of a normal, native Android application on the device.

While this was adequate for user testing on a prototype, I would argue it is not an elegant or satisfactory long-term solution of a finished product.

The necessity of creating a website shortcut on the device home screen by first typing in a URL and then creating a shortcut to said URL, rather than asking users to simply download an application, makes the process of installing the application more complex and likely more susceptible to user errors. Furthermore, the nature of running the application in a browser means the application is surrounded by the browser interface, including an address bar, back, forward, home and refresh buttons, and controls for multiple browser tabs. This added extraneous interface can likely both be confusing to an inexperienced user, and lead to errors or mishandling, for instance using the back button in the browser in an attempt to go back to a previous screen in the application.

The login page in DHIS2 also causes some issues. While a link to a WebApp in DHIS2 created on an Android desktop will take you straight to the application of you are already logged in to the DHIS2 instance, an unauthenticated user be taken straight to the DHIS2 dashboard rather than the application upon a successful login. From here, the user will either need to navigate the

DHIS2 dashboard and locate the application manually, or minimize the browser and press the application shortcut on the desktop again to access the application.

To compound the issue, logging in to a DHIS2 instance on a mobile device prompts the user for "Mobile Version" in a dropdown menu, allowing the user to choose from "Basic", "Smartphone" and "Desktop". The default "Basic" version does not give the user access to WebApps, unlike the two other choices.

Consequently, the lack of an Android DHIS2 dashboard app capable of running WebApps is a major drawback when developing HTML5-based applications for DHIS2 intended for mobile use.

8.8 Maintenance

To avoid a *sustainability failure* (Heeks, 2002) when implementing a digital health solution, a system must be maintained and supported after the initial implementation (Agarwal et al., 2016). Many sub-Saharan African countries, including Uganda, lack ICT-qualified personnel for maintenance (Kiberu et al., 2017), indicating that ease of maintenance would be beneficial for long-term sustainability. This could have an influence on the choice of development platform, as discussed in section 8.7 above, as local workforce proficiency should be taken into account in addition to the technical possibilities when deciding on a development platform.

A system like the eIDSR Sample Tracker application prototype, built to interact directly with another system, is especially vulnerable to sustainability failures, as changes in the parent system can render the two applications incompatible. As documented in section 6.3.4, while developing and testing the prototype application, there were multiple instances of changes being made to the eIDSR Tracker Capture form by HISP Uganda which required altering the prototype eIDSR Sample Tracker application to accommodate these changes and keep compatibility.

Because the system is built on passing data values to specific keys, or *unique identifiers* (*UIDs)*, in the API, a change in a UID, a removal or addition of a required field, or a change in accepted values in a form field could render the eIDSR Sample Tracker application outdated or obsolete.

This means the application needs regular maintenance, and the developers working on the eIDSR Tracker Capture form needs to be aware of how changes they implement to their system can affect the mobile eIDSR Sample Tracker application.

To minimize this maintenance and ensure maximal compatibility over time, it is my opinion that the data requirements for the eIDSR programme should be reviewed, and mandatory data should be reduced to a minimum, and the eIDSR Sample Tracker application should minimize the number of data entry fields to the minimum required by the parent eIDSR Tracker Capture form (see section 8.3). Besides benefitting the user experience and data collection, this will ensure reduced maintenance requirements due to the mobile application depending on fewer form fields.

While human maintenance of the system is necessary for sustainability, it is possible to imagine a certain amount of automatization in the maintenance process, further reducing the workload burden of keeping the application up to date. Doing a series of very specific calls to the API could in theory generate the fields needed for the eIDSR Sample Tracker application automatically.

Knowing that the UID for the eIDSR Tracker Capture Specimen Handling Form is vOc4kRUj4Ek, it is possible to find the fields used in the form by accessing the DHIS2 API at:

`/api/programStages/vOc4kRUj4Ek/programStageDataElements`

This returns an array containing an object for each field in the Specimen Handling form of the Immediate Case-Based Reporting Program. Using the UID from the dataElement.id variables of each field, we can access the Data Element itself at:

`/api/dataElements/{Data Element UID}`

From this we can access the Option Set UID for the given Data Element from optionSet.id, which finally can be used to access the corresponding list of options for the field in the API:

`/api/options.?filter=optionSet.id:eq:{Option Set UID}&fields=code,displayName`

This API query returns an array containing an object for each option, with a value for "code", meaning the value we will register into the form, and "displayName", the human-readable name of the option, which can be used to populate the form fields in the application with updated information and requirements.

Since this process involves a series of calls to the API, it will only work while the device is connected to the internet. Furthermore, an increased number of calls to the API would mean further delays in cases of slow internet connection (see section 7.5), so updating form field data should be performed periodically when connected to the internet, rather than every time the sample registration process is initiated. The DHIS2 Tracker API has a "lastUpdated" variable that can be compared with the last synchronization date in the application, making it possible to only do synchronizations when changes have been made to the relevant API locations.

By populating both the event registration and patient registration forms in the application with fields and options like described above, the application could be robust enough to handle all but major structural changes to the underlying eIDSR Tracker programme, given the application is connected to the internet at reasonable intervals.

8.9 The eIDSR Sample Tracker application as an extension of the eIDSR Tracker Capture Specimen Handling form

The eIDSR Sample Tracker application prototype is built on top of the existing Ugandan eIDSR DHIS2 system, specifically the eIDSR Tracker Capture Specimen Handling form (see section 5.2.2). While this structure was not carved in stone, changing the underlying DHIS2-based infrastructure was complicated by the involvement of multiple stakeholders and decision-

makers, including the Ugandan Ministry of Health. For this reason, challenges faced by the eIDSR Sample Tracker application prototype would usually be solved through changes in the application, rather than the eIDSR Tracker programme. However, some issues could benefit from modifications in the underlying structures.

Uganda's eIDSR tracker program is designed so that patients and cases are not separate objects, meaning that a patient is registered in the system with a built-in case, usually a disease that is either suspected or confirmed. However, patients with vague or ambiguous symptoms may be tested for multiple diseases, each of which should ideally be registered as its own case in eIDSR. As the system currently is designed, symptoms and classifications of the disease is registered to the patient, while tracking numbers and destination is listed for each single event related to a sample. This means every event registered on sample transportation must contain all relevant information on the sample itself, including the bar code value, adding redundant data checks with the server, and making the system a bit less flexible in terms of what information to register where. An eIDSR Tracker Capture application restructuring to let single patients have multiple cases, and each case contain multiple events, would make sample tracking and registration easier, by storing constant information regarding the specific case, like the barcode value associated with a sample, in the *case itself*, as opposed to the *patient* or the *event*.

This would reduce redundancy in the data, and simplify the process of searching for a matching barcode as detailed in section 6.3.1. Registering each sample taken as a separate case could mean removing the triple API search to find the patient ID that corresponds to the barcode on a sample, in favor of a single API call, reducing server load and waiting times. It also has the added benefit of enabling tracking patient's disease history over multiple health cases. While Uganda does not currently have a reliable way of identifying persons across multiple health visitations – most people do not have social security numbers or other forms of unique identifiers – having the option of adding multiple health cases to a single patient is a form of future-proofing the system.

Furthermore, a system where *patients* can have multiple *cases* would also aid in tracking batches of samples from regional hubs to CPHL in Kampala. This is not currently supported, and remains a challenge that a fully functional eIDSR Sample Tracker application must address. As documented in section 7.4.2, after samples have reached the regional hub, they will usually be packaged by type and put in batch envelopes, each marked with a single new bar code. While simply adding a field for batch barcodes to each event is possible in the current eIDSR implementation, identifying all samples contained in a batch would entail a very elaborate series of API calls in this approach, sorting through all registered events, and filtering out all duplicates due to the redundancy of individual and batch barcodes registered to each event. This is an inelegant solution, which could be a source of both errors and excessive loading times for the user. A separated case object with an optional field for a batch barcode in addition to the individual barcode for the sample, is a much cleaner solution, allowing events to be registered to all cases with a matching batch barcode in the API.

Like when linking sample to barcode value, batch barcode values must be linked to samples though user action. Ideally, the application could use the credentials of the logged-in user to decide if the user was presented with the option of batch-packing samples, hiding this option from Hub Riders, while displaying it to Hub Coordinators, avoiding confusion and reducing complexity. This approach could also be used to limit access to potentially sensitive information on patients to the appropriate personnel. However, as I observed during my field work, the roles of various health workers in Ugandan health facilities are sometimes fluid, and Hub Riders will perform the receiving and batch-packing of samples in the Hub Coordinator's absence. While a similar system of user privileges was implemented by the CPHL application, it was circumvented by the Hub Riders borrowing the Hub Coordinator's mobile device and login credentials. Whether to facilitate for this sharing of devices and credentials could hinge on privacy concerns, and strictness in accountability and reporting demands, but based on my observations of workplace practices and -culture in Uganda, a certain measure of flexibility and pragmatism is usually present to account for absent or unavailable personnel, or other unforeseen events.

If this approach is used to limit access to patient information by logged-in user, devices and login credentials must be secure, private, and nontransferable. To facilitate this, while still permitting some level of pragmatism, a sample tracking application should allow users to perform certain non-sensitive tasks that fall outside the users' regular function.

8.10 Proposal for the next stages of application development

Given the findings presented above, this section describes a proposed revision of the eIDSR Sample Tracker application prototype. This proposal is not intended to be regarded as a finalized state of the application, but rather the next major action taking step in the *action research cycle*.

Based on the feedback and observations generated during field work, interviews and user testing, my observations and experiences from the development process, as well as evaluating the application against Nielsen's (1994) heuristic principles (see sections 3.2.2 and 7.6), I propose the following changes to the application to be implemented and evaluated next:

Change the input field design from multiple form fields per page, to a step-by-step/"wizard"-like design with one input per page and a "next", "back" and "cancel" button. These buttons should be placed and labelled so they clearly communicate their actions, and include a confirmation prompt if the user clicks "cancel". The input fields included in the application should still be context sensitive, skipping redundant fields depending on user input. This answers both the user feedback concerning confusion around multiple form fields, when to press submit, and the third Heuristic Evaluation principle of allowing user control and freedom, making it possible to go back and correct previously entered information, and allow an "emergency exit" in the form of a cancel button. Similarly, the application should display a final confirmation screen with all the information registered by the user, before sending the data to the DHIS2 server, allowing the user to spot and correct any mistakes.

Simplify inputs, avoiding dropdowns or manual text input where possible. Some information can be represented visually rather than in text form, like the binary choices between male and female, or good condition and bad condition. In such a case, having two buttons with simple, recognizable male and female glyphs could potentially be preferable to a dropdown with the same information in written form. Use simple and concise language to describe the form field inputs. This could be especially helpful for users with low general, English, and digital literacy, and is consistent with the second Heuristic Evaluation principle, of providing a match between the real world and the application. When simplifying the application, remember to cater to expert users by including alternate, advanced workflows, or *accelerators*, whenever possible.

Where dropdowns are unavoidable, like for the "Notifiable Disease/Condition" field with its 74 options to scroll through, **add an autocompleting text input** to the dropdown, filtering the list by what the user types into the field. Display what information is requested by the user in clear and concise language, and include a form of in-app help icon to display expanded, context-sensitive help and documentation for the user.

Improve scanning feedback and experience by changing scanning direction to either work both horizontally and vertically, or at least give a visual indication to the user to show which direction to hold the device when scanning. As per the first, ninth and tenth Heuristics Evaluation principle, and based on my observations during user testing, give visual feedback to indicate that the scanning process is running, show approximate ideal distance to barcode being scanned, and suggest focusing the camera or improving light conditions if the scanning process persists outside reasonable timeframes.

Include other visual indicators of system status, like showing online status in a non-intrusive location in the user interface, either as a constant color-codes symbol, or as a small popup denoting change in online status.

In the absence of an Android DHIS2 dashboard app that supports importing and running WebApps as seamlessly as the desktop dashboard, **consideration should be given to re-develop the application as a native Android application**, rather than a WebApp for running inside DHIS2. This option is popular among several local HISP organizations, including HISP Tanzania, who currently offer several DHIS2 applications through the Google Play Store, including applications for malaria surveillance, and data visualization. When developing Android applications for DHIS2 use, compatibility with older, simpler Android devices is important, representative of what is being used by actual stakeholders.

Incorporate support for tracking batches of samples. This should be undertaken as a joint effort with HISP Uganda, since this would likely require structural changes to the underlying eIDSR Tracker program (see section 8.9).

Minimize the amount if maintenance needed to keep the system operational. Minimize required form fields, and get form options from the API, rather than hard coding the options, as per section 8.6.3.

Attempt a process of **reviewing the mandatory data fields** in eIDSR in cooperation with HISP Uganda and the Ugandan MOH, with an aim to only collect data needed for action and relevant indicators.

Evaluate options for **further simplifications of patient registration**, like creating empty patient objects for health personnel to fill out, as discussed in section 8.3.

Ensure sensitive patient information is kept safe, by restricting access to patient information to appropriate personnel, and evaluating the patient registration process.

Finally, importantly, and perhaps the biggest challenge to overcome: **integrate the sample tracking systems** for DHIS2 and ALIS, so a single mobile-based sample tracking application serves both data warehouses. The infrastructure, routines and funding put in place by CPHL for their tracking system could benefit eIDSR in an integrated solution. In this way, *scalability* and long-term *sustainability* can be addressed adequately.

8.11 Reflections on research conducted

The primary methodological framework chosen for this thesis was *action research* (AR), as described in section 3.2.1. Due to my extended period of living in Uganda and working with local the HISP implementation partner, I was able to complete multiple AR cycles, as detailed in section 5.3, centered around the development of the *high-fidelity* eIDSR Sample Tracker application prototype. This prototype served as a mediating *artifact* for facilitating discussions, sharing ideas, and garnering feedback from stakeholders, facilitating a participatory design approach and helping to bridge the gap between me as a developer, and various stakeholders, decision-makers and other users. Though the five distinct and essential phases of AR - diagnosing, action planning, action taking, evaluating and specifying learning - were present in all cycles, I found the process and content of these phases to vary considerably based on where I was in the development process. In the early stages of development, work was largely focused on functionality and proof of concept, making sure that the intended core functionality was plausible and achievable. This meant shorter, more focused cycles of development where evaluation and diagnosing were often closely tied to concrete issues surrounding functionality. The identification of general findings during the specifying learning step during the early cycles were mostly tied to the social and technical context surrounding HIS in Uganda, and the implications this might have for development or successful system adoption. In the latter stages of AR, as development increasingly focused on testing with users in the field, cycles tended towards more comprehensive changes and addressing external limitations or challenges, like inadequate digital infrastructure or -literacy.

These last cycles also incorporated elements from interaction design, particularly in order to evaluate changes made to the user interface. Because of the restrictions placed on my research, as detailed in section 7.7, which limited my field work to the western region of Uganda, field trips and user testing with stakeholders outside HISP Uganda team members was time-consuming and expensive, narrowing my options for repeated evaluation of changes made to

usability and interface in the application. Jacob Nielsen's ten Usability Heuristics for User Interface Design (1994) are widely cited in the literature on usability (see section 3.2.2), and provided a framework for evaluation of usability, and a set of universal guidelines for interface design. However, these principles not tailored to the technological and social context of Uganda or developing countries in general, and cannot replace field testing with local stakeholders. Assumptions on interface- and usability design made through this framework, should be subjected to field visit user testing to confirm their validity. Failing to involve all user groups in this way, and failing to take into consideration the existing ecosystem surrounding the application, violates the principles of the USAID mHealth Compendium (2015), and could lead to western-inspired software designs that are not appropriate for developing countries, which in turn is correlated with high failure rates in ICT4D projects (Heeks, 2002; Mars & Scott, 2010). Furthermore, as my research aim to understand mobile technology as a tool for supporting health reporting through an *interpretive* lens, accessing participant interpretations, rather than uncovering positivist and measurable facts, was the aim of this study, meaning participant feedback should be emphasized.

The primary tool for accessing other people's interpretations were the interviews conducted with a wide variety of stakeholders over the course of this research. Speaking to a large number of health workers throughout various districts in Uganda, across all levels of administration - from nurses at remote health facilities to District Health Focal Persons and NGO administrators - resulted in comprehensive insight into the cultural, economic, societal and digital infrastructure that surrounds the Ugandan health system. Using the prototype in interview situations where applicable to facilitate discussions and eliciting feedback from users and decision makers was a particularly effective method for data collection, and was supplemented by user testing and observations in the field. Planned interview subjects would frequently be unavailable, while other potential participants presented themselves during field work, requiring at times an opportunistic and sometimes improvisational approach to interviewing subjects. I found the difference in viewpoints and perspective between higher and lower levels of administration, as well as urban and rural workers, important to help illuminate the case from multiple viewpoints and accessing multiple interpretations. Gathering similar data from multiple locations and sources was done to ensure validity through *triangulation of sources*. Continual document analysis during the course of the research helped contextualize my finds, and provided another source for data to ensure a good measure of *methodological triangulation* in my research.

I found compiling my finds, observations, interviews, and personal reflections in a field journal, and then writing structured reports based on these journal entries, an effective and stimulating approach to collecting and analyzing data, helping me process and sort my finds and data. Due to the long-term, part-time nature of this study, processing and writing down my finds and reflections proved invaluable to help me settle back into this research after breaks.

Having to terminate the original work on ARV commodity logistics and reframing the study to work on IDSR, meant my finds on the specifics on ARV logistics were largely irrelevant for the

final thesis. However, I found that the thorough contextual understanding of the Ugandan health system acquired through these early field trips very valuable for the study. Similarly, my extended period of living in Uganda, and working with the local HISP implementation partner, afforded me a lot of insight of Ugandan society and the digital and humanitarian challenges in the country.

The secrecy surrounding my prototype application due to the CPHL sample tracking program, and the limitations it put on my research was not ideal, but being able to utilize the pilot infrastructure put in place by CPHL for sample tracking in West Nile for my fieldwork, provided valuable data, and represented a use of resources that would otherwise have been outside the scope of a master's thesis.

The two field trips to West Nile proved particularly valuable to understanding the context for the application, and its potential users. While my field visits generated a lot of data, I would ideally have liked to return multiple times to West Nile to continue testing the application through multiple AR cycles, but the distance from Kampala, coupled with resource- and time limitations, made further visits unfeasible. With the situation surrounding HISP Uganda and CPHL restricting my field work to the western part of Uganda, my access to participants was more limited than I would have preferred, and in a less politically charged research situation, I would have liked to establish participants for multiple rounds of user feedback and testing closer to Kampala.

As noted in Preece et al. (2015), developing the eIDSR Sample Tracker application as a high-fidelity prototype was time-consuming and resource demanding. A simpler, wireframe-based prototype could have saved time and given similar usability feedback from participants, but would have been unsuited to testing the technical and operational aspects of such an application. The high-fidelity prototype helped establish many findings about the validity of the technology and choice of platform, and remains a strong proof of concept for a finished application. However, potential future participant-based user interface design stages, like testing a step-by-step registration process, could elect to take a low-fidelity prototyping approach to save time and promote flexibility.

Over the course of the study, I questioned whether my research could be considered a case of *pilotitis*, as described by Franz-Vasdeki et al. (2015) as "isolated mHealth interventions that are successful in one context, but not 'rolled out' due to a variety of technical, practical, economic and often institutional and political barriers" (p. 35).

While the development of the eIDSR Sample Tracker application prototype could be described as a small-scale pilot project, this thesis was always first and foremost about the research and learning generated by the cyclical action research process, over a product-centric development process with a rolled-out product in mind. Still, I would contend that the prototype application developed as part of this study, is a strong foundation for further development of a finished product, and the literature-, feedback-, and observation-based suggestions for future iterations

of the system presented in 8.10 are intended to support both *scalability* and long-term *sustainability*. This study, and the prototype application developed as part of it, is also fundamentally based around *integration and interoperability* of data collection and HIS, as opposed to the fragmented and siloed approaches that make up a majority of unsuccessful mHealth initiatives (WHO, 2018a; Labrique et al., 2013)

9 Conclusions and future work

9.1 Conclusion

In this study, I sought to answer my research question "*How can mobile technology be implemented to support collection and transportation of biological samples in Uganda?"* by using an action research approach to identify a problem area and establishing design requirements, and then develop a high-fidelity prototype application through a series of iterations. The eIDSR Sample Tracker application prototype provided an artifact for shared understanding with participants, generating data and feedback, and facilitating user-designer communication in a participatory approach to the design and research process.

A mobile-based sample tracking application enables capturing data on the transportation and handling process that would otherwise be unattainable though traditional, paper-based solutions. Online, real-time reporting to the DHIS2 data warehouse from on-site locations, means data can be accessed and utilized by stakeholders *during* the transportation process, not just after the fact, providing unmatched accountability and precision. Utilizing the convergence of technologies offered in mobile devices to scan barcodes to identify samples, capture location coordinates from device GPS, and communicate with the DHIS2 instance to automatically complete or bypass certain data fields based on previously registered information, simplifies and streamlines the data collection process. However, this streamlined registration approach, and the expanded possibility of data collection afforded through mobile technology, runs the risk of enabling the collection of non-essential data that is not needed for action and relevant indicators. Furthermore, real-time online registration can lead to tasking transportation personnel with collecting sensitive information on patients, raising privacy concerns.

A *WebApp* communicating with the *DHIS2 API* to send data to an underlying *Tracker Program* is powerful and flexible, but renders the system susceptible to compatibility issues if and when changes are made to the underlying system. Similarly, some functionality, like tracking samples in batches rather than individually, requires changes to the underlying Tracker Program. Development and maintenance of the sample tracking application and the underlying Tracker Application should therefore be coordinated.

Utilizing web technology to develop a sample tracking application as a DHIS2 native WebApp allows for uninhibited customization of user interfaces, and the utilization of features not natively supported by DHIS2, like barcode scanning. Also, the relative ubiquity of web development proficiency can help facilitate maintenance after the initial implementation. However, the necessity of accessing a DHIS2 WebApp through a browser on mobile devices, limits their convenience and practicality, especially for users not familiar with digital technology.

The potential user base for a sample tracking application is Uganda will at least partially consist of personnel with varying degrees of lacking general-, digital-, and English literacy, and this

should be reflected in the interface and user experience design. Thus, involving the users and local stakeholders in the design and development of a system is crucial, and emphasis should be placed on the finds generated by interviews and observations, over established assumptions and practices. Infrastructural challenges, especially relating to online access, is a significant barrier to successful implementation of digital initiatives in Uganda, particularly in remote areas, and accounting for insufficient internet access is a strong prerequisite for implementing a successful digital solution.

In addition to these general prerequisites, implementing a mobile-based solution for tracking samples in Uganda has a resource-demanding set of initiative-specific requirements, like the distribution of digital devices, appropriate training, supplying vehicles for sample collection, maintenance of software and hardware, and job creation and renumeration. Funding these activities requires long-term government or donor financial support. By integrating the eIDSR Sample Tracker application with the ongoing rollout and piloting of the overlapping CPHL sample tracking system, the eIDSR Sample Tracker application can potentially utilize the infrastructure, routines and workforce put in place by CPHL.

9.2 Future work

The prototype application developed as part of this thesis showed a lot of potential as a product for tracking samples and providing timely and relevant data for Uganda's national data warehouse. There are, however, some several areas of inquiry that could be the focus of future studies.

While fieldwork for this thesis was conducted throughout multiple regions in Uganda, the latter stages of the research concentrated mainly on western Uganda, and the West Nile region in particular. This was a consequence of the access limitations placed on my research, but similar field work and user testing in other regions across the country would help ascertain if the findings are universally applicable to all of Uganda.

The proposals for future development of the application presented in this thesis are based on my findings and the literature, but represents recommended actions for future AR cycles, not an outline for a finished product. Further research focusing on usability and user experience is needed to ensure the system is sufficiently accessible for users with limited technical knowledge, and effective enough to not hinder data collection.

Integrating the application with the CPHL sample tracking system in a way which provides both the MOH DHIS2 data warehouse and the CPHL ALIS LIMS with timely and reliable data, remains an important issue to be solved, a process which will be both technical- and organizational-political.

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Appendix

Field Work Report from West Nile, June 2018

Presented below is the report I wrote after the first field trip to West Nile in June 2018. The text has been altered slightly to remove the names of the participants. The report includes appendixes with direct transcriptions of the notes I made during the interviews. Similar reports were written from each field trip, and sent to my supervisor in Oslo and the relevant staff at HISP Uganda.

Anders Baggethun, June 28th 2018

Report on Disease Surveillance in West Nile District, Uganda

Field work, West Nile sub-region, Uganda, June 12th to 14th

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Chapter 1 – Introduction

1.1 Background on the Fieldwork Project

In May 2018, growing concerns over the cooperativeness of the Ugandan Ministry of Health on outside contributions to their eLMIS ARV ordering system in DHIS2, prompted a change of my master thesis topic from ARV commodity ordering to Disease Surveillance (DS). HISP Uganda is currently in the process of rolling out a new DHIS2 application for monitoring Notifiable Diseases (ND), called eIDSR in West Nile, and a HISP representative would be working on system implementation in the area in June of 2018.

West Nile is a sub-region of Uganda, consisting of eight districts. Situated close to the borders of both South Sudan and The Democratic Republic of Congo, West Nile hosts more than a million refugees, resulting in a challenging epidemiological situation.

I travelled by car from Kampala to Arua in West Nile with a member of HISP Uganda on the morning of Tuesday June 12th 2018, with the intent of conducting a series of interviews with various stakeholders involved in Disease Surveillance and Outbreak Response.

1.2 Purpose of the Field Work

Having recently changed topic for my master thesis, one of my main objectives for this field trip was to gather data and information that would help me formulate a new problem statement and provide an understanding on the field of Disease Surveillance in general, as well as the specific situation and challenges in Uganda and the West Nile sub-region.

Furthermore, my research would help inform further development on the eIDSR app, both in terms of adding features or sub systems, and uncover structural, logistical or infrastructural challenges that might hinder a satisfactory implementation of the software.

1.3 Fieldwork Procedures and Methods

1.3.1 Planning

The fieldwork consisted of a series of semi-structured interviews with various stakeholders in the district of Arua in West Nile. With input from two members of HISP Uganda working with eIDSR, I wrote an interview checklist that formed the outline and structure for all the interviews that I would be conducting (see appendix A). Although a rough outline of who we would be meeting and at what times existed, experience told us that such appointments might not always be honored, and so we were prepared to do ad-hoc interviews or make arrangements on short notice. Our hotels were not booked in advance, allowing us to move to other areas and regions, should that be necessary.

During the interviews, I would take extensive notes in my notebook, and expand on these notes shortly after the interview was concluded, adding my thoughts and reflections, as well as elaborating on my hastily scribbled notes as needed.

1.3.2 Execution

In total, I ended up conduction seven interviews with the following ten people:

- District Surveillance Focal Person (DSFP) for West Nile at the Arua Referral Hospital (appendix B)
- Patient Support Activity Manager, Doctors Without Borders (MSF) (appendix C)
- Regional Surveillance Officer and Lab Mentor, IDI; Laboratory Specialist, IDI; and Regional Project Coordinator, Infectious Diseases Institute (IDI) (appendix D)
- Public Health Officer, UNHCR (appendix E)
- District Health Officer, Arua (appendix F)
- Clinical Officer, Doctors Without Borders (MSF) (appendix G)
- Lab Manager and District Lab Focal Person, Arua; and Quality Manager and Deputy Lab Manager. (appendix H)

These represent a good mix of stakeholders and decision makers, with different perspectives on the Disease Surveillance (DS) and Outbreak Response (OR) situation in West Nile and Uganda.

Of these interviews, several were improvised or ad hoc appointments, as several of our intended and arranged interview subjects were away or unreachable. The Patient Support Activity Manager of MSF, for instance, was a last-minute replacement for the MSF Field Coordinator arranged by the Arua DSFP, and interviews with the three IDI representatives had to be done by phone. The interview with the Arua District Health Officer (DHO) was made possible by simply walking into his office and asking for an interview.

Chapter 2 – Findings

2.1 Presentation of data

There was a broad consensus among the interview subjects that the West Nile region is not prepared for disease outbreaks. The District Surveillance Focal Person for West Nile at the Arua Referral Hospital (DSFP) said the district lacks capacity for diagnosis, treatment and investigation. The Infectious Diseases Institute (IDI) representatives noted that response time on outbreaks is poor, and active surveillance and information sharing between stakeholders needs to improve. The Public Health Officer (PHO) at UNHCR felt the NGOs in the area were reasonably well prepared for outbreaks, but explained that Uganda and West Nile lacks an existing health infrastructure to screen, diagnose and treat the refugees in the area, and that there is a lack of coordination during outbreaks. This lack of preparedness and coordination was repeated by the Clinical Officer at Doctors Without Borders (MSF), who also added that the district hospital does not have space or infrastructure for isolating contagious patients.

Reporting and diagnosing of Notifiable Diseases (ND) is inconsistent and unreliable, and often relies on NGOs to do active investigative work. The Public Health Officer at UNHCR stressed the need for ND symptoms to be picked up and reported earlier and more reliably. This sentiment is echoed by the IDI representatives I spoke to, claiming that the health facilities in the area severely underreport or fail to notice cases of ND symptoms. The Clinical Officer at MSF listed lack of reporting on ND from

health facilities as the biggest challenge facing DS/OR in the region, adding that several recent outbreaks have gone unnoticed until picked up by NGOs, including an ongoing anthrax outbreak that emerged more than a year ago, and a recent malaria epidemic. These were both discovered by partners (MSF and UNHCR respectively) through data analysis or investigation, but should have been picked up earlier.

Lack of commodities, especially Personal Protective Equipment (PPE), was repeated by nearly every interview subject as a major issue. The DHFP claimed they had only "hours" worth of PPE in case of an outbreak, the MSF representatives said there is very little commodities in stock in the region, while the Lab Managers at Koboko Hospital claimed they were systematically given too little PPE and commodities needed to gather samples, adding that this affected their ability to do collection and preliminary testing on biological samples in cases where a ND is suspected. The District Health Officer (DHO) in Arua, noted that there was some initial stock of commodities available for a first response to an outbreak, but once these are depleted, they would often rely on partners for additional commodities as the Ministry of Health (MOH) rarely delivered additional stock. The Public Health Officer at UNHCR concurred that the district does not have sufficient PPE. He explained that following protocol and taking the necessary precautions when handling suspected ND cases consumed a lot of commodities, exemplified with a recent tuberculosis patient who died exhibiting Ebola-like symptoms. The lab results for Ebola were eventually negative, but until this was confirmed, a lot of PPE was needed to secure against possible spread of infection. MSF, like most major partners, have their own supply of PPE and other commodities, and added that they generally receive the medicines and commodities needed during an outbreak, depending on the scale and severity of the outbreak. These MSF warehouses rarely stock out of important commodities or medicines, but are located in Kampala, and acquiring resources generally takes around 24 hours. These supplies, however, are mainly for MSF personnel, and UNICEF is the major non-governmental supplier of PPEs and other commodities in the region. Interestingly, MSF are working on implementing what they called "48-hour kits" in the region, meaning the district would be self-sufficient for the first 48 hours of an outbreak.

Both UNHCR and IDI representatives agreed sharing or redistributing needed commodities from nearby districts is viable.

Some confusion exists over the existence and validity of emergency response plans in the area. IDI and MDF believed no emergency preparedness plan existed, while UNHCR, the DSFP and the DHO and confirmed that it did, but they all expressed concerns that this plan did not automatically trigger additional funding or a concrete response from the government, thus rendering it largely useless. The UNHCR PHO noted that a plan without an accompanying budget cause inadequate response from the district authorities. The DSFP claimed the existing response plan required the MOH to respond to outbreaks, but this protocol was not followed. The UNHCR PHO in turn claimed that the MOH and the local government disagree on who is responsible for handling outbreaks, with the MOH calling for the district to supervise the situation themselves, while the districts look to the MOH to take charge.

Both the District Health Officer and the Disease Surveillance Focal Person in Arua said they were rarely allocated additional funding, non-medicine commodities and resources from the MOH during outbreaks. The DHO estimated that he received the medicines he needed to handle outbreaks from the MOH about 70% of the time, and the rest of the time he relied on the various NGOs and partners.

This lack of responsibility, role allocation and coordination between the various stakeholders permeates every aspect of the DS and OR situation in the region. While most partners have a reasonably clear view of what their own responsibilities and areas of operations are, a lack of a joint emergency preparedness plan and centralized coordination complicates the response to outbreaks. Both MSF and UNHCR noted that response is sometimes uncoordinated, and the DHFP admitted that keeping an overview of stocks during emergency is "tricky".

According to the DHO, the biggest DS and OR challenge in the region is logistics. Large distances and poor infrastructure hinders effective transportation of personnel, commodities and samples. The lab managers at Koboko Hospital confirmed that transportation of samples for testing in Kampala labs is an issue, and that they have used public transportation for sample transportation at least twice. They estimated that he processes of taking samples from a patient with ND symptoms, transporting them safely to a central lab in Kampala for testing and getting a result back could take anywhere from one to five days. The IDI representatives told me sample collection and testing take at least 72 hours at present, sometimes more. Noting that timeliness is important, both to preserve sample quality and to provide adequate outbreak response, they stated 24 hours as a target timeframe. The IDI representatives explained that dangerous samples are triple-packed for safety and transportation is done by a courier experienced in handling biological specimens.

According to IDI, internet access is a big challenge in the region. The DSFP at Arua Regional Referral Hospital did not have internet access at the time of the interview, expressing ignorance as to why, but suggesting that the arrangement with an NGO partner for internet could have expired. Koboko Hospital had internet provided by IDI, but claimed they always ran out before the month was over, sometimes being offline for weeks at a time.

The implementation and rollout of eIDSR in the region was still ongoing at the time of my field work, and none of the interview subjects had used the system for reporting yet. The DSFP had received training and a user's manual, but after failing a registration attempt, he largely gave up on using the system. He added that "SMS is easier" and expressed concerns that lack of roles and responsibilities could cause multiple- or no registrations of patients in the system. The IDI representatives were optimistic about eIDSR, expecting it to improve active disease surveillance, but refrained from giving specific feedback, as they were still learning the system. They added that the system should ideally cascade down to Health Clinic level and below, but lack of internet access in the region is a challenge in achieving this. The DHO admitted to being "not very familiar" with eIDSR, and the Koboko Hospital Lab had not yet used the system.

The varying NGOs and partners use their own Health Information Systems (HIS), which are not currently compatible with the government HIS. The UNHCR PHO stated that their system works well, but disliked the duplicate reporting caused by their system being incompatible with the government HIS, and added that the UNHCR would prefer if the government HIS allowed for better surveillance and more granular information, including metadata on whether the patient was a refugee or a Ugandan citizen. Similarly, MSF used their own ePoI system, which was not integrated with the government HIS, meaning data and reports were sent by e-mail or paper to other stakeholders.

Documentation exists on previous outbreaks, with the DHO sitting on data regarded as UNHCR as "ok", but described as "not so detailed" by the DSFP. MSF has their own database on previous outbreaks in the ePoI system.

The ongoing anthrax outbreak highlights many of the issues raised by the various stakeholders in these interviews. The outbreak occurred in one sub-county May of 2017 and is still ongoing as of June 2018, and has spread to two further sub-counties. At least two people and a large number of animals are confirmed to have died from the disease. IDI described the situation as "not under control", and added that it took a long time for the disease to be identified due to misdiagnosing and lack of reporting from Health Clinics. This lack of reporting from HCs was also confirmed by the DSFP, who added that samples should have been tested earlier. UNHCR claims they were the ones to raise the alert, having collected samples and confirmed the outbreak. Raising the alert for an anthrax outbreak did not trigger an immediate response from the MOH. UNHCR, IDI and the DSFP all reported that no additional funding was received from the government to handle the outbreak, and that response in terms of delivery of necessary antibiotics was inadequate and late. According to the DSFP, a year went by from the discovery of anthrax in the region until proper medicine was dispensed, and this delayed response is the biggest reason the outbreak is still ongoing. The IDI representatives noted that the response to the outbreak faces huge logistical and financial challenges, and reported that the region still did not have sufficient antibiotics to handle the outbreak, pinning the responsibility for this on the MOH. The anthrax outbreak has mainly targeted animals in the region, and this presents a unique set of challenges. The UNHCR PHO explained that they used veterinaries to collect animal samples, the IDI representatives advised that HISs needs to accommodate for animal samples as well as human samples, and the DSFP noted the need for special training and equipment to handle outbreaks among animals. When investigating the outbreak, IDI found that anthrax is still severely underreported throughout the region, and speculated that the slow and inadequate response from the MOH could be a result of lack of reporting and information on the outbreak.

2.2 Analysis of data and study results

Disease Surveillance and Outbreak Response in West Nile faces a multitude of issues, most notably a lack of timely and consistent reporting of symptoms of Notifiable Diseases. Outbreaks go unnoticed and cases are underreported, leading to poor timeliness of response. Many cases are only discovered through active investigation or screening done by NGOs. Adding to this is an unclear division of roles and responsibility, absence of a unifying preparedness plan, lack of commodities and funding, and a challenging infrastructural situation.

The newly implemented eIDSR system in the region could help improve active surveillance, helping NGOs and the local government to identify possible outbreaks earlier. This, however, hinges on better reporting quality from Health Clinics. At present, lack of internet access and computer infrastructure makes implementing the web-based version of eIDSR at Health Clinic level impossible, but reporting through mobile or SMS can hopefully increase reporting rates.

Integrating the system with the various stakeholder Health Information Systems would save time and facilitate communication and information sharing.

Commodities are scarce and spread among the various stakeholders. It is possible to move commodities from one district to another, but supervision of total stock and location is challenging during outbreaks. In general, the district has too little PPEs available.

Transportation, testing and reporting back results from bio samples takes too long, and is currently estimated at 72 hours by IDI and between one and five days by the Koboko lab managers. According

to IDI, the target should be 24 hours. Improving the logistics around diagnosing samples should help timely responses to outbreaks.

Emergency Response Plans are poorly implemented and does not automatically trigger a response from the government, and is not universally distributed among stakeholders. Having a binding and predictable response from the government when there is an outbreak might incentivize reporting and diagnosing.

Chapter 3 - Summary and Conclusions

3.1 Summary

Effective Disease Surveillance and Outbreak Response in West Nile is hindered by poor coordination, lack of resources and commodities, logistical challenges and lack of infrastructure. Local Health Clinics fail to report and test symptoms of notifiable diseases, allowing outbreaks to slip past government notice. Once outbreaks are confirmed, the Ministry of Health does not respond with sufficient resources and financial aid to handle outbreaks.

The availability and validity of Emergency Response Plans is unclear, but if they exist, they do not contain binding obligations or trigger financial support for the stakeholders, and serves as a rough guideline at best. Protective equipment and other commodities are scarce. The health infrastructure in the region is not prepared for outbreaks, lacking isolation wards, diagnostic equipment and capacity for treatment and investigation.

Collection of biological samples for testing is often done late, and sample transportation takes too much time. The various stakeholders in the region use unique and unintegrated Health Information Systems, necessitating duplicate reporting and complicating communications and coordination. The stakeholders also have their own warehouses, with varying types and levels of stock.

Documentation on previous outbreaks are available, but of limited quality.

Integration of eIDSR could help improve active surveillance, response and information sharing, but might be hampered by limited internet access and a lack of a sense of responsibility, as well as lack of awareness of when to raise alerts and report symptoms at Health Clinic level.

3.2 Conclusions and Way Forward

Disease Surveillance and Outbreak Response in West Nile is inadequate, and in need of strengthening, streamlining and standardization.

Acquiring Emergency Response Plans from the local government could help answer some lingering questions on how outbreaks are supposed to be handled, as would interviewing a representative of the Ministry of Health on the subject of Outbreak Response. Further field work in West Nile should focus on the implementation of eIDSR and the logistics surrounding reporting and diagnosing. Talking to Health Clinics about reporting procedures could prove enlightening. Investigations on the possibility of implementation between eIDSR and the various HISs in use by both NGOs and testing labs should be undertaken. I would also recommend interviewing representatives from labs in charge of testing bio samples in Kampala.

Appendixes

Appendix A – Interview checklist

I: Introductions

- Introduce myself and my project
- What is your name and occupation
    - How long have you had your current occupation
    - What are your responsibilities and tasks

II: Current situation

- What is the current epidemiological situation in the region?
    - Any recent or ongoing outbreaks?
- What challenges does your region face in terms of health (refugee camps, poor internet infrastructure, under trained staff etc.)
- Is your region prepared for outbreaks in terms of personnel, commodities and digital infrastructure?
- Who is responsible in the district for ordering for these supplies once there is an outbreak?
- From where are they procured?
- Which budget line is used?
- Which warehouses are involved in distribution?
- Which tools are used in management of the supplies?
- How is the inventory tracked and monitored at the facility / outbreak camp?
- What is the role of partners (WHO, UNHCR, IDI etc) in logistics management during outbreaks
- Do you have access to detailed data on previous outbreaks?
- What logistical challenges do you face? (Internet, accessibility, distances)

III: Last outbreak

- During the last outbreak in your region, how well would you consider the situation was handled in terms of:
    - Response time
    - Treatment of patients
    - Prevention of disease spread
    - Allocation of resources (personnel, commodities etc)
    - Logistics and transportation
    - Diagnosing of patients
    - Testing of bio-samples (speed and quality)
    - Overview of the developing epidemic situation
    - Economy
- Describe the biggest problems and challenges you faced during the last outbreak
    - Are these the same or similar the the problems and challenges you usually face during outbreaks?
- How did the computer infrastructure support your work during the outbreak?
    - What had to be done manually
    - What did not work as intended
    - Did you have to report the same data in multiple places?

IV: Computer systems

- Describe how you use HMIS in your job.
    - During outbreaks
    - After outbreaks
    - When there are no outbreaks
- Do you report, order or look up data in DHIS2 yourself?
- Have you encountered any problems with the computer software?

- Have you used the new DS software in DHIS2?
  - What are your initial impressions?
  - Was it easy to understand and use?
  - Any suggestions on further improvements?
- How does the regional office support the districts in logistics distribution during outbreaks?

Appendix B - Notes from interview with the Disease Surveillance Focal Person for West Nile at the Arua Regional Referral Hospital

Interview conducted Wednesday June 13th, 2018 from approx. 08.30 to 9.30 in subject's office at Arua Regional Referral Hospital.

- Worked at ARH since 2008
  - In charge of organizing DS
  - Second in command of common health at the hospital
- In terms of DS: Plan, monitor, logistics, investigate reporting, build capacity, search for diseases, coordinate health workers, keep an eye on the developing situation, report to MOH, follow-ups.
- Quarterly meetings with stakeholders
- There have been recent outbreaks:
  - Measles (April)
  - Anthrax (May last year – ongoing)
  - Rift valley fever (February)
- Recently a negative result on test for hemorrhagic fever
- The district is not prepared for these outbreaks
  - The district is dependent on outbreaks of ND triggering a response in terms of commodities and logistics
  - Protective gear (PPE) on hand for only hours of an outbreak
  - Lacks capacity for diagnosis, treatment and investigation
- Anthrax outbreak:
  - One year went by from the discovery of Anthrax in the region until proper medicine was dispensed
  - Anthrax was confirmed in May, but it triggered no response
  - Started in one sub-county, has spread to two more.
  - Had to use their own and NGO resources, no help from MOH
  - At least two people confirmed dead from Anthrax
  - Primarily affects animal population, but can spread from animals to humans.
    - Special training, expertise and equipment needed to deal with animals.
    - Informing the public is important to have them report dead animals, and avoid contact with them.
  - Hard to diagnose, misdiagnosed at first
  - Alarms were not raised by local HC, government was not notified
  - Sample should have been sent to lab for testing right away
  - When they did send a sample, they got the result back within a week.
  - The DHO has documentation on the outbreak.
  - The delayed response is the biggest reason for the outbreak still being ongoing.
  - Protocol was eventually followed
- A response plan exists that the MOH is supposed to follow. (Can we get our hands on this Response Plan?)

  - According to response plan, the hospital should have resources to begin the Outbreak Response, and then MOH needs to come in.
- A logistics management plan was created through support from WHO.
- The DHO is responsible for ordering commodities
  - The DHO has a small sum of money earmarked for DO, but need extra economic assistance from MOH, which they will not always receive.
- Supplies and commodities available in the area are distributed between the hospital and the DHO, as well as various NGOs.
  - This stock is maintained by Logistics Officers, using paper-based solutions.
  - Every stakeholder is responsible for their own supply and stock of commodities, no shared responsibility, except for MOH.
  - He says he can get an accurate overview of the total stock on short notice
    - However, having an overview during chaotic outbreaks can be "a bit tricky".
  - Lack of stock is an issue
- The DHO has documentation on previous outbreaks, which can be accessed.
  - These are "not so detailed".
- NGO's and partners working on DS and OR:
  - WHO, UNICEF, IDI, MSF, UNHCR
- Computer systems (eIDSR) have just been introduced
  - Not yet used the system
  - Received training recently
  - Has the user manual
  - Tried to register as a user in the system, but failed. Gave up.
  - "SMS is easier".
  - There is no clear distribution of roles and responsibility in terms of who uses the system for what.
    - Worried that patients could be registered multiple times by multiple users.
    - Alternatively, that cases go unregisters because nobody considers it their responsibility to register.
- Internet connectivity is poor.
  - No internet at the moment, no sure why.
  - "No longer there". "Not sure what happened"
  - Received internet support from a partner, but not sure if that arrangement is still ongoing

Appendix C – Notes from interview with Patient Support Activity Manager, Doctors Without Borders (MSF)

Interview conducted Wednesday June 13th, 2018 from approx. 9:45 to 10.00 in MSF offices at Arua Regional Referral Hospital.

- We were supposed to meet two other MSF representatives, who are involved in DS and OR, but both are away.
- The Patient Support Activity Manager works with ARV diseases, which can include OR, since immune deficient patients are even more vulnerable during outbreaks.
- MSF are involved in handling outbreaks in the district
  - Main MSF mandate is to respond to emergencies
  - Handles all sorts of issues during outbreaks

    - Supports other NGOs
        - For instance, MSF might prepare the camp and tents, while UNICEF provides clean water
- MSF are working on a plan to support emergency kits during outbreaks
- MSF have 26 people working in the area.
- They use their own HMIS system

NOTE THAT THIS INTERVIEW SUBJECT WAS A LAST-MINUTE REPLACEMENT AS INTERVIEW SUBJECT, AND WAS NOT PERSONALLY INVOLVED IN DS OR OR. AS SUCH, THE INTERVIEW IS SHORT AND GENERAL. SEE APPENDIX G FOR A MORE IN-DEPTH INTERVIEW WITH AN MSF REPRESENTATIVE ON THE SUBJECT MATTER.

Appendix D – Notes from interview with Regional Surveillance Officer and Lab Mentor, IDI; Laboratory Specialist, IDI; and Regional Project Coordinator, IDI

Interview conducted Wednesday June 13th, 2018 from approx. 11.00 to 12.00 by telephone from Hotel Desert Breeze, Arua

- IDI's main objectives are to enhance outbreak response through detection, identification, investigation and monitoring, as well as enhancements to reporting, and:
    - Training for health workers and communities
    - Logistics, such as planning transportation
    - Disease surveillance through stats and maps
        - Done in DHIS2
- IDI data officer was involved in eIDSR, but IDI has not yet been involved in the rollout.
    - Have access to the system
    - Still learning, too early for feedback
    - Training was done at district and NGO level
        - Should ideally cascade down to HCs and below
- Identified an anthrax case only two or three days prior to interview through investigation
- Anthrax outbreak has been ongoing since May 2017
    - The district was not prepared for such an outbreak
    - Took a long time for anthrax to be identified
    - Communication and reporting of cases did not happen
    - The MOH has not allocated sufficient resources to handle the outbreak
        - Some MOH resources have been received
    - Anthrax outbreak has affected many animals, and this is the biggest issue
        - Requires trained personnel, different commodities, public awareness campaigns and so on
    - "Some people" died last year from anthrax
    - The situation is not under control
    - Huge logistical and financial issues in anthrax outbreak handling
    - The district does not have sufficient antibiotics to handle the situation
        - Ordering these antibiotics is MOH's responsibility
    - Have not received financial aid from MOH
    - Found out the number of anthrax cases was much larger than reported by the facilities when they investigated the outbreak
    - They need to integrate animal samples into the lab system

    - MOH might have acted slowly or inadequately due to lack of information of the outbreak.
- It is easy to trade commodities with other NGOs in the region.
- In general, during outbreaks, WHO provides logistics, IDI provides training, surveillance and supplies management, UNICEF works on immunization.
- Response time on outbreaks is poor
- Health Facilities underreport and fail to notice Notifiable Diseases
- Sample collection and testing takes at least 72 hours at present
    - Goal is 24h
    - Timeliness is important for a lot of samples
    - Dangerous samples are triple-packaged
    - Sent through a courier experienced in handling medical samples
- No response plans exists, but they are being worked on
    - However, such plans are developed on a district basis, but should ideally be national.
- Information sharing between stakeholders needs to improve
- Active disease surveillance needs to improve
    - Currently weak due to lack of funding
    - Suspects eIDSR will aid in this
- Internet access is a huge challenge in the region

Appendix E – Notes from interview with Public Health Officer, UNHCR

Interview conducted Thursday June 14th, 2018 from approx. 08.00 to 08.45 at Arua UNHCR Headquarters

- UNHCRs mandate is to protect displaced people
- Provides Health and Social services for refugees in West Nile sub-region
- Not an implementing body
- Supervise, organize, oversee and coordinate refugee response together with Ugandan government
- West Nile is currently in a "mixed emergency":
    - Refugees still arrive every day from South Sudan and Kongo
    - Refugees who arrived years ago are still not "stabilized"
    - Over 300.000 refugees living in camps in the region
    - Situation is more stable now – fewer new arrivals this year
- Refugee crisis represents big challenges for DS
    - Lots of young children, pregnant mothers, sick people
        - Many walked for months w/o mosquito nets – malaria
        - HIV/AIDS is common
        - Most are poor
        - Many are not immunized
    - Uganda and West Nile does not have an existing health infrastructure to accept this many new arrivals.
    - Needed to establish immunization programs
    - Nutrition, ambulances, general health services important
- UNHCR does medical screening at the border.
    - Investigate those with symptoms of Notifiable diseases
    - Done by security personnel

        - Given training to look for certain symptoms
    - Identified cholera at border in 2016
    - Enables early identification of epidemic diseases
    - Critical questions asked to uncover possible diseases
        - Esp. people arriving from Kongo, where there is currently an ebola outbreak
    - NGO partners treated patients at the border before
        - Now that refugee numbers are down, the district handles this
- Last year's anthrax outbreak alert was raised by UNHCR
    - Took samples, and confirmed outbreak
    - District was not prepared for such an outbreak
    - New plan needed
    - There might exist a response plan for the district, but it does not trigger funding, and as such is largely useless.
    - Held meetings with government on anthrax outbreak
    - UNHCR response to the outbreak was timely, but they needed help from MOH
        - This help was not given
        - No funds from MOH to handle outbreak
    - Used veterinaries to collect animal samples
- Compiles weekly IDSR reports
    - Using own computer systems, a dedicated HIS for refugees
        - This system works well
        - Government HIS is "fine", but lacks disaggregation opportunities to separate refugees from non-refugees, which is important to UNHCR
    - Duplicate reporting – UNHCR uses own system and government system concurrently
- UNHCR has international procurement of resources and commodities, but also has to rely on national and government supply.
- Their supply is not earmarked refugees in case of an outbreak.
- UNHCR and other stakeholders are currently prepared for further outbreaks
- MOH feels that the districts should handle outbreaks themselves, while the districts feel the MOH should handle outbreaks.
    - The MOH should provide oversight and have a budget for OR
- Somebody should be responsible for all commodities and logistics and have a budget and response plan when an outbreak happens
    - Response is sometimes uncoordinated now
- Plans without an accompanying budget means the district will not do anything.
- Has access to MOH data on previous outbreaks, and the quality of this data is ok
- The threat of outbreaks is real
- Better surveillance systems are needed, with more granular information
- Symptoms of epidemic diseases needs to be picked up and reported earlier
    - Health facilities did not react to symptoms of notifiable diseases
- Normally, WHO and MOH coordinates logistics during an outbreak
    - For smaller outbreaks of common diseases (such as cholera), districts handle the situation and budget themselves, as this happens every year.
- the district does not have sufficient PPE
- If you observe protocol when treating cases, you run through a lot of PPE and other commodities

    - For instance: recently a man died of TB, but had symptoms that reminded of ebola. Required a lot of resources and commodities.
- Shares suspected ND cases with all other stakeholders, including MOH, IPs and NGOs.
- It is possible to have commodities in one region shipped to another in case of an outbreak

Appendix F – Notes from interview with the District Health Officer, Arua

Interview conducted Thursday June 14th, 2018 from approx. 09:00 to 09:30 at DHO offices, Arua

- NGOs are members of the district task force and have different responsibilities
- DHO has a hand in every aspect of DS and OR.
- The DHO must be informed on ND symptoms
- Teams verify if symptoms are confirmed to be of a ND include both NGO and DHO personnel.
- Help provide resources and manpower, as well as transports,
- A response plan exists, but it does not trigger any funding
    - Thus has to rely on partners to handle situation
- The district has some initial stock of commodities such as PPE for a first response to an outbreak.
    - After this, they need to rely on MOH and partners
    - Often, they will not receive additional resources
- Normally, funds for OR and epidemic control are kept by central government
    - Never received such funds
    - Only ever gotten funds and resources from partners/NGOs/UN
- The DHO sends requests for medicines during outbreaks to the MOH
    - Get medicines maybe 70% of the time
        - "If we don't, we talk to our partners"
- Not very familiar with eIDSR
- Biggest DS/OR challenges in the region:
    - Transportation – long distances and poor infrastructure
    - Transportation of samples
    - Establishment of case management
        - Erecting base camps for treatment, immunization and screening
        - Establishing capacity to treat people in the outbreak area
    - Community mobilization
    - Communication
- There is no budget to procure additional medicine during outbreaks

Appendix G – Notes from interview with Clinical Officer, Doctors Without Borders (MSF)

Interview conducted Thursday June 14th, 2018 from approx. 09:30 to 10:00 in MSF offices at Arua Regional Referral Hospital.

- MSF main focus is ARV
- Interview subject's background is in Epidemic Management
- MSF is part of the national task force on OR.
- MSF are planning to establish 48-hour-kits for most ND in the region
    - This means the region will be self-sufficient for the first two days to handle outbreaks
- MSF are monitoring the DS situation
- Constantly looking for symptoms of notifiable diseases
- They have their own supply
    - Biggest warehouse is in Kampala, which is 8h away by road
    - Organizing and sending resources generally take 24h
- "Normally, we get the medicines and commodities we need."
    - Depends on the nature of the outbreak
- They use their own ePol HIS system
    - ePol has data on previous outbreaks in the region
    - Send documents and reports to other stakeholders on paper or e-mail, no direct HIS communication
- They have gotten supplies from MOH, but it usually a lot of supplies come from UNICEF
- Not involved in ongoing anthrax outbreak
- The region is not prepared for outbreaks:
    - A month ago there was a suspected case of Hemorrhagic Fever
        - The response was completely disorganized
        - Hard to bring people to where they were supposed to be
        - No commodities available
        - Hospital director coordinated, but no plan
    - No emergency preparedness plan
    - The hospital says they need resources from the MOH, but this does not happen
    - Very few commodities in stock
    - Hospital does not have space and infrastructure for isolating contagious patients
    - No clear responsibility during outbreaks
        - This is the case in most regions in Uganda
    - "If you don't have a plan, [the district] cannot ask for funds [from the MOH]."
- Rarely have MSF warehouse stockouts, unless unpredicted scenarios happen
- Biggest challenge is lack of reporting from facilities
    - Nobody noticed a recent huge outbreak of malaria
    - District Surveillance Focal Person should have informed the MOH
        - "Perhaps he did not understand the data?"
    - From the dashboard, it was clear that an outbreak was happening, but no ND alert was raised.

Appendix H – Notes from interview with Lab Manager and District Lab Focal Person, and Quality Manager and Deputy Lab Manager, Koboko Hospital

Interview conducted Thursday June 14th, 2018 from approx. 11:30 to 12:15 in Lab offices in Koboko Hospital, 55km north of Arua.

- Koboko is close to refugee camps
- The lab does tests for facilities
    - Not for ND, these must be sent to labs in Kampala
- No ND warnings lately
- Last month was a suspected case of measles, which was later confirmed
- The lab can take samples and then send them to Kampala
    - Triple packing
- eIDSR has not been in use here yet
    - Because they have not needed to report anything
- The biostat is responsible for entering reports.
- Have been using paper up until now
- Got ND reports from HCs in the area and UNICEF, which was compiled by biostat.
- Aforementioned measles was last ND warning, in beginning of May
- Did follow-up testing on children in the area
- Did more active screening during the outbreak
- Have insufficient stock of PPE
    - They order from medical storage, but always receives too little.
    - NGOs supply some additional PPEs, but not enough
- Confirming ND samples takes a long time
    - Transport is an issue
    - Transport of dangerous bio-samples have been done by bus at least twice
    - Takes anywhere from 1 to 5 days to get a result
        - Results are sent back by e-mail
- Doing sample collection and preliminary testing is hard b/c they don't have kits.
- They have internet blackouts that can last for weeks.
    - IDI provides them with airtime, but they always run out before the month is over
    - If lab in Kampala cannot reach them by e-mail, they will follow up with a phone call
    - Will use phones to alert of ND if no internet