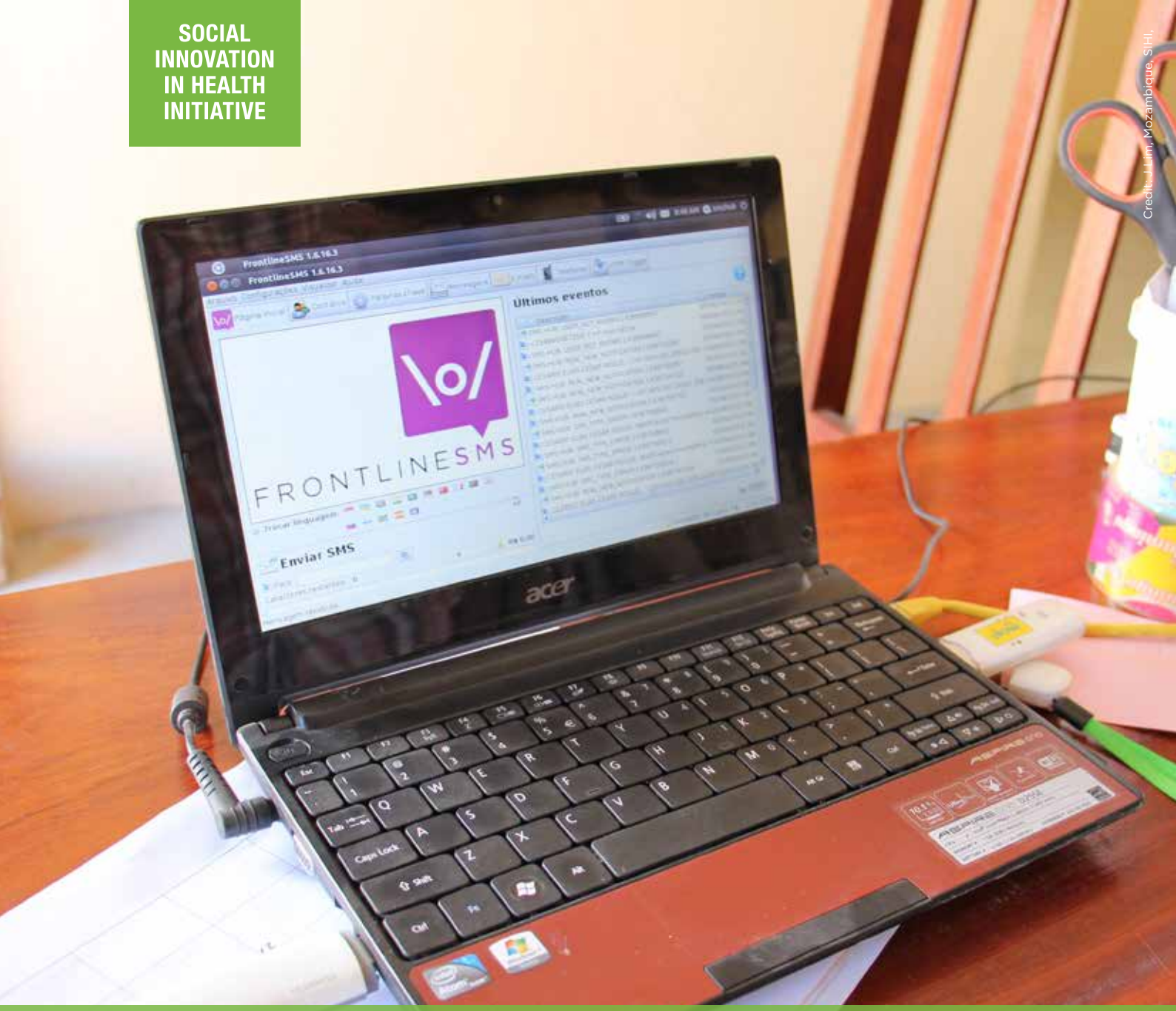
SOCIAL INNOVATION IN HEALTH INITIATIVE



Credit: J. Lin, Mozambique, SIHI

SMS-HUB LEPROSY CASE MANAGEMENT SYSTEM

CONTINENT	Africa
COUNTRY	Mozambique
HEALTH FOCUS	Neglected Tropical Diseases, Leprosy
AREAS OF INTEREST	Digital technology
HEALTH SYSTEM FOCUS	Information systems

SMS-HUB LEPROSY CASE MANAGEMENT SYSTEM, MOZAMBIQUE

A low-cost SMS-based technology system to support district health officials in the monitoring of leprosy cases in Mozambique, allowing for greater efficiency and improved case management.

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This case study forms part of the Social Innovation in Health Initiative Case Collection.

The Social Innovation in Health Initiative (SIHI) is a collaboration by the Special Programme for Research and Training in Tropical Diseases, at the World Health Organization, in partnership with the Bertha Centre for Social Innovation and Entrepreneurship, at the University of Cape Town, the Skoll Centre for Social Entrepreneurship, at Oxford University, and the London School of Hygiene and Tropical Medicine.

This case study was prepared by the Bertha Centre for Social Innovation and Entrepreneurship, Graduate School of Business, University of Cape Town, on behalf of the Social Innovation in Health Initiative. Research was conducted in 2015. This account reflects the stage of social innovation at that time.

SIHI Academic Advisory Panel: Lucy Gilson; Lenore Manderson; and Rosanna Peeling

For more information on SIHI and to read other cases in the SIHI Case Collection, visit www.socialinnovationinhealth.org or email info@socialinnovationinhealth.org.

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CONTENTS

ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
HIV	Human Immunodeficiency Virus
MZN	Mozambique Metical
NTD	Neglected tropical disease
SMS	Short message service
SQL	Structured Query Language
TPH	Swiss Tropical and Public Health Institute
US$	United States dollar
WHO	World Health Organization

CASE INTRODUCTION

The SMS-Hub Leprosy Case Management system (SMS-Hub) is an electronic system that uses a Short Message Service (SMS) to capture leprosy notification data. It is integrated and managed by the Neglected Tropical Diseases Department of the Mozambican Ministry of Health, with support from the local Leprosy Mission.

The SMS-Hub is used as a case management system, as well as a surveillance and monitoring tool. An SMS-based system was deemed most suitable as it does not rely on smartphones and can be used on any basic mobile phone. The system allows district and provincial health supervisors to capture all the case information normally captured in the paper-based register, in one SMS. In addition, basic error checking of the data can be done. All the data is stored on a central database where supervisors can easily access key statistics and clinical details of every leprosy patient. Access to individual patient data, such as patient name, location and disease severity, enhances supervisors' ability to provide follow-up care and ensures that patients are less likely to be lost in the system. It also provides valuable epidemiological information and allows supervisors to report drug stock levels and ensure appropriate distribution of the drug supply across the province. Mapping exercises using the SMS-Hub information enables the detection of hotspots of leprosy and areas of low service coverage. The SMS-Hub is grant-funded and was developed using open-source platforms such as FrontlineSMS and MYSQL, which helped keep the costs low. A user-centred design process was followed by engaging district health supervisors in the creation and evolution of the SMS-Hub. This bottom-up approach allows for continuous feedback and adaption to ensure the system's efficacy and usability.

The SMS-Hub case study shows how simple, low-cost, SMS-based mobile phone systems can improve the efficiency and effectiveness of disease surveillance in settings which previously relied on paper-based record systems. It illustrates how frontline health providers have valuable insights into the challenges affecting service delivery and, if given the space, support and opportunity, could develop novel ideas with scalable potential.

The system is very good. Very good because it allows us to understand the situation in our district. More than the district, we can understand the situation of [the] province, and more than the province, we can understand other districts. You just need to enter in the SMS system to get all the information … The advantage to me is when we have a new patient, we notify it, and the whole country knows that a new case has been diagnosed in Macomia … There are really good advantages for the leprosy programme. (Eleutério Maita, district supervisor of Macomia, Cabo Delgado) (Translated from Portuguese)

1. INNOVATION PROFILE AT A GLANCE

Project Details

Project name	SMS-Hub Leprosy Case Management System
Founding year of project	2011
Founder name	Dr Arie de Kruijff
Founder nationality	South African
Organization name	The Leprosy Mission Mozambique
Organizational structure	Nongovernmental organization
Size	Seven employees, one working on SMS-Hub

Innovation Value

Value proposition	A low-cost SMS-based technology system supporting district health officials in monitoring leprosy cases, allowing for greater efficiency and improved case management.
Beneficiaries	Patients and community members affected by leprosy. District health officials responsible for leprosy case notification.
Key component	• A technology system capturing data through SMS • A database facilitating the tracking and monitoring of leprosy patients

Operational Details of the Project

Main income streams	Grant funding
Cost considerations	Set-up costs of US$ 9 300 and running costs since initiation of US$ 800

Scale and Transferability

Scope of project	Implemented in the Cabo Delgado province in Mozambique. Partial implementation in other leprosy endemic provinces.
Local engagement	The SMS-Hub is integrated and managed by the Neglected Tropical Diseases Department of the Mozambican Ministry of Health, with support from the local Leprosy Mission.
Scalability	The system is appropriate for countries with • a national leprosy control programme, • the presence of a good mobile phone communication system or internet capabilities, • district health officials willing to undergo training.
Sustainability	• The Leprosy SMS-Hub system has been integrated with the National NTD Department • Annual operational costs are low and it requires minimal maintenance • The system's success is dependent on regular usage by district health officials. Currently, the majority of district and all provincial supervisors are properly trained and use the system in the provinces of implementation.

2. CHALLENGES

Leprosy is one of the oldest known diseases. It has historically been heavily stigmatised and has the potential to severely disable those afflicted (Chaptini & Marshman, 2015). In 1991, the World Health Assembly passed a resolution to eliminate leprosy as a public health problem by the year 2000. Elimination is defined as reduction of global prevalence below 1 case per 10 000 population. This was subsequently achieved based on a global average (Fine, 2007). However, at least three countries had not achieved elimination as of 2014, with many more failing to reach eradication (World Bank, 2015; World Health Organization, 2015a). And within a number of countries that have achieved a national average elimination, certain provinces or districts remain problem areas and have not achieved elimination. The achievement of global elimination has arguably contributed towards diminishing interest in the disease, which may have resulted in decreased capacity for monitoring, evaluation and research, a rise in disability in new cases detected, and an increasing delay in reporting a new diagnosis. In many countries, leprosy cases remain persistent, undiagnosed, and untreated (Fine, 2007; Smith et al., 2015).

Recognition of leprosy's remaining prevalence even after reaching elimination led to a call by the World Health Organization (WHO) for renewed political commitment, outlined in the Bangkok Declaration in 2013. The WHO highlighted the need for increased quality of leprosy data, among other elements such as improved logistical capacity, and integration of leprosy control programmes with those of other neglected tropical diseases (NTDs) and primary care services (World Bank, 2015; World Health Organization, 2015b). In Mozambique, a paper-based flow of information is used to document and transmit information across different administrative levels. District supervisors maintain the paper-based registry books and then report the figures to the Provincial Supervisor, who is responsible for manually aggregating all district-level data and passing it on to the national-level bodies involved. These paper records and letter-based communication between supervisors undermine the quality and reliability of leprosy data in Mozambique.

With the rise of mobile phone coverage, Short Message Service (SMS) is one tool that could be used to address the need for better quality leprosy data. Applications of SMS in the developing world have focused on HIV/AIDS and been based primarily in India, South Africa and Kenya, with positive reception by the population (Déglise, Suggs & Odermatt, 2012). Previous attempts have been made to develop a general public health surveillance system and medical data acquisition framework based on SMS (Mondal et al., 2013). Controlled impact studies have also shown the efficacy of an SMS notification system in numerous applications, such as community health worker performance (DeRenzi et al., 2012), and pulmonary function in paediatric patients with asthma (Yun et al., 2012). Implementation of an SMS-based system in leprosy control programmes to ensure continuous monitoring, evaluation, and treatment has been suggested (Al Qubati, 2012; Rachmani, Kurniadi & Hsu, 2013).

3. INNOVATION IN INTERVENTION AND IMPLEMENTATION

Dr Arie de Kruijff, the Country Director in Mozambique for The Leprosy Mission, recognised the need for a more reliable information system for leprosy case management. The existing notification system involved multiple manual, paper-based procedures to produce the necessary statistics for disease monitoring and surveillance. Coupling his own programming skills with the increased mobile phone coverage across Mozambique, Dr de Kruijff developed the SMS-Hub Leprosy Case Management System in 2011. The project goal as captured in the proposal was to improve the management of leprosy in Mozambique by improving the accuracy, reliability and availability of leprosy control information to and from leprosy service providers.

3.1 AN SMS-BASED DATA CAPTURING SYSTEM

The SMS-Hub Leprosy Case Management system is an electronic system that uses a Short Message Service (SMS) to capture leprosy notification data. It is used as a case management, as well as surveillance and monitoring tool. The SMS-Hub was developed using open-source platforms such as FrontlineSMS and MYSQL. An SMS-based system was deemed most suitable as it does not rely on smart phones and can be used on any basic mobile phone.

The system allows district and provincial health supervisors to capture all the case information normally captured in the paper-based register, in one SMS. In addition, basic error checking of the data can be done. All the data is stored on a central database where supervisors can easily access key statistics and clinical details of any leprosy patient. Ready access to individual patient data such as patient name, location and disease severity, enhances supervisors' ability to provide follow-up care and ensures that patients are less likely to be lost in the system. The system also allows supervisors to report drug stock levels and ensure appropriate distribution of the drug supply across the province. Additional functionality enables supervisors to receive notifications of new data entries within an area of responsibility (e.g. a provincial supervisor could opt to be notified when a district supervisor registers a new leprosy case.

Knowledge of the location of cases adds a valuable dimension to the epidemiological information provided by the SMS-Hub. Dr de Kruijff and other users have recently begun to map data to the village level in Cabo Delgado, enabling detection of hotspots of leprosy and areas of low service coverage.

Training has facilitated the adoption and use of the system by district supervisors. Access to the database is only provided to authorised personnel so that patient privacy is protected. Users needs to be registered on the system to access the data and different user lists can be defined with different access rights. Dr de Kruijff acknowledges that this may need to be addressed further in future scaling efforts. A web interface is being explored as a way to provide better encryption, ensure data confidentiality, and offer a more streamlined back-up process.

3.2. TECHNOLOGY DEVELOPMENT IN A BOTTOM-UP APPROACH

From the outset, Dr de Kruijff recognised the importance of engaging and including the district health supervisors in the design and creation process of the SMS-Hub. This bottom-up approach allowed for continuous feedback and adaption to ensure the system's efficacy and usability. From his experiences, Dr de Kruijff learned that issues on the ground ultimately determine the effectiveness of a health intervention, and should be addressed directly.

The answers are not made in isolated boardrooms or laboratories far away. Answers and solutions need to be field-tested and need to be grounded somewhere. (Dr Arie de Kruijff, Founder, SMS-Hub)

3.3. COST CONSIDERATIONS

The Leprosy Mission Mozambique's main funding source is The Leprosy Mission in England and Wales, which is largely funded from individual donors, grants from governments and institutions, community fundraising, and legacies (The Leprosy Mission England and Wales, 2015). The Leprosy Mission Mozambique also partners with the Leprosy Mission South Africa.

The Leprosy Mission Canada awarded a grant of MZN 391 861 (approximately US$ 10 000) to The Leprosy Mission Mozambique, for the development and implementation of the SMS-Hub, beginning in 2011. Start-up costs from two small netbooks, a router, 3 GSM dongles, and training of provincial supervisors lasting around three days (who in turn trained district supervisors) were approximately US$ 9 300. The system's use of open source software, such as FrontlineSMS and Ubuntu, minimises costs and facilitates adaptations as needed.

Annual costs from the required Internet connection and SMSs sent through Clickatell have been approximately US$ 800 to date, thus allowing SMS-Hub to operate on the original funds from the Leprosy Mission Canada. Text messages are sent through Clickatell and cost approximately 2 Mt per message (US$ 0.05 according to an

average exchange rate for 2015) making the system highly affordable for users. Although there is a process set up for reimbursing users for SMS costs, it is not an efficient or transparent process and is something that has been flagged for improvement.

4. OUTPUTS AND OUTCOMES

4.1. IMPACT ON HEALTH CARE DELIVERY

The fact that people seem to use it tells me that it's contributing something to the work that they do … and we see if we used statistics, we see it being used when people go out to the field to do supervision. So we then assume that people are not disappearing through the cracks. People are being followed up and treatment is completed as it should be. So I think in the flow of information and transparency, we feel it has contributed to the better management of leprosy. (Dr Arie de Kruijff, Founder, SMS-Hub)

While no formal impact evaluation has been performed for the SMS-Hub, Dr de Kruijff cites the voluntary, widespread usage of the system as indication that it has a positive impact upon supervisors' work in managing leprosy care. The SMS-Hub has achieved full coverage in its starting province of Cabo Delgado, with full-time use by all 16 district supervisors and the provincial supervisor. The SMS-Hub has also achieved some adoption, albeit not full coverage, in other provinces: according to a 2013 report by the Swiss Tropical and Public Health Institute (TPH), over 70% of district supervisors in the provinces of Cabo Delgado, Niassa, Nampula, Zambezia, and Sofala use the system (Castro, 2013). Dr de Kruijff also notes that while supervisors can use the system to report drug stock levels and holding stakeholders accountable, they do so only in sporadic and irregular fashion, necessitating increased commitment to this aspect of the SMS-Hub to increase the value of drug stock level reports.

The Leprosy Mission Mozambique lacks the capacity to gather all stakeholders and users of the SMS-Hub to perform independent monitoring and evaluation. The system relies on external reviewers such as the TPH to perform the necessary analysis of impact.

4.2. COMMUNITY AND BENEFICIARIES

Dr de Kruijff initially encountered reluctance from the SMS-Hub's potential end users in adopting the new technology in their work. *"At the beginning you had to push it, you had to motivate it, you had to get people to do it, but after a while they kind of clicked when they started understanding it. At the beginning it looked very complicated and they were frowning on it and then they started using it."* (Dr Arie de Kruijff, Founder, SMS-Hub) Since then, the end users of the SMS-Hub have voiced positive feedback, confirming the usefulness of the system in managing leprosy care.

The system is very good, very good because it allows us to understand the situation in your district. More than the district, we can understand the situation of your province, and more than the province, we can understand other districts. You just need to enter in the SMS system to get all the information … The advantage to me is when we have a new patient, we notify it, and the whole country knows that a new case has been diagnosed in Macomia … There are really good advantages for the leprosy programme. (Eleutério Maita, district supervisor of Macomia, Cabo Delgado) (Translated from Portuguese)

The provincial supervisor of Cabo Delgado has also expressed approval of the SMS-Hub, noting improvements in his province's performance.

Yes, it made a difference. My work has improved a lot! Also, the province of Cabo Delgado is considered the first national pilot to test the system, because we have done good work related to the registering of several cases of leprosy at the national level. It is the only province with evidence regarding good control of leprosy. The Ministry of Health, usually, has our information when it is needed, compared to other provinces. (Silvestre João, provincial supervisor of Cabo Delgado) (Translated from Portuguese)

Yet both Maita and João have also voiced concerns about the system. While the SMS-Hub has been uniformly adopted in Cabo Delgado, other provinces, such as Zambezia and Nampula, do not seem to have expressed as much interest. Dr de Kruijff's presentation at a Leprosy Congress also received only limited positive reaction from other countries. Maita and João have pointed out that the system depends heavily upon quality data being inputted from trained users and mobile network coverage; deficiencies in any of these could compromise the system's utility.

5. SUSTAINABILITY AND SCALABILITY

Sustainability is a key consideration for Dr de Kruijff to ensure a lasting positive impact for leprosy patients. Certain technical components will be essential to ensure both sustainability and scalability for the SMS-Hub, including: migration of the database from a physical computer to the Cloud; reliable infrastructure, specifically steady supply of electricity and mobile coverage; advocacy on multiple levels of the health system; and sustained funding, although minimal. The Swiss TPH 2013 report notes that Dr de Kruijff is the sole individual stakeholder with the technical capacity to maintain the SMS-Hub in its current form (Castro, 2013). This has implications for sustainability if he were to leave. While a shift to the Cloud would be advantageous in circumventing the need for a physical computer on the ground, Dr de Kruijff is aware that the technical expertise required is greater than his own. This expertise may have to be sought outside the country, something he has not had time to pursue. Reliable, steady electricity and mobile coverage are necessary as well. According to the Swiss TPH report, 50% of provincial supervisors sampled mentioned problems with mobile network coverage as a hindrance in use of the system. However, the same report expects these barriers to eventually diminish as mobile coverage increases within the country (Castro, 2013).

Aside from technical requirements, the SMS-Hub will also require increased political commitment to ensure both its long-term viability and its potential for scaling. While Dr de Kruijff has been able to engage health workers in Cabo Delgado, doing so beyond the province has proven difficult given his constraints in time and personal priorities. *"At the end of the day you'd need the political commitment a little bit top-down also. … You kind of need a champion on the country level and a champion on the provincial level, and then things can move forward. But you need somebody who is committed."* (Dr Arie de Kruijff, Founder, SMS-Hub)

Sustained financial resources will also be important to ensure the ongoing implementation of the SMS-Hub. While the system's low cost has enabled it to use only the initial grant from 2011, both Maita and João have expressed doubts that the Ministry of Health would be willing to integrate the system into its official budget. The system will need either a financial commitment from the Ministry of Health, or funding from an outside party.

If the SMS-Hub is able to achieve the above-mentioned technical requirements, political support and capital, the system's potential for scaling is promising. Dr de Kruijff hopes to extend current mapping efforts at the village level to the rest of the country. Dr de Kruijff also notes that leprosy care guidelines are standardised by the WHO, making the system appropriate for use in other leprosy-affected countries. Extending the system's scope beyond leprosy to other NTDs would also increase impact and potentially make the mapping of diseases in real-time possible in resource-constrained settings. It may also be possible to introduce additional avenues for accessing and updating the database, such as a web interface, and integrate the system into national health database systems, though this has not yet been fully explored. Dr de Krujff hopes to show the value of the system in a larger forum, such as the WHO or a Leprosy Congress, which may lead to support for pilot projects in other countries.

Privacy considerations will need to be taken if the innovation is scaled. While patient confidentiality has not been a problem in Mozambique, adequate safeguards and encryption will be required if the SMS-Hub expands to other regions or is placed on the Cloud. This is of particular importance in

countries like India, where leprosy is highly stigmatised. There will also be a need for dedicated monitoring and evaluation in any scaling effort, something that Dr de Kruijff lacks the capacity to provide beyond Cabo Delgado. Finally, Dr de Kruijff notes the importance of constant adaptation of the innovation:

One needs to be realistic in terms of a solution today is not a solution forever … In the future, SMS might not be so useful. People might have access to the web, and rather than send an SMS they would like to go on the Internet to notify your case. So if you build in that flexibility and those possibilities into your system so that you don't rely on just one feed, but you see that you are relevant to all ways of doing things. (Dr Arie de Kruijff, Founder, SMS-Hub)

6. KEY LESSONS

6.1. IMPLEMENTATION LESSONS

Getting Started

Reflecting on his experiences implementing the SMS-Hub for the first time, Dr de Kruijff realizes now that it would have been helpful from the outset to adapt the system to include other input streams and maximize access and usability. As he attempts to scale the innovation, he finds that he has less time to modify the system as needed, and feels that involving other experts at the start to make the system more modular and adaptable may have been a worthwhile investment.

Maintaining Efforts

To maintain the SMS-Hub, Dr de Kruijff has recognized the need to place control of the system in the hands of an institution with sustained funding and a vested interest in the system's continuation. Accordingly, he has transferred control of SMS-Hub to the National Neglected Tropical Diseases Department of Mozambique. Dr de Kruijff believes that for a health innovation to have a lasting impact, it is necessary to solicit investment and control from the government.

Overcoming Challenges

Dr de Kruijff encountered initial resistance from potential end users in Cabo Delgado when he began piloting the first iterations of SMS-Hub. Dr de Kruijff found that adopting a bottom-up approach and involving the end users in revising the system was imperative for overcoming initial scepticism and achieving widespread use in the province. Catering to the end user and ensuring an innovation's efficacy in real practice in the field should be performed when implementing a health innovation.

Dr de Kruijff has not yet achieved adoption of SMS-Hub in other Mozambican provinces and countries with high levels of leprosy. Doing so, he notes, would require increased advocacy for the system on the district, provincial, and national levels, which in turn would require more manpower than he is able to provide alone. Both technical expertise and full-fledged advocacy are necessary for implementation.

6.2. PERSONAL LESSONS

Dr de Kruijff credits his unique support network and recognises the value of collaborating with others: *"As a foreigner here in the country, you can't do everything on your own … My local staff has been key and has given a lot of perspective. We have lots of friends also in the missionary community, and that's really been great, great support; without them, we probably would not have stayed around for too long … The support from one's family has been great."* (Dr Arie de Kruijff, Founder, SMS-Hub)

Previously, during the early stages of the SMS-Hub, Dr De Kruijff sacrificed time with his family and friends to push the system forward. While he enjoyed it as an outlet for creativity and as something to break up his typical work routine, he has found that spending time with his family has become more and more of a priority, particularly as he raises three children with his wife. It has thus become even more important to involve others to maintain and scale the SMS-Hub, which still relies heavily on Dr de Kruijff for technical expertise.

CASE INSIGHTS

1. Low-cost, SMS-based mobile phone systems can improve the efficiency and effectiveness of disease surveillance in settings which previously relied on paper-based record systems. Using open source platforms and software helps contain costs.

2. Frontline health providers have valuable insights into the challenges affecting service delivery. These providers, if given the space, support and opportunity, could develop novel ideas with scalable potential.

3. When developing a new national technology system, especially one envisioned for national use, it is important to engage communities, users and external experts so that it is a bottom-up, human-centred design process. This improves adoption as well as adaption based on user-feedback and contextual realities.

4. Although individual champions are incredibly valuable for driving the development and adoption of an innovation, there is a danger for sustainability if only one person is responsible for implementation. Bringing others on board and diversifying the allocation of tasks increases the likelihood that the intervention will be continued beyond the involvement of the original champion.

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