

APPENDICES suppl1

Appendix A

Flow diagram of the sequence of the CHIS Delphi study

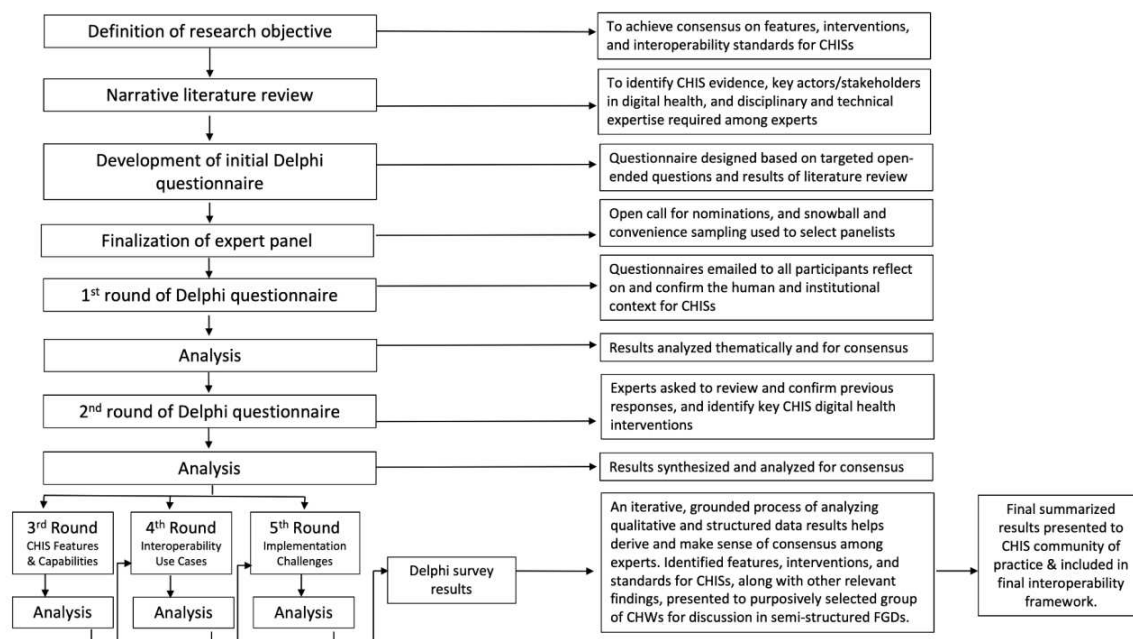


Fig 1. CHIS Delphi study flow diagram

A brief overview of the Delphi study approach is as follows: Based on responses to the first questionnaire (i.e., confirmation that responses have been thoroughly summarized and represented) the study team drafted and sent to the panel of experts a second questionnaire that sought to confirm these responses to ensure they thoroughly represented the range of responses that participants provided and reflect their prioritizations. This allowed experts to reflect on, clarify, and add to the breadth of responses. Each successive questionnaire served to refine, deepen, and elaborate upon the consensus by introducing further depth of input. This iterative and cumulative process of sending questionnaires, analyzing responses, and generating the next round of questionnaires continued up to five rounds.

Appendix B

Panelists were identified through an initial ‘open call’ for nomination of experts to participate in a Delphi study to build consensus on features, standards, and use cases for CHISs. The call was put out through the study team’s list of networks, including, but not limited to: personal and professional contacts, relevant networks and listservs (e.g., the Global Digital Health Network), open/public discussion boards and forum posts (e.g., OpenHIE forum, Community Health Toolkit Forum). The study team reviewed and enrolled applicants on a rolling basis, using snowball sampling to encourage applicants to send the call for nominations to other potentially interested and relevant participants, and/or to nominate other potential panelists. As part of the study team’s narrative literature search, we also identified potential scholars and practitioners from the field of community health and digital health. All participants were recruited remotely via email and asked to complete a (self-)nomination form.

Open call for nomination of experts to participate in a Delphi study to build consensus on features, standards, and use cases for Community Health Information Systems (CHISs)

Nomination DEADLINE: 13 August 2021

This study is part of a project being carried out by a consortium of organizations that include Medic, Dimagi, Ona, and the Community Health Impact Coalition. The consortium will convene a digital health community of practice (CoP) that includes a panel of experts to systematically work towards consensus on key feature sets, standards, and digital health interventions for Community Health Information Systems (CHISs).

Background

CHISs are used widely by organizations and governments in many low- and middle-income countries (LMICs), as well as high-income countries (HICs). The World Health Organization has released a Classification of Digital Health Interventions that lists a number of ways that digital technology can be used by patients, providers, or health system managers to improve health. However, there is not yet alignment on the primary use cases, core functionalities, and interoperability standards for these digital platforms.

The Delphi method is a grounded, robust approach to consensus-building that uses a series of questionnaires administered to experts; and each questionnaire is subsequently adapted based on the responses and analyses of the previous responses. This method is an iterative technique that has been widely used in information systems and health research as a means of obtaining the most reliable possible consensus from a group of experts. The Delphi method was chosen for this particular study because it is useful for situations where individual opinions and knowledge are selected, compared, and combined in order to address a lack of agreement or an incomplete state of knowledge. Through this study, we will identify and document in a structured way commonly supported digital health principles and practices that are deployed in the field today, but not yet commonly agreed upon.

Request for nomination

The panel of experts will include, but not be limited to, (i) digital health implementers, (ii) researchers, (iii) community health practitioners, (iv) government officials, (v) policy experts, and (vi) funders with deep experience in the following non-exhaustive list of specializations:

- CHIS design and development
- CHIS research and implementation
- Community health research and implementation
- Digital health or/and community health policy, governance, and regulations
- Funding of digital health and community health programs

We will seek an approximately even number of women and men as experts to serve on the panel, with diverse representation from different WHO regions (AFRO, PAHO, SEARO, EURO, EMRO, WPRO). While no minimum years of experience are required, we are seeking those who could reasonably be considered experts in the fields of digital and community health.

Anticipated impact and expectations

This study will address an exigent and articulated need by bringing the field of global digital health closer to an operationalized framework of standards and interoperability for community health information systems.

We anticipate that the results of this study will ultimately help establish standards that act as benchmarks for the design and implementation of digital health tools to support community-based service delivery. In turn, we hope these standards will also contribute to greater commensurability and sharing of community health systems data, and the overall interoperability and sustainability of digital health interventions.

Experts serving on the panel will contribute to helping establish these guidelines as a global public good, and will have the chance to bolster one's own expertise while learning from other thought leaders and practitioners in the field.

Experts will participate in no more than 6 rounds of questionnaires, each taking approximately 45 minutes to one hour each. Participants may be involved in other activities, e.g., review of results and manuscript writing, for an anticipated total time of 6-12 hours over a period of approximately 4-5 months. Experts will receive no monetary compensation for participating in the study.

How to nominate yourself or others

Please complete the nomination form by Friday, August 13, 2021.

All experts, whether self-nominated or nominated by another individual, must confirm their interest & willingness to join the panel and participate for the duration of the Delphi study. We kindly request that if you nominate someone else to serve on the panel, that you reach out to them directly to inform them of the study and their nomination as a potential expert.

Experts will receive confirmation of their submitted nomination, and can expect to hear from the study team within two weeks of submitting the nomination form.

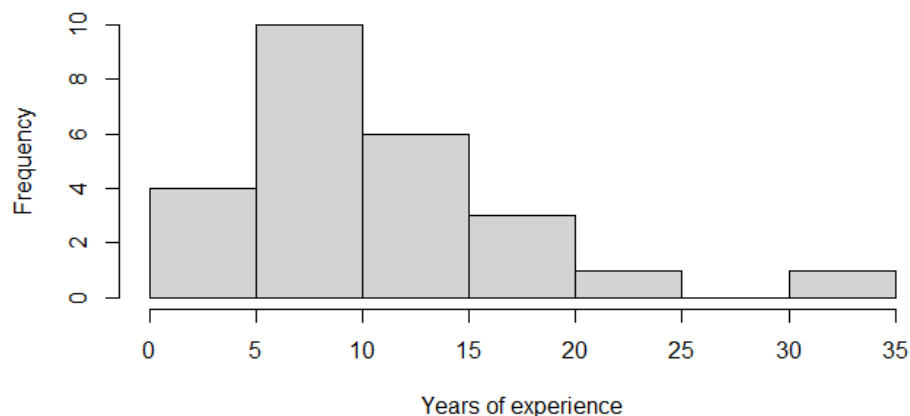
More information can be found on the study's background page and feel free to send any inquiries via email to Isaac Holeman (isac@medic.org) and David Citrin (citrin@medic.org).

Appendix C: Expert panel names and affiliations*, and cumulative CHIS/CH experience

Name	Affiliation
Shreya Bhatt	Chief of Staff, Medic
Mohini Bhavsar	Global Head of Digital Health Partnerships, Living Goods
Ermyas Birru, MS	University of Washington
Joaquin Blaya	VP Clinical Informatics, Accolade
Christina Bowles	Director, Last Mile Health
Vikas Dwivedi	Sr. Information Systems Advisor, The Palladium Group
Carol Kamasaka	Digital Health Advisor, JSI Uganda
Joy Kamunyori	Senior Health Information Systems Advisor, USAID Bureau for Global Health, Office of HIV/AIDS
Alexandra V. Kulinkina	Project Leader, Swiss Tropical and Public Health Institute
Neal Lesh	Chief Strategy Officer, Dimagi Inc
Peter Lubell-Doughtie	CTO, Ona
Akhil Malhotra	Domain Specialist, Thoughtworks
Remy Mwamba	UNICEF
Dr. Jessica Oyugi	Associate Partner / Associate Director Dalberg
Natschja Ratanaprayul	Technical Officer, WHO Digital Health and Innovations Department
Dr. Rashmi Rodrigues	Associate Professor, Community Health, St. John's Medical College, Bangalore, India
Scott Russpatrick	DHIS2 Product Manager, University of Oslo
Kalyesubula Simeon	Monitoring, Evaluation and Learning Strategic Lead at Joint Clinical Research Centre (JCRC/SPHLS), Lubowa, Uganda
Victoria Ward, MD	Clinical Associate Professor of Pediatrics, Stanford University School of Medicine

* Not all panelists completed the final survey and/or filled out acknowledgement information. We thank them for their contributions all the same, and for their commitment to improving digital tools in the service of better coverage, speed, quality, and equity in community health.

Distribution of years of experience in CHIS



Expert Panel Cumulative Experience in Community Health and/or CHIS

Median = 10 years [25th quartile = 6 years; 75th quartile = 15 years]

Appendix D

Table 1 - Summary of characteristics of CHWs who participated in the FGDs.

Gender (M:F)	Countries Represented	NGO vs Government	CHW age (Mean; Range)	Number of years experience as a CHW (Mean; range)	Salaried (Yes:No)	Used digital tools as part of their CHW (Y:N)	Digital tools used
5:5	Uganda; Kenya; Rwanda; Malawi	5:5	41.4; 18	11.7; 13	10:0	6:4	DHIS2, Integrated Community Health Information systems;

							Kobo; Communit y Health Toolkit; RapidPro
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Sampling

We recruited a group of 10 CHWs from Kenya, Malawi, Rwanda and Uganda who were part of the Community Health Impact Coalition network (an international non-governmental organization, chwimpact.org) and who were familiar with community-based research. CHWs were purposively selected to involve a range of geographic locations, past experience with digital tools (including CHISs), a range of ages, and to ensure an equal balance of men and women.

Data collection

The FGDs took place over two consecutive days with 5 CHWs per FGD. Groups were balanced for sex and were designed to contain CHWs who were familiar with each other in order to facilitate open discussion.

To capture a wide range of geographies, FGDs were conducted virtually via the Zoom video conferencing platform. CHWs were reimbursed for their time and the cost of a mobile data bundle to allow them to partake in the virtual FGD via video link. Groups were moderated by a researcher who had prior experience of conducting FGDs with CHWs, and who had reviewed the findings of the Delphi analysis prior to facilitation. A framework for questions was developed by the study team prior to conducting the FGDs, however the facilitator used open ended questions and encouraged discussion amongst group members where possible. The FGDs were conducted in English and recorded with the permission of the CHWs.

Data analysis

The recordings from the FGDs were transcribed verbatim, and a content analysis was performed by two researchers (one being the FGD facilitator). The transcripts were loaded into Dedoose software - a qualitative data analysis software application which allows for coding of data - and re-read to gain a meaningful understanding of the data.

Prior to the data analysis phase, three members of the research team met to decide on core subjects to explore; namely those which overlapped with the Delphi findings, including (i) the current roles and uses of digital tools to support CHWs work (included the benefits and challenges) (ii) key stakeholders who should be involved in the design of CHISs from the perspective of CHWs (iii) Desired features of CHISs (iv) Interoperability of CHISs.

Drawing upon the initial deductive thematic areas of exploration, subcategories were created. Where text was reviewed but did not fit into a predetermined category, a new (sub)category was created, taking an inductive approach. This process was undertaken independently by both researchers responsible for data analysis, who then met virtually to discuss the categories and subcategories and cross examine each other's coding.

FGD findings

Context - current roles and uses of digital tools - including CHIS - to support CHWs work

Whilst six of the CHWs used CHIS in their daily work (including CHW Toolkit, Integrated Community Health Information System (iCHIS) and RapidPro), four CHWs did not have experience of CHISs. The CHWs who regularly used CHISs cited data collection and managing patient follow up and referrals as the primary uses. To a lesser extent CHWs commented on the use of CHISs for disease surveillance and community education.

CHWs cited various benefits around CHISs to support their work, including management of data (e.g. visualizing trends in data, sharing of data, and improved data collection and management); streamlining workflows; the ability for peer-to-peer learning, automated task reminders and tracking their own performance. They also noted several challenges, including technical challenges (e.g. issues

with hardware, connectivity, infrastructure to support charging), digital literacy, a lack of cohesiveness (e.g. multiple digital platforms which were used differently in different areas), costs (e.g. paying out of pocket for data bundles), and accessibility issues with regard to the design of CHIS (e.g. visually impaired CHWs struggling to utilize the platforms due to the small on-screen text).

“Sometimes you are provided with data bundles, but most of the time you are not. You always ...use your own data bundles. So, you know, a Community Health Worker is paid less, sometimes a stipend, sometimes nothing, so you don't have anything to buy data bundles and all these things...” [Female CHW]

“... in my area, we have got one Community Health Worker who is blind, but at the same time has been given a tablet to use to capture data from the community. So, it's very, very tough for her because she has to use ground labor to collect data on her behalf.” [Male CHW]

Key stakeholders who should be involved in the design of CHISs from the perspective of CHWs

There was strong consensus expressed amongst the CHWs that they should be one of the key stakeholders consulted as part of the CHIS design process.

“I can say that involving us is very important because we are the users...nothing should happen about us, without us. And it is very interesting that most of the things that are about us have been happening without us... this is where the main gap has been since the beginning.” [Female CHW]

In general agreement with the Delphi experts, the other key stakeholders identified were government officials - at both a local and national level, community stakeholders (e.g. community leaders and clients) and NGO stakeholders.

Desired features of CHISs

Questions were posed to the CHWs regarding what features they felt would be most important to include in CHISs. Where CHWs did not have first hand experience of using CHISs, they were asked to comment on what they would consider most important in theory.

CHWs were in general agreement with the Delphi experts, citing viewing task lists to track scheduled visits, missed appointments and upcoming activities; viewing patient lists and registers; and creating care plans and workflows as important features. In contrast to the Delphi study findings, there was a sense amongst CHWs that viewing relevant laboratory findings was relevant to their job role and would be a useful function of CHISs. For example, one of the CHWs cited viewing rapid diagnostic test results for malaria as both relevant and important for understanding patterns of disease outbreaks in the areas he served and ways to address this (for example monitoring mosquito net use).

“... let's suppose it's a rapid test for HIV, for malaria, that is necessary for us. Even to share the information. In my village today, I have recorded five malaria-positives. But in my next village, they have tested two or zero malaria. So, at that time, you can even start thinking what steps have been taken in that village to get zero malaria...”

Others cited the ability to view training materials via CHISs (such as audio-visual training tools that could be shared with the community) as being potentially useful features, again in agreement with the Delphi panel.

Interoperability

CHWs were questioned regarding the interoperability use cases for CHISs, as well as potential challenges they envisioned. CHWs were generally in agreement with the Delphi experts, citing communication with central stock management systems being an important interoperability use case. One CHW commented on the need to understand medication stock levels at various health centers prior to referring patients.

“... it will be a good thing if we share the information about the stocks - the drugs... because I'm the one referring patients. I should refer the patient to the hospital knowing that there are drugs.” [Male CHW]

CHWs also anticipated some potential challenges with interoperability based on their past experiences, including issues around data sharing and privacy agreements:

“...I was working with some people from the UK. And it was very impossible to start this until they agreed to share data with the government.” [Male CHW]

A range of exemplar quotes from the CHWs corresponding to the Delphi Surveys can be found below in Appendix C, Table 2:

Table 2 - Select exemplar quotes from the FGDs with CHWs

Theme	Exemplar quotes
Current uses of CHIS	
Data collection	“We use this digital tool to collect data from pregnant mothers and children who have malaria; we collect data from them also. We collect data from children who are diagnosed with diarrhea, malaria, pneumonia, and pregnant mothers, and mostly, the under-five children who go for immunization.”
Managing patient follow up and referrals	“And also, the phone reminds you when the child must be followed up. When you collect his data that he didn't go to the facility to get immunization, the mobile app will remind you that this child went, or you have to follow up to see if he went to the facility to get the immunization or not. So that's the reminders that come or pop up every now and then.”
Surveillance and disease tracking	“...the surveillance and disease tracking, I use my digital tool”

Community education	“when I’m educating my community, I use it...”
Benefits of digital tools	
(i) Data related benefits	
→ Facilitating data collection and management	“It helps in data collection and management. These digital tools enable a Community Health Worker like me to collect, record and manage health data more effectively.”
→ Sharing of data across organizations	“...use of these apps through the digital technology of a smartphone is enhancing the transmission of reports from one level to the other level”
→ Observing trends in data	“...which is called Integrated Community Health Information System, it is quite easy for us to trace the environmental status of the household that we would like to visit. So you can easily scroll through the phone, have at least 20 or 30 households that have got problems with environmental sanitation, then you plan to visit that household and link with that household in order to raise the sanitation bar.”
(ii) Streamlining of workflows	“It’s quite very easy for us to plan an activity for the day because you just go through the tab, you know what activities to be done per day based on the area of interest that you’d like to focus on.”
(iii) Peer-to-peer learning	“It will help me to gain experience from the Community Health Workers in the village there, and from another district, just to share the information and to know how to handle the case in the same way.”
(iv) Automated task reminders	“it reminds you automatically. If it is reminding you, you cannot fail to do follow-up or fail to do other things because it is-- and even if you enter data, it’s very straight and very correct - because you go to the village, you ask the mama to enter

	the data at the same time you do that.”
(v) Tracking performance	“...it's quite very easy for supervisors to monitor individual performance. Now, because supervisors are capable of monitoring the individual performance of each and every Community Health Worker, it is quite very easy for them to boost the productivity of each Community Health Worker because each and every Community Health Worker can be assisted based on his or her individual shortcomings.”
Challenges of digital tools	
(i) Technical challenges	
→ Hardware issues	“So, there was this time when we were given handsets to use but those handsets were too small, and you see, it cannot contain the large information.”
→ Digital literacy challenges	“The first challenge is that most of the Community Health Workers are not much familiar with these smartphones, this technology. You know, if you go straight to the household, then you want to go to the child, you have to go certain steps - maybe 5, 6, 7 steps to go to that child, to get the child and know her nutrition status, vaccines, and whatsoever you can need for her. So, the steps itself is a task to the Community Health Worker who's not familiar with the smartphone.”
→ Infrastructure challenges (e.g. connectivity, charging capabilities)	“The other issue is about network connectivity in Malawi. You go to other areas, it's a very, very remote area that you cannot easily access internet services. So, this is a very, very big challenge in terms of using these smartphones.”
(ii) Costs	“In other ways, yes, sometimes you are provided with data bundles, but most of the times you are

	not. You always most of the times use your own data bundles. So, you know, a Community Health Worker is paid less, sometimes a stipend, sometimes nothing, so you don't have anything to buy data bundles and all these things. That's another challenge that I can mention”
(iii) Lack of cohesiveness	“So, it's not in the whole country, they cover just a few counties that they support.”
(iv) Access challenges (e.g. CHWs with disabilities)	“I would also think of considering these Community Health Workers who are blind. You'll find that maybe in other applications a blind Community Health Worker is having problems using the application just because maybe there's nothing in the application which can be taken by the Community Health Worker. For example, in my area, we have got one Community Health Worker who is blind, but at the same time has been given a tablet to use to capture data from the community. So, it's very, very tough for her because she has to use ground labor to collect data on her behalf.”
Stakeholders to involve in the design and development of CHIS	
(i) CHWs	<p>“ It is very crucial for us to be involved in anything that is about us because you cannot shave my head in my absence. It doesn't add up in any way that you can discuss the digital tools without the person who is going to use it. And that is the way the Global Health fraternity has got it wrong. That is the time that they have hit the wrong point. And I think the main problem that we are facing right now with Global Health Security, it's because of gaps like this...”</p> <p>“ And nothing should happen about us, without us. And it is very interesting that most of the things that are about us have been happening</p>

	without us. And this is where the main gap has been since the beginning.”
(ii) Government stakeholders	
→ Local government	“I think we need to make the local government be engaged in the implementation of this policy...”
→ National government e.g. MoH	“Actually, if you were talking of District Health Officers, maybe ministers and all those people, these things cannot come without their knowledge. As Community Health Workers, we get these things through all those processes. It is maybe designed from up there at the Ministry level, goes down to the district, and up to the District Health Officer. That much we know it happens like that. Maybe that’s why most of the members do not mention about that because that’s obvious. Things cannot not come down without their knowledge.”
(iii) Facility-based healthcare workers	“If you talk of illnesses, IMCI - Integrated Management of Childhood Illnesses, you cannot talk of this without talking to a clinician. So, all these things that we are talking about in the register, in the digital application, are cross-cutting. So, we need to involve all these stakeholders to come together and we brainstorm on how best we can do with this special application.”
(iv) Community members	
→ Community leaders	“What I wanted to add is I’m also suggesting involving the communities themselves. Sometimes, you can have a message, or you can have something for the communities, but you might find that when you take it there, it is rejected. Why? It is just because the community is not involved. So, first of all, to me, I’m suggesting if this development of the new

	<p>applications, or the use of digital tools will have started from the communities. In the communities, we have got local leaders whom we interact most of the time with, as the Community Health Workers. So, we might be having some small meetings with them, discussing with them what is coming in front of them about these digital issues so that maybe in other areas we might be assisted on what best can be done for them to accept it, or for the data to be captured in an effective way.”</p>
→ Clients/patients	<p>“What I wanted to add is I’m also suggesting involving the communities themselves. Sometimes, you can have a message, or you can have something for the communities, but you might find that when you take it there, it is rejected. Why? It is just because the community is not involved.”</p>
(v) NGOs	<p>“ ...a very important stakeholder - non-government organizations. These also have to be consulted because they will come up with a program to say we are supporting something to do with community health. So, they’ll come up with an application that doesn’t reflect some of the ideas that are incorporated in the customized reports that we’re using in our reporting system. So, it’s good to integrate them so that we have a common start.”</p>
Theoretical design features of ideal CHIS	
(i) Viewing a task list to track scheduled visits, missed appointments and upcoming activities	<p>“To me, I think the tool could give you the task. There should be a feature of the task - what you’re supposed to do, and when.”</p>
(ii) Create care plans and workflows	<p>“How we can schedule our work - we record appointments for those pregnant women, we have a reminder which can remind us that we have an appointment with a pregnant woman tomorrow, or in the evening, because we are</p>

	<p>serving as Community Health Workers, but also serving our family for another activity. So, we need those tools of reminder.”</p>
<p>(iii) 2-way SMS messaging between CHWs, supervisors and/or clients</p>	<p>“SMS also is key, because even today we had a meeting of the same - there is somebody piloting SMSing mothers to go to the facility. And these mothers are responding very fast, and they are giving directions of how they can go to the facility...”</p>
<p>(iv) Register of clients and ability to view client records</p>	<p>“...we need to have social demographic information about our community. Just if you point to a name, you get the whole information - How old is she or he? Is it married? Is it malnourished children-- I mean, just to get a status, a quick update about a patient.”</p>
<p>(v) Training materials and job aides</p>	<p>“To me, I think having those training materials on the side is also important. Because sometimes the app can lose its network. You find when a CHW has lacked data or airtime and needs the other resource book - the job aid to do the work, or for reminder.”</p>
<p>(vi) Access to lab tests</p>	<p>“... let's suppose it's a rapid test for HIV, for malaria, that is necessary for us. Even to share the information. In my village today, I have recorded five malaria-positives. But in my next village, they have tested two or zero malaria. So, at that time, you can even start thinking what steps have been taken in that village to get zero malaria and start-- is it because they have adopted to just use the mosquito net, for the moderners? Just to think big”</p>

Appendix G

Concise Essential Reading List

Ballard, M., Bonds, M., Burey, J., Dini, H.S.F., Foth, J., Furth, R., Fiori, K., Holeman, I., Jacobs, T., Johnson, A., Kureshy, N., Lyons, J., Malaba, S., Palazuelos, P., Raghavan, M., Rogers, a., Schwarz, R., Zambrun, J. (2018) CHW AIM: Updated Program Functionality Matrix for Optimizing Community Health Programs. Available: <https://bit.ly/39LLzLi>

Cueto, M. (2004). The origins of primary health care and selective primary health care. American journal of public health, 94(11), 1864-1874. Available: <https://bit.ly/2MNxROO>

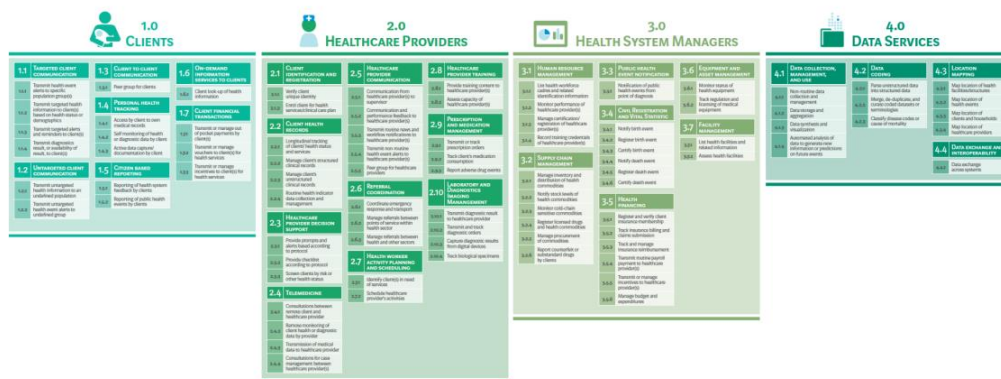
HRH2030: Strengthening Community Health Worker Programs. United States Agency for International Development (USAID). Available: <https://bit.ly/2O3zZCK>

Lefkowitz, B. (2007). Community health centers: A movement and the people who made it happen. Rutgers University Press. Description here: <https://www.jstor.org/stable/j.ctt19qgdq9>

WHO guideline on health policy and system support to optimize community health worker programmes. Geneva: World Health Organization; 2018. Licence: CC BY-NC-SA 3.0 IGO. Available: <https://bit.ly/3jdDUly>

Appendix H

WHO Classification of Digital Health Interventions



Source: Classification of digital health interventions. Geneva: World Health Organization; 2018(WHO/RHR/18.06). License: CC BY-NC-SA 3.0 IGO. Available here: <https://fd.ax/3Po>