Unmet Needs in Health Data in Low-Resource Settings

Data gathered in July 2020 unless otherwise indicated

Objectives

- Describe fundamental digital health actors and decision-makers.

- Identify key unmet needs in the LMIC health context and investment trends for select clients with a focus on care management.

- Landscape current digital health and data sector to understand how needs are currently being met.
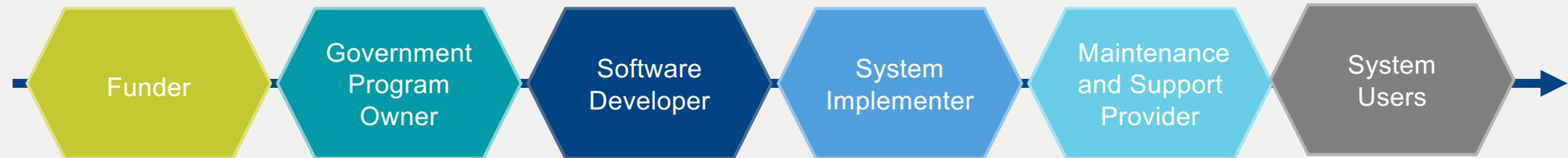
Recap: Value Chain Analysis

Recap: Methodology

Vital Wave and PATH teams conducted secondary research and 73 in-depth interviews with global subject matter experts and country actors. Data was analyzed using consistent value chain frameworks.

Value Chain Assessment

View market factors through the lens of the software value chain to determine incentives and disincentives for private-sector engagement and opportunities for global goods and develop actionable recommendations.

Funder → Government Program Owner → Software Developer → System Implementer → Maintenance and Support Provider → System Users

Expert Interviews- 15

- Supply Chain Information Systems
- Electronic Medical Records
- Master Facility Registry
- Lab Information Systems

Inform understanding of value chain actors, dynamics, and ecosystems at the global level

Country Interviews- 58

- Mozambique - 13
- Kenya – 21
- India/Uttar Pradesh - 24

Inform contextual use and deployment of digital tools in each value chain in a variety of market maturity levels

The three countries represent varying degrees of digital health market maturity and allow for extrapolation of conclusions from Mozambique, Kenya, and India to these digital health maturity levels more broadly.

Value Chain Roles

In LMICs, roles in the digital health value chain can be played by actors in the public, private, and NGO sectors.
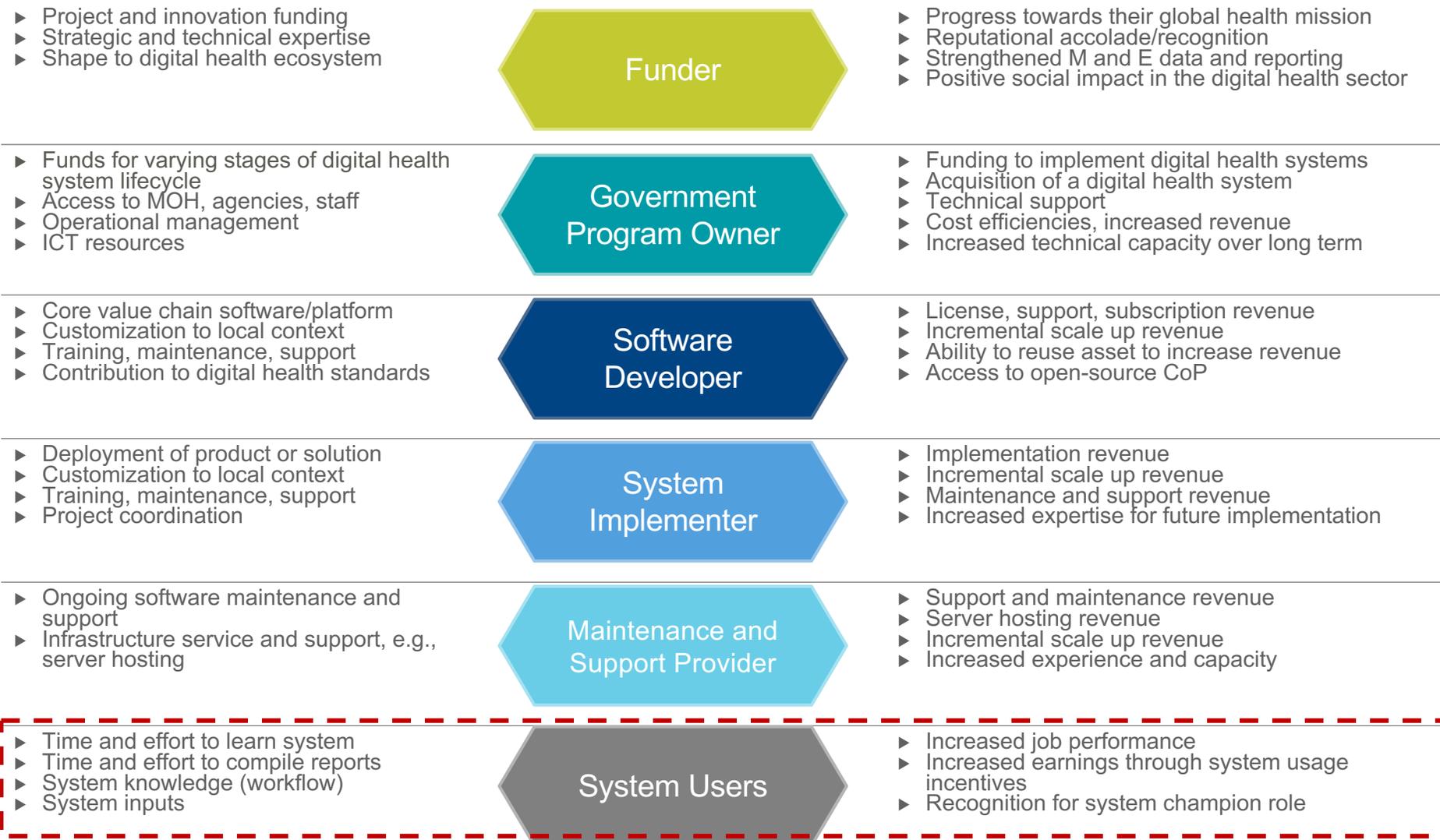
Role	Overview	Examples
Funder	**Provides short or long-term funding**	▸ Bilateral and multilateral aid agencies ▸ Foundations ▸ Governments
Government Program Owner	**Represents government program needs and oversees implementation**	▸ Government ministries or agencies (national, subnational level)
Software Developer	**Performs core software development and maintenance; may contribute to software customization and support**	▸ Global software companies ▸ Regional software companies ▸ Local software companies ▸ Government Health IT staff
System Implementer	**Manages software adaptation against program goals and initial deployment, often including training, partner management, and support**	▸ Global software companies ▸ Regional software companies ▸ Local software companies ▸ Government Health IT staff
Maintenance and Support Provider	**Provides ongoing system maintenance and support, including system and infrastructure upgrades**	▸ Software/Platform developer ▸ System implementer ▸ Government Health IT staff
System Users	**Utilize the solution software, often healthcare actors**	▸ Suppliers ▸ Government system administrators ▸ Central Medical Stores, Laboratories ▸ Warehouses, Transport/Logistics ▸ Facility users, e.g., health workers

Gives and Gets Underpinning Net Utility (ROI) for digital health

Value chain analysis looks at the balance of gives and gets for actors at a moment in time; the ability of a market to sustainably deliver a solution depends on maintaining positive net utility over the long term.

Typical Gives (Costs)

Typical Gets (Benefits)

Funder
Gives:
- Project and innovation funding
- Strategic and technical expertise
- Shape to digital health ecosystem

Gets:
- Progress towards their global health mission
- Reputational accolade/recognition
- Strengthened M and E data and reporting
- Positive social impact in the digital health sector

Government Program Owner
Gives:
- Funds for varying stages of digital health system lifecycle
- Access to MOH, agencies, staff
- Operational management
- ICT resources

Gets:
- Funding to implement digital health systems
- Acquisition of a digital health system
- Technical support
- Cost efficiencies, increased revenue
- Increased technical capacity over long term

Software Developer
Gives:
- Core value chain software/platform
- Customization to local context
- Training, maintenance, support
- Contribution to digital health standards

Gets:
- License, support, subscription revenue
- Incremental scale up revenue
- Ability to reuse asset to increase revenue
- Access to open-source CoP

System Implementer
Gives:
- Deployment of product or solution
- Customization to local context
- Training, maintenance, support
- Project coordination

Gets:
- Implementation revenue
- Incremental scale up revenue
- Maintenance and support revenue
- Increased expertise for future implementation

Maintenance and Support Provider
Gives:
- Ongoing software maintenance and support
- Infrastructure service and support, e.g., server hosting

Gets:
- Support and maintenance revenue
- Server hosting revenue
- Incremental scale up revenue
- Increased experience and capacity

System Users
Gives:
- Time and effort to learn system
- Time and effort to compile reports
- System knowledge (workflow)
- System inputs

Gets:
- Increased job performance
- Increased earnings through system usage incentives
- Recognition for system champion role

Deep dive: System Users

Personas display different user types

Fatuma is a community health worker.

She visits homes to educate the village about health issues.

She tracks births, reminds parents to take their children for immunizations, and teaches people how to prevent illnesses.

To Fatuma, digital health means…

o She reports births to the local clinic and receives immunization reminders via SMS.

o She receives information about health campaigns and disease outbreaks quickly.

o Critical information can be provided to her community in a timely and coordinated way.

Better data systems link health services to the community.

Ruth and her daughter live in a village with no health facilities.

- She must take time away from her family's farm to bring Esther to the clinic.

To Ruth and Esther, digital health means…

○ Ruth is alerted via SMS when it is time for Esther's immunizations.

○ Medicines and supplies are available for Esther when they travel to the clinic.

○ If Ruth goes to a different clinic, Esther's records will not get lost.

Better data systems result in better patient services.

Lucy is a nurse at a local clinic.

In addition to attending patients, she is responsible for record keeping, reporting, and ordering equipment.

She uses paper and pencil to track all her records and must complete a handwritten report to the district each month.

Photo: PATH/Will Boase

To Lucy, digital health means…

o Outdated paper and pencils registries are replaced by digital tools.

o She has visibility into which children are missing lifesaving vaccines through automatically generated reports.

o Equipment inventory and order planning are simplified.

o She can spend more time attending to patients.

Better data systems lead to better use of time and resources.

Photo: PATH/Will Boase

Abdu is a District Health Officer.

He plans, manages, and monitors health programs in his district and coordinates with the Ministry of Health.

He spends many hours working at the district level to improve data management and quality.

To Abdu, digital health means…

o District-level data can be aggregated quickly into reports.

o Accuracy and quality of data are improved.

o Decision-making and planning around program budgets, supplies, and staffing are facilitated.

Better data systems strengthens programs.

Joseph works for the Ministry of Health.

He is responsible for estimating and ordering medicines and health commodities for the country's immunization program.

He ensures that the national medical store is fully stocked.

To Joseph, digital health means…

o District-level data can be aggregated quickly into reports.

o Accuracy and quality of data are improved.

o Decision-making and planning around program budgets, supplies, and staffing are facilitated.

Better data systems lead to better use of time and resources.

Stakeholder Types Within Data Sciences

Health systems continually improve core functions through health system strengthening activities.

Human resources | Health finance | Health governance | Health information | Medical products | Vaccines | Technology | Service delivery

PROBLEM IDENTIFICATION	DATA CAPTURE	DATA TRANSFORMATION	DATA FOR IMPACT	HEALTH SYSTEM IMPROVEMENTS
Kumar	**Arjun**	Kumar uses data he received from the districts to assess existing supplies of malaria tests and medication.	Kumar orders additional supplies for districts and arranges distribution before the monsoon begins.	The additional supplies ordered by Kumar help prevent stockouts during the monsoon.
Deputy Director of Malaria Interventions, India	District Health Officer, India			
Kumar wants to understand malaria testing and treatment resource needs leading up to the monsoon season. He requests weekly updates on malaria cases from districts.	Arjun assesses the available data at a district level and new tools that can provide more granular data to meet Kumar's request.	Arjun shares these data with his district-level colleagues and identifies a trend in cases.	Arjun mobilizes a test-and-treat campaign in one community.	Arjun continues to monitor data regularly to inform further test-and-treat campaigns.

HEALTH IMPACT

Stakeholder Types Within Care Coordination and Delivery

Health systems continually improve core functions through health system strengthening activities.

Human resources | Health finance | Health governance | Health information | Medical products | Vaccines | Technology | Service delivery

PROBLEM IDENTIFICATION	DATA CAPTURE	DATA TRANSFORMATION	DATA FOR IMPACT	HEALTH SYSTEM IMPROVEMENTS
Rehema Health Facility Supervisor, Kenya	**Joyce** Nurse, Kenya	Rehema uses data she received from the facility to determine if more human resources are needed.	Rehema requests additional nurses to be sent to the clinic to meet demand.	The additional nurses help decrease staff burnout and help the facility meet their immunization targets.
Rehema wants to understand if a health facility is reaching its immunization targets following a campaign. She requests an update from the facility on patient visits.	Joyce registers all patients and records their immunizations in an electronic immunization registry. When a patient comes to the clinic, she can see their visit history.	Joyce can identify that there has been an increase in patients visiting the facility and shares these data with the supervisor.	Joyce can identify patients behind on immunizations and follow up with them to come to the clinic now that more nurses have arrived.	Joyce continues to monitor data regularly to see if there are significant increases or decreases in patient visits.

HEALTH IMPACT

Care Management Unmet Needs Assessment

Primary market research overview

Questions for Primary Research

The primary research focused on health data as they relate to the continuum of care and care management in LMICs. The aim was to gather information from individuals capturing health data (community health workers, physicians) and decision-makers who choose to adopt and implement digital health tools.

Research questions:

1. How are products chosen to adopt and scale?
2. How are health data collected and stored?
3. How are health data being used?
4. How could health data be used?
5. What are the key unmet needs?
6. What are the barriers to entry?
7. What is the scale of this problem?

Methods

We conducted hour-long interviews virtually. Due to the short timeline, we prioritized availability and included proxies for end users and decision-makers.

End users

- Physicians.
- Software developers
- Managers for community health workers.
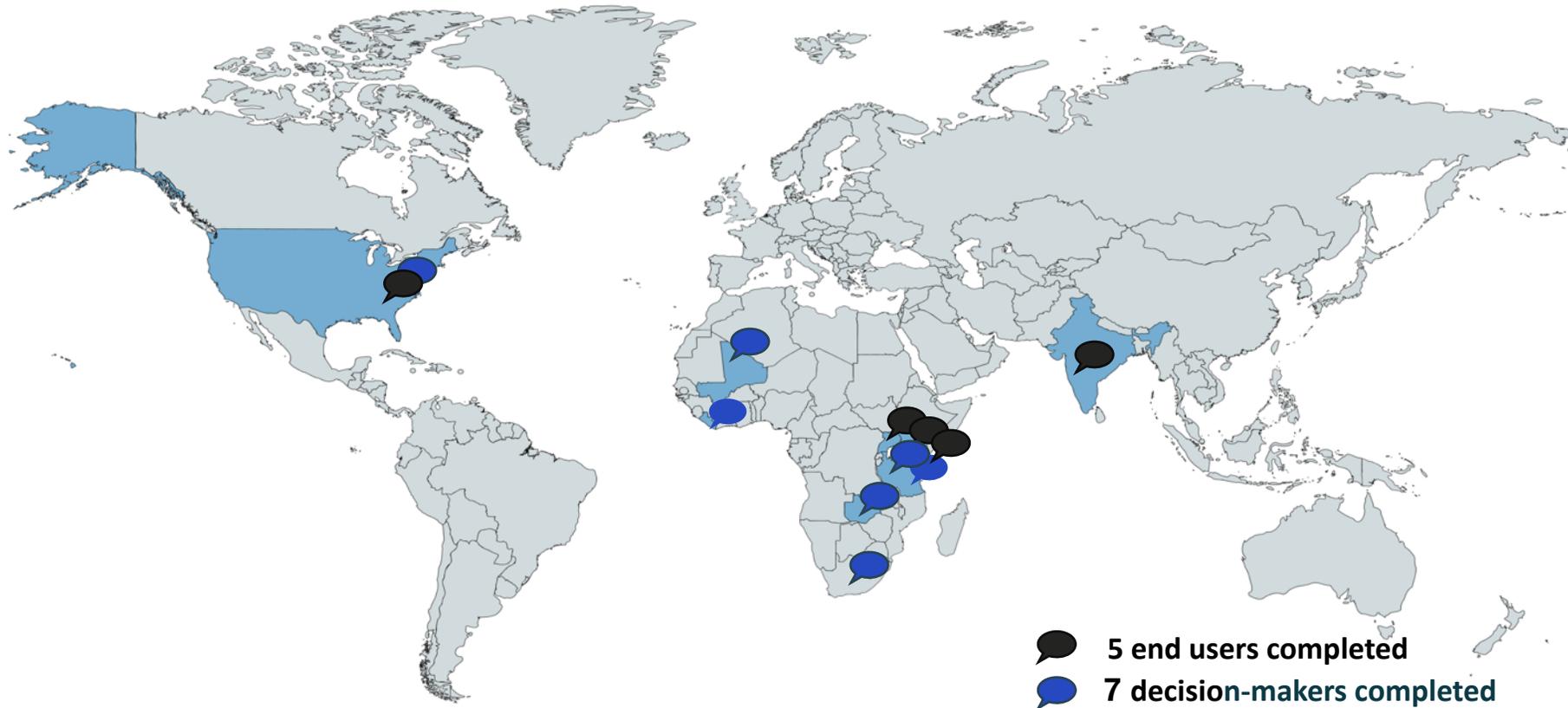- Advocates for community health workers.

Decision-makers

- CEOs of private hospitals.
- Advisors to the MOH.
- MOH officials working in ICT.
- Technology leads at nonprofits deploying digital solutions.

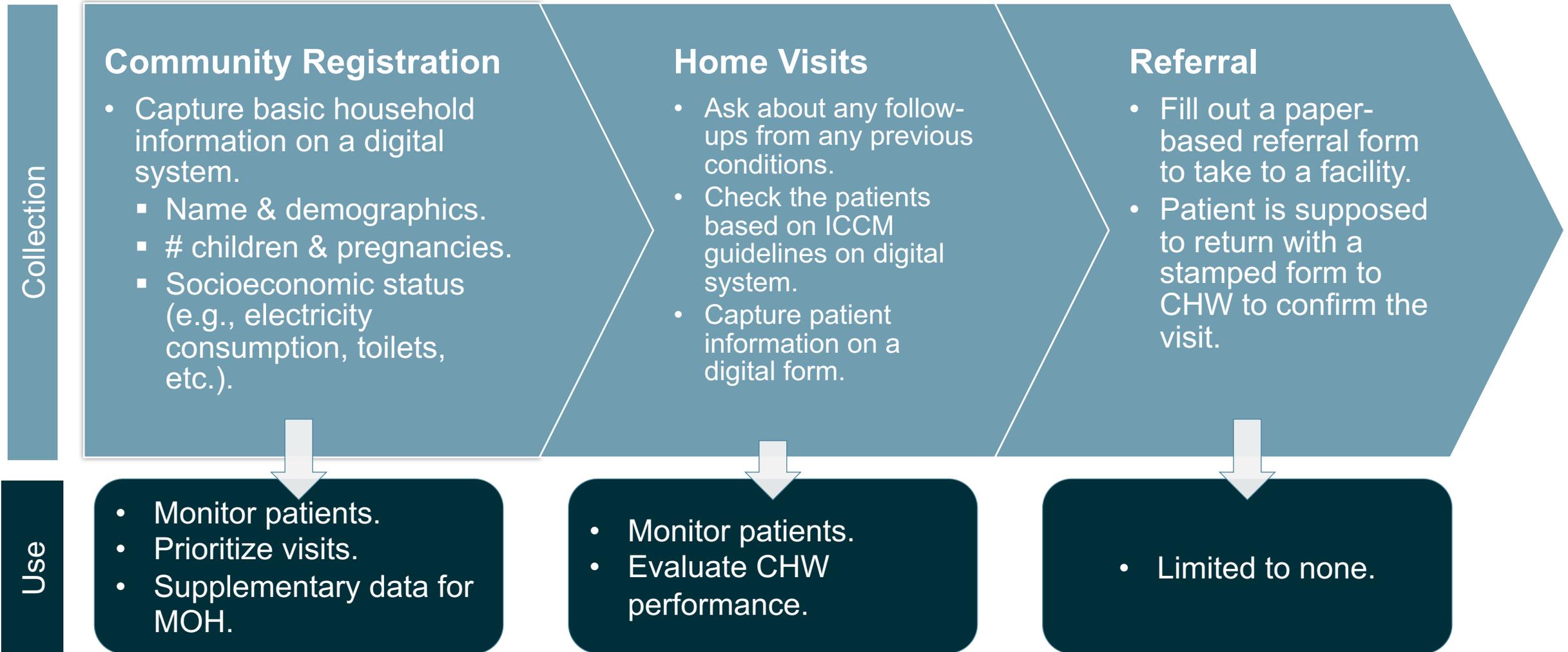# Limitations to Needs Assessment

- The sample size for this analysis is limited to 11 individuals and may not represent all perspectives.

- Participants had a heavier representation in Africa than in other LMIC geographies, with some countries represented with multiple individuals.

- The research took place during a global pandemic, which possibly skewed the results.

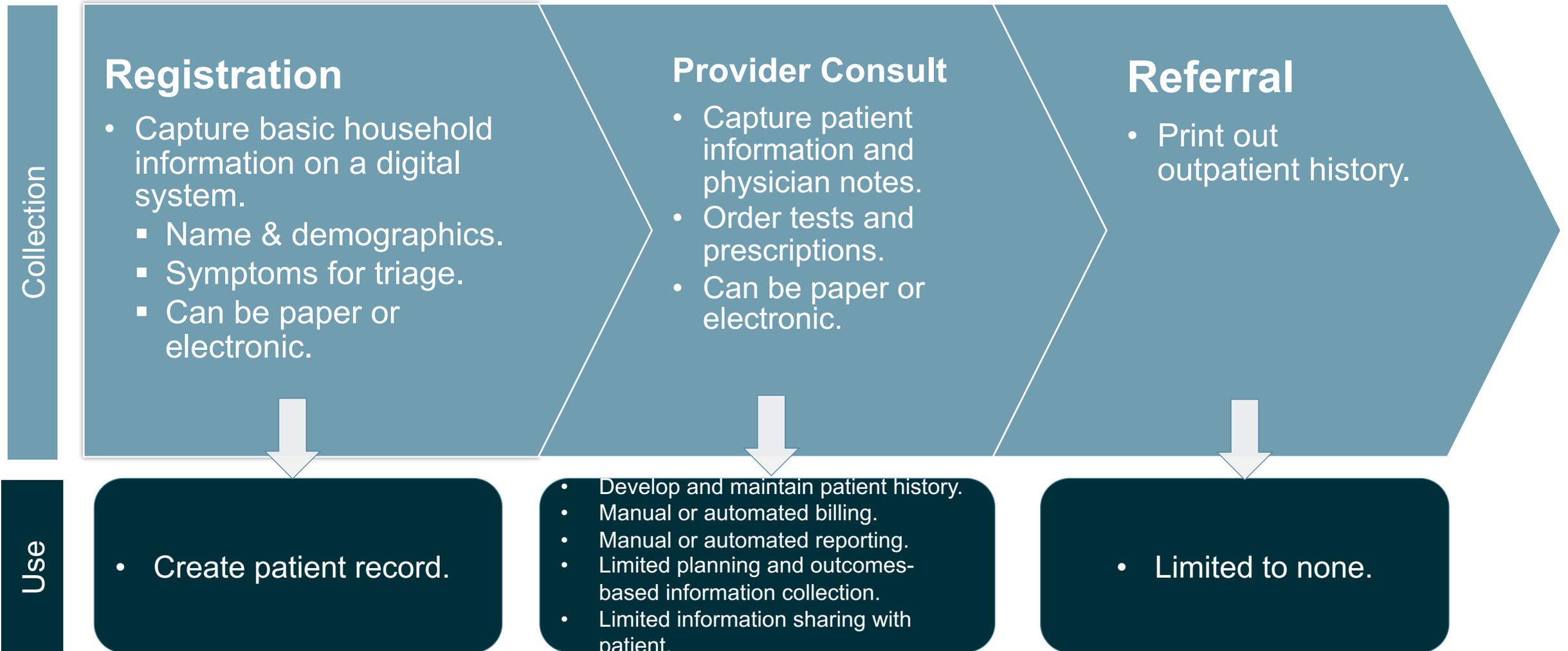# Map of Interview Respondents' Locations

5 end users completed

7 decision-makers completed

Created with mapchart.net ©

Health Data Journey: Community Health Workers

Collection

Community Registration
- Capture basic household information on a digital system.
  - Name & demographics.
  - # children & pregnancies.
  - Socioeconomic status (e.g., electricity consumption, toilets, etc.).

Home Visits
- Ask about any follow-ups from any previous conditions.
- Check the patients based on ICCM guidelines on digital system.
- Capture patient information on a digital form.

Referral
- Fill out a paper-based referral form to take to a facility.
- Patient is supposed to return with a stamped form to CHW to confirm the visit.

Use

- Monitor patients.
- Prioritize visits.
- Supplementary data for MOH.

- Monitor patients.
- Evaluate CHW performance.

- Limited to none.

Health Data Journey: Facilities

Collection

Registration

- Capture basic household information on a digital system.
  - Name & demographics.
  - Symptoms for triage.
  - Can be paper or electronic.

Provider Consult

- Capture patient information and physician notes.
- Order tests and prescriptions.
- Can be paper or electronic.

Referral

- Print out outpatient history.

Use

- Create patient record.

- Develop and maintain patient history.
- Manual or automated billing.
- Manual or automated reporting.
- Limited planning and outcomes-based information collection.
- Limited information sharing with patient.

- Limited to none.

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Data Collection and Storage

Paper-based systems

- Facilities using paper-based systems use simple ledgers, which include:
  - Name
  - Age
  - Symptoms
  - Single line for diagnosis
- Each program or disease vertical will have its own forms.
- Referral forms include symptoms and diagnosis.
- Forms are stored at the facility.

Digital systems

- Facilities with EMR systems collect a more comprehensive patient history, including:
  - Symptoms
  - Tests
  - Physician notes
- There is a debate between using local servers versus cloud storage. Factors under consideration include:
  - Storage space
  - Perceived data privacy
  - Cost
  - Capacity building

Care Management Unmet Needs Assessment

Primary market research key themes

Existing Systems Are Siloed, Creating Inefficiencies

"If the MOH is capturing some data, all the partners will want to collect the same information. So one CHW will have 3 or 4 phones with different software to collect the same information." (International NGO, no specific maturity level)

"Patients are given a new patient number at every interaction because finding files is difficult, and mistakes happen. You get different patient numbers too—you get a TB patient number and a malaria patient number. They have to collect the same data over and over again." (Maturity level 3)

"[For a referral], you get a referral sheet with your diagnosis. When you get to the facility, they will create a new record at their facility, collect all your basic information. They are supposed to use your same patient number. There are mistakes all the time and this does not happen." (Maturity level 3)

- There are many digital health solutions for CHWs, disease verticals, and facilities.

- Digital systems often do not have the ability to interact with other digital systems

- Patient history is limited as there are not continuous records, especially as it is shared across facilities and verticals.

- Data collection efforts are duplicated.

Unreliable Access to Internet and Power

"We look at solutions that say offline functionality, but they require an SMS and downloading from a link. We work in areas where it takes to 2 days to walk to the nearest cell tower, and you will not be able to download anything." (Maturity level 1)

"Right now, we capture information on paper and then type them into the EMR." (Maturity level 2)

- Internet connectivity remains a problem in many rural areas, making digital solutions challenging for clinics and remote workers.

- Connectivity challenges also means that paper records are deemed necessary in the event of Internet or power failure.

Interactions Vary Across Users

"We call them 'BBC'—born before computers." (Maturity level 2)

"When you have a patient load like we do, it is hard to sit down and type up notes." (Maturity level 2)

"At first there was quite a bit of resistance using computers. Many people feared the computers." (Maturity level 2)

- Physicians find it challenging to connect to patients with a computer between them.

- Physicians with a high patient load may not have time to capture information in an EMR in between patients.

- Older health workers do not like typing. The high workload combined with their low typing speed is enough to keep them committed to paper.

- For CHWs, they may appreciate having the phone. However, despite training, they might not understand how to use the software.

- In locations where paper records are still deemed necessary, EMRs just add to the workload.

Data Use Is Currently Limited Due to a Variety of Factors

"For CHWs, data is a black box." (International NGO)

"Appetite to use data is limited because our tools are not very intelligent." (Maturity level 3)

"We put information in DHIS2, but it does not tell us anything and the data accuracy is not good....Even funders prefer to use demographic health surveys to provide better estimates of health data, rather than the DHIS information." (Maturity level 4)

"[At our private facility], we have only used data for outcomes-based information." (Maturity level 2)

- For CHWs, data collection is mostly unidirectional. Data are collected for M&E. This includes monitoring CHW performance and informing program design. It does not inform their day-to-day work.

- In public facilities, electronic records are just digitized paper forms. They too are mostly used for M&E. They must be aggregated, manually or digitally, to be shared with the MOH.

- Data are not considered clean or accurate.

- Even in private facilities with EMR systems, data use is limited to outcomes-based analysis and some planning.

Barrier to Entry: Solutions Are Not Yet Sustainable

"[We] look at the cost of management and scaling. Can it manage my intended load? Can it be managed (do we have the knowledge to manage it) locally? Can they afford for someone else to do it? Do I have to pay for everything? What are the contracting structures?" (Maturity level 2)

"The big challenge is you have devices out there you need to upgrade. You need software. That was a lesson learned. Everything is fine if you have 10 tablets. If you have 1,000 and then you need to upgrade, that is a problem." (International NGO)

"The problem is that DHIS2 was not built for this data volume. We had to build on top of this….Funders do not want to fund infrastructure." (International NGO)

"Liberia is willing to wait for a standardized solution. They have seen the challenges other countries are facing." (Maturity level 1)

- There are many pilots but no scalable (or enterprise) solutions.

- Decision-makers have learned their lesson with respect to costs and load. They need to understand long-term costs, especially when the funders move on to other projects.

- This includes not only the cost of the software, but also hardware solutions.

- Sustainability also includes local capacity to maintain and build on the digital tool.

- Countries are still debating policies and standards for digital tools. The ecosystems are in flux.

- There is also a sense that it is not easy to evaluate software and hardware tools.

Value in Automation and Integration

"Doctors like ordering labs on the system." (Maturity level 2)

"We want to link the critical care unit and those devices to the desk and have remote log-in for a doctor to check on a patient. We want patients to be able to log in and look at their information." (Maturity level 2)

"Templates can make data entry easier; we have dashboards that I can see and will flag if you missed something, which is especially useful for new physicians." (Maturity level 2)

"We are trying to transition to completely to electronic. Temperature and observation charts are still done on paper. I'm not sure if this is [because of] the human being or the software. I think these parts are not very user friendly. (Maturity level 2)

"We want to integrate our systems. We are improving the layers so we can talk between the different systems. Tanzania health enterprise architecture is important." (Maturity level 2)

- For facilities with digital systems, integration across departments was important. It simplifies ordering tests and prescriptions, reviewing patient information, and billing.

- There is value-add in mandated fields, as it makes it easier to capture all necessary information.

Key Themes Summary

- Challenges are uniform across the regions tested:
  - Systems are not interoperable
  - Internet and power remain challenges
  - Comfort with digital tools varies across age and literacy

- Unmet needs are also uniform across the regions tested:
  - Easy-to-use dashboards and data visualizations
  - Integration across departments and automation
  - Clearly defined long-term cost and management structures (may be unique to MOHs)