

Strengthening Data Availability for Community Health Programming - A Review of Current Practices

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Abstract

There is always a fair amount of data collected, analyzed, stored and disseminated in various formats in the national health systems. In most cases, district and national health management teams are tasked by law to generate quality data for planning, budgeting, programmatic decision making and to respond to requests and needs from stakeholders such as donors. Valuable community health data should be ready-to-use at the point of service delivery and ideally at the household and community levels for real time decision making to improve performance and outcomes. Donors need evidence to measure progress towards the achievement of their objectives, and also to advocate for additional resources. The need for community data fluctuates temporally due to environmental, behavioral, economic, social and political factors. Data collection, management and analysis should be timely, constantly updated and tailored to reflect these fluctuations. Findings from multiple demographic and health surveys (DHS) that collated and analyzed large datasets from households, have shown the importance of collecting quality data, improving their availability and dissemination to build awareness of communities about emerging health issues, and to stimulate and increase data utilization for health programming especially in areas or contexts where there is no or little relevant information. We reviewed current community data collection and management practices, analyzed various sources of data, data usage, formats and performance indicators. We noted that community data ownership is key. Communities who generate health information, should be able to use their own data their data for self monitoring, program planning and implementation in collaboration with local health facilities.

Keywords: *community data – community health -home visits – data capture - data dissemination - community health worker.*

Introduction

One of the critical principles for the institutionalization of community health is the “*integration of community data into the health information system, including investment in innovative technology*” - Institutionalization of community health conference – Johannesburg, South Africa 2017 (11). Community data are information collected at the community level including data collected during home visits. Community data are generated in various sectors, domains and mostly in the social sciences such as community/village mapping, demography, anthropology and socio-economy. Public health programs are collecting data for planning, monitoring, resource mobilization and accountability. Quality data are indispensable for filling knowledge gaps, but also for determining the needs for additional information necessary for action. Scott et al (33) have defined community health worker as a person with the following characteristics i) has a supportive function in health service delivery, including provision of direct health services, health advocacy, and community agency ii) is directly connected to the communities the CHW serves, living in the community and accountable to the people there iii) has a lower level of education than trained health workers such as doctors and nurses. Health information collected at the household and community levels by community health workers (CHWs) are necessary for demonstrating efficacy, success, potential for replication and scale up (33). Also, community data could be used for advocacy targeting community leaders, donors and other stakeholders. However data are not always comprehensive, detailed and granular enough for full understanding by community actors who are more often low literacy. The Malawi Health Equity Network (MHEN) has demonstrated that it is critical to disseminate and make data available at the community level for accountability purpose, but also to enable community leaders to use the power of

data-driven interventions (9). For partners and donors' perspective, the evidence of return on investment or the possibility of leveraging promising community health interventions is attractive. However, this attractiveness is only possible if the data collected is exhaustive with full disclosure in terms accuracy, transparency and ethics. In addition, the process of obtaining valid and reliable data should be cost-effective and must reflect all the resources deployed including human and financial efforts.

There are several experiences highlighting the importance of improving data availability for decision making at the community level. Due to significant improvements in data availability and dissemination, the progress made in global health programs has gain momentum in showcasing progress and challenges especially in developing countries (15).

i) Micro and targeted data at the community level are necessary to understand the persisting hotspots of schistosomiasis (SCH) in many endemic countries where despite the declining burden of SCH following decades of mass treatments, the prevalence is still above treatment thresholds. Disaggregated data by age and gender as well as social and environmental and anthropological data are important to understand the issues of persisting hotspots and to propose local remedies. (20).

ii) Making data available implies minimizing missing opportunities to collect data. The “*systematic identification of the need of the client*” was a strategy introduced in family planning (FP) programming by *The Challenge Initiative* (TCI) in nine Francophone West African countries to systematically include questions and conversations around FP, maternal and child health to generate demand for services whenever a woman of reproductive age makes contact with primary health care facilities, community health volunteers or during outreach activities at the community level (12).

iii) In-depth data analysis and dissemination are helpful for solving key programmatic issues at the community health. For instance, maternal death audits are essential instruments for in-depth investigation of maternal deaths that could lead to understanding of root causes of maternal health issues and maternal deaths in communities. Making the maternal death audit data available through simple and user-friendly data visualization for community-led decision making has been critical for safe motherhood in Rwanda (32, 34).

iv) Lessons are learned in large multi country programs supporting the control or elimination of neglected tropical diseases. The community directed treatment with Ivermectin (CDTI) was a community driven approach initiated by the African Program for Onchocercias Control (35) which involved community led data collection, review and analysis through self-monitoring in onchocerciasis endemic villages. The CDTI data was disseminated during community meetings and the data were used to improve drug distribution, mop-up strategies and to minimize drop-outs, hard-to-reach and non-compliance.

v) To generate more data and increase the likelihood of finding Trachoma -a blinding disease affecting mostly rural communities in underserved settings – in the Democratic republic of Congo, community surveys, which included information about knowledge and practices and attitudes, were combined with a rapid field clinical assessment and a review of historical records in primary health facilities. Data were triangulated to increase data availability and quality through cross-checking and cross examination (19).

vi) Based on recent analysis of data from various sources (households/communities, schools and health facilities) in Cotonou and Porto Novo -two major cities in Benin- it was determined that tracking information about the village of origine of Lymphatic Filariasis (LF) patients living in urban areas and making the data available to the surveyors, was critical for an ecological and epidemiological assessment of the transmission of lymphatic filariasis in the two cities (8).

Methods

We conducted peer and gray literature reviews based on publication date, credibility of source (e.g., reputable journal, government signed, approved) and potential relevance to community health.

- For the peer review literature, we used iterative approach to conduct a thorough search on PubMed, Google Scholar, and e-library, including English-language articles published in the last fifteen years - inclusion criterion. The search strategy used keys words, themes and junctions to populate a data extraction matrix. We used medical subject headings (MeSH) terms: community health, community data, community health system, community health information system, and community based.

Title/abstract search were “Community-based services”, “household data” and “information dissemination” AND “information system”.

For the grey literature, we used a mixed approach – combining online searches in Google Scholar using similar terms with expert consultation, review of journal articles, meeting reports, other documents identified through article bibliographies. We searched both published and unpublished data, analyzed home based health prevention and care approaches (Malaria, Tuberculosis, HIV/AIDS, maternal and child health), technical briefs from the Maternal and Child Survival Program (MCSP, 2018). We analyzed information from current practices across global health and disease specific programs from non-profit organizations (IntraHealth International, CORE Group, Task Force for global Health). We scanned longer texts for relevant sections to review and noted additional references to seek out. Shorter texts were scanned for content. For all the gray literature materials chosen for use, we classified them into four categories, i) by their purpose: ii) information, iii) guidance, and iv) evidence-based. The main output from the literature reviews was a literature synthesis and key findings.

Results

Data identification

The processes of identification, collection and utilization of data are all inter related and data identification will ultimately help document specific community needs to support planning of activities. Community program data should be collected, analyzed and used within the community (29,15=6). Also, the data should feed into the local health facility data collection system and should also be interpreted/analyzed collaboratively with health workers. Data generation and utilization by community members and by health workers improve service delivery and allow regular interaction between health facilities and beneficiaries within health facilities catchments areas (29). Firstly, the determination of the information needed implies that stakeholders and community actors must undertake a detailed review of existing health interventions and related social activities involving communities (either community-based or community driven). Other data needs should be explored through community mapping, formative assessment and community dialogue. Program initiation, planning, monitoring and evaluation at the community level must be participatory for effective community engagement, smooth program implementation and for building ownership with clear expectations in terms of program delivery. Key indicators for community health interventions (table 1) should therefore be determined and proper mechanisms to improve data collection and established from the onset of any community health project.

Table 1. Illustration of community-based health indicators

<p>Health promotion and maintenance</p> <ul style="list-style-type: none"> • Percentage of people who have had a Primary Care Provider checkup in the past 12 months • Percentage of adults who receive regular dental checkups • Number of people in the community who own a cell phone, bicycle, radio set etc. • Number of people using latrines • Average number of prenatal care visits for pregnant women 	<p>Disease prevention</p> <ul style="list-style-type: none"> • Condom sales, especially among teens. • Teen pregnancy rates • The percentage of schools providing sex education • The number of homeless people tested for TB and other infectious diseases
<p>Health indicators unique to a community</p> <ul style="list-style-type: none"> • Average number of children per woman • Home visits to newborn and to post-partum mothers • Number of traditional birth attendants • Number and location of sex workers • Burdeen of malnutrition in the community 	<p>Equity and access to health services</p> <ul style="list-style-type: none"> • Groups with stigma/discrimination/marginalization • Distance between households and sources of potable water • Patient to primary care provider ratio • Percentage of people who have a usual primary care provider

<ul style="list-style-type: none"> • The number of miscarriages, stillbirths, and birth defects, both for the community for specific populations • Infant mortality rate and low-birthweight babies. • The incidence of malnutrition in children 	<ul style="list-style-type: none"> • Proportion of insured persons with coverage for clinical preventive services • Proportion of persons who receive appropriate evidence-based clinical preventive services • Percentage of uninsured families in the community. • Proportion of individuals who are unable to obtain or delay obtaining necessary medical care • The number of elders receiving in-home health and care services • Availability of emergency transportation in the community • Availability of ambulance and emergency medical services, particularly in rural areas
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Urban communities present a special and challenging situation for data generation due to the social and cultural heterogeneity of cities; In addition, urban communities are often time self sufficient with poor receptivity to household data collection (8). Community leaders and actors do not always have the technical skills to develop data capture mechanism and strategy. In addition, the capacity to analyze data at the community level is often non-existent or weak due to low literacy (16), so regular trainings, coaching with periodic refresher courses for community actors in data collection and analysis is needed and has been successful in Kenya (16). Detailed and relevant information is needed to support program implementation, to refine, update or adapt interventions whenever needed. In general, data collection is one-time off or done on a routine basis (Box 1). Health facilities outreach and campaigns (immunization, mass deworming) are periodic or implemented irregularly, whereas routine health services -- maternal and child health, family planning reproductive health and non-communicable diseases etc. generate data to be collated and analyzed routinely.

Box 1. Routine versus one-time information collection

Routine data collection	One-time data collection
Regular daily/weekly/monthly interventions	Campaigns / mass events /outreach
Baseline and end line data critical	Baseline information less critical than end-line
CHW /Volunteers involvement is key	CHW /Volunteers involvement is indispensable
Ratio CHW / population covered adjustable	Ratio CHW/Population covered critical but not always adjustable
Drop out / turnover /retention a key element	Drop out / turnover /retention not critical

Better planning and proper management are required to make useful data available. Communities and health program stakeholders should assess the resources needed for data generation in terms of time, costs, data format, and level of efforts. For example, home visits by community health workers are known to be time consuming and logistically challenging in areas where households are scattered and sometimes hard to reach. The organizational capacity of the communities and the manpower are essential for the determination of the level of investment in human and financial resources needed for self-monitoring and evaluation of health interventions.

a) Key actors for community information

Community health workers are the backbone of community health programs and they feed data into the community health system. Training and supervision of CHWs are mandatory for proper data capture at the community level. Sufficient time and resources should be deployed for capacity building, local learning and adaptation. CHWs should understand program deliverables, milestones and the expectations to engage themselves meaningfully and efficiently. It is essential for community health planners to share knowledge and information with all the community stakeholders. Anyone involved in

the community health activities should know why a specific data is needed, when and who needs the data. Likewise, it is important to avoid collecting data unnecessarily or information with no clear intention to use. Unused data put unnecessary burden on community volunteers, health workers and program beneficiaries.

b) Generating quality data

The data needs, the method of data collection and analysis for either community or health facility use, should be clearly defined (table 2,3 and 4). Data should be disaggregated by gender, age, location, socio-economic status and other demographics to allow in-depth analysis and decision making. Qualitative and quantitative data have different characteristics and separate techniques for information generation. For example, the analysis of detailed data can reveal problems related to equity, stigma and discrimination in terms of access to health services. The analysis of qualitative data is indispensable to understand the issues and barriers in their social context within the communities. Anthropological interviews for instance aim to obtain in-depth and contextual information about individuals or groups experiences, beliefs, perceptions, motivations or values. Qualitative data focus on the exploration of reasons, opinions and attitudes behind respondents' answers through asking probing questions for better understanding or to look for more information.

Quantitative data deriving from both secondary and primary sources could provide numeric, tangible and verifiable measurements that are reliable and practical for programming purpose. Points values collected at baseline, mid-term and end-line periods are critical for planning and monitoring and can be used for comparison within and between communities. Having a one-shop repository for community data is central to the availability and utilization of data for decision making. With support from WHO and NGOs working in the field of community health, indicator compendiums have been developed to ensure that key measurements are prioritized in the monitoring of community health projects (e. g tuberculosis and community-based deworming projects) (14). A compendium of community health indicators could help streamline data management and analysis and highlight priority interventions.

Table 2. Information needs

Priority Questions	Expected answers	Planning steps and Analyses
What is the focus?	List of populations to reach with prevention interventions, care and support activities	1. Understand the current community program context 2. Gathering key district, health facility and community demographic and epidemiological data
What to do?	Right combination of evidence-based interventions at the community-level	1. Determine the package of community health services and support for targeted populations 2. Analysis of key activities
Where to target activities?	List of priority geographic areas of focus	1. Assess alignment of current investments and program focus 2. Determine priority locations and populations and set targets 3. Analyze sites, volume of activities and integration
How are we doing across intervention areas?	Assessment of adherence to plans, targets, and expenditures	Project total resources required to implement strategic plan and reconcile with planned funding level
Whom to partner with?	List of community stakeholders to engage in development of collective responses	1. Make use of Civil society and external stakeholder engagement strategy 2. Set site, geographic, and mechanism targets and budgets

Community-centered Health systems strengthening (CC-HSS) assessment	List of costed HSS activities that contribute to scale-up activities in priority locations	<ol style="list-style-type: none"> 1. Understand the current program context 2. Determine program support at the community level 3. Determine monitoring strategy for planned activities in accordance with requirements and assess workforce capacity
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Table 3. Data needs and sources

Data for strategy and advocacy	
Information needs	Potential sources
<ol style="list-style-type: none"> 1. Highlights and key points in national community health 2. Strategies for communicable and non-communicable diseases 	<ul style="list-style-type: none"> • National community health policy/strategy • National Diseases specific master plans (Maternal health, Reproductive health, family planning, Malaria national plans, HIV/AIDS etc.) • Donor supported plans • National Health Development Strategic Plans • Stakeholder engagement and consensus • Consultations with implementing partners
<ol style="list-style-type: none"> 1. Demographics 2. Estimated size of key and priority populations 	<ul style="list-style-type: none"> • National Statistics Bureau • National Health Information Systems • Local census data?
List of evidence-based practices for community health	<ul style="list-style-type: none"> • Websites (includes recent scientific evidence, and technical area) • Costing and cost-effectiveness studies
Do current community health programs adhere to their intervention models, program plans, or service standards?	<ul style="list-style-type: none"> • Program conceptual model • Program results or strategic framework • Program performance monitoring plan • Donors supported program reports • Quality assessments
Do community health programs remove gender barriers, close gaps, and address harmful norms?	<ul style="list-style-type: none"> • Gender Strategy document • Gender Analysis Frequently Asked Questions
Description of unmet need for services at the community level Gaps and bottlenecks Structural and cultural community barriers	<ul style="list-style-type: none"> • RHIS or HMIS • CSOs documents • Government reports (i.e., Ministry of Health) • Procurement profile for key commodities • Governance, Leadership, and Accountability documents • National Service Delivery • Strategic Investments, Efficiency, and Sustainable Financing documents • Strategic Information • Donors reports • Quality assessments
Civil society's ability to advocate and engage government Public availability of government audit information	<ul style="list-style-type: none"> • Governance, Leadership, and Accountability • Survey data
Health system structural and cultural barriers	<ul style="list-style-type: none"> • Civil society engagement process guidelines • Legal environment assessment • Stigma index

c) Improving data availability

In our review we found five main systems and platforms for strengthening data availability and usage for community health programming: i) community health workers registry, ii) community-based health information systems (CBHIS), iii) electronic data capture storage and usage iv) community databases v) community initiatives. Data availability implies accessibility in formats tailored to specific contexts – taking into consideration the level of literacy- and the intended purposes. There are variety of means and ways to make data available; usually data are collected and stored in simple registers, online databases, cloud-based platforms etc. Survey data are usually stored and managed by health facilities, NGOs and donors. There are important improvements in measurement designs, data collection, processing, storage and availability. Close collaboration between primary health care and communities allow information sharing, updates and increased utilization of data. In 2015, in the cities of Cotonou and Porto Novo (Benin), a complex and extensive survey was conducted in 191 households to assesses the transmission of lymphatic filariasis (LF) a disabling disease transmitted by mosquito species (8) - These two cities were areas with scarcity of LF data especially in terms of the detection or notification of clinical cases of LF -lymphoedema and hydroceles – known as LF morbidity cases. The questionnaires in the households yield the following statements from the participants: "*This disease does not exist in this city*"; "*You have to go to northern Benin to meet this disease*"; "*this disease is found only in marshy areas*"; etc. Although these comments revealed low awareness of urban LF even in areas where transmission is highly suspected. Also, there were few health workers (nurses) who were not informed that the disease was transmitted by mosquito bites. If health workers are unaware of the disease, they would not certainly think about testing for LF when they receive cases of edema of lower limbs, especially those that have been around for some time. furthermore, most health workers are knowledgeable about the disease and its complications but think less about it during clinical practice. Overall, the individual, the community, the Health Center staff and physician's awareness were all shown to be deficient. This could have negatively affected the ability to assess patient care as well. To compensate the low level of knowledge about LF, training of health workers in both cities about the disease and its diagnostic are necessary. According to the health workers, due to stigma, LF patients stop going to health centers when the disease progresses to the stage of elephantiasis or hydrocele. At these stages of the disease, they do not seek conventional care. They rather seek care from traditional healers. This recourse to non-conventional traditional treatment is because most of the population think that elephantiasis "*is the result of a spell and that nothing from modern medicine procedure can reverse their disfigurement*". The lack of proper care for people suffering from elephantiasis in health centers can also explain their reluctance to use modern medicine, hence the need to organize mass awareness campaigns. In all health centers, there are reporting and notification forms for documenting diseases of public health interest into the national health information system. unfortunately these reporting forms makes no mention of the LF; this could explain the lack of information on these diseases and the need to revisit the diseases -report form, collate data from traditional healers and heads of households in the community (8). These type of community data should be triangulated with institutional data (health facilities and schools) to improve availability, trackability and overall quality.

a) Community health workers registry

The WHO guideline (37) on health policy and system support to optimize community health worker programmes (WHO, 2018) suggests that *practising CHWs document the services they are providing and that they collect, collate and use health data on routine activities, including through relevant mobile health solutions. Enablers for success include minimizing the reporting burden and harmonizing data requirements; ensuring data confidentiality and security; equipping CHWs with the required competencies through training; and providing them with feedback on performance based on data collected* [Recommendation 11]. In fact, community health workers are the critical source and the channel of community health information, generating and making data available for use. CHWs require key health information to do their jobs, and their supervisors and managers require data to monitor their work. Likewise, governments and donors need information to better plan community health programs, and to monitor progress against goals (16, 5). The development of a CHW registry is critical for improving data availability. The registry is a repository of CHW information which should be updated

regularly to provide real time information about community health activities including the number of CHWs, their profiles, contact details, trainings, drop-out rates, incentives, catchment area etc. The registry tracks critical personnel data, and its implementation is one of the first steps in a national plan to transform and professionalize community-based health workforce in a country. The registry provides health officials with the data needed to understand the size and scope of the existing community health workforce and to integrate these workers into the health system, while accounting for their contributions to health outcomes. The registry produces insights on workforce density and distribution, performance, incentives, training, and more, which help the ministry standardize the practice of community-based health care going forward. (IntraHealth Uganda, 2017) (13).

b) Community-based health information system

Community-based health information is defined as the way data are collected at the community level and how the data are managed, analyzed, flow and are used for planning and monitoring by various including CHWs, governments, partners and donors. Community health information system involves health and related services provided to communities outside of facilities (24, 26). In countries where community fora, community review meetings and other community gathering platforms are established, communities and health facilities work jointly to address data generation, review of existing information and gaps. Regular meetings and discussions among community leaders contributes to real adaptation and better utilization of community data. Data should be shared during community and health facility meetings for feedback and action in the health facilities catchment's areas to improve health programming. Data from CBHIS should enable sharing of data among community-based services and between community-based services and higher-level health facilities; for example, the *connect project* in Tanzania links community data collected by CHWs with the district and the health management information system-HMIS- (31,18). A complete integration of the CBHIS into the HMIS with harmonization of indicators would avoid redundant data and duplicative efforts in data collection, analysis, and reporting. In addition the CBHIS data should feed into national health information system to provide an opportunity for additional data generation outside the health facilities and specifically health activities, social and environmental data at the community level (21). The district health information system -DHIS2 - provides a platform to link community data to information from health facilities (22, 23). Community data should be included into the DHIS2 to create user-friendly dashboards for programmatic use at the community level. Experience from Guinea during the Ebola epidemic crisis has shown the critical need to have timely detailed data through DHIS2 dashboard for to increase preparedness and readiness during before and during the outbreak at the community level (27). Overall, Community-based health information should be centered on accountability and policy change which are critical for community driven health intervention (table 4).

Tools and approaches are proven effective in data generation to support public health programs. The "My Village My Home" (MVMH) tool is a poster-sized material used by volunteers and community officials to record the births and vaccination dates of every infant in a community. It allowed community leaders, volunteers, and health workers to monitor the vaccination status of every young child in participating communities and guided reminder and motivational visits. Assessments in India where the tool was implemented suggested that it improved vaccination timeliness and coverage - 49% to 80% coverage of identified and eligible children for all vaccines. In Malawi, village heads and volunteers undertook a census of infants in their community listing every child, in order of their birth, on the MVMH tool and recorded the dates of vaccinations already received. They added new children shortly after they are born and become aware of and added new vaccinations on the tool either during regular home visits or at the end of a nearby outreach session. Official health information system coverage data, which are not very reliable, do not show the impact of the community monitoring and other actions at district level. However, immunization coverage appears to be nearly 100% in communities where infant tracking and monitoring using the MVMH tool is well implemented (an estimated 90% of the communities) (33).

Table 4. Data sources for prevention and support

Prevention, support and rehabilitation at the community level	
Information needs	Potential sources
Behavioral factors and environmental conditions including water, sanitation and hygiene	<ul style="list-style-type: none"> • Research or special studies – observation reports and surveys • DHS data especially Key Indicator Surveys and population-based surveys
Community health partners mapping analysis of stakeholders and their influence, contribution, and capacity	<ul style="list-style-type: none"> • Map of community stakeholders
Advocacy initiatives to promote human rights, patient rights, and community mobilization	<ul style="list-style-type: none"> • Operational research and/or implementation science that assesses barriers to services by key populations • Tests service delivery models that reduce barriers to service access • Outcome evaluations of programs that promote, protect, or respect human rights • Survey data on stigma and discrimination • Stakeholder engagement on RMNCH, Malaria, AIDS policies and human rights
<ol style="list-style-type: none"> 1. Women of reproductive age 2. Pregnant women 3. Female Sex Workers 4. OVC/PLHIV 	<ul style="list-style-type: none"> • HMIS • DHS • Special studies • Programs reports
<ol style="list-style-type: none"> 1. Description of populations at risk of acquiring specific diseases 2. Description of populations for specific health conditions 	<ul style="list-style-type: none"> • Government reports • National demographic and epidemiological data • HIV- and AIDS-related surveillance data • Behavioral surveillance data • Population survey data • Routine health information system (RHIS)
<ol style="list-style-type: none"> 1. Current community-based prevention service coverage for priority populations across government and donor programs. 2. Estimated prevention targets in comparison with coverage, to determine level of unmet need for community-based prevention services 	<ul style="list-style-type: none"> • RHIS or HMIS • Ministry of Health reports • Donors supported program reports • UN (i.e., WHO and UNAIDS) • DHS • Special studies at the community level
<p>Cost of monitoring activities at the community level</p> <p>Estimated expenditures of community health activities</p> <p>Carrying costs of current community health activities</p>	<ul style="list-style-type: none"> • Budgets and Operations • Procurements plans and reports • Costing and cost-effectiveness studies • Program and/or performance evaluations or other special studies • Implementing partner engagement
<p>Measurable deliverables</p> <p>Are current community health programs targets being achieved?</p>	<ul style="list-style-type: none"> • Program conceptual model • Program results and Strategic framework • Program logical framework • Program performance monitoring plan
Quality of community health programs	<ul style="list-style-type: none"> • Performance quality assessments • Surveys, research and special studies

c) Electronic data capture and use

Electronic data capture and data visualization are becoming commonplace especially with advances in mobile technology permitting real-time data collection, management and analysis. Electronic data platforms enable on-the-spot data validation with the accuracy needed for data processing, quality assurance, and the facilitation of data reporting for timely use and/or dissemination. Other advantages include: i) user-friendliness by field workers, ii) cost-effectiveness in terms of logistics and human resources, iii) timeliness, rapid synchronization and triangulation of data (18). In a highly functional community data management and reporting system, digital technologies are employed to make data systems more efficient, useable, or scalable and/or leverage data to improve the quality, speed, or equity of services (24). One systematic review suggested that there were cost savings of 24% when CHWs collected data using personal digital assistants compared to when they used traditional manual methods of data collection and transmission (25,26). Online libraries and platforms improve the searchability of data. They are often accessible to peripheral levels of the health systems in many developing countries. The use of GIS and mobile devices are indispensable for the generation of a large quantity of valuable information which can be collated, analyzed and made available in real time. Natural resources, demographics, water and sanitation data are important information which can be generated and managed in direct collaboration with communities through community mapping. It is necessary to help community health workers and volunteers build capacity for electronic data capture and interpretation.

d) Community health program databases

The reliability, validity and availability of community data is paramount to the success and to the sustainability of public health interventions. Community-led and community-based interventions must have robust and reliable information available in a trusted and constantly updated data warehouse. Health facilities should maintain a good and strong information system which includes the collection, storage and management of community data accessible to community stakeholders. Health facilities must appoint personnel to manage community data with dedicated personnel working to ensure data collected and management through standard operating procedures and data management and analysis protocols, and then link community health program databases to national health information systems. Rwanda has an established community health information systems including systematic recording of maternal deaths and audits (32). Likewise, the northern states of Kano and Kaduna in Nigeria have community based polio data collected by volunteer community mobilizers (VCM) and transmitted to program databases linked to the federal national health system (6). Ideally all the healthcare entities at the community level (private drugstores, traditional birth attendants and traditional health practitioners should provide data and information to feed into community program database.

e) Community initiatives for data generation and utilization

In Rwanda the Community Action Cycle (CAC) is an initiative that encourages community participation in the prioritization of their health problems as well as the implementation and monitoring of local action to address those issues. In the district of Nyaruguru the CAC led to the identification of 332 community groups, one per village, to oversee leading collective action plans to address key community reproductive health and child health issues. Each community went through a participatory process of analyzing health issues, prioritizing them, reflecting on barriers, and planning solutions. For example: many pregnant women not completing four antenatal care visits; low family planning prevalence; and lack of toilets. The initiative impacts an estimated 293,494 people (17).

In Mozambique, too often, community members are engaged superficially and are not integrated into the decision making around how to address the needs of their communities. Traditional birth attendants (TBAs), previously operating with no formal link to the health system, were trained in data collection by professional health workers and they reported their data directly to their own community leaders for analysis and to support decision-making. Communities tracked their own accomplishments toward: safe motherhood and institutional deliveries; water, sanitation, and hygiene; family planning; and other critical health needs. Beyond the training that TBAs received to educate women about the importance of care from and support referrals to the health system, they reported to their own community leadership councils (CLC) about their success in shepherding women under their charge from the first antenatal

care visit through to institutional delivery and immunizations. Empowered with data, TBAs and CLC members were able to recognize these barriers and changed course to make sure the women affected got the care they needed, maintaining the uptick in institutional delivery rates. Together, TBAs and CLC members used their newfound expertise in data collection and use to build a referral tracking system through which they monitored pregnant women's uptake of critical maternal health services. The TBAs described the importance of data in helping maintain success despite the underperforming health centers. In addition to TBAs' and CLCs' clear roles, responsibilities and strong relationships, it was their community-generated and -owned evidence that supported their success as leaders and stewards of their community's health. It was this data that fueled their ability to adapt when complexity struck, to solve problem, and to take ownership of the solution (1).

Discussion

The collection and use of data are essential to quality improvement and have the potential to positively impact health outcomes. New evidence suggests that CHW use of data at the community level could help to improve service delivery and ultimately result in better health outcomes (26, 30, 31); and it is generally admitted that household data belong to local communities which should be empowered to use the data as needed for planning, self monitoring, for equity and for the application of local solutions to solve programmatic issues and other bottlenecks (32,33). Viable integrated community health platforms rely on a key function of local learning and adaptation which implies availability of the data at the local level for decision making. In a review conducted by Ibe et al (4) on CHWs documents from 22 countries, it was shown that although policy and related documents provide guidance for all CHWs cadres to track data from home visits, case management and other services, document life events, manage commodities and/or monitor outbreaks in all the 22 countries, very few specific guidance on data use at the community level and how to involve the community in data analysis or decision making -16 out of 22 countries, 72% - (33).

Most data repositories from public health programs are not available in primary health care facilities; neither are they available at the community level. Some data are also complex and difficult to be understood and used by the communities. Simple formats including data visualization -dashboards, are critical for making data user-friendly and easy to understand by community members. Empowering communities to use data for decision making is essential for identifying data needs and improving data availability. For example, in Kenya the *Omia Diere* community embraced mobile technology, consequently it became the center for visits by other communities who want to learn about it. The community unit became the center for data generation, analysis, and quality assurance, which led to improved activity reporting (11). Likewise, pilot implementations of community health projects in Guatemala, Egypt and China using a specifically developed mobile phone application to collect data, and an online expert survey were completed with community reviews to assess validity and feasibility of the indicators and their corresponding questions (22).

Communities have health needs specific to their environment and context, stemming from the prevalence of a specific disease or condition, or from a special occupational issue. The causes here may range from the environmental (for example pollution of drinking water or poor air quality), to genetic issues (for example an ethnic group that's susceptible to a certain disease). Examining some community-level data can help identify and respond to these conditions. An assessment to identify community health problems for instance, might rely on indicators such as the incidence of a disease or medical condition either in the community at large, or in a social, ethnic, or geographic group. Community data can also provide information about the effects of community projects and initiatives; for example, a reduction in the number of people who are unable to obtain or have to delay medical care due to high costs might be an evidence that the new clinic in the area is helping a previously underserved population (2).

CHWs generate a lot of data from their activities at the community level. Oftentimes, data may be reported up the channel to the formal health systems with little reference as to how it can be used to guide work or improve performance at the community level (25). An important prerequisite for making effective use of data is to institutionalize the use of data for shared accountability at the community level by building the capacity of the community and the health system to understand the importance and

relevance of data (30). The communities should be oriented by health facility workers on the basics of the health issues and the interventions to address those issues, and how to assess progress in addressing the health problems. For instance, in the health extension workers program in Ethiopia, households are provided training on a package of 16 high priority health interventions, and relevant knowledge and skills are transferred to households so that they can take full responsibility for maintaining their own health and encouraging their neighbors to do the same (2). Data from community surveys could measure differences in health, education, social life, livelihood and empowerment between people with disability and other community members. The analysis of these differences yield specific information to community health managers, donors and government agencies, to help carry support advocacy activities, help improve accountability and to guide decision making. The community-based rehabilitation (CBR) indicators for instance were developed to support WHO and its member states in their efforts towards strengthening community based rehabilitation, by generating evidence on its effectiveness (24,37). It's important that the community health planners collect and analyze data that reflect current social and health conditions of local communities (10, 36). For instance, smoking is a major cause of lung cancer, so measuring lung cancer rates in a community ought to tell us about smoking rates. It does, but it tells us about smoking rates 20 or 30 years ago, because that's how long it may take many cancers to develop. The same is true for heart attacks and cholesterol -the current condition of your heart reflects eating and exercise habits of 20 years ago as much as your current ones.

Conclusion

There are several community based data collection designs, and data sources developed by countries with support from technical partners and funders. It is important to ensure that the data are constantly made available to users at the point of service delivery especially at the community level; for that purpose, interoperability, data visualization, user-friendliness and timeliness are essential requirements. For a programmatic perspective, long term investment in quality data generation and improved data availability should be addressing three key questions: What is missing at the lowest level (household) where the data is generated? What information is indispensable? and which data will make a difference from a programmatic standpoint? Responses to these questions would undoubtedly help communities and health planners conceive the best systems for data generation and the best platform for dissemination. The communities initiatives demonstrate how data can create a stronger and more resilient local health system, one capable of continuing to deliver positive health outcomes well into the future.

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