Supporting Citizen Researchers: Action-Research for Health System Change

HSR 2020 Skill-Building Session | January 27, 2021

A Joint Session by:

Neeta Hardikar – ANANDI (India)

Vincent Mujune – formerly of GOAL (Uganda)

Walter Flores – CEGSS (Guatemala)

Angela Bailey – Accountability Research Center (USA)

anandi આનંદી

CEGSS Centro de estudios para la equidad y gobernanza en los sistemas de salud

GOAL

Accountability Research Center

hsr2020 SIXTH GLOBAL SYMPOSIUM ON HEALTH SYSTEMS RESEARCH بحوث النظم الصحية

Plan for Virtual Session

15 minutes – introductions / settling in (Angela)

30 minutes (part 1 = big picture) – each presenter (Neeta, Vincent, and Walter) has 10 minutes to discuss the background/overview of the work/approach, role of citizens as agenda setters/data collectors/analysts/advocates, outcomes observed

15 minutes – Discussion / Q&A with participants (Angela)

30 minutes (part 2 = deep dive on a tool) – each presenter (Walter, Neeta, Vincent) has 10 minutes to explain more in depth one of the tools used in citizen-led research/analysis

15 minutes – Discussion / Q&A with participants (Angela)

10 minutes – wrap up (similarities and differences of approaches), any final questions/observations, sharing resource links, etc. (Angela, Neeta, Vincent, Walter)

anandi આનંદી

CEGSS Centro de estudios para la equidad y gobernanza en los sistemas de salud

GOAL

ACCOUNTABILITY RESEARCH CENTER

hsr2020 SIXTH GLOBAL SYMPOSIUM ON HEALTH SYSTEMS RESEARCH بحوث النظم الصحية

Part 1: Supporting Citizen Researchers

Action-research is defined by purpose: it is focused on learning from action to inform change strategies and advocacy campaigns.

India

Uganda

Guatemala

anandi આનંદી

CEGSS
Centro de estudios para la equidad y gobernanza en los sistemas de salud

GOAL

ACCOUNTABILITY RESEARCH CENTER

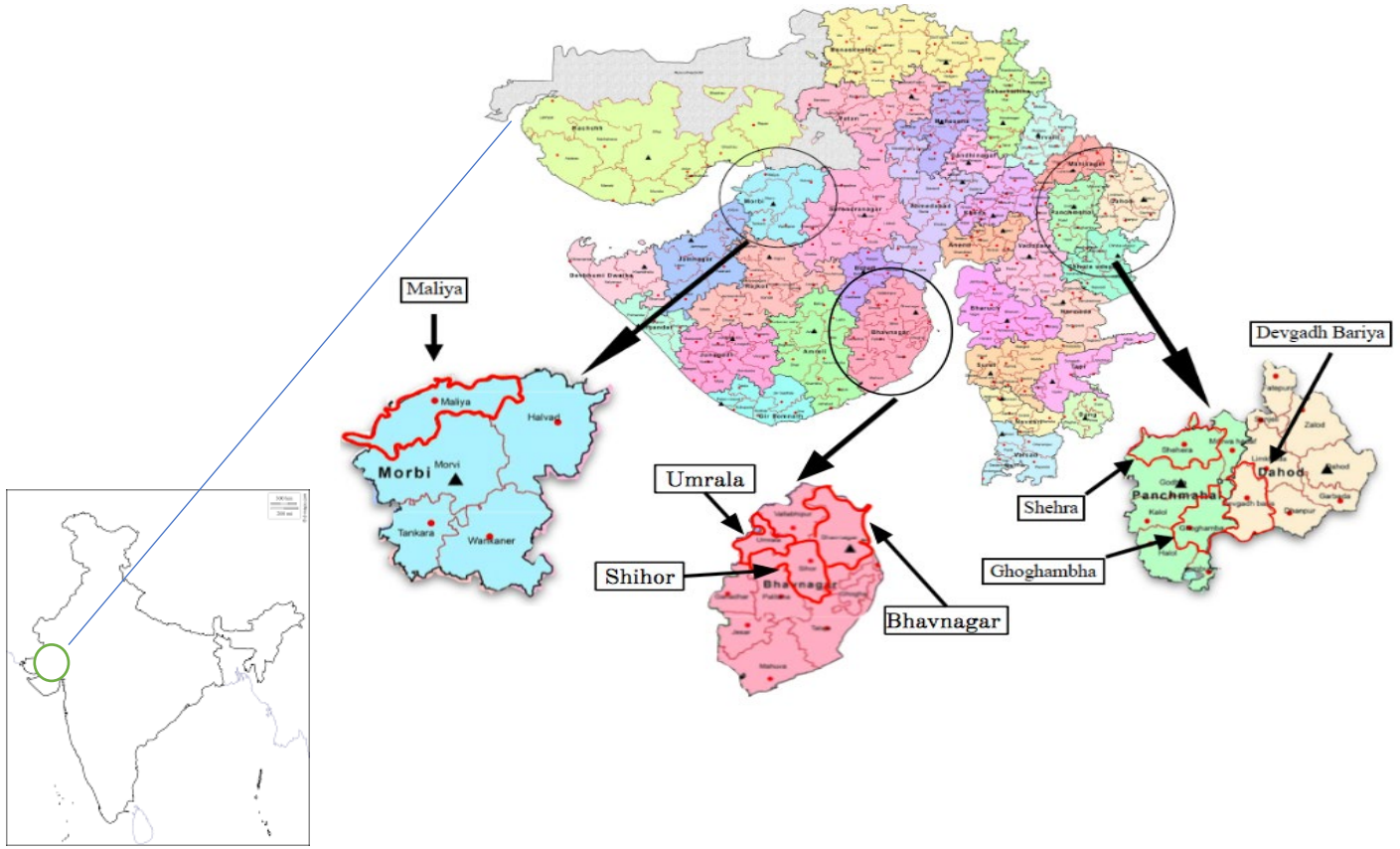
hsr2020
SIXTH GLOBAL SYMPOSIUM ON HEALTH SYSTEMS RESEARCH
بحوث النظم الصحية

Neeta Hardikar - ANANDI (India)

Feminist activist Neeta Hardikar's work with ANANDI (meaning "joyfulness" in Gujarati) emphasizes women's human rights in rural and tribal India with focus on building and strengthening grassroots organizations in leadership of women. Over 20 years of work as grassroots activist, researcher and facilitator for rights of women and youth connects her with generating data for community-led advocacy for movements and campaigns demanding people's right to food, health, work and human rights, nationally. As director ANANDI Technical Support Unit and a practice lead for strategic leadership and women's livelihoods she focuses on feminist organizing and strategies for gender mainstreaming with civil society organizations, academic and research institutions and state led programs. neeta@anandi-india.org | @ANANDIGujarat

ANANDI – Area Networking and Development Initiatives

- Organise tribal, dalit and other vulnerable communities since 1995
- Build leadership of women to bring women's concerns in the centre of all development processes
- Promote women's human rights , livelihoods rights and social justice
- Partner with 7 collectives to focus on people's right to food, work, health, education, social security and violence free society for women and girls
- In Dahod and Panchmahaals in eastern tribal belt; and Morbi and Bhavnagar in the Saurashtra region of Gujarat



Mission, Approach & Strategy

Mission

Promoting women and young leaders to work towards change that is based on social justice, sustainable development, accountable governance and fraternity.

Approach & Strategy

- Form women's collectives to change the nature and directions of the systemic forces affecting marginalized communities
- Organize collectives to become change agents for improved living conditions and sustainable livelihoods
- Empowerment through collective processes
- Recognise marginalization and intersectionality at the core of the process of development

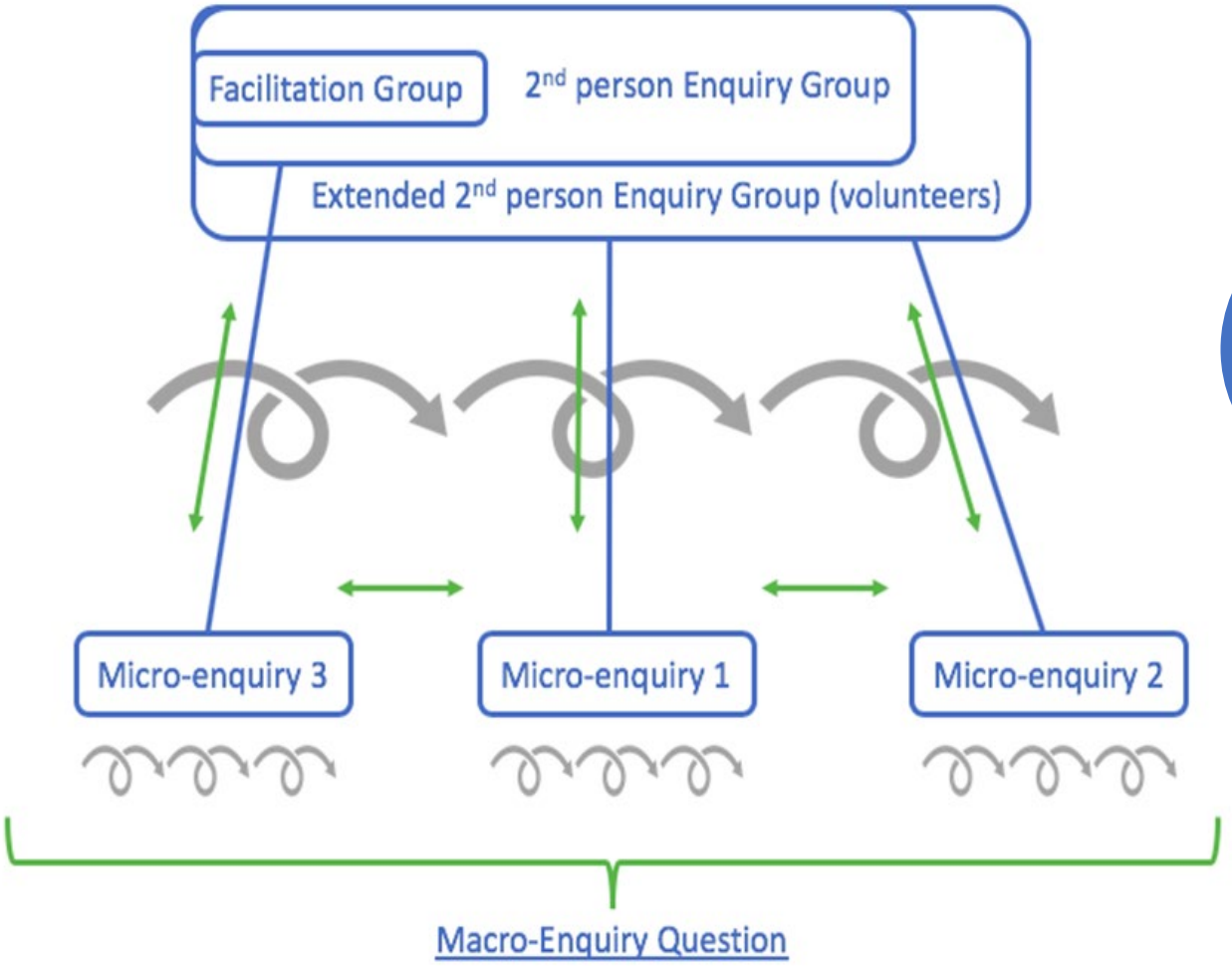
Why Community Data?

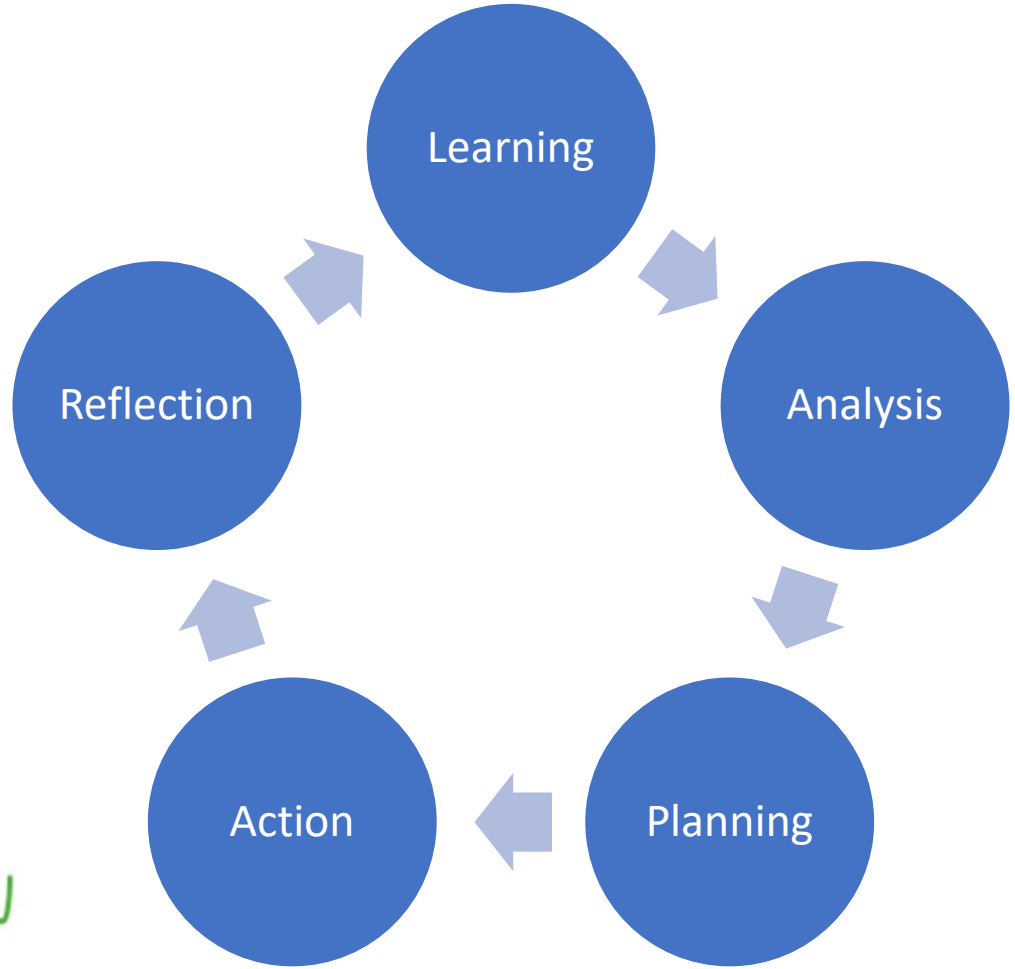
- ANANDI understands that in the evidence based advocacy and accountability work data is crucial
- Community ownership and their central role in strategies regarding “when” and “where” to use data is an empowering process
- Tools and processes of Participatory Action Learning Systems facilitate the process of empowerment and accountability through the community-collected data
- Improves accountability of Gram Panchayat and state strategically for public programs including the health and nutrition services outcome.
- PALs is rooted in the participatory learning approach of learning- planning – analysis – action and reflection as a continuous cycle.
- Tools were developed with the “Bhaneli- Ganeli” – “Literate and wise” leaders to capture data on maternal health, nutrition services and rights of women and girls with nearly 200 aspects of services of the ICDS, health department and other social determinants of health

Community Data Indicators

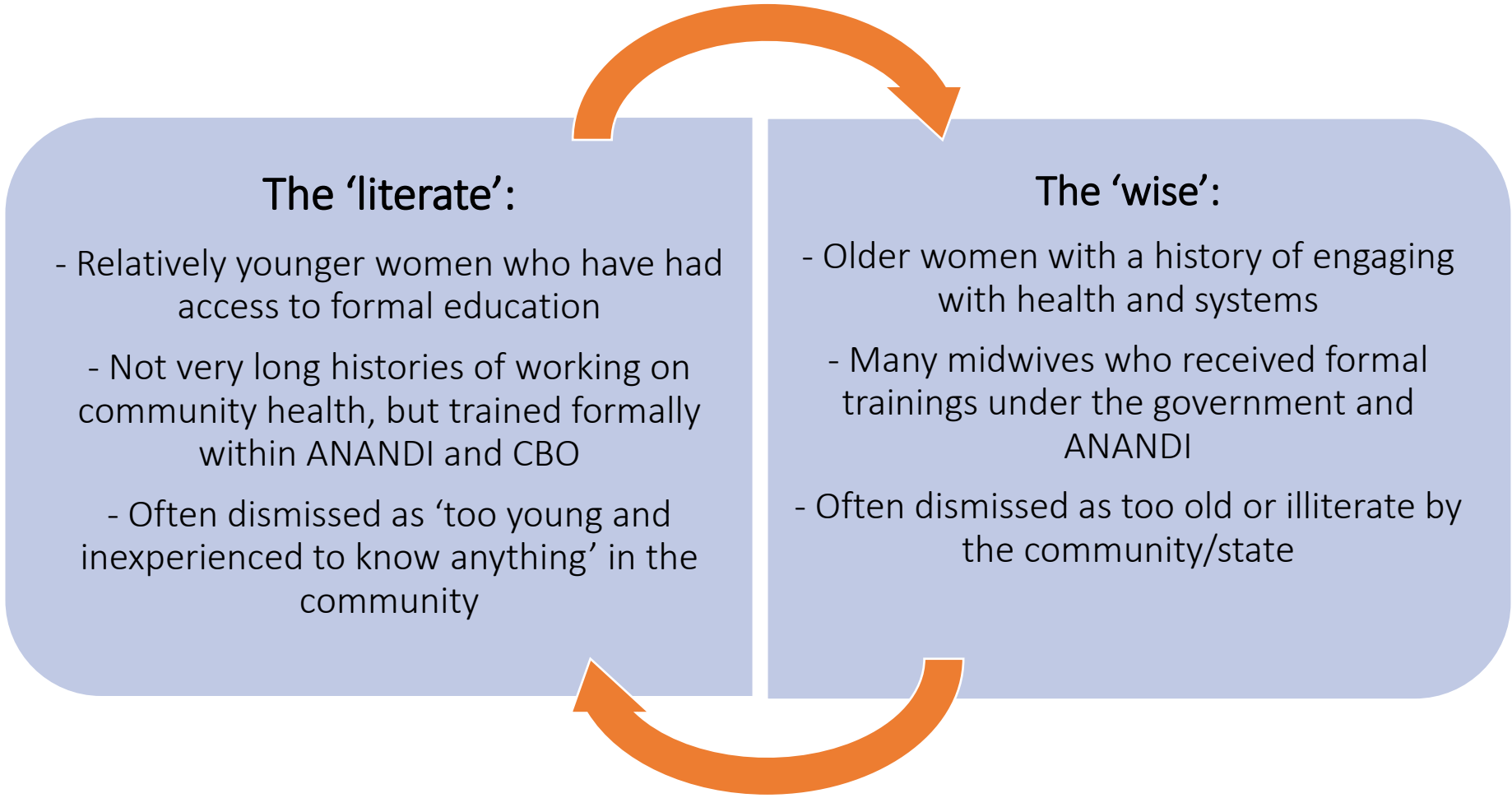
- On preparatory process, meetings and home visits before Village Health Nutrition Day – to mobilise and ensure mobilisation of the migrant women in ANC and PNC and children for immunization and ICDS services
- Participation and accessing services in VHND
- Mobilisation and accompany women in ANC for the PHC level PNC clinic
- Information on social determinants – access to water, nutritional food security, wage work profile, family support, sanitation and rest and safety during ANC and PNC
- Tracking of high risk pregnancies, severely malnourished children – with illness
- Access to public health services, quality, approach of the health staff

Participatory Methods for Identifying Indicators





About the Community Researchers



Aspects of Community Research Process

Recognising experience and practice as knowledge and building on it

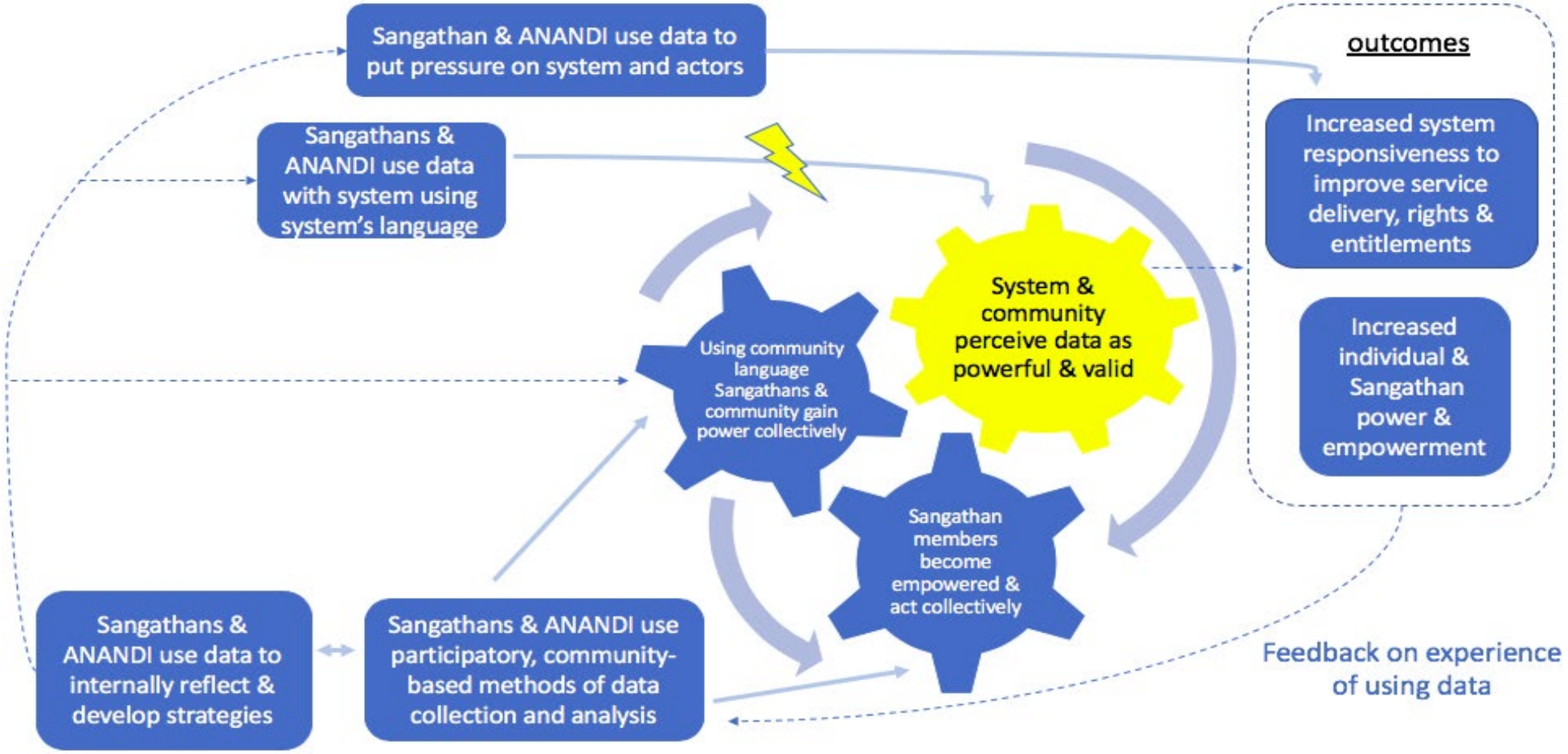
Building solidarity and collaboration, across age-groups and skill sets

Combining health, nutrition and human rights; foregrounding care work

Primary accountability to *sangathan* and community; support to frontline health workers

Using a range of skills for community engagement and evidence-building

Community-led Monitoring for Empowerment and Improved Access to Health and Nutrition



Vincent Mujune - GOAL (Uganda)

Vincent Mujune led GOAL Uganda's accountability and people-centered advocacy work for health up to December 2020. He supported community-led processes using participatory evidence generation and analysis methods that engage affected communities, build their capacities and strengthens the influence of marginalized households on the health system for better health outcomes. Vincent is a member of Uganda's Civil Society Budget Advocacy group and has trained civil society actors on people centered advocacy in Sri Lanka, Malawi and Sierra Leone. vincentmujune@gmail.com | @vincentmujune

The views and opinions expressed in this presentation are those of the presenter and do not necessarily reflect GOAL's position.

People-Centred Advocacy

- GOAL Uganda led a project called "Accountability Can Transform Health" from 2014 – 2018
- A large part of the strategy was to support almost 400 community advocates leading 18 sub-national advocacy campaigns
- People-Centered Advocacy is a systematic process owned and led by those affected by an issue using evidence to influence people with power at different levels to make sustainable change in practices, policies, laws, programs, services, social norms and values for the betterment of those affected by the issues.
- Monitoring was not a "one-off" exercise. Advocates collected evidence to monitor the progress with their advocacy issue throughout campaigns.

Research *About* versus Research *By*

	Research *about* affected communities	Research *owned & led by* affected communities
Who sets the research agenda?	Researchers / CSOs	Communities affected by an issue
Methodology	Highly technical expectations, data collection by trained persons	Relatively simple and driven by the need to prove magnitude of a problem
Ownership of data	More with the research lead or CSOs	More with affected community
Analysis of data / Making sense of data	Usually led by researchers or CSOs	Communities lead the analysis /making sense from data
Goal of the research? Whose Voice is prioritized?	Evidence used by CSOs/researchers for reforms	Citizens use their evidence to directly push for reforms while building citizen competences for evidence-based engagement

Community Advocates

- 400 community advocates selected by their community peers in 18 districts – they worked in groups monitoring multiple health facilities and combining their monitoring data

"When I was selected, at first I was worried if I would be able to represent the community. When we first went to the health center, we asked for documents like the supervision book even though we did not know what the documents should even look like. When we went to the technical people they would dodge around, and the district officials asked us what our qualifications were. If I have a problem does it matter if I have a qualification? If I don't have training, does it matter, because I'm suffering? Once district officials told us our letter was misplaced, so we gave them another copy. Eventually, we asked for signature as proof of delivery. In the beginning, they used to ask us 'who trained you? What is your qualification?' and they were harsh and sent us away. I cannot ask them what they did but we are seeing changes. Even last week, we took messages of appreciations, but asking for more."

~ Patricia O. Community Advocate

Data Collection Tools

EVIDENCE COLLECTION TOOL

Issue: Patients are not getting treatment because health center staff are absenting from duty.

Name of the health centre: ……SUB COUNTY: ……

Name of the community representatives: …… Date: ……

No. of health center staff allocated……

Questions

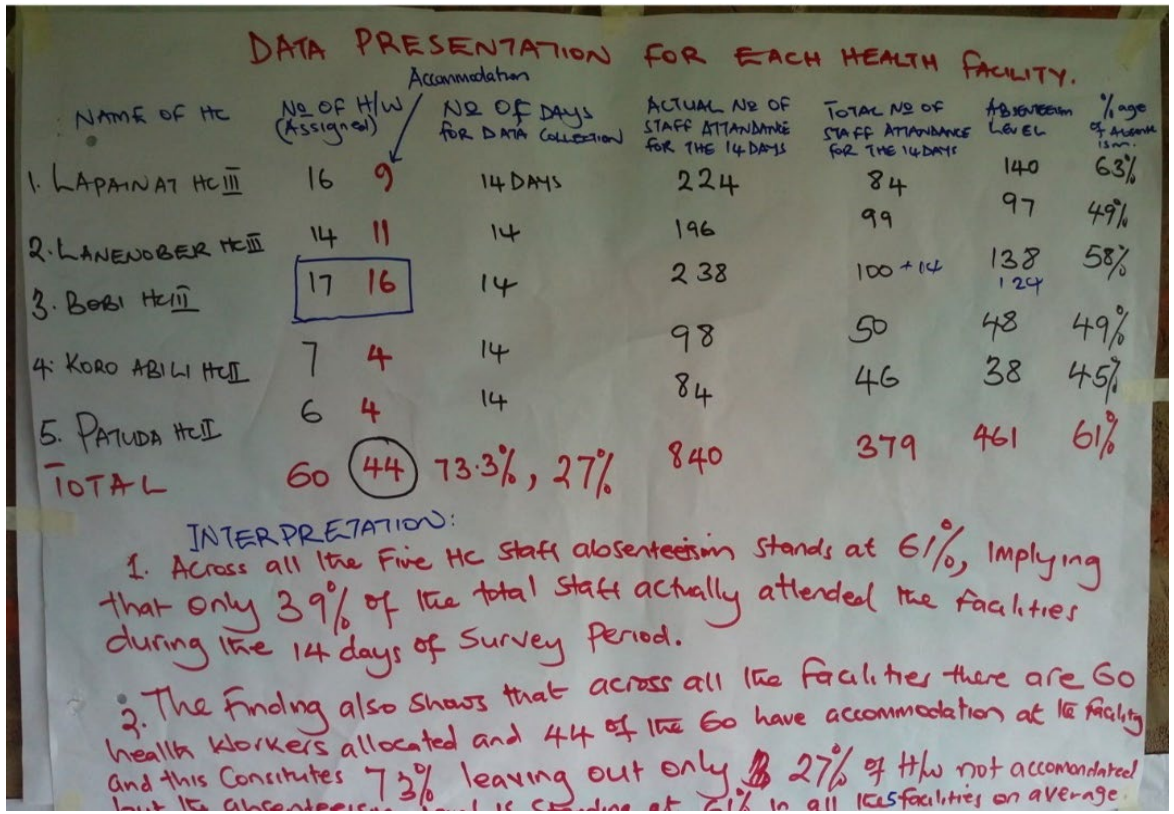
Question 1: At what times does the health center staff always starts work

Name of Health Centre staff	Post	Where HW stays?	Date……		Date……		Date……		Date……	
			Time Arrived	Time Departure	Time Arrived	Time Departure	Arrived	Departure	Arrived	Departure

Other data collected by advocates while monitoring health facilities

- Does the health centre have staff accommodation?
- How many health centre staff are posted and working in this health center?
- How many times has this health center been supervised in the last six months?
- How many health center are on leave?
- How many health center staff are having other jobs/work other than the job they are holding at the facility?

Participatory Data Analysis & Use



Data compiled by community advocates who coordinated monitoring of health worker attendance in 5 govt. health facilities.

Photo Credit: Robert Ofiti, HEPS-Uganda

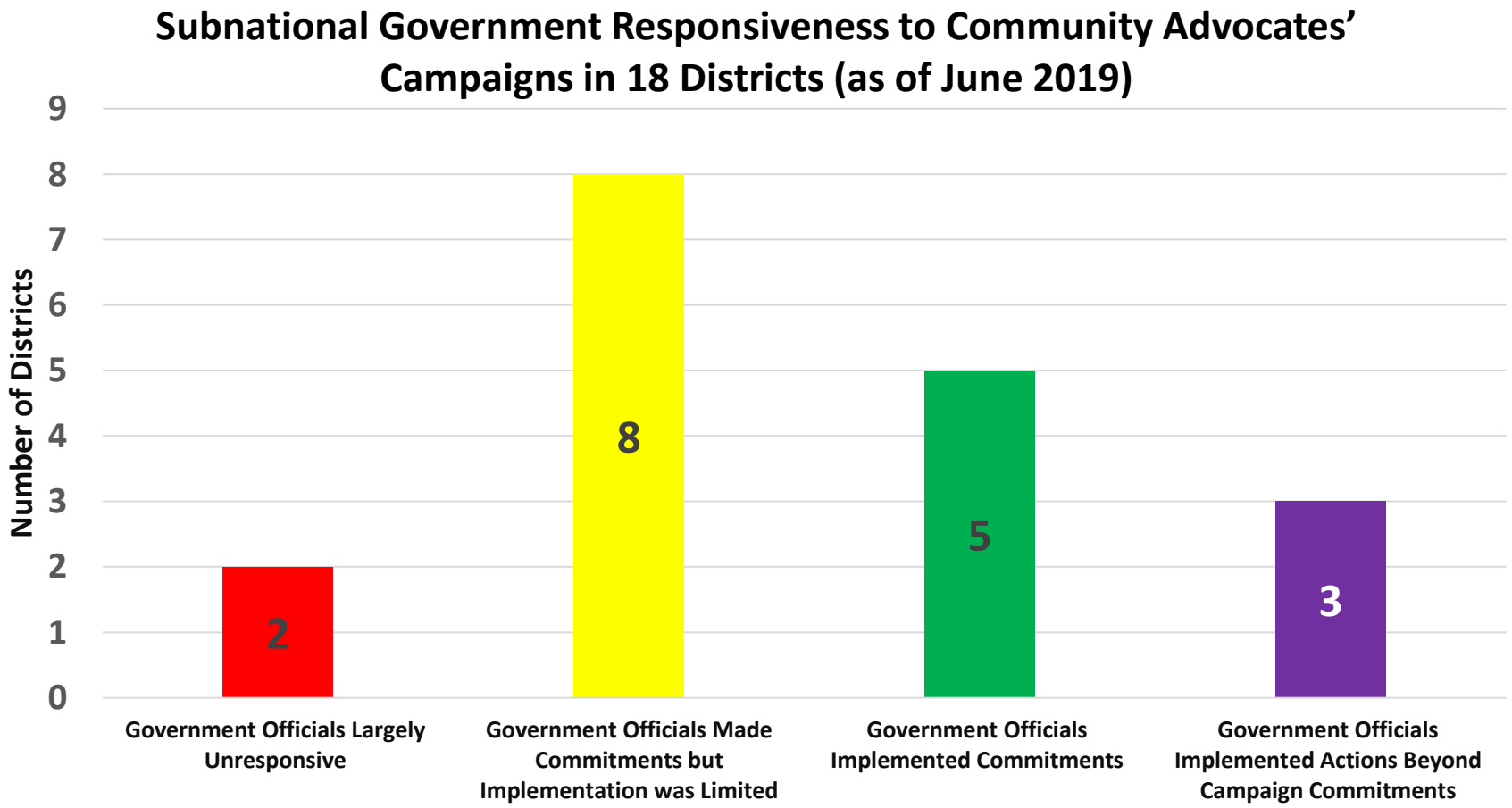
Excerpt from Advocacy Petition Using Community Monitoring Data

"The evidence collected by community advocates in Lira district confirmed that patients were waiting for long hours to get treatment and some were missing treatment as a result. We found out that 85% of Health Centre staffs arrive late and leave duty early; on average at 10:34am and depart at 4:23pm. There are 81 staff employed in the health centre staff covered by the community advocates. We found 81 staff houses available in the six health facilities, but staff lived in only 41 of them. Examples in Ongica HC III, staff are sleeping in 13/16 houses, Barapwo HC III, staff are sleeping in 5/14 houses, Barr HC III, staff are sleeping in 9/14 houses, Anyangatir HC III, staff are Sleeping in 2/12 houses and in Akangi HC II, staff are sleeping in 6/7 houses."

Learning from Citizen Monitoring

1. Community advocates' intensive monitoring in health facilities provided more realistic data than sporadic government supervision visits and staff record books, which are prone to abuse
2. The extensive details made it very clear to government officials that the advocacy petitions were backed by significant monitoring efforts by community advocates.
3. The process of gathering their own evidence instilled confidence and propelled advocates' campaigns
4. In at least **7** districts identified additional issues for advocacy and collected evidence to inform new / special campaigns
5. In 13 of 14 districts focusing on absenteeism, district-level officials went to verify evidence presented by community advocates. The high rate of follow-up investigations to verify advocates' reports and feedback from targeted officials indicate they were impressed by the detailed data collected and presented to their offices.

Government Responses to Advocates



Source: GOAL Uganda "Heat Map" compiled from multiple program monitoring sources.

Walter Flores - CEGSS (Guatemala)

Walter Flores is the former director of the Center for the Study of Equity and Governance in Health Systems (CEGSS), a Guatemalan civil society organization specializing in applied research, capacity building and advocacy around health rights of indigenous and marginalized populations. He is a steering committee member of the Community of Practitioners on Accountability and Social Action in Health (COPASAH), a global network of CSOs working towards improving healthcare services through human rights, accountability and social mobilization. He holds a PhD and a MCommH from the Liverpool School of Tropical Medicine, UK. Walter has researched, taught and consulted in more than 30 countries of Latin America, Africa, Asia and Europe. waltergflores@gmail.com | @waltergfloresm

CEGSS
Centro de estudios para la equidad y gobernanza en los sistemas de salud

Guatemalan Context

- Indigenous population (40% of total) experience the worst social and economic indicators. Barriers to access health services is directly related to malnutrition, quality of life and life expectancy
- Systemic exclusion of indigenous caused by structural discrimination and unequal power relations
- YR 2002 New Descentralization Law, transfering responsibilities and resources to local government (municipal)
- YR 2004 New Health Act recognizing the right and responsiblities of citizens to participate in planning, monitoring and evaluaiton of healthcare services
- YR 2006 CEGSS first project :
  - How to use the new legal framework to promote the participation of indigenous people in the planning and monitoring of services in rural indigenous municipalities of Guatemala?
  - Are communities able to use the new spaces for collective demands to authorities to improve access and resource allocation to local healthcare facilities?
- Work started in 5 municipalities

Citizen-led Accountability

- Independent and autonomous citizen action
- Using the existing legal framework (national and international) norms, policies and standards
- Rights literacy campaigns among population
- Capacity building:
  - To monitor public policies and services and demand accountability from authorities
  - Strategic advocacy to engage with the State (in addition to health sector, Parliament, Judiciary system, National Ombudsman and others)

Key Actors:
Right to Health Community Dedenders

CEGSS
Centro de estudios para la equidad y gobernanza en los sistemas de salud

Community Defenders: Are Users of Public Services

CEGSS
Centro de estudios para la equidad y gobernanza en los sistemas de salud

Community Defenders:
Volunteers who want to improve services for their families, neighbors, and communities

CEGSS
Centro de estudios para la equidad y gobernanza en los sistemas de salud

Part 1: Discussion / Questions / Comments ?

anandi આનંદી

CEGSS
Centro de estudios para la equidad y gobernanza en los sistemas de salud

GOAL

ACCOUNTABILITY RESEARCH CENTER

hsr2020
SIXTH GLOBAL SYMPOSIUM ON HEALTH SYSTEMS RESEARCH
بحوث النظم الصحية

Part 2: Tools & Tips for Citizen-led Research

In Part, each presenter will focus in more detail on a tool used by citizen researchers in each country.

Guatemala – video about CEGSS / Health Rights Defenders (Walter)

India – Health report card from ANANDI (Neeta)

Uganda – Commitment log used by advocates during campaigns (Vincent)

anandi આનંદી

CEGSS Centro de estudios para la equidad y gobernanza en los sistemas de salud

GOAL

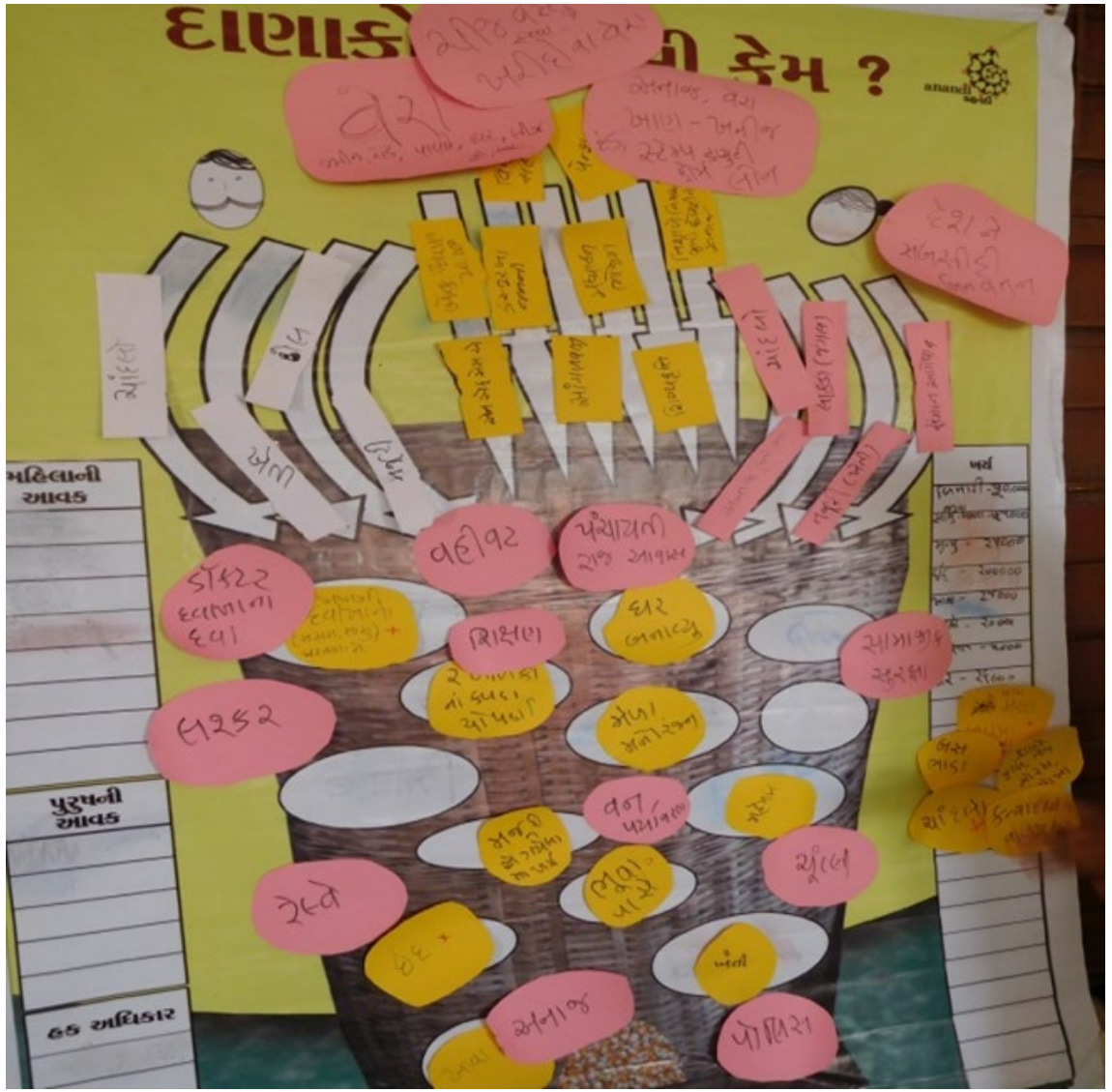
Accountability Research Center

hsr2020 SIXTH GLOBAL SYMPOSIUM ON HEALTH SYSTEMS RESEARCH بحوث النظم الصحية

Guatemala – video

- Independent and autonomous citizen action
- Using the existing legal framework (national and international) norms, policies and standards
- Rights literacy campaigns among population
- Capacity building:
  - To monitor public policies and services and demand accountability from authorities
  - Strategic advocacy to engage with the State (in addition to health sector, Parliament, Judiciary system, National Ombudsman and others)

Critical Analysis, Research, and Capacity-building



Community Monitoring, Accountability, and Action

Health Report Card for *Gram Sabha*

anandi આનંદી

ગામનું આરોગ્ય : ગ્રામસભા માટે રીપોર્ટ કાર્ડ :

ફળિયાનું નામ :

(ના આંકડાઓના સુક્ષ્મ અભ્યાસને આધારે તૈયાર કરેલ અહેવાલ)[1]

ક્રમ	માપદંડ	ચિત્ર						સારું/ ચિંતાજનક
૧૦	રસ્તામાં સુવાવડની (જન્મ) સંખ્યા							
૧૧	સુવાવડમાં ૧૦૮ કે સરકારી વાહનનો ઉપયોગ - સંખ્યા							
૧૨	સુવાવડમાં ખાનગી વાહનનો ઉપયોગ - સંખ્યા							
૧૩	ઘરે થયેલ માતા મૃત્યુની સંખ્યા							
૧૪	સંસ્થામાં થયેલ માતા મૃત્યુની સંખ્યા							
૧૫	ગામમાં થયેલ બાળ મૃત્યુની સંખ્યા							
૧૬	ટીબીના દર્દી -સંખ્યા							
૧૭	ટીબીના દર્દીને સારવાર - સંખ્યા							

◆ **કુપોષણ**

ક્રમ	માપદંડ	ચિત્ર	હાલની પરિસ્થિતિ		સારું/ ચિંતાજનક
૧	બાળ પોષણ શિક્ષણ કેન્દ્રમાં જોડાયેલ બાળકોની સંખ્યા				
૨	બાળ પોષણ શિક્ષણ કેન્દ્રમાં જોડાયેલ બાળકોમાંથી કુપોષિત બાળકોની સંખ્યા				

Commitment Logs

- A tool for capturing all forms of commitments made by target audiences engaged by community advocates.
- Specify the actions taken by community advocates to engage a given target audience
- Track commitment made towards the advocacy "ASK" made to the target audience.
- This tool will help guide follow up efforts and reflection on progress with the advocacy agenda.
- Updated whenever an action has been taken.
- Details will be subject to review and reflection by the entire team of community advocates after 2 months during their Participatory Data Analysis sessions.

Date	Action taken	Target audience	Advocacy space utilized	Commitment/ pledge made	Timeframe for Commitment	What shall we do to follow up this commitment / pledge	When shall we follow up	Who will follow up	Status of commitment (Achieved, Not Achieved, Partially Achieved)
16/3/2017	Meeting with the audience.	COA	Meeting	The COA committed to come and meet up the CAs in their repective places so that he could follow up the issue that was raised.	2 weeks from the time of the meeting.	A physical follow up will be done on The CAO to see that he fullfills his commitment.	25/4/2017	Mr. Male Musa.	Not achieved -the CAO did not fullfill his commitment.
16/3/2018	Meeting with the audience.	DHO	Meeting	The DHO to call for a meeting of the incharges of the five health centres to discuss the findings and also do more investigation.	2 weeks time.	A physical follow up will be done on The DHO to see that he fullfills his commitment.	25/4/2017	Mr. Male Musa.	Not achieved -the DHO had not done any thing to his commitments.

Wrapping Up / More Resources

Organizations

CEGSS https://cegss.org.gt/en/

ANANDI https://anandi-india.org/

GOAL Uganda
https://www.goalglobal.org/countries/uganda/

Accountability Research Center
https://accountabilityresearch.org/

Presenters

Walter Flores – waltergflores@gmail.com

Neeta Hardikar – neeta@anandi-india.org

Vincent Mujune – vincentmujune@gmail.com

Angela Bailey – abailey@american.edu

hsr2020
SIXTH GLOBAL SYMPOSIUM ON HEALTH SYSTEMS RESEARCH
بحوث النظم الصحية