Learning Exchange Report

Report on the 'Think-in' on Community Health Worker Voice, Power, and Citizens' Right to Health

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ACCOUNTABILITY RESEARCH CENTER

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Cover Photo: Participants from around the world joined in June 2017 Learning Exchange: Community Health Worker Voice, Power, and Citizens' Right to Health, held at the School of International Service. The workshop was supported by ARC (American University) and AMDD (Columbia University).

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Acknowledgements

I. Background

Community health workers (CHWs) are increasingly put forward as a remedy for lack of health system capacity, including addressing challenges associated with low health service coverage and with low community engagement in the health system. CHWs are often explicitly mandated or implicitly expected to enhance or embody health system accountability to the populations they serve.

While definitions vary, CHWs are generally community-based workers who: are members of the communities where they work; are (at least in part) selected by the communities they serve; and are required to represent and/or deliver health services (WHO, 2007). CHWs are also commonly envisioned as being answerable to the community for their activities, and they often perform a linking function between communities and the health system (WHO, 2007).

'Accountability' is also a term with numerous definitions, but can be thought of as "the continuing concern for checks and oversight, for surveillance and institutional constraints on the exercise of power" (Schedler, 1999). In the context of a discussion about CHWs, several useful typologies of accountability can be helpful. Accountability can flow 'downward,' from the health system to the community. It can also flow 'upward,' from health care workers to their managers, policymakers, and in some cases, to funders. 'Mutual accountability' refers to the notion of accountability among equals, such as CHWs working on the same team.

Because of their links with both communities and the health system, CHWs may be well-placed to act as agents of downward accountability. More specifically, they can further health system accountability for fulfilling the right to health of all residents. The right to health encompasses equitable, non-discriminatory access to quality health services and to the social determinants of health (such as education and clean air), as well as meaningful citizen participation in the health system.

Margareth Zanchetta (L-Brazil/Canada) a public health researcher interprets for colleague Francisco Vilela (R-Brazil). Since 2001, he has worked as a Community Health Agent in the state of Rio de Janeiro, Brazil.
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II. Convening Description

Though CHW programs may include an implicit or explicit expectation that CHWs foster health system accountability to the community (and vice-versa), this area has been little studied or discussed in policy fora outside of a few studies in India (Saprii, Richards, Kokho, and Theobald, 2015; Scott and Shanker, 2010). The Averting Maternal Death and Disability Program at the Columbia University Mailman School of Public Health and the Accountability Research Center at the American University School of International Service sought to spark consideration of CHWs and accountability by convening a two day 'think-in' in June 2017. The objectives were as follows:

- To share experiences across countries, disciplines, and professional experiences related to how CHWs perceive and experience both upward and downward accountability

- To co-elaborate basic propositions about the potential for CHWs to foster accountability within the health system and between the health system and the community

- To co-elaborate a research agenda related to CHWs and accountability

Thirty researchers, health advocates, and program implementers from eight countries attended. While many country experiences were discussed, the meeting focused in particular on the experiences of Brazil, India, South Africa, and the United States. These countries were selected because, with the exception of the United States, they have large, scaled-up CHW programs where there have been at least some instances of CHWs facilitating—or demanding—greater health system accountability.

During a June 2017 learning exchange on community health workers, Margareth Zanchetta (L-Brazil/Canada) a public health researcher interpreted for colleague Francisco Vilela (R-Brazil). Since 2001, he has worked as a Community Health Agent in the state of Rio de Janeiro, Brazil. Credit: © Ariel Frisancho Arroyo

III. Focus Country Descriptions

The following paragraphs provide key details of the CHW programs in the focus countries. These details are helpful for understanding the subsequent discussion.

a. Brazil

In 1991, the Brazilian Ministry of Health launched a national CHW program modeled after a pilot program for maternal and child health in the state of Ceará (Ávila, 2011; Macinko and Harris, 2015; Tendler and Freedheim, 1994). Today, the CHWs are part of the Family Health Strategy (FHS), a decentralized universal health access program (Perry, Akin-Olugbade, Lailari, and Son, 2016), where they work as part of a multidisciplinary team of providers (Macinko, de Souza, Guanais, and da Silva Simoes, 2007). CHWs in Brazil must have completed at least eight years of schooling, and they receive up to three months of CHW-specific training. The CHW are residents of the communities they serve, and each is responsible for approximately 150 households, or 750 people, and is expected to visit each household on a monthly basis (Johnson et al., 2013). Their job functions include chronic disease management, triage and referrals, antenatal care, breastfeeding support, screenings and immunization, health promotion (i.e. hand hygiene, healthy diet, and physical exercise), contact tracing and household assessment for health protection, data collection, health education groups, and liaising between the health system and community leaders, among others (Johnson et al., 2013). In 2013, the number of CHWs in Brazil exceeded 257,000 (Johnson et al., 2013).

b. India

CHWs have been used to deliver health care services and education in India since the 1970s. In 2005, the Indian Government introduced the Accredited Social Health Activist (ASHA) as part of the National Rural Health Mission (NRHM) strategy to achieve the Millennium Development Goals (Bajpai and Dholakia, 2011).

The ASHA was based in part on the Mitanin Program, a CHW initiative in the Indian state of Chhattisgarh. The ASHA is a trained community health activist who works as an interface between the community and public health system. She is generally married, widowed, or divorced, between the ages of 25 and 45, and a resident of the village where she works. An ASHA should be literate and have at least an eighth grade education, with preference given to tenth grade or higher (National Health Mission, 2014). According to national guidelines, ASHAs are selected through a participatory public process, though in practice, this is not always the case (NHSRC, 2011). Once selected, ASHAs are expected to undergo 23 days of training; however, this too has been poorly enforced, with many ASHAs receiving inadequate training (Bajpai and Dholakia, 2011; NHSRC, 2011). The primary functions of the ASHA are: 1) 'link worker,' building bridges between rural and vulnerable populations and health service centers; 2) 'service extender,' delivering first-contact health care, such as birth control or simple drugs; and 3) 'social change agent,' serving as a health activist to create awareness and mobilize the community (Saprii et al., 2015; Scott and Shanker, 2010). ASHAs receive performance- and service-based compensation for completing certain tasks, such as facilitating immunization, antenatal care appointments, and institutional deliveries (Saprii et al., 2015). There are currently 873,759 ASHAs in India, with each covering a population of about 1,000 (National Health Mission, 2016).

c. South Africa

South Africa does not have a national CHW policy, though CHWs have been part of the South African public health landscape for many years. This has been a source of frustration for CHW advocates, in part because in the last 20 years the number of CHWs has increased significantly as part of efforts to address the HIV and TB co-epidemics (Schneider, Hlophe, and van Rensburg, 2008). In 2011, primary health care reform validated the role of CHWs in delivering health and social services at the community level, and incorporated CHWs into the

formal health system through Ward-Based Outreach Teams (WBOTs). Each team is comprised of a nurse, health promotion practitioner, and six CHWs (Nxumalo and Choonara, 2014). According to the national guidelines, each WBOT should serve a population of about 7,660 people (Joint Primary Health Care Forum, 2011). Each CHW should serve 80 to 150 households, depending on whether they cover rural or urban areas; no CHW should serve more than 250 households (Friedman, 2005). WBOTs' core service delivery functions at household level include registering high risk patients, providing household members with education on common diseases, and providing psychosocial support such as referral for social grants where needed. CHWs also provide basic treatment for common illnesses, such as oral rehydration solution for children with diarrhea (Joint Primary Health Care Forum, 2011). CHWs are paid monthly stipends by the government; however, these stipends are meager (ranging from 800 to 4,000 ZAR, or about 80 to 400 USD) and often delayed (Dageid, Akintola, and Sæberg, 2016; Gonzalez, 2014; Thamela, 2016). Implementation of WBOTs has varied by province (Mampe, Schneider, and Reagon, 2016). There are estimated to be 65,000 CHWs operating nationally (Nxumalo, Goudge, and Manderson, 2016).

Thokozile Mercy Maboe (L-South Africa) is the Founder and Director of Qondisa Institute for Community Health Care Workers. Marie Kinsella (R-USA) is Director of Community Programs for the Partnership for Maternal and Child Health of Northern New Jersey. Credit: © Jonathan Fox

d. United States

For years, community health workers have provided a variety of services in the United States. In the 1990s, there was a coordinated effort to professionalize the field, and CHWs from across the country adopted the term 'community health worker' as an umbrella term for the more than 60 titles being used across the workforce. At that time, CHWs also began to standardize training and organize into professional networks and associations (Anthony, Gowler, Hirsch, and Wilkinson, 2009). The United States has no national-level community health worker program, although in 2010, the Patient Protection and Affordable Care Act (a national law) made provisions for CHWs in recognition of their contributions to health care and outcomes (Brownstein and Allen, 2015). CHW programs are run by local governments, NGOs, universities, and hospitals with the aim of connecting marginalized and vulnerable populations to health and social services. In these various contexts, CHWs perform a wide range of roles, including case management, disease prevention, outreach, health education, client advocacy and empowerment, and health system navigation, with most focusing on chronic disease (Anthony, Gowler, Hirsch, and Wilkinson, 2009). In May 2016, the Bureau of Labor Statistics estimated that 51,900 CHWs were operating nationally, making an average of $19.80 per hour, or $41,170 per year. The states employing the most CHWs were California, New York, Texas, Massachusetts, and Illinois, while the highest concentrations of CHWs were found in Alaska, Vermont, Washington DC, Massachusetts, and Oklahoma (Bureau of Labor Statistics, 2016).

IV. Thematic Summaries

In an effort to concisely communicate the discussions and conclusions of the 'think-in', we describe the first panel—a boot camp on CHWs and accountability—and then proceed to **thematic summaries** of issues and research propositions that emerged over the course of the meeting. As such, we do not describe every presentation, but rather present a **synthesis of emergent themes**. We hope that the gains in terms of brevity and analytic synthesis outweigh the loss in recording the details and richness of the presentations and discussions. Where context would be especially helpful, we have added some background information to the synthesis of emergent themes. For example, in the discussion on CHW unionization, we cite examples and reports from a few countries, even though these citations were not necessarily explicitly discussed in the 'think-in'.

The agenda, including a list of participants, is attached as Annex 1. As noted, the first panel was a discussion of the respective fields of CHWs and accountability. Dr. Kerry Scott, an independent consultant and an Associate at the Department of International Health of the Johns Hopkins School of Public Health, outlined several key issues for consideration in CHW program design. These issues have implications for accountability. For example, requiring that CHWs have many years of edu-

During a June 2017 learning exchange on community health workers, Prof. Jonathan Fox (ARC director) and Prof. Lynn P. Freedman (Director of AMDD) discuss with colleagues including Walter Flores (Director of Center for the Study of Equity and Governance in Health Systems – CEGSS) and Marie Kinsella (Director of Community Programs for the Partnership for Maternal and Child Health of Northern New Jersey).
Credit: © Ariel Frisancho Arroyo

cation may mean that they are wealthier and less able/trusted to represent community needs to the health system. On the other hand, more educated CHWs may be more equipped to provide the government health services that community members want, aiding government fulfillment of the right to health. These issues are summarized in Table 1.

Table 1. **Issues for Consideration in CHW Program Design**

Nomenclature	CHWs as: extenders, providers, activists, or volunteers
Degree of professionalism	How much are CHWs trained and are they paid a salary? How many hours/week do they work?
Tasks	May include educating community members about health concerns and the health system, providing drugs, delivering commodities, accompanying patients to health facilities
Selection process and criteria	Who selects CHWs and are there minimum requirements for the position (years of formal education, gender, place of residence)?
Supervision	Who supervises and monitors CHW work?
Career progression	Opportunities for CHWs to complete further training and obtain higher level jobs

Scott also described debates and tensions, some of which have been resolved, and some of which persist. In actual CHW experience, many of these tensions are not as dichotomous as they appear in policy debates. For example, a given CHW may feel exploited in some contexts, and empowered in others.

Table 2. Debates and Tensions Regarding CHWs

liberator		lackey
self-motivated		self-interested
volunteer	**VERSUS**	employee
activist		extender
of and for the community		of and for the health system
empowered		exploited

Following this introduction to CHWs, Dr. Jonathan Fox, Director of the Accountability Research Center, provided an overview of the broader field of accountability and proposed how the field may be applied to health systems questions.

Fox described what accountability failures in the health system might look like to users of the health system. Considering the community's perspective can help shift the conception of the interface between the health system and its users from something that happens in the "last mile" of service delivery to something occurring in the "first mile" of the citizen-state relationship, thereby placing people, and not services, at the center of the equation (Boydell, Fox, and Shaw, 2017). From the perspective of community members, health systems often fail to provide responsive care, or any care at all. However, citizens cannot easily diagnose the drivers of these failures; the causes of the denial of health rights appear to be a black box. Most problems have multiple causes that are shaped at multiple levels of the health system. Thus, a fundamental challenge is that finding solutions and demanding accountability requires pinpointing responsibility and identifying entry points. Where can CHWs fit into this accountability ecosystem? How can they identify entry points, and how can they help the community to do so?

Fox posed a few key questions for consideration:

1. How do we leverage CHWs' role as bridges between state and society to promote public accountability? (Public accountability refers to accountability of the public sector to the people.)

2. How can CHWs engage in collective action? Collective action would require CHWs operating as social actors with a group identity, and not just as a collection of individuals.

3. Who are CHWs' key allies?

4. What do win-win strategies that empower *both* CHWs and their communities look like?

5. How can such strategies reach scale—with both territorial reach and reaching the upper echelons of the political/power structure?

In the subsequent discussion, participants raised some issues that became leitmotifs of the two-day 'think-in.' These included:

- **Conflict of interest.** Is there an inherent tension in the notion that CHWs, as governmental employees, can and should advance government accountability for residents' right to health? Since they are compensated by the government, are CHWs inevitably compromised as advocates?

- **Diminishing community structures and community mobilization.** CHWs are individuals addressing the health concerns of individuals. In some contexts, CHWs address just one or two priority health areas. Does this individualized approach take pressure off the community and the local government to foster collective efforts that address the social determinants of health? Does focusing on CHWs as potential agents of accountability reproduce the erroneous assumption that CHWs can be understood in isolation from the larger health system, or that community health is separate from broader processes of political contestation? (Nxumalo et al., 2016)

- **CHW agency.** While there may be some space for CHWs to generate accountability, the potential role

of community actors has been idealized. We need to consider the real power dynamics that undercut CHWs' ability to be agents of accountability. CHWs are often low-income women. Perhaps they prioritize pay, professionalization, and career progression, and not facilitating downward accountability (Topp et al., 2015). What if we are undermining their objectives by making them part of an academic conversation on accountability?

- **Health system accountability to CHWs.** CHW programs can be plagued by poor implementation and exploitation, including late payment of CHW salaries and scapegoating CHWs for health system failures. Supporting CHW advocacy for their labor rights may lay the foundation for CHWs to act as agents of accountability. The more empowered CHWs are as a collective, the more they have the power and political space to represent community needs to the health system.

- **Contestation of the notion of accountability.** Though this meeting is about government accountability for fulfilling the population's right to health, we need to acknowledge that accountability is a contested concept. Different stakeholders have different understandings of accountability. For example, some people may wish to focus exclusively on CHWs as salaried workers who must be accountable to their employers to deliver cost-effective care.

- **Contestation of the notion of empowerment.** CHW empowerment is a frequent justification for CHW programs. However, what is meant by empowerment is not always explained. Through their work as CHWs, women may leave the home more than they otherwise would, learn about health issues and the health system, and interact with members of their community and local leaders. In brief, as described by one participant, they are empowered to further the government agenda—not necessarily to question it (Maes, Closser, Vorel, and Tesfaye, 2015b).

- **Contestation of the notion of community.** The word "community" is often assumed to describe an idealized, harmonious setting. Participants raised several questions related to power dynamics within communities, the geographic boundaries of com-

munities, the cohesion within a community, and ways that communities can exclude minority groups. Being honest about these dynamics is essential to thoughtful consideration about how CHWs can represent community interests to the health system and facilitate health system accountability to the community (Maes, Closser, and Kalofonos, 2014).

The following pages present syntheses of themes that emerged in presentations, plenaries, and small group discussions.

a. What does accountability look like?

As noted, the convening was focused on to what extent CHWs are able to advance health system accountability for fulfillment of the right to health. We did not attempt to comprehensively explore and describe what this accountability would look like, but participants mentioned several accountability outcomes that they attributed to CHW activities. Some of these included:

- Improvements in health service availability, such as ambulances and drugs

- Decreased health care worker absenteeism

- Improvements in the social determinants of health, such as increased availability of clean drinking water

- Grievance redress in cases where health providers are disrespectful or refuse to serve patients

- Community priorities and lived experience communicated to decision-makers by CHWs

- Improvements in community knowledge of health entitlements, ability to access services, and service utilization

- Community receives desired/needed health services directly from or via the CHW

Many participants noted that these improvements could foster a virtuous circle; once CHWs saw improvements in their communities, their confidence to push for further improvements grew. Moreover, the accountability

improvements were more likely to occur and more enduring if ground level pressure catalyzed by CHWs and others was accompanied by advocacy, dialogue, or capacity building efforts at a higher level of the health system. This is one example of what Fox has described as "vertical integration" (see text box).

b. The state society interface and CHW program design

The state society interface refers to the points and fora where citizens and representatives of the state interact. The position of the CHW within this interface, as well as the broader relationships between the local government and the community, shape the CHW's capacity to play an accountability role.

In carrying out their duties, CHWs **may bring patients to the state health system and bring the state health system to the patients**. They may also have a **formal role in structures that bridge the state society divide**, such as Village Health Committees. A CHW program may rely on an organization that bridges this divide—a so-called **'boundary organization.'** Finally, in some contexts, CHWs themselves have altered the design of the program and changed the power relations at the state society interface by **unionizing and otherwise demanding labor rights** and professional recognition. We discuss each of these factors below.

Bring patients to the state health system and bring the state health system to the patients

As noted, in most contexts, CHWs have a formal mandate to serve a linking function; Scott explained that this linking function can run the gamut from 'extender' to 'activist.' CHWs comprise a bridge between community members and the formal health system, which is often simply used to deliver health services to community members who would otherwise not have access, thereby employing CHWs primarily as "another pair of hands" for service delivery (Walt, 1990). But this bridge can also provide a platform through which CHWs can function as "cultural brokers" (McKenna, Fernbacher, Furness, and Hannon, 2015), facilitating dialogue on health matters between the health system and the community. Finally, CHWs can serve as "agents of social change" (Lehmann, Friedman, and Sanders, 2004) or "liberators" (Werner,

Box 1. "Vertical integration"

"Vertical integration tries to address power imbalances by emphasizing the coordinated independent oversight of public sector actors at local, subnational, national and transnational levels … [and] across as much as possible of the governance process – from policy debate and agenda-setting to the formulation of policy and budget decisions, as well as to their implementation throughout different agencies and levels of government. … [The goal is to] reveal more precisely not only where the main causes of accountability failures are located, but also their interconnected nature."

(Fox and Aceron, 2016)

1981), advocating on behalf of their communities on topics relating to social determinants of health. The cultural broker and social change agent roles are akin to that of an "interlocutor" (Tembo, 2013) described in the accountability literature. Interlocutors are individuals capable of identifying problems in the community and conveying them to the health system to seek solutions (Tembo, 2013).

Participants described very concrete ways CHW programs bring patients to the health system and vice versa. They explained that South African CHWs are effective at delivering health services, including in particular HIV treatment support. Mitanins in Chhattisgarh escort patients to the health facility, provide linguistic translation, and help patients to navigate the health system. As the Mitanin program learned that accompanying patients was not sufficient to ensure that patients received quality, respectful care, the program took further steps by creating help desks. Help desks, which are located in Primary Health Centers, are staffed by Mitanin facilitators who have received additional training. The help desk staffers assist patients in navigating the facility, including in addressing problems such as provider demands that patients make informal payments.

Participants noted that this bridge role brings advantages as well as challenges. Some CHWs are in a "gray zone" of simultaneously being part of the state and not part of the state (Shiffman, 2002). They offered the metaphor

of two boats. If one boat—the community—goes in a different direction from the other boat—the state—the CHW can be left stranded in the middle. Thus, as a matter of program design, deciding where a CHW stands in relation to the state and society is important. Selection processes, supervision, and job descriptions all shape where a CHW stands. For example, a CHW selected by a nurse at the local health facility will feel differently accountable from one selected by a participatory committee of community members. Volunteer CHWs engaged by NGOs who hope to one day be hired by the Ministry of Health may also feel accountable to the state.

Others noted that in some cases, CHWs may be thought of more accurately as the lowest level cadre doing the least respected work, rather than as health system extenders. In other words, they are not only a bridge from the health system to the community and vice-versa, they are functionaries at the bottom of the health system hierarchy, doing work that higher level functionaries do not wish to do. The social role—educating, listening, and assisting patients—is task-shifted down to the CHW because the tasks are considered unimportant. In this way, CHWs may be enabling the health system to fulfill certain elements of its mandate, but CHW power and respect is low, making it difficult for them to represent community needs and priorities to the health system (Zanchetta et al., 2009). It is a significant challenge for CHWs to try to empower community members when they are not empowered themselves.

Weak relationships between CHWs and their communities can similarly hamper CHW programs. Motivated CHWs who are officially tasked with educating the community about the health system, but who feel disrespected by the community, may not be able to realize their bridging function.

Research that explores CHW and program implementer perceptions of where the CHW stands, and how their position enables them to do their job and to put their values in practice (Ruano, Hernández, Dahlblom, Hurtig, and Sebastián, 2012), may help to shed light on the efficacy and implications of their bridging role. For example, motivated CHWs who are officially tasked with educating the community about the health system, but who feel disrespected by the community, may not be able to realize their bridging function.

Play a role in structures that bridge the state society divide

Many communities have councils or committees to handle the administration of community matters, and many have groups specifically dedicated to health-related issues. In some contexts, CHWs have an informal or formal role in these structures. For example, Village Health Committees (VHCs) can be an important source of support for CHWs, with some studies showing a link between the level of support a CHW receives from VHCs and that CHW's performance and satisfaction (Kahssay, Taylor, and Berman, 1998; Kalyango et al., 2012). In certain countries, CHW engagement with community-based structures is mandated as part of the national CHW policy (Kok et al., 2016). Although VHCs may represent a potential tool for CHW accountability efforts, it should be noted that in some contexts VHCs are not operational on a consistent basis, in part as a result of financial, human resource, or geographic challenges (de Koning et al., 2014).

Participants discussed CHW engagement in VHCs and similar structures in several countries. Mitanins in Chhattisgarh are officially the leaders of VHCs. In this role, they organize VHCs to monitor access to local government services and to act collectively to demand improvements. The VHCs also conduct community audits of maternal and child deaths.

Participants with experiences from several countries noted that CHW involvement with VHCs and similar bodies could enhance their confidence and provide a platform for collective action. However, there was general agreement that VHCs are merely a platform; their existence and CHW participation in them does not necessarily facilitate collective action. Thus, research might address the ways that VHCs can enable CHWs and vice-versa, as well as the relevance of contextual factors related to VHC functioning.

CHWs and boundary organizations

In rare instances, the organizational interface between CHWs and the state is mediated by a so-called boundary organization. In their daily work, CHWs may bring the state health system to the community and vice versa. But, the design, evaluation, and supervision of the program may be led by an organization that itself straddles

the state society interface. Such hybrid organizations are connected to the state, but also have the autonomy to question the state.

The Mitanin program in Chhattisgarh is the most well-known example. The State Health Resource Center in Chhattisgarh is a quasi-governmental entity that also has links to academia. They have a formal role in both CHW program implementation and learning.

Participants explained that this and other boundary organizations can create political space, making policy-making based more on evidence than it otherwise would be. The boundary organization creates a buffer, lessening the influence of politics. Yet, connection to the state confers some degree of political influence, so the learning is more likely to be applied to adapt and change the program.

A few colleagues pointed out that governmental agencies outside the health ministry could play a similar boundary role. For example, ombudsman offices, national human rights institutions, and other entities have created space for accountability demands (Yamin and Frisancho, 2015). These organizations might not be subject to the same political imperatives as the Ministry of Health.

Several people noted that such boundary organizations should be the subject of research for their implementation and learning functions (Nambiar, Muralidharan, Garg, Daruwalla, and Ganesan, 2015). Too often, we act as if CHW and other health system activities implement themselves, and we ignore the role that the actual implementers play. As a result, the stories that get told about programs may lack the critical ingredients that enabled their success (or engendered their failure). In addition to their role in program implementation and learning, the mediating or buffering role of boundary organizations is ripe for exploration. While understood to be on the periphery of the state-CHW-community relationship, these organizations may play a determinative role in creating space for innovation, learning, and rights claiming. Researchers should consider not only organizations that are specifically focused on the CHW program, such as the State Health Resource Center in Chhattisgarh, but also boundary organizations that may play this 'space-creating role' such as ombuds institutions.

CHWs and labor organizing

Many CHWs face difficult working conditions. They also witness the difficulties community members have in accessing health care. To advocate for change in their own employment conditions and/or in health policy, in some countries CHWs have unionized, formed professional associations, or otherwise engaged the state as a collective actor. In hierarchical government health systems where CHWs occupy low-status positions, collective voice and action may be especially helpful in pushing for change.

In India, Accredited Social Health Activists (ASHAs) have staged a number of protests and strikes at both the state and national levels seeking increased wages and government employee status (Express News Service, 2014; Jha, 2016; Tribune News Service, 2015; Tribune News Service, 2016; Zee News, 2015), and have met some success (India Today, 2017). The All Pakistan Ladies Health Workers Welfare Association has pursued a legal strategy rather than political advocacy, resulting in a number of favorable rulings from Pakistan's Supreme Court (Daily Times, 2017). In the United States, the Massachusetts Association of Community Health Workers has on two occasions drafted legislation themselves and found a sponsor to introduce their bills into the House of Representatives; both bills were signed into law (Mason et al., 2011).

While the collective action efforts described above have focused on improving conditions for CHWs themselves, the same mechanisms could theoretically be used to advance the interests of the communities CHWs represent. In Peru, NGO-hired CHWs formed committees that arranged trainings and lobbied the government for better health, while also raising funds to pay for their own activities (Bhattacharyya, Winch, LeBan, and Tien, 2001).

At the convening, the example of the United States and Brazil were discussed in depth. Due in part to the fragmented nature of the health system in the United States, CHWs have little professional power or recognition. Of the 50 states, only 15 have any formal scope of practice for CHWs. There is no national legislation on CHW education or scope of practice. Yet, as a general rule, health providers are not seeking to do the tasks that CHWs do. Thus, CHWs may be health system extenders at the bottom of the hierarchy, but they lack the professional

status to be recognized for this work or to leverage their expertise to improve the health system.

Brazil presents a very different context from the United States. While there is a robust private sector, services to the poor are generally provided through a regulated state-run system. CHWs play a formal role in district Family Health Teams, and they have unionized. For example, in Rio, CHWs formed a union in 2007 that fills three primary functions:

- Representing CHWs on labor related issues at the local level, such as negotiating access to sunscreen as an occupational health and safety concern

- Advocating for CHW priorities at the federal level, such as lobbying for a federally established minimum wage for CHWs

- Participating in general community meetings to increase CHW input and visibility

The union states that they promote the rights of the populations CHWs serve, insofar as CHWs themselves come from the community. The union engages in both adversarial and cooperative tactics to accomplish their goals, including a recent 100-day strike to establish a minimum wage. They rely extensively on social media and traditional print media to share their message and to organize. CHW members attend monthly meetings, and, since 95% of CHWs are women, the union is perceived as a mechanism for social progression and empowerment.

Participants expressed that labor organizing can shift the position of the CHW, and thus the dynamics of power. As noted, CHWs can have their 'feet in two boats.' A union or professional association might pull them more firmly into the 'community boat' by creating solidarity within the profession, providing a counterweight to the employer. For example, Lady Health Workers (LHWs) in Pakistan held strikes in response to government threats of termination for refusal to work on polio campaigns—this at a time when polio workers were being murdered by anti-government forces. As a result of the strikes, the government agreed to grant LHWs basic job security, thereby mediating a power dynamic that otherwise might have firmly positioned LHWs as state

functionaries. This sort of counterweight to state power can foster stronger alliances between CHWs and the community, ultimately boosting CHW capacity to promote health system accountability to the community. In other words, labor organizing could be one win-win strategy that empowers both CHWs and their communities. However, a few participants pointed out that professionalization can also take CHWs further away from the community, as they are distinguished from their poor neighbors by education, salary, and political power. Moreover, labor organizing can feed political tensions. For example, in Brazil, CHWs have the trust of the community and the power of the union. They have enough power to question local political representatives. For their part, local political representatives may try to leverage the power of the CHW program to garner votes and even confer privileges (clientelism).

While there is an extant body of research on CHW motivations and professional ambitions, there is much less on how and when labor organizing or the creation of professional associations may advance CHW and community goals. Participants pointed out the potential of such organizing to have great impact, but also to have negative impact. There was robust agreement that the case of Brazil merits further study, as do the sub-national efforts in South Africa, India, and the United States.

c. Trust

Trust can be another important feature of the CHW-community relationship, and can be fostered from the very beginning of a program by engaging the community in discussing and defining the CHW's role (Scott and Shanker, 2010), as well as through the CHW selection process (Singh, Cumming, and Negin, 2015).

Several voiced the notion that community trust in CHWs was essential for promoting health system accountability to the community; trust was a precondition. If community members do not trust CHWs, then CHWs cannot meaningfully fulfill a bridging function. They may bring the health system to the community and vice-versa, but the CHW may not be trusted because her approach undermines rights. In this scenario, the CHWs likely feel accountable for different goals rather than for assisting the government in fulfilling the right to health. They noted several factors that can promote trust:

- Engagement of the community in selecting and supervising CHWs

- Perception that CHWs are using program funds and/or obtaining incentives for service delivery appropriately and fairly

- CHWs are able to meet community expectations in terms of knowledge and service delivery capacity (Nxumalo et al., 2016)

Many participants pointed out that the development of trust is not linear. In other words, community perceptions about whether or not CHWs are using program funds fairly probably relate to preexisting assumptions about CHW motivation. Some noted that the accountability literature fails to explore trust and motivation. Economic approaches to accountability prioritize incentive structures, without attention to *why* health workers are motivated to act in certain ways. As the discussions regarding trust show, implementing incentive schemes to try to get CHWs to do certain things can affect CHW motivations and community trust.

Dr. Maryse Kok presented the following graphic, based on research in multiple countries, outlining the factors shaping performance of CHWs.

Figure 1. Situating Communtiy Health Workers within Complex Adaptive Health Systems
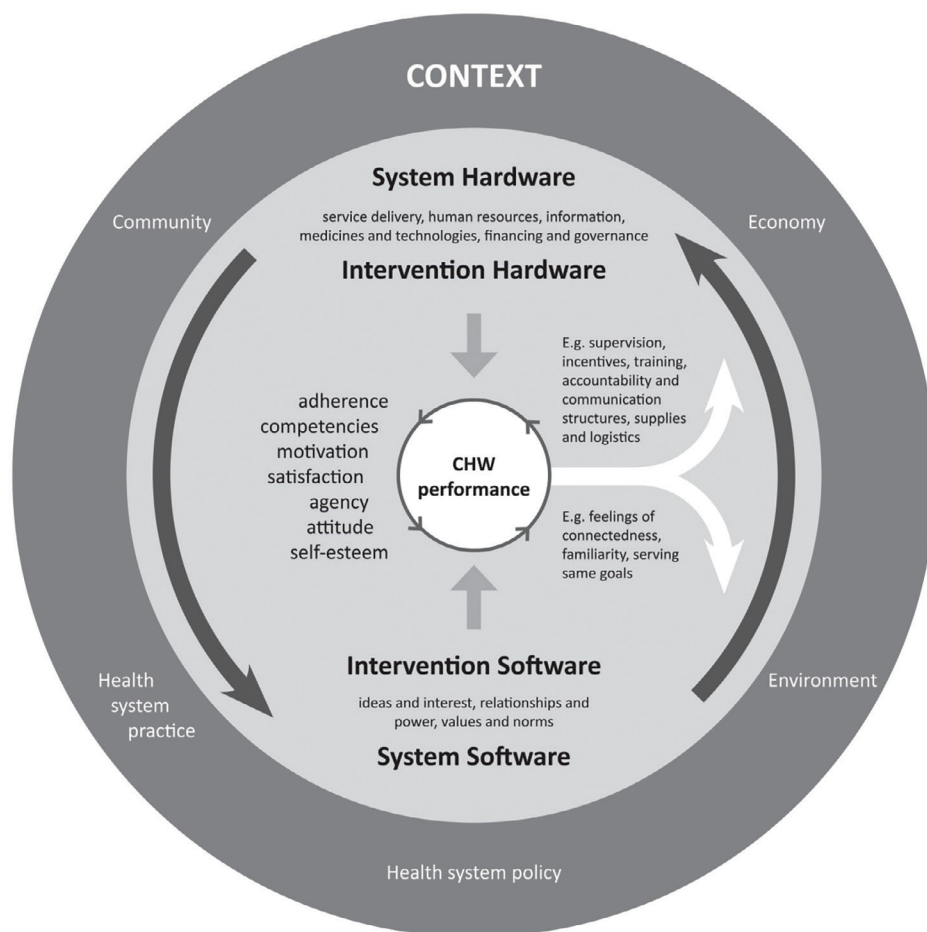
Citation: Kok, M. C., Broerse, J. E., Theobald, S., Ormel, H., Dieleman, M., and Taegtmeyer, M. (2017). Performance of community health workers: situating their intermediary position within complex adaptive health systems. *Human Resources for Health, 15*(1), 59.

Building on this, a few participants felt strongly that CHWs' status as government employees made community trust in CHWs impossible in many contexts. In places where communities do not trust government, government-employed CHWs will never be beyond suspicion; they are by definition an agent of the government (the conflict of interest thesis). Some felt that the entire health care encounter should be ring-fenced from questions regarding monetary incentives; patients should not worry that a CHW or a provider are providing information or care based on a financial incentive they expect to receive. This has particular resonance in countries where CHWs receive financial incentives to bring patients for health services, such as vaccination or delivery in a facility. Participants opined that trust develops best when the community, providers, and CHWs are all co-producers of health, and where health is not subject to market forces of supply and demand.

Trust is a social phenomenon. There was widespread agreement that its precursors and manifestations are contextual. Trust in CHWs is inseparable from larger questions about community trust in the government. Thus, from a research perspective, the avenues of potential enquiry proliferate. They could include looking at non-governmental cadres in the context of low trust in the government, CHWs as agents to build community trust in the government, and how CHW scope of practice shapes community trust in CHW intentions and competence. Like accountability, trust can be thought of in an ecosystem. Thus, research on trust might include the perspectives of many different stakeholders, including, for example, CHWs, community members of different groups, and health providers.

d. Cross-cutting issues

The following issues arose in the context of several different themes. They are discussed briefly below.

Urban vs. rural

Several participants described ways in which CHW programs function differently in urban and rural contexts. These differences are not always what one would expect. For example, VHCs are reportedly more responsive in urban areas of Chhattisgarh. Program implementers expected VHC operations to be more difficult in urban areas, as urban populations are often comprised of recent migrants from rural areas. This diversity can make collective action and cohesion more difficult, as residents do not have shared experiences and assumptions; they may not even know each other well. In contrast, the State Health Society found that urban CHWs and VHCs were better able to facilitate dialogues and contact local officials, whereas VHCs in rural areas needed much more support. Some stated that this was because rural residents were more reluctant to engage power.

On the other hand, some who had conducted research or implemented programs in urban areas noted that community receptivity to CHWs may be lower in urban contexts. This could be because there is less community cohesion to serve as a platform for CHW activities. This in turn makes collective action more difficult. Moreover, urban residents may be less amenable to CHWs as they aspire to higher quality, 'modern' services. They prefer to see biomedical providers, and are not receptive to trained lay people like CHWs.

Risk

There was widespread agreement that asking for accountability can entail risk. There are many examples of CHWs being punished for advocating for their own rights or for the rights of their communities. This can include being fired; being denied financial incentives to which they are entitled; or obstruction, smear campaigns, or noncooperation from health providers and local officials. Risk may be particularly acute in cases where CHWs are female and/or otherwise represent a group that is systematically marginalized, such as lower caste groups or members of racial or ethnic minorities.

Risk is incurred not just in the professional realm; CHWs can also face risk in the domestic and social realms. CHWs—particularly females—may be shunned by their families or communities for leaving the house and interacting with strangers. Indeed, they may face physical risk by traveling alone and/or at night.

Some felt that the research and literature on CHW empowerment has focused on CHWs overcoming risk, without attendant focus on the potential differences between CHWs' individual leadership aspirations and aspirations of the greater community. This relates to the notion that CHWs can be empowered to carry out the

government agenda. Decreasing risk may help CHWs to more effectively bring the health system to the community and vice versa, but it does not necessarily mean that CHWs are more equipped to push the health system to do more than they otherwise would to fulfill the right to health. The dynamic between risk and empowerment is even more complicated in cases where the state may intentionally create fora that are ostensibly for empowerment that, in function, all but discourage CHWs from asking questions (Maes, Closser, Vorel, and Tesfaye, 2015a). In these cases, the government opines that CHWs are empowered, while CHW experience is very different. The disconnect between governmental efforts to empower CHWs and reality does not necessarily stem from a cynical governmental plot to foster faux empowerment; it could also stem from difficulties in implementing programs that challenge prevailing norms and power dynamics. In other words, there may be consensus among decision-makers in the capital city, but that does not mean that frontline workers tasked with facilitating empowering groups have the will, expertise, or political space to do so (Ruano, Sebastián, and Hurtig, 2014).

This discussion led to participants calling for research and sharing on risk and empowerment, with attention to the interplay among different types of risk (e.g. physical risk, social risk). Moreover, the empowerment objectives of CHW programs might be examined from the perspective of social norms and political power (Maes et al., 2015b), as well as from an implementation perspective. The emerging field of implementation in global health is well-suited to explicate some of the factors associated with failure to realize empowerment goals.

State capacity

State capacity cannot be ignored in a discussion about accountability; the extent to which governments fulfill the right to health of their residents depends on many factors, including their own capacity. For this reason, several people pointed out that accountability efforts may be more successful when they are accompanied by efforts to build state capacity to deliver responsive health services. Both political will and state capacity are necessary but not sufficient. Thus, though it was not discussed as a central feature of research propositions, there was widespread agreement that state capacity is integral to any research on accountability.

Donors

Donors were not widely discussed, but there was agreement that in many contexts, the notion of accountability is understood to apply first to donors. In this scenario, governments should be accountable to their donors for carrying out funded programs efficiently and with fidelity. This 'think-in' was about government accountability to residents, but it would be naïve not to acknowledge the real role that donors play in the dynamics of power in some settings. Moreover, because donor power is often tacitly assumed – rather than explicitly stated – it often fails to make it on to research agendas.

Even more complicated, in some contexts, real accountability can work against the donors' desires. For example, donors may prioritize health service coverage indicators enshrined in global goals over the human rights of community members. In the name of accountability to these donors and the goals, governments may ask CHWs to coerce community members into receiving services, such as vaccination or delivery in a health facility.

Context and history

The importance of context and history is now a truism in discussions about development and public administration. Indeed, a central question of the 'think-in' was to ascertain in what contexts CHWs can reach up into the accountability system to shift power relations. Describing relevant contexts was thus part of our goal. In that sense, the 'think-in' underlined the relevance of context, including on a sub-national level. The discussions comparing urban versus rural or New Jersey versus other U.S. states showcased the ways that different social and political environments shaped CHWs' ability to do their jobs, as well as their ability to affect shifts in power relations.

The uniqueness of the Mitanin program underscored the importance of history. Program planners trying to extract lessons from Mitanin should be cognizant of the fact that the program is very much a product of a particular time and place. The state of Chhattisgarh was formed in 2000, providing an opportunity for innovative, culturally relevant efforts to build community and develop the state (Sundararaman, 2007).

In Ethiopia, a series of historical factors—the rise of strong state power, the development of the MDGs, the

expansion of the global war on terror, and a global recession—greatly influenced the evolution of the national CHW program, including key program features such as a reliance on volunteer labor (Maes et al., 2015a).

Similarly, we heard about how the HIV and TB co-epidemics in South Africa led to a huge increase in health expenditure, increased activity by NGOs, and increased activism by patients. These increases, combined with post-apartheid reorganization of the health system and the long history of CHWs in the country, laid the groundwork for an enhanced CHW program at scale.

In contrast, the example of the United States showed how contemporary political dynamics can undercut CHW programs. Program implementers described how community mistrust of CHWs in New Jersey is growing. Since the 2016 election of Donald Trump and other politicians deploying anti-immigrant and 'tough on crime'

rhetoric, undocumented populations, as well as poor, marginalized groups fear contact with the state. The most basic of CHW functions—bringing state health care services to the community—is compromised by understandable community reluctance to engage these services.

Scale

There are many examples of pilot projects where CHWs or other intermediary actors foster governmental accountability. The challenge is to create the conditions for the implementation of such a program at scale, with sufficient flexibility to account for local contexts. Participants at the convening agreed that scale was the ultimate objective, and that planning for scale should happen at the beginning of a pilot project. However, examples of success are few. The imperative and challenge of scale remained an unanswered priority question throughout the two days.

V. Synthesis of Research Agenda

As described in greater detail in the thematic summaries above, the following questions emerged as basic research questions and propositions during the 'think-in':

- How do CHWs and program implementers perceive CHW positionality in the state society interface?

- How does the CHW program design and intended CHW function shape accountability relationships?

- Can educational and training institutions assist CHWs in achieving upwards/downwards accountability?

- What activities (e.g. civil society actions, supportive supervision) can create space for CHWs to achieve accountability?

- How can VHCs enable CHWs (and vice-versa)?

- What role do boundary organizations play in CHW program implementation and learning, and how might they mediate or buffer the interface between CHWs and the state?

- How and when can labor organizing or the creation of professional associations advance CHW and community goals? What is the scope for alliances between CHWs and other frontline health workers? Can these alliances protect CHWs from backlash that may ensue when they pursue accountability?

- How does community trust in the government (or lack thereof) influence perceptions of and trust in CHWs, and how might CHW programs in turn impact this trust ecosystem?

- How do CHWs perceive risk and empowerment in their role, and how does this relate to CHW program objectives?

- How do CHWs see themselves relative to other social actors?

- What is the accountability ecosystem for CHWs? How do CHWs exercise power in daily interactions with all kinds of actors?

- Recognizing that different types of CHWs are diverse, how can we develop a typology or mapping of features of CHW programs to understand their focus, scope, ownership, contractual nature, and motivation?

- Given the fragmented nature of some disease-specific CHW programs, CHWs need broader mandates to be effective agents of accountability. What are the disincentives to integrate CHWs programs in different contexts? This might include budgeting, patronage, and the way donors operate in-country.

- How can we facilitate greater institutional responsiveness to concerns raised by CHWs and communities?

- There have been significant discursive and policy changes over time regarding CHWs. How have these changes impacted political commitment and programs?

The critical role of national (and sub-national) context was emphasized for all these questions, as were implications for scale.

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Annex 1 – Agenda

Community Health Worker Voice, Power, and Citizens' Right to Health
American University | Washington, D.C.
School of International Service | Abrahams Founders Room
June 12 – 13, 2017

Objectives
• To share experiences across countries, disciplines, and professional experiences related to how CHWs perceive and experience both upwards and downwards accountability
• To co-elaborate basic propositions about the potential for CHWs to foster accountability within the health system and between the health system and the community
• To co-elaborate a research agenda related to CHWs and accountability

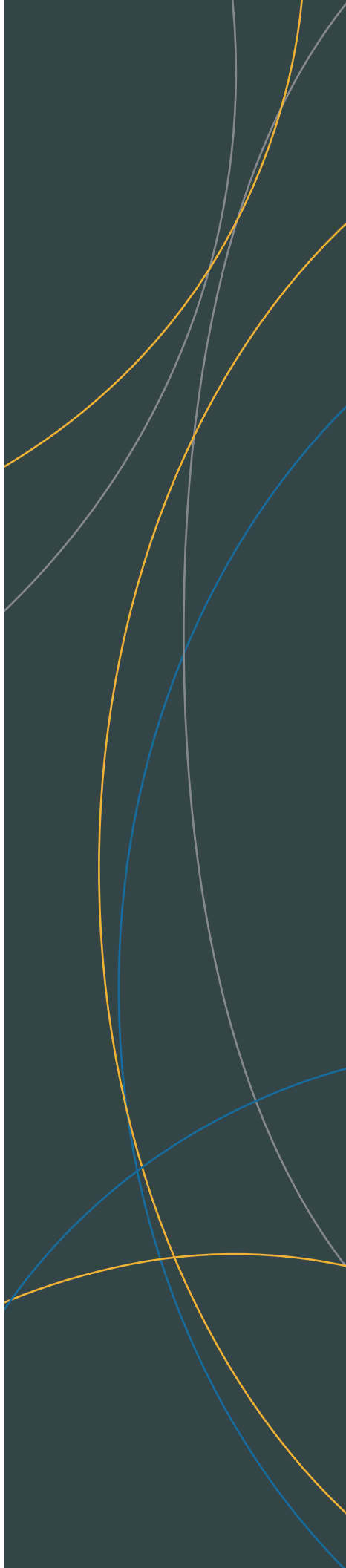| Open Network for Wireless Internet Access: AUGuest-byRCN |
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| Monday, June 12th 2017 |

Time	Session	Moderator
08:30 - 09:00	Greetings and light breakfast	
09:00 -10:30	**Opening and Introductions** • Welcome and meeting framing – Jonathan Fox and Lynn Freedman • Introductions and why you were interested in participating in this dialogue (two minutes each) • Review objectives and agenda – Marta Schaaf • Briefly synthesize participants' interests and introduce jargon busting – Stephanie Topp Explain to participants that we will be keeping a running register of key (1) jargon terms and (2) possible tensions (e.g., how can CHWs act as agents of accountability when they perceive their most important task as providing their supervisors with data on increased coverage?).	Jonathan Fox, ARC/SIS, AU
10:30 -10:45	Stretch and Refill Your Coffee/Tea	
10:45 -12:00	**Bootcamp on CHWs and accountability** In this session, experts in CHWs and transparency and accountability will provide a brief overview of their respective fields – assumptions, key players, global policy landscape, tensions in the field. Speakers (25 minutes each) • CHWs: global policy landscape, competing views on what CHWs are, and an emic perspective on accountability – Kerry Scott • Transparency and accountability: overview of the field and application to health systems questions – Jonathan Fox Discussion	Marta Schaaf, AMDD

Time	Session	Facilitator
12:00 -1:00	Lunch	
1:00 -2:00	**CHWs, community and governmental structures (VHC, panchayats, etc.)** This session will highlight the diversity of experiences regarding CHW collaboration with broader health governance structures, and what the implications of this are for CHW exercise of voice, power, and accountability. Speakers (15 minutes each): • Maryse Kok, Reachout • Samir Garg, SHRC, Chhattisgarh • Thoko Maboe, LifeLine, South Africa Discussion	Lynn Freedman, AMDD
2:00 - 3:15	**CHW power and accountability** This session will discuss the various mechanisms, opportunities, and limitations to CHWs exercising power, and what the implications are for accountability. This may include labor organizing, professional associations, and advocacy for or against incentives. It will cover experiences where CHWs have formed professional associations, and discuss to what extent these associations have advanced a review of national and international policy reform initiatives. Lessons and limitations will be discussed.Post-it notes – new confusing terms Speakers (15 minutes each): • ASHAs' power in the health system; comparison between Bihar and Chhattisgarh – Arshima Shah • CHW power, labor organizing, and hierarchy – Svea Closser • The CHA Union of Rio State – Francisco Vilela • CHWs and power in a fragmented health system – Ilise Zimmerman Discussion	Lauren Carruth, Assistant Professor School of International Service, American University
3:15 - 3:45	Coffee/Tea Break	
3:45 - 5:00	**Small group work** Groups will discuss, note, and report back on tensions and themes that came to the fore during Day 1. This will be a preliminary discussion on the research agenda.	Angela Bailey, ARC
5:00 - 5:15	**Closing** Summarize the key takeaways from the day.	Stephanie Topp, James Cook University
5:.30 - 7:30	**Evening Reception by Zenful Bites and Mixin' Mimi**	All
Tuesday, June 13th 2017		
8:45 - 9:15	Coffee and light breakfast	
9:15 - 10:45	**CHWs, community activism, and the social determinants of health** This session will introduce some key concepts and lessons regarding when and how CHWs have been engaged in community activism, including representing the communities' needs to the health system. We will also discuss when they have addressed the upstream social determinants of health. By upstream social determinants of health, we refer to factors such as exclusion, discrimination, power dynamics within communities, and mutual mistrust between the health system and communities. Speakers (15 minutes each): • Margareth Zanchetti, Ryerson University • T. Sundararaman, Tata Institute of Health Sciences; Peoples Health Movement • Nonhlanhla Nxumalo, Centre for Health Policy, Wits University • Marie Kinsella, Partnership for Maternal and Child Health of Northern New Jersey Discussion	Sara Bennett, Johns Hopkins University

Time	Session	Moderator
10:45 - 11:00	Stretch and Refill Your Coffee/Tea	
11:00 - 12:15	**Civil society monitoring** Panelists will discuss what insights gained about CHW programs and CHWs and accountability from civil society monitoring and engagement. Speakers (15 minutes each): • Walter Flores, CEGGS • Abhay Shukla, SAATHI, People's Health Movement • Ariel Frisancho, Catholic Medical Mission Board Discussion	Meike Schleiff, Future Generations
12:15 - 13:15	Lunch	
1:15 - 2:15	**Brainstorming and prioritizing** Participant discussion of research gaps will structure the small group for the afternoon. Participants will identify topics for small group discussions later in the afternoon.	Marta Schaaf, AMDD; Stephanie Topp, James Cook University
2:15 - 3:30	**Towards a practical research agenda** Small group work: Divide into self-selecting interest groups, assign 1 topic to each. Have them develop recommendations for steps that could and should be taken over the next year: (1) Define research gap and research questions. (2) Answer the "so what" question/ why this is important. (3) Which combinations of research methods are most appropriate for addressing the priority research questions identified. Would cross-country research add value? (4) How can we ensure the findings can be applied in real life implementation (research utilization). Have them capture them on flipchart paper.	Rachel Robinson, Associate Professor School of International Service, American University
3:30 - 4:00	Coffee/Tea Break	
4:00 - 5:00	**Small group report back and possible next steps** Small Group report back to plenary and facilitated discussion Allow each group up to 5-7 mins to report. Plenary discussion will consider the following questions: • What needs clarification? • What are strengths and limitations of each proposed agenda? • Which recommendations seem most feasible? • What could be done in the short-term? What would require longer-term commitment?	Ana Lorena Ruano, CEGGS
5:00 - 5:30	**Takeaways, suggestions for next steps and closing**	Jonathan Fox, ARC/SIS, AU; Marta Schaaf, AMDD
	Commentary writing committee meeting	

Annex 2 – Participants

1. **Nicole Angotti,** American University
2. **Angela Bailey,** Accountability Research Center, American University
3. **Sara Bennett,** Johns Hopkins University
4. **Lauren Carruth,** American University
5. **Svea Closser,** Middlebury College
6. **Arshima Dost,** Brunel University
7. **Daniel E. Esser,** American University
8. **Walter Flores,** Center for the Study of Equity and Governance in Health Systems, Guatemala
9. **Jonathan Fox,** Accountability Research Center, American University
10. **Lynn Freedman,** Averting Maternal Death and Disability Program, Columbia University
11. **Ariel Frisancho,** CMMB Peru
12. **Samir Garg,** State Health Resource Centre, Chhattisgarh, India
13. **Dhananjay Kakade,** Open Society Foundation
14. **Marie Kinsella,** Partnership for Maternal and Child Health of Northern New Jersey
15. **Maryse Kok,** Royal Tropical Institute, Amsterdam
16. **Thokozile Mercy Maboe,** Qondisa Institute for Community Health Care Worker
17. **Nonhlanhla Nxumalo,** Centre for Health Policy, Wits University
18. **Suchi Pande,** Accountability Research Center, American University
19. **Rachel Robinson,** American University
20. **Ana Lorena Ruano,** Center for the Study of Equity and Governance in Health Systems, Guatemala
21. **Marta Schaaf,** Averting Maternal Death and Disability Program, Columbia University
22. **Meike Schleiff,** Future Generations
23. **Kerry Scott,** Independent research consultant, Bangalore, India; Department of International Health, Johns Hopkins School of Public Health, Baltimore, USA
24. **Jeremy Shiffman,** American University
25. **Abhay Shukla,** SATHI
26. **Sundararaman Thiagarajan,** School of Health Systems Studies, Tata Institute of Social Sciences
27. **Stephanie Topp,** James Cook University, Australia
28. **Francisco Vilela,** State of Rio de Janeiro Community Health Agents' Union
29. **Nina Yamanis,** American University
30. **Margareth Zanchetta,** Ryerson University, School of Nursing
31. **Ilise Zimmerman,** Partnership for Maternal and Child Health of Northern New Jersey

ACCOUNTABILITY RESEARCH CENTER