Learning from international experience on approaches to community power, participation and decision-making in health.

Case Study: Lusaka district health office, Zambia
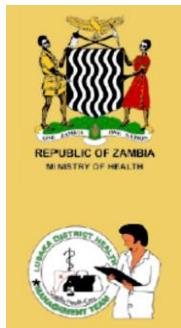
Key features:

This case study of work by the Lusaka District Health Office tells the story of sustained participatory approaches used since 2005 in urban Lusaka on participatory priority setting, planning, budgeting and health action by communities and frontline health workers on local health committees and on community health literacy that is now scaling up to national level.

Features of the work that could potentially be adapted elsewhere, include

- The use of participatory reflection and action (PRA) approaches to organise community experience, analysis and action in health literacy and in mechanisms for dialogue between communities and health workers.
- Facilitating PRA in health committees for joint community and service planning and action.
- Building joint health services and community identification of needs and actions, with support for voluntary community roles and for community champions and voice to sustain the process.

The work has sustained and spread due to various factors, including the social power and confidence built within communities from the PRA processes; a horizontal, rather than top down, spread; facilitating participation mechanisms involving elected community members and frontline health workers; providing forums for wider sharing of experience across localities; accessible online reporting of the work; and a committed leadership able to sustain and advance the processes.

Introduction to the site and its practices:

The Zambia government has had a commitment post 1990 to participation of stakeholders, including local communities, in health service planning and delivery. Sustained participatory approaches have been used in <u>Lusaka urban</u>, institutionalized to <u>national level</u>. These include work on health literacy, and with <u>health centre committees</u> involved in participatory priority setting. <u>Participatory methods were used in comprehensive primary health care (PHC),</u> linking with other sectors and with community health workers (CHWs) and health literacy facilitators in culturally appropriate approaches, including to track and support uptake and to raise policy/political attention and support. Lusaka District Health Office (LDHO) has, for example, prepared a constitution for its HCCs, and with partner support has trained HCCs in planning and budgeting and held nine Annual General Meetings for NHCs. Participatory reflection and action methods have been used since 2006 to support community participation in planning, budgeting, implementing and reviewing primary care services in Lusaka, as described in a video at https://vimeo.com/72914294.

Communities identify their priority health problems or issues to be addressed, reflect on their causes, dialogue with health workers on actions and mobilise local resources to solve problems. Communities are the change agents. They are trained in health literacy, act with the local health workers on identified priorities, and use participatory monitoring tools to review progress. These approaches have increased informed, self-determined participation in planning and budgeting by NHCs, community members and local health workers. They have increased mutual respect between community members and health workers, and increased awareness on the constraints health services face in the resources health centres are allocated from district and central level. In communities where health literacy facilitators have been trained, the communities make plans and input to budget decisions. They identify problems and lobby for funds both from the health system and from local and international agencies.

The Lusaka District Health Management Team (LDHMT), now the Lusaka District Health Office (LDHO) is the local health authority for Lusaka district within the Ministry of Health Zambia responsible for the work. The case study was prepared in February 2017 by Rene Loewenson (TARSC), with Dr Clara Mbwili-Muleya, Principal Clinical Care Officer LDHO and Idah Zulu Lishandu, LDHO.

Context:

Zambia is a lower middle income country. It is experiencing economic growth, largely from mining, but also has persistently high levels of poverty and socio-economic inequality. In 2013 Zambia's gross national income/capita PPP was US$3 070, the life expectancy at birth in 2012 was 57 years and 74% of the population lived on less than US$1 per day in 2010 (WHO 2015). Zambia had 7.8 nurses and midwives / 10 000 people in 2012, and a per capita expenditure on health of US$80 (WHO 2015). Lusaka province covers 21 8961 km2, with eight districts, namely; Lusaka, Chongwe, Luangwa, Kafue, Chirundu, Chilanga, Shibuyunji and Rufunsa. Lusaka province has the fastest population growth in the country, with 85% of its population urban and Lusaka as the capital city of Zambia has 1.7 million people (UNDP, GoZambia 2013). Nearly a

Source: CSO,MoH TD RC, Unz Marco International Inc, 2009 Map of Zambia showing provinces

quarter of the population live below the poverty line (24.3%), lower in urban than rural areas. The unemployment rate is 11% (UNDP, GoZambia 2013). The 15-49 year literacy rate among women and men in the province is 68% and 83% respectively (CSO et al., 2014). Health seeking behaviours are often influenced by cultural and religious beliefs and practices. For example, traditional healers are often visited before going to allopathic health providers and some religious sects do not allow their members to attend health care services, preferring spiritual healing through prayers. On the other hand, the presence of extended families and traditions can facilitate the community networks and interactions needed to organise health activities, particularly in the high density areas of Lusaka.

Between 2000 and 2010, Infant and child mortality in the province declined to 68 and 115 per 1000 respectively, but maternal mortality was still high in 2010, at 357/100 000. The national HIV prevalence rate is estimated at 13.3% (CSO et al., 2014) of whom 21% were on antiretroviral treatment in 2013 (UNDP and GoZambia 2013). The province has a high but declining malaria rate and deficits in access to safe water and sanitation (UNDP and GoZambia 2013). Zambia has a mixed profile of communicable and non-communicable diseases. The national health strategy gives priority to improved environments and food safety, control of epidemic outbreaks, health promotion and primary health care services for family health, communicable and chronic conditions (MoH Zambia 2011). Generally the public sector dominates the delivery of health services. Public health facilities are organised under the Ministry of Health (MoH), the Ministry of Defence, the Ministry of Home Affairs and, more recently, the Ministry of Community Development, Maternal and Child Health (MCDMCH). The MoH owns 80% of health centres. Private health services include faith-based providers and mission–owned facilities, mainly in rural areas.

Lusaka has a relatively high share of its heath expenditure at health centre level (Chitah and Jonsson 2015), and the policy intention is for primary care services to be available, accessible and to have good outreach to local communities (MoH Zambia 2011). A basic package of services has been set with defined interventions for all levels of care, although it has not yet been used to operationalize priority setting or resource allocation for services. Health posts (HPs) and health centres (HCs) are found at community level, and refer to district hospitals, then to provincial and then national tertiary hospitals. Lusaka district, being a capital city, has all levels of health services from health posts to the University Teaching Hospital, a tertiary facility. The mandate of LDHO, however, ends at district hospital level. LDHO collaborates with NGOs, other public sector and private health providers, especially those at health centre level, to provide various health services and public health programmes in nationally prioritised areas at community and household level. This includes interventions for common conditions, including for maternal and child health, HIV and AIDS, tuberculosis, water and sanitation and malaria. LDHO also implements activities to strengthen health systems and improve service coverage, including through staff recruitment, financing and public health outreach. It identifies needs and delivers services for them, although staff recruitment and allocation of funds is largely decided at central level.

The Lusaka District Administration supervises, co-ordinates and monitors the operations of all government departments' and other co-operating organisations in the formulation and implementation of programmes in the district. A District Development Coordinating Committee carries out integrated planning. A District Council with elected representatives from civic leaders links planning with communities to integrate community inputs. Zambia made a policy commitment to participation of stakeholders, including local communities, in health service planning and delivery. The Central Board of Health developed and disseminated in the 1990s a *Citizens' Charter of Rights* covering rights to health care, to be involved in planning and priority setting and to communicate grievances through neighbourhood health committees (NHCs) (Unza et al., 2011). NHCs were set up nationally in the 1990's as a vital link between the community and the health system, provided for in the 1995 National Health

Services Act. In 2006, as part of wider health reforms, this Act was repealed removing the legal mandate of NHCs. They continue to function, however, drawing their mandate from national health strategic plans, annual plans and budgeting handbooks (LDHMT, TARSC 2015). A new National Health Services Act is still in process and the contents are not yet finalized.

The participatory practices:

LDHO has a history of over a decade of using participatory reflection and action (PRA) approaches to strengthen primary care level health service delivery in the district, working with TARSC and other organisations in a Regional Network for Equity in Health in East and Southern Africa (EQUINET). These activities, while largely conducted as PRA meetings, were also used to strengthen the role of the NHCs as a more formal, sustained space for participatory interactions.

According to government guidelines, NHCs:
- identify health needs in the community, collect community evidence and plan and work with the health center staff on shared concerns, together with community based organisations; and
- support information exchange between health services, communities and community health volunteers.

HCC chairpersons planning at district level © M Daka 2013

The NHC constitution guides that communities select from local residents, and take into account gender representation in and the non-partisan nature of the NHC. The community is informed through outreach on the elections through public awareness activities and elections are held with district observers. The community elects willing community members from the neighbourhood of a HC to be in the NHC, excluding politicians or health service workers / employees. Should community members have concerns with the representativeness of the NHC they can raise this with the district and call for redress or fresh elections. The NHC elect a chairperson as leader for the area who becomes a member of a health centre committee (HCC) at the health facility. The HCC involves community members and health staff, with the HC nurse-in-charge the secretary and a chairperson from amongst the NHC chairpersons. Community members in the HCCs and NHC are trained on the health system, and have a mandate with to work with the community and with organisations that work with communities on health. In 2005, before the work described in this case study commenced, Ngulube et al. (2005) found that despite the policy intentions, planning and budgeting for PHC was not participatory and the NHCs were poorly organized for, or involved in their role. The civil service culture made it difficult for community actors to feed into and benefit from the intended bottom-up approach set in policy.

The processes described in this case study started in 2006. The 'Zambia Equity Gauge' in Lusaka city (and rural Chama district) targeted health providers from each health centre and community health volunteers from each district. Growing public health problems in Lusaka motivated community members, health workers and LDHO to strengthen community-health centre partnership and accountability and the information sharing needed for planning, budgeting, resource allocation and action at HC level. Various participatory tools (described in the hyperlinked resource) including 'problem trees, ranking and scoring, market places' and others were used to identify needs, system barriers and areas for change. The issues raised included poor communication between and within health workers and community members, poor understanding of roles; health workers' perception of low health knowledge in the community and community members feeling powerless and unappreciated by health workers. They reported few forums or resources for health workers and the community to exchange as equal partners.

PRA methods were used to address these factors, and build a shared identification of problems and actions to remedy them across health workers and community members. This had an impact on the health system. Information sharing between health workers and community members increased, community members were more confident in approaching health workers for information and health workers provided information to them on planning and resource allocation. The actions varied: For example George HC and community used the process to set a strategy to tackle an impending cholera outbreak, together with community volunteers in the area. The resulting well-planned preventive strategy led to significantly fewer cholera cases and deaths than in previous years, despite the heavy rains. In other HCs the process enabled frontline health workers and communities to get information on locally collected funds and their allocation and to participate in decisions on how the funds are spent (Mbwili Muleya et al., 2008).
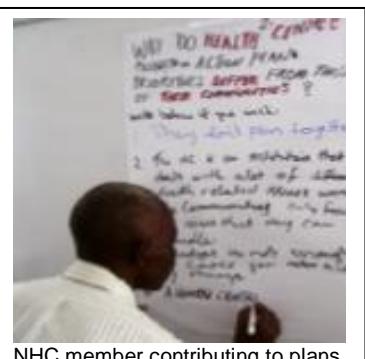
NHC member contributing to plans © C Mbwili Muleya 2004

The organised use of PRA tools led to increased mutual respect and understanding between health workers and community members; improved their communication and interaction and strengthened the inclusion of their priorities in health plans (MoH Zambia et al 2012).

By the end of this first phase of work the community members gained in confidence and enthusiasm to see the process move forward. HWs too noted the benefit of improved communication with the community, but some feared being 'exposed or losing power.' *'…We are still stuck as there is need to sit down with management and PRA team so that we can iron out a few things, such as removing the few gaps that are existing.' (*Health worker, Mandevu HC) (Mbwili Muleya et al., 2008).

In 2008/9 in Lusaka these PRA methods were used to assess the feasibility of their scale up to new health centres, while consolidating and building capacities to institutionalise the approaches in existing ones. An iterative spiral PRA model shown in *Appendix 3* was used by health workers and community members at the selected health centres. This model starts with local experience, builds shared analysis of problems and their causes, identifies and takes action on prioritised problems and reviews the learning from the actions taken (Loewenson et al., 2014). PRA Facilitators from LDHO, NHC members and health workers and HC nurses-in-charge participated. The HCC and health centre management identified the health worker and community participants, given their respective mandates. Experiences, issues and areas for change were identified using participatory tools during combined workshops of health workers and communities, followed by implementation of the activities planned. Regular review meetings were held to reflect on activities and outputs achieved, followed by further actions needed. A pre and post-intervention questionnaire administered to participants provided a quantitative review of impact, complementing self-reported perceptions of change (MoH Zambia et al 2012).

Many HCCs identified environmental health as a priority. As actions, they carried out clean-up campaigns, with local government support for chlorine, garbage trucks and other inputs. They managed and improved public toilets and hammer mills for maize grinding and participated in programmes for improved housing and solid waste management in the area. They took a wide lens on health and wellbeing and involved many other sectors and actors. Chaisa HCC negotiated with an international partner to provide bicycles and support local entrepreneurship, while in George HC land was donated to the HCC for the local community to generate income from healthy food production. Other interventions were more directly focused on service performance and uptake, such as HCCs supporting mobile phone appointments and follow up of HIV positive mothers, or distributing and monitoring use of mosquito nets. The HCCs mobilised local resources for these actions, including from their own activities, with some further funding from the district health offices from government grants (LDHMT, TARSC 2015).

This wider application of the PRA approaches in Lusaka strengthened community and health centre partnership and accountability and community voice in planning, budgeting and implementation activities at health centre and community level, and supported the functioning of the NHCs and HCCs. The planning and budgeting decisions made by the NHCs and HCCs were binding on the participating communities, local stakeholders and the health facilities and, through this, the district and MoH. LDHO has since 2005 further formalized the role of its HCCs by working with the NHCs to prepare a constitution for its HCCs, and has trained HCCs in planning and budget processes. The NHCs have also strengthened their own exchange of experience and practices, meeting as a collective of all NHCs in Lusaka in an Annual General Meeting each year in the past nine years to date (LDHMT, TARSC 2015)..

LDHO and the NHCs and HCCs have since explored a range of approaches for organizing and using evidence on conditions and community priorities. For example community photography in PRA approaches (or photovoice) was complemented other forms of evidence to support the negotiating power of HCCs. Photovoice is a PRA tool that puts cameras into the hands of community participants to represent their own conditions and priorities through visual images and photo-stories. LDHO trained community members, health workers and district health officials who were members of HCCs in Kanyama and Matero Ref in photography and provided them with cameras to photograph conditions affecting their wellbeing. The groups shared their images, to view their different experiences and to identify shared issues. The issues raised included blocked sewers, health facility corruption, poor water supplies and solid waste management. HCC members used the photographs as evidence in existing processes, such as local clinic and district health meetings, to stimulate discussion on solutions to problems identified, and to promote dialogue with other sectors on actions to address the issues raised (LDHO and TARSC 2016).


Uncollected garbage Lusaka 2011
© F Machingura TARSC - Health workers and communities planned joint action to address uncollected garbage in residential areas, in public places in the central Business District

This process led to the resolution of various public health problems prioritised by communities, such as the unblocking of a sewer system in Matero compound and the clearing of garbage in Kanyama compound. Photos were also used to show and build community confidence in change, with photos before and after interventions.

While these processes focused on members of the NHCs and HCCs, LDHO also initiated in 2010 a wider community level health literacy process with people in Lusaka city's community, also using PRA, to strengthen their health literacy (HL), that was institutionalised within the city in 2010. HL shares information and builds skills for health action. Using the spiral of PRA, HL as applied in Lusaka draws evidence from lived experience, facilitates community level diagnosis, provides relevant health information and stimulates action and engagement with health systems. It provides a process within which communities can express and shape their health programmes and primary health care services. It thus builds collective capacities within communities to articulate their health needs, monitor delivery of health service commitments and participate in shaping their services. Building on prior work and with initial support from TARSC, Zambia specific HL materials were developed and a core of HL facilitators trained. The HL manual integrated now familiar PRA methods with relevant local information on health and health services (see the resource in *Appendix 2*). Community health literacy sessions were held in the city, starting with Matero, Chipata and Chilenje HC catchment areas and then spread to other areas.

The HL training in Lusaka aimed, as for prior processes, to build community capacities and interaction with primary care level health workers and other sectors. HL sessions in communities shared information and prioritised actions on health and local health services. The NHCs, church, youth, businessmen, civic leaders, residents' development committees, police, teachers, TV and print media and the local council authority were involved in this work. Community members trained as facilitators were nominated by NHC members in dialogue with health centre staff. Over a series of repeated meetings and training sessions with the communities, the HL facilitators used the manual to stimulate and organise community exchanges and interactions with frontline health workers on health needs and service gaps or barriers and used this information to set shared action plans for prioritised issues. When needed they invited relevant information inputs from services to plan and take action. While the initial focus of the HL was on more visible priorities identified by the community, the training widened to less well recognised issues such as non-communicable diseases. The process was supported by the management of LDHO and by personnel familiar with the PRA from prior work. A monthly reporting framework and regular review meetings were used to assess and discuss progress and baseline and post surveys implemented to evaluate the impact on service performance (TARSC and LDHMT 2011).

Health literacy training, Zambia 2016 © Shana

In the HL, the communities raised and acted on a range of issues. Some related to issues at the clinics:
- *"Health workers do not care; they wait until there is Cholera outbreak for them to start thinking of action. Health workers with the MOH should do something before disease outbreak! So as communities we are bitter and angry at them!"* Communities had rejected volunteers training them on environmental causes of outbreaks and demanded that health workers take this role. Health workers explained that this is a city council function and it was agreed that there be joint action between health workers, communities, MOH, Lusaka City Council (LCC), CSOs and other stakeholders to clean the city to prevent cholera, malaria and other diseases of unsafe environments.
- *"Health workers are too slow; they take their time with each patient knowing that the queues are long and we would have paid some bus fare to get to the clinic, this makes it difficult to respect them when we talk to them".* Inadequate staff and long queues leading to long waiting times at the health facility discouraged service use. While having adequate health workers at each facility was an issue for higher levels of the Ministry of Health, communities and health workers felt that it was better to jointly demand improvement in this area.

Cleanup campaign in Chipata Lusaka © I Zulu 2013

- Health workers too raised their concerns in the dialogue: *There is unnecessary personal confrontation between health staff and patient due to the arrogance of communities. Communities are not honest. They often dump critically ill patients at the health facilities with no trace of contacts.* Health workers rejected the confrontational or rude manner that some people used to claim rights to care and felt that the community did not appreciate their workload or their roles. The suspicion, distrust, anger and resentment from one group to the other were evident when the programme began. In the HL programme these tensions were discussed, together with their causes and their impact on service delivery, using a range of PRA methods to structure, organise and enable voice of different groups (like social mapping, the 'but why method' and others).

Other actions in the HL programme related to cross sectoral actions to address environments for health, such as removal of waste in markets; clean up campaigns in public spaces, involving health workers, community health workers, HL Facilitators, community members, market vendors, media, police, Ward Development committee members and local government officers. In the HL programme, the wider community (this time beyond the NHC and HCC members) took up the role of problem identification and problem solving, identified and engaged the stakeholders needed for actions, and mobilised resources for the actions from local stakeholders. Community members worked in their zones to implement the strategies identified in collaboration with civic leaders and with the local authority. The information brought by service workers in response to what people identified as priorities strengthened their actions. For example, making clear the ways mosquitoes breed helped to highlight and raise action on the open potholes and long grass around homesteads that facilitates the spread of malaria (TARSC and LDHMT 2011). The activities raised the confidence of communities to organise informed action and to mobilise the institutional resources and people needed to address health problems they were facing (MoH Zambia et al., 2012). It positioned the communities as change agents.

Every three months of working on action plans those involved would meet to review their work, reflect on their experience and evaluate their progress, using a wheel chart to review changes against identified outcomes (see *Appendix 4*) and progress markers to review whether strategic steps were being achieved.

The 'progress marker' method was adapted locally from an Outcome Mapping approach (Earl et al., 2001) as a qualitative monitoring tool. Progress markers are identified by participants in relation to identified actions on what participants would
- 'Expect to see' (usual situation)
- 'Like to see' (higher level or improved situation)
- 'Love to see' (more ideal situation)
(See example below).

These are used to monitor and discuss progress and review the strategies used, particularly for the like to see markers, noting that the 'love to see' progress markers would probably take longer to be achieved.

The positive feedback from the HL programme and its impact on improved SDH and health led to its recognition by Ministry of Health (MOH) and subsequent launch of HL as a national programme in 2012 by the then Minister of Health, Honourable Dr. Joseph Kasonde (see *Appendix 1* for the news report).

Table 2: Progress Markers 2007 group

Problem: Inadequate Information And Communication On Planning Process

EXPECT To See Progress Markers		*Progress Monitoring					
		GEORGE			MANDEVU		
		1	2	3	1	2	3
1	HC staff meetings with CMs having schedules, agendas & minutes.		■	■	■	■	■
2	HC staff & CMs disseminating or sharing information on planning and any other current issues		■	■	■	▦	▦
3	HC giving CMs feedback on planning activities and any other current issues as soon as it is received		■	■	■	■	■
4	HWs & CMs respecting each others views during meetings & discussions		■	■	■	■	■
5	Participants who attended the 2007 PRA orientation workshop sensitizing or sharing the information with their immediate workmates and colleagues.		■	■	■	■	■
LIKE To See Progress Markers							
1	HC providing necessary materials & simplified guidelines to CMs on planning process		▦	■			
2	HCs & CMs beginning the planning cycle activities without being prompted by higher level						
3	HC providing & sharing information to CMs on budget allocation & expenditure for HC			■	■	■	■
LOVE To See Progress Markers							
1	75% of HWs conversant with planning process						

Key: Done ■   Started/Ongoing ▦   Not Started/not done ☐

Factors and inputs affecting the participatory practices:
The work between 2005 and 2008 showed that sustaining participatory approaches progressively de-mystifies and increases dialogue and community involvement in planning and budget processes, resolving issues in the interface between communities and health workers. When the PAR was scaled up to new areas of Lusaka in 2008/9, it was found to build communication, trust, transparency and accountability. It did not require significant resources, but did need to be encouraged by feedback and strategic review. At the same time scaling it up and sustaining it was seen to demand capacity building and mentorship as part of the routine duties of those facilitating the process. This was noted to take time, formal responsibilities to co-ordinate and follow up on activities, good facilitation capacities and leadership and management support to institutionalise the process (MoH Zambia et al., 2012). The turnover of both staff and community members called for a range of refresher training, briefings and information sharing to orient and build support from new people. For example, summary brochures on the work were circulated to all LDHO departments to ensure that the work is known by all personnel and health workers requested guidelines for the activities(Mbwili Muleya et al., 2008).

Despite the achievements and successes of HL programme, there were challenges in getting it prioritised at higher levels, especially at central MoH level, as curative programmes were often given higher priority. Collaborating partners sometimes had different targets and objectives for participating. The support from the Minister of Health was invaluable in advancing and sustaining the programme, as was the HL network technical and financial support from and exchanges on experiences in neighbouring countries in the regional network, EQUINET. The willingness of the communities to participate was a key enabler, as was the support and commitment of the district level health management team.

Time is critical. Sustaining the process was important to enable repeated and deepening cycles of action and learning in the PRA and HL processes. Equally with the NHCs and HCCs, it took several years for confidence to grow in a more united and effective community voice that was able to influence public budgets for primary care level and community health (LDHMT, TARSC 2015).While the practice has now strengthened the HCC role in planning and budgeting in Lusaka, it is seen to be important for the law to bring back their legal mandates post 2006, with clear guidelines for HCC functionality. Other factors were raised as important for the effective functioning of NHCs and HCCs, including having clear criteria for selection of NHC members; clear roles for NHCs and HCCs and their members and clear relationships with other community structures and with governance mechanisms at higher levels of the health system; harmonising incentives for their members; training for NHC/HCC members and sensitisation of health workers and management on NHC/HCC roles to facilitate the allocation of resources for their work (MOH Zambia et al., 2016). Information flow was also seen to be vital, both between services and communities and for NHCs / HCCs to meet to review and share practices (MOH Zambia et al., 2016).

The HL work and the engagement with HCCs and NHCs is now being expanded beyond Lusaka in a national scale up. In light of the positive outcomes from the work done in Lusaka District, the MoH in Zambia started in 2012 to scale up the HL to other health districts in the country and to institutionalise the HL programme. The Minister of Health, Dr Joseph Kasonde, said in 2012: *I see this exercise as the beginning of a major movement: a movement to transform our society into a community of health literate men, women and children who will be the fertile soil upon which the seeds of healthcare will thrive.* (MoH Zambia et al. 2012).

A top down model for HL training of central level ->province -> district -> health centre -> community was felt to take too long to get to community level and produce change, and to not build the community experience needed to be a HL trainer. An alternative model was adopted where by each province trains HL facilitators at HC level in the districts, as was done in Lusaka. It drew initially on the HL facilitators from Lusaka, who helped local HL facilitators, and the HL was implemented at community level. The most capable HL facilitators then trained facilitators in other districts in the province (MoH Zambia et al., 2016). As a mentorship strategy, each trained district has a focal point person for HL in the district health management, and a senior officer from the central level MoH supported the HL training conducted in the provinces. The MoH formed a HL stakeholder technical working group; and supported the modification of the Zambian HL Manual that was used during the scale up to the provinces, including through supporting it within a Result Based Financing (RBF) project under the MoH. The RBF programme, while aimed at incentivising health workers on service performance, had found after two years of implementation that community participation was low in all intervention districts, affecting its performance. As a result the MOH-RBF team worked with LDHO to include their 11 districts in the ongoing scale-up of the full HL activities under MOH & MCDMCH to boost the demand side of the programme (RBF and MoH Zambia

2015). The roll out of the HL programme has since taken place in these 11 districts in all nine provinces of Zambia, together with Lusaka and five further districts.

Various processes have been identified to sustain these processes over time. Facilities have been encouraged to put HL in their action plans and HL is a component in the national health strategy for improving social determinants of health. The consistent involvement of community members in the activities has also contributed to the programmes continuity. Finalising the policy guideline on HCCs will further strengthen and make clear the policy framework for the range of participatory processes described in this case study.

Perceived or measured outcomes:

Pre and post intervention surveys and reports from health workers and communities of the initial 2006-8 PRA work found improved interaction between health workers and community members and increased confidence of community members in inputting to planning processes (Mbwili Muleya et al., 2008). *We have seen better interaction between Community members and Health workers [since the PRA intervention]. They are able to express themselves even in areas we think they can't comment. Health Workers are seen participating in planning. This time they don't need guidance but they were even guiding. We have appreciated their inputs.* (Sister In Charge, Chipata HC 2007). There seemed to be a spillover effect on communication, as health workers also observed improved interaction with clients. Community members reported in a post intervention survey improved participation in their health centre planning and budgeting and in decisions on allocation and use of funds.

The participatory approaches used in Lusaka with NHCs and HCCs provided a space for and increased the level of informed, self-determined participation by community members and frontline health workers in planning and budgeting and the mutual respect and understanding between them. The HCCs contributed to ownership of plans and budgets generated at community level. In 2005 most presentations on plans and budgets at the NHC annual general meeting were done by health workers and non-state actors. Since 2012 in areas where HCCs have been trained and supported, the HCC members themselves have presented the plans and budgets of the HC, and have prepared displays and reports on what they are doing on health. HCCs and NHCs have lobbied for resources for community activities on health and for improvement of the health centre, including for events to report back to

Advocacy march of health workers and community members, Matero Lusaka © I Zulu 2011

communities and other stakeholders (LDHMT, TARSC 2015).The HCCs have also mobilised other sectors to support actions on SDH with positive impact.

There is some evidence of the effect of these activities on health outcomes. Cholera, for example, was endemic in Lusaka up to 2010. The 2017 LDHO health information system reports on cholera cases in the four HCs covered by the PRA and HL work (Chilenje, Chipata, Matero and George). In total these HCs had 1330 cases of cholera in 2009 and 82 cases in 2010. In 2011 the total number of cases fell to 4, and in 2012 to 2015 to zero (at a time when other areas still reported cases). While it is not possible to solely attribute the positive outcomes to the programme, the removal of waste sites that used to be a site of disease and abuse and the measures for community health literacy and action are perceived to have made an important contribution (LDHMT, TARSC 2015; MoH Zambia et al., 2012). Neither can the gains be seen as permanent. When for various reasons the HL activities were interrupted and communities relaxed their efforts in Lusaka in 2015 (even while they were rolling out elsewhere), cholera returned to these areas, with the 2017 LDHO health information system reporting 176 cases in 2016.

Beyond these disease indicators, the processes described in the case study were reported to lead to a range of system and social outcomes. HL provided the space for communities to express and shape their health programmes and services at Primary Health Care level, especially when using participatory methods. It generated community capacities to articulate their needs, present their conditions, negotiate

for the resources that improve their health, monitor the delivery on the health service commitments and participate in shaping their services (TARSC, LDHMT 2011).

The key informants/focal points for this case study indicate that the bottom up approach used has supported conflict resolution and improved relationships between health workers and communities in a previously tense environment. It created 'an equal platform' for dialogue to identify and resolve problems affecting both community members and health providers, supported by HL teams. Community members saw their concerns being heard and their own power to produce change. "*Community members have become part of the change process themselves*". There was a shift in perception on health in the community that health is "not just about taking medication but it is about having healthy environment and health relationships". The processes have stimulated service organisations to be involved and contribute resources to solutions to health issues identified by the community. Officials in-charge of health issues see these changes taking place with minimal financial resources, but with increased stakeholder involvement and representation.

Areas for shared learning:

In the reports on the initial processes, various **insights and areas of learning are shared relevant to new processes**: It was noted that the changes take time, especially in complex processes like budget and planning, and that their planning and design need to address potential challenges like the adequacy and turnover of health personnel in the primary care services; competing demands on people's time; poor understanding of different roles; and service providers' fear of shifting control to communities (Mbwili Muleya et al., 2008). This called for processes that involved communities in discussing the problems and the solutions; that change mindsets on meaningful participation; that integrate the processes into the roles and functioning of health centres, with time, capacity building, information sharing, mentoring and resources for health workers and community volunteers for the activities involved. It also raised the need to ensure that key authorities are informed and updated on the work being done and signal leadership support (Mbwili Muleya et al 2008).

Now that the process has been implemented over more than a decade, it has built **learning and insights on the more mature process**, and on what has enabled it to deepen, sustain and spread. These insights from key informants indicate that:

- *Social power and the confidence in communities* to articulate the processes and their benefit itself becomes a sustaining factor. For example in Zambia, it has often been the communities themselves who explain the nature and value of the process to other communities and districts and to local and national leaders and health authorities, including to a Ministerial briefing in 2015. They have kept the demand for the processes alive in changing institutional contexts.
- *The PRA processes* have given communities power in drawing on their own experience and generating collective knowledge and learning in an accessible way. While these processes were not well understood in the early days, interest in them has grown as word of their impact has spread. The inclusion of health officials in training activities has also strengthened their understanding of and support for the processes.
- *Horizontal spread,* rather than top down, has been a sustainable and more legitimate strategy for reaching new communities, spreading the processes through those with experience of it.
- *Formalising the role of the mechanisms for social participation* (NHCs and HCCs) enables the dialogue between communities and health services, especially when this is consolidated in formal documents (such as the NHC constitution) that are used in policy backed by a social understanding that is translated into practice. Their role is also supported by having ordinary community members elected by the community in these mechanisms, with participatory dialogue and community input on their constitution and roles.
- *Mechanisms for exchange across local areas*, like the NHC AGM, have supported sharing of experience and knowledge and built collective analysis and voice across localities and districts.
- *Documenting the work, including online, and being part of a regional network* meant that people heard about and raised interest in the work more widely. This helped to build trust in and respect for the work by different institutions. Reporting also helped with transparency on the processes. Hence new districts visited in the national outreach had already read about the work in online reports, and communities could see what had been done elsewhere in these reports.
- *The processes take time* need to be *sustained by values, commitment, and persistence.* For people, institutions and processes to change takes time, and there is need to sustain processes during periods when the situation is less conducive, so they can advance when windows of opportunity exist. This was pertinent in relation to the level of prominence given by the health sector leadership to health promotion and social determinants of health, with increasing

prominence in more recent years in Zambia, or to respond to perceived need for social roles to enable other successful outcomes, as was the case with the RBF. It raises the importance of leaders within the community or services that can sustain the processes over less conducive periods, noting that this is driven by a commitment to the values that support the work.

Key informants suggest that many of the **features of the work could potentially be adapted / adopted** elsewhere, including:

- the health literacy training using PRA approaches
- using participatory mechanisms to build strengthened capacities for and a clearer understanding of the role of mechanisms for dialogue between communities and services (such as HCCs and NHCs),
- working with teams from health services and communities,
- supporting voluntary community roles and
- building community champions and voice to sustain the process.

Indeed the work is already part of a regional network (EQUINET) where similar approaches are being applied and learning shared in several other east and southern African countries. The local UNICEF office is using resources such as the NHC constitution in other settings. Local government personnel and personnel from other countries (USA, Italy, Sovenia) have visited and drawn experiences on the work. The NHCs are now also playing a role in the work of other sectors – such as in identifying recipients of cash transfers- due to their connection with the community.

At the same time some **unique features of the Zambian context** need to be taken into account, including the accessibility of national and political actors to community representation; the central position of the public sector in health and primary health care orientation; the opportunities and the spaces within communities (halls, meetings) to integrate and sustain the participatory processes. The presence of committed health sector personnel in LDHO and in the Ministry of Health was an important factor in ensuring continuity despite changing personnel and conditions. The support of and exchanges in a regional network also contributed to the work. These contextual features in Zambia may not exist in other settings, but played an important role in enabling the potentially adaptable practices.

The team in the Lusaka site is interested in **learning from other sites in the project** on how they have organised and supporting participation of community members. From high income countries they are interested in understanding how they are engaging and involving communities at higher income levels as this may inform how the work in Lusaka reaches into these communities. The team in Lusaka is also interested in learning how, and with what methods, other sites are involving community members in decision making on health services.

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Appendices:
Appendix 1 Media on the work

At https://vimeo.com/72914294 and DVD

News story on the HL programme

Appendix 2: Zambia Health Literacy manual

Health Literacy Manual

for people centred health systems

Zambia

HEALTH FOR ALL; ALL FOR HEALTH

HEALTH IS A CLINIC AND YOUR RIGHT AND YOUR RESPONSIBILITY

Training and Research Support Centre with
**Ministry of Health (MoH), Zambia and Lusaka
District Health Management Team (LDHMT) Zambia**
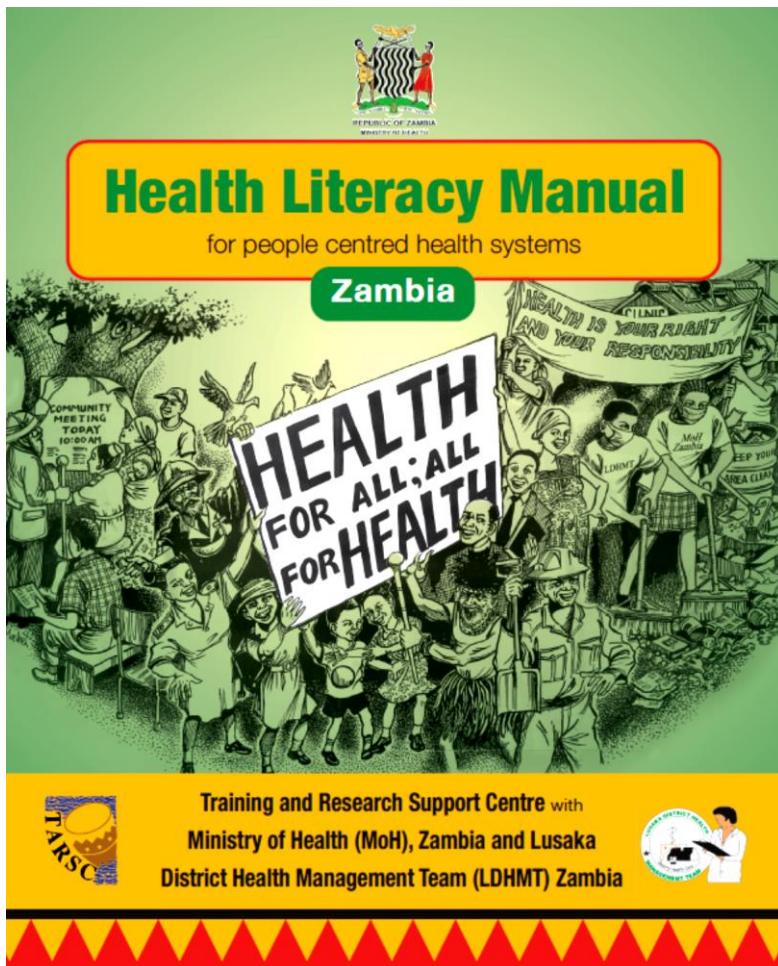
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SECTION 1: Promoting Health

Please refer to the glossary if there are words you don't understand in the manual. If you cant find them in the glossary you can also ask your health literacy facilitator for further information.

Appendix 3 Participatory reflection and action approaches

See for further information Loewenson R, Laurell AC, Hogstedt C, D'Ambruoso L, Shroff Z (2014) Participatory action research in health systems: a methods reader, TARSC, AHPSR, WHO, IDRC Canada, EQUINET, Harare, www.equinetafrica.org/bibl/docs/PAR%20Methods%20Reader2014%20for%20web.pdf

Processes of participatory reflection and action (PRA) or participatory action research (PAR), imply that those most directly affected by conditions affecting heath and health service performance actively participate in data gathering, analysis and in debating policy reforms and monitoring their implementation. Participatory action research (PAR) has several key features.

- Those who are usually the subjects of research or those who experience a problem are the active researchers and agents of change in PAR. Those affected by a problem are the main source of information and the lead actors in producing and using the knowledge for action and change. The PAR facilitator is a trusted person who can facilitate the process.
- Secondly, it involves developing, implementing, and reflecting on actions as part of the research process to build new knowledge. PAR seeks to understand and improve the world by changing it, where those affected by problems collectively act and produce change and learn from it to produce new knowledge. PAR is transformative.

PAR does this is through a spiral of repeated cycles, where the experience of, and learning from action and transformation of reality becomes the input to a new round of collective self-reflective inquiry. The PAR process follows steps to:

1. Systematize local experience, to organize people's own shared lived experience and situation.

2. Collectively analyse this experience and identify problems and their causes.

3. Reflect on the experiences and views of problems and their causes to choose actions that will address the problems.

4. Take action, and review the changes produced to learn from the actions.

Figure 1: The cyclical and spiral process of participatory action research
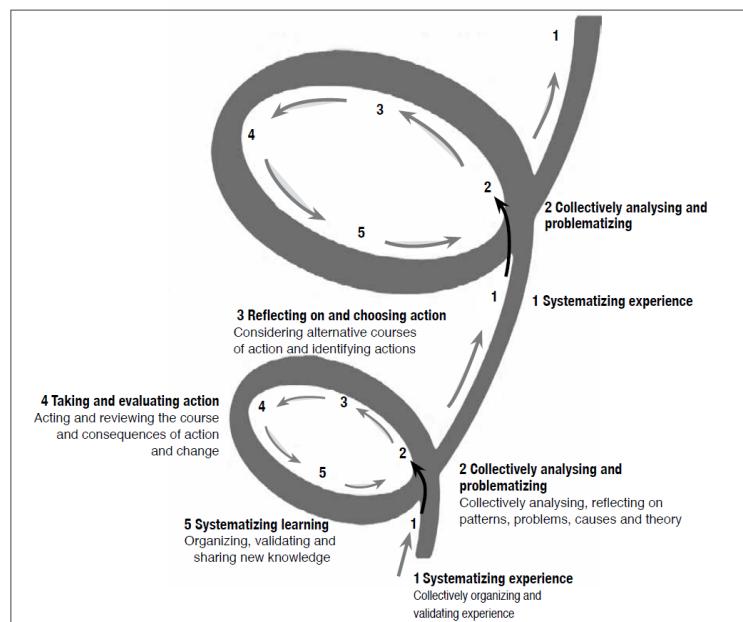
Source: Loewenson et al 2014

5. Use the learning to produce new knowledge.

Each repeat of the spiral draws in wider relevant knowledge to further inform analysis and action. In doing so, we construct knowledge from lived experience and action; and bring this into a collective domain. This needs to be done with rigour so that the learning and knowledge can be systematized and shared

Health systems are complex social systems that reflect and affect the values, norms, and institutions in society. Participatory action research (PAR) draws on the paradigms of critical theory and constructivism, enhances people-centred health systems and may use a range of qualitative and quantitative methods. Participatory approaches seek to transform the role of those usually addressed as the subjects of research, to involve them instead as active researchers and agents of change. Participatory approaches have been used to study and act on a range of health systems issues -from action on social determinants of health, through community health outreach, to improving quality of services.

Appendix 4 Using a wheel chart for participatory evaluation

Text quoted from Loewenson R, Laurell AC, Hogstedt C, D'Ambruoso L, Shroff Z (2014) Participatory action research in health systems: a methods reader, TARSC, AHPSR, WHO, IDRC Canada, EQUINET, Harare, www.equinetafrica.org/bibl/docs/PAR%20Methods%20Reader2014%20for%20web.pdf

The wheel chart can be used to collectively review a range of dimensions in situations, processes or outcomes that provide a quantitative means of assessing change when repeated over time. Participants work in groups as relevant to the process. These may be social groups with different experiences of the process or outcomes, for example. They draw a blank wheel chart on flipchart paper and mark each 'spoke' on the wheel with points from 1 to 5, with 1 nearest the centre. Each segment is labelled with the feature under inquiry, such as the outcomes or process changes intended, dimensions of participation, and so on. Participants collectively assess the level of the outcome. For each segment of the wheel, they discuss the situation or outcome and decide on the level. Once they've decided, they shade the area of the segment to show this.

The wheel chart can also be used to reflect the level they intend for an outcome, or what the situation should be. This can be marked in each segment with a squiggly line (as in the diagram).

The space between the two markings creates a clear visual picture of the gap between what the situation should be (squiggly line) and what it is now (shaded area). The levels may also be quantified, to give a measure of the difference. After the chart is completed it is 'interviewed'. This involves the groups discussing the differences and similarities between each of the wheel charts or, if the charts are repeated over time, the differences over time and what is driving – or blocking – the change. If the wheel chart is used to measure progress over time, the shaded area would reflect the situation at the start and future squiggly lines or new charts would document any changes.

In all cases the chart is used as a basis for discussion to explain what changes have taken place, what is causing them and what can be done about them. The ratings and interpretation of the collective group are recorded. The wheel chart has been used extensively in participatory work in the pra4equity network in EQUINET in east and southern Africa to reflect on dimensions of participation in health systems and how they have changed through participatory action research processes..

See for further information Loewenson R, Kaim B, Mbuyita S, Chikomo F, Makemba A, Ngulube TJ (2006) Participatory methods for people centred health systems A toolkit for PRA methods, TARSC, Ifakara, Ideas Studio, Harare