

## IDRC REPORT: PHM SOUTH AFRICA COUNTRY CIRCLE

### 1. Background and rationale to the research

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[not applicable information from country report]

### 2. Aims and objectives

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[not applicable from country report]

### 3. Literature review and country context [merged with section 5]

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#### Contextualising health activism in postapartheid South Africa<sup>i</sup>

What are the conditions under which civil society mobilisation for health for all has taken place in postapartheid South Africa? Many South Africans continue to live at or below the poverty line. In 1995 about 53% of the SA population lived below a poverty line of R322 per month. This proportion had declined by five percentage points, to 48%, in 2008.<sup>ii</sup> However, during that time the SA population increased from 40.6 million to 48.7 million, i.e. in absolute terms the number of individuals living below the poverty line in SA went from 21.5 million in 1995 to 23.4 million in 2008.<sup>iii</sup> Poverty remains racialised and gendered: A larger proportion of South African women (61%) live in poverty as compared to men (39%).<sup>iv</sup>

Data on trends in employment and income inequality are equally worrying. Estimates of unemployment based on a narrow definition of the term suggest unemployment declined from 29.4% in 2001 to 23.6% in 2009. However, estimates based on a broad definition of the term suggest a decline from 40% to 32.5% over the same period.<sup>v</sup> According to the Congress of South African Trade Unions (COSATU) 1.1 million jobs were lost during 2009-2010. It estimates that, as a direct consequence, 5.5 million South Africans have been impoverished. Women, youth and black South Africans make up the largest proportion of the unemployed.<sup>vi</sup> Between 1995 and 2008 the share of national income going to the richest and poorest 20% of the population remained almost constant, with the bottom 20% earning about 2% of national income and the richest 20% earning a share of 70%.<sup>vii</sup>

During this period South Africa's Gini co-efficient remained constant at about 0.67.<sup>viii</sup> In other words, in the post-1994 period (after the advent of political democracy) South Africa has experienced virtually no redistribution of income from its wealthiest citizens to its most impoverished. By 2010, this situation had not improved much: half of South Africa's population was living on 8% of the national income.<sup>ix</sup> In addition, much as in the pre-1994 era, income inequality remains racialised and gendered: In 2007 almost three-quarters (71%) of households headed by African women earned less than R800 per month; 59% of these households "had no income." In households headed by African men the comparable figures are 58% and 48% respectively.<sup>x</sup> The extent and intractability of inequality is particularly worrying in the context of the HIV/AIDS epidemic, given that research shows HIV prevalence is positively correlated to income inequality (as opposed to only poverty).<sup>xi</sup>

Despite significant public transfers to the poorest of the poor, especially between 1993 and 1999,<sup>xii</sup> access to sufficient quantities of basic services such as electricity and water is limited by the ability of citizen-consumers to pay for them.<sup>xiii</sup> By 2009 government efforts resulted in only 4% of households being without access to basic water infrastructure,<sup>xiv</sup> 23% without access to sanitation (as compared to 50% in 1994), and 27% without access to electricity (down from 51%).<sup>xv</sup> Nevertheless, low-income households frequently experience service disruptions or become increasingly indebted to the state or service-providers because of their inability to pay for more than a very basic free allocation of water and electricity. A major government welfare initiative since the late 1990s has resulted in a very large increase in those receiving social grants with the current number of recipients totalling over 16 million.

These data clearly indicate that, notwithstanding various government programmes, many South Africans have experienced the deterioration of their social determinants of health since 1994.

### Historical overview of health activism in South Africa

Mobilisation for the right to health, or for “health for all”, has a long history in South Africa. Pre-1994 health workers, particularly community health workers and progressive health professionals, took a leading role in health activism. During this period much health activism focused on de-racialising health care services, training more black health care workers, developing a national network of community based primary health care clinics (particularly during the 1940s), and exposing and preventing the involvement of health workers in human rights abuses (particularly during the 1980s and early 1990s). In the postapartheid period social movements, community-based organisations, progressive lawyers and community health workers (CHWs) have taken a leading role in health activism. Their actions have resulted in laws and judicial decisions that require equitable access to health care services and private health insurance schemes for LGBTI and HIV-positive patients, an expanded basket of services (including HAART) being offered at primary health care facilities, a movement for greater involvement of community members in the governance of clinics, mass mobilisation for improved sanitation services in informal settlements, and in revisions to the proposed National Health Insurance scheme which, as a result of civil society pressure, includes certain categories of non-citizens as beneficiaries.

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In 1942 the government appointed the South African National Health Services Commission (commonly referred to as the Gluckman Commission) to investigate how South Africa could institutionalise a National Health Service. After extensive nation-wide consultation with civil society organisations, the Commission published its recommendations in 1944. It argued that the state could only improve public health by implementing a free, racially inclusive public health system that provided equal benefits to all South Africans and which prioritised preventative health care services.<sup>xvi</sup> It argued that these services should be decentralised, so that care was easily accessible to all communities, and so that community-members could be involved in decision-making about how to address the priority health needs in their areas. The Commission also advocated for the creation of a welfare state that could provide various services – e.g. nutritional schemes, public housing, and free education – that would improve the social determinants of health of all South Africans.

The Gluckmann Commission’s recommendations for universalising, democratising, deracialising and decentralising health care services were heavily influenced by the work of Drs. Sidney and Emily Kark. In

1940, the Karks founded a health centre in Pholela, a Zulu reserve in East Natal, which successfully used community-based primary health care services to improve health outcomes in the area. Throughout their careers, the Karks emphasised the importance of training community health workers who could provide basic clinical services to community members, and work as health activists promoting reforms that improved the social determinants of health affecting individual patients and their families.<sup>xvii</sup>

The Gluckman Commission's emphasis on implementing a free, centralised and non-racial health care system would not be pursued until after the unbanning of the African National Congress in 1990. The health care policies pursued by the apartheid state between 1948 and 1990 deepened the pathologies of the health care system that this Commission sought to address: the health care system was characterised by a lack of coordination, service provision was racially discriminatory, and the bulk of public money went to curative services, not primary health care services. In addition, some medical professionals were complicit in human rights violations, including the abuse and torture of anti-apartheid activists.

In response to increased levels of political repression during the 1980s, an important counter-movement emerged in the health care sector: progressive health professionals started recruiting and training lay health workers who also acted as anti-apartheid activists. The Progressive Primary Health Care Network (PPHCN), established in 1987, consisted of anti-apartheid medical practitioners who trained volunteers to provide primary health care services in the absence of good quality public services, particularly in rural areas.<sup>xviii</sup> These practitioners set out to "[contextualise] the political, economic and social conditions that give rise to ill health" and "emphasised community accountability, comprehensive health care and [ensuring] that health workers use their knowledge and skills to service the needs of the disadvantaged".<sup>xix</sup>

Other progressive health organisations that preceded the PPHCN and advocated for the rights to health and social services during the 1980s include the National Medical and Dental Association (NAMDA, formed in 1982), the Organisation for Appropriate Social Services in South Africa (OASSSA), and the Health Workers Society (HWS, formed in 1980). They were united in their opposition towards the apartheid state. Some organisations, e.g. the HWS, rejected the hierarchical distinction between professional and non-professional health workers, whereas others, e.g. NAMDA, restricted their membership to professional workers. In July 1992 these organisations and others merged into a single organisation, the South African Health and Social Services Organisation (SAHSSO), which set out to oppose discrimination and exploitation in the health and social services sectors, promote primary health care and community participation in decision-making about health, and contribute to the development of progressive policies.

After the transition to democracy in 1994 many activists moved out of civil society organisations and took up positions in the newly elected ANC government. This movement of health activists into the state led to a decline in the number of voluntary civil society organisations advocating for the right to health, and to the emergence of non-governmental organisations (NGOs) that now dominate civil society. In comparison to their apartheid-era counterparts, postapartheid NGOs are more commercialised and professionalised entities. They often adopt organisational structures and technocratic management practices that mimic those of private sector organisations. During the period immediately following the transition to democracy these civil society organisations sought to offer practical, financial and political support for the state's efforts to improve the material welfare of the majority of the population. Therefore, they positioned themselves as auxiliary service providers in the government's efforts to formulate and implement pro-poor policies.<sup>xx</sup>

Civil society organisations' positive orientation toward the state became more antagonistic in the late 1990s. By 1996, HIV/AIDS prevalence had increased dramatically in South Africa. Despite the need for an effective medical response to this epidemic, for many years the denialist Mbeki government hampered access to highly active antiretroviral treatment (HAART) for people living with HIV/AIDS (PLWAs). From the early 2000s onwards NGOs stepped into the vacuum created by the government's refusal to provide HAART. Many local NGOs secured funding from foreign governments (e.g. PEPFAR), international organisations (e.g. the Global Fund) or philanthropic foundations (e.g. the Clinton Health Access Initiative) to provide services to PLWAs. These NGOs often hired community health workers (CHWs) To support their efforts to expand treatment access. CHWs were mainly responsible for doing HIV/AIDS prevention and education activities, and for promoting treatment adherence amongst PLWAs who had started HAART. These interventions generated a large workforce of lay health workers: today an estimated 72000 CHWs are active in South Africa.

South African community health workers (CHWs) are a large and heterogeneous group incorporating a wide range of auxiliary health care providers including home-based carers, lay counsellors, and "community care workers", among others. They may be based either within the community or at a clinic, or operate as a go-between. CHWs are generally either volunteers or "employed" through management NGOs who usually pay stipends, either through government disbursements or independent funding. Community health workers (CHWs) were selected as the focus of this case study for a number of reasons.

There are no standard conditions of service in this sector and many CHWs work on a voluntary basis (sometimes earning a stipend - often less than R2000 per month) or are paid very low wages. CHWs are typically expected to pay for their own transport, protective gear (e.g. gloves or masks), and training. They sometimes subsidise the household expenses of their patients out of their own meagre income (e.g. by buying them food so that they can take their medicine as prescribed). Unlike their counterparts in the 1940s and 1980s, the CHWs of the HIV/AIDS era do not necessarily identify as health activists. In part this might be attributed to the general depoliticisation of postapartheid South African civil society, the fragmented state of civil society organisations in their communities, and a shortage of resources to invest in organising work. Many CHWs are women who often bear the bulk of responsibility for care work (e.g. cooking, cleaning, and child care) within their own households and this may limit the time they have available to do activist work outside the household.

Very recently the South African government created the new category of state-employed community health workers (CHWs) whose work emphasizes surveillance and referral rather than the provision of care. The new system is being implemented unevenly and at each province's discretion Overall the idea is that about 40,000 community health workers (CHW) will be employed by the state – with the requirement of literacy in English and numeracy this might include employing young people with these skills, despite the high unlikelihood that they will have been CHWs before. The institutionalisation of the state-employed community health workers (and, perhaps a cadre of home-based carers) risks dividing this workforce into those with these state jobs and those without. Carers who are employed by the state as CHWs may well find it difficult to take on the roles of activists and mobilisers, as progressive civil society organisations like the PHM-SA envisage.

In July 2015 the National Union of Care Workers of South Africa (NUCWOSA) was being formed, initiated by Workers' World Media in Cape Town and drawing on the already-existing Community Care Workers'

Forum. While it will certainly mobilise these health care workers, it is not impossible that their preoccupation with the current crises in work and conditions of employment will overshadow the political work that could be done by this cadre of health workers. PHM-SA will need to decide how it locates itself in relation to this – and any other representative structures that may develop.

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The period between 1990 and 2000 was also marked by the writing of a constitution that underpinned a legislative and policy environment that was characterised by an unqualified commitment to formal equality, and a qualified commitment to substantive equality. During this period many civil society organisations contributed to constitutional and legislative reforms that prohibit and/or criminalise discriminatory practices that prevent women from accessing reproductive health care services (particularly abortion), people living with HIV/AIDS (PLWAs) from accessing health insurance, and lesbian, gay, bisexual, transgender and intersex (LGBTI) people from accessing appropriate health care services.<sup>xxi</sup>

This tradition of legal mobilisation was used to great effect by the Treatment Action Campaign (TAC), a social movement that advocates for universal access to highly active antiretroviral treatment (HAART) and related health services for PWAs. Since its founding in 1998 the Treatment Action Campaign (TAC), an independent organisation has focussed on ensuring that affordable and effective anti-retroviral treatment is available to everyone in South Africa, regardless of their citizenship status or their material means.<sup>xxii</sup>

TAC has won a number of victories, often by combining mass mobilisation and litigation. In April 2001 the TAC and its allies abroad, particularly ACT UP in the USA, successfully pressured a coalition of pharmaceutical companies, known as the Pharmaceutical Manufacturer's Association (PMA), and their supporters in the US government to withdraw a lawsuit the PMA had brought against the South African government in 1998 for importing generic and much cheaper versions of anti-retroviral drugs.<sup>xxiii</sup> In 2002, after five years of activism aimed at securing a PMTCT programme, TAC sought and won recognition for the right of pregnant women to access an anti-retroviral drug, nevirapine, at all public health facilities capable of providing a PMTCT service.

Other organisations have also used litigation to advance the right of vulnerable groups to health care services. In 2012 TAC, The WITS Justice Project and the Centre for Applied Legal Studies submitted amicus curiae briefs to the Constitutional Court in the case of *Dudley Lee v Minister of Correctional Services*.<sup>xxiv</sup> The organisations' briefs supported prisoners' rights to be held in detention facilities that do not increase their risks of contracting illnesses, and to access health care services when they need to.<sup>xxv</sup> These briefs did not form part of a broader campaign to promote prisoners' access to health care services. Nonetheless, the judgment helped to elaborate the state's duty to promote the health of prisoners – and of South Africans more generally.<sup>xxvi</sup>

Civil society organisations have also used rights language, and have advocated for legislative reforms, in order to ensure that stigmatised groups are not criminalised or otherwise discriminated against by public and private institutions. These civil society organisations see these demands for “equal rights” and “equal treatment” as a first step in ensuring that members of stigmatised groups can access health care services that meet their needs. This form of organising has been used by organisations that defend the rights of sex workers and members of the LGBTI community. For example, the Sex Workers Education and Advocacy Task Force (SWEAT) advocates for the decriminalization of sex work. The demand for

decriminalization partly justified on the grounds that “it makes it easier [for sex workers] to get HIV prevention and treatment services, and other health services”.<sup>xxvii</sup>

Another important example of this kind of work is the campaign, conducted in the early and mid-1990s, to outlaw unfair discrimination on the basis of sexual orientation by retaining S8(2) of the Interim Constitution of 1993. Led by the National Coalition for Gay and Lesbian Equality (NCGLE), a coalition representing 65 member organisations,<sup>xxviii</sup> the campaign lobbied for retaining the freedom from discrimination on the grounds of sexual orientation clause in the draft constitution and chose to ground their claims by demanding “equality” rather than “gay rights”.<sup>xxix</sup> The NCGLE successfully lobbied the Constitutional Assembly for the inclusion of sexual orientation in Section 9 of the Constitution. Together with the SAHRC the NCGLE submitted a High Court application for the decriminalization of same-sex conduct in August 1997 and advocated for workplace reforms that would promote same-sex partners’ inclusion in their partner’s medical aid benefits, with limited support from trade unions.<sup>xxx</sup>

Many community-based organisations (CBOs), often described as “survivalist” organisations, also emerged during the 2000s. Unlike NGOs they do not position themselves as an extension of the government and instead operate parallel or in opposition to official state structures.<sup>xxxi</sup> CBOs use a variety of legal and illegal tactics to meet their members’ basic needs. For example, they have used courts and other state institutions to demand improved service delivery in their community, and they have challenged the government’s continued commodification of basic goods and services by reconnecting households to the electricity grid despite their inability to pay for this service.

Many CBOs faced difficulties in maintaining their membership and organisational structures during the early and mid-1990s, though these organisations have become more prominent since the late 1990s. The initial decline of CBOs came about because these organisations lost their most experienced and skilled leaders during the 1990s. Many activists chose to take up employment in local and national government structures rather than continuing to serve in leadership positions in the community-based organisations (CBOs), NGOs, unions or political organisations they had been active in during the anti-apartheid struggle. After the ANC government introduced the neoliberal GEAR policy in 1996, and failed to address the massive job losses and high levels of unemployment associated with this macroeconomic policy, CBOs once again emerged as important sites for responding to the continued commercialisation and non-delivery of basic goods and services to poor South Africans.

In this context and in the wake of the formation of TAC and the rise of ‘AIDS activism’ and after the successful inaugural Peoples Health Assembly in Bangladesh a small group formed the South African circle of PHM in 2003. Its founding members included health practitioners and academics who had been active in NPPHCN and SAHSSO in the late 1980s and early 1990s and who, although supportive of AIDS activism, were concerned about its narrow and treatment-centred emphasis to the exclusion of social determinants of health and other issues central to the implementation of comprehensive Primary Health Care, and, indeed, a comprehensive approach to HIV/AIDS. PHM now represents, within health, that group of civil society formations that situate their analyses and activities in a political economy framework and are critical of neoliberal policies that fail to address the stark inequities in South Africa.

Research conducted by the Right to Know (R2K) campaign suggests that civil society organisations that are critical of the ANC government, or who organise outside of established channels, are increasingly subject to increased state surveillance and harassment by state security agencies.<sup>xxxii</sup> Politicians sometimes represent these organisations and their most prominent members as agents of foreign

governments,<sup>xxxiii</sup> criminals,<sup>xxxiv</sup> or as engaged in illegitimate activities that are aimed at “regime change”. Even civil society organisations that are not vilified in this manner have found it increasingly difficult to organise in the wake of legislative reforms,<sup>xxxv</sup> legal judgments<sup>xxxvi</sup> and increasingly violent policing practices<sup>xxxvii</sup> that have the effect of limiting the right to protest and the right of access to information.

#### 4. Methods

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The following techniques were used to gather data for this research: desktop analysis, surveys, participant observation, focus group discussions, key informant interviews, participation in training or knowledge-building workshops (e.g. PHM-SA training/awareness-raising) and meetings (e.g. union gatherings), attendance at a legal trial hearing, ethnographic research. Below we give more information about how data were collected for different components of this research.

##### *History and contemporary political context and of health activism in South Africa*

The literature review was compiled by doing a **desktop analysis** of secondary literature on health activism in South Africa. This entailed searching for relevant academic literature using the “Google Scholar” search engine. The following search terms were used: [“civil society” + health + activism + “South Africa”]; [“post-apartheid” + “civil society” + “South Africa”]; [litigation + “social rights” + “South Africa”]; [“community health workers” + “South Africa” + “primary health care”]. We also collected grey literature from current and former PHM-SA members. The latter literature was obtained on request of the researcher during informal conversations or in the course of an interview.

The literature review focused on how researchers and academics, rather than activists themselves, have framed the organisational, political and theoretical significance of post-apartheid activism generally and health activism in particular. In addition, the primary data collected during the course of this research project – i.e. on the National Health Insurance (NHI) Coalition, the South African People’s Health University (SAPHU), and the National Health Assembly (NHA) – offer insights into activists’ own articulations of their work and its significance.

Grey literature was used to gather data on PHM-SA’s engagements around knowledge generation (e.g. pamphlets, letters to the newspaper, etc), its participation in global governance processes (e.g. a submission to Lancet-University of Oslo Commission on Global Governance for Health), and its movement building activities (e.g. posters advertising public meetings).

##### *National Health Insurance (NHI) Campaign*

Key informant interviews were used to collect data on the NHI Campaign. Senior members of PHM-SA who were active in the NHI Campaign (David Sanders, Louis Reynolds) were asked to assist in generating a list of individuals who were active in conceptualising and driving the NHI Campaign, or who represented organisations that joined the NHI Coalition. The Coalition was comprised of civil society organisations that supported PHM’s call for a people-centred NHI.

The researchers developed an elaborate formal interview schedule that spoke to the main research questions contained in the IDRC research protocol (see Appendix B). In practice, the researchers used the interview schedule as a guideline to structure the interviews and to ensure that they touched on the main

research themes. On average, interviews lasted about 60-90 minutes. Six interviews were conducted with individuals who served on the steering committee of the coalition. The interviews took place in Cape Town and Johannesburg between June 2015 and April 2016. Follow-up conversations (via Skype and email) took place with two of the interviewees and several interviewees shared additional literature/documents on the NHI Campaign with the researchers.

Participants were asked to give written or verbal informed consent to participate in the interviews, and for interviews to be recorded. Audio recordings and non-verbatim summaries were generated for most interviews. Verbatim transcriptions were generated for five interviews (one of which was focused on gathering data on SAPHU; four focused on the NHI Campaign).

### *SAPHU*

In evaluating the two SAPHUs held in 2013 and 2014 a mixed methods approach was used, including **participant surveys, document analysis, qualitative interviews and focus group discussions**. This report foregrounds the second SAPHU for as the evaluators had easier and fuller access to various aspects of this event and its role players. During SAPHU 2, the following data collection methods were used:

- **Participant surveys:** a pre-course questionnaire was administered to the participants during registration on the first day, and a post-course questionnaire on the last day (in appendices A and B). Participants' names were included to enable us to match the pre and post-course surveys. From the 46 participants, 42 were received beforehand and 44 afterwards.
- **Participant observation** at the five days of SAPHU2 (1 – 5 December 2014) by Penny for some of Monday, all of Tuesday, some of Wednesday afternoon, Thursday morning and all of Friday; and by Anneleen on some of Wednesday and Friday.

After SAPHU2 various documents were reviewed. In addition, **participant focus group discussions** were held with SAPHU2 participants from Gauteng, Western Cape, Northern Cape and the Eastern Cape. Informed consent was obtained from each person and they were assured of confidentiality. **Key informant interviews** were held with a range of individuals - the convenors of SAPHU2 comprising staff and steering committee members of PHM-SA and directors of the partner organisations; other members of the steering committee, an adult education specialist and a few SAPHU1 and 2 participants. The interviews were semi-structured to facilitate both the comfort of the participants and to allow for spontaneous insights to be offered.

The questions in the interview schedules were developed to honour the very detailed TOR as well as the themes in the global guidelines for local data collection for the CSE4HFA research, which were mapped together thematically. The resulting schedule was very extensive, however, making them too long and unrealistic. Therefore while bearing in mind the main themes of the research the researchers customised each to suit the interviewee –such that the schedules were not doggedly followed and the interviewer exercised judgement regarding the value of pursuing every last detail. Invariably there was not enough time, which also required that the researchers selected those aspects they thought most helpful to this project. Where possible, the researcher had more than one session with the informants, having identified missing information that needed to be pursued.



The interviews and focus group discussions (FGDs) were recorded and together with the notes taken, are saved in a protected folder by the evaluator. They were all transcribed, either by the evaluator herself or by a professional transcriber.

Informed consent was obtained from all key informants. While they were assured of confidentiality, the researchers did mention that anonymity would not always be possible or necessary. In order to ensure the informants' confidentiality no names have been given, unless this is entirely unavoidable.

### *Community Health Worker Capacity Building*

The research team for this theme comprised members of PHM-SA and the Division of Social and Behavioural Sciences (DSBS) at the University of Cape Town's School of Public Health. The team has a combination of both practical and academic research experience. The research team met regularly throughout the process to discuss findings and plan directions for subsequent research.

Fieldwork was carried out by DSBS researchers, following discussion with PHM-SA. Fieldwork locations were chosen according to interest or invitation and fieldwork was conducted in five of South Africa's nine provinces: the Western Cape, Eastern Cape, Northern Cape, Gauteng and Free State. Primary data were collected through extensive **qualitative interviews and participant observation**. In the process, researchers interacted with multiple stakeholders including CHWs from around the country, CHW labour movements, non-governmental organisations that facilitate community health work, and relevant supportive civil society activist organisations. Activities included **individual and group interviews** and **participation in training or knowledge-building workshops** (e.g. PHM-SA training/awareness-raising) and meetings (e.g. union gatherings), as well as **attendance at the trial hearing** of Free State CHWs who were arrested for protesting their suspension from work.

Interviews were usually fairly informal and aimed to elicit informants' own stories about their experiences, rather than closed questions with little space for additional explanation. Guiding questions focused on challenges and motivations in day to day life and work, the future of the health system, practices of self-organising, politics of legitimacy and representation, and CHW relationships with supporting civil society organisations. Our rationale for this methodology was that in-depth, multi-province **ethnographic research** allows for a more complex but also a more nuanced, comprehensive and accurate view. In order to counteract the focus on quantitative measurement often dominant in donor, employer and global health discourses, we also believe this ethnographic research enriches the more common vision of CHWs as "little more than caricatures of humble and heroic health technicians who wield technologies including bikes, smartphones, forms, medicines, and diagnostics; who transmit information for monitoring and evaluation; and who save lives" (Maes, 2015:1).

The material collected thus far includes **non-verbatim interview transcripts, some audio recordings, and field notes with extensive detail** (comprising summaries and general reflections on interviews and workshops). Data analysis has been concurrent with the process of research and has proceeded in several rounds, all grounded in a comprehensive ethnographic approach. Firstly, as with all qualitative data analysis, a process of iterative analysis of the data (and relevant additions to the interview guide) was conducted throughout the data collection period. Secondly, a thematic analysis was conducted on the interview data to identify key themes and initial conclusions, as presented in this report. At a later stage, data from other ethnographic assessments of similar topics and relevant context (e.g. policy shifts and

the current nature and status of activism in the country) will be combined with the findings from the thematic analysis to produce a number of peer-reviewed publications.

## **5. Different country contexts as regards the health movement**

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*This section was consolidated with section 3, as agreed with David Sanders.*

## **6. Capacity Building**

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Developing the capacity of grassroots activists is one of PHM-SA's main thrusts – be this through developing PHM-SA activists or those in other organisations (like the Women on Farms Project, the Learning Network, community health forums etc). PHM-SA's capacity building is about developing a broader and deeper awareness of the political economy of health and Primary Health Care. 'Capacity building' is loosely understood to include raising the public's awareness of political analysis regarding health (which could be said to border on advocacy) as well as the more usual sense of its being about developing and educating people.

### Informal capacity building

Significant activist education happens through learning-by-doing. This includes experiential learning, with its crucial elements of reflection and critique. In PHM-SA in Cape Town, opportunities for this include:

- working with other organisations on local health-related issues – like on sanitation with Mamelani (a small community-based NGO) and with a number of organisations in the Eastern Cape on Child Rights Campaign; and
- in the bi-monthly 'members' meetings' in which local issues are raised and discussed among members, experiences shared and agendas for action / support are developed.
- single-issue public meetings are held every alternate month. They are typically attended by 50 or more members from Cape Town civil society. PHM-SA has progressive experts and/or affected persons speak on current health issues.
- PHM-SA's public presence in debates – through letters to the newspaper and statements it issues through newspaper articles – also serves to raise awareness about the political economy of health.
- PHM-SA has held two national People's Health Assemblies, where current issues were debated towards developing platforms for action.

### Formal capacity building

For PHM-SA, formal programmatic 'training' comprises

- training medical students on request.
- workshops at Public Health Association of South Africa (PHASA)
- the South African People's Health University (SAPHU) – see below for more on this; and
- training members of other organisations and trade unions on request – e.g. the National Education Health and Allied Workers' Union (NEHAWU) and National Union of Metalworkers (NUMSA); the Learning Network on health committees, members of health committees through

the Metro Health Forum in which it addresses issues like the NHI, community participation, role of health committees etc.

#### *South African People's Health University (SAPHU)*

PHM-SA is part of the 'Medico network' convened by the progressive German-based Medico International. It comprises five South African organisations working with community care workers – ostensibly in support of the self-organisation of CHWs – namely Section 27, Khanya College, Sophiatown Community Psychological Services in Johannesburg, Sinani in KwaZulu-Natal and PHM-SA in Cape Town. The network was initiated in February 2014 when Medico convened a meeting with these five organisations to submit a funding proposal to the German government to fund work in this area. Medico's criteria for selecting these particular organisations are not known.

Sophiatown Community Psychological Services and Sinani provide psycho-social support for patients and care workers, among others; Section 27's work is characterised by human rights litigation; and Khanya College has been supporting community care workers' struggles in Gauteng for some time. PHM-SA's role in the network is to build capacity and mobilise on the ground.

One of the main capacity-building activities that PHM-SA undertakes is the South African People's Health University (SAPHU). It is a five-day capacity building programme designed for about 45 people working in community-based health work. The idea to run a local South African People's Health University annually arose from a discussion within the PHM-SA steering committee, after the International People's Health University (IPHU) was held in Cape Town in 2012, prior to the People's Health Assembly 3 (PHA3). SAPHU's have been held on an annual basis since the first SAPHU was held in December 2013.

SAPHUs are aimed at training a new generation of health activists. SAPHU 1 focused on primary health care and its place in the proposed new policies of NHI and Re-engineering Primary Health care. This SAPHU was held for a mix of NEHAWU cadres (shop stewards and officials responsible for education) and selected civil society members. SAPHU 2 focused on developing an understanding of the primary health care approach, the proposed NHI for South Africa and the activist role of CHWs. Dedicating SAPHU2 to CHWs represented a 'key strategic shift ... towards a more community-based focus for our capacity building and advocacy training, without excluding engagement with the state on the NHI at the 'macro-political' level. This and related shifts informed the design of the next iteration of SAPHU 3, which also focused on capacitating CHWs to work as agents of change and community mobilisers and advocates for health in their communities.

SAPHU participants come from all over South Africa and have included union members (specifically members of the National Education, Health and Allied Workers Union – NEHAWU), senior members of community health workers' organisations, and members of organisations that belong to the Medico partner network. They are recruited in two ways: their organisations select them to attend SAPHU and/or through an open application process managed by PHM. Preference is given for participants that hold senior or leadership positions in their organisations as these individuals are best positioned to pass their learning on to others in their organisation.

#### *Evaluating SAPHU's contribution to capacity building: a case study of SAPHU 2*

This section discusses research that focused on the efficacy of the second SAPHU in generating a new cadre of health activists. Other SAPHU's are discussed where relevant.

Following the stalling of the NHI Campaign, PHM-SA shifted its focus to primary health care (PHC) given its crucial role in delivering a national health service, and to community-based health workers (CBHWs) in particular. The second SAPHU was a key component in PHM-SA's CHW campaign. For the past few years the PHM-SA has worked closely with the NGO Wellness Foundation which has been working with care workers for about 14 years and with the membership-based South African Care Workers' Forum (SACWF). In May 2013, the three organisations convened a two-day Public Health Forum attended by 98 community care workers (CCWs) representing over 50 organisations. The purpose was to 'reaffirm the importance of community care workers in South Africa's health system and to expose the terrible working conditions that many community care workers are experiencing'.

The report of that Forum noted that '[t]housands of these workers, the vast majority women, work in the homes of the poorest of the poor bringing basic wound care, TB and HIV treatment, empathy, care and rehabilitation to those in desperate need'. It ended by proposing that 'apart from providing an essential health service through home based care, CCWs can play a central role in transforming the health of their communities as agents of change. This requires a shift in thinking about the meaning of community participation in health. Instead of being the lowest paid lackeys of a dysfunctional health system, they would be liberators, freeing people from the scourge of ill health.'

Dedicating SAPHU2 to CBHWs, then, was one way of PHM-SA's beginning to transform CBHWs into these 'liberators', these 'agents of change'. Quite how this might happen - or may have been expected to happen - is addressed later. Suffice here to raise the issue of whether or not the SAPHU participants (many of whom were carers) were activists, or were interested in becoming so. Is SAPHU about developing activists from scratch - or supporting the development of embryonic or existing activists? And/or is it about building a cadre of (organic) activist leaders who can develop other activists in their local settings? Answering these questions and being clear about how SAPHU may make a difference beyond its limited reach by clearer selection of participants is thus important.

In some respects SAPHU 2 worked well. For example, during SAPHU2 the facilitation and aspects of the curriculum were appreciated; PHM-SA met new people and its reputation was enhanced. In other respects, however, it was not sufficiently focused, and fell short of directing the learning process towards a fuller realisation of PHM-SA's intended aims for SAPHU. If the purpose of SAPHU is to build activists and contribute to the building of a social movement for Health for All, it currently falls short of realising this as it might. For example, SAPHU2 participants were diverse - with some seeming not to have the vigour/much interest in becoming activists at all, while others had a form of 'quiet activism' which was different to the more militant expressions of activism by some participants. Many participants did not know what SAPHU was about before they arrived and did not know what to expect, resulting in some completely inappropriate expectations (like wanting to learn more skills in treatment and care).

With the exception of the social determinants of health, the core messages at SAPHU2 were not clear enough and some up-to-date information that affected CBHWs was not offered. The discussions were not sufficiently directed when they needed to be. So, for example, the desire to develop political analysis competed with the agenda regarding CBHWs' working conditions - and was not facilitated firmly enough to optimise both. While there were three main aspects of the curriculum - CBHWs' working conditions; policies and political analysis; and psycho-social interventions and support - these were not well

integrated. In addition, there were no activist skills, which is odd for a programme that intends to develop activists. In focusing on conceptual / political education, PHM-SA has not included in its offerings any activist-related skills development, despite their intentions to do so. Although learning-by-doing is the best way to learn some aspects of activism, some things can be taught (like ways of undertaking advocacy, strategic analyses etc).

Despite documented intentions there were no plans to follow up with the participants and very little follow-up was initiated by PHM-SA – apart from contact with sister organisations in the normal scheme of things, including through the Medico network. So not only does PHM-SA not know what the participants have done since attending SAPHU2, it also has not organised them into its own structures where these exist. When interviewed a few months after SAPHU, some participants (from an area where there was a PHM-SA circle) did not even know of its existence. Those that implemented what they had learned did so with little support – which could have comprised a pack of materials to propagate particular messages – and reported feeling disbelieved and/or a bit beleaguered. While SAPHU as an event was appreciated by the participants and was well run under under-resourced circumstances, it does not seem to have been framed within a larger strategy to build activism.

SAPHU 2 aimed to strengthen the knowledge and skills of CBHWs in policy and political analysis, and in advocacy, mediation and activism. It focused on both militant as well as quieter forms of activism. The programme does not duplicate present education and training of CBHWs, but focuses on aspects usually neglected in other programmes.

Based on an extensive evaluation after SAPHU 2, radical changes were introduced to the curriculum. For SAPHU 3 organisations were engaged months prior to the SAPHU. They have committed to supporting activism for transformation within their organizations, communities and the health system. Participants were recruited through organisations and before arriving at the SAPHU, the chosen participants and the organisation had to send a case study to the SAPHU sub-committee. These case studies were used for critical analysis of the social determinants of health, and for planning strategies for community mobilisation and intersectoral campaigns to implement on return to their organisations after the SAPHU and National Health Assembly (NHA).

In addition members of PHM-SA assisted with the selection of organisations and assisted the selected participants to prepare a case study from their area in preparation for SAPHU. The mentors will support participants for approximately 6 months after SAPHU. Thereafter mentors and selected CHWs/CCWs will be brought back to share what they have achieved in a 2-day follow-up workshop in late November/early December 2016. Mentorship will thus be required pre- and post-short course (and ongoing as needed). Based on the evaluation of SAPHU 2, SAPHU 3 started with just 3 provinces (Gauteng, Eastern Cape and Western Cape) with eight participants from each project (2 CHWs/CCWs from four different projects in each province) to develop a critical mass and for depth and sustainability. PHM-SA hopes to run SAPHU in a similar way for the other 6 provinces over the next two years, funding permitting.

Since returning, the participants have reported back to their organisations, and with the help of their mentors, are planning implementation of their projects. Overall there is a positive feeling about implementation of projects that could start a growing movement for HFA, but a fair amount of follow up and support will be needed.

*Health Committees*

In July 2014, the Klipfontein Sub-district Health Forum in Cape Town approached the People’s Health Movement (PHM) for input and training on the National Health Insurance (NHI). The Health Forum is part of a wider umbrella body for Health Committees in the Western Cape called the Cape Metro Healthcare Forum (CMHF). The CMHF had been involved in a capacity building project with the University of Cape Town (UCT) and the Learning Network on Health and Human Rights (LN) since 2013 aiming to build the capacity of Health Committees to function as vehicles for community voice in relation to the health system. In the course of this training, the Health Committees in the Klipfontein sub-district identified the need for input to understand what is the National Health Insurance and how they should respond. Through the LN, PHM SA was approached to provide training to organised Health Committees in three sub-districts in the course of 2014. While the initial impetus for the training was the NHI, much of the training covered a broader political economy of health and an understanding of nature of Primary Health Care in its full political, social and economic context.

This training helped to build a wider solidarity between PHM and the Health Committees. When, in 2015, the Western Cape Health Department finally began to produce a policy on Health Committees, which it had been promising for the preceding 7 years, the Health Committees approached PHM for assistance, both in facilitating workshops for Health Committees and in advocacy actions. Health Committees are mandated by the National Health Act but the details of how Health Committees should be formed and what roles they have are left to Provincial legislation. Even though Health Committees had been active in the Cape Metro for more than a decade, the lack of a policy has undermined their functionality and effectiveness. Thus, when a Draft Bill on Health Committees was developed in 2015, Health Committees were pleased to welcome the putting down on paper of regulations at last, but were very concerned about the contents of the Bill, which took community participation backwards from how it is conceptualised in the idea of Primary Health Care, and in previous draft policies in the Metro, which were never formally adopted.

Thus, PHM worked with the CMHF to help run consultative workshops on the Draft Bill so that Health Committees could get together, review the Bill in detail and make submissions. This was a way for Health Committees to have a say in shaping the Bill. Seven sub-district workshops were held.<sup>xxxviii</sup> PHM also supported a CMHF protest directed to the Provincial Minister of Health and other advocacy by the CMHF protesting the inadequacy of the Bill. This experience led to the inclusion of Community Participation and the Role of Health Committees in building the Health System as a key theme of the National Health Assembly in June 2016 with a series of actions proposed nationally. This has helped to spread advocacy in the Western Cape to a national level on community participation. Work with Health Committees will also continue in the Western Cape as the province has just adopted the Draft Bill, virtually unchanged from what was first put out for public comment – an action antithetical to the idea of Community Participation in Primary Health Care.

## **7. Knowledge Generation**

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PHM-SA’s knowledge generation activities are aimed at advancing an understanding of the global and national political economy of health and health systems in order to transform this system. It undertakes this task through knowledge generation, campaigns and capacity building interventions. Its

communications are directed at target groups (e.g. health professionals and members of health governance bodies), other activists (within and outside of the health sector), and the general public.

PHM-SA has a comprehensive political economy analysis that makes it unique in SA. It is the only organisation with a socialist analysis of health and health systems. However, its ability to convey this frame and translate it into broad-based action/a mass movement for health is weak. This raises the question of whether PHM should position itself as an organisation that politicises and animates health activists who don't necessarily identify as PHM-SA members, rather than trying to build a mass movement, which it may have limited capacity to do in a sustained manner.

This section describes typical knowledge generating activities that PHM-SA undertakes and explores some of the reasons for its difficulties in popularising its approach to promoting health for all. Where researchers collected data on the impact of these activities this has been included below. PHM-SA's knowledge generation and dissemination activities are aimed at raising public awareness about the local and global dimensions of the political economy of health and health systems in South Africa. Globally PHM-SA members do this by contributing to Global Health Watch. In contributing to this research project, a founding member of PHM-SA commented that, *"I think our impact has been mainly in keeping the radical vision of primary health care [PHC] alive and in raising consciousness about the social determinants of health [SDH] within civil society. Of course this is impossible to measure, but I guess this has broadened the vision of [other health civil society organisations such as] TAC as well as Section 27, especially recently."*<sup>xxxix</sup>

The following knowledge generation activities are undertaken locally:

- **hosting public meetings, including provincial and national health assemblies.** "Ordinary" public meetings are primarily held in Cape Town, where PHM-SA is most active. They are advertised on social media (Twitter and Facebook), via the PHM-SA email list, and on posters that are put up at partner organisations. Sometimes the meetings are hosted in collaboration with partner organisations. Alternatively PHM-SA may provide representatives of partner organisations a platform to discuss a specific topic. These meetings attract an audience of 50 to 100 people – often attendees are health practitioners and activists. PHM-SA subsidises transport to these meetings and also provides a meal (lunch) during the course of the day. At each meeting a register of participants and their contact details is filled out. Provincial and National Health Assemblies are organised in collaboration with partner organisations (e.g. most recently with TAC and Section 27) and are aimed at creating a people's movement for the right to health.

The meetings are organised around specific themes but all meetings tend to focus on themes that relate to PHM-SA's focus on the political economy of health and health systems. More than one interviewee commented on the fact that it is difficult to mobilise people and build a mass movement around a complex and broad based issue such as the political economy of health and health systems. One interviewee gave the following example: *"...if someone says to me you've got HIV this medicine if you have access that medicine will stop you dying from HIV, fight for that medicine then I will fight for that medicine. Particularly if I know that medicine is affordable and the pricing issues is just profiteering by pharmaceutical company. If someone says to me you've got HIV um if we were ever going to treat you, the first thing that we were going to do is to make sure there is enough human resources in the health system, there is enough money in the health system, there is quality health care systems, there is primary*

*health care then it is less mobilizing and it is hard for me to enter into that ... that's my personal critique of health activism of the last twenty or thirty years which is, which has accomplished very little and in fact if anything has lost ground significantly, it is that there needs to be a serious discussion about how do you, how is health activism actually undertaken.”<sup>xi</sup>*

This difficulty of moving people from understanding the structural factors that affect health to actively participating in a mass movement for the right to health remains a challenge for PHM-SA. One interviewee commented that public meetings more frequently create opportunities to forge one-on-one relationships with other health activists rather than being places where organisational alliances are established: *“I remember when I worked at PHM, I went to talk about PHM and the right to health at the sort of first gender health conference I mean I think they had in Woodstock so I mean they were but... I think often the connections are built on individuals rather than sort of structural organizational thoughts. So I think often they happen ad hoc. I know you and used to work there and I know... I mean it has often worked that way ...”<sup>xi</sup>*.

- **engaging in debates and panel discussions on radio and television.** National broadcasters (e.g. the *South African Broadcasting Corporation* and *e-TV*) and community radio and TV stations (e.g. the Cape Town based *Bush Radio* and *Cape Town TV*) often invite PHM-SA to participate in discussions about health care matters. Most recently PHM-SA has used these platforms to raise awareness about the potential pro-private sector bias of the NHI and about the poor working conditions of CHWs.
  
- **writing letters to newspapers and government officials.** PHM-SA has used this form of communication to raise public awareness about health care crises and to pressure government officials to address these crises. For example, letters have been used to draw attention to:
  - o the poor quality of living conditions and child nutrition in refugee camps that the City of Cape Town established during the xenophobic riots of 2008;
  - o the importance of ensuring that public sector health workers, particularly junior doctors and community health workers, are remunerated fairly, have decent conditions of employment and are allowed to exercise their rights to organise;
  - o the fact that striking workers, particularly those in hard-to-reach locations (e.g. farmworkers), struggle to gain access to health care services during times of political conflict and that this must be corrected;
  - o the risk that the NHI scheme, in its current guise, may further weaken the capacity of public health facilities to provide decent services to patients and strengthen the role of private sector providers;
  - o the importance of prosecuting and revoking the licenses of medical practitioners who were complicit in human rights abuses during apartheid;
  - o poor governance of health institutions and systemic health crises in specific provinces of South Africa, notably the Free State and Eastern Cape Provinces, and the responsibility of provincial officials in solving these problems; and



- o the activities of corporate lobbying groups who advocate against using TRIPS flexibilities and for national policies that offer strong intellectual property rights protections to pharmaceutical firms.
- **issuing statements of solidarity in support of progressive political organisations or initiatives demanding greater accountability and transparency in government**, e.g. a coalition of civil society organisations calling for President Zuma to step down, student activists campaigning for the reduction and elimination of fees at tertiary level, and miners at Marikana who were massacred by the South African Police Service.
- **providing feedback on government policies e.g. through submissions to parliamentary committees, meetings with government officials or letters in the press.** PHM-SA has commented on policies such as the *NHI White and Green Papers*, the *National Sanitation Policy*, and the *Draft Amendment Regulations on the Consumer Protection Act Regulations* (which defined the permissible use of GMO foodstuffs and labelling requirements in this regard). One of the interviewees mentioned that collaborating on policy feedback not only generated new information, but also offered health civil society organisations the chance to build (and in some cases, rebuild) working relations with each other, *“there was a definite tension between the setting up of TAC and the campaigns of TAC and traditional public health activism, who would be associated with organizations such as People’s Health Movement uh um. You know [some] people ... were very critical of TAC at the outset it was said to be narrow [they and] assumed that the health care system wouldn’t be able to support a vertical programme like an anti-retroviral treatment programme um that’s you know that we are moving away from the vision of the Alma Ata Declaration, away from the ideas of primary health care. So actually although it was never declared as such there was a kind of split in ah public... you know people who believe in the right to health and were campaigning for the right to health and that split you know continued for probably a decade. Um they did their thing and we did our thing... it was really around this idea of national health insurance that’s you know there was an opportunity that was seen for a coalescence again of progressive forces within civil society and within the trade unions who were all working on the right to health. Um so that’s how the coalition came about I mean we began, different organizations began to speak to each other.”*<sup>xlii</sup>
- **developing/contributing to pamphlets and information booklets with partner organisations**, particularly unions and umbrella bodies comprised of progressive civil society organisations (e.g. a pamphlet on the NHI developed for the Democratic Left Front). These efforts don’t always shift the analysis of partner organisations. For example, one interviewee commented on the fact that the critiques PHM developed around the private health sector during the NHI Campaign did not seem to resonate with Section 27 and NEHAWU, one of its partners in the NHI Coalition: *“So there was a feeling, and I could be wrong, but on the basis of Section 27’s work that, you know, they, they... didn’t have a clear perspective on NHI particularly the private-public partnership component. Whereas, PHM is, was, very clear about free at point of service, that using the term insurance was actually, you know, a problem... even the [position of] no public funds for private profit, I mean, that was not necessarily agreed by NEHAWU or Section 27”*.<sup>xliii</sup>

In other instances PHM's research and analysis influenced other progressive organisations' work. These organisations were not necessarily part of health civil society, but through their work with PHM-SA have come to incorporate health as a focus of their work in other areas. For example, PHM influenced the Alternative Information Development Centre's Budget Justice Campaign: "[AIDC] included NHI as sort of one of the core demands within the call for budget justice and also AIDC as a partner for PHM had done their tax booklet, looked at how NHI could be financed. So [through this partnership] we had some, some sort of concrete research on how NHI could be financed..."<sup>xliv</sup>

- **writing articles for academic journals and popular publications.** Some members of PHM-SA work as academics and researchers and have contributed articles to peer-reviewed journals (e.g. articles on global governance for health in the Lancet) and to popular publications aimed at a broader readership (e.g. articles on the NHI in *Amandla* magazine, a local publication distributed nationwide). For many years PHM-SA also published a journal, *Critical Health Perspectives*, which used a political economy of health lens and covered topics such as the health impact of climate change, globalisation and health, health financing, and the history of the primary health care approach.
- **solidarity actions**, e.g. organising public meetings or issuing/signing-on to statements of support on topical issues like a civil society statement condemning the assassination of an anti-mining activist, Sikhosiphi "Bazooka" Rhadebe, in the Eastern Cape Province in March 2016, and hosting a public meeting drawing attention to the systemic underpinnings of the Ebola pandemic that affected West and Central Africa in 2014-2015. One interviewee described the value of PHM-SA's wide scope of work as follows: "I think one of the good things politically, people in the People's Health Movement and drivers of the People's Health Campaign have a very strong international perspective. They know what is going on the world so we don't become introspective of the South African situation. I think politically they are good there."<sup>xlv</sup>

## 8. Global Governance for Health

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A senior PHM-SA member, David Sanders, participates in WHO Watch. No other members of the South African country circle have participated in this.

In January 2013 PHM-SA contributed a case study on the extractive mining industry to the Lancet Commission on Global Governance for Health. The submission focused on the health, environmental and socioeconomic costs of gold and platinum mining in South Africa and advocated for the implementation of laws that would prevent mining companies from externalising these costs to the public sector, workers and mining-affected communities.

## 9. Campaigns

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PHM-SA has undertaken two campaigns since its formation. The earliest of these was the campaign for the right to health. A more recent campaigns advocated for a "people's National Health Insurance (NHI) scheme". This section gives a brief overview of the strengths and weaknesses of each campaign.

### The Right to Health (RTH) Campaign

PHM-SA'S first major campaign was the RTH campaign, which it launched in February 2007. The rationale for campaigning around this issue was that this was what PHM-Global was focussed on at the time. PHM-Global developed a template along with a set of implementation guides for analysing the entire health system from a rights point of view. However, PHM-SA found this template unworkable. It therefore decided to replicate PHM-India's RTH campaign. That campaign was organised around community monitoring of local health services and hearings and tribunals in which community members, the health department and the Indian Human Rights Commission participated in.

In comparison to the Indian campaign, PHM-SA's campaign focused more on the social determinants of health and not only on monitoring the quality of health care services. For example, RTH marches saw participants holding up posters that emphasised the importance of decent housing, sanitation services, access to clean water, and access to jobs for improving health outcomes. During public hearings and workshops community members often identified these issues as more urgent than improving access to health care services. PHM-SA used the information from workshops and hearings to lodge submissions on housing and diarrhoea in children with the South African Human Rights Commission.

The RTH campaign activities generated a lot of interest in two of the Cape Town communities – Khayelitsha and Manenberg – where they were held. The campaign also received support from unions such as COSATU. However, it did not enhance PHM SA's membership - mainly because the activities were not consciously used toward this end. Participants in activities were not followed up and recruited as dedicated PHM members.

The RTH campaign did not end as the result of a conscious decision based on an environmental scan, but petered out because more pressing issues took over. In addition campaign activities, e.g. workshops, were rather randomly organized without a clear logic and never formed part of a coherent campaign like in India. In the wake of the RTH campaign PHM-SA decided to continue campaigning on the right to health in the context of the NHI. More specifically, it committed to focusing on the role of CHWs within the NHI.

Major lessons learned during this campaign:

- campaigns should be developed in light of local circumstances and should speak to issues that will mobilise support from communities and other civil society organisations.
- it is important to have a campaign plan mapped out. A successful launch is no indication of a successful campaign.
- single issue campaigns tend to generate more support but don't necessarily address systemic issues well.

### The NHI Campaign

The NHI Campaign was launched by PHM-SA in 2011 in response to the publication of the Green Paper in August of that year. The Campaign led to the formation of the NHI Coalition (NHIC) at the end of 2011, which comprised the following progressive civil society organisations: People’s Health Movement South Africa (PHM-SA), SECTION27, Treatment Action Campaign (TAC), Black Sash, Rural Health Advocacy Project (RHAP) Rural Rehab, Rural Doctor’s Association of South Africa (RuDASA), Passop, EarthLife Africa, Africa Health Placements (AHP). The coalition set out to develop a collective response to the Green Paper and to raise awareness amongst citizens and activists about government’s proposed NHI.

PHM-SA bore the primary responsibility for driving the campaign and directing and coordinating the work of the NHI Coalition. Beyond commenting on the content of the Green Paper, PHM-SA sought to use the coalition to drive a campaign for a “people-centred NHI”. Framing the campaign in this way allowed PHM to locate the campaign within the debate on health system change that was taking place at the time, but also qualified it and allowed space to explain the pro’s and con’s of the government’s proposal.

The NHIC intervened in the NHI process because it presented an opportunity to engage the government on reforming the crisis-ridden public health system. However, coalition members did not feel that the 2011 Green Paper offered the best strategy for doing so. Its criticisms of the Green Paper were that the private health care sector remained an important provider of care under this scheme, that it offered no guarantees that public health facilities would be improved (particularly in rural areas and informal settlements) or more employees would be hired by government, was unclear about how the government would ensure efficient, equitable and transparent governance of the NHI fund, made no commitment to scrapping user fees in the public sector, retained regressive taxation rules with respect to health insurance schemes, and included only citizens, permanent residents and officially recognised refugees as beneficiaries. The Green Paper was also problematic in that it focused narrowly on financing health care services, but made little mention of the need to improve the social determinants of health or of increasing public participation in decision-making about health care budgets and services.

Based on this critique of the Green Paper, the NHIC campaigned for a revised NHI Bill which would guarantee:

- free services at public hospitals (no user fees at the point of care);
- the elimination of subsidies to the private health care sector;
- funding and filling vacant public sector posts; and
- improvements of public sector clinics and rural hospitals and their accreditation as providers under the NHI.

There was some debate within PHM-SA about whether it should also demand that the government refuse to accredit private hospitals as NHI service providers. PHM-SA’s strategy was to measure the government’s proposed policy changes against these principles/demands and to oppose those aspects that maintain or potentially worsen prevailing inequities. Towards this end a number of campaign activities were organised between December 2011 and 2013 when the NHIC was most active. These included:

- a public meeting in March 2012 that was co-hosted by TAC and PHM-SA. The meeting aimed to raise awareness amongst progressive civil society organisations about the NHI and the NHIC’s engagement with it.

- coalition members attended a National Consultative Health Conference on the NHI, which was hosted by the National Department of Health, on 7 and 8 December 2011 and distributed to all participants the response by the NHIC to the Green Paper .
- meetings of NHI Coalition members, coordinated by PHM-SA, to decide on the scope and content of the campaign. Due to financial and human resource constraints these meetings were held on an *ad hoc* basis and relied on teleconferencing.

In interviews key informants were ambivalent about the success of the NHI Campaign. They agreed that NHI coalition encouraged health activists to speak on the NHI with one voice despite their political differences (e.g. some organisations advocated for the dismantling of the private health sector whereas others opposed this), increased awareness of the NHI amongst health activists and members of the public, and allowed activists and organisations in the health sector and beyond to pool resources and build working relationships.

However, they also indicated that the coalition worked most effectively as a coalition when asked to endorse specific statements or submissions. For the most part coalition partners pursued capacity-building and awareness raising on the NHI within their organisational structures/routine work and not under the umbrella of the NHI Coalition. For example, TAC included information about the NHI in workshops with its activists, dedicated an issue of its magazine, *Equal Treatment*, to the NHI, discussed the matter at its National Council Meeting in 2012 and conducted some monitoring activities at NHI pilot sites. PHM-SA organised its first SAPHU with a view to training a new layer of health activist leaders that could support the work of the NHI Campaign and conducted community-empowerment workshops that focused on the links between the SA health system, the burden of disease and the social determinants of health in poor communities.

According to the activists interviewed for this research, the following factors hampered the success of the NHI Campaign in effecting policy-change, building capacity, knowledge generation, and contributing to movement-building:

- lack of sufficient funding and a dedicated budget and staff to drive the work of the NHI Campaign. A small group of PHM-SA members were responsible for doing the bulk of the organising, coordination and media-outreach work on the campaign. Most of them worked on a part-time basis. During the course of the campaign (2011-2013) PHM-SA had three different coordinators each with different skill sets. Record-keeping and “hand-over” of NHI Campaign materials and processes were not done in a systematic manner.
- partner organisations did not necessarily prioritise the NHI Campaign and were often difficult to contact and/or did not deliver outputs/meet agreed upon deadlines.
- all the coalition members, including PHM, found it difficult to sustain its NHI Campaign work in the face of more urgent health crises requiring attention, e.g. the near-collapse of the Eastern Cape Province public health system during the same period.
- government’s delay in releasing the NHI White Paper (which was eventually published in December 2015, four years after the publication of the Green Paper) made it difficult for coalition

partners to keep this a “topical” issue in the minds of their members, partners and the broader public.

- TAC’s structure as a membership-based organisation limited the time and energy it could spend on the NHI Campaign in the absence of a clear mandate from its members that this was an organisational priority.
- the campaign did not manage to partner with/create a broad coalition of public health facility users which could potentially have contributed to movement building through the NHI Campaign.
- there was no clear consensus amongst Coalition partners on the core tenets of the Campaign, specifically with respect to the desirability of a policy that further entrenched the commodification of health care services. In addition coalition partners disagreed about the strategies that should be used to advance the Campaign, e.g. the utility of publishing a “Shadow White Paper”. One interviewee reflected on the difficulties of keeping the coalition alive as follows, *“There was no focus, what was the core demand. There wasn’t really, you know, you need consensus at least on one core demand and I found that almost impossible to get.”*
- Personality conflicts/tensions amongst NHI Coalition members. For example, one interviewee said they felt like they stepped *“into a situation where you know there might have been fall outs that I didn’t know about or ja.”<sup>xlvi</sup> I think personalities was a big issue. And I mean that is something that I did differently when I [moved to my next job] I didn’t wait for people to like each other.”*
- A lack of clarity about the other institutional and political forums in which PHM or NHI Coalition members served and that could be used to advance the NHI Coalition’s positions on the NHI and/or an NHS that embraced Health for All principles.
- No big or sustained Campaign activities aimed at pressuring the government to release the NHI White Paper or financing plan. More broadly, the campaign had a limited/low media profile and produced very few campaign materials that could be used by organisations and individuals inside the coalition (and beyond).

In summary, the NHI campaign was successful in stimulating progressive activist thinking on health system reform in South Africa. It also helped to forge tentative working relationships amongst civil society organisations (within and outside the health sector) that are committed to promoting the right to health. It is unclear, however, to what extent the coalition was successful in affecting the content of the NHI White Paper.

## 10. Movement Building

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As already mentioned, PHM-SA has a comprehensive political economy analysis that makes it unique in SA. It is the only organisation with a Socialist analysis of the health system. It seems, however, that its ability to convey this and translate it into broad-based action is weak. The data collected for this research

project does not provide reliable evidence that PHM-SA's activities directly impacted the scope, ideological orientation and efficacy of health activism in South Africa. However, it does provide plausible evidence that PHM-SA has influenced thinking within health civil society – and civil society more broadly – about progressive health policy.

It is useful to understand what it takes to develop and sustain programmatic activism, if that is PHM-SA's aim – and that this is not a quick process. Various points were made during the interviews conducted by Penny Morrell during her evaluation of SAPHU 2 about the importance of sustained leadership; the delicacy of organisational affiliation and alliances (where PHM-SA loses relationship with organisations when their members leave the PHM-SA steering committee); the variability of conditions on the ground (as evidenced in many examples above); the vagaries of funding; and that organising invariably takes a long time.

PHM-SA's local and provincial structures are currently not well developed – for two apparent reasons. Firstly, there is ambivalence within the organisation about the issue of membership. Although PHM-SA's constitution makes provision for both individual and organisational membership PHM-SA is aware that globally PHM is essentially a network of organisations and does not comprise members per se, so much as individuals or organisations who see themselves as part of the movement and who have engaged at different levels. As such PHM-SA is not assertive about signing up members or building structures – about constituting the organisation – and 'members' of PHM-SA are understood to be anyone who attends a public meeting. Curiously, it does have 'circles' in various provinces (rather than 'branches') that seem to consist of people who meet and engage in activities; and certainly there would be people who identify as supporting (being a member of?) PHM-SA.

There is no clear system for signing up members of PHM-SA – and certainly none to resign! The 'membership database' is reported to have about 600 people on it, but there is little confidence in this. Apparently PHM-SA does not make a habit of following up potential members however – including "people that had attended particular public meetings" noting that "especially if there was another issue, one could do some kind of follow up over email even." There are disagreements in the steering committee about the state and functionality of the database and mailing list, however – a problem which seems to have been intractable but which is one of the most basic tools for building membership!

#### *Network of organisations*

As South African civil society is increasingly fractured, building alliances is all the more important – and" it creates more hands to do the work because capacity in all organisations is very low." In the quest to build a people's health movement more broadly, however, PHM-SA's efforts may end up producing members for another organisation – for example the SA Care Workers' Forum (SACWF). But while this may contribute broadly to building a health movement, it does not build PHM-SA's capacity, without which it will not have the strength to broaden its engagement.

While macro frames and interests remain important, then, the locus of working in alliances is often relatively intimate, requiring care and (sometimes uncomfortable) compromises. Coalitions and partnerships are hard to work in, raising issues relating to who takes leadership roles, who drives the work and how to negotiate ideological differences – quite apart from inter-personal dynamics.

#### *SAPHU*

If SAPHU is to contribute to the building of a social movement more broadly, there need to be structures into which to do this. While PHM-SA can direct people to partner organisations, this can be in addition to, not instead of, organising them into PHM-SA structures. For example, PHM-SA could strategically select a few geographical areas where there is the kernel of PHM-SA organisation and make a commitment to support the building of circles in those areas only, for a significant amount of time. It could regenerate its membership systems (realising its constitution), signing up all current members and setting up administrative mechanisms which disaggregate members by levels of involvement and interests. PHM-SA could then actively recruit SAPHU participants into its structures and activities.

### *NHI Coalition*

A recent example of an alliance is the NHI Coalition which PHM-SA established in response to the NHI Green Paper, with a view to campaigning for a People's NHI. A number of organisations (Soul City, Section 27, TAC, the Black Sash etc) commented on and endorsed the PHM-SA's critique and attended a follow-up meeting at which many actions were agreed to. The coalition did not proceed much beyond this, however – both as the NHI legislation stalled but also as the PHM-SA co-ordinator, Thoko, who was going to drive the (ambitious programme of) work left the organisation, so tasks were not allocated to each coalition member and not much happened.

From a distance, our sense is that the NHI Coalition sounds to have been too ambitious and the difficulty of co-ordinating an ongoing alliance, underestimated. PHM-SA needs to be realistic about what is do-able given its capacity and politics – and to work incisively where it can add the most value.

### *Working with labour*

PHM-SA worked with NEHAWU prior to, and at, SAPHU1. This was at the instigation of a founding steering committee member who thought it imperative to work with the organised working class who were working in the health sector but do not know much about the politics of it. As part of the governing tripartite alliance, NEHAWU in particular plays a key role in influencing health policy (e.g. they put the NHI on the agenda in Polokwane) but they are not informed; for instance they did not know that the NHI is not a national health system as they had supposed.

More recently PHM-SA has worked with the NUMSA at a national level – following the dual membership of a PHM-SA steering committee member in both the AIDC and PHM-SA. As a result, the PHM-SA was the only health organisation at a large national exhibition of civil society organisations convened by NUMSA. PHM-SA will continue to develop a relationship with them, especially in the context of their leading role in the current development of the United Front.

## **11. Conclusion**

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Since the advent of democracy in 1994 progressive civil society in South Africa has declined in strength and focus, with the notable exception of the treatment action movement, spawned by a dramatic public health crisis and based in a mass movement predominantly composed of HIV-affected youth.



PHM-SA emerged in the early 2000s globally and in South Africa it began as a small organization with a comprehensive political economy analysis that makes it unique. It is the only organisation with a socialist analysis of health and health systems.

PH-MSA has been consistently active in analyzing and publicizing infringements of the right to health – including inequities in the social determinants of health. It has been consistent and vocal in promoting comprehensive primary health care as the core strategy for health development and applied this understanding in its critical support for various national and local health policies. This critical approach has been promoted in its capacity building and knowledge generation activities and has informed its campaigns.

However, its ability to convey this framework and translate it into broad-based action/a mass movement for health is weak. This has been partly a result of weak capacity but also because its message is often seen as too complex. Nonetheless, there is evidence that PHMSA has influenced the thinking and actions of numerous individuals and even of other civil society and mass organisations.

This raises the question of whether PHM should position itself as an organisation that politicises and animates health activists who don't necessarily identify as PHM-SA members, rather than trying to build a mass movement, which it may have limited capacity to do in a sustained manner.

## Appendix A: Researchers involved in collecting data for the PHM-SA Country Report

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Alex Paone (DSBS, UCT)

Alison Swartz (DSBS, University of Cape Town)

Anneleen de Keukelaere (PHM)

Bridget Lloyd (PHM-SA)

Christopher J Colvin (DSBS) – CHW case study: project lead; research dissemination

David Sanders (PHM-SA; University of the Western Cape) – principal investigator (PI)

Lauren Paremoer (PHM-SA; Political Studies, University of Cape Town)

Megan Harker (PHM-SA)

Penny Morrell (freelance adult educator, project practitioner and activist who works broadly on issues relating to public health and social justice; she is a supporter but not a member of PHM-SA).

Zara Trafford (DSBS, UCT)

## Appendix B: INTERVIEW PROTOCOL ON THE NHI COALITION AND CAMPAIGN

Questions based on the "CSE4HFA Phase 1 Guidelines for Country Teams"<sup>xxvii</sup> and the "CSE4HFA Draft Integrated Protocol V4" document<sup>xxviii</sup>

### I. Background Questions

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1. *Could you please give a brief overview of your organisation's work?*
2. *Can you recall what issues/focus areas your organisation was prioritising when the NHI Coalition was established?*

### II. Questions about the history of the NHI coalition and campaign (including the political/ socioeconomic context and leading reasons for the campaign)

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*Introductory statement [to be read out loud before asking the questions that follow]:*

*The NHI Campaign was launched in 2010 by PHM-SA in response to the government's proposals to establish a National Health Insurance Scheme. The campaign was led by a Coalition of civil society organisations – known as the NHI Coalition – which was formed that same year.*

*It had two main goals: to build a "consensus amongst health activists on the way forward to achieving universal access to quality health care for all in South Africa"<sup>xxlix</sup> and to "build a coalition of progressive health and social justice organisations to ensure that South Africa's health system reforms, including the National Health Insurance, ensure universal access to quality health care for all in South Africa."<sup>l</sup> These goals were being advanced in a context of massive cuts to public health budgets and retrenchments of public health personnel in the wake of the introduction of the neoliberal GEAR policy in 1996.*

*In order to advance these goals the Campaign issued five immediate demands. These were that government should<sup>li</sup>*

- *offer free services at public hospitals (i.e. cancel user fees);*
- *stop subsidising the private sector through tax incentives;*
- *more broadly, ensure that no public funds were used for private profit;*
- *ensure that public health facilities were properly staffed by filling and funding vacant posts; and*
- *ensure greater equity in health care by upgrading and accrediting township and rural hospitals.*

3. *How were you/your organisation involved in the NHI Campaign? Why did you decide to join it?*
4. *How sustained/consistent was your organisation's involvement in the campaign?*
5. *What resources did your organisation contribute to the campaign? How effectively were they used?*
6. *What made it difficult for your organisation to participate in the campaign? What facilitated your organisation's capacity to participate in the campaign?*
7. *What strategies did you use to minimise the factors that undermined your participation and to maximise factors that facilitated your participation?*
8. *Did your organisation join the NHI Coalition? Why/why not?*

### III. Questions about the actors/organizations involved

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9. *How widespread and consistent was civil society involvement in the campaign?*

10. How did different actors contribute to the campaign? Did different actors have different responsibilities?

#### IV. Questions about the goals, objectives, strategies and targets of the campaign as they evolved during the campaign

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11. Coalition Building: What strategies did the campaign use to mobilize participation, build coalitions, sustain participation, and enhance skills/capacities for activists involved in the campaign?

12. Actions: What strategies did the campaigns use to achieve its demands? e.g.: demonstrations, petitions, lobbying (meeting with politicians, policy influencers), media, social media, education/awareness (e.g. community mobilizing, popular education).

13. Which constituencies/audiences - individuals, organisations, or institutions - did the campaign target? Why did they choose these target audiences and did they change over time?

14. How did changes in the political context affect the goals of the campaign, the strategies it used, and its policy/program influence?

15. How did changes in the internal context affect the goals of the campaign, the strategies it used, and its policy/program influence?

16. What strategies did the Campaign use to assess its successes and shortcomings?

#### V. Questions about the underlying logic, including the longer-term scenarios of social change that informed choice of issue and strategy

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17. What was the implicit or explicit program logic of the campaign?

18. What knowledge was accessed for the campaigning, and how (i.e. through what means such as internet, journals, community members, books, social media, policy reports, other...)?

19. What new knowledge did the campaigning generate, and how was it disseminated (i.e. through what means...)?

#### VI. Questions about the role of the campaign in terms of organisational development

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20. What capacity-building opportunities (to enhance participation, sustain participation, improve campaign impact) were used in the campaign? How effectively did the campaign make use of these opportunities?

21. Did the campaign change how the HFA specific issue was discussed in the media, by politicians and by other CSOs? Did these changes reflect/align with the campaign demands? Have these changes been sustained over time?

#### VII. Questions about global/transnational dimensions of the campaign

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22. Was there a call for international solidarity? (Why/Why not?)

a. If yes, how effective was this relationship? What did it contribute to the campaign and/or the work of the coalition?

23. Was there a link with campaigns outside SA that deal with a similar issues? (Why/Why not?)

b. If yes, how effective was this relationship? What did it contribute to the campaign and/or the work of the coalition?

#### VIII. Closing questions

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24. In your opinion, how effective was the NHI Coalition and Campaign in achieving their goals and objectives? What changed (if anything) in actual policies/programmes to indicate that some of the campaign's demands were being met?
25. What is the main lesson learned with regard to setting up a coalition for campaigning. Would you do anything different next time?
26. Is there anything else you would like to add?
27. Are there any other people or organisations you think we should interview about their involvement in this campaign or the NHI Coalition?

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This section denominates money values in South African currency, ZAR or "R". At today's exchange rate 1USD = 14.36ZAR

ii National Planning Commission, Republic of South Africa, *Human Conditions Diagnostic* (June 2, 2011), 2. Accessed March 29, 2014.

[http://www.npconline.co.za/MediaLib/Downloads/Home/Tabs/Diagnostic/Diagnostic\\_Human\\_conditions.pdf](http://www.npconline.co.za/MediaLib/Downloads/Home/Tabs/Diagnostic/Diagnostic_Human_conditions.pdf); The Presidency, Republic of South Africa, *Development Indicators 2009* (2009), Accessed March 29, 2014. <http://www.thepresidency.gov.za/learning/me/indicators/2009/indicators.pdf>; Congress of South African Trade Unions (COSATU), *A Growth Path towards Full Employment - Policy Perspectives of the Congress of South African Trade Unions, Draft Discussion Document* (2010), 11-12. Accessed March 19, 2014. [www.cosatu.org.za](http://www.cosatu.org.za)

iii The Presidency, *Development Indicators*, 25

iv National Planning Commission, *Human Conditions*, 2

v The Presidency, *Development Indicators*, 21

vi National Planning Commission, *Human Conditions*, 4

vii National Planning Commission, *Human Conditions*, 2

viii The Presidency, *Development Indicators*, 25

ix Pravin Gordhan, *Budget Speech 2010* (February 17, 2010), accessed September 4, 2014. <http://blogs.timeslive.co.za/hartley/2010/02/17/pravin-gordhans-budget-speech-full-text/or> [www.treasury.gov.za/](http://www.treasury.gov.za/); COSATU, *Growth Path*, 12

x COSATU, *Growth Path*, 12

xi Fraser-Hunt, *The South African HIV/AIDS Epidemic*, 143

xii Haroon Borhat, Sumayya Goga, and Carlene Van der Westhuizen. *Welfare shifts in the post-apartheid South Africa: A comprehensive measurement of changes*. (Development Policy Research Unit, University of Cape Town, 2007). Improvements in access to formal housing have been particularly significant. Between 1996 and 2008 the proportion of households living in formal dwellings increased from 64% to 74%. However, during this same period the number of households not living in a formal dwelling declined marginally from 16% to 13%.<sup>1</sup> Moreover, almost half of the population (46%) live in formal dwellings that have 3 rooms or less; 17% of households in formal dwellings stay in one-room brick and mortar structures. See COSATU, *Growth Path*, 17.

xiii Doreen Atkinson, "Taking to the Streets: Has Developmental Local Government Failed in South Africa?" In *State of the Nation: South Africa 2007*, eds. Sakhela Buhlungu, John Daniel, Roger Southall, and Jessica Lutchnan (Pretoria: HRSC Press, 2007), 53-77.; Jacques Pauw, "The Politics of Underdevelopment: Metered to Death – How a Water Experiment Caused Riots

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and a Cholera Epidemic," *International Journal of Health Services* 33, no.4 (2003): 819-830; Marcelle Dawson, "The Cost of Belonging: Exploring Class and Citizenship in Soweto's Water War," *Citizenship Studies* 14, no.4, (2010): 381-394, Patrick Bond and Jackie Dugard, "Water, Human Right and Social Conflict: South African Experiences," *Law, Social Justice & Global Development* 1, (2008): 1-21, accessed March 28, 2014, [http://www2.warwick.ac.uk/fac/soc/law/elj/lgd/2008\\_1/bond\\_dugard/](http://www2.warwick.ac.uk/fac/soc/law/elj/lgd/2008_1/bond_dugard/); Ebrahim Harvey, "Managing the Poor by Remote Control: Johannesburg's Experiments with Prepaid Water Meters," In *The Age of Commodity: Water Privatisation in Southern Africa*, ed. Greg Ruiters and David McDonald (New York: Earthscan, 2005), 120-127; Antina von Schnitzler, "Citizenship Prepaid: Water, Calculability and Techno-Politics in South Africa," *Journal of Southern African Studies* 34, no.4 (2008), 899-917.

xiv COSATU, *Growth Path*, 17. Government provides these citizens with access to "a minimum quantity of 25 litres of potable water per person per day within 200 meters of a household not interrupted for more than seven days in any year and a minimum flow of 10 litres per year for communal water points". The Presidency, *Development Indicators*, 30

xv COSATU, *Growth Path*, 17; The Presidency, *Development Indicators*, 31-33

xvi The Commission argued for bringing health care services "within reach of all sections of the population, according to their need, and without regard to race, colour, means, or station in life". Quoted in Van Rensburg, *History of Health Care*, 75

xvii Mervyn Susser, "A South African Odyssey in Community Health: A Memoir of the Impact of the Teachings of Sidney Kark" in *American Journal of Public Health* 83, no.7 (July 1993): 1040.

xviii This network included organisations such as XX, XX and NAMDA. The latter organisation was formed in response to Steve Bantu Biko's death in detention. The Network embraced the WHO's definition of the right to health as a "state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". They were committed to creating the political, structural and medical conditions that would enable all South Africans to realise the right to health. See The National Progressive Primary Health Care Network, *What is "Progressive Primary Health Care"?* Scanned copy of a National Progressive Primary Health Care Network Pamphlet. Accessed at : <http://www.disa.ukzn.ac.za/webpages/DC/ChAug89.1024.8196.000.027.Aug1989.9/ChAug89.1024.8196.000.027.Aug1989.9.pdf> Date and Author Unknown [11 January 2013]

xix Testimony of Dr. B Kistnasamy on Day 2 of TRC Health Sector Hearings at Cape Town, 18 June 1997. Transcript of hearings available at: <http://www.justice.gov.za/trc/special/health/health02.htm> [10 January 2013]

xx (Habib 2005, 678-9)

xxi Albertyn, Catherine. "Women and the transition to democracy in South Africa." *Acta Juridica* (1994): 39-63. Additional information about women's and feminist organisations that preceded the Women's National Coalition, as well as the organizational practices and political tensions within the Coalition, can be found in the following sources: Fester, Gertrude. "Women's organisations in the Western Cape: vehicles for gender struggle or instruments of subordination?." *Agenda* 13, no. 34 (1997): 45-61. The following articles provide information about the rise and decline of the women's movement in South Africa. The focus is on women's activism in the 1990s (and not always on health activism in particular): Hassim, Shireen. "Voices, hierarchies and spaces: reconfiguring the women's movement in democratic South Africa." *Politikon: South African Journal of Political Studies* 32, no. 2 (2005): 175-193 and Hassim, Shireen. "From presence to power: women's citizenship in a new democracy." *Agenda* 15, no. 40 (1999): 6-17. For an overview of the views aired by civil society organisations during public hearings on proposals to cut the Child Support Grant see Johnson, Krista. "The trade-offs between distributive equity and democratic process: The case of child welfare reform in South Africa." *African Studies Review* 43, no. 03 (2000): 19-38; Jacklyn Cock, "Engendering Gay and Lesbian Rights: The Equality Clause in the South African Constitution," *Women's Studies International Forum* 26.1 (2002): 35-45 (p.37); <http://www.africafiles.org/printableversion.asp?id=3804> [9 February 2015]; Mazibuko Jara, "Gay and Lesbian Rights; Forcing Change in South Africa" in *Southern Africa Report* Vol 13 No 3, May 1998 , Page 31 - "Rights" Contains information about coalition-building; strategies to achieve legal and policy reforms, victories, and further objectives of the organisation. Cock – Engendering Gay and Lesbian Rights (for coalition building politics); Mbali, Mandisa. *South African AIDS activism and global health politics*. Palgrave Macmillan, 2013; Mbali, Mandisa. "Gay AIDS activism in South Africa prior to 1994." *From social silence to social science: Same-sex sexuality, HIV & AIDS and gender in South Africa* (2009): 80-99 and Mbali, Mandisa. "The Treatment Action Campaign and the history of rights-based, patient-driven HIV/AIDS activism in South Africa." *Democratising development: The politics of socio-economic rights in South Africa* (2005): 213-44

- xxii The Constitution states that the Bill of Rights “enshrines the rights of all people in our country” and TAC has emphasised this in its activism. Section 7 of the Constitution of the Republic of South Africa (1996); Interview with Gavin Silber; Jackie Boule and Tenu Avafia, *Treatment Action Campaign Evaluation, 29 June 2005*, pgs.23-24. Available at: [http://tac.org.za/sites/default/files/annual\\_reports/FinalTACEvaluation-AfaviaAndBoule-20050701.pdf](http://tac.org.za/sites/default/files/annual_reports/FinalTACEvaluation-AfaviaAndBoule-20050701.pdf) [2 January 2013]; Steven Friedman and Shauna Mottiar, *A Rewarding Engagement?: The Treatment Action Campaign and the Politics of HIV/AIDS*. A Case Study for the UKZN Project Entitled: Globalisation, Marginalisation and New Social Movements in post-Apartheid South Africa (2004), pg.10. Available at: <http://www.tac.org.za/Documents/AnalysisOfTAC.pdf> [3 January 2013]
- xxiii Mark Heywood, “Debunking ‘Conglomo-talk’: A Case Study of the Amicus Curiae as an Instrument for Advocacy, Investigation and Mobilisation” in *Law, Democracy & Development*, Vol.5, No.2 (2002), pp.133-162; Susan K. Sell, “TRIPS and the Access to Medicines Campaign” in *Wisconsin International Law Journal*, Vol.20, Issue 482 (2001-2002), pp.481-552
- xxiv *Lee v Minister of Correctional Services* (CCT 20/12) [2012] ZACC 30; 2013 (2) BCLR 129 (CC); 2013 (2) SA 144 (CC); 2013 (1) SACR 213 (CC) (11 December 2012)  
<<http://www.saflii.org/za/cases/ZACC/2012/30.htm>> (16 March 2015)
- xxv John Stephens, “What Should the State do Now That It Has Lost the Dudley Lee Case?” <<http://groundup.org.za/content/what-should-state-do-now-it-has-lost-dudley-lee-case>> (12 December 2012) (accessed 16 March 2015).
- xxvi Werksmans Attorneys, “Constitutional Court Victory for Former Inmate has Implications for Healthcare of All South Africans”. <[http://www.werksmans.com/virt\\_media/constitutional-court-victory-for-former-inmate-has-implications-for-healthcare-of-all-south-africans/](http://www.werksmans.com/virt_media/constitutional-court-victory-for-former-inmate-has-implications-for-healthcare-of-all-south-africans/)> (accessed 16 March 2015).
- xxvii SWEAT, *Decriminalisation of Sex Work Fact Sheet*. <http://www.sweat.org.za/campaigns/decriminalisation-of-sex-work-fact-sheet/> [20 February 2015].
- xxviii Jacklyn Cock, “Engendering Gay and Lesbian Rights: The Equality Clause in the South African Constitution,” *Women’s Studies International Forum* 26.1 (2002): 35-45 (p.37)
- xxix Cock, Engendering Gay and Lesbian Rights, p.37-8
- xxx <http://www.africafiles.org/printableversion.asp?id=3804> [9 February 2015]; Mazibuko Jara, “Gay and Lesbian Rights; Forcing Change in South Africa” in *Southern Africa Report* Vol 13 No 3, May 1998 , Page 31 - "Rights" Contains information about coalition-building; strategies to achieve legal and policy reforms; victories; and further objectives of the organisation. Cock – Engendering Gay and Lesbian Rights (for coalition building politics)
- xxxi (Habib 2005, 685)
- xxxii <http://www.r2k.org.za/2016/04/26/stand-against-surveillance-fix-rica-now/>;  
<http://www.r2k.org.za/2015/04/28/publication-big-brother/>
- xxxiii Marianne Merten, The Sinister Securocracy: Mahlobo chills the nation’s spine, 27 April 2016, <http://www.dailymaverick.co.za/article/2016-04-27-the-sinister-securocracy-mahlobo-chills-the-nations-spine/> [29 April 2016]; The Citizen – Editorial, “Scapegoating NGOs an Old Trick”, 28 April 2016, <http://www.citizen.co.za/1092942/scapegoating-ngos-an-old-trick/> [29 April 2016]
- xxxiv Greg Marinovich, *Murder at the Small Koppie: The Real Story of the Marikana Massacre*. Cape Town: Penguin (2016)
- xxxv Examples of such legislative reforms include the proposed Protection of State Information Bill (commonly referred to as the “Secrecy Bill”), the continued enforcement of the apartheid-era National Key Points Act, and the Regulation of Interception of Communications and Provision of Communication-related Information Act (Rica).
- xxxvi Free state workers –illegal gathering
- xxxvii <http://www.r2k.org.za/2014/09/09/r2k-secrecy-report-2014/>
- xxxviii These took place in Khayelitsha, Tygerberg, Langa, Kleinvele, Philip, Mitchells Plein, and Klipfotein.

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| xxxix  | LR reflection on PHM’s contributions to and impact on health activism in South Africa.                                       |
| xl     | KI 1interview  |
| xli    | KI 2interview  |
| xlii   | KI 3interview  |
| xliii  | KI 3 interview   |
| xliv   | KI 3interview  |
| xlv    | KI 4 interview   |
| xlvi   | “Ja” means “yes” in Afrikaans.   |
| xlvii  | Please refer to pgs. 5 & 6 of this document, which discusses the research strategy for the "Campaigns and Advocacy"          |
| xlviii | The most relevant research questions here appear under Research Activity 2.1 - Local Campaign Case Studies on pgs.49 and 50. |
| xlix   | NHI Case Study Write-Up Template, provided by TM via email   |
| l      | NHI Case Study Write-Up Template, provided by TM via email   |
| li     | PHM-SA, <i>Building the Campaign for a People’s Health System</i> , provided by TM via email                                 |