

# THE CONTRIBUTION OF CIVIL SOCIETY ENGAGEMENT TO THE ACHIEVEMENT OF HEALTH FOR ALL (CSE4HFA)

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## Annex 9: Personal narrative of experienced activists

### Introduction

The aim of this project was to document the narratives of long term People's Health Movement health activists, in order to understand in a detailed way the processes, motivations, necessary learning, dilemmas and strategies, impact and achievements of health activism. The rich qualitative data collected in this project is intended to supplement the analysis of the broader project.

### Methodology

Fifteen interviews were completed from January 2016 to October 2017. Eight of the participants were men and seven women. All participants were involved in civil society engagement through the global People's Health Movement and located in different countries across the world (including South Africa, Australia, India, UK, USA, Belgium, Italy, Philippines, Vietnam, Nicaragua and Brazil). This meant the interviews were conducted in a number of locations, by different interviewers and through different modes: both in person, through skype and phone.

A purposive sample was recruited through PHM networks. A narrative guide was developed through email consultation with the PHM Steering Group. A draft was sent out and revisions made in response to comments by four members of the group. The narrative guide contains twenty questions and was sent to all participants before the interview, along with a consent form and information sheet about the project. Participants had the option of writing their answers to the questions on the narrative guide form and emailing it back, or to be interviewed.

Only one participant sent through responses as written notes (as well as participating in an interview) but many used the narrative guide to prepare for the interview. As there were questions on historical events participants found this to be helpful and would refer to their notes during the interview. Due to the semi-structured and open ended nature of the interview questions, interviews ranged in time from one to three hours allowing rich data to be explored.

Interviews were conducted in English, though English was not necessarily the predominant language of all interviewers or interviewees and were recorded and transcribed.

Following the interview phase, a second stage of deeper thematic analysis was undertaken. A coding framework was developed after preliminary analysis of the interview transcripts, in which general themes were drawn out by the research team. The transcripts were coded through the computer software NVivo 11. One transcript was double coded to insure research rigor and analytical

continuity before commencing coding. In concert with data analysis, relevant literature was also collected.

The study received ethics approval by the Senate Research Committee of the University of Western Cape and Flinders University’s Social and Behavioural Research Ethics Committee (SBREC).

Our focus in this annex is on drawing out from the activists’ narratives the implications for the five generic themes at the centre of this research and concluding with suggestions for policy makers and funders.

## Implications for the generic themes

### Movement building

The interviewees had extensive experience in civil society and provided reflections on movement building. One overarching lesson from the narratives were that movements typically have long roots, and new movements tended to build on the achievements and momentum of existing movements. For example, in South Africa, health advocacy was bound up with the history of the “*politics of the country and the liberation struggle*” (Kate). The apartheid system necessitated health activists to establish alternative health structures that would treat non-whites. After the apartheid regime ended, activism adapted to include primary health care advocacy such as recognition of community health workers, which transformed again as the primary health care landscape in the country changed to emphasise political economy of health and the changing nature of non-government organisations (towards being more business-like and less focused on activism).

### Communities worked with

The communities and groups interviewees mentioned working with are listed in the table below:

Communities and groups worked with	
<ul style="list-style-type: none"> <li>○ Aboriginal health workers</li> <li>○ Academic community</li> <li>○ Activists</li> <li>○ Civil Rights movement (US 1960S)</li> <li>○ Community health activists</li> <li>○ Community health centres</li> <li>○ Developing country health activists</li> <li>○ Disability activists</li> <li>○ Feminist health practitioners</li> <li>○ Grassroots community groups</li> <li>○ Indigenous people</li> <li>○ Interdisciplinary public health communities</li> <li>○ International nutrition community</li> <li>○ IPHU students</li> <li>○ Local councils</li> <li>○ Major political parties</li> <li>○ Migrant and refugee communities</li> <li>○ NGO employees/volunteers: eg. OXFAM</li> </ul>	<ul style="list-style-type: none"> <li>○ Occupational health activists</li> <li>○ Peace Corps</li> <li>○ People with disabilities</li> <li>○ People with mental health problems</li> <li>○ Public Health Association (PHA)</li> <li>○ PHA’s PEHSIG (Political Economy of Health Special Interest Group)</li> <li>○ PHM</li> <li>○ Policy writers</li> <li>○ Primary health care staff</li> <li>○ Public health professionals</li> <li>○ Specific populations- migrants, LGBTQIA, women</li> <li>○ Students- medical, health science, allied health, nutrition, social science, political science, law</li> <li>○ Trade unions</li> <li>○ Rural farmers</li> <li>○ WHO</li> <li>○ Women’s groups</li> </ul>

The narratives provided examples of varied pathways to activism, illuminating the potential for movement building by fostering these pathways. Some interviewees began as health care providers or health promoters that exposed them to health inequities and detrimental social determinants of health impacting on people's lives, and became activists alongside their clinical work. For some, activism was a response to oppressive regimes, and for others, activism complemented their more traditional academic work. Several interviewees noted how large People's Health Movement projects including the International People's Health University, WHO Watch, and Global Health Watch allowed recruited activists pathways to continue to grow as activists.

### **Collective action**

Our analysis of movement building was informed by Melucci's theory of collective action, which highlights the dialectic between on one hand having a small elite group of organisers (a vanguard) or on the other, fostering mass mobilisation. Approaches among interviewees were divided. Irene argued that mass mobilisation builds the power of the collective and leads to cultural change:

*"Personally I think it's important to create links to create a critical mass of people to bring about change. Though I do acknowledge that change can happen in many ways ... I don't think the only way is to be politically exposed or active. But I feel that what is missing now is bigger groups of people mobilising, alliances, networks that are able to make an impact, to aggregate power"*

In contrast Nicolas argued while mass mobilisation is important, a small, avant garde group is necessary for sustained action:

*"First of all we had the outbursts around the WTO summits or around the IMF summits where the windows broken and police forces and tear gas and afterwards very little. Look at the Wall Street movement – 99:1- it has fizzled out; it's not dead but it has fizzled out. Look at what the Spring Revolution brought us in the Middle East. We have a military dictatorship in Egypt. ... when the people have had enough the whole thing explodes and you have a semi revolutionary or very active participation of people that is growing, gains visibility in the media and whatever, but at that time you have to find an avant garde which is capable of sort of sitting aside and begin looking at potential"*

### **Lessons on movement building**

Nicolas argued that it was critical for movement building to be proposing an alternative, rather than just denouncing the status quo:

*"This outburst of energy that we see in street protests that are denouncing the things that are wrong in this world have to be followed by an organised preparation of announcing in terms of what alternatives we are going to propose. This is absolutely key for activism."*

This quote highlights the benefits of the different forms of activism noted in the narratives, that ranged from street protests, through to advocacy movements, and global policy advocacy projects such as WHO Watch and Global Health Watch.

Finally, the narratives suggested that passion was central: *"I think that's an important part of activism is you have to keep a passion for what you're doing"* (Kate), suggesting movement building needs to harness and sustain this passion.

## Campaigning and advocacy

### **Linking local, national and global campaigns**

Activists raised crucial issues about how local, national and global campaigns can be linked. The participants voiced concerns that not maintaining links to the local community and grass roots activism would lead to a disconnection with the people who they are supposed to be representing at the national and global levels. As Samy pointed out, remaining connected to the local is about accountability - *“If you don’t have constituency - you’re not accountable to anybody, even ethically”*. If they were not working at the local, the discussion often then turned to how and in what ways were they then able to act as a *“tool for a broader community”* (Irene). Activists believed that they need to balance the tension between acting locally and globally consciously:

*“But that’s a balance that’s not always very easy to maintain, and global work, in itself, can suck people into a long-term commitment which often draws them away from their connection to work at the national and local level”*. (Indra)

Some reported that local action tended to be working with people who had same ideals and values whereas nationally and globally the advocacy was trying to work with people who may have different values and ideas:

*“And I guess for me that’s one of the biggest differences is local communities you’re often working towards a common vision of what you’re wanting whereas working on national policy or global what we’re trying to do is influence people who are often not coming with the same progressive thinking as what we’ve got.”* (Kate)

As the global and local become more connected, Michael and Lila point to the necessity to understand how they interact and argue that it is important for activists to work at both levels.

*“... ill-health and suffering are unnecessary and avoidable but that to change that unfortunately will require not just reforms like improved access to health care, which should be struggled for, but will require much, much more than that. And, unfortunately, in a globalised world that struggle, although focused at the local level, it’s going to have to be global as well and that’s very difficult and it’s going to require great sophistication, an ability to integrate both in one’s own thinking and strategy and in one’s actions, integrate with other sectoral struggles which we don’t do very well in PHM. And most of all to try, which we also don’t do well, to identify and give support to people who are the marginalised and who are in their own way struggling or just accepting what they suffer.”* (Michael)

*“One of the problems has been that when the policies get changed, all the work you’ve done at the grassroots can get neutralised ... So, working on the policies have been more difficult, and the vested interests are very deep rooted, and, you know, from the bureaucracy to the politicians to the big corporations. And, what is happening is that, on many of the policies – like those who are working on food - working at the local, like, National Food Security Act, this is the entitlement that one should get as food ... they say you buy from the market. But, the market food prices are spiralling – so, unless you look at the trade component of it also – so this interconnectedness, of*

*the different policies – the financial policies towards what WHO are doing. What the bilateral and regional trade agreements are doing. But, each looking at these sectoral policies, and working with the grassroots alone is not enough.” (Lila)*

Long-term activists were well aware that newer activists needed some guidance to be able to appreciate the links:

*“Now, what we keep telling our young activists is that this is not the real world. Geneva is very, very isolated from the real world in a sense, so don’t get lost here – we are here to do something, but unless we can add that to what we are doing where we live and work, this is all flop. So, we understand the importance of working at the global level, especially in a context when many policies are unfortunately being decided at global centres of power. So, it’s important to do that, but that has to be tempered, with the necessity to continuously link this work with what’s happening in our situations.” (Indra)*

### **PHM is not an NGO**

PHM was clearly positioned as a movement by the activists which was often contrasted with NGOs. The difference between the two was clearly portrayed.

*“I mean at the moment if we look at civil society in (name of country) there’s a lot of what (name of fellow activist) calls ‘BONGOs’ which are ‘brief case only NGOs’ and basically where you can feel quite out of sorts because people are working for NGOs that have got no activist background whatsoever. It’s not on their mind, they are there because they can get an extremely good salary.” (Kate)*

For this activist passion was a key element of a movement and contrast with people who were seen to be involved in campaigns because it was part of their job:

*“There’s a lot of people working in civil society as real NGOs doing clinical type work that should really be done by government but with the lack of government they’re doing it. So it’s a job rather than a passion.... we’ll have an International People’s Health University or when we had the People’s Health Assembly and you invite people and you realise what you’ve got is completely unpoliticised people and probably what they’re more interested in is will this course help me get another job, is this a platform onto another job.” (Kate)*

### **Minimal resources for campaigning**

Campaign strategies can be shaped by the availability of resources which are nearly always in very short supply:

*“We end up doing almost everything, to putting up chairs in a meeting, to writing policy briefs to try to secure money.” (Indra)*

This also relates to the observation that much campaign activities are not glamorous:

*“a lot of organising is actually mundane, day to day stuff, it is not glamorous. It is not about an ideolog putting down her or his ideas on paper, and everybody starts following. A lot of it is really nitty, gritty, hard work at the lowest levels, including, as I said, arranging chairs, making sure that the room has been booked, that the trains is all scheduled, and stuff like that... The devil lies in the detail. Activism is not glamorous. If you’re looking for glamour, join a corporate bank.” (Indra)*

Others noted that activists have to be prepared to do the “boring stuff like photocopying”. Another constant campaign issue was how successful PHM had been at involving young people.

*"I would say that we failed at being able to harness the interest of young people for a long time and now we're getting more involved. And I think that the more we can get young people into positions of leadership the more that we'll be able to change because young will influence young."* (Kate)

### **Value of linking with other organisations**

Campaigns are important to mobilising movement. One activist was clear that she had considered stepping down from PHM-Europe at one point because it did not have a focus on European issues. She described how this had changed when PHM-Europe became involved with the European network Against the Commercialisation for Health. This example shows the importance of PHM linking with other networks and campaigns to increase both effectiveness and critical mass. These developments have seen PHM-Europe move from doing very little campaigning to spearheading PHM's action on World Health Day against the commercialisation of health and relabelling the day People's Health day.

Campaigns can easily become diluted without solidarity between organisations and networks:

*"So you create the space and then the trade union does it's own and a small political party does its own, the other association does its own, so it's very fragmented."* (Irene)

There is a strong dialectic between campaigns which deal with specific issues (often cited was the campaign for affordable drugs which had introduced many of the activists to health activism) and working on the structural underpinnings of the single issues (e.g. neo-liberalism, colonialism). PHM's niche was seen to particularly be attention to campaigning on these structural issues. Yet even those totally committed to this approach found the sheer magnitude of such campaigns could be overwhelming:

*"Sometimes I feel like these huge structural processes- one side of me questions this, then the other side says come one, you still have to try."* (Irene)

Central to the frustration of campaigning on structural issues against very powerful forces was the issue of power which was never far from the surface in the interviews.

*"The way we are today, the concentration of power and economic power is continuing even 40 years after I started fighting against it but when we go when we think we have gone forward and made a small victory the other side is making two victories; we have to basically keep up in this rat race I mean we think that we organise and we have our meetings and we have our plans but on the other side they also have and they have the money and they therefore have one above us always so it's frustrating."* (Nicolas)

### **Reactive campaigns versus proactive**

A common theme was that the political economy in the world is very hostile and becoming more hostile to health. This means that campaigns are very often reactive and opposing new developments and so gives little scope to be proactive about what developments would be desirable Elaine discusses an example of reactionary activism. In this instance the government was moving towards privatisation of public assets and threatening to cut health and social services. It highlights how much energy and time reactionary activities consume, so that proactive activities get squeezed out of the agenda. She describes how a network of public health organisations opposed watering down and privatisation of a public health insurance scheme:

*“Also, you know, opposing the privatisation, commercialisation of health services and privatisation of essential social determinants of health services like electricity, water and so on. We can see at the moment with energy what a state the privatisation of electricity was and how much it has - energy has become a social determinant of health and really affects people’s health. I think those are the main - and defending Medicare...we lost all the federal government funding to the association, because we ran such a successful campaign I think. I think it was a mark of our success. That was a really important policy, to get universal, publicly funded health care for Australia and that was a good campaign but what you realise over the years is it’s just a constant battle to maintain that.”*

Many of the activists echo the reality that their battle was constant and that they felt they were running just to keep still. Activists keep going because of their sense of commitment and the solidarity they gain from working with others. All agreed with the sentiment expressed by one that while conducting reactive campaigns *“At the same time, one should still have and fight for a much more radical vision.”* (Michael)

Similar tensions were evident between working to improve curative service and working to improve underlying determinants of health. Nearly all the activists described the ways in which they combined both. Those who are clinicians described how they used their clinical experience as a launch pad for campaigns. For example one described how a food relief effort in an African country was implemented alongside a program to provide longer term food security and *“selected the foods on the basis of what people said that they wanted to grow, what we knew were nutritious foods and would comprise a child-friendly nutritious diet.”* (Michael)

## Capacity building

### **Formal learning pathways to activism**

While this study was not investigating particular training programs in depth, the participants commented on formal and informal capacity building opportunities that they were involved with. The following example illustrates how capacity building in activist organisations goes beyond developing individual knowledge and skills. Recruitment, local context, follow up and interpersonal relationships were all important elements in formal learning programs.

From her experience with IPHU in South Africa, Kate commented on the program’s ability to invest in young people’s learning. She also argued a greater focus is needed on recruiting and developing the skills of local people and improving support post training. Kate said:

*“I think then there’s the reality of the situation is that you come from X organisation and your mandate is to do XYZ and suddenly you get told but hey you can do a whole lot more than that and this is how you should be influencing policy and these are issues around the politics of health and globalisation and access to medicines. Only a fraction of that is going to be relevant to you and your organisation. And I’ve had people contacting me and saying well I’ve attended this fantastic IPHU, I’m all inspired and now what! So how do we harness people ... we’ve got to find ways of being able to bring more people’s voices in.”*

### **Individual capacity**

The individual capacities of this group of activists developed through participation in the processes of activism as well as through their professional training and workplaces. Ivan described how his training as a medical doctor led him into engaging with working class communities and activism:

*“After graduation I went to work as a GP, a general practitioner, in a workers’ community, and that was a – I was working there in a medical centre off some progressive organisation, group of progressive doctors. It’s called Doctors for the People, and they were working in this – they set up some medical centres in workers’ neighbourhoods. So, for me, that was my first encounter with trade union activism, with local activism, with the community activists, and so this is how I got involved in what we can call health activism.”*

Health and medical training opened up individual pathways to activism not often available to activists not working in the medical domain. The medical fields hold power due to the dominance of biomedical approaches to health, and thus many of the long term health activists discussed using their positions to create change from within systems as well as outside of them.

### **Organisational culture**

In the early 1990’s Kate worked for a community health organisation where *“a pre-requisite to employment was that you had to have an activist background, not necessarily health activism”*. The organisation had a strong political orientation in which they *“perceived that there was a lot of skills that you gained as an activist that would help you with working in communities”*. In this case the organisation was not so much concerned with building numbers, but rather developing the capacity of individual workers who were providing health care services and creating an organisational culture of solidarity within the organisation and with marginalised community members. As Kate explained *“we were training the community health workers, we were supporting them but we were also supporting programs of action to improve the conditions within which the community lived and to lobby for better services”*.

The activists’ narratives pointed to *reflexivity* as a tool for capacity building. Reflexivity was described by many of the participants as an essential skill for activism, as it helps to manage tensions which arise in the self and the group, build relationships and support continual learning. Rohit described how reflexive practice guides his activism and his approach to mentoring younger activists:

*“But as you do in life, and try to change the world around you, please remember you have to change the world inside you... And every activist and everybody who comes here knows that you’ve got an inside learning and an outside learning. So when you go and even an activist will do something, it works, it doesn’t work, doesn’t matter. We have to understand why it worked, why it didn’t work. But you sit back and reflect: have you learned something about yourself?”*

*“I think community is very important: bringing together, building good relationships, learning from each other ... so even our whole learning program here, we call it a community of learning. This is a learning program in which 20 of you will go through it one year experience. Three times 20 of you will go to three - 20 different communities in India. You will come back, and each time we will analyse the experience of 20 of you from 20 communities. So the whole learning becomes collectivised.”*

Irene discussed why reflexive practice has been important to building her individual capacity, stating *“It helps you to adjust because in this activism you need to adjust a lot, you need to ... it’s a high*



*relational activity.*” She emphasised the importance of creating spaces within civil society groups which strengthen interpersonal relationships, solidarity, reflection and learning. Irene argued this can lead to accepting and accommodating peoples’ differences and strengths, and building a greater diversity of skills.

*“So if you put me in a conference hall, I am perfectly at ease. If you put me in a ballroom and you ask me to dance, I may not be, and some other people will. So if you change completely as a setting the strengths of other people can appear, be manifest. And that’s what we did in the group process. We started introducing different methodologies and different moments in which we were either staying by ourselves, in which we are using arts, and that helped me to be exposed in areas of myself that are weaker, that I perceive as weaker because I’m not very confident, not very good in drawing. Nevertheless, exposing my weakness allowed other people to reposition me. So Irene is not only the one who has always the nicest thing to say in the best way, and we all feel speechless because she said everything. Instead, all of a sudden, Irene is the one who made a very stupid drawing and we can laugh on it, or we have this moment to share. This for me was liberating in one sense because I could step out of that fixed role, and put a lot of dynamic in the group. And it was also liberating because I always felt, or often felt the idea of leading, even if you aren’t in a position of leading, but the point is that if you change setting, then you’re not forced in that thing anymore. It was much more organic to the group development.”*

These examples demonstrate how important organisational culture is to sustaining the capacity of civil society groups. Reflexivity and openness to learning about the self and others are key tools for developing an organisational culture which nurtures capacity building.

#### **Individual capacity and advice for managing dilemmas:**

Throughout their activist careers the participants’ individual capacity was challenged by personal, professional and political dilemmas. The activists discussed strategies for managing the pressures of activism. Sharing these strategies is important for building personal and interpersonal skills and contributing to the collective knowledge.

Many of the activists offered advice on the importance of self-care and in engaging in healthy activities, balancing personal and activist responsibilities and looking after your mental health.

*“Be strategic. Think twice. Don’t sacrifice yourself at no cost. This is very important. Have a balance of your personal life and your activism. Make time, as much as possible, for people you love.”* (Samy)

*“So, one is physical exercise, which I enjoy, so, I run and exercise and I try and do it every day, as much as I can, it’s really important. And then the rest is, yeah, just paying enough attention to friends, family, the normal stuff... wellbeing and the new fad is mindfulness. But just making sure you sleep enough and – all the things that we know as doctors and public health about what the ingredients of mental health are, and just paying attention to that. Burn out, yeah. I think time management is part of it.”* (Sean)

*“I get support from professionals, which is good in terms of mental health, but also just being more careful about how much you load up and don’t load up.”* (Elaine)

*“So you must give time on to that’s another thing which we have done is always find a little time for quiet reflection, for a little holiday. And not to feel guilty. But that’s I find a problem with*

*activists. You start feeling guilty about the nice things of life. The comfortable things of life. But, you see, they're all human beings, and you need some time to recover. After all, even a mobile needs a few - ours have been put into a little plug and get charged. And it's safer not to be using the mobile while you're charging it, because you could get a shock also, they say ... So I think that's a very important strategy is to have - to know that you batter needs charging."* (Rohit)

Some spoke of the support of comrades as a key component of managing personal dilemmas and sustaining their motivation for activism.

*"To always be with like-minded people, so to always get back to friends, to always have people around to get re-inspired. On many occasions you get broken for some reason or another, especially when it's not only health activism, when it's political activism (or both together). The best I found, at least the strategy I followed, is to always jump back to my comrades and get immediately with them, and listen to other stories and get inspired. But also another strategy - and I did it on some occasions - is to get away for a while when it's too hard. So I practice both these strategies: to take a break sometimes (but never been long), but mostly to get with people."* (Michael)

Sean emphasised the importance of appreciating the processes of activism rather than becoming too absorbed with results, which may lead to disappointment.

*"... recognising that it's not, what's important is not winning. But it's that whole thing of participating or engaging, regardless of the outcome and it's the doing that counts, not the outcome. Because I think if you're fixation with winning or - you know fixated too much on the outcome - obviously outcomes are really important but if you're over fixated on that, you end up doing things that may not necessarily be the right thing to have done, or you end up pushing too hard or trying too hard or again, being disappointed. So you've got to kind of think about the process and think about the enjoyment of the process; that's really important, enjoying what you do."*

## Knowledge generation, storage, dissemination and access

The health activists' in this study collected, generated and deployed knowledge in numerous ways to challenge hegemonic discourses of health and society which they understood as creating and sustaining health inequities. Following Carroll's (2015) framework discussed in the main report, we look at some of the ways in which the activists deployed counter-hegemonic knowledge practices.

### **Accessing scientific, technical, institutional, legal information to strengthen movement strategy and policy dialogue**

One of the main avenues that this group of activists challenged hegemonic knowledge was through examining, researching, synthesising and deploying technical, scientific and legal information. This occurred through advocacy work, writing policy proposals, interacting with government and community organisations, academic research and writing, and speaking at conferences and meetings in local and global spaces.

Over his activist career Indra has participated in many knowledge generating activities to disrupt and challenge inequitable systems, including through the People's Science Movement in India. In 1984 a Union Carbide gas leak caused the death of thousands of people. Emboldened by this incident Indra said the group focused on researching and educating through science, *"not just in the context of its potential as a liberator, but also its context of how it's misused under Capitalism, and the kind of social control that you require over science"*. Questioning how scientific knowledge was being misused and silenced by the Indian government and big industries became central to the groups activism in developing counter-hegemonic knowledges. The People's Science Movement employed this strategy across many issues including access to medicines and the pharmaceutical industry, and a health literacy program which educated and mobilised people around issues of health care, water, sanitation and nutrition.

A number of the participants in this study fall into the category of "academic activists". While recognising their positions within the dominant system as potentially reproducing hegemonic power dynamics (such as only producing texts in the English language), they viewed themselves as a tool for activism in which their positions afforded them the agency and power to elevate the voices of marginalised community members and disseminate knowledges from their lived experiences. They often used their social capital and technical skills for creating policy dialogues with people in positions of power and advocating for progressive policies. As an internationally recognised academic Elaine explained:

*"the other role that I think I do play is sort of linking community based movements to some of the global movements, like the work we've done with (name of organisation). You know, how do you bring the work that a local community does to a broader international audience?"*

### **Demystifying hegemonic 'truths', like 'there is no alternative', in order to nurture agency and engagement**

Michael discussed several activities he was involved with that were aimed at countering hegemonic 'truths' and providing alternative sources of knowledge. While living in the UK in the late 1970's Michael was part of an alternative media production group who wrote a bulletin documenting atrocities occurring in Southern Africa, including infringements on human rights, which were not being published in British Media. In his academic capacity Michael was also involved in setting up a number of foundational university and informal courses on public health and the political economy of health, engaging health professionals and others and equipping them with political and practical tools for health activism.

Sean spoke of encouraging health professionals to become activists and thus challenge the hegemony of the medical systems they work within. He stated:

*"I think as a doctor, or when you're trained as a clinician, and you become a kind of social activist or a public health type activist, you tend to get brought up in a culture that predominantly conservative. And so I've always been interested to know how, in particular, medical students or medical professionals end up resisting the kind of dominant hierarchical authoritarian conservative culture of medicine and – pursue a path that is much more kind of socially progressive ... I've essentially deliberately chosen, over the last 5 years, to work with professionals, working in health, to try and find ways to harness their voice, their mandate, and their social power to be a bit more effective."*

These examples demonstrate how providing alternative knowledges to the mainstream hegemonic truths can nurture engagement with health activism and the agency of individuals.

## **Empowerment of the dispossessed through bringing lived experience into discourse and reshaping world views**

Emma drew on her many years of experience working as doctor in disadvantaged communities delivering health services, training and popular education programs. She stated:

*"I think always learn from the masses because they will always tell you what their needs are ... you have the knowledge and the skills, but they should be the ones who really work, you work with them but not you work for them. You work with them because they should be part of this development work, it's not you alone, and you have to listen to them. I think that's the learning there, to listen to the people and learning, analyse with them what is happening; and together you can come up with a course of action that will really lead towards a positive development because you're with them."*

The emphasis here is on the value of experiential knowledge, and how together the health worker/activist and community members build knowledge and decide on actions.

*"When I started out working in communities that was in 1981, I was fresh graduate of medicine, I was with a community there on a program run by the Catholic Diocese, and they put me along the River, seven towns who have not seen a doctor for years. So I was there attending to them and they were very happy and I learned the language ... Then I learned more about the community situation because I also had exposure, I cared for them, lived with them; I stayed with peasant farmers, with a family of farmers, living with them for two weeks learning how to plant, or to show the way they work; and workers, because they were in the urban area, I would go visit, live with them, I did occupational health with them. So it was studying the issues together with the people." (Emma)*

The activists point to the many ways that health activism can empower disadvantaged people through sharing knowledge and reshaping their world views. This approach can also bring their lived experience into mainstream discourse to reshape the world views of the mainstream conscious and those in positions of power.

In the 1970s Angela worked in a coastal village in Central America delivering a community-based health program, training community leaders as part of a joint project with a government department and an NGO. Angela used her position in the community to empower local leaders with legal knowledge that was being withheld from them by their government. In this example Angela highlights the value of assisting marginalised people to understand their situations through sharing knowledge, and also how knowledge is tied to power relations which in this instance eventuated in her having to leave the country.

*"We taught the people the constitution of (name of country), but it was written in mestizo and so it was a subversive document. That was my crime, teaching the people the constitution. My crime was having subversive literature... We taught the constitution to local people who are the Justice Department in a little village. They don't have judges and things like that, but they helped to solve the problem locally, and these are isolated villages up and down the river, no highways and nothing like that. The river is the only way of communicating."*

Angela discussed how through employing popular education techniques and engaging in Paulo Freire's (1968) theories of 'conscientization', she learnt how to engage with local people to develop their political consciousness; making them aware of the social and political contradictions of their

social worlds, initiating a desire to take action against the oppressive elements impacting their lives. Angela explains:

*"I learned interactive educational techniques while I was working with migrant workers, because I couldn't use a lot of paper with them - they were basically Spanish-speaking people with very little knowledge of English - and so we would have to have (I suppose you would call them) focus groups. We'd have discussions with people and help them learn where they could go on the stream that I mentioned, where they could get help ... in (name of country) it became dramatically visible to people, the injustice. But when I was first in (name of country) while I was still working for the peace corps, and I was really interested in the way they were working, their methodologies, and when I went to work there one of the priests gave me Paulo Freire's book and he said 'here's the theoretical basis; here's what you've got to get in your head, because you can't stand up there and give a lecture, you have to know where people are coming from', and that's why this whole decoding process is so important."*

*"Some people are not so political and so we have to build a consciousness around those things that we're working on. But when people are repressed, because they're defending their water source or trying to stop a mine or a road from being built to get to the mine or whatever, all those kind of things ... People get it, even if they're not political. They get that something is wrong with the system and it's destroying their lives. So what we're trying to do now is build it on those things locally and share the experiences across our country."*

Angela also recognised that *conscientization* can be problematic. While knowledge can be empowering, it can also cause disillusionment and a sense of disempowerment by the system.

*"One of the saddest experiences was when I was doing a whole series of sessions of conscientization with these farmers that lived in this feudal society on the plantations, and one of them came to the conclusion that there was no way that, as long as they were living in that situation, that they would be free, that something had to change. And so when that moment comes you have to be very careful because that person may decide to do something that means they will lose their life for doing it. That's why, when we were doing conscientization there were people who were saying 'you are causing people to join the gorilla forces, and so that's subversion because you know that they're going to go out and fight and that they will probably be killed', so am I responsible as a person because somebody decides, after a session that they've been in with me, that they want to now join the armed struggle? That's pretty heavy duty, so you have to be careful about how you deal with it. You can't say 'what you need to do is show him the companeros'. They have to make that decision themselves."*

More recently, Angela discussed the People's Health Movement in Latin America and their decision to incorporate the cosmivision philosophy of native people into their structure. This is an example of valuing experiential knowledges that are alternate to the mainstream and incorporating them into discourse to construct new ways of viewing and experiencing the world.

*"The People's Health Movement in Latin America has made some pretty important decisions. We have taken the philosophy of the cosmivision of native peoples to be the driving force for the People's Health Movement in Latin America and that's the whole concept of buen vivir. Right now we've been working on a paper that we're sharing now in the month of July as part of an investigation that's going on about buen vivir and how to help people understand, who are not from indigenous communities, what this really means."*

*The indigenous communities and some very forward-looking academics in Ecuador, understand that we are in a crisis of civilisation and the model is not working and so what model can work. The concept of buen vivir provides us with a model that is not exploitive of our planet, that recognises that we have to take care of water and we have to source this water”*

### **Knowledge dissemination and access**

In the narratives the activists shared their concerns for new forms of communication and collective action. There was some debate over whether social media and online activities such as “clicktivism” were a hindrance to activism or whether they represented another mode of communication. The merits of social media were viewed differently and largely this reflected a generational difference. On the one hand concerns centred on whether social media has eroded collective action practices in activism, and that the power of people coming together in person, learning from each other and organising activities has deteriorated. One activist stated:

“Activism is all around changing something, and what is it you're trying to change and do it in person don't do it on Facebook or through WhatsApp or social media of some sort. That can complement what you're doing but it can't be the core of what you're doing. Just do, get up and do. It's be passionate about things... and I also still think social media has got something to do with it because it takes away people's ability to verbalise and vocalise and speak out and go and say it.”

While Ivan presented a quite different perspective while commenting on the role of social media in campaigning:

“So it plays a very important role. Many older activists were distributing leaflets in the street when they were younger activists, and the equivalent today is tweets on Twitter...”

I think that's what we as older activists have to understand. It's just communication. So I think it's extremely important. It has a very important role to play whereas, yeah, it was leaflets and flyers, print, newspapers before. Today it's social media. Tomorrow it will be something else but it's just communication, and communication is central to activism. Without communication, there is no activism. Yeah, so that's why I think it's extremely important, but unfortunately it develops so fast that for some of us activists it's hard to understand how important it is and how it develops...

... it's just another tool, and it doesn't change the way activism works. It's just another medium. It's just another way of communicating.”

### **Reflection on how health discourse has changed over time**

A benefit of examining the narratives of long term health activists is being able to comprehend how discourse has impacted on the social world and how dominant knowledges have changed or prevailed. For example, Nicolas discussed how the concepts *health equity*, *social determinants of health*, and *health for all* have entered the mainstream consciousness, and the role evidence gathering and knowledge dissemination has played.

*“I think that what most of us, the senior activists in the Primary Health, in the People's Health Movement, we are already advocating from our empirical knowledge 25 or 30 or more years ago is now becoming more and more mainstream, based on what is called gathering evidence-based*

*information and data. So the realities have changed in a way that we have information now that validates what we ideologically were already saying, not only empirically, there was research about it 25 to 30 years ago and that has signified the switch. We are not outcast activists with a hot head anymore. Some of the things we were saying and we were rejected 25-30 years ago because we were hot headed activists are now mainstream.”*

## Policy dialogue and governance

### Policy dialogue engaged in

Interviewees recounted many instances of engaging in policy dialogue as a key activism strategy. The areas in which interviewees had engaged in policy dialogue are listed in the table below:

Policy issues	
<p>Health care:</p> <ul style="list-style-type: none"> <li>○ Access to medicines</li> <li>○ Broadening biomedical model of health within institutions</li> <li>○ Children’s health</li> <li>○ Community healthcare</li> <li>○ Health governance</li> <li>○ Healthcare access for all</li> <li>○ Healthcare budgets</li> <li>○ Healthcare for specific groups: migrants, guerrilla groups</li> <li>○ Indigenous people’s health and social support</li> <li>○ Medical aid/relief</li> <li>○ Mental Health policy</li> <li>○ NHS (UK)</li> <li>○ Primary healthcare</li> <li>○ Privatisation of healthcare</li> <li>○ Public health insurance</li> <li>○ Public health promotion</li> <li>○ Refugee health</li> <li>○ Rural healthcare</li> <li>○ Women’s health/safety</li> <li>○ World Health Assembly</li> </ul>	<p>Social and environmental determinants:</p> <ul style="list-style-type: none"> <li>○ Childcare</li> <li>○ Deforestation</li> <li>○ Environmental health</li> <li>○ Nutrition/child malnutrition</li> <li>○ Occupational health</li> <li>○ Water and sanitation</li> </ul> <p>Commercial determinants of health:</p> <ul style="list-style-type: none"> <li>○ Food industry (e.g. GM foods)</li> <li>○ Anti-tobacco campaigns</li> <li>○ Intellectual property rights</li> <li>○ Palm oil plantations (Indonesia)</li> <li>○ Pharmaceutical companies/producing harmful drugs</li> <li>○ Trade agreements</li> <li>○ Trans National Corporations</li> </ul> <p>Political and economic determinants:</p> <ul style="list-style-type: none"> <li>○ Anti-regime work or support for political parties</li> <li>○ Economics of public health/ political economy of health</li> <li>○ Labor rights/informal/unpaid work</li> <li>○ Land rights</li> <li>○ Millennium Development Goals</li> <li>○ Nuclear Weapons</li> <li>○ Population control</li> <li>○ Reproductive rights/bodily autonomy</li> <li>○ Sustainable Development Goals</li> </ul>

### Challenging vested interests

In many cases, policy dialogue involves challenging vested interests, including commercial interests. Sami reflected: *“You’re challenging interests. And don’t be naïve to think that sitting on the same table with a pharmaceutical company is going to lead to a fair game. They are more powerful than you and me.”* There were in some cases extreme costs and risks associated with policy dialogue

activism, ranging from activists who had been assassinated, injured, arrested, or exiled by oppressive regimes, through to NGOs losing government funding for advocacy.

As noted earlier, a variety of forms of activism were present in the narratives. Policy dialogue was seen to complement other forms of activism such as work with communities. There was a risk evident of people seeing community work as more 'authentic' activism than engaging in policy dialogue, that community work was "*rooted in a context that is real, that is made of people*" (Irene). Indra stressed how activism includes activists from academia who engage in policy dialogue:

*"There is a tendency to create this distinction between, so and so is an academic, so and so is an activist, and both may hold the same political position, may aspire to the same thing, but one is an academic by virtue of the day job that you're doing. And one is an activist by virtue of not doing that day job ... some of them are very good friends ... who are in academia, who I think are activists. And so, I think their primary recognition is as an activist and not as an academic."*

Interviewees also noted the value of policy dialogue in being able to pursue the radical vision Michael talked to in the Campaigning and Advocacy section, and address underlying structures and causes that community work could not.

### **Making policy dialogues accountable to communities**

Interviewees voiced concerns that not maintaining links to the local community and grass roots activism would lead to a disconnection with the people who they are supposed to be representing at the national and global levels in policy dialogue. As mentioned in the Campaigning and Advocacy section, remaining connected to local communities was about accountability. If they were not working at the local community level, the discussion often then turned to how and in what ways were they then able to act on behalf of communities in policy dialogues.

### **Making power evident**

One important lesson Rohit shared was that structural power relationships and inequities that are evident in community work risk being hidden in policy dialogue work, and thus policy dialogue work requires vigilance and reflection to guard against reinforcing these power inequities:

*"So you have class, caste, patriarchy, social exclusion. At the community level, it's stark and you can see. But it's not as if it doesn't exist at the district level or at a national level because, in a way, our political systems, our social systems just - what do you call - replicate themselves at different levels... It's more subtle at the other levels, you know, like racism or even things like elitism because people are more educated."*

Moreover, in order to create a policy dialogue and influence policy, activists often work with government bodies and thus have to balance competing interests:

*"so work at the local level, as well as at state levels, or provincial levels, as well as the national levels, with the government, against the government. In India, we straddle both, so there are occasions when these – so for example, the Literacy program was really working with the government. Even in the health sector, we do work with the government. Many of us, including me, are part of government task forces. But at the same time, We retain our independence, and I'm often very, very critical of the government on many issues."* (Indra)



### **WHO Watch and Global Health Watch**

WHO Watch, a program of sending activists to report on and advocate on the World Health Organization, and Global Health Watch, a public health book now in its fifth edition, were noted by some interviews as good examples of global work that was important for civil society to engage in. Interviewees were positive about the success of these strategies – that WHO Watch had gone from struggling to engage young activists to receiving more applications than they could include, and that the Global Health Watch publication had “a position now which is established in the activist/academic community of Public Health” as a “useful publication”. Another interviewee noted that “a lot of people give us very positive feedback about it.” Working on the Global Health Watch was also cited by a number of interviewees as an entry point into further Peoples Health Movement activism.

## **Suggestions for policy makers and funders**

### **Funding for core infrastructure costs**

A number of activists highlighted the problem that increasingly funding is only available to cover costs of projects but not basic infrastructures costs for a network like PHM which does not have a membership structure to produce annual fees. We’d suggest that consideration be given to funding infrastructure for global networks such as PHM which operate more as a network of networks than as a membership organisation. One activist argued the case thus:

*“If you can get a society that’s prepared to resource people to argue the public good then that really helps and if you haven’t then it becomes very difficult. PHM, from about after 2000 through ‘til probably the global financial crisis, we did have organisations, particularly in Europe, who would fund and we could have quite a strong secretariat but that’s been whittled away now and it’s much, much harder. You really do need a sort of society that’s prepared to pay for an international movement because either someone has to give their time or someone has to pay for time. You can do so much on volunteer effort but at some point you do need societal support for the movement.” (Elaine)*

Furthermore, as described in the discussion on global local relations, the world has become more globalised and local issues are intrinsically linked with global issues. Therefore, there is increased need for policy makers and funders to support international activities and organisations such as PHM whose work is centred on advocacy and analysis. Funding must be considered for activities beyond projects and services.

### **Universities and Academic Freedom**

Many of the activists in PHM combine their activism with an academic career. They have been fortunate to work in Universities that respect the tenets of academic freedom and this means that they do not have to be fearful of repercussions for their activism. One activist put it thus:

*“I’ve been able to manage both careers in academic and been a very – what’s the word? Overt and open activist. Political activist, and I’ve been able to continue to be successful in an academic career whilst continuing a track of activism and hopefully I’ve helped to make activism respectable and something that you shouldn’t be fearful of. Consequently, trying to encourage people to not be worried about the impacts of being socially and politically active on their careers.”*

*That it is possible to manage both things, although there is a risk, and that you have to be prepared to take a risk at the same time.” (Sean)*

For some activists, however, taking on political issues with institutions such as Universities and health departments had become more difficult:

*“... and if you seek to address a personal agenda, an agenda which arises from your own political commitments, and it runs counter to the agenda of the structures in which you’re working you’ll get very quickly penalised and crushed.” (Peter)*

Thus academic freedom may be compromised and University staff may be persecuted for their activity as happened recently in relation to Turkish academics. We suggest that Universities need to protect and maintain the importance of academic freedom so that their staff are able to engage freely in civil society activity including in the part of their jobs, which are allocated to community service.

### **Health is political and this should not scare funders**

Funders and policy makers are frequently reluctant to support more progressive groups because they are seen as overly political. Our narratives indicate that health is inevitably political and many of their stories reinforced this point. To give one example:

*“I remember being invited to South Africa in the 1990s, such an exciting period, you know, Apartheid had fallen, they were full of enthusiasm for - you know, had new primary health care policies, but over the years having watched how that promise hasn’t been entirely fulfilled and realising how intimately health policy is tied up with politics, you know, it’s completely about politics. Just looking at the US now under Trump and the threats to the very modest Obamacare, you can just see what a fiercely fought political issue health is because of the potential for commercialisation.” (Elaine)*

Consequently, funders should be prepared to fund groups who are explicit about the political underpinning of their advocacy. They should also be prepared to fund advocates who are not working on a specific health issue but who are looking at the structure factors that lay beneath the surface yet drive many situations of poor health and health inequities. As one said

*“Well, we have lots of problems these days because there’s no money for our work. My organisation has a financial crisis, but so does almost every other organisation because of neo-liberal policies and people don’t want to give money to troublemakers, right? So it’s very hard to get support...” (Angela)*