

Challenging injustice: giving voice to people's right to health



Summary report of an evaluation of the People's Health Movement November 2004

Introduction

This summary report is one output from a three-year participatory evaluation exercise¹ that has helped to engage the PHM leadership in an analytical learning process based on ongoing experience. The evaluation has looked into the preparation of the PHA, the Assembly itself, and follow-up activities. Led by Exchange – a networking and learning programme on health communication – it has assessed the current status of PHM activities, explored ways to reinforce and enhance current accomplishments, and examined approaches to strengthen and sustain monitoring mechanisms. The full evaluation report - **Keeping the promise: The people's response to health for all** – is available on the PHM website: www.phmovement.org. This summary was written by Andrew Chetley and Cecilia Muxi, members of the international evaluation team.

¹ The evaluation process has used a combination of techniques and tools and a variety of sources and informants to ensure a reflective process that enabled the diversity of the PHA participants and their goals to be expressed. Structured, semi-structured and open-ended interview techniques as well as regional and international focus group sessions and reflection workshops were held to elicit feedback from participants, organising group members, media, and other interested stakeholders. Participant observation during PHM organising group planning meetings between 2001 and 2003 has also informed the process. As an additional process, in May 2003, members of the International People's Health Council (IPHC) – one of the original partners in the PHA process – agreed a complementary evaluation process of their own activities that has provided insight into the relationship between IPHC and PHM. Between May 2003 and November 2004, work has continued on organising, systematising, reviewing and digesting the information from all these sources to enable it to be presented concisely.

From PHA to PHM

A global People's Health Movement (PHM) began to emerge in December 2000, when nearly 1500 people from over 90 countries met for five days in Savar, Bangladesh to re-establish health and equitable development as top priorities in local, national and international policy-making. In the intervening four years from this initial People's Health Assembly (PHA), the movement has stumbled, struggled, and become stronger, and today is having an increasing impact on health policy and practice.

An indicator of the impact that PHM is now having comes from its interaction with the World Health Organisation. In December 2000, despite being invited at the highest level to attend the PHA, no one was officially representing the WHO. In January 2004, several representatives from the WHO attended the PHM activities around the World Social Forum in Mumbai, India and were requested by the Director-General's Office to explore closer engagement with the PHM.

Strong and ongoing activities have been taking place in Asia (particularly South Asia) and in Latin America. Within South-East Asia and the Pacific and the Middle East, events connected to the 25th anniversary of the Alma Ata declaration on Primary Health Care were used during 2003 to help mobilise further action. Communication processes within the movement are improving related network functioning and governance. More attention is now being paid to building and developing strong and effective alliances and working relationships with other networks, movements and organisations, as well as to engage in an strategic thinking planning exercise, including the development of a communication strategy.

The People's Charter for Health, elaborated through a worldwide consultative process and finalised and endorsed at the PHA, has been spontaneously translated into more than 40 local languages. This indicates the degree to which the Charter and its demands for social, political and economic change to improve health reflect and resonate with the reality of the situation facing the millions of people living in poverty.

PHA : A unique approach to social mobilisation

A key feature of the People's Health Assembly (PHA) is that there was no real model for this type of exercise. There are many examples of international meetings, but few that feature a focus on people's voices or that start from local experience.

This People's Health Assembly – the first of its kind – was a unique social mobilisation exercise. In country after country, it involved people in village meetings, in district meetings, in national events, in regional workshops to prepare for the global gathering in Bangladesh.

Along the way, the voices of the people were heard:

- articulating their demands for better health, justice, peace and equity
- reaffirming their rights and responsibilities to be involved in the decisions that affect their lives and their health

- confirming that the right to health is one of the basic human rights to which they are entitled.

The five-day meeting in Bangladesh provided an opportunity for people involved in health, development, human rights, agriculture, trade and economics, the environment and many other fields to converge, to share ideas and continue a process of building a coalition to drive change. Anyone who took part in the PHA describes it as a transformational process. It changed their lives. The challenge now is to see if the inspiration, solidarity and linkages that occurred can be sustained.

A significant outcome of the process is that it has begun to elaborate new models for organising, new approaches to giving voice to the vulnerable and new ways to advocate for social change.

Anger at injustice

A young village health worker from Nepal enacted for everyone the plight of a young woman who was typical of many she worked with in villages. She was in bonded labour, had no food, no money. Her husband had died. Now, in order to feed her child, she would have to offer her into bonded labour. How could she put her daughter through the misery that she had faced all her life? Her final, impassioned cry was 'God help me or let me die.'

Thelma Narayan from India responded to this by adding that the story reflected the situation of millions of women in Asia and highlighted the gender inequality of poverty and ill health. 'It is the suffering that moves us,' she said. 'Our anger at the injustice has led us to develop strategies to cope. What we are recognising is that this is a global phenomenon and therefore the response needs to be global. We need to address the issue of power and to look at how power affects the lives of people. It is our role to influence those who hold power.'

Planned achievements

The PHA process aimed to develop and endorse a People's Charter for Health and to achieve a further seven outputs:

- hearing the unheard
- re-enforcing the principle of health as a broad cross-cutting issue
- sharing and enhancing knowledge, skills, motivation and advocacy for change
- improving communication between concerned groups and institutions
- developing enhanced cooperation between concerned actors in the field
- enhancing media interest in health/equity issues
- increasing involvement of the poor in the dialogue process.

PHA participants surveyed feel strongly that the unheard did have an opportunity to be heard; that health was reinforced as a cross cutting issue and that skills and knowledge were shared during the Assembly itself. There was a less strong sense that communication between different groups and opportunities for enhanced cooperation happened. There was some uncertainty as to whether media interest was enhanced or to what degree the poor were really involved. Those are not surprising findings: communication processes, sustained interest and participation and involvement are all characteristics that require time and sustained interaction. In many ways, these are the challenges the newly developing movement is facing.

'The Assembly provided an opportunity for all of us to listen to those voices and to become one with their struggles. The declaration of the Charter will be but one step in making these voices heard by policy makers, governments and international organisations.'

Dr Qasem Chowdhury, Gonoshashaya Kendra, Bangladesh

A transforming experience

On balance, the overall impression of the Assembly itself from participants was that it was a unique, transforming experience. It had a profound impact on the 1500 people who attended, and nearly all of them have communicated with others about the experience in some way.

As a judge from India who attended said, 'The biggest achievement was making the world aware that the health of the common folk had to be a matter of international concern'.

The process that was set in motion to develop the PHA and get the event held was a positive one. It involved a number of organisations and networks, consulted widely on content issues, and reached out to a large audience to encourage involvement and participation. However, there were also difficulties: not least the overwhelming burn out and exhaustion of some of the organisers who faced severe stress in trying to cope with growing and unexpected numbers of participants. The sheer volume of people who attended meant that some of the carefully planned mechanisms to deal with debate and arrive at clear positions on many issues were not able to function. The issues were certainly raised and the problems articulated; clear expressions of possible solutions were not always reached. Many of the people involved in organising the event are highly critical of the outcomes.

A major failing of the process was the lack of a plan (and the resources – human and financial - to carry it out) about how to follow up the Assembly and maintain the enthusiasm and solidarity that was expressed. As a result, some of the dynamism of a new popular movement was initially lost. It was nearly a year after the PHA that the ideas for evolving a People's Health Movement that built on the first Assembly and began to work towards implementation of the demands in the People's Charter really began to develop. In that sense, the words of a professor of medicine based in the UK have some relevance: 'It was a remarkable and memorable achievement, but now what?'. Those words are echoed by a representative from a civil society organisation in India who said, 'The idea was good. The implementation could have been better.'

Taking the PHM forward

Up until the beginning of 2003, any assessment of the efforts to move the PHM forward would have had little to say that was positive. Although much work was going on behind the scenes, little was visible on the ground, and where it was, it appeared patchy, sporadic and largely uncoordinated through 2001 and 2002. Through 2003 and into 2004, greater coherence is beginning to emerge.

A large factor in the slow follow up to the PHA lay in the lack of a clear strategic plan and a corresponding communication strategy to reach out to different audiences. More recently, planning processes have come into effect that are addressing this and beginning to develop strategic approaches and concentrate on improving internal and external communication.

Other issues that the PHM needs to address include:

- maintaining and growing the movement (including the dynamics of networking)
- leadership and governance
- strategic thinking and planning (including communication and evaluation strategies).

Networking, linkages and alliances

There are enormous challenges in trying to maintain an effective network that combines a broad range of organisations and individuals. Networks, organisations, and individuals involved in the PHM work on a wide range of issues – from the very specific to the very broad – and at a number of levels – local, national, regional and international.

Related to this is the issue of linkages to other networks, movements and organisations that are working on issues that impact on health. Enhanced cooperation is important so that the PHM is visibly seen as a pro-active, inclusive and welcoming movement and is a platform that enables people to participate, without them having to convert to a particular belief, ideology or approach.

The synergy and interaction between the PHM and the International People's Health Council (IPHC) – one of the original eight groups involved in developing the PHA – is an example of this.

An area where the PHM has underperformed – although there are signs of improvement – is in generating media interest and helping to shape the external environment so that dialogue on public health issues is more of a reality. This is not an easy area of work and forging stronger and more effective alliances with networks of media personnel and those that work with media is likely to be a useful strategy to pursue.

Leadership and governance

Although there has been some discussion of possible structures (a series of interacting 'circles' or associations of people and organisations working on particular topics) to provide guidance and leadership for the PHM, there are still many unresolved issues. This is to be expected in what is a 'young movement'. However, an encouraging comment that emerged in the evaluation process is that it is a young movement 'with wisdom'.

Strategic thinking and planning

The dynamics of movements and many networks are that they often respond to situations as they arise: a policy has been issued that needs to be challenged; a threat to the environment has become evident; a human right has been violated. Something

needs to be done now, with urgency. People need to be mobilised to take action. However, all of this needs to be put into the context of a strategic framework which is light and flexible while providing a unifying planning guide.

Lessons learned

During the period from the end of the PHA to the present time, many lessons have been learned and increasingly are being put into practice to improve the work of the PHM.

These include:

- the need for more coordinated communication and information sharing – internally and externally. Externally, there is a greater visibility of the PHM in some arenas and fora. More could be done, but the signs are encouraging
- the importance of review and reflection processes to stimulate analysis of the work, rather than simply undertake activities – this is increasingly being incorporated into PHM steering group sessions and is enabling a more strategic vision to emerge
- allowing more time for planning and coordination of strategy – in 2003, there was a strong urge to have a second PHA sometime in 2004. It soon became evident that there was insufficient planning time for such an event and it has been put back to 2005. This has also allowed for a recognition that although there was no model for the 2000 PHA - now there is a model, imperfect and in need of improvement, but the planning time is now available to make those improvements
- better documentation of activities – which relates to internal and external communication. Internally, there is now much better documentation. This still needs to be better translated for external audiences to make more use of the communication channels that PHM has available, but it is an essential first step
- more clarity and transparency on how activities are funded, how funds are being shared and made to work more effectively in combination and with complementarity
- the importance of prioritizing and selecting key areas for action – the Charter has a wealth of action points. Any meeting or workshop is capable of generating long shopping lists of things that need to be done. Selecting a few of these that can be done is a skill that enables action to be effective. This is something that the PHM needs to continue to develop and practice to enable it to maximise its impact.

Conclusions

There were seven outputs identified in the original project proposal for the PHA. These outputs have been assessed in terms of pre-Assembly, the PHM itself, and the PHA follow up. Certainly, if we had had this exercise done 18 months earlier, it would have portrayed a more negative picture in terms of the post-PHA follow up.

This underlines the point that the development of the PHM is a social process, one that it is difficult to accelerate. It takes time to build trust, relationships, working practices and principles.

It is important that there is a continual reflection process within the PHM to focus not simply on the results, but on the way those results were achieved.

People's voices

An area that is more difficult to assess is the degree to which the voices of the unheard are more evident, including in the planning, leadership and governance of the movement. For the realities of vulnerable people to have impact on policy debates and to lead the demands for social change, considerable work needs to go into strategic positioning of the stories and the messages they contain. Support for the people whose voices are being raised needs to be strong. Their capacity to express themselves in ways that will impact policy audiences needs to be developed. And they need to be engaged in the analytical process that helps to draw out meaning from their experience, which helps them, in the words of Saul Allinsky, to digest that experience.

Their satisfaction with the results of any policy dialogues needs to be continually assessed. This is one of the biggest challenges facing the PHM.

From lessons learned to strategic thinking, planning and action

Is the PHM an appropriate platform for facilitating the voices of the unheard to be heard? In 2004, indicators show moves in the right direction:

- There has been some enhanced co-operation. Links that are evolving with key stakeholders have visible positive trends.
- Enabling dialogue and discussion in a number of forums is increasing, but there is scope for more.
- Communication strategies and practices – both internal and external – are improving. The Secretariat is demonstrating leadership, and the response of many participants in the movement to share information is becoming more evident.

Diversity

One of the exercises that the evaluation team did with nearly 80 people in 2003 in Geneva was to encourage them to identify how they came into contact with the PHM and how they pictured their involvement. The routes, the pathways, the doors through which they entered were diverse and spread over time.

The images of the movement that they drew were also diverse, but had some common elements. The ideas of joining hands, connecting and working together and of waves of energy, surging and growing were two powerful currents. Above all, the pictures they drew were a celebration of diversity and it is that diversity that is the main strength of the PHM. Sustaining and maintaining a diverse, flexible and effective movement that serves as a platform for social change is the challenge that now faces the PHM.

What does the movement or network hope to achieve in three years? In five years? In 25 years? What is the direction in which the movement is moving? What are ways it might get there, and how will it know it is making some progress? These are questions

that need to be embedded in the strategic thinking and planning of any effective movement or network.

'A revolution of hope' - the view of the PHM from Latin America

During a reflection workshop held in Nicaragua in late 2001, participants identified the specific characteristics that they felt made the People's Health Movement different and complementary to other social movements or networks.

It is a call to **all** peoples for the creation and development of a **transforming power for society**. The movement is not exclusive; it calls on all peoples to constitute a force to create substantial and significant changes in their different societies.

It is a **unifying** movement.

It proposes a **different revolution**: a revolution of hope.

It is a **solidarity** movement.

It struggles for the **dignity of people**.

It is a movement **rooted in the community**.

It shakes **awareness**.

It generates a **sense of belonging**. It offers participants the possibility of becoming part of a great movement of social transformation. Participants do not feel isolated, but connected and coordinated with common purposes.