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CSO Participation in Health, Research and Policy: A review of models, mechanisms and measures

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Executive Summary

Introduction

Civil society organisations (CSOs) can participate in health research and policy in a variety of ways. As with other complex socio-political interventions, replicating participation methods across contexts, in the same way and to the same effect, is clearly impracticable, if not impossible. However, an overarching understanding of participation processes, effects and explanatory principles is required to inform policy, strategic action and further research. This paper reviews organising frameworks and explanatory principles in the literature which could inform the design and evaluation of CSO participation with health research and policy and in wider social development contexts. This paper is structured using broad thematic categories that are highlighted below.

Imperatives for CSO participation in health research and policy

Several governments increasingly require CSO participation in decision-making and there are legal obligations and human rights standards on the same. In resource-strapped countries, CSOs provide services to supplement government service. The far-ranging determinants of health and societal development require collaboration across a range of societal actors, sectors and geographical boundaries in policymaking. However, despite the strong imperatives and some successful examples of CSO participation, there are growing concerns about the nature, costs and effects of these initiatives; evaluation criteria, explanatory principles and empirical data on participation initiatives are difficult to come by.

Definitions and boundaries

One of the main barriers to deriving explanatory principles, evaluation criteria and agreed-upon strategies for action is the lack of clearly defined concepts and boundaries of CSO participation in research and policy. Various definitional and boundary issues are discussed in this paper, including the concept of CSO legitimacy and what constitutes 'matters of public concern'. Some working definitions are provided, e.g. public policy is broadly defined as the formalisation of a set of decision activities on issues in which several actors in society have a stake.

CSO participation in research

There are several ways in which CSOs may engage with and influence research. In conducting research, special caution is advised to avoid 'development ventriloquism' wherein experts, based on their own research objectives, frame the thoughts and words of individuals and communities in disadvantaged situations. CSOs can also evaluate research conducted by others; in the context of influencing pro-poor policy, it is necessary to go beyond traditional scientific evaluation criteria and use other criteria, such as critical change criteria, that determine consciousness about inequalities and injustices, representations of the perspectives of the less powerful, clear historical and values contexts, and consequential validity of the research. Similarly, evidence can be framed differently, e.g., technical, ideological, moral and economic frames, to influence socio-political discourse. The role of CSO participation at key research interfaces is also discussed, from review processes, to collaborative research, through to research communication and evaluation.

Using evidence to influence policy

Community empowerment and action are powerful catalysts of social change, but change need not always be confrontational and can also be effected through participation in socio-political dialogue and negotiations. Approaches to facilitate social empowerment and build negotiation capacities and skills are discussed in this section. In this context, health literacy is an important concept and is defined as the skills and competencies that people develop and use to seek out, comprehend, evaluate and use health information and concepts to make informed decisions, reduce health risks, and increase quality of life. The mass media often set public agendas and frame issues in ways that can subtly or dramatically influence policy. CSOs need to be media savvy, and tips on evaluating media content and writing press releases are provided. This section discusses the potential of the internet as a means for CSOs to communicate and mobilise and a UN initiative that provides more equitable access to research publications for not-for-profit and research institutes in developing countries. However, there are still great inequities within and across countries regarding internet access. In this context, the internet may be viewed as just another tool used by the elite, even if these elite happen to be academic institutions or CSOs.

CSO participation in policy processes

Participation in policy processes can be analysed from the perspective of whether public policy or policy research imperatives drive these interactions, or whether deliberative democracy approaches are employed and CSOs take a more active role in setting the agenda for policy interaction. This section highlights the need for localised models of participation, wherein different contexts there is ongoing dialogue among policy institutions, scientific expertise and wider civil society. The importance of stakeholder analyses and socio-political networks in policymaking is emphasised. Organising and managing diverse networks for different purposes seems the strategy most likely to facilitate meeting complex policy and programme challenges. A range of different mechanisms and measures of participation is discussed and a matrix of public involvement is presented. This matrix helps analyse different types of participation in decision making using two axes of the nature of public involvement: collectivistic to individualistic and holistic to particularistic, different configurations of which may be required in decision-making processes.

Evaluating CSO participation in research and policy

The lack of systematic evaluation of participation against defined criteria and objectives is a major barrier to developing understandings on the influence of CSO participation on research and policy as well as on health and development outcomes. There are several additional difficulties with undertaking evaluations of participation effects and outcomes. Evaluations tend to be defined by relatively short-term funding or project cycles. Health and development changes, however, may be more long term in nature and could occur totally unrelated to these cycles. In addition, the range of factors influencing research, policy, health and social change makes it difficult to attribute these to any single process or actor. Using lessons learned from diffusion of innovations research and human rights standards for assessments of health and development, key evaluation principles are outlined.

Discussion: an integrated perspective on participation and policy

This final section of the paper provides a brief summing up or overview of how the different aspects of CSO participation discussed in earlier sections can be used to influence research and policy processes. A 'decision cell model' of policy processes provides a framework to help integrate the various concepts and themes and to indicate how CSOs could apply these concepts to influence policy processes. In conclusion, it is hoped that the concepts and ideas discussed in this paper will contribute to the ongoing and critical dialogue on the design and evaluation of CSO participation in research and policy. In addition, it is hoped that the paper will encourage debate on how the interests of individuals and communities who are disadvantaged are considered and addressed in these processes. However, in order for CSO participation to take effect and make a difference, we will need to move beyond theoretical discussions and apply these understandings to strategic action and rigorous analyses of whether and how CSO participation influences policymaking as well as individual wellbeing, equity, and societal development.

1. Introduction

The essential need is the improvement of the methods and conditions of debate, discussion, and persuasion [between scientific expertise, the state, and wider society]. That is the *problem of the public* (Dewey, 1954: 208).

In a remote tribal area of India, a 1991 census indicated a negative growth rate owing to high mortality, particularly from malaria. The staff of a community health programme, MITRA, in a mission hospital in that area realised that medical anti-malarial strategies of distributing chloroquine were not making a difference. The MITRA team reviewed the literature for alternative options in combating malaria, e.g. from Africa, consulted with malariologists, studied endemic sites, and identified the predominant mosquito vector, while ascertaining that people in the villages believed that drinking contaminated water was the cause of malaria. Given the impracticability and undesirability of deploying bio-environmental measures in the hills and streams where the tribes lived, the team determined from the evidence that the most effective strategy would be personal protection adopted on a mass scale: a 'people's movement against malaria' (Oommen et al., 1999).

MITRA launched a public awareness campaign to convey the 'essentials of the epidemiology of malaria in a demystified, digestible form'. Multiple prevention options were put in a menu format. The people chose to use insecticide-treated mosquito nets and education strategies. There were no subsidies, the people themselves were responsible for the production and purchase of the mosquito nets and, although health education continued, the programme did not provide health services until services were sought.

Over the next decade, through MITRA (which means relationship or friendship) a partnership for health was forged across 48 villages, addressing malaria control and other public health problems. It coordinated with government services, trained health workers, set up a primary school, obtained expert help in giving the tribal language a script, and promoted the development of various economic schemes, e.g. related to the production and sale of tribal craft. By 2002, MITRA had seen a significant reduction in morbidity in participating villages and an over 40 percent decrease in mortality compared with the rates in 1991. The morbidity and mortality in surrounding villages that were not part of the programme continued to be extremely high (Oommen et al., 1999; Oommen, 2003).

On learning about the success of the MITRA programme, government and donor agencies approached the team and proposed scaling up the programme to other regions. Dr John Oommen, head of the community health programme, was at a loss as to what advice to give. He observed that 'Asking us to scale up MITRA is akin to asking someone to identify 10 of their closest friends and then giving them money to go out and make 100s of friends in exactly the same way while explaining to others how to do the same' (Oommen, 2003; personal communication).

The MITRA story is an emblematic example of CSO participation with research that informed decision making and improved health outcomes; it also highlights a paradox for research on complex policy and social interventions. Replicating complex social interventions in exactly the same circumstances, in the same way, and to the same effect, is clearly impracticable, if not impossible. However, an overarching understanding of societal interventions and effects is required to inform policy (Mays et al., 2001; Pawson, 2002, 2003). Pawson (2003) suggests that, instead of asking the question 'what works?', reviews and syntheses of research on complex policy and social interventions should take a 'realist' approach and ask 'what works for whom, how, and in what circumstances?' The resultant explanatory principles could then usefully guide policy, programmes, and further research (Pawson, 2003, 2002). Following this realist review approach, this paper focuses on identifying organising frameworks and explanatory principles in the literature that could

inform the design and evaluation of CSO participation with research and policy in the health sector and in broader social development contexts.

This paper is written as part of ODI's Civil Society Partnerships Programme funded by DFID, which aims to improve the capacity of Southern civil society organisations (CSOs) to influence 'pro-poor policy' (http://www.odi.org.uk/cspp). The remit for this paper is to review and synthesise the literature on the links between CSOs, evidence and policy, using perspectives from the health sector. The annotated bibliography linked with this paper includes studies of civil society engagement with health research and policy across different countries.

The literature across different academic fields, including policy science; development and participation; philosophy; health services research; research utilisation; and public engagement with science, offers valuable insights on different aspects of CSO participation in research and policymaking. However, syntheses of these perspectives seem to be required in the effort to develop more complete and integrated understandings of the design and evaluation of CSO participation in research and policy and of ways this influences more equitable policymaking and ultimately contributes to individual and societal wellbeing. To this end, this paper undertakes a synthesis of a range of multidisciplinary literature and focuses on reviewing and categorising organising principles, models, mechanisms, and measures of CSO participation in health research and policy. It is divided sections dealing with the following themes:

- Imperatives for CSO participation in health research and policy
- Definitions and boundaries
- CSO participation with health research
- Using evidence to influence policy
- CSO participation in policy processes
- Evaluating CSO participation in research and policy
- Discussion and recommendations: a reorientation of policy analysis and participation strategies

2. Imperatives for CSO Participation in Health Research and Policy

This first section of the paper discusses a range of imperatives for CSO participation in health research and policy, and highlights some of the key problems and issues facing the design and analysis of such initiatives. This will provide a context for the discussion on participation models, mechanisms, and measures in later sections.

The formalisation and analysis of civil society participation in health research and policy was, in part, catalysed by changes that occurred at a global level in the mid-20th century. Several countries signed treaties, such as the United Nations' International Covenant on Civil and Political Rights (ICCPR), which recognised the right of individuals to participate in shaping decisions which influenced their lives. The ability and freedom to participate in public affairs is now recognised as a basic right of citizens, as well as 'the primary end and the principal means of development' (Sen, 1999: 36). Further, the far-ranging determinants of health and societal development were seen to require increasing collaboration across a range of societal actors, sectors, and geographical boundaries (Woodward et al., 2001; UNEP et al., 2004; Brown, 2001; Cornwall, 2000). In resource-strapped countries, CSOs provide services to supplement government services, for example, in Kenya 87 percent of the clinics and hospitals are run by CSOs (UNEP et al., 2004). CSO participation extends beyond service provision to health research and policy. Reflecting on the Framework Convention on Tobacco Control as one of the most successful and far-reaching public health negotiations in history, the then WHO Director General noted 'Social scientists, economists, public health experts, women's groups and lawyers have worked with us for the last three years delivering accurate information to the treaty-making process, and taken public health science and research into the highest levels of political decision making' (Brundtland, 2001).

Analysts point out how civil society participation in research and policy has led to the generation of new data sources, more sensitised and knowledgeable stakeholders, empowered advocacy groups, increased accountability, and meaningful, sustainable policy change (Innes, 1998; Epstein, 1996; Khilnani, 2001; Cornwall, 2000), as indicated in the following emblematic examples. The impact of CSOs on health research and policy is vividly illustrated in the HIV/AIDS activist movements, not only in more industrialised countries, but also in countries such as Thailand, Uganda, and Senegal (Piot, 2000; Epstein, 1996). The success of the international research programme on diarrhoeal diseases is largely credited to the ongoing interaction among scientists, policymakers and various civil society groups in the design, conduct and communication of research and policy. This approach resulted in context-appropriate strategies being employed in different countries, which then saved the lives of millions of children through health education and the use of oral rehydration therapy (Department of Child and Adolescent Health and Development, 2002).

The changing nature of illness and healthcare also spurred the need for wider and more active participation in health. In the 21st century, prevention and treatment of illness hinge on lifestyle and behaviour change. Vertical immunisation campaigns and prescription of antibiotics were effective strategies against the major killers of the previous century: infectious diseases. Prevention and treatment of illnesses linked to health behaviours and lifestyle, however, need the informed and active participation of the people, who must adhere to long treatment regimens and make the required behaviour changes and lifestyle choices. Between the rich and the poor, and between different demographic groups, there are significant inequalities in access to health services and in health outcomes, highlighting the need for more equitable participation in realising the interests and rights of people who are in disadvantaged situations (Hunt, 2003; WHO, 2003; Werner, 2002). There is also increasing evidence that civic engagement, and factors such as social cohesion, interpersonal trust, and perceived citizen power, correlate with health and socioeconomic outcomes (Campbell et al., 1999; Kawachi, 2001).

Although lack of education and inequitable access to information and information technologies still remain a barrier to informed participation (UNEP et al., 2004; Cooke and Kothari, 2001), the information revolution and education campaigns of the latter half of the 20th century have had considerable effect. More information resources have been created, and public research and policy information have become more easily available (Cornwall, 2000). CSOs increasingly use the internet and mobile phones to access and share information and to raise awareness and mobilise resources and people. Interestingly, a more informed civil society, rather than one more accepting of science and policy, may actually be more critical and demanding. It is generally observed that people are becoming less fatalistic about their lives, less deferential about authority, and more openly engaged in deliberations of risks, rights, and solutions (Irwin, 2001; Fischer, 2003; Abelson et al., 2003; Cornwall, 2000; Werner, 2002).

In this context, governments increasingly require public consultation and commentary in technical decision making (UK House of Lords Select Committee on Science and Technology, 2000; Butschi et al., 2002; Roth et al., 2003). Public policy, health research, and service agencies view civil society participation in their decision making and review processes as a means to improve responsiveness, accountability, and uptake of policy and services (Abelson et al., 2003; Crawford et al., 2002; Innes, 1998; Drager et al., 2000; Cornwall, 2000; Cooke and Kothari, 2001). Initiatives by national health services and research bodies to promote greater interaction between civil society and scientists in advisory, review, research, and decision-making processes are generally well received (Irwin, 2001; Leshner, 2003; US Department of Health and Human Services, 2000; UNEP et al., 2004; Witten and Ramasubramanium, 2000).

However, despite the strong imperatives and successful examples of CSO participation, there are several concerns about the nature, costs and effects of these initiatives. In light of more demanding and less deferential publics, CSO participation in policymaking is sometimes used as a quick fix for legitimacy and acceptability. In these situations, participation may at best be an advisory process, or otherwise be used as a means to legitimise decisions already made, or as a tactic to allay or dilute controversy and dissent (Khan, 1999; Cornwall, 2000; Cooke and Kothari, 2001). While civil society participation in political and operational decision making may be accepted and encouraged, there are several barriers to participation in legal and economic decisions (Scruton, 1982; Khan, 1999; Cooke and Kothari 2001). There are also growing concerns about the legitimacy of CSOs themselves, particularly with regard to whose interests they represent and to whom and for what they are accountable (Chinkin, 2000; Brown, 2001); the issue of CSO legitimacy will be further discussed in the following section on definitions and boundaries.

Recent controversies and crises highlight differences among policymakers, scientists and wider civil society, as was evident in the media coverage on the need for affordable antiretroviral drugs for HIV/AIDS, on the BSE (Bovine Spongiform Encephalopathy) crisis in the UK, on concerns about the link between MMR (Measles – Mumps – Rubella) vaccines and autism, and on the health implications of biotechnology and genetically-modified (GM) food (Piot, 2000; Epstein, 1996; Irwin, 2001; Collins and Evans, 2002). While pluralism and differences in perspective can contribute to healthy debate in society and to more informed policymaking, without good management of participation and debate, these differences could instead lead to mistrust and social fragmentation.

Finally, despite strong imperatives, it is not clear how and to what extent interactions of state and civil society actually lead to better policies and services. There are growing inequities in socioeconomic development and in access to services, which in turn lead to adverse health and societal outcomes (Werner, 2002). There are examples of successful, and not so successful, cases of how CSO participation can address inequities and catalyse desired health and societal outcomes (ibid.). In general, though, evaluation criteria, explanatory principles and empirical data on the

costs, logistics and outcomes of participation initiatives are difficult to come by. For example, one review of deliberative methods in health decision making 'identified only one systematic attempt to evaluate a particular method – the citizen's jury – using pre-defined evaluation criteria' (Abelson et al., 2003). There is growing concern about the systemic spread of poorly articulated and uncritically adopted normative prescriptions for civil society participation in policymaking, and some consider this a 'new tyranny' (Cooke and Kothari, 2001). Overall, there is a clearly identified need to move beyond advocacy and anecdote to strategic action and rigorous analysis of civil society participation in research and policy ,and of how that participation influences health and societal outcomes (Abelson et al., 2003; Crawford et al., 2002; Irwin, 2001).

3. Definitions and Boundaries

One of the main barriers to deriving explanatory principles, evaluation criteria, and agreed-upon strategies for action is the lack of clearly defined concepts and boundaries of CSO participation in research and policy. There are several issues still unresolved in defining even basic concepts, such as civil society, policy and evidence. This section of the paper will briefly discuss these.

Theoretically, 'civil society' refers to all institutions and networks outside the official public sector and the household which aggregate individuals based on shared interests, goals, needs and functions. Civil society could thus broadly include advocacy groups, trade unions, academic institutions, the media, professional associations, hospitals, religious organisations, and even corporations (Khilnani, 2001; Cooke and Kothari, 2001). Practically speaking, however, the approaches and activities that define private sector organisations have set them apart from current conceptualisations of civil society. Making that distinction, DFID defines CSOs as 'organisations that work in an arena between the household, the private sector and the state to negotiate matters of public concern'.[1]

Building on DFID's definition, Pollard and Court (2005) acknowledge that

> identifying clear lines of separation between CSOs and households, the private sector and the state can be problematic. Many CSOs have complex and multifaceted relationships within these other sectors and may be dependent on them for financial backing, political status and other kinds of resources. [ODI's] definition focuses on the nature of the work undertaken by CSOs ('to negotiate matters of public concern') rather than the nature of those organisations and their dependencies.

ODI's list of CSOs includes non-governmental organisations, faith-based institutions, community groups, professional associations, trade unions, media organisations, research institutes and think tanks.

'Matters of public concern' is another area where boundaries and definitions are amorphous. CSOs operate at many different levels, including global, regional, national and local. Defining matters of public concern at all these levels is no straightforward task. John Dewey's explication of the 'public' could usefully inform this discussion. Dewey proposes that the point of departure in defining the 'public' is the objective fact that human acts, including communication, have consequences on others (Dewey, 1954). These consequences may be confined to the people directly engaged in the act, in which case the transaction is a 'private one'. In other instances, when a human act may have consequences that 'extend beyond [those] directly concerned and affect the welfare of many others, the act acquires a public capacity' (ibid.: 13).

Dewey cautions that the public sphere should not be confused with the 'social' or even with the 'socially useful', and proposes that the boundaries of the **public** should be 'drawn on the basis of the extent and scope of the consequences of acts which are so important as to need control, whether by inhibition or by promotion' (ibid.); with public officials and organisations performing this regulatory role. However, Dewey acknowledges that the institution of official structures could result in the protection and propagation of the institutions themselves, at the expense of matters of public concern. Therefore, in order to negotiate matters of public concern effectively, Dewey identifies that 'the essential need is the improvement of the methods and conditions of debate, discussion, and persuasion between scientific expertise, the state, and wider society' (ibid.: 208).

In this context, **public policy** can be broadly defined as the formalisation of a set of decision activities on issues in which several actors in society have a stake. Matters that require public

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[1] This is taken from the DFID Information and Civil Society Department website (www.dfid.gov.uk).

regulation and policy activity will vary with context and require negotiation. For example, recent UK government initiatives on controlling smoking and alcohol consumption, promoting healthy nutrition, and regulating child-care services have led some to accuse the government of interfering in individuals' lives, i.e. of being a 'nanny state'. Others make the case that the consequences of smoking and alcohol, obesity and inappropriate child-care could have long-term public costs in terms of health and societal risks and healthcare costs.

Matters of public concern and the socio-political contexts in which they occur are also continually changing. It is not clear whether public officials and organisations, once instituted, are responsive to those changing contexts. There is a need for ongoing deliberation and negotiation among civil society, state, science, the private sector and other actors in society on matters of public concern. Finding the appropriate tools and methods to facilitate the same continues to pose a challenge to societies everywhere (Dewey, 1954; Irwin, 2001). These issues continue to be debated in forming public policy. A distinction could be made between public policies that operate in the public sphere and policies that CSOs may make within their own organisations (Pollard and Court, 2005; Cooke and Kothari, 2001). This paper focuses on public policy processes unless otherwise specified.

Since the 17th century at least, science has been positioned as an authoritative and reliable source of knowledge to guide policy (Robertson, 1905), but its role and authoritativeness in policymaking is increasingly questioned. Scientific **evidence** can be defined as the interpretation of data, where data is information generated using scientific methods – scientific method being variously defined across disciplines (Stevenson, 1996; Smith and Wynne, 1989). Since both scientific method and evidence involve certain assumptions and interpretation, evidence may be framed differently based on different perspectives and objectives. Experts may thus interpret the same data differently, as often happens in a court of law or in policy deliberations, which brings into question the role and 'authoritativeness' of both evidence and expertise in policymaking. Further, there are ongoing tensions between technocratic and democratic considerations in policymaking (Nelkin, 1975; Collins and Evans, 2002; Irwin, 2001). As Nelkin (1975: 37) observes, 'The complexity of public decisions seems to require highly specialized and esoteric knowledge, and those who control this knowledge have considerable power. Yet democratic ideology suggests that people must be able to influence policy decisions that affect their lives.'

Public policy necessitates taking into account a wide range of factors beyond specialised technical foci, though these latter may provide important perspectives to inform policy considerations. For example, in health policy, the predominantly clinical focus in health research has meant that while evidence on the effectiveness of drugs and other health interventions is available, there is less evidence on their social acceptability, cost effectiveness, long-term effects, and equity implications – all important considerations for policy (MacIntyre et al., 2001). Dewey recognises the role of expertise in policymaking, not in 'framing and executing policies, but in discovering and making known the facts [otherwise dispersed and disorganized], upon which the former depend' (Dewey, 1954: 365), as well as in carrying out specific technical functions.

The role of CSOs in policymaking is also increasingly questioned. CSOs are variously situated within and among public policy, academia, the private sector and the community and seem well placed to negotiate matters of public concern and policy. However, it is not always clear what authority CSOs have to do so and whose interests they represent when they do. Nor is it always apparent to whom and for what they are accountable. Chinkin (2000) notes that

> *[CSOs] are often non-democratic, self-appointed, may consist of only a handful of people, and determine their own agendas and priorities with a missionary-like or elitist zeal. Their own decision-making processes may not be transparent and are concealed behind a deluge of information. They do not have to address the full range of options that must be considered by State elites, but can limit themselves to their own concerns. The other side of the coin of representation is accountability. [CSOs] are acquiring a measure of international legal personality through procedural rights of access and standing, but their accountability has barely been addressed.*

There are, however, different bases of legitimacy that CSOs could use to derive and establish their legitimacy in research and policy processes. In 1947, Weber explicated three types of legitimate authority: rational, traditional and charismatic. Brown (2001), in an analysis focused on CSOs, describes four bases for CSO legitimacy in policy interaction: moral, technical, political and legal. Synthesising these approaches, legitimacy could potentially be established on the following bases:

- **Rational-legal**, based on legal or formalised requirements for CSO participation
- **Traditional**, in terms of customary or historical roles and positions held
- **Charismatic**, through compelling leadership and communication styles
- **Moral**, through making explicit values and ethical imperatives
- **Technical**, in terms of specialised functions performed
- **Political**, through persuasive political argument and action

Representative would be an additional source of legitimacy for CSOs, where they explicitly represent the interests of specific societal groups and are recognised by those groups to do so.

While this categorisation provides some insight into possible approaches for building legitimacy, it is not clear to whom and how different types of legitimacy can be 'proved', or what evidence is required to do the same. This is a serious challenge for CSOs (Pollard and Court, 2005).

The preceding discussion highlights the need for further deliberation and definition of key concepts required to understand and inform CSO participation with research and policy, and to clarify different elements fit together. As one step towards this end, this paper highlights a range of models, measures and mechanisms which, by categorising and organising different elements of CSO participation in research and policy, provide frameworks to facilitate dialogue, piecing together different perspectives and explanatory principles.

4. CSO Participation in Research

This next section of the paper discusses different ways in which CSOs may engage with research and evidence: conducting and evaluating research; engaging with research conducted by others; interacting at key research 'interfaces'; and framing research evidence to influence policy.

4.1   Conducting and evaluating research

CSOs may conduct research themselves and there are volumes of methods texts available on a range of different research methods on the particular perspectives and limits of each (Patton, 2001; Bland, 2000). There is also extensive information on the resources, skills and capacities required to conduct and communicate research, and on the systems within which these activities take place (Pang et al., 2003; OECD, 1997). The discussion in this section will mainly focus on approaches to evaluating research quality, whether conducted by CSOs or other organisations.

With regards to research methods, just one point will be made on the need to consider alternative research methods from the perspective of developing pro-poor policy. Currently, research aimed at informing pro-poor policy seems fraught by the phenomenon of 'development ventriloquism' (Ndolamb, 1991), wherein experts, based on their own research objectives, frame the thoughts and words of individuals and communities in disadvantaged situations. Even participatory research methods are criticised, as they are sometimes just used as a means to render a diversity of perspectives into formats more amenable to traditional methods of research analysis and for bureaucratic processing (Mosse, 2001). Alternative methods may need to be developed and recognised to allow for the voices of the poor to be heard directly.

An innovative method, the photo novella was designed by a project in rural China to facilitate direct expression by people who are disadvantaged. The project trained women to use cameras to record and reflect on different aspects of their lives, especially their health needs. The photo novellas were then used to facilitate discussion and increase collective knowledge among the women as well as to inform policymakers about rural women's health needs (Wang et al., 1996).

Similarly inspired by Paulo Freire's approach to education for empowerment as well as by feminist methodologies, related methods have been used effectively in other contexts, e.g. in the production of health literacy and health education materials. Participants engage in developing such materials through processes by which they critically reflect on both their circumstances and themselves as agents empowered to transform those circumstances (Rudd and Comings, 1994; Werner, 2002). The concepts of empowerment and health literacy will be further discussed in later sections of this paper.

Although narrative methodologies, both visual and verbal, show promise in development research, Atkinson (1997) cautions against a 'neoromantic construction of the social actor'. He points out that the relationship between life and the life narrative is far from simple. In narratives, the unusual and suspenseful tend to have more value than the mundane. Narratives may be constructed from perspectives of cognitive and material deprivation, narrative styles and substance, influenced by existing social structures and power dynamics. The criteria used to determine the comparative worth of different narratives may not be made explicit. Therefore, while the value of narratives and local perspectives should be appreciated, they should be subjected to the same rigorous analysis as other forms of research information.

There are several sets of criteria that could be used to assess research quality in general. Each set of criteria is associated with a particular perspective and philosophy, even though there may be some overlap. Using different research assessment criteria would necessitate addressing differences in the methodological and philosophical stances associated with those criteria (Mays and Pope, 2000; Patton, 2001). Outlined below are some approaches and criteria that are used to evaluate the conduct and products of research (Patton, 2001: 544).

- **Traditional scientific research criteria** include validity, reliability, generalisability, minimisation of bias, methodological rigour, and testing causal hypotheses.

- **Social construction criteria** include acknowledging and taking into account the development of and influences on research-generated knowledge, particularity – or doing justice to particular cases, transferability of knowledge across contexts, triangulation of perspectives, and enhanced understanding.

- **Artistic and evocative criteria** include the extent to which new or novel perspectives are provided, aesthetic quality and interpretative vitality, creativity, authenticity, and the ability to connect with and move audiences.

- **Critical change criteria** include an increased consciousness about inequalities and injustices: their sources and nature, representations of the perspectives of the less powerful, identification of strategies for change, clear historical and values context, and consequential validity.

- **Evaluations standards criteria** include utility, feasibility, accuracy, level of systematic inquiry, evaluator competence and integrity, ethics, responsibility, fairness, and respect for a diversity of interests and values.

The People's Health Movement (PHM), an alliance of CSOs, social activists, academics and health professionals from over 75 countries, views the data produced by the WHO and UNAIDS as deficient, particularly with reference to social construction and critical change criteria. The PHM proposes to bring out an alternative world health report, Global Health Watch, using research that takes into account these factors. Through this, PHM also aims to analyse why national and international health targets are not being achieved and to 're-establish health and equitable development as priorities for local, national, and international policy' (www.phmovement.org).

4.2 Public engagement with science models

Another way CSOs can participate in health research is by engaging with research primarily conducted by others. There are four models of public engagement with research that could usefully inform the discussion: the deficit; contextual; lay expertise; and the participation or collaborative (Pleasant et al., 2003; Irwin and Wynne, 1996; Lewenstein, 1992). In these models, a distinction is often made between 'lay' knowledge and the technical knowledge of scientific research.

The **deficit model** is based on the assumption that there are knowledge deficits in society that can be filled with scientific 'fact'. This is a useful model for basic science education, to inform further research, and for health education. For example, promoting awareness and reporting of skin patches is critical to leprosy control efforts. However, critiques of the deficit model focus on the paucity of incontrovertible fact, especially as relates to societal change and development and a lack of awareness of contexts and processes through which 'facts' are deliberated and shaped – including in the scientific process (Figueroa et al., 2002; Ziman, 1992; Irwin and Wynne, 1996; Lewenstein, 1995). Using the example of leprosy control again, different interpretations of scientific information, e.g. of case and treatment definitions, as well as the implications of that information in different contexts, e.g. perceived importance of the problem and stigma associated with leprosy, are all factors that influence leprosy eradication efforts (Lockwood, 2002).

The **contextual model** widens the scope of the deficit model, in that it acknowledges a context of use for scientific knowledge. In this model, scientific knowledge is viewed in the light of particular problems, audience interests and user values. Studies from different disciplines and countries show that information that is not congruent with existing cultural values, socio-political imperatives and individual world-views may not be attended to or assimilated (Aronson, 1995; Frenk, 1992; Lindsay, 2000). However, this model also envisages a unidirectional process and assumes that problems, interests and values are predefined and relatively static, and that scientific knowledge to meet these needs pre-exists (Irwin and Wynne, 1996).

The **lay knowledge model** depicts a reverse unidirectional process where lay knowledge flows into science. The lay knowledge model highlights the importance of local and indigenous knowledge and practices. For example, it is estimated that traditional medicine provides for the primary healthcare needs of around 80 percent of the world's population (WHO, 1993). A second aspect of the lay knowledge model is the recognition that non-scientific knowledge could influence the use of scientific knowledge (Wynne, 1992). For example, socio-political imperatives and cultural understandings about health often influence the perceived relevance and use of health research (Frenk, 1992).

The **participation or collaborative model** depicts exchange and interaction among scientists, state, and various publics in scientific processes and communication. This model is aligned with studies on the sociology of scientific knowledge which explicitly take into account how science, state, and society are inextricably linked and influence each other in myriad ways (Ziman, 1992; Irwin and Wynne, 1996; Lewenstein, 1995). As an example of participatory research in practice, provisions and requirements in New Zealand's Treaty of Waitangi and the Resource Management Act provide a legal framework for participatory approaches in research and informing policy. Participatory research on environment and health issues in New Zealand, then, integrates knowledge from a range of scientific and community sources, including indigenous knowledge (Witten and Ramasubramanium, 2000). There are, however, growing concerns about the potentially pernicious costs involved in such collaborations and insufficient data on whether the effects and outcomes justify those costs.

4.3   Interactions at research 'interfaces'

Research, policy and civil society collaborations and participation can also be studied at various research 'interfaces' (Hanney et al., 2003).

- **Research priority setting**. Criteria for research priority setting and resource allocation are generally ill defined, but could include (Drager et al., 2000; COHRED, 2000): relevance; acceptability; costs; equity implications; evidence of effectiveness; feasibility; potential health benefits and risks; and the degree to which stakeholder priorities are satisfied. Some of those criteria are reflected in guiding principles synthesised by the Council on Health Research and Development (COHRED) for Essential National Health Research strategies. These were developed through consultations and lessons learned from research priority-setting exercises in developing countries.

- **Research commissioning and resource allocation**. In health research, the '10/90' gap is an area of increasing concern, where 90 percent of health research resources is allocated to meeting the needs of 10 percent of the world's population (Global Forum for Health Research, 2000). Civil society organisations can play a key role in setting research agendas and negotiating more equitable allocation of research resources.

- **Research review processes**. Several national and institutional health research boards are increasingly requiring CSO, lay and patient participation in their ethics and research project

selection and review panels (Pleasant et al., 2003; Leshner, 2003; Crawford et al., 2002). While that participation is generally well received, there are some concerns about the utility and costs, and lack of data on the effects and outcomes of that participation (Leshner 2003; Crawford et al. 2002; Pleasant et al. 2003).

- **Conduct of research**. Various ways in which CSO can participate in health research were discussed in the preceding section of this paper.

- **Research syntheses and technology assessments**. In biomedical research, over two million journal articles of varying quality are published annually (Ad Hoc Working Group for Critical Appraisal of Medical Literature, 1987). There is a need for reviews and syntheses of research evidence to focus further research, as well as to inform health policy and practice. The Cochrane Collaboration, through its methodologically rigorous systematic reviews focuses on synthesising quantitative experimental data from clinical trials and scientific publication across several countries to establish the effectiveness of health interventions (Clarke and Oxman, 2003). However, research information that influences research, policy and practice may not always be in the form of experimental data or scientific publications. Evidence may also be communicated through policy briefs, project reports, media coverage and websites, as well as narratives and interpersonal communication. This requires the further development of appropriate means of research synthesis (Dixon-Woods et al., 2005; Mays et al., 2001; Pawson, 2002).

- **Communicating research**. There are multiple sources of research information: scientific publications; mass media; policy briefs; issue networks; and interpersonal communication. There is proof that multiple modes of communication shape scientific processes and evidence and are required to facilitate research uptake (Lewenstein, 1995; Grimshaw et al., 2001; Figueroa et al., 2002). Once information is attended to, it is subject to interpretation, deliberation and negotiation before it is used. The following section further examines different aspects of the framing and communication of evidence.

4.4   Framing evidence

Just as there were different approaches that could be used to evaluate research, there are different approaches that could be used to interpret and frame evidence. In the US, public commentary is a requisite component of federal rule making. Roth et al. (2003) analyse how evidence was framed, or how and what evidence was highlighted, in written public commentary on FDA regulations to restrict the sale of tobacco to minors. They identified five ways in which evidence was framed to influence policy.

- **Scientific frames** include evaluations of overall research quality and more specific arguments about problem definition, study design, measurement, and interpretation of results, including charges of bias, misinterpretation, and fraud.

- **Ideological frames** invoke freedom of choice rights, and the necessity for or threat of government intrusion.

- **Economic frames** focus on the proposed rule's costs (for example, to government or the tobacco industry), its potential impact on the local, state and national economies, and the costs of tobacco-related illnesses.

- **Political frames** invoke federal pre-emption of state and local laws, enforcement of the proposed rule, and other strategic motivations for it.

- **Procedural frames** invoke the adequacy, appropriateness or fairness of the rule-making process itself.

In their analysis, Roth et al. conclude that the government emphasised the use of scientific frames, whereas civil society commentators used political and ideological frames that were identified to be 'more fundamental than the scientific evidence' and thus undermined the credibility of the proposed regulation. This example highlights how CSOs could influence policy by challenging and reframing the evidence on which the policy is based.

5. Using Evidence to Influence Policy

There are several ways in which CSOs could use research evidence to influence policy as well as health, equity and societal outcomes. This section of the paper looks at the use of evidence for social empowerment and action, in policy negotiations, to build health literacy, and in media matters.

5.1   Social empowerment and activism

Social empowerment and activism is another way CSOs can affect equity, health and societal outcomes and influence-related policies. This mode of CSO influence is illustrated in the now classic example of Project Piaxtla, in rural Mexico. In the 1960s, villages in the foothills of Mexico's Sierra Madre Mountains were not served by health services. Founding a village-based health programme in Piaxtla, David Werner facilitated the training of local health workers and health promoters, the development of health education and healthcare information in easy-to-understand language and pictures, and the creation and adaptation of health technologies using available resources. Most importantly the collaborative processes employed helped people diagnose their health needs and work together to overcome them. Over the next two decades, people's health dramatically improved. For example, there was an 80 percent reduction in childhood deaths in the villages (Werner, 2002; www.healthwrights.org).

While the initial focus of the project was on curative and preventative healthcare, through the process of 'community diagnosis' – a method inspired by the 'education for liberation' approach of Brazilian lawyer and educator Paulo Freire – villagers identified that a major cause of their ill health was poverty. They further identified that a major cause of their poverty was that they had no land of their own and were forced to work for meagre wages on farmland unconstitutionally appropriated by a few powerful landholders – a defining problem in Mexican history. The villagers mobilised to demand their constitutional rights. The process was not always peaceful and included violent confrontations with the landowners and police and invasion of the farms. The government and the landowners recognised the villagers' strength and changes were eventually made. 55 percent of fertile riverside land was redistributed to landless farmers. The villagers now manage Project Piaxtla. Practical lessons learned in their initiatives to improve health and overcome other obstacles to health are recorded in a series of books: *Where There Is No Doctor*, *Helping Health Workers Learn*, and *Disabled Village Children*. These have influenced community health projects worldwide.

Community action is a powerful catalyst of social change. However, change need not always be confrontational and can be effected in a variety of ways, including through participation in socio-political dialogue and negotiations. This will be discussed in the next section.

5.2   Negotiating policy and health development

Policymaking involves a series of decisions and actions taken by a range of actors which are and have to be continually negotiated. Negotiation is therefore a key skill CSOs need to develop in order to influence pro-poor policy. Valuable insights on building negotiation skills are provided in a Drager et al. (2000). The product of a longstanding collaboration between the WHO and the Conflict Management Group, their book identifies principles and best practice for negotiation based on 'real-world experiences' of policy negotiations in over 40 developing countries, in health, planning, finance, development and other sectors.

Drager et al. identify four main **components of negotiations** in the design and implementation of health policy: prepare for decision making, e.g. through syntheses of reliable data on the negotiation topic and stakeholder analyses; select priorities and strategic options to provide flexibility; create conditions for successful implementation; and implement for results and learning.

Four **negotiation practices** are also highlighted: identify all parties involved, e.g. using a stakeholder analysis as discussed earlier; consider the interests, priorities, hopes and fears of all parties; develop multiple options and scenarios, keeping in mind that circumstances change and the need to be flexible; apply criteria and standards that are independent and verifiable to help make ongoing decisions.

Table 1 Negotiating health and development

	Components	Practices
PREPARE	• Select priorities and strategic options • Create conditions for successful implementation • Implement for results and learning	• Identify all parties involved • Consider the interests of all parties • Develop multiple options • Use independent standards and criteria

Source: adapted from Drager et al. (2000).

5.3   Health literacy

Building skills and capacities in the conduct and evaluation of research, in framing and communicating evidence, and in negotiating policy and development, is therefore essential for CSOs for effective influencing of policy and catalysing of more equitable development. In the context of health decision making and development, health literacy is a useful concept for elucidating the knowledge and skills required for informed and effective participation. Health literacy is defined as the skills and competencies that people develop and use to seek out, comprehend, evaluate and use health information and concepts to make informed decisions, reduce health risks and increase quality of life (Zarcadoolas et al., 2005). Health literacy can be considered as having the following dimensions (Nutbeam, 1998; Zarcadoolas et al., 2005):

- **Fundamental** literacy: reading, speaking and numeracy skills, and competence in comprehending print as well as spoken language.
- **Science and technology literacy**: knowledge of basic health, science and technology and an understanding of scientific uncertainty and change.
- **Community/ civic literacy**: knowledge of sources of scientific and policy information and how to interpret them. This domain includes media literacy skills and knowledge of civic and governmental processes.
- **Cultural literacy**: recognising, evaluating and using socio-cultural knowledge, norms, worldviews and identities in order to interpret and act on health information as appropriate to a given cultural context.
- **Communicative/interactive literacy**: cognitive and literacy skills which, with social skills, enhance participation in everyday activities and allow knowledge to be applied to new situations.
- **Critical literacy**: skills which allow for a critical examination and application of information.

Individual organisations may or may not have the range of skills and resources required to build these multiple capacities across multiple groups. Therefore, forming partnerships and collaborations for the same would be critical (Piotrow et al., 1997).

5.4   Media matters and the internet

The mass media often set public agendas and frame issues in ways which can subtly or dramatically influence policy (Bryant and Zillman, 2002). Many people get much of their health information from media (Brown and Walsh-Childers, 2002). There is also growing evidence that the media influence health policy agendas, utilisation of healthcare interventions by practitioners, and individual health behaviours (Grilli et al., 2002).

Figure 1 Writing an effective press release: the inverted pyramid

Interesting and informative headline
Date of press release

Summary sentence/lead – 5Ws and
H (who, what, when, where, how

'Quotable quote'

Most important details

↓

Least
important
(get cut)

Close with:
Conclusion or call to action
Contact details for follow-up
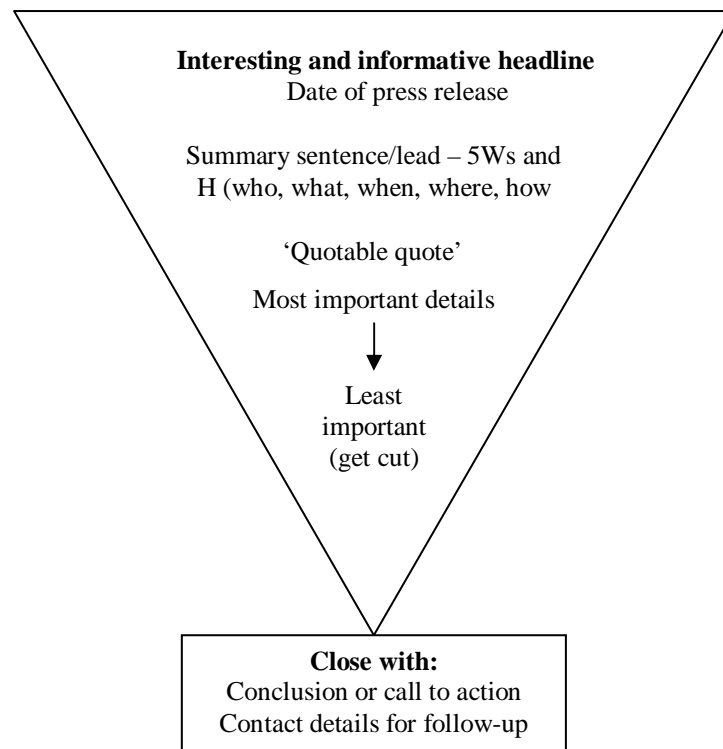
There are several sources of health information in the media; while there are often issues with the credibility and accuracy of such information, it is also true that mass media may have more checks in place to provide accurate information than, say, in informal interpersonal networks. Further, the issues covered in the media tend to reflect or project issues of societal importance. However, it is important to realise that the mass media are run as businesses and that the use of advertising for revenue and the need to 'sell stories' can influence both the topics covered and the content of media information (Pleasant et al., 2003).

Thus, CSOs need to be 'media savvy', not only to get their perspectives into the media, e.g. through writing compelling and 'newsworthy' press releases (see Figure 1), but also to evaluate the content, sources, and implications of media information for socio-political agendas (ibid.).

Access to media is a basic social development issue, and there are considerable inequities in access to media information within and between countries. Further, there are differing levels of media fairness and freedom. Thus, studies of media access, fairness and freedom would also be required to develop understandings on the role of the media in influencing equity and development agendas (Pleasant et al. 2003; Brown and Walsh-Childers, 2002).

The internet is a medium that is increasingly viewed as a democratising tool and a powerful means of communication and mobilisation for CSOs. While its potential is undeniable, internet communication also poses several challenges and concerns. For instance, there are concerns about the effects of computer-mediated communication on interpersonal relationships, for building shared meanings and experiences and for dealing with conflict, all usually achieved through face-to-face communication (Nie, 2001). There are wide gaps in internet connectivity across the world. The capacity to access, use and manage technology and content needs to be developed. Also, ensuring basic supporting infrastructure for connectivity, e.g. for electricity, also remains a challenge in some countries (Kuruvilla et al., 2004).

The United Nations Health InterNetwork project is one example of an initiative aimed at facilitating more equitable access to health research information through internet technologies that support health research and services, particularly in developing countries (ibid.). In a significant step towards facilitating more equitable access to health research information, the Health InterNetwork Access to Research Initiative (HINARI), a collaboration of the WHO and six main biomedical publishers, provides non-profit institutions in developing countries with a vast electronic library of information on public health of more than 2,000 current scientific publications. This initiative has been described by the WHO Director General as 'perhaps the biggest step ever taken towards reducing the health information gap between rich and poor countries'. (Details on eligibility criteria and registration are available on the website at http://www.healthinternetwork.org/.)

Despite initiatives such as this, the great inequity in access the internet remains a fundamental problem, particularly in the context of addressing the concerns of people in disadvantaged situations and in less industrialised countries. In this context, the internet may be viewed as just another tool used by the elite, even if these elites happen to be academic institutions or CSOs.

6. CSO Participation in Policy Processes

Having considered a variety of ways in which CSOs engage with research and communicate evidence to influence policy and societal change, this section examines how CSOs participate in more formal policy processes. CSO participation in policymaking can be analysed from various angles: models of public participation; the role of policy networks and stakeholder groups; and different mechanisms and types of participation.

6.1 Models of public participation

Participation in policy processes can be analysed by from the perspective of who or what defines or drives the interactions. Irwin (2001) proposes a threefold categorisation of these interactions.

The **social research model** *is* driven by public policy or research goals and institutions. It aims to elicit public views in a representative process across the population and in a timely manner for policymaking. The relevance of the pre-framed agendas for participants outside the research and policy systems is variable. This approach does not allow for much interpersonal interaction among the various actors; in the context of research, this could in fact be seen to bias the process. The advantage of this model is that interaction through public policy institutions has the potential to inform policy directly and influence resource allocation and action.

The **deliberative democracy** participation model is largely defined by civil society goals and CSOs taking a more active role in setting the agenda for policy interaction. Although this approach allows for more flexibility than the social-research model, it is often limited in the range of people and resources involved, and may have relatively weak practical or policy links. That having been said, the deliberative democracy approach had considerable impact in the HIV/AIDS-related activist movement which used evidence-informed advocacy and coordinated action to: influence health research agendas; impact policy; facilitate more affordable and equitable access to antiretroviral drugs; and catalyse changes in public health behaviours (Piot, 2000; Epstein, 1996).

A third model, the **localised model**, takes into account the contextual, complex and changing nature of the relationship among public policy institutions, scientific expertise and wider civil society, and the need for ongoing interaction. Irwin notes that the localised model 'fits less easily into the operational frameworks of policymaking institutions – although it does have important policy implications in terms of the advocacy of greater contextual sensitivity and the establishment of more open and two-way knowledge relations'.

6.2 Policy networks and stakeholder groups

In relation to a specific policy problem situation, networks of different stakeholder groups may pre-exist or form. It is often through networks that CSOs and other stakeholder groups deliberate on evidence and influence policy. A stakeholder group can be defined as a group of people or institutions that are affected by a specific problem, have a common interest on a particular issue, or could influence a proposed policy in a similar way (Drager et al., 2000; Brugha and Varvasovsky, 2000; Reich, 1996). Stakeholders can be categorised on at least three levels, according to:

- Affiliations with policy and civil society institutions;

- Potential roles in relation to the issue being considered, e.g. researchers; policy analysts; public officials; politicians; advocates; opposition; communicators and media; implementers; potential beneficiaries; and those potentially at risk;

- Specific positions taken in relation to a particular topic or problem.

Given the fluid nature of policy processes and the varying degrees to which stakeholder interests and roles are explicit or may change during the process, stakeholder analyses have to be conducted carefully, continually and critically during policy processes.

Membership in networks around a particular policy issue may be fixed or impermeable to outside participation, as in the so called 'policy iron triangles' of politicians, bureaucrats and defined interest groups (Heclo, 1978). However, on some issues more flexible and fluid networks may form; these are known as policy subsystems and advocacy coalitions (ibid.; Sabatier, 1992). Given that networks operate on the basis of knowledge-based interactions, they are sometimes seen as epistemic communities or 'invisible colleges', each with their own norms and practices (Haas, 1992; Knorr-Cetina, 1999). Influential networks or influential actors within them can control the interpretation of a policy problem and thus also control the substance and nature of political discourse on a problem situation (Heclo, 1978; Sabatier, 1992; Huckfeldt et al., 2004). As an additional dimension of political power, Bachrach and Baratz (1962) show that power operates not only through shaping policy deliberation, but also by keeping issues off policy agendas resulting in 'non-decision making'.

It is important to realise that within networks, individuals may hold diverse opinions. The discursive power by which those opinions are communicated, the strength of network relationships, and situations that pitch different networks against each variously contribute to differing levels of convergence in political opinion among members (Huckfeldt et al., 2004). Policy networks can be analysed by identifying salient policy issues, mapping stakeholders and the networks they form, and then analysing the strength of relationships within those networks and the perceived power of different stakeholders within and among networks on a particular issue (ibid.).

In order to identify principles underlying the management of networks and their implications for governance, leadership and policy, Goodwin et al. (2004) analyse networks across a range of sectors – defence, biotechnology, crime, health and social care. They identify three basic types of active networks.

- **Enclave networks** operate through cohesive forces connecting members by shared values, trust and commitment to certain goals. There is usually no central authority or institutionalisation. These networks have great value for mobilising support and creating 'bottom-up' legitimacy, but can be unstable owing to lack of resources and institutional support.

- **Hierarchical networks** have organisational structure and are coordinated by steering groups or other authoritative bodies. These networks can be efficient at coordinating and implementing predefined tasks, but may fail from over regulation and bureaucratisation and the lack of a mandate to manage its members.

- **Individualistic networks** are driven by single individuals or organisations that develop affiliations in relation to a particular task, e.g. through procurement of services. Such networks can provide innovative and flexible means of working, but can result in conflict and competition, as there is no long-standing relationship to facilitate shared understandings and approaches.

Rather than privileging any one type of network over another, organising and managing diverse networks for different purposes seems the strategy most likely to facilitate meeting complex policy and programme challenges (ibid.).

6.3   Participation mechanisms

There is a wide variety of mechanisms used to facilitate civil society debate and discussion in decision making, some of which are listed in Box 1.

Box 1 A review of participation mechanisms

• advisory committees • advocacy and special interest groups • citizens' juries/panels • community-based and participatory research methods • consensus conferences • deliberative polling • Delphi techniques • focus groups and nominal group techniques • fundraising and community dinners	• large-scale public engagement initiatives • lobbying • negotiated rule making • public hearings and consultations • public opinion surveys • referenda • representation on steering groups and review boards • policy scenario workshops • science and policy workshops

Source: adapted from Pleasant et al. (2003).

Institutional frameworks and capacities influence how participation mechanisms are used and to what effect (Fischer, 2003; Cornwall, 2000). For instance, one pragmatic consideration is that some national constitutions require that certain governance functions, such as those of the civil or judicial services, are not subject to amendments by public deliberation or popular choice (Scruton, 1982). Also, almost paradoxically, although participation is often associated with shared control and decentralisation, strong leadership seems required to enable effective participation. For example, a survey across 45 local (*município*) health systems in Ceara, Brazil, where decentralisation is central management tenet, indicated that good management practices led to decentralised local health systems rather than vice versa. Additionally, a regression analysis of the data indicated that association between decentralisation and performance seemed to be an artefact of factors relating to informal management practices and political culture (Atkinson and Dave, 2004).

Similar findings resulted from an ethnographic study of participation in health services provision in Uganda, which in addition questioned the ability and interest of civil society to participate in health services decision making. The Uganda study concluded that 'To succeed in the long term, devolution and participation must take place in the context of a strong state, able to ensure consistent regulation, and a well informed public backed up by a participatory political culture' (Golooba-Mutebi, 2005: 165).

In addition to effects of institutional processes, the logistics related to the design and management of participation initiatives also need to be better understood. Different participants can influence policy differently. For example, one reason suggested for 'what went wrong' in the 1993–4 healthcare reform initiative in the US is that only certain groups with previous or special interests in the process participated, thus skewing the results (Brodie, 1996). In any participation effort, the level to which communities and individuals within those communities are interested in dialogue and collaboration may change and cannot be taken for granted (Butschi et al., 2002; Dugdale, 1999; Cooke and Kothari, 2001; Golooba-Mutebi, 2005). It is assumed that public policy and civil society institutions have different types of power and knowledge. How these powers and knowledges

develop, manifest and influence participation and policy process will vary and may be difficult to assess (Walt, 1994; Brugha and Varvasovsky, 2000; Drager et al., 2000).

6.4   Levels and types of participation

There are various approaches used to assess the nature and level of participation in the literature. In a WHO and UNICEF-supported project to identify factors influencing civil society participation in health decision making, Bichmann et al. (1989) reviewed over 200 case studies from different countries. Their analysis highlights five key domains for analysis of participation.

- Needs assessment
- Leadership
- Organisations involved
- Resource mobilisation
- Management

In each domain, a five-point scale is used to rate the level of community participation: narrow, restricted, mean, open, and wide. The combined rating from all five domains then provides an overall measure of the level of community participation and could be represented on five axes of a spider graph. Other researchers have described levels of socio-political participation based on different categorisations but overlapping criteria (Arnstein, 1969; Litva et al., 2002; Naylor et al., 2002). For example, Litva et al. adapt Arnstein's ladder of participation to categorise the nature of participation in decision making, using an ascending hierarchy of participation ranging from: manipulation; therapy; informing; consultation; placation; accountable consultation; partnership; delegated power; through to citizen control.

There are critiques of hierarchical approaches to assessing participation. It is not clear whether the different levels in hierarchical scales are equidistant. It is also not clear what type of decision processes are being considered; participation in operational matters may easily be accepted, but participation in financial decision making may be more contentious (Khan, 1999). The approach taken by Bichmann et al. addresses different types of decision making, but the other categorisations do not. Further, the language in hierarchical scales seems to suggest that the goal is everyone participating all the time, whereas this may be impracticable, inefficient and even ineffective (ibid.; Cooke and Kothari, 2001). For example, in Switzerland direct democracy and public referenda are an integral part of policymaking, but now different modes of civil society participation are being explored to enable more effective meeting of public and decision-making needs, interests and capacities in relation to different topics (Butschi et al., 2002).

To address these issues, Khan developed and tested a matrix of public involvement to analyse different types of participation in decision making, as mechanisms may be applied differently in different contexts (see Figure 2).

The public involvement matrix is structured along two axes. The first extends from **collectivistic** to **individualistic**, based on whether everyone who may be affected by the policy participates or whether individuals choose to participate depending on their interest in the topic and the specific type of services they want. The second axis takes into account whether the mechanisms encourage people to think in **holistic** terms about the larger common good, or rather in terms of **particularistic** needs and interests.

Figure 2 The public involvement matrix
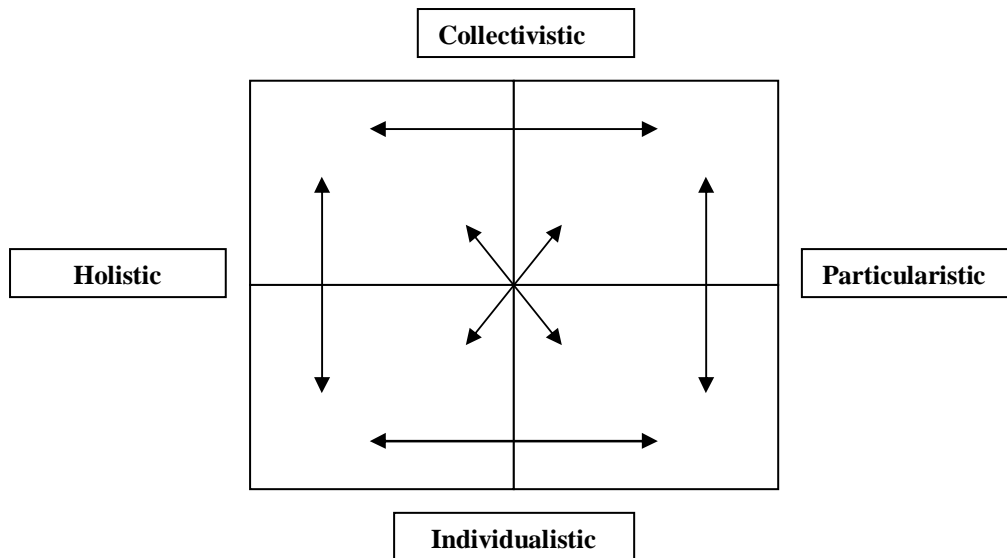
Source: Khan (1999).

This matrix was applied and validated through a series of European case studies on state and civil society dialogue on health, education and planning. In their analysis, Khan shows that, although participation mechanisms may be located primarily in one of the cells, they could move laterally or vertically along the two axes depending on the topic and the type of policy process involved.

When designing or evaluating participation in policy processes, it is important to recognise that, even if there were evidence that collective action would lead to both holistic and individual benefit, people may still act primarily to satisfy their individual needs. This phenomenon and the resultant loss for individuals themselves and for society as a whole has been studied in various contexts and is referred to as the 'tragedy of the commons' (Hardin, 1968).

Assessing mechanisms and types of participation is an area which requires much further research, including on: the comparative strengths and weaknesses of mechanisms; the appropriateness of mechanisms for different objectives; underlying assumptions and implications of different types of participation; and cost effectiveness, particularly in resource-strapped contexts (Abelson et al., 2003; Crawford et al., 2002).

7. Evaluating CSO Participation in Research and Policy

'Cheshire, would you tell me, please, which way I ought to go from here?' 'That depends a good deal on where you want to get to' said the Cat. 'I don't much care where –' said Alice. 'Then it doesn't matter which way you go' said the Cat. '– so long as I get somewhere' Alice added as an explanation. 'Oh, you're sure to do that' said the Cat, ' if only you walk long enough' Lewis Carroll in Alice in Wonderland.

The lack of systematic evaluation of participation against defined criteria and objectives is a major barrier to developing understandings on the influence of CSO participation on research and policy as well as on health and development outcomes (Crawford et al., 2002; Cooke and Kothari, 2001; Abelson et al., 2003; Irwin, 2001). There is also a lack of agreement on basic definitions and assessment methods, which hinders monitoring of change and learning across different contexts. Thus, with regards to evaluating participation outcomes, it is often not clear where we need to go nor how we are going to get there.

There are several additional difficulties with undertaking evaluations of participation effects and outcomes. Evaluations tend to be defined by relatively short-term funding or project cycles. Health and development changes, however, may be more long term in nature and could occur totally unrelated to those cycles. In addition, the range of factors influencing research, policy, health and social change makes it difficult to attribute such changes to any single process or actor. For example, the eradication of smallpox is one of the greatest success stories in public health, but attribution of that success is complicated. Inoculations against smallpox were given as early as the 10th century in China and a few centuries later in the Ottoman Empire, where the practice was observed by Lady Montague. Over the next 200 years, before smallpox was finally eradicatedin the 20th century, it was necessary to have: concerted effort by prominent advocates around the world, such as Lady Montague, George Washington and Francisco Balmis; scientific advances by researchers like Edward Jenner; political commitment from governments; coordination of smallpox eradication initiatives by international organisations; and widespread civil society engagement across several countries (Gross and Sepkowitz, 1998).

In dramatic contrast, Nevirapine – a drug to prevent mother to child transmission of HIV – had a virtually unprecedented speed of uptake, with widespread activism and demand for the drug less than one year after the first clinical trial, particularly in Africa. Activist groups in South Africa made a successful legal argument, based on the Right to Health provisions in the South African constitution, against the South African government itself for restricting access to Nevirapine to a few pilot sites (Annas, 2003). Within a year of that ruling, however, there were growing concerns and controversies around identified flaws in the research process, allegations of unethical cover-ups of side effects, and debates on the equity and human rights implications of this case (www.cbsnews.com/stories/2004/12/14/world/main661117.shtml). The Nevirapine example highlights the need for careful and ongoing evaluation of research, participation and policy processes and outcomes. It also echoes lessons learned from analyses of diffusion of innovations research.

Over the past 30 years, diffusion of innovations has been a defining concept across a range of development sectors (Rogers, 1995). However, the short-term, process-focused nature of diffusion evaluation led to several problems with long-lasting implications for development and equity. The diffusion of innovations approach was strongly critiqued, particularly in Latin America (ibid.; Figueroa et al. 2002). Main concerns included:

- Promoting a pro-innovation bias in development assessment where the adoption of the research or innovation was considered an end in and of itself. This resulted in long-term effects being

ignored, such as inequities created by differential access to innovations or by differential exposure to associated risks.

- Overlooking wider socio-political contexts and influences that could affect the way in which the innovation was used, thus hindering understanding of how those factors influence not only development processes, but also the use and misuse of research-based innovation and policy, which in health could have fatal consequences.

- A failure to consider alternative options which may have been more appropriate and affordable, particularly in developing country contexts where such options may have been stifled by development innovation 'hard-sell'.

These lessons from diffusion of innovations research are valuable. More comprehensive approaches to assessment are being developed and tested, which is important particularly from the perspective of influencing policies to promote equity and social development, given the range of factors involved in influencing those outcomes.

The emphasis in this paper is on identifying organising principles, in this case on evaluating the effects and outcomes of participation. The 'rights-based approach to development' provides an important orientation for evaluating participation in the context of developing pro-poor policies and facilitating equitable health and development outcomes. Special Rapporteur of the Commission on the Human Right to Health, Paul Hunt, outlines (2003) key components for assessments of health, development and human rights:

- **Baseline data** is fundamental to assessment and to monitoring change, but a serious gap in many health and development contexts. For example, a basic requirement to monitor the realisation of human rights – including non-discrimination, the right to participation and the right to health – is that every citizen is counted. However, even basic data from registration of births and deaths or from censuses is patchy at best in several countries (Tomasevski, 2001).

- **Structural indicators** identify whether or not there are in place key structures and systems, in terms of the institutions, infrastructure and capacities required to realise established targets and benchmarks. Such structures include legislation, policies, mechanisms, institutions such as health services, as well as capacities in terms of skills and resources.

- **Process indicators**, as the term suggests, provide information on the process and mechanisms of policy and programme implementation. By providing a measure of activity levels, process indicators facilitate monitoring progress of mechanisms and programmes towards defined policy objectives.

- **Outcome indicators** help assess progress over time towards achieving defined health, development and human rights targets or benchmarks. Whereas process indicators assess the effort in terms of the level and manner of policy implementation and use, outcome indicators assess the results of policy implementation and use.

- **Benchmarks and targets** provide standards against which process and outcome indicators can be monitored and evaluated to provide an idea of the extent to which desired change is achieved in the intervening period. Examples of targets and benchmarks include human rights and legal standards with regard to participation and non-discrimination, the Millennium Development Goals, and other local, national and international targets for health and development.

Assessment data should be disaggregated based on the prohibited grounds of discrimination (gender, age, race, socioeconomic status, religion etc.); targets and benchmarks should reflect this. Indications of failures to meet benchmarks and targets, or evidence of unexpected effects, would signal the need for action in the form of policy adjustment, reallocation of resources, revising implementation strategies, or considering alternative options. Ideally, benchmarks and targets should be set by means of stakeholder participation to ensure relevance and buy-in.

Reviews of approaches, methods and tools to assess various structural, process and outcome indicators of CSO participation in research and policy indicate that considerable theoretical and methodological development and testing is ongoing, for example: of health impact assessment indicators, especially as relates to equity and gender considerations (WHO, 2003); on analysing the processes and outcomes of communication for social change (Figueroa et al., 2002); on assessing health promotion outcomes (Nutbeam, 1998); on evaluating complex policy interventions (Mays et al., 2001); on analysing the utilisation of research in policymaking (Hanney et al., 2003); on assessing the processes and effects, including media coverage, of public engagement with health research (Pleasant et al., 2003); on measuring social capital in health and development (Kawachi, 2001; Campbell et al. 1999); and on analysing influencing factors in globalisation and health (Woodward et al., 2001).

It is hoped that by highlighting a range of models, measures and mechanisms, this paper provides frameworks to inform the design and evaluation of CSO participation in research and policy and to debate further on definitional clarity and methodological development on this topic.

8. Discussion and Recommendations: an Integrated Perspective on Participation and Policy

This paper has reviewed and categorised several models, measures and mechanisms related to different aspects of CSO participation in health research and policy. As such, this review could be used to further define, deliberate, design and evaluate different aspects of participation initiatives. The references used in this paper supplement those in the accompanying annotated bibliography, providing a rich source for further reading on these issues. However, this discussion could be taken one step further in terms of asking how the range of models, mechanisms and measures reviewed in could be integrated to provide a coherent and integrated perspective on CSO participation in research and policy. This final section of the paper provides a brief summing up or overview of how different aspects of CSO participation can influence research and policy processes.

In this section, a 'decision cell model' (Kuruvilla and Dorstewitz, forthcoming) is used as a tool or framework to help integrate various concepts discussed earlier and indicate how CSOs could apply these concepts to influence policy processes. This model was developed in response to commonly identified problems with the linear 'stages' model of policymaking (Figure 3).

Figure 3 Prototypical elements of linear instrumental models
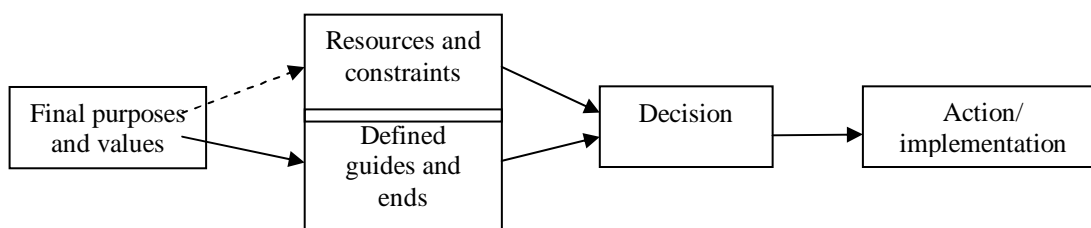
Source: Dorstewitz and Kuruvilla (2005).

While several useful insights into policy processes have resulted from analyses of individual policy stages, there are several serious problems with using the overall stages model, particularly in terms of the 'linear instrumental rationality' that underlies these models. In linear instrumental models, a defined end is the starting point for policy processes; means are then defined to meet this end (Dorstewitz and Kuruvilla, 2005). A fixed or defined end is shaky ground on which to base policymaking first of all, as ends and goals can be framed differently to different effect. For example, Kingdon (1995), in an empirical analysis of policy agenda setting, discusses how the goal of facilitating disability access in public spaces could be framed as a civil rights issue or as a transport issue, and he points out that these alternatives are associated with very different policy considerations, socio-political groups and goals.

Ends may also need to be redefined in the light of experiences on the ground and changing socio-political contexts. Then there are the moral ramifications of excluding values and goals from further deliberation (Dorstewitz and Kuruvilla, 2005). Dewey explains that we do not fully comprehend 'ends' until we valuate the means to those ends in terms of their costs and consequences, and this valuation needs to be an ongoing and iterative process (Dewey, Theory of Valuation Later Works 13; Reconstructions in Philosophy Middle Works 12). In addition, linear stages models do not capture the interactive, dynamic and contextual nature of policymaking. As Walt and Gilson (1994) note,

Much health policy wrongly focuses attention on the content of reform, and neglects actors involved in policy reform (at the international, national and sub-national levels), the processes contingent on developing and implementing change and the context in which policy is developed.

Based on key perspectives from pragmatist philosophy, particularly John Dewey's epistemology of agency and his 'logic' of inquiry to resolve problematic situations (Dewey, Experience and Nature Later Works 1; Logic: Theory of Inquiry Later Works 12), it has been proposed that a revised rationality for decision making, situational transactive rationality, could help address these problems (Dorstewitz and Kuruvilla, 2005). The decision cell model was informed by this rationality critique and by empirical and theoretical analyses of policy processes. Discussions on rationality in policymaking and on the development of the decision cell model are detailed elsewhere (ibid.; Kuruvilla and Dorstewitz, forthcoming).

In this section, the decision cell model is used as a tool or framework to help integrate a range of perspectives on how CSOs can participate in research and policy and negotiate matters of public concern. Figure 4 provides a schematic of the decision cell model and of different functional elements that broadly constitute policymaking.

Figure 4 The decision cell: an integrated and interactive model of policy processes
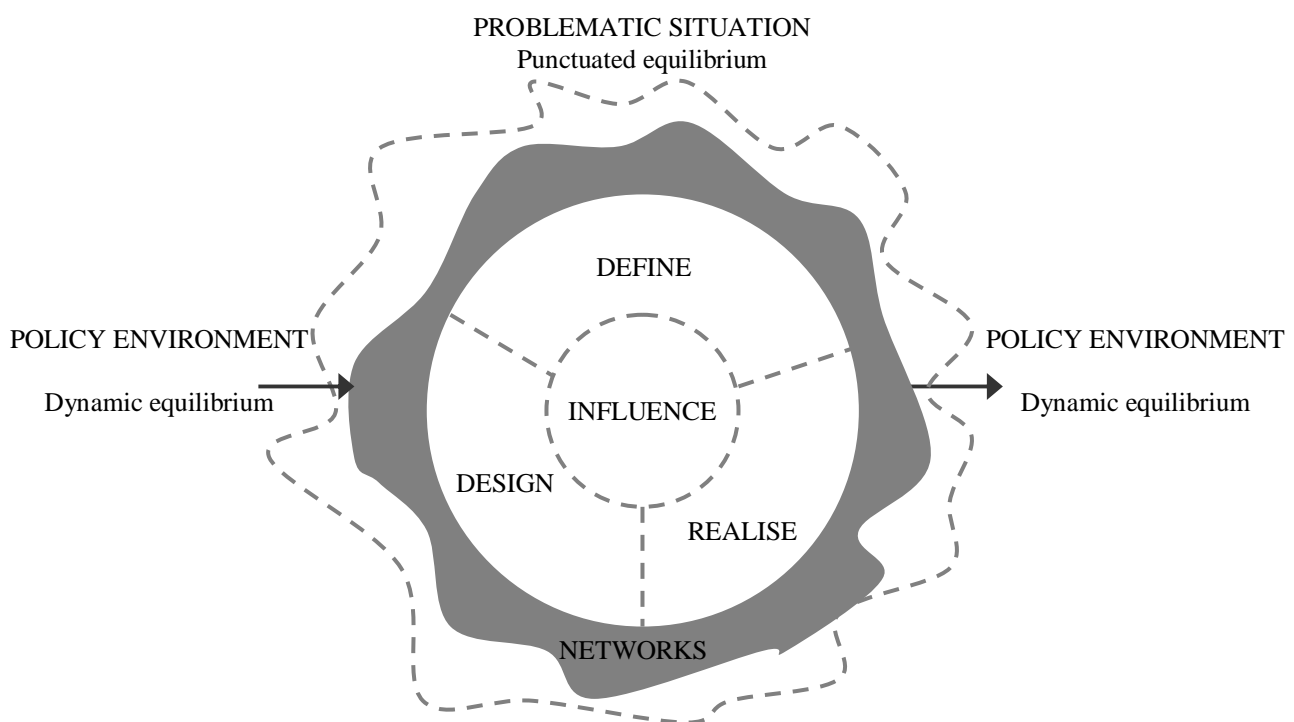
Source: Kuruvilla and Dorstewitz (forthcoming).

The cell-shaped representation indicates that this model is constituted of interdependent activity modes that function together as a system. First, this means that different decision activities may take place separately or concurrently in different phases, but are nevertheless interlinked and influence each other. Secondly, all processes are considered *formative* for policy, as opposed to the focus on some 'dramatic moment of political decision making' in linear stages models (Friedman, 1973). Each element in the decision cell model will now be outlined in relation to the models, mechanisms and measures of CSO participation in research and policy discussed in previous sections of this paper.

Policy environments can be characterised as having institutional, technological, legal, political, economic, demographic, ethical, ecological and cultural dimensions (Hall, 1977; Dorstewitz and Kuruvilla, 2005). These environments may contain habitual and relatively unproblematic events and interactions, but when the flow of events is interrupted or challenged for any variety of reasons, a **problematic situation** arises. Prior to processes of problem definition, this is basically an indeterminate state or a sense of 'punctuated equilibrium' (Baumgartner and Jones, 1993) which requires further inquiry. A problematic situation thus provides a basis for socio-political agency (Dewey, Logic: Theory of Inquiry Later Works 12; Dorstewitz and Kuruvilla, 2005). The concept of problematic situations broadly ties in with earlier discussions in this paper on recognising 'matters of public concern' in which several actors in society potentially have a stake and which therefore require policy activity.

In relation to a specific problematic situation or policy problem, **networks** of actors and institutions with particular interests and perspectives on the issue may pre-exist or form and interact with policy processes through various participation and deliberation **mechanisms** (Heclo, 1978; Friedman, 1973). There are several institutional and structural factors influencing the nature of participation in policymaking, including: the degree to which policy networks are established and allow for new membership; the openness of policy institutions to new ideas; and the range of interests represented in policy processes (Howlett and Ramesh, 2003; John, 1998). These are considerations of particular importance in the context of challenging the status quo and representing the interests of people in disadvantaged situations. CSOs could influence how equitably various interests are represented in policy networks by conducting and using stakeholder analyses and influencing policy processes through diverse configurations of networks (Drager et al., 2000;Goodwin et al., 2004), as discussed in previous sections.

In relation to a problematic situation, actors, institutions and networks involved may engage in various ways with four main decision activities or policy processes: define, design, realise and influence. The distinction among these activities is not rigid and is made on the basis of the main functional emphasis in each process; the model explicitly recognises interactions and iterations between these activities. Each of these decision activities will now be described, and the relevance of various themes discussed in this paper will be highlighted in this context.

Define is a decision activity that institutes a policy problem and delimits a problematic situation. The functional emphasis in this decision activity is on structuring the problematic situation in order to understand the problem better and seek solutions. In order to orient themselves in a problematic situation, actors develop and test various definitions and scenarios. As discussed earlier, different actors can frame policy problems differently. The mass media play an important role in this phase, by reflecting and shaping issues of perceived importance in society. Thus, a range of differing and competing perspectives may be generated. There are several ways in which CSOs can influence how policy problems are defined, including: conducting research on the problematic situation; facilitating analysis of problems by those in disadvantaged situations; framing evidence to define the policy problem; and using different criteria to evaluate research and evidence presented by others. These issues have been discussed in corresponding sections of this paper.

Design is an activity whereby different approaches to addressing the policy problem are evaluated and negotiated until there is commitment to a particular approach. Agreements have to be reached among various stakeholders on operational definitions, strategies and allocation of resources and roles. This is probably the most technical phase in policymaking, e.g. with the use of technical assessment methods and modelling. As discussed earlier, several governments now require civil society participation on decision-making bodies and also public comment on proposed policy approaches. Thus, while CSOs may or may not be directly involved in the technical aspects of this activity, they can play a critical role in this phase by building health literacy capacities, both their

own and those of their constituencies, to understand and evaluate different policy approaches and their possible consequences, especially in terms of health, equity and social development. Further, CSOs can influence agreements on possible policy approaches in policy negotiation processes, as outlined by Drager et al. (2000) and described earlier.

Realise, as the word suggests, incorporates elements of 'putting into practice' and of 'evaluating or learning' and is in line with the pragmatist concept that any effectuated change implies a changed experience and thus breaks down the boundary between 'implementing change' and 'learning from experience' (Dewey, Logic: Theory of Inquiry Later Works 12). This activity is focused on restoring harmonious experience or equilibrium. Activities in this functional phase include implementation of agreed upon approaches and evaluation strategies. CSOs can play a critical role in this phase through their involvement with policy processes 'on the ground' and by assessing the impacts of the selected approaches, particularly on disadvantaged communities. For example, the services provided may be inadequate or fail to meet human rights standards in terms of non-discrimination regarding access to those services. This learning would then require changes in practice, redefinition of the problematic situation, or renegotiation of elements of policy design.

Influence is a functional interface linked with definitive or dominant ideas and interests from the other decision activities, which then shape the entire policy process. Thus, this phase both is influenced by and influences the other decision activities. Empirical evidence indicates that formative ideas and interests gain influence through a combination of strategy, timing, resources, power dynamics and negotiation among stakeholders with different interests and perspectives (Kingdon, 1995; Howlett and Ramesh, 2003; Walt, 1994). As discussed earlier, political power operates not only through defining a problem situation, but also through keeping issues off policy agendas (Bachrach and Baratz, 1962). It is, therefore, important to analyse not only what issues are influential in policy processes, but also what issues have been kept out. In effect, interacting at key research and policy interfaces, building health literacy, negotiation skills and evaluation capacities, and learning to manage networks effectively are all strategies which CSOs could usefully employ to influence which ideas and interests define policymaking.

A problematic situation may be resolved and equilibrium restored in a variety of ways, e.g. when the problem is addressed satisfactorily; through ongoing adjustment and interaction to maintain equilibrium; by people accommodating to the problem and learning to 'live with it'; if new or more pressing problems emerge; or the issue is viewed as a transient fad or episode (Dewey, 1938, 1954; Walt, 1994; Howlett and Ramesh, 2003; Kingdon, 1995). In order to resolve a problematic situation and to maintain equilibrium in ever-changing socio-political contexts, there is need for ongoing and critical dialogue that represents the interests of all those who have a stake in various matters of public concern. In line with this thinking, Irwin (2001: 16) advises that:

> *Rather than seeking a perfect solution to the relationship between science and democracy ... it is necessary to adopt a flexible or situationally appropriate approach to all models and technologies of community. In that way, the relationship between science and society should not be about the search for universal solutions and institutional fixes, but rather the development of an open and critical discussion between researchers, policymakers and citizens.*

In conclusion, it is hoped that the concepts and ideas discussed in this paper will contribute to the ongoing and critical dialogue on the design and evaluation of CSO participation in research and policy. In addition, it is hoped that the paper will encourage debate on how the interests of individuals and communities who are disadvantaged are considered and addressed in these processes. However, in order for CSO participation to take effect and make a difference, we will need to move beyond theoretical discussions and apply these understandings to strategic action and rigorous analyses of whether and how CSO participation influences policymaking as well as individual wellbeing, equity, and societal development.

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