

# Making research matter: a civil society perspective on health research

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**Abstract** Complex global public health challenges such as the rapidly widening health inequalities, and unprecedented emergencies such as the pandemic of human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) demand a reappraisal of existing priorities in health policies, expenditure and research. Research can assist in mounting an effective response, but will require increased emphasis on health determinants at both the national and global levels, as well as health systems research and broad-based and effective public health initiatives. Civil society organizations (CSOs) are already at the forefront of such research. We suggest that there are at least three ways in which the participation of CSOs in research can be increased: namely, influencing commissioning and priority-setting; becoming involved in the review process and in conducting research; and through formal partnerships between communities and universities that link CSOs with academic researchers.

**Keywords** Health services research; Delivery of health care; Nongovernmental organizations; Primary health care; Epidemiologic factors; Health priorities; Policy making; Social justice; Consumer participation; Evidence-based medicine (*source: MeSH, INSERM*).

**Mots clés** Recherche en santé publique; Délivrance soins; Organisations non gouvernementales; Soins santé primaires; Facteurs épidémiologiques; Choix d'une politique; Justice sociale; Participation consommateurs; Médecine factuelle (*source: MeSH, NLM*).

**Palabras clave** Investigación sobre servicios de salud; Prestación de atención de salud; Organizaciones no gubernamentales; Atención primaria de salud; Factores epidemiológicos; Formulación de políticas; Justicia social; Participación comunitaria; Medicina basada en evidencia (*fuentes: DeCS, BIREME*).

Arabic

Bulletin of the World Health Organization 2004;82:757-763.

Voir page 762 le résumé en français. En la página 762 figura un resumen en español.

## Introduction

It has taken an epidemic of the magnitude of that of human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) to prompt a re-examination of the policies and actions required to achieve health for all. This challenge will require interventions that ameliorate the underlying local and global social and environmental health determinants, ensure greater equity in access to sustainable health systems and assist in the rebuilding of public health capacity in poor countries and poor communities.

Research can assist in achieving these goals, but will require increased emphasis on global, national and local health determinants. It should stress population health perspectives, health systems research with a focus on implementation, and studies of the effectiveness of strategies designed to bring about progressive social and economic change. Civil society organizations (CSOs) can play an important role by influencing, generating or using such research. CSOs are already taking the lead in research investigating the broader determinants of health at the global and national levels. Examples of participatory research also show how engagement with CSOs can improve

health systems. Experience demonstrates that research findings are more successfully implemented when they are part of campaigns involving mobilized groups of citizens.

There is a growing realization of the need for engagement with civil society. However, "civil society" is a problematic term. Broadly, it refers to social relationships and organizations outside either state (government) functions, or market-based relations that define people simply as "consumers" rather than more collectively, for example as citizens, neighbours or colleagues. In a narrower context, civil society includes organized groups concerned with public interests. For the purposes of the present study we have excluded organizations aimed at promoting private business interests. We see CSOs as a broad grouping that incorporates nongovernmental organizations (NGOs) and less formally organized groups that may be based in local communities such as youth groups or women's groups. This article, presents a "civil society perspective", and although it draws on the authors' combined 90 years of experience in working in and with CSOs, it should not be interpreted as *the* civil society perspective. The plurality of CSO interests precludes any such interpretation.

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Ref. No. 04-011114

(Submitted: 5 January 2004 – Final version received: 23 June 2004 – Accepted: 1 July 2004)

There are at least four different and non-exclusive ways in which civil society is involved in health research:

- as funders (primarily the charitable disease-based health organizations such as “heart and stroke” or “cancer” societies);
- as users (which raises the issue of the relevance of health research to CSOs);
- as generators (whether or not in some form of relationship with university-based researchers); and
- as subjects (the role of CSOs in affecting policy and broader social changes that improve health equity).

Any health research that gathers information from individuals or groups in the context of their daily lives is also providing a civil society perspective to that research. Increasingly, local communities, particularly indigenous or disadvantaged groups that have historically been treated as passive subjects in health research, are demanding more active forms of participation in all phases of the research cycle. Active participation, and more equitable relations between researchers and community members, sometimes described as “participatory action research” can increase the relevance of the research to CSOs. The ethical and power-relational issues of the relationships between communities and researchers are vitally important, but are outside the scope of this article.

Our principal concern in this article is with the second and third relationships, i.e. with CSOs as users or generators of research knowledge. We first discuss the global context within which health research must engage, and assess the currently dominant approach to health research. We then describe what we consider to be the priorities for health research of interest to civil society, and conclude with some suggestions for increasing such research.

## The current context of health research

A key imperative for health research must be a sharper focus on both the growing divide in health and wealth between the world’s rich and poor, and on the unacceptable gap between unprecedented knowledge about diseases and their control and the implementation of that knowledge, especially in poor countries. This situation demands directed and innovative research responses to analyse the causes of this situation and to point towards solutions at the global and local levels, both within and outside the health sector.

An analysis of disaggregated data for infant mortality and life expectancy shows that the gap between rich and poor countries is widening substantially. Sub-Saharan Africa is the most notable example of this growing divide. A combination of new and old infectious diseases — in particular HIV/AIDS — and rising rates of noncommunicable diseases have resulted in the populations of countries such as Kenya, South Africa, Zambia and Zimbabwe losing more than 10 years in life expectancy in a short period of time (1). In many of these countries this situation is exacerbated by public health systems that have all but collapsed as a result of chronic underfunding and loss of personnel, with an accelerating “brain drain” that is reaching crisis proportions and raising ethical questions regarding recruitment by the wealthy countries (2, 3). The problem of dysfunctional health systems has been aggravated by ill-considered and inappropriate reforms in the health sector (4). A stark reflection of the undermining of health systems is the dramatic fall in immunization rates for the six basic childhood vaccines in poor countries, despite the impressive

increases in coverage during the 1980s and the subsequent intensive WHO-driven campaigns for the eradication of polio and measles (5).

The context for this scenario is economic globalization, characterized by the growing dominance of a global financial and trading system that is rapidly integrating poor countries into an increasingly monopolized world economy and is leading to greater disparities in wealth between and within countries. For instance, in 1999, 28 of the 48 countries in sub-Saharan Africa had an average per capita income of less than US\$ 1 per day, compared with 19 of 36 countries in 1981 (1). These economic changes started with structural adjustment programmes (SAPs) in the 1980s. In many countries the SAPs resulted in significant restructuring in the public sector and reduced social provision. This had negative effects on education, health and social services for the poor, particularly in Africa (6).

To make matters worse, the level of overseas development assistance (ODA) decreased substantially during the past decade and has only recently begun to increase again. However, health assistance has never represented a large portion of ODA, averaging between 4% and 6% of total multilateral assistance (1975–1998: 5-year moving average) (7).

The HIV/AIDS pandemic in sub-Saharan Africa can be considered as much a product of the increased poverty and retrenched public health systems, as of the lack of knowledge about prevention or lack of access to antiretroviral drugs (8, 9). The situation is made worse by the increasing brain drain of health professionals, including health academics and researchers, from the public to the private sector and from Africa to wealthy nations (10).

On the basis of the above considerations, health research must give priority to:

- underlying health determinants (examining the causes of the increasingly unequal burden of ill-health between and within countries);
- health systems implementation, including individual service provision, community governance models, detailed case-studies of comprehensive primary health care and population-based approaches (to determine the factors that influence the success of interventions delivered under normal programme conditions and to measure their impact); and
- strategies of social change (analysing what forms of social mobilization — local, national or global — are best able to effect policy changes for improving underlying determinants and health systems).

We contend that these issues, and their social and political contexts, are the central concern for many CSOs, and it has often been research initiated by CSOs and their advocacy that first brought these concerns to political light. Examples of the research work of CSOs are listed in Table 1. CSOs do also lobby for more basic health research into disease treatment, e.g. for HIV/AIDS, cancer and neglected diseases. Even in treatment-focused campaigns, however, CSOs often draw attention to the problems of inadequate health systems or underlying health determinants.

## Health research: its current focus and relevance

Health research of the three types described above still accounts for only a small fraction of global health research. When health research, as reflected in published articles, is classified, it is clear

Table 1. Examples of health research on globalization processes conducted by civil society organizations

Group	Issue
Oxfam	Unequal trade rules favouring wealthy countries
Save the Children (United Kingdom) Wemos (Netherlands)	Trade agreements and health (general)
Canadian Centre for Policy Alternatives; Training and Research Support Centre (Zimbabwe)	General agreement on trade in services and public health systems (specific)
Equinet (Southern Africa)	“Brain drain” of health professionals
Treatment Action Campaign (South Africa)	Trade agreements and essential drugs
Médecins Sans Frontières	Orphan diseases (diseases for which no or few effective drugs exist)
Jubilee campaign	Debt relief/cancellation
Eurodad	Development assistance
Afrodad	Poverty reduction strategy papers
Canadian Council for International Cooperation	Trade versus aid
Centre for Public Integrity Council of Canadians Municipal Services Project	Privatization and corporatization of water services
Social Watch	Monitoring of millennium development goals
International Baby Food Action Network	Multinational infant formula marketing
Health Action International	Access to essential drugs

that the overwhelming emphasis, both in terms of funding and number of publications, is on fundamental and clinical research. In public health research, the focus is predominantly on descriptive and analytical epidemiological research (i.e. research to answer the questions: what, why, where and who?). Less emphasis is placed on efficacy research (testing interventions in a controlled situation) and hardly any on implementation research — the “how” of translating current research knowledge into practice within existing health and social systems (11–13).

Efficacy research has been strengthened recently by the Cochrane Collaboration, whose focus has mainly been on conducting systematic reviews of the evidence in support of (mostly clinical) interventions. However, the Cochrane Collaboration has tended to neglect the three types of research that we argue are important to CSOs, or that provide useful information to policy-makers. This neglect derives mainly from the Cochrane Collaboration’s paradigm that values quantifiable outcomes measured under controlled conditions more highly than qualitative and process-oriented outcomes. Rogers (14) examined the implicit promises of fairness in evidence-based medicine (EBM); namely to avoid discrimination through objective processes, and to distribute effective treatments fairly. Her analysis indicated that even within industrialized countries, EBM turns

attention away from the sociocultural factors that influence health and focuses on a narrow biomedical and individualist model. She is pessimistic about the potential of EBM taking on an equity agenda, pointing to the dominance of commercial forces in shaping the research agenda and underpinning the 10/90 gap in research (i.e. the fact that only 10% of global health research funds are allocated towards solving those problems responsible for 90% of the world’s burden of disease). Involvement of civil society groups in the design of randomized controlled trials could play a part in making EBM more responsive to equity issues.

Health systems research remains marginalized and was dominated in the past decade by cost-effectiveness studies. Central to cost-effectiveness research is the analysis of clinical and public health interventions expressed in terms of DALYs (disability-adjusted life years) saved. This form of research has been used to construct clinical and public health “packages” of interventions that are now being promoted by international institutions and incorporated by governments as components of their health sector reform policies. These packages are almost uniformly supported by governments and criticisms of them tend to come from civil society groups such as the People’s Health Movement. They point out that this cost-effectiveness analysis is applied only to interventions with direct and easily measurable outcomes and not to broader inputs such as water provision, which have both direct and indirect impacts on health. This approach conflicts with and undermines comprehensive primary health care, which insists that health systems combine health care with interventions that address the underlying determinants of poor health (15–17). The comprehensive primary health-care approach recognizes the importance of human processes (e.g. community participation), and caring in health development. These approaches are less easy to subject to cost-effectiveness analysis, and the momentum to assess their worth is most likely to come from civil society which does not have ready access to research funds. Detailed and comparative case-studies of the results of long-term implementation of comprehensive primary health care are needed to identify those programme and contextual factors that lead to success in health development. Such studies may be retrospective or prospective.

While not necessarily disregarding cost-effectiveness analysis, health systems research should focus primarily on the operational aspects of the development and functioning of health systems, using a combination of quantitative and qualitative methods and involving practitioners in critical reflections on their own practice. Health systems research has a powerful potential to bridge the implementation gap through testing and evaluating activities and systems while simultaneously enhancing the capacity of health staff to evaluate and improve their performance (18, 19). CSOs can play a key role in ensuring that health systems research reflects community concerns with equity and access as much as funders’ concerns with cost-effectiveness.

There has been increasing attention paid in the literature to the problem of translating research findings (even those of appropriate research) in such a way as to have an effect on practices and policies (20). A number of authors have noted that lack of understanding by researchers of policy development and decision-making processes is a significant barrier to using research (21–23). Furthermore, practitioners and policy-makers often lack the skills to use research evidence and are under such time pressure that they have little opportunity to reflect on the

value of research. Such is the significance of the problem that Lomas (21) concluded that deliberate processes were needed to encourage effective research transfer and suggested that CSOs should be involved in research processes from the outset.

## Civil society organization-oriented health research

Reducing the 10/90 gap, which primarily affects poor countries, is a fundamental civil society priority for health research (24).

The lack of equity in funding research into the causes, consequences and interventions related to the greatest burden of disease has attracted both the attention of health researchers and CSO advocacy. But even if this inequity is redressed the question remains of what type of research will be funded. The recently announced “winners” in the Bill and Melinda Gates Foundation “Grand Challenges in Global Health” emphasized technological breakthroughs in neglected diseases (25), promoting research of the “fundamental discovery, “clinical” or “product development” type. But, although worthy, these grand “technological” challenges ignore the persisting grand “political” issues that must also be addressed. These political challenges are precisely those that relate to greater equity in access to underlying social and environmental health determinants and sustainable health systems, and to rebuilding the public health research capacity in poor countries (26).

## Research on underlying determinants of health

It is important that research into underlying health determinants identifies risks not only in local and national contexts, but also in a global one (26); that is, research should link local phenomena to globalization processes that condition and constrain local possibilities. The national level is also important. National governments negotiate or agree to the rules of globalization (e.g. trade agreements and conditions for debt relief or development assistance). National governments, acting within the opportunities or constraints created by globalization processes, also make decisions regarding resource allocation that can dramatically affect equity in access to services and to underlying health determinants at local levels (27, 28) (Box 1).

CSOs, many of them global in scope, have been at the forefront of research on globalization processes, although not

always with an explicit health focus (Table 1). In the course of such work, they often collaborate with academic researchers. Academic researchers, in turn, make frequent use of research reported by CSOs. These reports, though not necessarily as rigorous as a formal “systematic review”, reflect a breadth uncommon in most university-based research. They usually have an explicit policy focus and are often developed specifically for advocacy campaigns. The same pattern is found in local research on health determinants.

## Research on health systems implementation and intervention studies

Even in poor countries, the most significant predictors of population health are income, level of education and gender equity (29). For poor groups within countries, however, untreated illness is a major barrier to both income generation and education, while spending on medical care is a major reason why many families in poor countries fall into poverty (30). Indeed, publicly funded (cross-subsidized) health systems can contribute to reducing two important underlying health risks: poverty and income inequality. A study in the Canadian province of Manitoba found that the non-cash health benefits of its publicly funded health-care system, when monetized, decreased the post-tax and transfer income ratio (the distribution of income after taxation and direct welfare (money) transfers to eligible low-income individuals has been taken into account) between the top and bottom 10% of Canadian income groups by 20% (31).

Detailed case-studies, combining quantitative and qualitative methods, generally provide the information necessary to understand why health systems do or do not work well in providing care that is not only efficient, but also effective and equitable. Health systems research needs to shed more light on the importance of, and barriers to, primary health-care approaches that link health-care interventions to underlying health determinants, and hospital-based care to community contexts, engaging citizens and CSOs in the research process. In particular, research on the mechanisms of community governance is needed to determine which models allow for effective community management. Participatory research conducted through partnerships between academics and civil society groups has

### Box 1. The group of eight (G8)'s “fatal indifference” — global health research on underlying determinants

Two of the authors were involved in a study assessing the commitments made by G8 countries (Canada, France, Germany, Italy, Japan, the Russian Federation, the United Kingdom and the United States) to global health and development at their summits in 1999, 2000 and 2001 (33). We analysed these commitments by classifying “promises kept” ( $n = 10$ ) or “promises broken” ( $n = 17$ ), their adequacy in tackling the problems they addressed and their relationship to G8 neoliberal prescriptions for economic growth. Some examples include:

#### Promises kept

- The Global Fund to Fight AIDS, Tuberculosis and Malaria was established (“primed” with initial contributions of US\$ 1.3 billion).
- Agreement was reached (in August 2003) on flexibility in the World Trade Organization's Agreement on Trade-Related Intellectual Property Rights (TRIPS) to ensure access to essential medicines (although considerable uncertainty still surrounds implementation).

#### Promises broken

- Work towards the International Development Goals (now renamed as the Millennium Development Goals) through enhanced development assistance was compromised by the failure of the G8 to deliver on promised increases in their overseas development assistance; recent increases (in 2002) were inadequate to meet the need.
- “Strong” national health systems are not being supported (G8 development assistance for health actually declined during the study period, i.e. 1999–2001).

The research relied heavily on other studies conducted by dozens of international and national CSOs, as well as work by the United Nations and other multilateral agencies.

**Box 2. Health systems research meets primary health care needs — rural hospitals, household food security and malnutrition**

Research and development work to improve the management of severe childhood malnutrition in rural hospitals has been continuing in the impoverished former Transkei “homeland” in South Africa since 1998. The research involved detailed situational assessments, analyses and implementation plans, all of which included paediatric ward staff, and has been successful in reducing case-fatality rates by 33% across 11 hospitals. Research revealed that most of the children who were successfully rehabilitated returned to food insecure homes and, although all households qualified for a government welfare provision to poor families (the Child Support Grant (CSG)), none was receiving it, despite strenuous efforts on the part of most caregivers. Their testimony and these research findings were used in an advocacy campaign comprising formal submissions to government, newspaper articles prompting questions in parliament and a prime-time television documentary. The latter prompted immediate intervention by the Minister of Social Development. This, and continuing advocacy efforts in collaboration with an alliance of child welfare nongovernmental organizations, has resulted in a sharp and sustained increase in CSG distribution and greater attention to the role of household food insecurity as a causal factor in malnutrition, although much work remains to be done (18, 19).

much promise as a means of harnessing local knowledge and laying the foundations for the application of the knowledge generated by research (32) (Box 2).

### Research on strategies for policy change

There are two aspects to consider in research on strategies for policy change. The first aspect involves examining the role of CSOs in influencing policy change in a critical manner, including their roles at different levels of political organization. Poverty action groups and trade unions, for example, have often been influential in changing welfare and minimum wage policies in wealthy countries. Global CSOs, such as Health Action International and Médecins sans Frontières, have played important roles in campaigning for domestic and international policies to ensure access to essential drugs. But not all the efforts of CSOs are effective; significant debt relief or cancellation remains elusive despite the efforts of the Jubilee campaign (33). What strategies, with what buttressing by health research, would enable greater success in lobbying for “healthy public policies”? Another set of questions relates to the representativeness and accountability of many CSOs. Are CSOs effective in enabling ordinary citizens to voice their health concerns? Or are they becoming elite groups, in particular at the global level, operating with economic rationales similar to those of the institutions they are trying to influence (34). Finally, how strong are the links between CSOs working on local health equity issues and those working at national and global levels? And are these links influencing the effectiveness of the health advocacy work of CSOs at each of these levels?

A second aspect of social change research examines the conditions under which research evidence influences policy change. Policy-making is fundamentally about power and interests, and anecdotal experience suggests that research findings are used more successfully when they are part of campaigns involving mobilized groups of citizens.

## Conclusion

### Promoting participation and partnership of civil society in health research

There are three ways in which the participation of CSOs in research — as users or as generators — can be increased. These include: influencing commissioning and priority-setting; becoming involved in the review process and in research production by changing funding rules; and through formal partnerships between communities and universities that link CSOs with academic researchers. These are not alternatives; each offers

important ways in which research outputs can be influenced to reflect more closely the interests of civil society.

Currently CSO voices have very little influence over the research priorities that are set. This may in part account for the near absence of research on the social and economic determinants of health or the political economy of health, and the emphasis on diseases prevalent among the affluent populations of industrialized countries.

Opening up processes of peer review to non-academics to allow them to comment on the relevance of research may improve the increasingly criticized process of peer review (35). CSOs in both wealthy and poor countries are underrepresented in the formal processes of generating new health research. Research funding “rules” could be adapted to encourage better representation, for instance by allowing remuneration of CSO staff. The increased interest of many research funders in supporting partnerships between communities and universities also has tremendous potential. The benefits of such “partnership research” depend greatly on the quality of the relationship between academic researchers and CSOs; for example, a shared vision, overlapping theories of social organization and transformation, and respect for differing knowledge claims (“scientific” and “lay”). A critical issue for poor countries, notably those in sub-Saharan Africa, is rebuilding their academic research capacity that has been weakened by chronic underfunding and the “brain drain”: this presents a challenge to north/south “partnerships” with respect to research funding and institutional support.

CSOs are mainly committed to activist campaigns aimed at changing policy and less concerned with the “reward structure” of academic research, which respects methodological rigour, peer-reviewed publications and competition for grants. A partnership approach to the generation of health research allows both academic researchers and CSO advocates to excel in their respective areas without one being subordinate to the other. Such an approach might overcome some of the historical deficit in health research, best summed up by paraphrasing one of Marx’s famous theses: “Most health researchers to date have only studied the world; the point, however, is to change it for the better.” ■

### Acknowledgements

Professor David Sanders and Professor Fran Baum are members of the Global Steering Group of the People’s Health Movement.

**Conflicts of interest:** none declared.

## Résumé

### Donner plus d'importance à la recherche : un point de vue de la société civile sur la recherche en santé

Les défis complexes auxquels est confrontée la santé publique à l'échelle mondiale, tels que l'élargissement rapide des inégalités devant la santé et les urgences sans précédent comme la pandémie de VIH/SIDA, exigent une réévaluation des priorités actuelles des politiques, des dépenses et des recherches dans le domaine sanitaire. La recherche peut aider à mettre sur pied une réponse efficace, mais elle devra mettre davantage l'accent sur les déterminants sanitaires, tant au niveau national, que mondial, ainsi que sur les systèmes de santé et les initiatives de santé

publique présentant une large assise et une grande efficacité. Les organisations de la société civile (OSC) sont déjà aux avant-postes de telles recherches. L'article suggère qu'il existe au moins trois manières d'accroître la participation des OSC dans la recherche, à savoir influencer sur l'attribution des projets et la fixation des priorités, participer au processus d'examen par les pairs et à la conduite de recherches et s'impliquer dans des partenariats formels entre les communautés et les universités, liant les OSC aux chercheurs universitaires.

## Resumen

### Dar más importancia a la investigación: papel de la sociedad civil en las investigaciones sanitarias

Los complejos desafíos de la salud pública mundial, como el rápido aumento de las desigualdades sanitarias, y la irrupción de emergencias sin precedentes como la pandemia de virus de inmunodeficiencia humana/síndrome de inmunodeficiencia adquirida (VIH/SIDA) exigen una reevaluación de las actuales prioridades de las políticas, los gastos y la investigación sanitarias. La investigación puede ayudar a articular respuestas eficaces, pero para ello hay que hacer más hincapié en los factores determinantes de la salud a nivel nacional y mundial, así como en las investigaciones sobre sistemas de salud y en las iniciativas

de salud pública generales y eficaces. Las organizaciones de la sociedad civil (OSC) están ya a la vanguardia de esas investigaciones. Sugerimos que hay al menos tres opciones para ampliar la participación de las OSC en las investigaciones; a saber: su influencia en el encargo de trabajos y la fijación de prioridades; su implicación en el proceso de revisión y la realización de investigaciones; y el establecimiento de fórmulas formales de colaboración entre comunidades y universidades que vinculen a las OSC con los investigadores del ámbito académico.

# Arabic

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David Sanders et al.

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