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Raising the Profile of Participatory Action Research at the 2010 Global Symposium on Health Systems Research

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ABSTRACT

By involving citizens and health workers in producing evidence and learning, participatory action research has potential to organize community evidence, stimulate action, and challenge the marginalization that undermines achievement of universal health coverage. This paper summarizes and analyzes results of two sessions on this research model convened by the authors at the First Global Symposium on Health Systems Research in Montreux, Switzerland, November 16-19, 2010. In so doing, it reviews case studies and experiences discussed, particularly their contribution to universal health coverage in different settings. The paper also reflects on challenges faced by participatory action research, and outlines recommendations from the two sessions, including creation of a learning network for participatory action research.

KEYWORDS Community-based participatory research, health services research, health care systems, community health planning, learning networks

BACKGROUND

A universal health system values and ensures the right to health care, entitling all citizens in a country to access the same range of services according to their need and pay for these services according to their income. Knowledge of how to finance, organize, and manage health systems is necessary, but not sufficient, for achieving universal coverage. The systemic processes that produce marginalization and inequality also need to be made visible, understood, and challenged. This includes understanding how health systems as complex social systems reflect and affect social values, and are capable of exacerbating or reducing inequity.[1] The resulting knowledge can be used to inform public health policy, and at the same time may influence the political processes that shape policy and interventions.

Through the collection, analysis, and interpretation of evidence, health systems research (HSR) is one source of new knowledge to inform pathways and policies for attaining universal coverage. Given the many dimensions of health systems, HSR uses multidisciplinary approaches drawn from public health, health economics, and behavioral and social sciences.[2]

Participatory action research (PAR) changes the traditional research paradigm to transform the role of those usually participating as the subjects of research, to involve them instead as active researchers and agents of change.[3-4] PAR methods systematize local experience and organize shared collective analysis on relationships and causes of problems. PAR links such analysis to reflection and action, organizing shared experience and perception to generate new learning and knowledge. In so doing it can strengthen the connection between public actors and the political forces shaping public policy. By involving citizens and health workers in the production of evidence and learning, it can strengthen the legitimacy of research findings and challenge disabling power imbalances that undermine policies aimed at achieving universal health coverage.[3-6] In their work on PAR, Minkler and Wallerstein describe its use to study a range of health systems issues—from action on social determinants of health, through community health outreach, to improving quality of services.[3]

As with other areas of research, PAR has limitations and challenges, both in design and application. The methods are not well known by practitioners mostly acquainted with more conventional public health research approaches. The work takes time to build trust and allow for involvement, discussion, and reflection by communities; and it requires mentoring to support facilitation skills. The core method for knowledge production—collective validation by homogenous groups—often is not applied rigorously.[7,8] Findings are specific to particular communities and sites, limiting possibilities for meta-analysis across PAR sites. This affects scale and generalizability of findings, the latter requiring triangulation with other sources of evidence, such as results of quantitative surveys or health information systems. Furthermore, empowerment and dialogue are not automatic outcomes of PAR.[6,9] PAR findings often point to structural determinants demanding action at higher levels of authority than those found within communities. These difficulties raise issues for how to institutionalize participatory research and practice.

This paper summarizes and analyzes discussions from two sessions on PAR convened by the authors at the First Global Symposium on Health Systems Research in Montreux, Switzerland, November 16-19, 2010. In the first session, researchers from...
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Guatemala, India, East and Southern Africa, and Canada presented their experiences using PAR approaches in HSR. This was followed by a marketplace in which approximately 50 delegates raised and debated key points on PAR's unique contributions to achieving universal coverage in health systems; the reasons for PAR's low profile and infrequent use in building health system knowledge; and recommendations for the Symposium. In a follow-up session, the authors presented the major issues raised in the marketplace discussions, and delegates briefly presented and exchanged their own PAR experiences. Delegates referred to presentations and discussions from both sessions to draw conclusions on implications for future participatory research on health systems and for follow-up action to build a PAR learning network.[10]

FOUR CASE STUDIES OF PARTICIPATORY ACTION RESEARCH ON HEALTH SYSTEMS

Guatemala: Engaging citizens and front-line health workers to influence health policy
A civil society coalition implemented PAR beginning in 2007, using participatory community monitoring to ascertain whether public policies and resources were addressing local access to health care. The experience of this partnership of rural citizens, front-line health workers and researchers in Guatemala showed that in a context of inequities in health and access to health care, PAR can provide evidence for citizens usually marginalized from policy, to monitor public policies and facilitate demand for relevant interventions from local and central governments.[11,12] Community leaders actively involved in the initial six municipalities are now serving as facilitators to expand the work to new municipalities.

Maharashtra, India: Community-based monitoring of health services
In the National Rural Health Mission (NRHM), Maharashtra state in western India, communities carried out three rounds of community-based monitoring between mid-2008 and late 2009, to track, record, report, and develop evidence on the state of public health services in villages, as experienced by the people themselves. Data was gathered through report cards filled out at village, primary health care, and rural hospital levels, with indicators based on service guarantees stated in the NRHM implementation framework. Public hearings and quarterly dialogue between state and civil society addressed issues raised. Service ratings improved over the three rounds.[13,14]

East and Southern Africa: Strengthening people-centered health systems
A learning network and ‘pra4equity’ listserv (pra4equity@equinetafrica.org) provided a communication channel for exchange and dialogue across 19 sites in 7 countries implementing PAR on areas of common focus, to examine the interface between communities and health systems using shared design and tools. Three individual studies from Zambia, South Africa, and Democratic Republic of the Congo reported on local problems identified and addressed. The common methods and learning network facilitated collective validation of barriers to universal health coverage. Results showed that communities prioritize causes of ill health at a more structural level than health workers. Health services were found to have high legitimacy but low capabilities for social roles. The results showed that failing to address these social barriers to uptake can lead to wasted resources in health services—for example, through poor adherence to treatment—and also to vicious cycles of ill health in communities.[15–18]

Canada: PAR within a movement for universal health coverage
Work on community health centers located PAR within the context of a wider movement for universal coverage initiated in 1962 and advanced in the following three decades.[19] The presence of community-elected boards in local health centers facilitated raising research questions from the community.[20] As a result, PAR provided evidence to support development of a community health center for poor women, and evidence on medication needs and patterns of use that motivated development of an essential drugs list. The PAR approach provided a means to draw on the community and ensure that new learning was organized and known within the community.

DISCUSSING EXPERIENCES OF PAR AND ITS RELEVANCE TO HEALTH SYSTEMS

The two sessions highlighted that there is a rich experience in PAR, and far more practice taking place than is being published. Delegates proposed usefulness of documenting and systematizing case studies of PAR in HSR.

Case examples presented from different continents all indicated that PAR approaches can enhance communication within health systems and among health personnel, communities, and others; as well as enhance mutual respect among these different groups for their respective experience and roles. PAR provides a means for recognition and early detection of health problems that may be unrecognized—including chronic diseases in communities, work-related health problems among health workers, and those related to social determinants of health. PAR methods encourage sharing of analysis and power between primary care health workers and communities, to the benefit of both. The PAR process builds cycles of learning, reflection, and action; and stimulates communities and local levels of health systems to develop and implement locally determined plans.

In the marketplace session discussion, delegates raised twelve further examples of PAR work in South Africa, India, Lesotho, Zambia, Malawi, Zimbabwe, Egypt, Argentina, Venezuela, Cambodia, and in multi-site international studies. These experiences provided examples where PAR has elicited community values, identified community assets for health, and built understanding of social and systemic barriers to health care coverage. As in studies presented in the first session, those described by delegates were often implemented with vulnerable communities, such as commercial sex workers or users of harmful drugs. PAR was found to be an effective way of organizing community evidence and perceptions to improve health system functioning, especially when findings were triangulated with evidence from other sources.

Various methods were described. Some involved community members in data collection, using traditional tools such as questionnaires; others used report cards and checklists to document community perceptions and experiences; while others used tools to facilitate more collective processes for raising, organizing, and interpreting evidence; e.g., ranking and scoring methods and social mapping. Health authorities or trade unions with structures from community to national levels were reported to have facilitated
Delegates recommended: addressing challenges of PAR in Health Systems Research—Delegates' observations on limitations of PAR in building health systems

Delegates observed that PAR's contribution is limited by the following factors:

- PAR may be perceived as an inferior approach to research, or "not real science." This view is reinforced by the fact that PAR is not taught in medical or health science courses. It also reflects a tendency to discount knowledge held by communities;
- It is difficult to test PAR methods using traditional scientific criteria, due to reliance on subjective evidence, different approaches to validating knowledge and difficulties generalizing from specific sites;
- PAR raises demands for implementation, requiring time, people, patience, and resources. These demands and the fact that outcomes are not predictable may discourage funders; and
- There are difficulties moving from local experience and knowledge to national health systems, limiting the scale and impact of PAR and its ability to challenge inequities in power at higher levels.

Delegates’ conclusions on PAR's unique contribution to achieving universal health coverage

Delegates were in agreement that PAR contributes to this goal through the following approaches and mechanisms:

- Providing conditions and processes that encourage social empowerment, by strengthening collective power in affected communities (including health workers); confronting and changing power dynamics that perpetuate inequities; building shared understanding of conditions and their causes; and providing a means for people to articulate their thoughts and experience and demand needed health inputs and services;
- Increasing potential to strengthen local levels of health systems, through generating and promoting use of local-level evidence, supporting ownership and involvement of people in health systems, and enhancing dialogue between health workers and communities;
- Organizing demands for services prioritized by communities; and
- Linking knowledge generation to its use in action.

Delegates’ recommendations for tapping PAR potential and addressing challenges of PAR in Health Systems Research—Delegates recommended:

- Making clearer links between PAR and the health equity and social determinants of health agenda, recognizing communities as best placed to identify and act on issues related to social determinants of health;
- Embedding PAR methods within routine health system planning, implementation, and evaluation, such as through community monitoring of quality of care;
- Using a mix of PAR and other research methods in HSR, recognizing the value and limitations of PAR approaches cited earlier; and
- Creating opportunities for exchange and learning on PAR to share experiences, processes, and methods; to pool learning from different contexts; and to build conceptual models and wider understanding, use, and replication of PAR.

BUILDING A LEARNING NETWORK FOR PAR ON HEALTH SYSTEMS

Issues raised in the discussion highlight the need for exchange across PAR sites, to build capacities; share resources, capacities, and methods; address conceptual and methodological debates on PAR; and better document and disseminate PAR results. Delegates suggested that a learning network could facilitate this exchange by bringing together researchers across different PAR sites.

Such a network could provide opportunities to share local learning and provide a forum for building a community of practice. Delegates proposed initiating a learning network to provide the following:

- a communication channel through a listserv;
- a website portal providing resources and links to members websites;
- a repository of resources, photos, case studies, and methods;
- an inventory of institutions working with PAR; and
- opportunities for face-to-face meeting and exchange of evidence, methods, and lessons learned.

Initially, as an interim tool for shared communication and to widen involvement in follow-up to this discussion, the pra4equity listserv already set up in East and Southern Africa [pra4equity@equinetfrica.org] was widened to subscribe people from other regions.

Strengthening PAR approaches in HSR is also part and parcel of wider efforts aimed at building greater constituency, credibility, and capacity for HSR globally.[21] This was reflected in the closing plenary session of the Global Symposium on HSR, when Etiayo Lambo, Nigeria’s former Minister of Health, called for any strengthening of HSR to involve the policy and practice communities in the research process, especially in data gathering and analysis, "using problem-solving, action-oriented approaches like operations research and participatory action research."[22]

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