Participatory Action Research

Training Exchange Day

Kigali 28-29th April 2023

Session 1: What is PAR?

Disclaimer

This project was funded by the National Institute for Health and Care Research (NIHR).

What is PAR?
Concepts, contexts and case study

Learning outcomes (Session 1)

1. Describe participation as a concept
2. Appreciate contextual influences
3. Relate cases examples

1. Concepts

Participation in health systems

- Those affected involved in decisions, actions over health care
- Goals of radical transformation, social and political change / justice
- Long policy support. Renewed interest (coproduction, CEI, CAs)
- Many interpretations. Risks of elite capture. Policy ≠ practice

The people have the right and duty to participate individually and collectively in the planning and implementation of their health care ***WHO, 1978***

…community participation policies can become regressive, imposing greater risks and responsibilities upon more disadvantaged communities in return for lower levels of power ***Rolfe, 2018***

Participation for health systems strengthening

"… if the objective is improved conditions for the poor, then the outsider, with help from the rural poor themselves, must try to identify and understand processes, linkages and opportunities for change" (Chambers, 1983)

How to achieve involvement of people in health?

"…it might be argued that…the scientific knowledge needed to radically improve the health of the majority of the world's population already exists and…what is mainly required is knowledge of how to achieve the massive, widespread involvement of people themselves…in determining health priorities and how to allocate scarce resources. Community participation, has therefore, come to be seen as a way of rapidly improving the health services available for the majority of the world's people" (Oakley, 1989)

Normative support

- WHO Alma Ata 1978 defining event for modern public health
- Universal policy of essential healthcare for all enshrined in Declaration of PHC
- Central enabling mechanism - active involvement of people in services

PHC defined as "essential health care made universally accessible to individuals and families in the community by means acceptable to them, through their full participation and at a cost that the community and country can afford" (WHO, 1978)

Participation in the Declaration of PHC

"…the process by which individuals and families assume responsibility for their own health and welfare and those of the community, and develop capacity to contribute to their and the community's development. They come to know their own situation better and are motivated to solve common problems. This enables them to become agents of their own development instead of passive beneficiaries of development aid"
(WHO, 1978)

Normative support to lack of clarity!

- Declaration accepted by >150 states. Decade of widespread adoption
- WHO and UNICEF practice guidelines (1980s and 1990s)
- Wide implementation, international interest, case studies, practice frameworks
- Persistent lack of clarity over interpretations of the concept
- Major barrier to consistent implementation

Complex, contested concept

- Participation is a political process engaging people in social institutions
- Varied interpretations e.g. community participation, community development , community organisation, community involvement , community engagement , community empowerment, community mobilisation and community action
- Implementation varied by power and control deemed legitimate to devolve to lower levels incl. individuals

How do we make sense of this?

Arnstein's Ladder of Citizen Participation, 1969

- Embraced power implications

"… the redistribution of power that enables the have-not citizens, presently excluded from the political and economic processes, to be deliberately included in the future. It is the strategy by which the have-nots join in determining how information is shared, goals and policies are set, tax resources are allocated, programs are operated, and benefits like contracts and patronage are parcelled out. In short, it is the means by which they can induce significant social reform which enables them to share in the benefits of the affluent society" (Arnstein, 1969)

A LADDER OF CITIZEN PARTICIPATION

Sherry R. Arnstein

The heated controversy over "citizen participation," "citizen control," and "maximum feasible involvement of the poor," has been waged largely in terms of exacerbated rhetoric and misleading euphemisms. To encourage a more enlightened dialogue, a typology of citizen participation is offered using examples from three federal social programs: urban renewal, anti-poverty, and Model Cities. The typology, which is designed to be provocative, is arranged in a ladder pattern with each rung corresponding to the extent of citizens' power in determining the plan and/or program.

The idea of citizen participation is a little like eating spinach: no one is against it in principle because it is good for you. Participation of the governed in their government is, in theory, the cornerstone of democracy—a revered idea that is vigorously applauded by virtually everyone. The applause is reduced to polite handclaps, however, when this principle is advocated by the have-not blacks, Mexican-Americans, Puerto Ricans, Indians, Eskimos, and whites. And when the have-nots define participation as redistribution of power, the American consensus on the fundamental principle explodes into many shades of outright racial, ethnic, ideological, and political opposition.

There have been many recent speeches, articles, and books[1] which explore in detail *who* are the have-nots of our time. There has been much recent documentation of *why* the have-nots have become so offended and embittered by their powerlessness to deal with the profound inequities and injustices pervading their daily lives. But there has been very little analysis of the content of the current controversial slogan: "citizen participation" or "maximum feasible participation." In short: *What* is citizen participation and what is its relationship to the social imperatives of our time?

Citizen Participation is Citizen Power

Because the question has been a bone of political contention, most of the answers have been purposely buried in innocuous euphemisms like "self-help" or "citizen involvement." Still others have been embellished with misleading rhetoric like "absolute control" which is something no one—including the President of the United States—has or can have. Between understated euphemisms and exacerbated rhetoric, even scholars have found it difficult to follow the controversy. To the headline reading public, it is simply bewildering.

My answer to the critical *what* question is simply that citizen participation is a categorical term for citizen power. It is the redistribution of power that enables the have-not citizens, presently excluded from the political and economic processes, to be deliberately included in the future. It is the strategy by which the have-nots join in determining how information is shared, goals and policies are set, tax resources are allocated, programs are operated, and benefits like contracts and patronage are parcelled out. In short, it is the means by which they can induce significant social reform which enables them to share in the benefits of the affluent society.

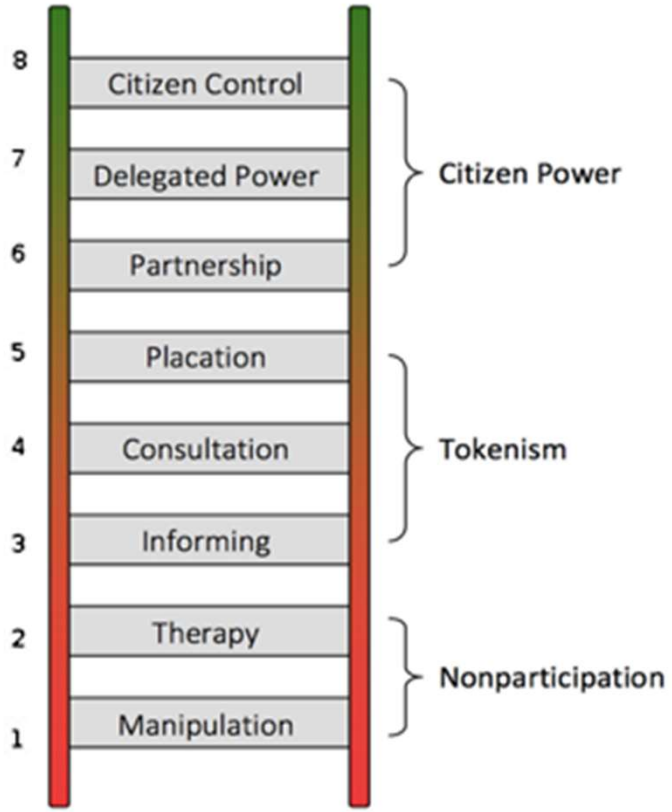
EMPTY RITUAL VERSUS BENEFIT

There is a critical difference between going through the empty ritual of participation and having the real power needed to affect the outcome of the process. This difference is brilliantly capsulized in a poster painted last spring by the French students to explain the student-worker rebellion.[4] (See Figure 1.) The poster highlights the fundamental point that participation without redistribution of power is an empty and frustrating process for the powerless. It allows the power-holders to claim that all sides were considered, but makes it possible for only some of those sides to benefit. It maintains the status quo. Essentially, it is what has

FIGURE 1 *French Student Poster. In English, I participate; you participate; he participates; we participate; you participate . . . They profit.*

Sherry R. Arnstein is Director of Community Development Studies for The Cemmenes, a non-profit research institute in Washington, D.C. and Chicago. She is a former Chief Adviser on Citizen Participation in HUD's Model Cities Administration and has served as Staff Consultant to the President's Committee on Juvenile Delinquency, Special Assistant to the Assistant Secretary of HEW, and Washington Editor of *Current Magazine*.

A Ladder of Citizen Participation, Arnstein, 1969



1 Manipulation and 2 Therapy. non participative, cure or educate the participants. achieve public support by PR.
3 Informing. one way flow of information
4 Consultation. attitude surveys, neighbourhood meetings and public enquiries. Window dressing ritual
5 Placation. Allows citizens to advise but retains for power holders the right to judge the legitimacy or feasibility of the advice.
6 Partnership. Power is redistributed through negotiation between citizens and power holders. Shared decision-making responsibilities.
7 Delegated power to make decisions. Public now has the power to assure accountability.
8 Citizen Control. Participants handle the entire job of planning, policy making and managing a programme.

http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html

"Situated practices"

- Artificial separation 'good' or 'bad'
- Consider 'situated practices'
  - Reflect contexts and dynamics of participation, consider e.g.:
  - Who is participating?
  - How does participation takes place?
  - In what context(s)?
  - For whose purpose(s)?

doi:10.1093/cdj/bsn010
Advance Access Publication 5 June 2008

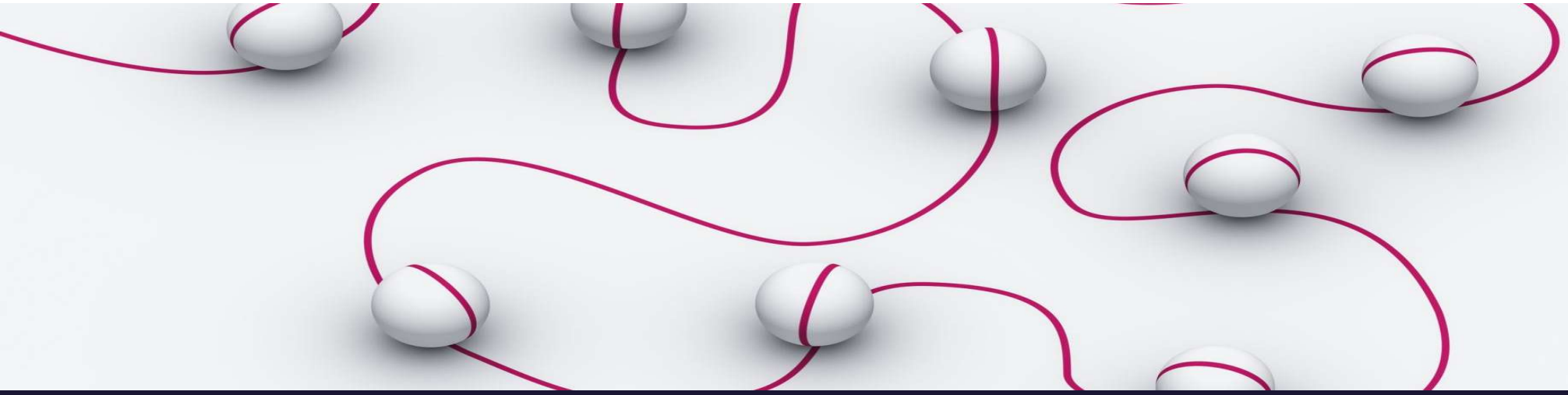
Unpacking 'Participation': models, meanings and practices

Andrea Cornwall

Abstract The world over, public institutions appear to be responding to the calls voiced by activists, development practitioners and progressive thinkers for greater public involvement in making the decisions that matter and holding governments to account for following through on their commitments. Yet what exactly 'participation' means to these different actors can vary enormously. This article explores some of the meanings and practices associated with participation, in theory and in practice. It suggests that it is vital to pay closer attention to who is participating, in what and for whose benefit. Vagueness about what participation means may have helped the promise of public involvement gain purchase, but it may be time for more of what Cohen and Uphoff term 'clarity through specificity' if the call for more participation is to realize its democratizing promise.

Introduction

The widespread adoption of the language of participation across a spectrum of institutions, from radical NGOs to local government bodies to the World Bank, raises questions about what exactly this much-used buzzword has come to mean. An infinitely malleable concept, 'participation' can be used to evoke – and to signify – almost anything that involves people. As such, it can easily be reframed to meet almost any demand made of it. So many claims to 'doing participation' are now made that the term has become mired in a morass of competing referents. This article unpacks some of the meanings that 'participation' has come to carry and explores the diversity of practices that are labelled as 'participatory'. In doing so, it seeks to bring some of the 'clarity through specificity' that Cohen and Uphoff (1980) called for at the end of the 1970s, the decade in which participation first hit the development mainstream, but which has remained elusive.



Summary - concepts

- Participation recognizes and enables those at the heart of the issue to address it
- Not simply an intervention, instrumental and substantive, interchangeable means and end
- Complex, contested concept. Be aware of a range of interpretations
- Fuller forms seek to shift power towards those affected to know, understand, act and transform

Where are we 40 years after Alma Ata?

Analysis

BMJ Global Health

Alma Ata after 40 years: Primary Health Care and Health for All—from consensus to complexity

Susan B Rifkin

THE MILBANK QUARTERLY

CURRENT ISSUE ARCHIVE NAVIGATION

JUNE 2019 (VOLUME 97)

Forty Years After Alma-Ata: At the Intersection of Primary Care and Population Health

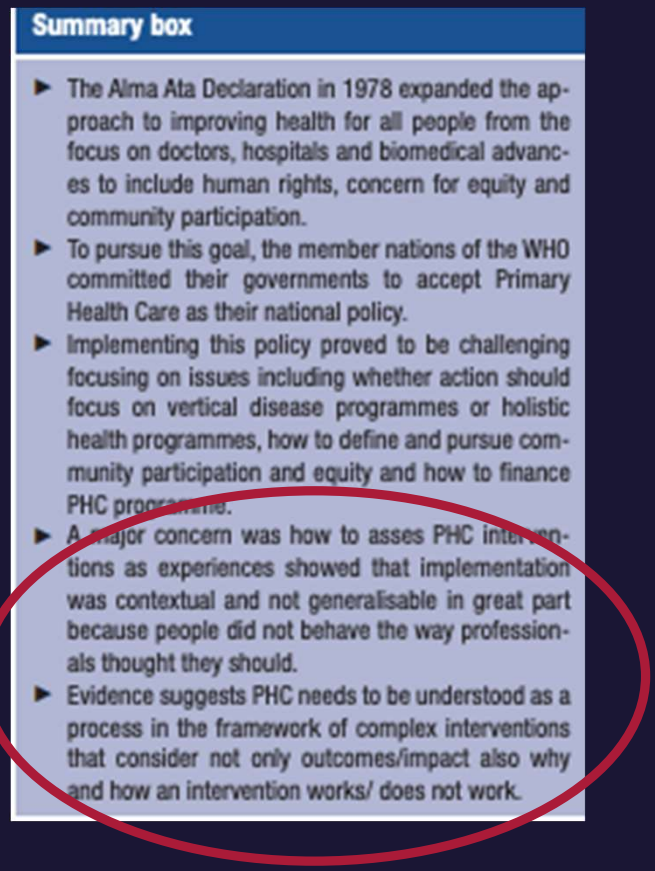
OPINION

Authors:

SANDRO GALEA

MARGARET E. KRUK

The Declaration of Alma-Ata[1] was adopted in September 1978 at the International Conference on Primary Health Care in Alma Ata (today called Almaty), Kazakhstan. The document was the first international declaration that put primary health care front and center to the goal of achieving health for all, initially with a low-income lens in mind and, soon after, adopted also for high-income countries. The centrality of primary health care has since been adopted as a core organizing goal by the World Health Organization (WHO) and has withstood the test of time despite some early criticism about the breadth and lack of specificity of the original Declaration.[2]



Summary box

- The Alma Ata Declaration in 1978 expanded the approach to improving health for all people from the focus on doctors, hospitals and biomedical advances to include human rights, concern for equity and community participation.
- To pursue this goal, the member nations of the WHO committed their governments to accept Primary Health Care as their national policy.
- Implementing this policy proved to be challenging focusing on issues including whether action should focus on vertical disease programmes or holistic health programmes, how to define and pursue community participation and equity and how to finance PHC programme.
- A major concern was how to asses PHC interventions as experiences showed that implementation was contextual and not generalisable in great part because people did not behave the way professionals thought they should.
- Evidence suggests PHC needs to be understood as a process in the framework of complex interventions that consider not only outcomes/impact also why and how an intervention works/ does not work.

2. Contexts

Political and health systems contexts: Legal frameworks

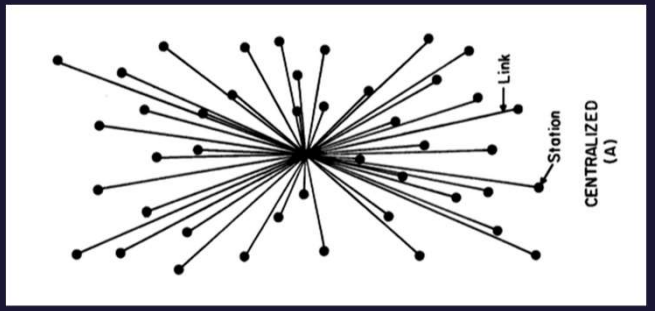
- Powerful tools to recalibrate balance of power. E.g.:
  - Decentralisation legislation
  - Right to health laws
  - Health acts
  - Freedom of information laws
- Risk of elite capture

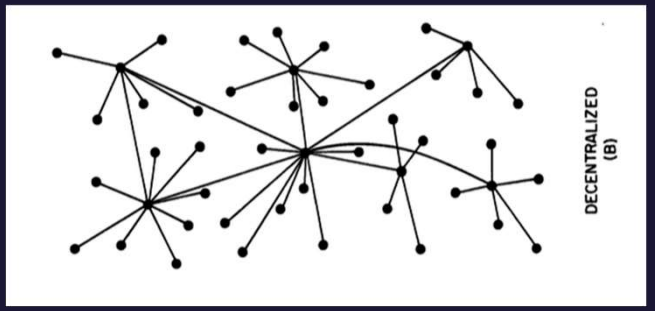
"The right to participate in political and public affairs should be enforceable by law and its denial should be open to judicial challenge"

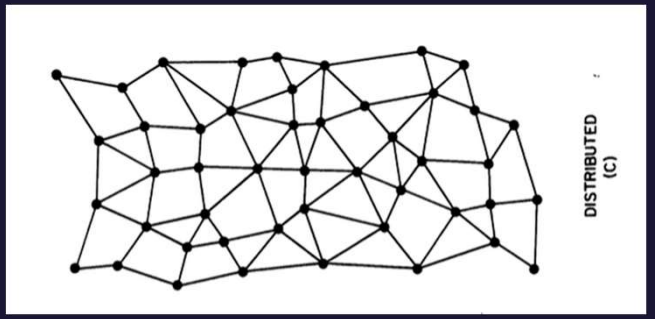
UN High Commissioner for Human Rights

Decentralisation

- Decentralisation: transfer of decision authority from the centre to the periphery
- In many settings translates into responsibility without resources and authority
- Authority, autonomy and capacity of local officials to make and implement decisions remains constrained in many settings

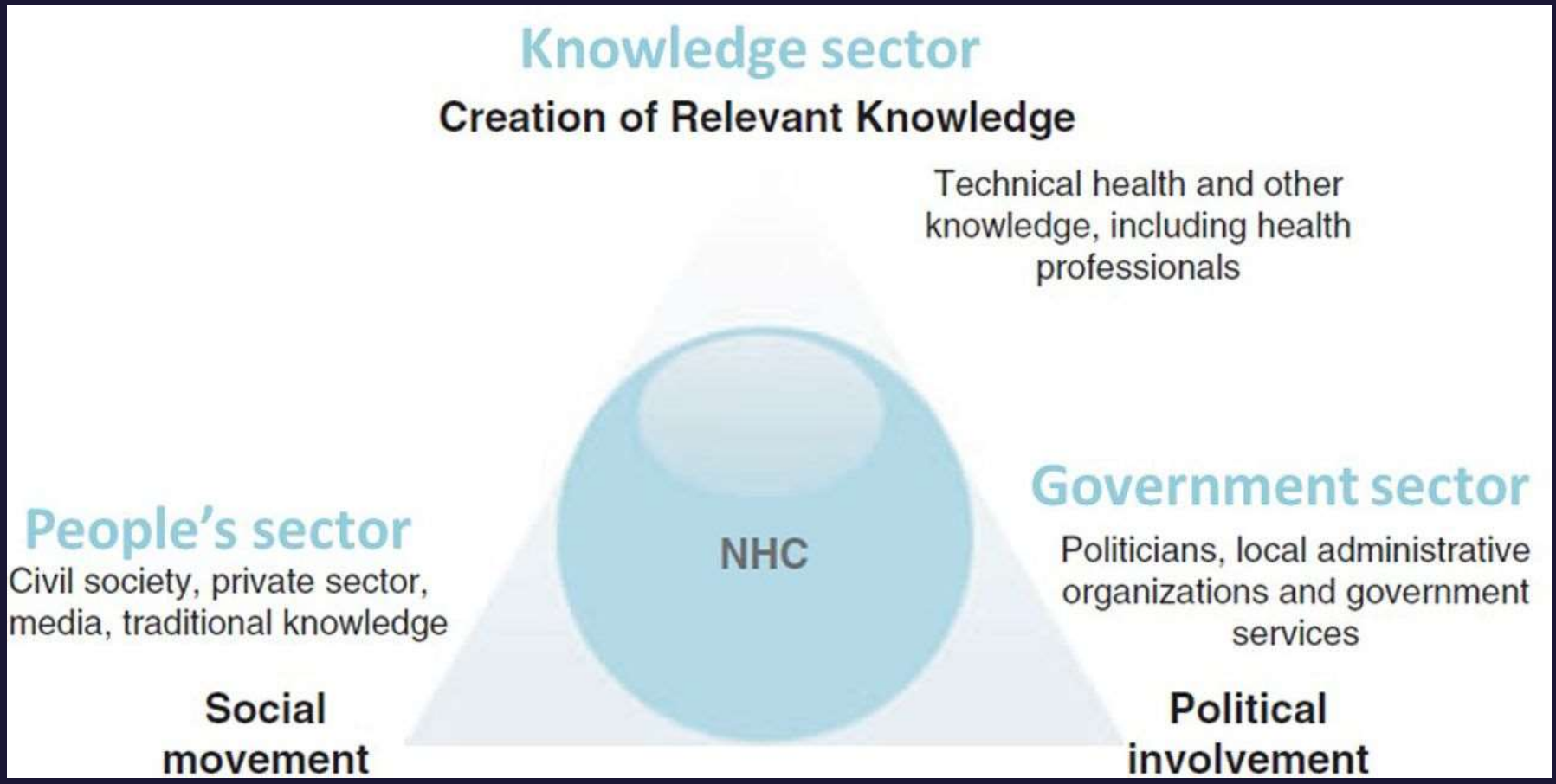






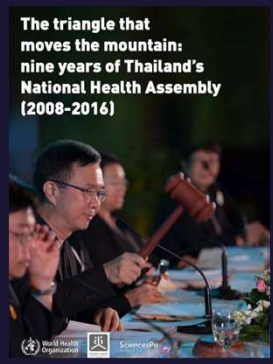
Health Acts: Thailand

‘the triangle that moves mountains’



Source: Rajan et all 2019

National Health Assembly, Thailand



Achievements

- Platform brings together stakeholders to discuss complex health challenges regularly. Recognized national public good
- Attention to process, more than the event, allowed for steady improvement in quality
- Key vehicle for bringing evidence more strongly into policy discussions

Challenges

- Integration of resolutions into policies
- Capacity and coordination to select the right representatives

Lessons

- (1) provision of balanced, factual information; (2) inclusion of diverse perspectives to ensure expression of untapped viewpoints; (3) opportunity to reflect on and discuss freely a wide spectrum of perspectives

Source: Rajan et all 2019

Innovations in Scotland

Community Empowerment (Scotland) Act 2015

Citizens' Assembly
of Scotland
Seanadh Saoranaich
na h-Alba

Participation in Rwanda and Ethiopia?

- Gacaca (conflict resolution)
- Umuganda (service day)
- Ubudehe (community dialogue)
- Imihigo (local governance)
- District open days
- Abunzi (local dispute resolution)
- Community Juries (local dialogue and consensus)
- Village Councils (local leadership)
- National Women's Council
- National Youth Council
- National Council of People with Disabilities
- National Dialogue Summit
- National Children's Summit

COVID-19


Original research

BMJ Global Health

Community engagement for COVID-19 prevention and control: a rapid evidence synthesis

Brynne Gilmore ,[1] Rawlance Ndejjo,[2] Adalbert Tchetchia,[3] Vergil de Claro,[4] Elizabeth Mago,[5] Alpha A Diallo,[6] Claudia Lopes,[7] Sanghita Bhattacharyya[8,9]

- Communities play critical roles in infectious disease outbreaks
- Complements responses, addressing health inequalities and building future resilience
- Widespread support, limited understanding of how to operationalise, especially in settings and among populations most severely affected
- Concern over the lack of involvement of vulnerable communities in COVID-19 responses

Community participation is crucial in a pandemic

Published Online
May 4, 2020
https://doi.org/10.1016/
S0140-6736(20)31054-0

Community participation is essential in the collective response to coronavirus disease 2019 (COVID-19), from compliance with lockdown, to the steps that need to be taken as countries ease restrictions, to community support through volunteering. Communities clearly want to help: in the UK, about 1 million people volunteered to help the pandemic response[1] and highly localised mutual aid groups have sprung up all over the world with citizens helping one another with simple tasks such as checking on wellbeing during lockdowns.[2]

Global health guidelines already emphasise the importance of community participation.[3,4] Incorporating insights and ideas from diverse communities is central for the coproduction of health, whereby health professionals work together with communities to plan, research, deliver, and evaluate the best possible health promotion and health-care services.[5]

Pandemic responses, by contrast, have largely involved governments telling communities what to do, seemingly with minimal community input. Yet communities, including vulnerable and marginalised groups, can identify solutions: they know what knowledge and rumours are circulating; they can provide insight into stigma
work v
lective
becaus
commu
come u
full ran

***Panel:* Steps to community participation in the COVID-19 response**

Invest in coproduction

- Fund dedicated staff and spaces to bring the public and policy makers together
- Create spaces where people can take part on their own terms (eg, avoid bureaucratic formalities or technical jargon)
- Move beyond simply gathering views and instead build dialogue and reflection to genuinely codesign responses
- Invest not only for this emergency but also for long-term preparedness

Work with community groups

- Build on their expertise and networks
- Use their capacity to mobilise their wider communities

Commit to diversity

- Capture a broad range of knowledge and experiences
- Avoid one-size-fits-all approaches to involvement
- Consciously include the most marginalised

Be responsive and transparent

- Show people that their concerns and ideas are heard and acted upon
- Collaborate to review outcomes on diverse groups and make improvements

Global Public Health ›
An International Journal for Research, Policy and Practice
Volume 16, 2021 - Issue 8-9: Politics and Pandemics

Enter keywords, authors, DOI, ORCID etc

Submit an article | Journal homepage

1,892
Views
6
CrossRef citations to date
16
Altmetric

Articles

Beyond command and control: A rapid review of meaningful community-engaged responses to COVID-19

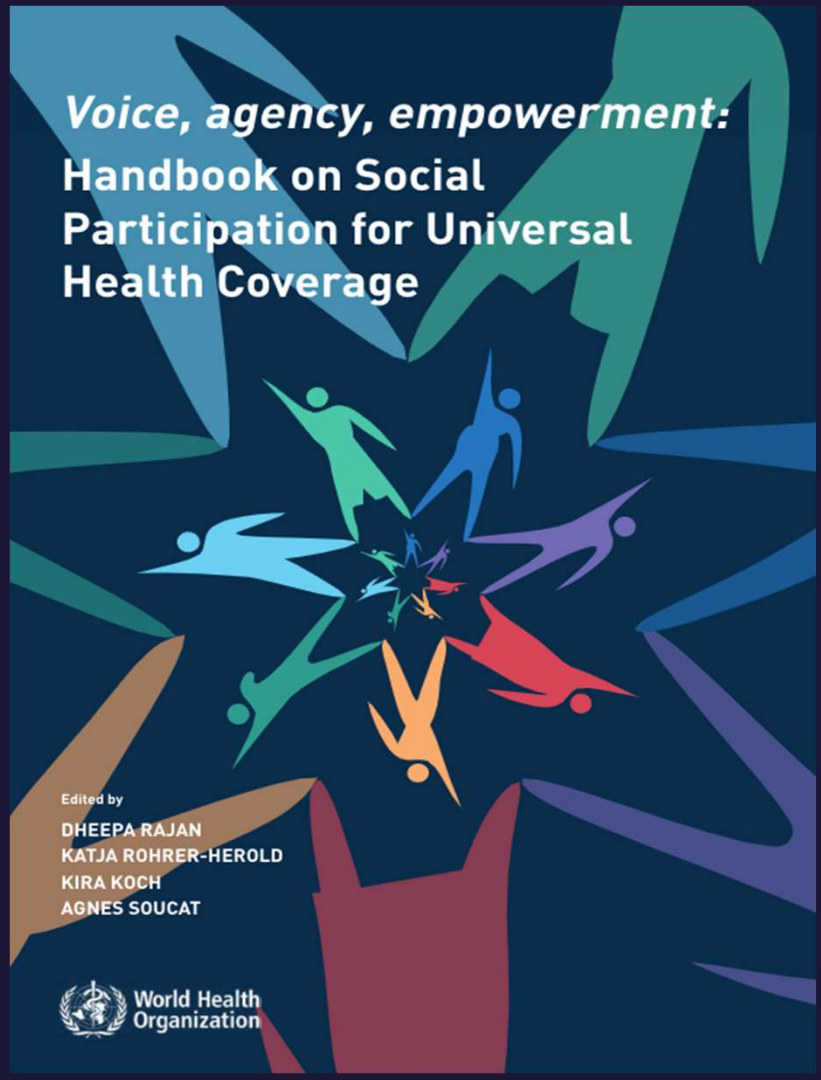
Rene Loewenson, Christopher J. Colvin, Felipe Szabzon, Sayan Das, Renu Khanna, Vera Schattan P. Coelho, ...show all

Pages 1439-1453 | Received 30 Oct 2020, Accepted 25 Feb 2021, Published online: 18 Mar 2021

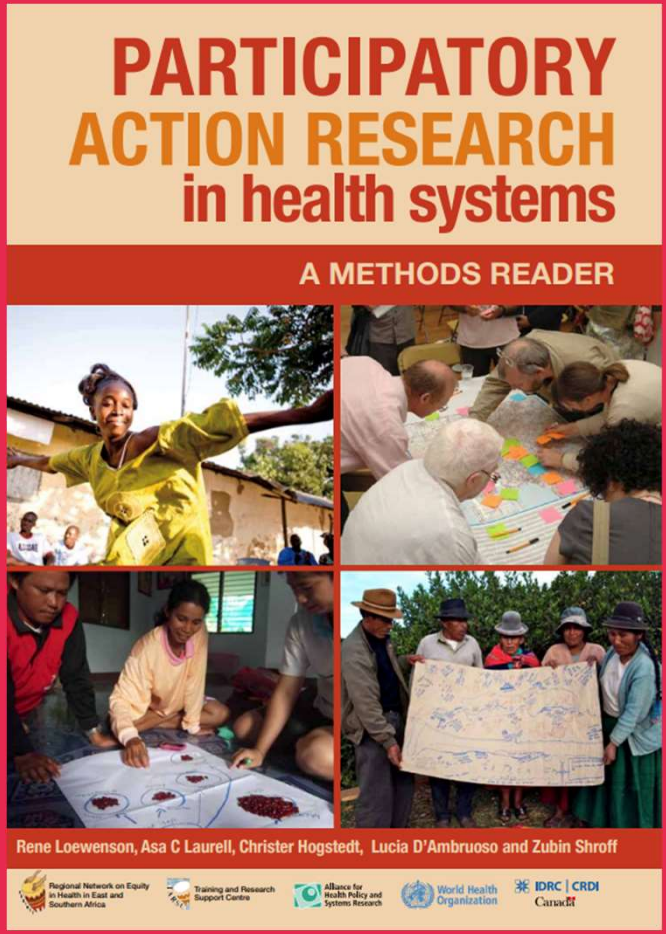
Download citation | https://doi.org/10.1080/17441692.2021.1900316 | Check for updates

Summary

- Efforts of range of stakeholders, key to effective design, implementation and uptake
- Threats of social elites dominating process, or lack of realistic expectations
- Careful and systematic documenting of processes of participation, mobilisation end engagement
- Explicitly state political bases within efforts to identify and share practical applications and experience



3. Case study


PARTICIPATORY
ACTION RESEARCH
in health systems
A METHODS READER
Rene Loewenson, Asa C Laurell, Christer Hogstedt, Lucia D'Ambruoso and Zubin Shroff
Regional Network on Equity in Health in East and Southern Africa
Training and Research Support Centre
Alliance for Health Policy and Systems Research
World Health Organization
IDRC | CRDI
Canada

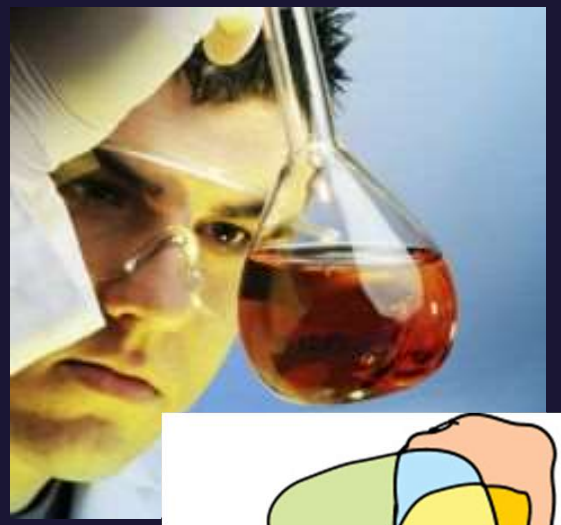
Participatory research

Theory

- Participatory research disrupts conventional subject-object separations in science
- Power is recognised and redistributed between researchers and participants

Practice

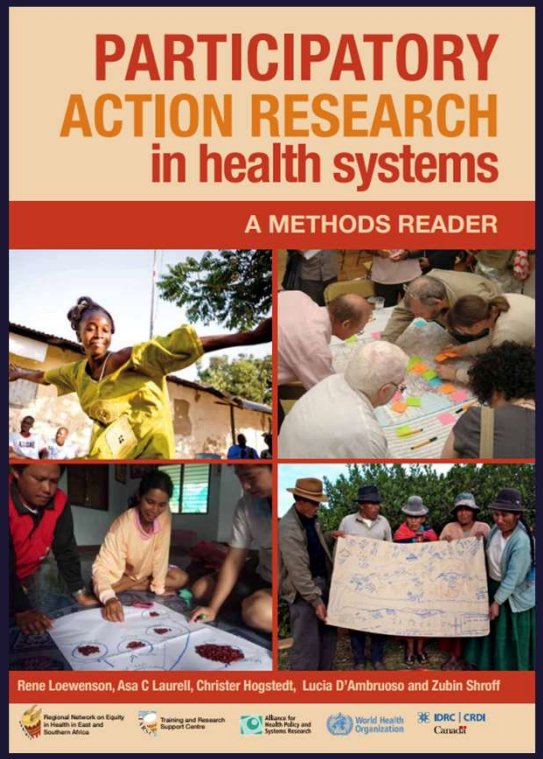
- “equal distribution of power is one of the greatest challenges of research methodology” (Shamrova and Cummings 2017)

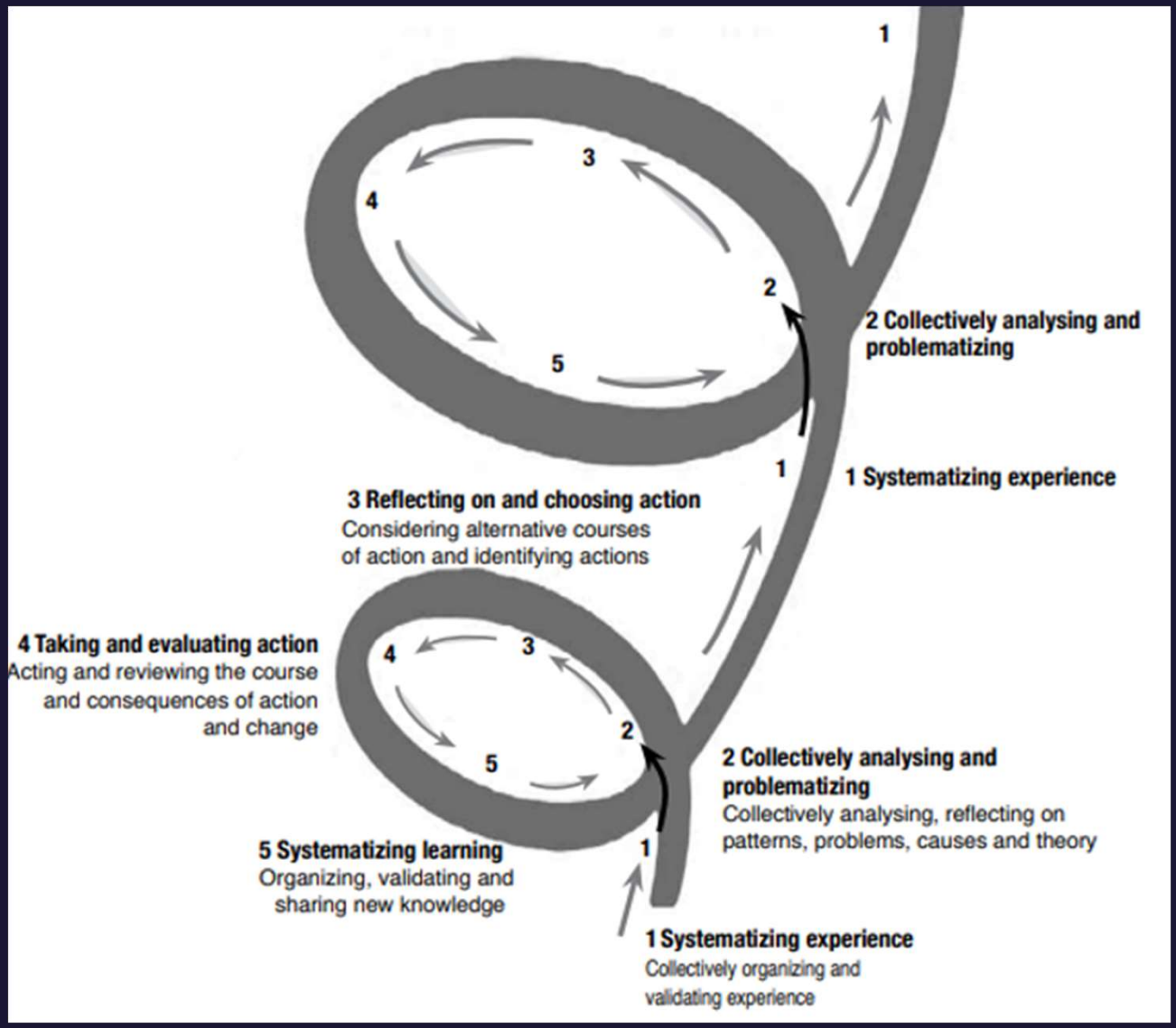


Participatory Action Research

"PAR is not a research method by itself, rather it is a post-constructivist epistemological orientation that highlights the importance of subjective experiences in knowledge construction" (Shamrova and Cummings 2017)

FIGURE 1 *French Student Poster. In English, I participate; you participate; he participates; we participate; you participate . . . They profit.*





Source: Loewenson et al 2014

PAR Principles

- SUBJECTIVE PERSPECTIVES: People's individual opinions/experiences are central
- HOMOGENOUS GROUP: Group with shared conditions, interests, and concerns
- COLLECTIVE VALIDATION: Only issues recognised by group are registered
- NO DELEGATION: Those dealing with issue are primary actors generating information

vapar

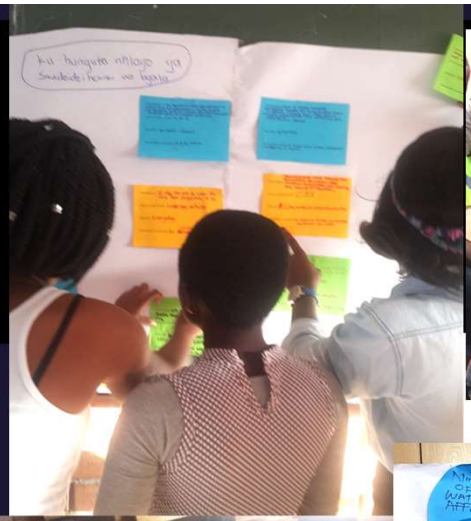
Context

- Complex burden of disease, entrenched inequalities
- DHS revival/ limited voice/authority community/HCW
- Mature surveillance system. 120,000 popn, 420km2
- HIV/AIDS, maternal and child mortality reductions, external mortality, chronic illness increasing


MAVERICK CITIZEN

Fear and loathing: Patients battle with the hardships of Mpumalanga's health facilities

Sources: Daily Maverick 2022; MRC/Wits Agincourt; Primrose and Makause, unequal neighborhoods in Johannesburg, South Africa unequalscenes.com



3 Reflecting on and choosing action
Considering alternative courses of action and identifying actions

4 Taking and evaluating action
Acting and reviewing the course and consequences of action and change

5 Systematizing learning
Organizing, validating and sharing new knowledge

1 Systematizing experience
Collectively organizing and validating experience

2 Collectively analysing and problematizing
Collectively analysing, reflecting on patterns, problems, causes and theory

1 Systematizing experience

2 Collectively analysing and problematizing

Source: Loewenson et al 2014


19/09/2017 12:45

PAR Framework

Table 2. Schedule of workshops and PAR tools and techniques.

Community-based group (priority health topic)	Focus topic (tools and techniques)							
	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Week 7	Week 8
A (AOD)	Workshop 1: Topic selection (ranking and voting)	Workshop 4: Causes/ Impacts (problem tree)	Workshop 7: Impacts/ Actors (Venn diagram)	Workshop 10: Action (action pathways)	Workshop 13: Causes/ Impacts (problem tree)	Workshop 14: Impacts/ Actors (Venn diagram)	Workshop 15: Action (action pathways)	Workshop 16: Reflection and next steps (facilitated discussion)
B (AOD)	Workshop 2: Topic selection (ranking and voting)	Workshop 5: Causes/ Impacts (problem tree)	Workshop 8: Impacts/ Actors (Venn diagram)	Workshop 11: Action (action pathways)				
C (Water)*	Workshop 3: Topic selection (ranking and voting)	Workshop 6: Causes/ Impacts (problem tree)	Workshop 9: Impacts/ Actors (Venn diagram)	Workshop 12: Action (action pathways)				
Ranking and voting	To identify priority health topics of relevance to the community. A list of health priorities was developed during the discussion, after which participants voted for the topics of highest relevance using adhesive stickers. The voting progressed through two rounds with discussion and agreement at the end.							
Problem tree	To understand and 'unpack' nominated topics from different perspectives. Through facilitated discussions using a tree diagram visible to all, participants identified cause-and-effect relationships at various levels from root (tree roots) to intermediary causes (trunk and branches) and consequences and other effects (tree pods), building subjective perspectives into shared accounts through consensus.							
Venn diagrams	To understand impacts and actors involved. Collective account developed with Venn diagram made from cardboard circles of different sizes and colours to indicate relationships and interactions between various actors and institutions, identifying internal and external organisations active in the topic and how they related to one another in terms of contact and collaboration.							
Action pathways	To articulate overall goal(s) to address the issues identified and visualise and depict stepwise actions and actors to achieve these. The action pathway was collectively developed to represent moving towards a desired goal via a series of interconnected steps and events.							
Photovoice	To visually convey lived experience. Participants given basic training in photography, research ethics and digital cameras to take photographs illustrating the topic or condition as it existed in the physical environments. Photographs presented and discussed in meetings, and captions developed to describe what images conveyed.							
Facilitated discussion	On reflections and next steps: to reflect on experiences, outputs and how the process should be carried forward to engage government and non-government organisations. Participants discussed differences and similarities between the workshop outputs, cross-verified each other's outputs and reflected on the process and future development							

Source: Oladeinde et al, 2020

(i) Collective capabilities

Expanding who participated and sharing control surfaced shared concerns, connected health to other sectors, revealed major issues

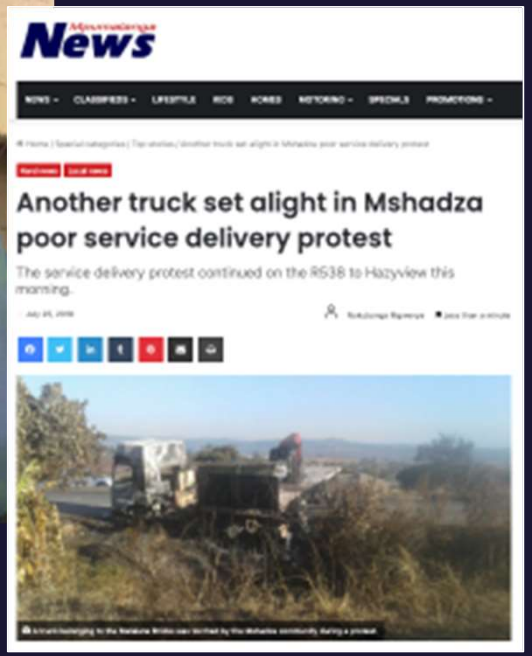
Community stakeholder workshop 2015

Community stakeholder workshop 2019

(ii) Regular learning spaces

built shared ownership/responsibility, new relationships and trust

Multisectoral action planning workshop 2019



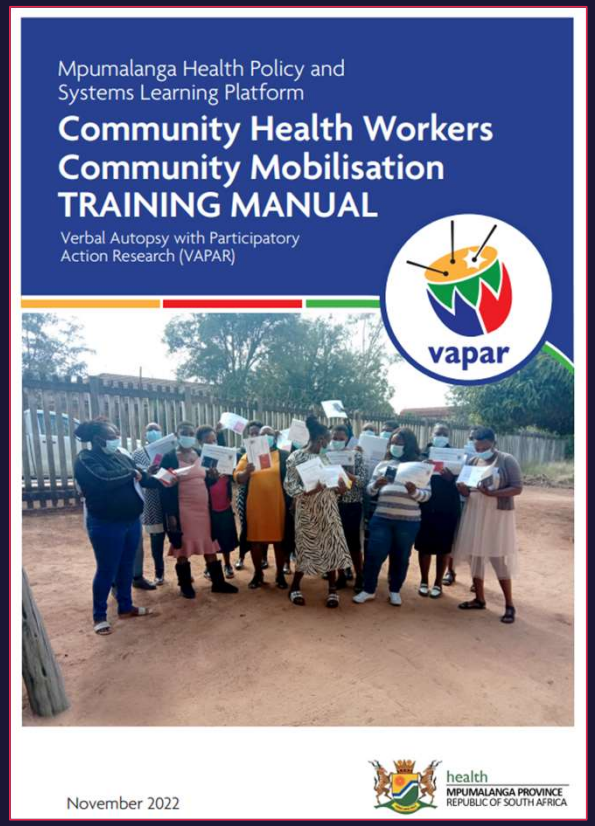
"There have been a lot of service delivery protests in communities, but they did not accomplish much – everyone realized that it is time to shift our ways of thinking and initiate dialogue, unite and collaborate and create sustainable partnerships to solve community problems"

Community stakeholder

Image credit: Mpumalanga News, 2018

(iii) Embedding in health system

institutionalising evidence generation and use at different levels



Summary: “Voice needs teeth to have bite”

- **‘Safe spaces’:** credible, actionable evidence, inclusive, informed, adaptive process
- **Enabling togetherness:** raising community voice for action and learning, with authorities
- **Formal recognition**: combining ‘claimed’ and ‘invited’ spaces
- **Long term engagement:** with higher levels: *problems aren’t just local*

Source: Fox 2015

Reflection: “Radical potential, with pitfalls”

- Mutual respect, dignity and connectedness. Researcher competencies
- Researchers navigate conflicting worlds/worldviews
- Sustainability, reconstituting spaces to rework agency
- Under-theorization of power, dislocation from radical politics

Completion of CHW community mobilisation training, May 2021

Source: Kindon et al 2008

Any Questions?

Learning outcomes (Session 1)

1. Describe participation as a concept
2. Appreciate contextual influences
3. Relate cases examples

Acknowledgments

This research was funded by the NIHR (NIHR133712) using UK aid from the UK Government to support global health research. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR or the UK government, the Court of the University of Aberdeen, the Board of Directors of the University of Rwanda, the Board of Directors of Addis Ababa University, the Board of Directors of The Sanctuary, or our International Advisory Board.