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Overview

- 1. Background
- 2. Context
- 3. Methods
- 4. Results



Background I

Action on health inequalities: who is responsible?

- Health inequalities driven by social and structural factors
- Health inequalities are social issues with social causes
- Health systems can reflect/reinforce social norms... can also confront them!
- Those most directly affected should be directly involved in progressive transformative action



Image credit: FAO/Giulio Napolitano/scalingupnutrition.org

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Background II

Participation in health systems?

- 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**



Objectives

How to build and sustain community power in PHC for health equity



- <u>Objective 1</u>: conduct a theory-informed analysis of pro-equity community power-building in PHC in a setting of structural deprivation
- Objective 2: develop practical guidance to support development of the process as a sustainable PHC component

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Context I

Post-apartheid societal progress?

- · South Africa most unequal country in world
- >50% popn in poverty, unemployment 34%
- HIV prevalence 40-50x black vs. white
- HIV risk 8x higher adolescent females vs. males
- PHC system: equitable provision, prevention, promotion, and participatory governance
- Deep disconnects between policy and practice



Image credits: UPPER IMAGE Primrose and Makause, unequal neighborhoods in Johannesburg, South Africa unequalscenes.com; LOWER IMAGE Maria Mokoena, 62, with her seven orphan grandchildren. Alexandra township, Johannesburg, South Africa; 2012 TIME Magazine

Context II

Policy recognition & support, implementation challenges

- 2-tier health system: majority heavily dependent on an under-resourced public sector
- Complex 'quadruple' burden of disease, entrenched inequalities
- National Health Insurance in 2012
- District health system revival to connect people with services.
 "WBPHCOTs" w/major CHW role



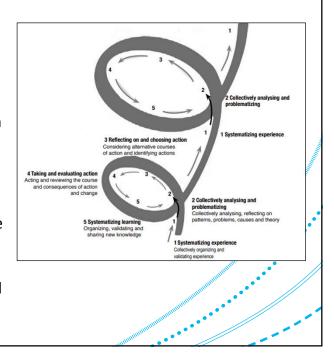
Image credit: Two community health workers went house to house in a community in Cape Town, South Africa, testing residents for H.I.V. Kim Cloete New York Times

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Methods

Participatory Action Research (PAR) → 'learning platform'

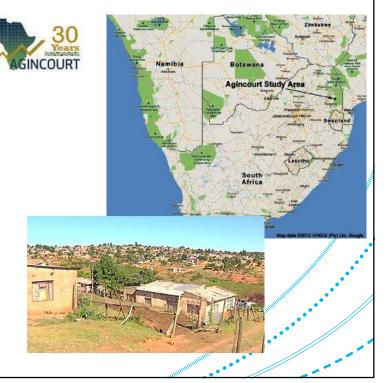
- PAR process emphasises local expertise, democratisation of knowledge production and empowerment through collective action-learning
- PAR framework with series of reiterative cycles connecting service users and providers to generate and act on evidence of practical, local relevance (incl. VA)
- Rooted in HPSR: health systems complex, adaptive, human, and relational, accessed through interactions and intersections



Source: Loewenson et al 2014

Study setting MRC/Wits Agincourt HDSS

- One of southern Africa's largest and oldest population cohorts, popn 120,000 450km2 31 villages
- Rural homesteads, multigenerational deprivation
- Little formal sanitation, unaffordable electricity, high unemployment, and limited economic base /labour migration and reliance on social grants



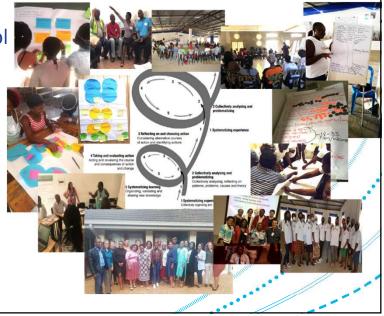
age credits: Daily Maverick 2022; MRC/Wits Agincourt

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Participant recruitment, data collection

Progressive expansion of local ownership and control

- <u>Cycle 1</u> 2017-19: 48 community, 18 services pax
- Cycle 2 2019-20: 53 community pax, interrupted COVID-19 redesign
- Cycle 3 2021-22 'rapid PAR' training 9 CHWs and 27 community members, plus 3 community mentors (39 pax total), 18 services pax



Data analysis

Community power building, Popay et al 2020



Emancipatory Power Framework (EPF) ('inward gaze')

- 'Power within': collective capabilities internal to community, incl. recognition of shared interests/values;
- 'Power with': power evolving when communities work with other agencies/communities;
- 'Power to': collective capabilities associated w/community action, including establishing structures/ opportunities for collective action

<u>Power Limiting Framework (LPF)</u> ('outward gaze')

- **Compulsory power** 'direct and visible': exercised by/through, e.g., police, local and national legislation
- **Institutional power** 'less visible': organizational rules, procedures, norms, e.g., who are decision-makers
- Structural power 'invisible': systematic biases in social institutions, generating/sustaining hierarchies of class, gender, ethnicity and resources, opportunities, status
- Productive power 'operates through practices':
 Invisible, operates through diffuse social discourses and practices to legitimate some forms of knowledge, while marginalizing others.

Source: Popay et al, 2020

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Results, Cycle 1

Regular engagement, and learning to address shared concerns, initiated 'power within'

- AOD abuse and lack of safe water key PH priorities, locally
- YA and WRA nominated as people affected by/excluded from action to address these issues
- Hard to reach perspectives important but challenging
- Sensitive, assertive facilitation necessary

Description
Participants are those directly affected and the primary researchers taking lead roles forming teams to identify problems, define, analyse, and develop solutions
Focus issue should be deliberated over, and consensus on the nature of the problem and actions to address the issues identified among a social group with shared conditions
People's individual experience are central to the process and are the foundation upon which collective knowledge is developed, respecting each other's opinion, as opposed to imposing ideas/opinions on others.
Recording observations that all participants identify as important but does not negate differences in perception and experience, but the group must reach consensus on collective findings. Corroboration of information and experiences.

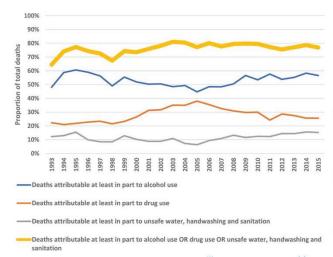
Source: Loewenson et al 2014

Cycle 1, cont'd

Shared concerns, connected health to other sectors, revealed major issues, built 'power within'



Visual evidence on lack of clean, safe water, and alcohol and drug abuse, Sources: Hove et al, 2019; Oladeinde et al, 2020



Proportions of total deaths attributable at least in part to alcohol and/or drugs and/or water 1993–2015. Source Matilla et al. 2020

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Cycle 1, cont'd

Dialogue with authorities developed 'power with' Process taken up by district initiated 'power to'



"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: VAPAR 2018; Mpumalanga News, 2018

Cycle 2 Expanding who participated and sharing control deepened 'power within', and extended 'power with'



- Community stakeholders owned discussions, leading, and facilitating the deliberations
- Identifying key actors affirmed stakeholders using their voice and courage to reach out and connect
- Creating partnerships and capacity and building new connections further enabled identification of, and engagement with, those with the power to act

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Cycle 2, continued

Developing collective and cooperative mindsets

"...we really understand.... that they won't fix the water problem overnight... what matters is that we have already taken the step of approaching people who we know are dealing with water. This is us taking responsibilities for our problems."

Youth participant, Cycle 2

"We can use the methods to solve community issues, for example when there is no water or electricity people may decide to strike where they usually destroy infrastructure but now that there are people like us who have been exposed to these methods we can opt and encourage everyone to use this approach since it is peaceful and attracts attention."

Community stakeholder, Cycle 2



COVID-19

Rapid co-redesign extended 'power to' with new structures, processes and opportunities for cooperative action learning

- Cycle 2 interrupted and co-redesigned
- Consultations during lockdown: Rural communities and providers shared realisation that CHWs first line response, but lacked support
- Revealed urgent need to formalise dialogue spaces for collective action
- · Expanded spaces for local decision-making
- · Difficult design decision



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Cycle 3 Regular process connecting/sustaining structures/opportunities for action drove 'power within', 'power with', 'power to'

- Training programme community mobilisation CHW competencies
- CHWs gained new capabilities for public speaking, analysis, application of tools
- New CHW alliances, CHWs' agency reworked in more empowered ways
- Systems commitments: clinic OMs, outreach nurses highly supportive
- Collective reflection → sub-district scale up of CHW learning platform



Cycle 3, continued

Developing collective and cooperative mindsets

"The VAPAR training was good...I learned a lot about respect, communication and how to use all the tools we learnt during the training. Most importantly, I learnt the power of working together as CHWs, communities and traditional authorities. If communities can master this approach of working together, we can solve a lot of issues that our communities come across every day."

CHW participant, Cycle 3

"I can use the skills I learnt during the training to work with community members and other CHWs to identify the challenges we have and work together to solve them." <u>CHW participant, Cycle 3</u>



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Summary

Power-building dynamics non-linear; different components progressed in different ways in each cycle, and overall

- 'Power within' expanding community control prioritising mutual respect, and connectedness in these spaces
- 'Power with' collective development and implementation of local action plans with community and authorities
- 'Power to' partnerships formalised and process taken up by DoH. Mutual empowerment. Longer term engagement: with higher levels of the system: problems aren't just local
- WIP...





Objective 2: Practical guidance

LAUNCHING A NEW RESOURCE FOR COMMUNITY HEALTH WORKERS (CHWS)

"The manual, from the department's perspective, particularly at the sub-district level, inspires a great sense of pride about the realisation of the possibility of building capacity for this cadre of emerging health care workers in South Africa. The manual will go a long in providing a practical and a formal tool to guide Community Health Workers through their day to day work with communities."

Mr R Mabika Acting sub-district **PHC** manager

www.vapar.org

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Establishing, expanding, connecting **Practice framework** and sustaining spaces for cooperative action learning D'Ambruoso et COMMUNITY al, 2022. (community capabilities/neighbourhood conditions, 'inward gaze')

SERVICES

(social, institutional, structural and systems influences, 'outward gaze')

KNOWLEDGE

(researchers as mediators between people and state 'social processes')

- conditions, 'Inward gaze')
 Marginalised communities are experts in their own
 lives and capable of representing themselv@sound
 process in people's live detailities
 Ground in Community and the community of the community of the community of the community actors directly
 times dates, languages, processes
 Renegotiate core principles, including on power,
 regularityo develop shared vision. Reflect on
 fit/functionality of methods and tools, develop new ones
 and adopt existing
 Community is fluid and changingnegotiate
 representation continually. Rework to respond to local
 conditions and events
- representation continually. Nework to respond to local conditions and events "Hard to reach" groups and processes have challeng with engagement and maintaining lim@arsistent, honest engagement is necessary, managing e.g., expectations about the potential for change and risk expectations about the potential for change and risk understand and factor into process more nuanced understandings of power structures and dy namics along lines of race, sex, class (and others, occupation etc.)
- and systems influences, 'outward gaze')

 Connect those with power to adth data and evidence and
 cocreating these through the process. Avoid preoccupation with
 the local, and assumptions that problems are only local
 Mitisectorial dialogue often does not exist or is
 dysfunctional relationships and development of mutuality with
 different levels and sections is time consuming but worthwhile
 Ensire 'safe to fail' processionitise respect and
 connectedness, and embracing 'failures' as learning opportunit
 in ps, chologically safe spaces for shared reflection, adaption,
 and sipport

- ent/chment/empowerment
 6. Power is fulld and changing with multiple, overlapping, obmplex adaptive systems at play that are more and less 5. visible Systems and complexity thinking account for multiple overlapping forms of disadvantage, discrimination arising from social and institutional contexts with systematic blases related t6. gender, class and ethnicity.

- Navigate different worldviewSocument and appreciate multiple ov erlapping complex adaptive systems and fluid power dynamics. E. g. flowledge from the marginals not seer as valid, not scientific. Work to combine different forms of In pst condoptein sate spectra and functions of and support according to the community actors as active change agents at higher levels of system, and service providers to engage without fear to develop shared rights and responsibilities for health and health services 4. Commit to ongoing saleflection and critique avoid reproducing existing hierarchies. Address risk of dislocation from core principles: continual self reflection, use of section of the conditional self-reflection and critique avoid from core principles.

 - from core principles. Continual set reflection, use of participatory theory processes criticipablic health observatories occupy strategically important positions between statutory services appulpitations served Recognise that participation is a form of power; work theorise power as fluid and circulating-complexity and systems thinking frameworks needed

Realising radical potential: building community power in primary health care through **Participatory** Action Research. Research Square

