Critical perspectives on community engagement, involvement, and participation in global health research

24 April 2023

Dr. Christina Laurenzi

Institute for Life Course Health Research

Stellenbosch University, South Africa

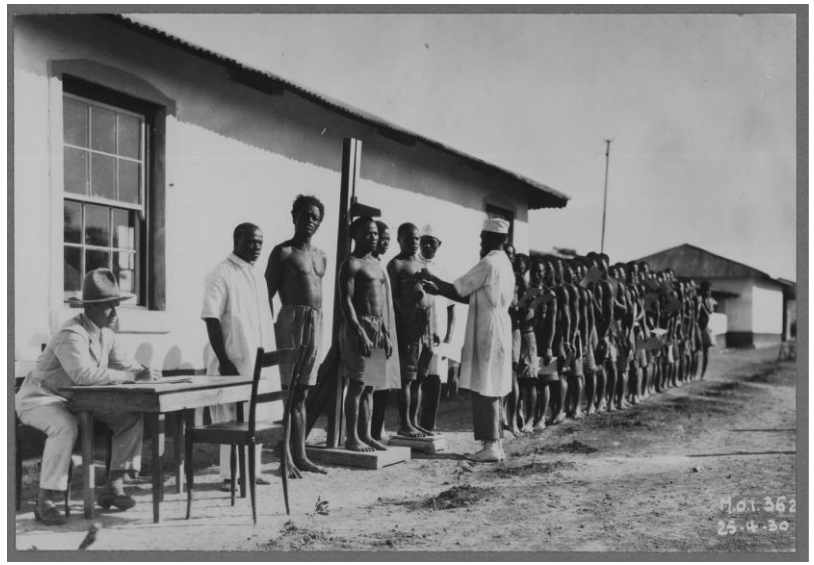
Stellenbosch
UNIVERSITY
IYUNIVESITHI
UNIVERSITEIT

Today's objectives

- Tracing the trajectory of global health interventions and research
- Reflecting on:
  - The concepts of research 'subjects' and communities
  - How knowledge is formulated
  - The importance of expanding engagement, involvement, and participation

Global health in historical context

- Tropical medicine / colonial medicine: emphasis on sanitation, hygiene, and a broader civilising mission, embedded in the colonial project
- Linked to Christianity/morality, expansion of empire, and increasing labor productivity
- Building this (colonial) workforce was also a means to improve quality of life, expand access to biomedical interventions, and respond to large-scale health emergencies



Global health in historical context

- Social medicine: health as guided by social, political, and economic determinants
- Human rights, universalism
- In many places, linked to anti-colonial response, nation-building efforts
- Barefoot doctors in China, community health worker programmes expanded elsewhere

Global health in historical context

- International and global health emerging as a technocratic, more top-down space
- Clinical but also increasingly technical roles to implement programmes at scale, increasingly globalized objectives
- From individual nations to multilateral involvement: World Health Organization (est. 1948), World Bank, UNICEF
- Mass vaccination, disease eradication campaigns (polio, smallpox)

Global health in historical context

- Later, enacted through the Millennium Development Goals (2000), Sustainable Development Goals (2015)
- Programming, attention around key issues (e.g. HIV/AIDS, TB), alongside research funding
- Other major funders emerge: GAVI, PEPFAR, Gates Foundation
- Technical interventions, sometimes top-down, sometimes more holistic, with an evidence-generation mechanism through academic partnerships, multilaterals, NGOs, and government agencies/partners

Where do “communities” fit?

- Communities have variable involvement, voice, space to participate (in programming as well as research)
- Existing power dynamics reinforce hierarchies in global health spaces
- Emergence of coordinated, multi-level advocacy campaigns that can elevate certain epidemics, e.g. HIV

Where is global health knowledge, evidence, and practice based?

- In recent years, research programs have moved to bridge the divide between medicine and public health
- Proliferation of international health, public health, global health programs in university settings (undergraduate and graduate level), mainly in high-income settings
- Imbalances persist in funding, infrastructure, knowledge creation, intervention coverage

Where is global health knowledge, evidence, and practice based?

- Funding schemes have tended to favor institutions from high-income settings
- Better resourced to begin with, stronger oversight/reporting mechanisms, a more robust research and training pipeline, and the cycle continues
- “Helicopter” research – extracting, rather than co-generating, knowledge and data

Tensions

- Between external forces and communities
- Between control and self-determination
- Between global interests and local concerns
- Between activists and technocrats
- Between those with means and those without


COVID-1984
THE REAL KILLER!
I WILL NOT INJECT A VACCINE !!!
DEAR GOVERNOR & BILL GATES, WE WILL NOT BAHH TO YOUR ORDERS
Liberty over Fear!

Current trends in global health scholarship and practice

- Examining and critiquing traditional hierarchies (age, geography, gender, race, position)
- Considerations about power and privilege in spaces linked to funding, partnerships
- Emerging and growing field centered around ‘decolonization’ of global health
- Questions of equity, capacity strengthening, knowledge exchange
- New programs and partnerships to encourage development and sustainability of Southern-led research

What Do Global Health Practitioners Think about Decolonizing Global Health?

MADELON L. FINKEL
MARLEEN TEMMERMANN
FATIMA SULEMAN
MICHELE BARRY
MELISSA SALM
AGNES BINGAWAHO
PETER H. KILMARX

*Author affiliations can be found in the back matter of this article

ABSTRACT

The growing awareness of colonialism's role in global health partnerships between HICs and LMICs and the associated calls for decolonization in global health has led to discussion for a paradigm shift that would lead to new ways of engagement and partnerships, as well as an acknowledgement that colonialism, racism, sexism, and capitalism contribute to inequity. While there is general agreement among those involved in global health partnerships that the current system needs to be made more equitable, suggestions for how to address the issue of decolonization vary greatly, and moving from rhetoric to reform is complicated. Based on a comprehensive (but not exhaustive) review of the literature, there are several recurring themes that should be addressed in order for the inequities in the current system to be changed. The degree to which decolonization of

CORRESPONDING AUTHOR:
Madelon L. Finkel, Ph.D.

Analysis

BMJ Global Health

Global health education in high-income countries: confronting coloniality and power asymmetry

Hoda Sayegh,[1] Christina Harden,[2] Hijab Khan,[3] Madhukar Pai ,[4] Quentin G Eichbaum,[5] Charles Ibingira,[6] Gelila Goba[1]

To cite: Sayegh H, Harden C, Khan H, *et al*. Global health education in high-income countries: confronting coloniality and power asymmetry. *BMJ Global Health* 2022;**7**:e008501. doi:10.1136/bmjgh-2022-008501

ABSTRACT

Contemporary global health education is overwhelmingly skewed towards high-income countries (HICs). HIC-based global health curricula largely ignore colonial origins of global health to the detriment of all stakeholders, including trainees and affected community members of low- and middle-income countries. Using the Consortium of Universities for Global Health's *Global Health Education*

SUMMARY BOX

⇒ Global health as a field is plagued with power asymmetries that overwhelmingly favour high-income countries.
⇒ These asymmetries are replicated in global health education and the education's role in upholding these power asymmetries is underemphasised in

PLOS GLOBAL PUBLIC HEALTH

REVIEW

Funders: The missing link in equitable global health research?

Esmita Charani[1,2,3]*, Seye Abimbola[4,5], Madhukar Pai[6], Olusoji Adeyi[7,8], Marc Mendelson[1], Ramanan Laxminarayan[9,10], Muneera A. Rasheed[11]*

Questions linked to decolonization of knowledge

What kinds of knowledge are most valued?

Where does expertise reside?

Who is involved in creating and refining evidence? Whose voices count?

Who governs who gets to participate, and how?

How are hierarchies set up and maintained in the research domain?

Continuing this thread

- Beyond high-low income research partnerships, where do community members come in? (Who comprises the “community”?)

- Reflecting on what engagement, involvement, and participation looks like – in theory, in practice, and in the most aspirational terms

- What ethical responsibilities do we have to community members?

Go to **www.menti.com** and use the code **8841 5576**

What does the term "community" bring to mind?

Mentimeter

Towards community engagement, involvement, participation

- More global health research has begun to include provisions for community consultation, involvement, engagement and leadership

- Community advisory boards or groups as sometimes required

- Equity extended beyond balance of research teams in high + low-resource settings – to involve research participants / representatives from these groups

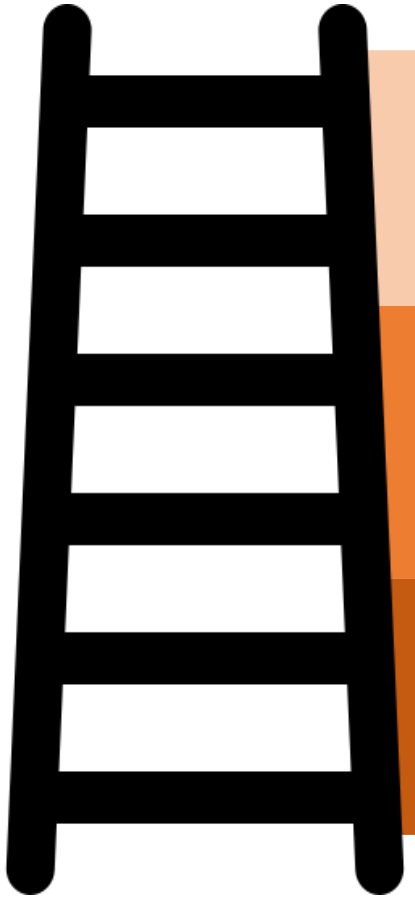
Ethical obligations to research participants

- Recognition of human dignity (confidentiality, privacy)
- Informed consent (autonomy)
- Minimising harms, maximising benefits (beneficence / non-maleficence)
- Social and clinical value (research that is needed)

Essential ingredients vs. ideal ingredients – a spectrum

Declaration of Helsinki, WMA, 2013

Participatory models of engagement



Citizen control
Delegated power
Partnership

Placation
Consultation
Informing

Therapy
Manipulation

Degrees of citizen power

Degrees of tokenism

Non-participation

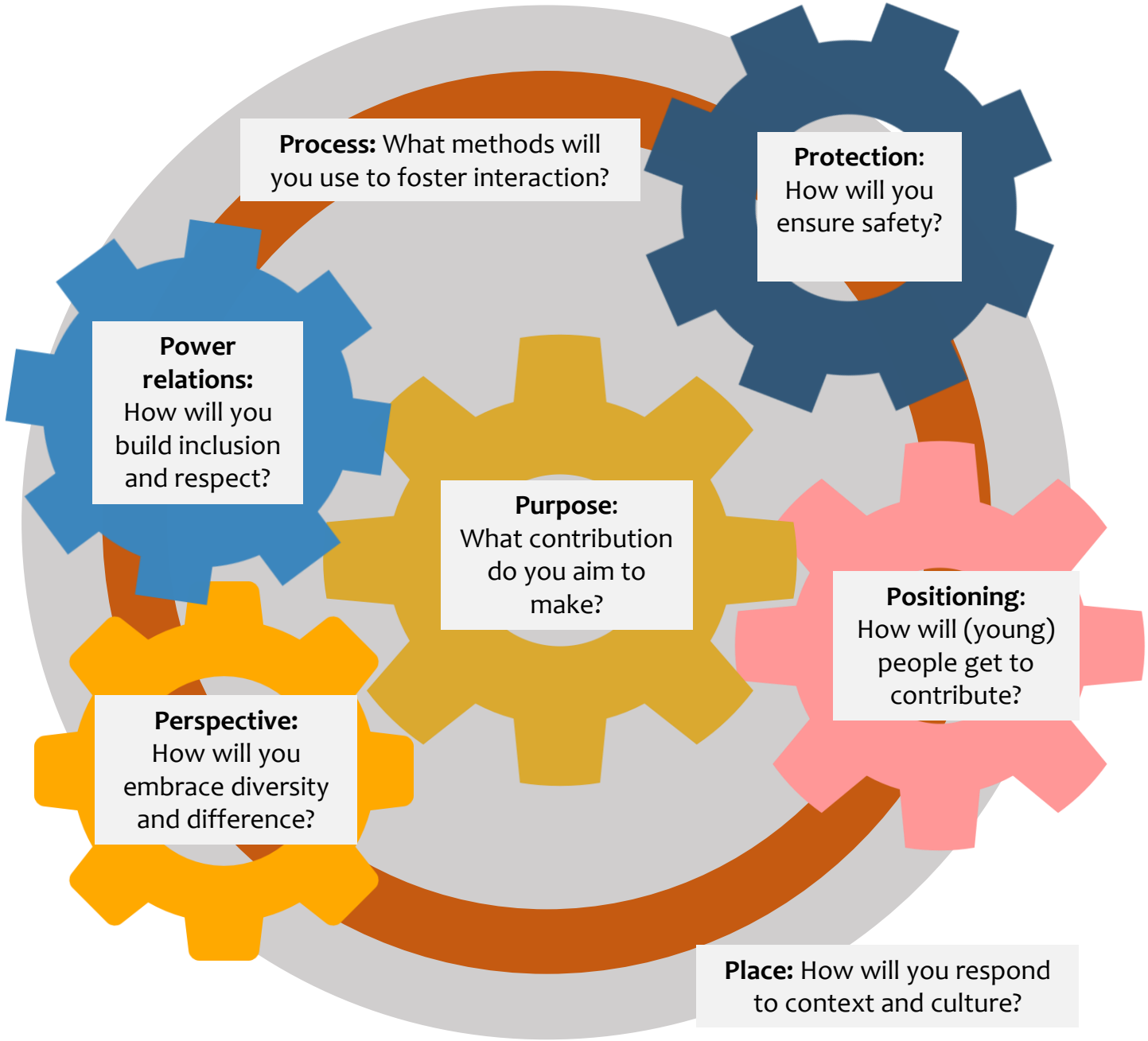
Active

Responsive

Passive

Arnstein's Ladder of Citizen Participation

P7 model of engagement



Adapted from Cahill and Dadvand (2018)

Avoiding pitfalls of community engagement

- Tokenism → **Co-production / solution-building**
- Manipulation → **Transparency**
- Miscommunication → **Clarity around expectations**

Lessons from the Equi-Injury collaboration

- **Context matters:** Project embedded in multiple sites within multiple countries, each with distinct social, cultural, political, economic, systemic realities

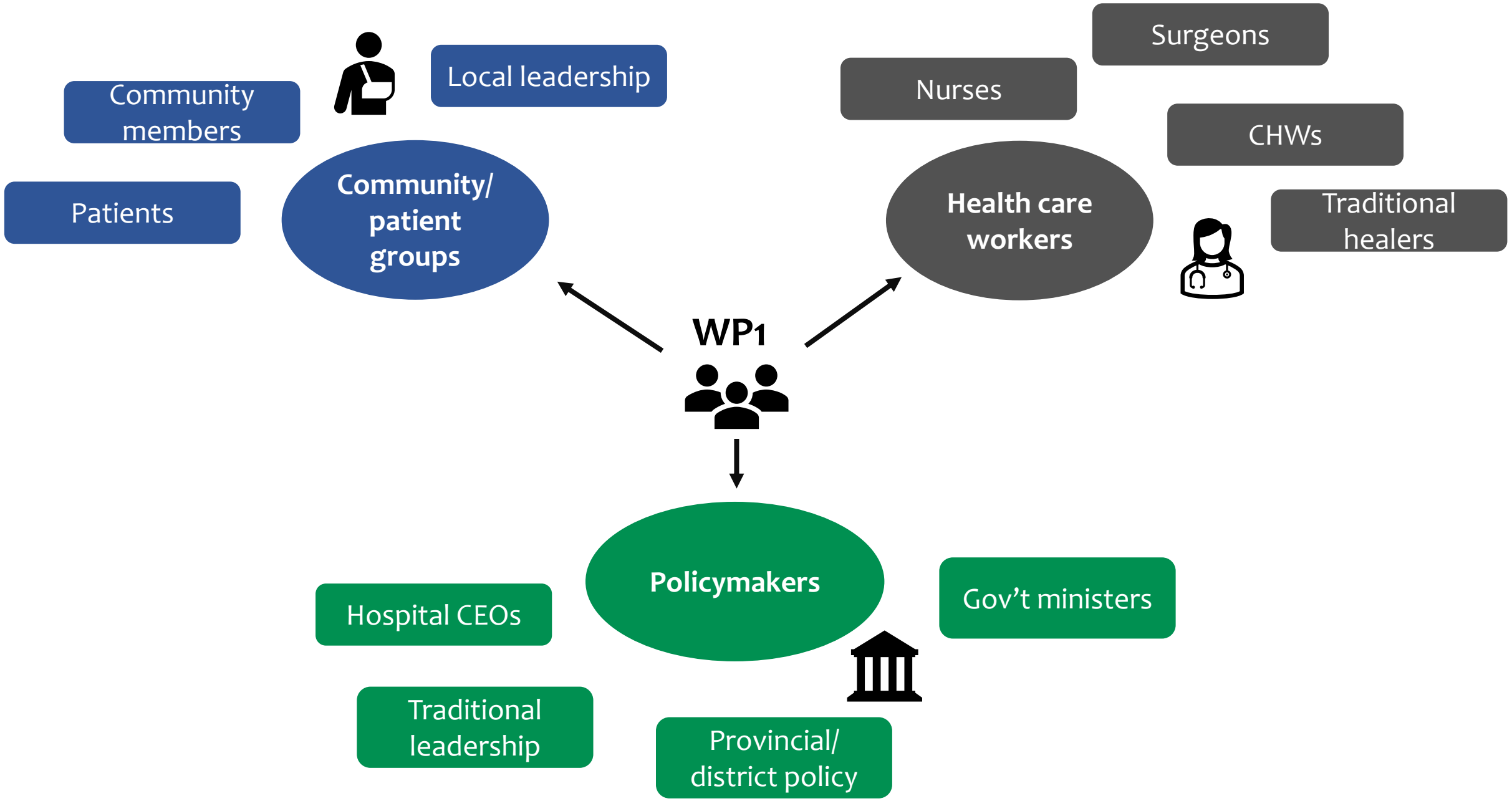
- **Methods can shape findings:** The questions we ask, and the methods and measures we select, shape the knowledge we are able to generate

Lessons from the Equi-Injury collaboration

- **Collaboration is inherently challenging, but critical:** Bridging siloes as key to identifying solutions, pragmatism (but not tokenism) as an ideal guiding principle

- **Issues and actors are dynamic:** Interests of actors are not static – they change over time and space

- **Equity:** Aims of achieving equity in health care access should mirror equity in research spaces


Community members
Local leadership
Patients
Community/ patient groups
Surgeons
Nurses
CHWs
Health care workers
Traditional healers
WP1
Policymakers
Hospital CEOs
Gov't ministers
Traditional leadership
Provincial/ district policy

Questions & discussion

Key readings

- Arnstein SR. A ladder of citizen participation. Journal of the American Institute of planners. 1969 Jul 1;35(4):216-24.
- Au, S., and Cornet, A. (2021). Medicine and colonialism. In *Medical histories of Belgium*, Manchester, England: Manchester University Press. available from: <https://doi.org/10.7765/9781526151070.00009> [Accessed 17 April 2023]
- Brazelton, M. A. (2022). Health for all?: Histories of international and global health. *History Compass*, 20(1), e12700. https://doi.org/10.1111/hic3.12700
- Cahill, H. and Dadvand, B., 2018. Re-conceptualising youth participation: A framework to inform action. *Children and Youth Services Review*, *95*, pp.243-253.
- Charani E, Abimbola S, Pai M, Adeyi O, Mendelson M, et al. (2022) Funders: The missing link in equitable global health research?. PLOS Global Public Health 2(6): e0000583. https://doi.org/10.1371/journal.pgph.0000583
- Declaration of Helsinki, WMA, 2013. https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/
- Lenette, Caroline, 'Why Decolonize? Participatory Action Research's Origins, Decolonial Research, and Intersectionality', Participatory Action Research: Ethics and Decolonization (New York, 2022; online edn, Oxford Academic, 19 May 2022), https://doi.org/10.1093/oso/9780197512456.003.0002, accessed 21 Apr. 2023.
- Vidyasagar, D. Global notes: the 10/90 gap disparities in global health research. *J Perinatol.* 26, 55–56 (2006). https://doi.org/10.1038/sj.jp.7211402
- Wernli D, Tanner M, Kickbusch I, Escher G, Paccaud F, Flahault A. Moving global health forward in academic institutions. J Glob Health. 2016 Jun;6(1):010409. doi: 10.7189/jogh.06.010409. PMID: 26955471; PMCID: PMC4766794.