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

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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

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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 labour 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

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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

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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)

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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

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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

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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

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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

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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

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Pictures representing Covid-19 pandemic

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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

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First page of three articles:

What Do Global Health Practitioners Think about Decolonizing Global Health? Ann Glob Health 2022 Jul 27;88(1):61.

Global health education in high-income countries: confronting coloniality and power asymmetry. BMJ Global Health 2022;7:e008501.

Funders: The missing link in equitable global health research? PLOS Glob Public Health. 2022; 2(6): e0000583.

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Questions linked to decolonization of knowledge:

Where does expertise reside?

What kinds of knowledge are most valued?

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

Who governs who gets to participate, and how?

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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?

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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

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Ethical obligations to research participants

Recognition of human dignity (confidentiality, privacy)

Informed consent (autonomy)

Minimizing harms, maximising benefits (beneficence / non-maleficence)

Social and clinical value (research that is needed)

Essential ingredients vs. ideal ingredients – a spectrum

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 are hierarchies set up and maintained in the research domain?

Participatory models of engagement

Arnstein’s Ladder of Citizen Participation

Arnstein's ladder is a model for understanding how the degree of citizen participation in government can affect public perceptions of legitimacy, authority and good governance. It presents different levels of public participation, with the 'most desirable' forms of participation found the higher you move up the ladder.

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P7 model of engagement

The 7 aspects of engagement (responsiveness, curiosity, discovery, anticipation, persistence, initiation and investigation) were developed in 2011 as part of a research project into children with complex learning difficulties and disabilities.

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Avoiding pitfalls of community engagement

* Tokenism
* Manipulation
* Manipulation

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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

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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

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Community/ patient groups

* Community members
* Patients
* Local leadership

Policymakers

* Hospital CEOs
* Traditional leadership
* Government ministers
* Provisional/district policy

Healthcare workers

* Nurses
* Surgeons
* CHWs
* Traditional healers

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Questions & discussion

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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]

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Cahill, H. and Dadvand, B., 2018. Re-conceptualising youth participation: A framework to inform action. Children and Youth Services Review, 95, pp.243-253.

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