

Reimagining *Global Health Ethics*: a view from the Global South

Anant Bhan

Researcher, Bioethics, Global Health, Mental Health, Health Policy

Adjunct Professor, Yenepoya (deemed to be University)

PI, Sangath (Bhopal Hub)

X/Twitter: @AnantBhan

Linkedin: <https://in.linkedin.com/in/anant-bhan-53233b11>

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(With regards to Equity)
Ethics of inaction as important as the ethics of action

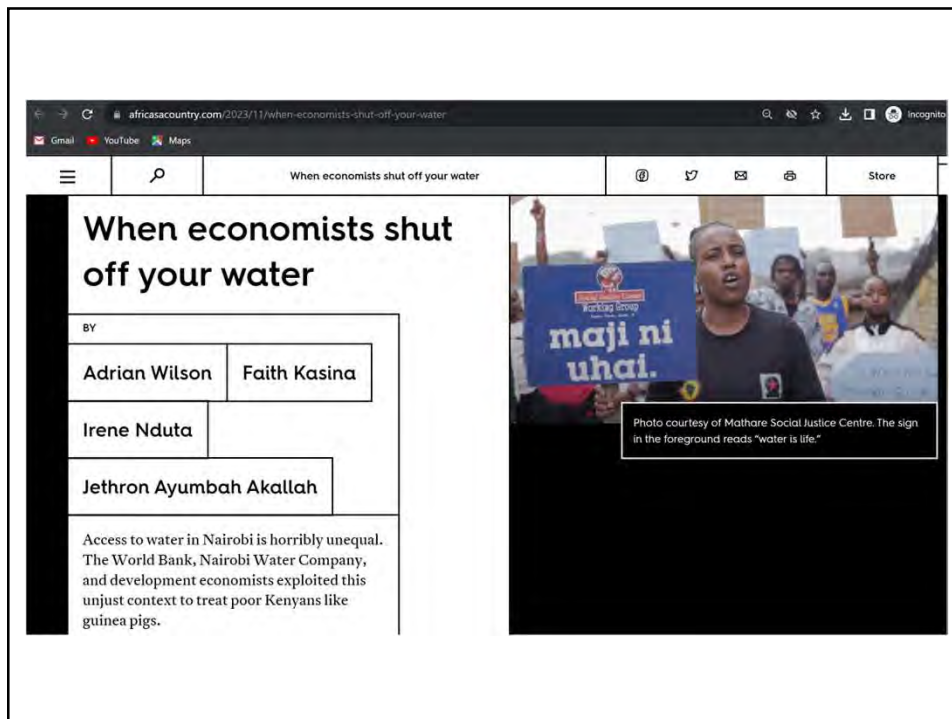
Almost 40 yrs years ago. Dec 1984 Bhopal- witnessed the worst industrial accident in history, a testament to corporate crime, and government complicity. A case study of how poor or missing regulation, lackadaisical industry safety norms, and insensitive exploitative MNC ownership left thousands devastated, families of many of who continue to suffer today, waiting for fair compensation, and to be able to truly understand the magnitude of the gas exposure's long term effects.

Pic: Raghu Rai

J Marion Sims

- 19th-century physician lionized as the “father of gynecology
- invention of the *Sims speculum* & the development of a surgical solution for vesicovaginal fistula

<http://jezebel.com/columbia-mayor-asks-south-carolina-to-remove-sculpture-1797898453>



When economists shut off your water

BY

Adrian Wilson	Faith Kasina
Irene Nduta	
Jethron Ayumbah Akallah	

Access to water in Nairobi is horribly unequal. The World Bank, Nairobi Water Company, and development economists exploited this unjust context to treat poor Kenyans like guinea pigs.

Photo courtesy of Mathare Social Justice Centre. The sign in the foreground reads “water is life.”

Introduction: Ethics

- Ethics, derived from the Greek ethos, or “behaviour”, is concerned with questions about ***right versus wrong*** conduct and what constitutes a good or bad life, as well as the justificatory basis for such questions, the **situations in which values conflict (e.g. ethical dilemmas), and the systematic analysis and resolution of these conflicts**

WHO Global Health Ethics: Key Issues. 2015

Applications in health ethics/bioethics

- Research Ethics
- *Responsible Conduct of Research*
- Clinical Ethics
- Public Health Ethics
- Global Health Ethics
- Organizational Ethics
- Ethics of Disaster and Humanitarian Response

Principles of Bioethics

- **Autonomy:** informed consent, confidentiality, rights to biological material, data, use of samples, vulnerability
- **Beneficence & Non-maleficence:** direct or indirect benefits during and after the study, risks or harms, degree of foreseeable risks (probability), conflict of interest issues
- **Justice:** participant selection, protection of vulnerable, addressing stigma/discrimination, coercion, equitable distribution of risks/benefits/opportunities to participate, post-trial benefits

BELMONT REPORT, 1979: focused on 3 principles- Respect for persons, Beneficence and Justice.

Autonomy as a central concept in bioethics

- **Autonomy as a key principle**
- Respect for autonomy has been criticized at times as it maybe discordant with the role of family and community (which can be repressive) in some contexts, especially LMICs
- Relationship ethics or ethics of care views commitments and relationships to others as the basis of ethical life (Gilligan 1982)

Global Health Ethics

- Global health ethics is a relatively new term that is used to **conceptualize the process of applying moral value to health issues that are typically characterized by a global level effect or require action coordinated at a global level.**

Stapleton et al. Global Health Action. 2014; 7: 10.3402/gha.v7.23569

Key ethical issues: global health

- Justice: access to quality health which is of quality- **is also a key equity issue .**
- Health in low-resource countries often compromised by social determinants, such as **poverty, malnutrition, poor education, unhealthy living conditions, as well as by corruption in the public and private sectors**
- Health justice often requires focuses on reducing unfair and avoidable health inequities

WHO Global Health Ethics: Key Issues. 2015

Kass N: Six Step PH Ethics Framework

1. What are the public health goals of the proposed intervention, policy or program?
2. How effective is the intervention, policy or program in achieving its stated goals?
3. What are the known or potential burdens of the program?
4. How can the burdens be minimized? Are there alternative approaches to achieve the same goals?
5. Is the program implemented fairly?
6. How can the public health benefits and the accompanying burdens be balanced? What procedures will best allow for the fair consideration of differing views?

Am J Public Health. 2001 November; 91(11): 1776–1782.

Ethical values: TB care & control

- **Social justice/equity** – A focus on social justice calls attention to the underlying root causes and existence of inequalities in society and requires that we explicitly address them
- **Solidarity**: Infectious diseases such as TB increase the risks of harm for whole populations. Such risks can be reduced where strong community ties result in cooperative action to enforce the conditions for flourishing, disease-free lives
- **Common good** – An infectious disease not only threatens the health of an infected individual, but of the whole population.
- **Autonomy** –generally seen as guaranteeing individuals the right to make decisions about their own lives, including health care.
- **Reciprocity**- Within societies it is common for some members to put themselves at greater risk of harm for the sake of others... includes an obligation to minimize the risks to individual care-givers (by providing protective equipment) as well as positive interventions to treat and compensate individuals when harm occurs as a result of providing care

WHO TB Ethics Guidance. 2010

Ethical values: TB care & control

- **Effectiveness** – The idea of effectiveness includes the duty to avoid doing things that are clearly not working, as well as the positive obligation to implement proven measures that are likely to succeed.
- **Subsidiarity** – This value promotes the idea that decisions should be made as close to the individual and communities at local level as possible. The idea is that this ought to result in decisions reflecting local interests, concerns and beliefs, and ensure the highest possible involvement by the public.
- **Participation** – This principle requires that the public be encouraged to participate in the decision-making process, and that reasons be provided for decisions.
- **Transparency and accountability** – This principle requires that decisions be made in an open manner, and that the decision-making process be fair, responsive and evidence based.

WHO TB Ethics Guidance. 2010

Applying a (self) critical ethics-infused lens

Need to interrogate the nature of global health research

- Choices- who decides? – driven by local disease burden? Or funder priorities?
- Choice of platforms?- digital health gaining major currency now.
- Focus often on high-end technologies and tertiary care– at the cost of fixing broken health systems, and need for primary health care
- Lack of comprehensive approach to addressing triple burden of disease in LMICs: communicable, non-communicable, and accidents/mental health needs

Sustainability of interventions

- Many unique innovations get ‘tested’ in community settings
- Done in “project mode”
- But end up withering away after project funding gets over
- Sustainability and long-term examination of benefits, risks, need for adaptation needed

Photo Courtesy:

<https://www.youthkiawaaz.com/2016/09/mental-health-in-madhya-pradesh/>



Politics and Pandemics

Ron Klain, J.D.

This year marks the 100th anniversary of the deadliest event in U.S. history, the Spanish influenza epidemic of 1918, which killed more Americans than World Wars I and II combined. Although

of a devastating pandemic, the medical community may have to enter theatres of operation beyond the laboratory bench and the treatment unit and publicly engage with controversial issues

be impossible to reverse even if we wanted to.

But what about less beneficial changes and trends that are making us less safe? There are three in particular in which the medi-

N ENGL J MED 372:7 NEJM.ORG DECEMBER 6, 2018

2391

What is making us less safe?

- a) rising tide of isolationism and xenophobia
- b) growing tide of antiscientific thinking and resistance to evidence-based medicine
- c) disease-related dangers from climate change.

What can the medical (bioethics/global health) community do in the face of these threats?

- Requires us to become more politically engaged
- Stepping up pressure on policymakers to adopt the measures needed to improve our (collective health security and address social determinants of health)
- need to counsel about building out and improving our global response (and health) systems.
- step into the public arena to take on unpleasant and contentious political issues such as isolationism, climate change, and demagogic populism.

Where do the solutions lie?

Global Health Ethics

- Criticism within bioethics about the domination of academic discourse from the global north

Layer	Possible measurement options
Knowledge-producer	Individual <ul style="list-style-type: none"> Hosting of cocreation workshops to develop the evaluation tools appropriate to measure epistemic justice Power analysis study to understand mechanisms and structures that lead to injustices Bibliometric analysis focusing on geographical and institutional location of first and senior authors Analysis of conference agendas or webinar series to identify the geographical and institutional origin of dominant speakers Deliberative studies to help understand whether and to what extent testimonial silencing occurs in global health ethics and quantitative studies to help understand how common these experiences are
	Institutional <ul style="list-style-type: none"> Social network analysis to reveal core and periphery institutions in global health bioethics as well as the evolution of networks over time Studies aiming to identify factors that enable or challenge the establishment and success of bioethics centres or departments in Southern locations
	Journal <ul style="list-style-type: none"> Qualitative studies to help understand whether and how journal review processes promote epistemic (in)justice Quantitative studies to understand the geographical locations of editors, reviewers and authors
	Funder <ul style="list-style-type: none"> Qualitative studies to investigate how priorities are set for ethics funding schemes and by whom Deliberative study to investigate perceptions and experiences of epistemic injustice by Southern scholars Analysis of grants awarded on topics in global health ethics, focusing on geographical and institutional locations of primary applicant(s) and coinvestigators Analysis of ethics grant eligibility criteria to explore the extent to which they foster or reduce epistemic injustices
Knowledge-applied	<ul style="list-style-type: none"> Citation analysis to understand conceptual evolution in global health ethics Analysis of grants awarded on topics in global health ethics, focusing on whether epistemologies, theories, concepts, methods or values from the global South are used Analysis of the global health ethics literature to assess what philosophical and ethical theories are being applied by scholars
Knowledge-solicited	<ul style="list-style-type: none"> Systematic review(s) of empirical global health ethics literature to assess whose perspectives and experiences were solicited and whose voices are missing or marginalised Content analyses of international ethics guidelines to determine the extent to which they draw on principles, values and concepts derived from diverse epistemic perspectives Conversation analysis of public discussion forums or public commentaries on draft guidelines to determine the nature and location of contributors Power analysis to understand how power differentials play out in committee discussion and decisions or outputs Analysis of the composition of committees and working groups articulating ethics guidance relevant to global health research and governance

Pratt B, de Vries J. J Med Ethics 2023;49:325–334. doi:10.1136/medethics-2022-108291

Table 2 Ethical responsibilities to promote epistemic justice

Layer	Actor	Possible responsibility
Knowledge-producer	Funders of global health ethics	<ul style="list-style-type: none"> Allocate funding to ethics scholars from the centre and periphery who are diverse in their geographical, social and epistemic locations Allocate funding to institutions in the centre and the periphery without disproportionately allocating funding to 'powerhouse' institutions from the centre Allocate funding to support the development of strong and sustainable bioethics departments in global South institutions Enrol students from the centre and periphery who are diverse in their geographical, social and epistemic locations
	Bioethics education programmes	
	Journals that publish global health ethics	<ul style="list-style-type: none"> Have a substantial number of editors and reviewers who are based in the periphery Ensure journal content and publishing in them is accessible (eg, financially and language-wise) to ethics scholars from the periphery Publish ethics scholars who are diverse in their geographical, social and epistemic locations Ensure that peer-review comments where people are asked to explain their work in relation to dominant theories or cultural contexts are filtered out in the editorial process
	Research institutions with ethics scholars	<ul style="list-style-type: none"> Hire ethics scholars from the centre and periphery who are diverse in their geographical, social and epistemic locations Create safe spaces where experiences of epistemic injustice can be shared in ways that are safe, supported and transformative
	Global health ethics scholars	<ul style="list-style-type: none"> Actively build research teams that span the centre and periphery and are diverse in their geographical, social and epistemic locations Create spaces where the perspectives and experiences of scholars in the periphery (geographically or epistemically) can be recognised, heard and included in deliberations Build collaborative partnerships with individuals in periphery locations (geographically and epistemically) that provide opportunities for meaningful co-leadership
Knowledge-applied	Funders of global health ethics	<ul style="list-style-type: none"> Create funding opportunities that support intercultural dialogues at the foundation and project levels of global health ethics Create funding opportunities to apply knowledge from the global South
	Bioethics education programmes	<ul style="list-style-type: none"> Create opportunities for intercultural dialogue among students Ensure there is required content (eg, an entire subject or several subjects) studying philosophical and ethical traditions from the global South Ensure that curriculum content introduces students to different epistemologies and ways of being that impact on a consideration of ethics in global health
	Journals that publish global health ethics	<ul style="list-style-type: none"> Publish content from scholars with Southern epistemic perspectives equally as those who do not—or at least as much as possible considering potential limitations in the number of papers being submitted
	Research institutions with ethics scholars	<ul style="list-style-type: none"> Reward ethics scholars for conducting research from Southern epistemic locations equally as those who do not (eg, by promotion and performance review criteria)
	Global health ethics scholars	<ul style="list-style-type: none"> Reflexively interrogate one's own practice in regards to what epistemologies, theories, concepts and methods are used and be intellectually curious about theories and epistemologies from the global South Conduct or collaborate on ethics research that applies knowledge from the global South Contribute to methodological innovation that reflects Southern epistemic locations
Knowledge-solicited	Funders of global health ethics	<ul style="list-style-type: none"> Create funding opportunities for empirical ethics research that solicits knowledge from the global South
	Bioethics education programmes	<ul style="list-style-type: none"> Include training in empirical methods and in conducting research with socially marginalised populations in the global North and global South
	Journals that publish global health ethics	<ul style="list-style-type: none"> Publish content that reports empirical ethics studies that solicited voices from the global South, especially studies that include the perspectives of those considered marginalised
	Research institutions with ethics scholars	<ul style="list-style-type: none"> Reward ethics scholars for soliciting voices from the global South in their empirical work (eg, by promotion and performance review criteria)
	Global health ethics scholars	<ul style="list-style-type: none"> Conduct or collaborate on empirical ethics research that solicits knowledge from the global South

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Need for reframing ethics principles?

- Autonomy
 - Justice, Equity, Access
 - Beneficence
 - Beneficence
 - Non-maleficence
 - Non-maleficence
 - Justice
 - Autonomy (interrogate nature of)
-

Nothing About Us, Without Us

When critical medical decisions are made, patients must have a seat at the table

Nandita Venkatesan and Anant Bhan



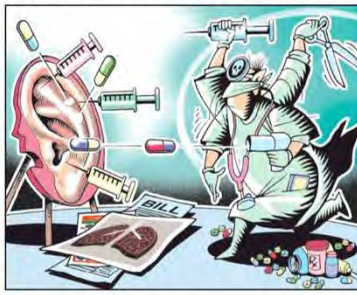
In September 2016, the health ministry's Central Tuberculosis Division constituted a national expert group to tackle India's biggest infectious disease crisis. With India home to the highest number of TB patients globally, formation of the panel, consisting of doctors and bureaucrats, was seen as an important step to provide technical expertise and guidance on TB management and shape national policy for TB control.

A month before that, the health ministry set up an expert committee in August 2016 to finalise a method, and to arrive at a formula to calculate the monetary compensation for patients fitted with pharmaceutical giant Johnson & Johnson's (J&J) faulty ASR (acetabular surface replacement) hip implants.

What was common to the two committees? None of them had any patient representation. Noting this, the patient groups fighting for compensation from J&J summarily rejected a government approved formula to compensate them for damages. Faced with consistent criticism, the government convened a meeting of the impacted patients with health authorities. But a place for patients on the decision making table is still sorely lacking.

This is a serious health policy shortcoming. Patients have often been short-changed and are not consulted on critical decision making regarding their health needs. It's time this changes for the better. Including patients in decision making is crucial as healthcare in its policy formulation and delivery is often hierarchical, and there is a strong power differential between providers/ the state and patients.

Patients directly impacted by any policy need to be considered as vital stakeholders. Health policy decisions are often based on expert opinions and sometimes evidence, but hardly include the perspectives and experience of a patient. Patient involvement can help better address their needs, devise solutions



which maximise patient adherence, and aid in communicating risks and implications of treatment choices.

Moreover, patients, with their first hand experience of navigating the labyrinthine healthcare setup and the challenges of managing illnesses and concomitant adversities, come with an in-depth understanding of ground realities. Including patients in committees which deliberate on issues which impact them, seeking and encouraging patient inputs in devising guidelines and policy decisions, inclusion of disease survivors/ patient advocates in health conferences are pathways to achieve a more inclusive approach.

One of us (NV) fought an 8 year-long battle against two bouts of intestinal TB that started during her first year of undergraduate college. She underwent six surgeries, and had to endure multiple medications including month-long courses of painful injections. Just two days after her 24th birthday she became deaf, a brutal side effect of an anti-TB injection named kanamycin.

All along her treatment, she was kept in the dark regarding such a possible side

Just two days after her 24th birthday one of us became deaf, a brutal side effect of an anti-TB injection named Kanamycin. All along her treatment, she was kept in the dark regarding such a possible side effect

effect, which meant the hearing loss came as a body blow and pushed her into acute clinical depression. With stigma around diseases like TB still high, patients often continue to suffer in silence than raise their concerns. Therefore, there has been very little awareness among physicians, health policy makers about the catastrophic impact of such devastating side effects on patients. Especially so in diseases where stigma continues to be a hindrance, decision makers need to hear the voices of, and heed to the demands of those impacted—the patients.

There is a long history of struggles in areas such as HIV where advocacy by

those living with the disease contributed greatly to the formulation of national and global responses. Mental health service user discourses have been at the forefront of bringing much-needed attention to hearing the voices of those often overlooked in the name of vulnerability.

Cancer survivors, and patients and families of those living with rare diseases have been campaigning for more research on these conditions, as well as access to newer drugs and medications, including raising their voices about high drug prices, and lack of government support. The TB survivor movement is also growing in strength and stature in India, and has been campaigning around issues like improving diagnosis and new medications.

In countries like the UK the field of PPIE (patient and public involvement and engagement) is emerging and being provided funding. PPIE aims to offer people a say in their own care and treatment, and how much they want to be involved in decision making around their care and treatment. These efforts are now being replicated with contextual adaptation in countries like Sri Lanka.

"Nothing for nobis, sine nobis" (Nothing about us, without us) has been a demand and a call to action by the disability rights and other movements. We need to extend this concept to patient involvement. Speaking at the first UNGA high-level meeting on TB in September at the UN headquarters as a TB survivor representative, one of us (NV) made a compelling statement about listening to patients: "I cannot hear you today. But I will make sure you hear me, loud and clear!"

Ironically, she has been appointed to the WHO Civil Society Task Force on TB. It's high time we offer such opportunities to patient advocates in India, involving patients proactively and purposefully will help ensure that it's not just a cabal of academics/ experts, policy makers, civil society representatives who make decisions on their behalf. We believe this will lead to better and more equitable individual and population level outcomes.

Nandita Venkatesan is a journalist with The Economic Times and a patient's rights advocate. Anant Bhan is an adjunct professor and researcher in bioethics at Sonoma State University, Ukiah, California.

Lived experiences of HEALTH PROVIDERS



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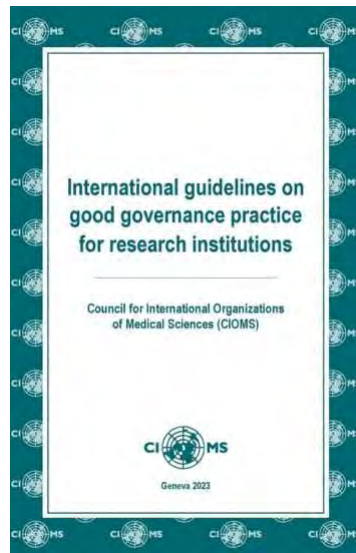
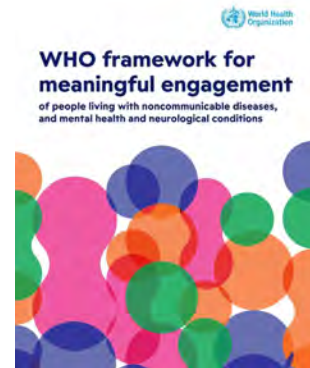
“We are everyone’s ASHAs but who’s there for us?” a qualitative exploration of perceptions of work stress and coping among rural frontline workers in Madhya Pradesh, India

Ritu Shrivastava^a, Lochan Sharma^a, Mehak Jolly^a, Romi Ahuja^a, Radhika Sharma^a, John A. Naslund^b, Jyotsna Agrawal^c, Rahul Shidhaye^d, Seema Mehrotra^e, Steve D. Hollon^e, Vikram Patel^b, Deepak Tugnawat^a, Ananth Kumar^f, Anant Bhan^a, Ameya P. Bondre^g

WHO framework

WHO has defined meaningful engagement as:

1. the respectful, dignified, equitable inclusion of individuals with lived experience
2. in a range of processes and activities
3. within an enabling environment
4. where power is transferred to people
5. valuing lived experience as a form of expertise and applying it to improve health outcomes.



Most regulations focus on the responsibilities of researchers and the sponsors, but provide little or even no details on means to achieve them.

In particular, there is limited guidance on the governance of research institutions even if it is central to defining the context in which research involving human participants is conducted.

Instead of adding more rules or revising existing ones, it seems a priority today to improve the research environment.

https://cioms.ch/working_groups/principles-of-good-governance-for-research-institutions/

THANK YOU

anantbhan@gmail.com

Twitter/X: @AnantBhan

Linkedin: <http://in.linkedin.com/pub/anant-bhan/11/33b/532>

