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Bayingana, Alice, Bhakuni, Himani orcid.org/0000-0003-0884-7866, van de Kamp, Judith et al. (4 more authors) (2025) Dignity-based practice in global health research:a framework of expectations. The Lancet Global Health. e1627-e1635. ISSN: 2214-109X

https://doi.org/10.1016/S2214-109X(25)00242-6

Dignity-based practice in global health research: a framework of expectations

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Global health research is generally done by researchers, whether locally or internationally, based in locations other than the study locations and by people with more power than the marginalised groups they research. It therefore has a tendency towards unjust practices that sideline, distort, or erase the knowledge and interpretations of the marginalised groups while favouring those of the researchers. To develop a framework of expectations for practices that respect the dignity of marginalised people, we sampled and synthesised complaints about knowledge practices in global health published in 12 journals from 2017 to 2023. We identified four sets of expectations—transparency, non-extraction, democratisation, and transformation—across eight stages of research: funding decisions, framing of issues and posing of research questions, ethics approval, data collection, data analysis and interpretation, immediate or direct use of data and knowledge produced, dissemination of findings, and long-term or indirect use of data and knowledge produced. These expectations affirm the dignity of marginalised groups as knowers, sense-makers of knowledge, and seekers of transformational change.

Lancet Glob Health 2025; 13: e1627–35

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Introduction

The past 10 years have seen a rise in critical discourse around knowledge practices in global health, meaning practices involved in the production, use, and sharing of knowledge to advance health equity globally.[1,2] Global health knowledge tends to be produced from a physical distance (by researchers based in locations other than the study locations) and from a social or political power distance (marked by differences such as income, gender, race, ethnicity, caste, and class between researchers and the populations they research).[2,3] As people with more power produce knowledge and create meaning out of the health experiences and aspirations of people with less power, global health research tends to be fraught with unfairness, injustice, and forms of silencing and privileging that favour the continuity of unjust power and resource arrangements over their redress or dismantlement.[2]

Ethical issues in research have focused on developing ethical principles to minimise exploitation and the risk of harm to research participants, as contained in the Nuremberg Code[4] and Belmont Report,[5] which were developed in the wake of atrocities committed in the 20th century by the US Government and the Government of Nazi Germany in the name of science.[4,5] Such principles have been articulated in multiple ways. For example, research must respect individuals' right to autonomy, create sufficient value to outweigh any risks, limit the risks to which participants might be exposed, and have a reasonable distribution of benefits and risks.[6–8] Subsequently, prompted by HIV/AIDS activism and the proliferation of HIV research on marginalised groups, considerations for equity (ie, health equity as a primary goal of research efforts) and justice (ie, fairness in how those efforts are enacted and how associated risks and benefits are distributed as a principle underpinning such efforts) were more explicitly incorporated into research ethics principles.[9–10] These principles are well meaning and have, over time, led to substantial shifts towards fairer research practices. However, the principles were not devised to address the various power dynamics involved in the practicalities of producing, using, and sharing knowledge across the matrix of domination that governs the world.[8–11] The principles were also primarily devised with specifications tailored to clinical and biomedical research and, to a lesser extent, empirical social research more broadly. As such, they remain incomplete.

However, building on long-running critiques of knowledge production by feminist, Black, Indigenous, and Global South scholars,[11–15] a growing body of work referred to as the complaints literature[2,16] in the field of global health has called into question knowledge practices that are often taken for granted.[2] This literature shows the wide gaps that still exist between what is currently considered to be ethical knowledge production on the health of marginalised groups and what might be deemed as dignity-based knowledge practices. Dignity is understood here as the innate quality of being worthy of respect and honour intrinsically possessed by every human being. Although discussions in medical and research ethics have been rightfully concerned with different forms of dignity,[17] an often missed concern is epistemic dignity, or the dignity of people as knowers.[3,18] The complaints literature offers future opportunities and suggestions on the premise that health equity is unattainable as a goal of health research without serious consideration of the full dignity of those who are researched, both in the knowledge production process and as a goal of knowledge production, thereby necessitating dignity-based knowledge practices.[3,18]

In this Health Policy, we present findings of a synthesis of the complaints literature: a framework of expectations for dignity-based practice in research done in relation to marginalised groups. Although much of the literature has focused on the Global North–Global South axis of power and marginalisation, some of it has also tackled axes that can operate within the Global North or Global

South, such as gender, class, sexuality, disability, and rurality versus urbanity, as well as relations within the Global North between racialised or Indigenous populations and dominant, White populations.[11] Considering these relations and their intersections is essential for gaining a comprehensive understanding of power dynamics and the ethical pitfalls that might arise in health knowledge production, use, and sharing.

Methods

Database development

We built a database of the complaints literature (2017–21) in an earlier described process[2] and updated it (2022–23; appendix pp 2–6). The timeframe captured in this database began just before a sharp increase[2] in the quantity of complaints literature in the late 2010s to early 2020s, when two global health journals—*BMJ Global Health* in 2019[19] and *The Lancet Global Health* in 2021[20]—published editorials inviting them. We purposively selected these two journals to build the database and then selected ten additional journals, considering the need for both disciplinary and geographical diversity. We manually searched the journals' archives to identify articles written as if in response to two prompts: what is wrong with health research, and what can or should be done about it? We included 208 articles in the analysis that were published in English. From each article, we coded and extracted the complaints, the proposed solutions to the issue of the complaint, and the stages of knowledge production, use, and sharing relevant to the complaints or solutions. This information, along with explicitly stated or implicitly inferred expectations, were put into a spreadsheet. Each article was analysed by two different authors and discrepancies were resolved through discussion.

See **Online** for appendix

Categorisation of expectations

Through inductive content analysis, we identified nine categories of expectations: the practice of reflexivity; justifying or openly declaring the rationale for normative choices; ensuring democratic participation and self-determination in all decision making; prioritising the needs and perspectives of the actors most proximate to an issue or problem; connecting actors within a system to one another to facilitate social learning and action; ensuring that activities are not extractive, but leave a legacy; ensuring reciprocity in the activities' benefits; prioritising a focus on root causes or causes of causes; and prioritising efforts to change unjust status quos.

We subsequently refined these nine categories into four broader categories through three processes: by combining some categories, by linking expectations of how research should be conducted (the what) to commitments regarding how the world works or should work (the why), and by juxtaposing relationships between researchers and the researched (category one: transparency, with commitment to epistemic pluralism); between knowledge production and the researched (category 2: non-extraction, with commitment to serving the researched); between knowledge production and who decides the form it takes (category 3: democratisation, with commitment to self-determination of the researched); and between knowledge production and its purpose (category 4: transformation, with commitment to changing unjust status quos). In a similar inductive process, we sorted the expectations into eight identified stages in the research process: funding decisions; framing of issues and posing of research questions; ethics approval; data collection; data analysis and interpretation; dissemination of findings; immediate or direct use of data and knowledge produced; and long-term or indirect use of data and knowledge produced.

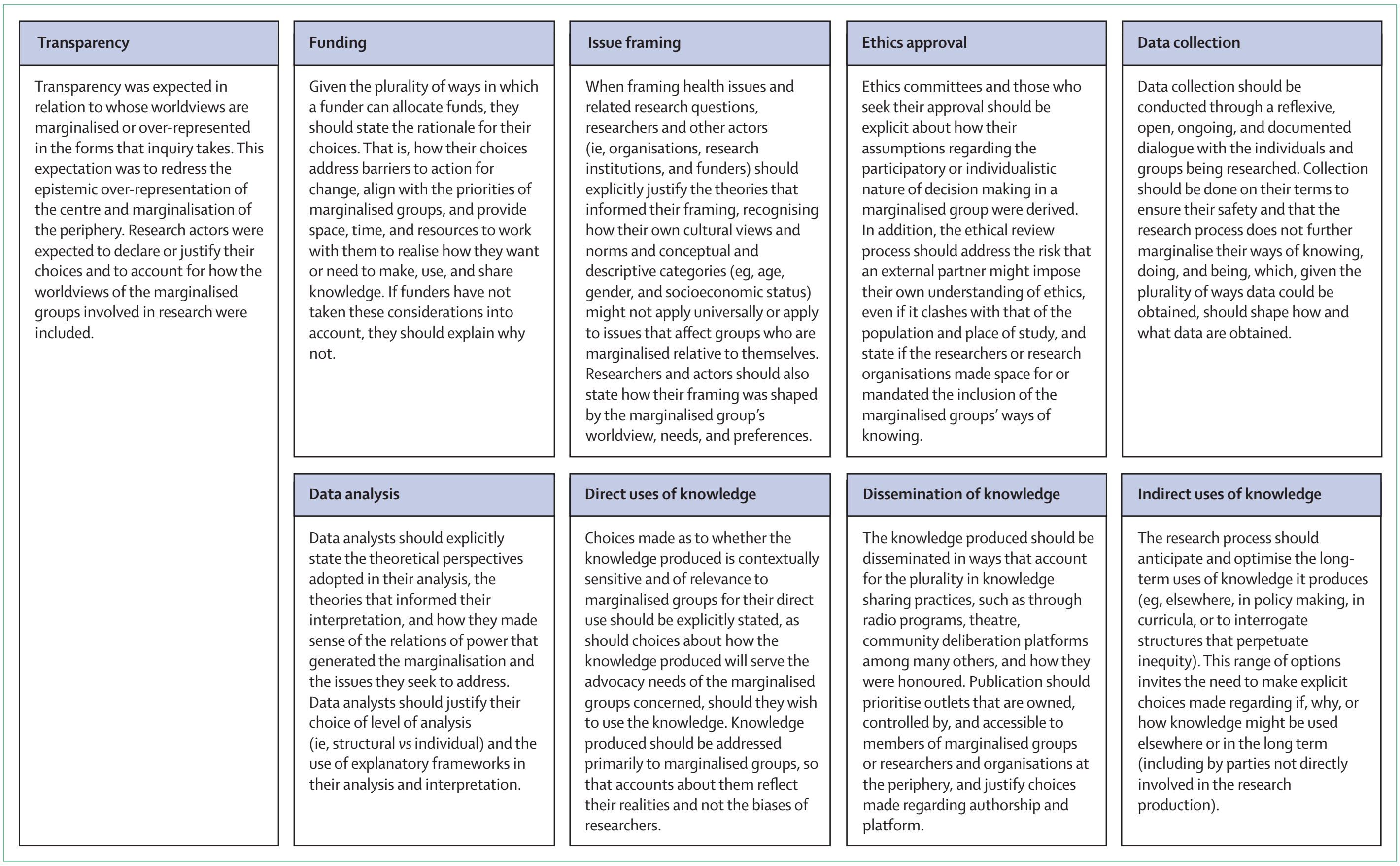
Our findings are a result of a process of abstraction in which generality was prioritised over particularities of the articles included in the sample, such that the expectations might apply beyond the Global North–Global South axis to axes within the Global North or Global South. The appendix provides details of the search, data extraction, and data analysis processes (pp 2–6), references to all articles included in the analysis (pp 7–31), and quotes for each expectation at each stage of research (pp 32–36).

Findings

Of the 208 articles included, 34 (16·35%) were original research papers, the remaining being editorials, viewpoints, commentaries, and various other think pieces. Of the articles, 85 (40·87%) had the first, last, or sole author affiliated to an institution in the Global South. 119 (57·21%) of the 208 articles were published in the two global health journals (*BMJ Global Health* and *The Lancet Global Health*), with 27 (12·98%) published in social science journals and 62 (29·81%) published in eight regional journals. Below, we present the expectations and how each applies to the eight stages of research (figures 1–4), using text paraphrased from quotes from the complaints literature. We note that the expectations are not mutually exclusive but are co-constitutive, with overlaps between expectations and across stages of research. We also note that the statements about what should be done in the presentation of our findings are not ours but were derived from and suggested by our analysis.

Transparency

The expectation of transparency was to acknowledge or fulfil a commitment to epistemic pluralism and relates to the epistemic over-representation of the centre and marginalisation of the periphery in the forms that inquiry takes or the purposes it serves. Dominant assumptions and ideas about what counts as valid knowledge and knowledge making about health and inequity are often



Transparency

Transparency was expected in relation to whose worldviews are marginalised or over-represented in the forms that inquiry takes. This expectation was to redress the epistemic over-representation of the centre and marginalisation of the periphery. Research actors were expected to declare or justify their choices and to account for how the worldviews of the marginalised groups involved in research were included.

Funding

Given the plurality of ways in which a funder can allocate funds, they should state the rationale for their choices. That is, how their choices address barriers to action for change, align with the priorities of marginalised groups, and provide space, time, and resources to work with them to realise how they want or need to make, use, and share knowledge. If funders have not taken these considerations into account, they should explain why not.

Issue framing

When framing health issues and related research questions, researchers and other actors (ie, organisations, research institutions, and funders) should explicitly justify the theories that informed their framing, recognising how their own cultural views and norms and conceptual and descriptive categories (eg, age, gender, and socioeconomic status) might not apply universally or apply to issues that affect groups who are marginalised relative to themselves. Researchers and actors should also state how their framing was shaped by the marginalised group's worldview, needs, and preferences.

Ethics approval

Ethics committees and those who seek their approval should be explicit about how their assumptions regarding the participatory or individualistic nature of decision making in a marginalised group were derived. In addition, the ethical review process should address the risk that an external partner might impose their own understanding of ethics, even if it clashes with that of the population and place of study, and state if the researchers or research organisations made space for or mandated the inclusion of the marginalised groups' ways of knowing.

Data collection

Data collection should be conducted through a reflexive, open, ongoing, and documented dialogue with the individuals and groups being researched. Collection should be done on their terms to ensure their safety and that the research process does not further marginalise their ways of knowing, doing, and being, which, given the plurality of ways data could be obtained, should shape how and what data are obtained.

Data analysis

Data analysts should explicitly state the theoretical perspectives adopted in their analysis, the theories that informed their interpretation, and how they made sense of the relations of power that generated the marginalisation and the issues they seek to address. Data analysts should justify their choice of level of analysis (ie, structural *vs* individual) and the use of explanatory frameworks in their analysis and interpretation.

Direct uses of knowledge

Choices made as to whether the knowledge produced is contextually sensitive and of relevance to marginalised groups for their direct use should be explicitly stated, as should choices about how the knowledge produced will serve the advocacy needs of the marginalised groups concerned, should they wish to use the knowledge. Knowledge produced should be addressed primarily to marginalised groups, so that accounts about them reflect their realities and not the biases of researchers.

Dissemination of knowledge

The knowledge produced should be disseminated in ways that account for the plurality in knowledge sharing practices, such as through radio programs, theatre, community deliberation platforms among many others, and how they were honoured. Publication should prioritise outlets that are owned, controlled by, and accessible to members of marginalised groups or researchers and organisations at the periphery, and justify choices made regarding authorship and platform.

Indirect uses of knowledge

The research process should anticipate and optimise the long-term uses of knowledge it produces (eg, elsewhere, in policy making, in curricula, or to interrogate structures that perpetuate inequity). This range of options invites the need to make explicit choices made regarding if, why, or how knowledge might be used elsewhere or in the long term (including by parties not directly involved in the research production).

Figure 1: **Presentation of the expectation of transparency across eight stages of research**

implicit and undeclared, but are nonetheless present in all processes involved in research. By being invisible, assumptions and ideas of validity and rigour that undervalue marginalised groups and their relationships to health and knowledge are taken for granted and entrenched in and through research practices. This entrenchment can further misunderstanding and misrepresentation of what is being studied and might reproduce the ignorance of or dismissiveness towards other ways of knowing that are available, but marginalised, in academia or communities. These other ways of knowing, making knowledge, or thinking about health could be more suitable for making sense of a health issue or a group's relationship with health and health systems. The expectation of transparency was that these choices of ideas, methods, models, tools, theories, frameworks, and concepts that are often taken for granted should be made explicit and justified so that they are available for scrutiny. The worldviews of the researched should be explicitly privileged or the reasons for not doing so explicitly justified.

Non-extraction

The expectation of non-extraction was to fulfil the commitment that research should primarily serve the epistemic, learning, and material needs of groups being studied. Due to historical and ongoing political and economic factors, global knowledge production on health and inequity tends to be arranged in ways that are extractive, exploitative, and serve the material, learning, or knowledge needs of people and entities other than those who are researched. This production perpetuates the uneven distribution of research benefits and risks in favour of those people and entities (eg, communities, groups and organisations) at the centre over those who are more peripheral. Such unevenness can result from accepted norms and practices across research processes. The expectation of non-extraction was that knowledge production on health should primarily serve the needs of those on or with whom research is done; the benefits of the knowledge produced should be clearly and quickly reflected in the people and entities being researched, including by recognition of and appropriate remuneration for their contributions. The needs of people and entities who are researched should direct knowledge production goals, activities, and decisions, and there should be investment in efforts to redress the history of extractive knowledge production on marginalised groups.

Non-extraction

Non-extraction was expected regarding where and to whom the risks and benefits of knowledge making, use, and sharing accrue. This expectation was to ensure that knowledge production primarily serves the material and learning needs of groups being studied, although this has not historically been done. Actors were expected to make sure that knowledge production was not exploitative but primarily benefited the marginalised groups on whose backs it was produced.

Funding

The rules governing funding arrangements should place marginalised groups in positions of agency and power to redress and prevent the reproduction of historical exploitation. The rules should consider both the short-term and long-term benefits that could accrue to and the costs that might be borne by marginalised groups, as momentary need or desire to secure funds might displace such long-term considerations.

Issue framing

Given that marginalised groups' engagement in research in which researchers are the only experts is marked by a legacy of exploitation, framing should be through a process of continual learning, reflection, and relationship building and maintenance. It should also consider the power imbalances between researchers or organisations at the centre and those at the periphery, and between marginalised groups and researchers.

Ethics approval

The ethics approval process must go beyond standardised procedural requirements to ensure that marginalised groups who bear the burdens of research benefit from it directly, both materially and epistemically. In addition, it should hold researchers who see it as their right to extract knowledge at any cost (eg, to satisfy their curiosity or career needs) accountable, and address how large funding can distort ethics approval decisions in ways that disregard potential harm to marginalised groups.

Data collection

Data collection should be a two-way learning process between data collectors and marginalised groups. The work of local interviewers, gatekeepers, translators, and researchers—given their local fluency, access, and trust—should be recognised and appropriately compensated in all stages of research, including authorship. These individuals' local knowledge ecosystem's capacity should be developed to become self-sustaining and they should be able to use and adapt knowledge tools for their own purposes.

Data analysis

Data analysis should be led by or conducted alongside marginalised groups and researchers and organisations at the periphery to facilitate learning how to conduct and interpret analyses if needed, gaining further knowledge about their own circumstances and strengthening their capabilities. Analysis done in this way also allows researchers to learn and incorporate the plurality of factors that influence, limit, or advance marginalised groups' agency.

Direct uses of knowledge

Researchers and organisations should make the knowledge produced, and the data underpinning it, locally and freely available and accessible, as well as recognise the different priorities of local participants and the people they represent, activists, advocates, leaders, policy makers, researchers, and research organisations. Knowledge and data sharing should be responsive to the diverse and immediate learning needs of the marginalised groups involved.

Dissemination of knowledge

The knowledge produced should be disseminated in ways that reflect and promote mutual learning between marginalised groups and researchers, and between researchers at the centre and those at the periphery. Publications should be open access, freely available, outside the extractive commercial publishing sector, and should account for how knowledge, resources, and opportunities are shared in the research process.

Indirect uses of knowledge

The research process should be structured such that researchers and research organisations at the centre build long-term, mutually beneficial relationships with marginalised groups and with researchers and research organisations at the periphery that legitimise diverse forms and sources of knowledge, as well as accounts of and pathways to change. With this process, the learning that emerges and accrues over time in such a relationship makes the centre no longer needed.

***Figure 2*: Presentation of the expectation of non-extraction across eight stages of research**

Democratisation

The expectation of democratisation was to fulfil the commitment to ensuring that people should have the ultimate say in what, how, and to what end research is done on or with them. When a community participates in research, whose questions are being answered? How much say do communities have over what and how data are collected and what happens to the data? The traditional approach in most current arrangements is that researchers decide the terms of engagement and the interests of funders, researchers, and other powerful people and entities drive what is studied, to what end it is studied, how it is studied, who is studied, and who does the studying. The expectation of democratisation was that knowledge ecosystems would function such that people in the group being studied would lead in all decisions on research and its products, such that they get to set their own research and knowledge priorities, decide how and to what end their data are used, and how the data are produced. More than tokenistic inclusion, this expectation demands that marginalised groups have control over the knowledge production apparatus and direct it towards their needs first and foremost. Given the history of extractive and violent research of and on marginalised groups by outsiders, the expectation was that democratisation could be a necessary first step towards redress.

Transformation

The expectation of transformation was to fulfil the commitment to attend to the causes of causes or conditions that create or perpetuate the status quo or problems being studied. This expectation relates to how structural or upstream causes of problems being considered are often neglected for more downstream or individual and behavioural causes. Downstream, empirically observable causes tend to be dominant in research over more upstream, less empirically capturable causes, as much of the research that is funded and supported focuses on technical fixes and immediate causes of health issues and inequity at the expense of the structural change and causes. This pattern is considered favourable to powerful entities (who are also often the funders and commissioners of research), whether private or public, with a vested interest in maintaining the status quo. This expectation was to shift towards identifying, acknowledging, and orienting research towards dealing with these upstream forces that affect the health of people and health inequities between people and groups. These forces include historical and current colonial and neocolonial political and economic arrangements; extractive economic and health systems; environmental injustices; commercial, political, structural, and social

Democratisation

Democratisation was expected in the relationship between the community or group that is studied and researchers who study them. This expectation was to ensure that people had the ultimate say in what, how, and to what end research was done on or with them. Actors were expected to make sure that people in the group being studied led all decisions on research and its products.

Funding

To redress past, current, or potential distrust between funders and marginalised groups (due to research that did not or does not prioritise their benefits and control), funding arrangements should ensure that the terms of engagement are continuously revisited, that the voice of the researched is heard, valued, and protected, and that the research is done through local organisations or researchers, aligned with their own priorities instead of funders'.

Issue framing

Research questions should be generated by or with the marginalised groups being studied, who should also establish the value of the research to resolve issues of concern to them and how studies and their purposes are framed. If and when needed, researchers should provide data to marginalised groups, let them discuss its meanings, implications, and next steps, and account for how power imbalances might lead researchers to impose their own framings.

Ethics approval

Ethics committees and those who seek their approval should seek to remove social, political, and economic barriers to the participation of marginalised groups, and of researchers, organisations, and oversight entities at the periphery in formulating the rules of engagement and how groups are consulted and give consent. These committees and individuals must ensure co-creation of the rules in continuous dialogue throughout the research process.

Data collection

Data collection should centre the contribution and leadership of the marginalised groups involved to avoid bias that might come from outsiders' framing of issues. It should centre marginalised groups' worldviews and leadership in acquiring, appraising, and assessing data, and ensure that the data collection serves primarily the needs of the marginalised groups and not the needs of funders, researchers, or organisations at the centre.

Data analysis

The terms of engagement in analysis and interpretation should be crafted by or with marginalised groups, local researchers, and local organisations. This approach centres their expertise on how to make sense of the inequity they experience and of the data generated, how to analyse and interpret them to align with and inform their worldview and preferences, and what to do with the results of the analysis and interpretation.

Direct uses of knowledge

The processes involved in research should include in-depth consultations with leadership of marginalised groups and the researchers and research organisations at the periphery to inform tangible changes and improvements in the process of research itself and the direct uses of its product. These processes should recognise that they are experts in the policies and practices that affect them, and that the usefulness of the knowledge depends on its relevance to them and their trust in the process that produced it.

Dissemination of knowledge

The terms that govern how knowledge is disseminated should be decided by or alongside people, groups, and organisations that the data represent as central participants. This strategy is to redress barriers to knowledge they might have experienced, to prevent the spread of mistrust and misinformation, and to ensure that they are represented in decision-making spaces to share the knowledge produced in ways that can generate transformative change.

Indirect uses of knowledge

The structure through which research is conducted should put the decision-making power on the long-term uses of knowledge in the hands of marginalised groups, who shoulder the risk of being researched, and researchers and research organisations at the periphery who are proximate to them, shaping what and how knowledge is presented in other locations, classrooms, and to the public.

Figure 3: **Presentation of the expectation of democratisation across eight stages of research**

determinants of health; structural racism, sexism, classism, and ableism, and many others.

Discussion

Interpretation

Discourse around transparency in health research is not new, with existing focuses on declarations of conflicts of interests, detailed reporting of research methods, and reflexivity and positionality.[8,21–25] The expectation of transparency in this framework calls for declarations and justifications of what and why specific worldviews, theoretical frameworks, and ways of approaching and organising inquiry were considered and used in all steps of research. These considerations tend to be marginal in mainstream discourse on fairness in health research,[2,26,27] but are often considered in the work of Black scholars,[28,29] Indigenous communities,[30] disability and patient collectives,[31–33] and in anthropological research on health knowledge making.[34,35] The expectation of transparency was in response to how epistemic prejudice[28] obscures the plurality of ways of knowing, producing knowledge, conceptualising health inequity, and the interests and values that determine which research questions are pursued using which methods, all of which can produce a harmfully monocentric[36] view of health or health knowledge. Instead of defaulting to the status quo and donor-imposed approaches to question and issue framing, choice of categories and concepts, data collection and analysis, dissemination, and use, actors that govern and conduct research are thus expected to explore all possible and appropriate ways of approaching and conceptualising the health of marginalised groups in the contexts of their research, including those from other academic disciplines, from outsiders within,[37] and from various marginalised ways of knowing.[14] Transparency might contribute to unsettling the taken-for-granted forms that research into the health of marginalised groups tend to take, and might generate consciousness of and allow for the space to approach problems in ways that are more fitting for each place and problem. This approach could in turn allow for meaningful participation and leadership from the communities that are studied in this process.[26]

Non-extraction is also common in discussions and recommendations regarding fair and ethical conduct of research with marginalised groups around where and to whom the benefits and risks of knowledge making, sharing, and use accrue. This expectation is typically framed as non-exploitation, reciprocity or beneficence,[6] responsiveness to health needs and priorities, equitable benefit sharing,[22] and as a duty to provide ancillary care and specific standards of care to participants of research.[10,38]

Transformation

Transformation was expected in the purpose of research; to what end we make, use, and share knowledge. This expectation was to redress the reality that structural or upstream causes of problems are too often neglected for more proximate, individual, and behavioural explanations. Actors were expected to make sure that the goal of knowledge production was to primarily transform the conditions that created or perpetuated the problems being studied.

Funding

The rules governing funding arrangement should require a focus on redressing past and current knowledge practices that generate or perpetuate inequity; earmark funds to capture, analyse, track, and report data on upstream determinants of inequity; enhance understanding of political and economic barriers to change; facilitate researchers' understanding of policy making; and limit procrastination on necessary actions by people with power.

Issue framing

The framing of research should avoid using concepts and categories that reify unnatural differences and perpetuate supremacist notions and instead use those that resonate with the groups being researched and those that challenge unjust differences. Questions and issues should be framed in terms of understanding and responding to the effects of upstream determinants of inequity and let these understandings frame any efforts at quantification, reform, or intervention.

Ethics approval

The entities that govern ethical research engagement should redress the impacts of exclusionary practices that silence marginalised groups' voices in research governance by elevating and privileging these voices as a necessary condition for change. These entities should also address the social, political, and economic conditions that make marginalised groups vulnerable to exploitation in research engagements and ensure there are rules to focus analyses on the upstream determinants of inequity and ill health.

Data collection

Data collection should focus on marginalised groups' aspirations for structural change by obtaining and making available data to challenge power and data that do not shift responsibilities for inequity onto individuals or marginalised groups in ways that burden those with little privilege and privilege those who are better off. Data collection should not silence or falsify data collected on politically sensitive issues.

Data analysis

Data analysis should use theories that explain the social structures and relations of power that underpin the inequities experienced by marginalised groups to fully capture and challenge those social structures and power relations. Data analyses should use framings and categorisations that are politically sensitive, illuminate rather than obscure the upstream contributors to inequity, and focus on the structural rather than the downstream behavioural aspects of inequity.

Direct uses of knowledge

Engagement with the structures that shape health, ill health, and the health inequities experienced by marginalised groups should be included in the immediate uses of knowledge produced. This inclusion might require that researchers work outside their discipline to advocate for addressing the upstream determinants of inequity and work with marginalised groups so that they can more effectively advocate themselves for systematically redressing power imbalances.

Dissemination of knowledge

The dissemination of knowledge should be optimised for impact on upstream determinants of inequity, rejecting the injunctions for knowledge sharing to be apolitical. Knowledge platforms at the centre and the researchers with privileged access to them should use their power to disrupt the structures in academia that marginalise researchers and research organisations at the peripheries and advocate for their inclusion in roles with influence at the centre.

Indirect uses of knowledge

The research process should incorporate consideration for potential long-term uses of knowledge to inform how to engage with researched communities, students, the public, and powerholders on upstream causes of inequity. This incorporation should be done by taking stock of the fullness of marginalised groups' worldviews and engaging with the history and politics structuring inequity. Knowledge produced should help students and the public to critically examine and dismantle structures that perpetuate inequity.

Figure 4: **Presentation of the expectation of transformation across eight stages of research**

These discussions and recommendations, however, tend to focus on relationships between individual participants, researchers or research teams, and sponsors.[27,39] Although the expectation of non-extraction in this framework includes duty to participants, it extends to the epistemic aspects of research in how questions are posed, issues are framed, and data are analysed. As the expectation demands, non-extraction should be done through continual and mutual learning and in consideration of the power imbalances between actors at the centre and periphery. The role of third parties should also be considered, including how funders and ethics review committees create the conditions for such epistemic non-extraction. This framing is in line with various anthropological and sociological studies of health knowledge making.[35,40–46] This expectation was, in part, on the premise that knowledge production has historically privileged the epistemic roles of groups other than those on or with whom research is done. As such, knowledge produced on or with marginalised groups should draw on and, in the process, enhance their epistemic contributions. Research should be conducted in ways that do not replicate existing unfair and extractive division of labour[47,48] in which local or peripheral researchers receive neither the benefits of research nor similar compensation to their foreign or central counterparts.[49]

Calls to involve communities and research participants in knowledge production and priority setting are common, with ideas such as co-production, participatory research, and community engagement abundant and even included in widely adopted research ethics guidelines, such as the Declaration of Helsinki (2024)[50] and the Council for International Organizations of Medical Sciences guidelines.[22] However, these recommendations and guidelines have thus far not addressed directly or substantially the power that researchers and funders of research hold on much of the research process.[27,51] By adding to existing guidelines and discussions of power, the expectation of democratisation is for the community from which participants are drawn to be in control of and at the centre of the research process. It echoes work produced by marginalised communities in the Global South and Global North that foregrounds power dynamics in research, including Indigenous communities, disabled and patient communities, and others whose work privileges these standpoints.[31–33,43,51–57] The expectation was to avail all necessary data, competencies, and resources to communities for them to make better sense of their circumstances and put these tools to use in the ways they see fit. The expectation was also to emphasise that inquiry into health starts from the needs and interests of marginalised groups and communities instead of those of more powerful entities that control the organisation of power, resources, and processes involved in knowledge production.[1,2]

There have been calls to include as core considerations the social, economic, commercial, and political determinants of health in the way research on health is conceptualised, done, reported, and used.[58–61] However, these upstream structural conditions that determine collective health and ill health continue to be marginalised in global and public health research and in ethics guidelines for how to approach research.[61] Instead, narrow downstream conceptualisations that tend to perpetuate what has been called a deficit or damage-centred perspective in research on marginalised groups are used.[61–63] This expectation suggests that if we are concerned with health equity and if knowledge production is to ameliorate the conditions of the most marginalised, researchers and research organisations should orient their research and its products towards efforts to redress these structural conditions. These individuals and groups should also move towards the availing of capacities, resources, and space for groups being researched to understand—and to bolster their own attempts to address—the problems that underpin the health issues and inequities they live with. The expectation of transformation was in response to the way that downstream, individual, or behaviour-focused research, which is the standard in much of global public health research, often serves to perpetuate harmful ideas about what and who is responsible for ill health and health inequity, and as an excuse for procrastination and deflection of responsibility and the imperative to act.[64,47]

Future actions

This framework of expectations provides a starting point towards protecting and affirming the dignity of marginalised groups as knowers of their own health and what determines or undermines health in their lives and settings.[3,18,64] It is also a start to redressing the structural factors that contribute to health and epistemic, social, economic, and political inequity and indignity. Each expectation can be seen as having a spectrum of demands (panel). At the lower end are demands to acknowledge and account for the effects of marginalisation on knowledge production, and at the upper end are demands for actions to redress this marginalisation. Actors that govern and conduct research can work in a range of ways, from preserving the current centre–periphery dynamics to undoing this dynamic to centre those at the margins.

The range of possible actions for each researcher, institution, organisation, or field to meet these expectations is vast. Although this framework of expectations is not itself a set of guidelines for practice, it can provide a starting point for rethinking policies, systems, and ethics guidelines for research.[3] It has implications for how researchers, funders, regulatory institutions, and knowledge platforms promote health equity and epistemic justice in transformative and lasting ways. It also has implications for how existing guidelines for ethical research can redress harms done by historical and current epistemic privileging of specific people, groups, interests, and ways of knowing over others.[12,61] Our future research will include a comparative analysis of existing guidelines for health research, considering these expectations. Further research should refine these expectations for specific situations in consultation with the specific marginalised groups and explore how these dignity-based expectations might be institutionalised not just in procedure, but also in practice.

Reflexivity and limitations

What is presented in this Health Policy is only one of many possible interpretations of these data, informed as it is by the authors' personal and professional experiences. AB and SA were born, raised, and educated in their

Panel: The extent of demand within expectations

Transparency
- Lower demand: to acknowledge and account for different ways of knowing and making sense of what is being studied.
- Higher demand: to privilege the way that the researched know and make sense of what is being studied and provide justification when this is not done.

Non-extraction
- Lower demand: to ensure that participants and researchers in their communities get material and learning benefits from being researched or participating in research.
- Higher demand: to ensure that the primary goal of research is to serve the material and learning needs of the people being researched.

Democratisation
- Lower demand: to give participants and communities involved in research a seat at the table on decisions in all steps of the process.
- Higher demand: to ensure participants and communities involved in research take the lead on all decisions in the research process.

Transformation
- Lower demand: to acknowledge and account for the structural and upstream conditions that determine the health of those being researched.
- Higher demand: to orient knowledge production towards supporting researched people and communities in their activities to understand and transform the structural and upstream conditions that determine their health.

respective African countries of origin, where they also worked in global or public health. AB and SA have also studied and worked in the Global North, including on global and public health research projects based in the Global South. Their unsettled and unsettling outsider-within perspectives make up the main standpoint from which this Health Policy was conceptualised, and the data were analysed and presented. HB and LR have similar backgrounds and experiences to AB and SA, but from south Asian countries. Although RvdG and JvdK are from Europe and JL is from Australia, they have all had experiences with global and public health research in both the Global North and Global South. This combination of authors' experiences, including advocating against unfair or unjust knowledge practices in various forums, brought together the multiple perspectives that informed this interpretation of the data and their presentation.

By including only articles published in English, our analysis leaves out many viewpoints that are not expressed in writing or are written in other languages. It also over-represents the thoughts and complaints of researchers who are often much less marginalised than the groups and communities they study. The analysis also overrepresents authors based in the Global North, which is expected because the structure of academic publishing tends to privilege these voices through various gatekeeping mechanisms.[2,19,65,66] The inclusion of journals published in the Global South might have had a balancing effect on this over-representation, but there were fewer complaints articles in the peripheral journals, potentially because the audience of complaints tends to be the powerholders in the Global North,[2,19] and due to the more diffuse nature of peripheral journals (ie, there are more of them and therefore fewer articles on any given topic in each journal). Nevertheless, affiliation with an institution in the Global North or Global South and publication in a central or peripheral journal are not themselves sufficient markers of epistemic location or standpoint.[2,12,67] Complaints and proposals from researchers from the Global South, Indigenous researchers, and researchers who might be marginalised on the basis of race, gender, ability, and sexuality who are affiliated with Global North institutions were included in this analysis.

Conclusion

This work highlights persisting gaps in efforts to make health research more ethical by amplifying the complaints of those who do this work. Although there have been commendable efforts to address the effects of physical and power distance on how and what research is done, these expectations elucidate the ways that these efforts have not been sufficient and provide a base to think about what can be done to further them. This synthesis begins to map out how dignity-based practices could contribute to reorienting knowledge production, use, and sharing towards the amelioration of health inequity and epistemic marginalisation. In this way, efforts put towards health equity would be owned by and truly reflect and serve the needs and interests of marginalised groups, instead of potentially further marginalising them.[28] This framework can serve as a starting point for thinking and working towards a world in which the margins become centres in their own right.

Contributors

AB, HB, and SA conceived and designed the analysis. AB and LR conducted the literature search, guided by SA and HB. AB, HB, JvdK, JL, RvdG, and SA did data extraction and analysis. AB wrote the first draft of the manuscript. All the authors critically revised the article and approved the final version.

Declaration of interests

SA was Editor in Chief of *BMJ Global Health* during the period covered in this synthesis and was author, co-author, peer reviewer, or handling editor of some of the articles included in the synthesis. This work was initiated during SA's tenure as the 2020–22 Prince Claus Chair in Equity and Development at Utrecht University, Netherlands. All other authors declare no competing interests.

Acknowledgments

HB and JvdK were financially supported by the WOTRO Science for Global Development Programme of the Netherlands Organisation for Scientific Research (W 02·24·112), linked to SA's tenure as Prince Claus Chair in Equity and Development. AB and SA were funded by the Australian Research Council through a Discovery Early Career Researcher Award (DE230101551) for a project titled "Towards Dignity-Based Practices in Global Health". The funding source had no input in the production of this work. Kerstin Klipstein-Grobusch (Utrecht University, Netherlands) contributed to the initial development of the database.

References

1 Koplan JP, Bond TC, Merson MH, et al, and the Consortium of Universities for Global Health Executive Board. Towards a common definition of global health. *Lancet* 2009; **373:** 1993–95.

2 Abimbola S, van de Kamp J, Lariat J, et al. Unfair knowledge practices in global health: a realist synthesis. *Health Policy Plan* 2024; **39:** 636–50.

3 Abimbola S. When dignity meets evidence. *Lancet* 2023; **401:** 340–41.

4 Annas GJ, Grodin MA (eds). The Nazi doctors and the Nuremberg Code: human rights in human experimentation. Oxford University Press, 1992.

5 Adashi EY, Walters LB, Menikoff JA. The Belmont Report at 40: reckoning with time. *Am J Public Health* 2018; **108:** 1345–48.

6 The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Belmont Report: ethical principles and guidelines for the protection of human subjects of research. US Department of Health and Human Services. 1979. https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html (accessed May 3, 2024).

7 The Nuremberg Code (1947) In: Mitscherlich A, Mielke F. Doctors of infamy: the story of the Nazi medical crimes. Henry Schuman, 1949.

8 World Medical Association. Declaration of Helsinki. World Medical Association. 1964. https://www.wma.net/wp-content/uploads/2018/07/DoH-Jun1964.pdf (accessed May 3, 2024).

9 Emanuel EJ, Wendler D, Grady C. What makes clinical research ethical? *JAMA* 2000; **283:** 2701–11.

10 Benatar SR, Singer PA. A new look at international research ethics. *BMJ* 2000; **321:** 824–26.

11 Collins PH. Black feminist thought: knowledge, consciousness, and the politics of empowerment, 2nd edn. Routledge, 2000.

12 Harding S. Is science multicultural? Postcolonialisms, feminisms, and epistemologies. Indiana University Press, 1998.

13 Ndlovu-Gatsheni S. Epistemic freedom in Africa: deprovincialization and decolonization. Routledge, 2018.

14 Smith LT. Decolonizing methodologies: research and Indigenous peoples, 3rd edn. Zed Books, 2021.

15 Quijano A. Coloniality and modernity/rationality. *Cult Stud* 2007; **21:** 168–78.

16 Ahmed S. Complaint! Duke University Press, 2021.

17 Van Der Graaf R, Van Delden JJ. Clarifying appeals to dignity in medical ethics from an historical perspective. *Bioethics* 2009; **23:** 151–60.

18 Bhakuni H, Abimbola S. Epistemic injustice in academic global health. *Lancet Glob Health* 2021; **9:** e1465–70.

19 Abimbola S. The foreign gaze: authorship in academic global health. *BMJ Glob Health* 2019; **4:** e002068.

20 The Lancet Global Health. Global health 2021: who tells the story? *Lancet Glob Health* 2021; **9:** e99.

21 Nicholls SG, Langan SM, Benchimol EI, Moher D. Reporting transparency: making the ethical mandate explicit. *BMC Med* 2016; **14:** 44.

22 Council for International Organizations of Medical Sciences. International ethical guidelines for health-related research involving humans, 4th edn. Council for International Organizations of Medical Sciences. 2016.

23 Uniform requirements for manuscripts submitted to biomedical journals: writing and editing for biomedical publication. *J Pharmacol Pharmacother* 2010; **1:** 42–58.

24 Saleh S, Masekela R, Heinz E, et al, and the Equitable Authorship Consensus Statement Group. Equity in global health research: a proposal to adopt author reflexivity statements. *PLoS Glob Public Health* 2022; **2:** e0000160.

25 Poirier B, Haag D, Soares G, Jamieson L. Whose values, what bias, which subjectivity? The need for reflexivity and positionality in epidemiological health equity scholarship. *Aust N Z J Public Health* 2023; **47:** 100079.

26 Petteway RJ, López-Cevallos D, Mohsini M, et al. Engaging antiracist and decolonial praxis to advance equity in Oregon public health surveillance practices. *Health Aff* 2024; **43:** 813–21.

27 Kumar R, Khosla R, McCoy D. Decolonising global health research: shifting power for transformative change. *PLOS Glob Public Health* 2024; **4:** e0003141.

28 Green JJ, Centellas KM, Willoughby E. Epistemic prejudice and geographies of innovation: health disparities and unrecognized interventions in Mississippi. *Med Anthropol Theory* 2019; **6**.

29 Petteway RJ. On epidemiology as racial-capitalist (re)colonization and epistemic violence. *Crit Public Health* 2022; **33:** 5–12.

30 Watego C, Whop LJ, Singh D, et al. Black to the future: making the case for Indigenist health humanities. *Int J Environ Res Public Health* 2021; **18:** 8704.

31 Hipple EE, Jones N. A path wayward: resisting 'evidence-based' discourse in favor of critical access, engaged relational pedagogy, and a politicized somatics special issue: disability justice in social work: section II - practice. *J Sociol Soc Welf* 2024; **51:** 126–51.

32 Rose DS. Mad knowledges and user-led research. Springer Nature, 2022.

33 Kalathil J, Jones N. Unsettling disciplines: madness, identity, research, knowledge. *Philos Psychiatry Psychol* 2016; **23:** 183–88.

34 Wendland CL. Opening up the black box: looking for a more capacious version of capacity in global health partnerships. *Can J Afr Stud* 2016; **50:** 415–35.

35 Biruk C. Cooking data: culture and politics in an African research world. Duke University Press, 2018.

36 Said EW. The text, the world, the critic. *Bull Midwest Mod Lang Assoc* 1975; **8:** 1–23.

37 Collins PH. Learning from the outsider within: the sociological significance of Black feminist thought. *Soc Probl* 1986; **33:** S14–32.

38 Benatar SR, Singer PA. Responsibilities in international research: a new look revisited. *J Med Ethics* 2010; **36:** 194–97.

39 Yassi A, Breilh J, Dharamsi S, Lockhart K, Spiegel JM. The ethics of ethics reviews in global health research: case studies applying a new paradigm. *J Acad Ethics* 2013; **11:** 83–101.

40 Crane JT. Scrambling for Africa: AIDS, expertise, and the rise of American global health science. Cornell University Press, 2013.

41 Nyirenda D, Sariola S, Kingori P, et al. Structural coercion in the context of community engagement in global health research conducted in a low resource setting in Africa. *BMC Med Ethics* 2020; **21:** 90.

42 Parker M, Kingori P, and the Good and Bad Research Collaborations. Good and bad research collaborations: researchers' views on science and ethics in global health research. *PLoS One* 2016; **11:** e0163579.

43 Kalinga C. Caught between a rock and a hard place: navigating global research partnerships in the Global South as an indigenous researcher. *J Afr Cult Stud* 2019; **31:** 270–72.

44 Benton A. HIV exceptionalism: development through disease in Sierra Leone, 1st edn. University of Minnesota Press, 2015.

45 Geissler PW, Pool R. Editorial: popular concerns about medical research projects in sub-Saharan Africa—a critical voice in debates about medical research ethics. *Trop Med Int Health* 2006; **11:** 975–82.

46 Collyer FM. Global patterns in the publishing of academic knowledge: Global North, Global South. *Curr Sociol* 2018; **66:** 56–73.

47 Emmanuel A. Unequal exchange: a study of the imperialism of trade. New Left Books, 1972.

48 Hickel J, Hanbury Lemos M, Barbour F. Unequal exchange of labour in the world economy. *Nat Commun* 2024; **15:** 6298.

49 Bangura I, Chakraborty A, Garcia-Hernandez A, et al. Ethical failures in global health research: violations of Sustainable Development Goal 8, decent work for all. *Lancet Glob Health* 2022; **10:** e619.

50 The World Medical Association. Declaration of Helsinki—ethical principles for medical research involving human participants. 2024. https://www.wma.net/policies-post/wma-declaration-of-helsinki/ (accessed Nov 6, 2024).

51 Egid BR, Roura M, Aktar B, et al. 'You want to deal with power while riding on power': global perspectives on power in participatory health research and co-production approaches. *BMJ Glob Health* 2021; **6:** e006978.

52 Crane J. Unequal 'partners'. AIDS, academia, and the rise of global health. *Behemoth: a Journal on Civilisation* 2010; **3:** 78–97.

53 Crane JT. Dreaming partnership, enabling inequality: administrative infrastructure in global health science. *Africa* 2020; **90:** 188–208.

54 Anderson K, Cidro J. Decades of doing: Indigenous women academics reflect on the practices of community-based health research. *J Empir Res Hum Res Ethics* 2019; **14:** 222–33.

55 Morton Ninomiya ME, Pollock NJ. Reconciling community-based Indigenous research and academic practices: knowing principles is not always enough. *Soc Sci Med* 2017; **172:** 28–36.

56 Epstein S. Impure science: AIDS, activism, and the politics of knowledge. University of California Press, 1996.

57 Inckle K, Brighton J, Sparkes AC. Who is "us" in "nothing about us without us"? Rethinking the politics of disability research. *Disabil Stud* Q 2023; **42:** 3–4.

58 Braveman P, Gottlieb L. The social determinants of health: it's time to consider the causes of the causes. *Public Health Rep* 2014; **129** (suppl 2): 19–31.

59 Mialon M. An overview of the commercial determinants of health. *Global Health* 2020; **16:** 74.

60 Lena HF, London B. The political and economic determinants of health outcomes: a cross-national analysis. *Int J Health Serv* 1993; **23:** 585–602.

61 Breilh J. The social determination of health and the transformation of rights and ethics. *Glob Public Health* 2023; **18:** 2193830.

62 Tuck E. Suspending damage: a letter to communities. *Harv Educ Rev* 2009; **79:** 409–28.

63 Fogarty W, Lovell M, Langenberg J, Heron M-J. Deficit discourse and strengths-based approaches: changing the narrative of Aboriginal and Torres Strait Islander health and wellbeing. Lowitja Institute, 2018. http://hdl.handle.net/1885/294418 (accessed Feb 18, 2025).

64 Owen D. Epistemic dignity and racial justice. University of Alabama. 2016. https://www.academia.edu/29835804/Epistemic_Dignity_and_Racial_Justice (accessed Nov 6, 2024).

65 Abimbola S. Knowledge from the Global South is in the Global South. *J Med Ethics* 2023; **49:** 337–38.

66 Abimbola S. The uses of knowledge in global health. *BMJ Glob Health* 2021; **6:** e005802.

67 Code L. Ecological thinking: the politics of epistemic location. Oxford University Press, 2006.