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The absurdity of research registration for community-oriented knowledge coproduction

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We thank Eboreime and Abimbola for raising a crucial issue in their recent *BMJ Global Health* editorial,[1] asking whether a priori registration of research is necessity or absurdity. The structural barriers, colonial roots and power imbalances within global health research are widely recognised.[2–7] Requiring a priori registration of research (including trials) is a clear absurdity, adding yet another barrier to limit the participation of researchers and people in communities in low-income and middle-income (LMIC) settings. As practitioners and researchers based in or working with community-based organisations (CBOs), we outline below the challenges of a priori registration for CBOs and other groups with limited resources, and why requiring a priori registration has the potential to systematically exclude important perspectives and methodologies of communities. We then propose alternate ways that accountability can be achieved for research and interventional studies in global health and beyond.

The largest determinants of health are political, socioeconomic and cultural.[8] Health research must therefore work across disciplines, incorporating the social sciences and their research methodologies, and treat populations as active human participants and not mere objects of research. Requirements for research registration builds on the colonial roots of global health where institutions in high-income countries for decades have conducted research among ‘subjects’ in countries they had colonised. Biomedical perspectives, high-tech solutions and ‘disciplinary supremacy’ where randomised controlled trials are held as the highest form of evidence in global health research can undermine the integrative and social determinants perspectives of public health. These values drive the funding, and therefore the research agendas and methods of these high-income country institutions, which in turn influence government policies and funding flows. Given that this is the status quo, it is essential to build structures that facilitate participation of community voices and organisations in global health research.

Summary box

- Requirement for a priori registration of research builds on the colonial roots of global health, excluding community-based researchers from global conversations.
- When communities and community-based organisations (CBOs) coproduce knowledge, it is more relevant, acceptable, appropriate, responsive and effective in generating change.
- Recognising the inherent value of studies which are small, specific, local, descriptive, observational or which focus on implementation reorders the current hierarchies of rigour and contributes to decolonising global health.
- Registration provides one pathway to public accountability, but perhaps a more rigorous pathway to accountability is long-term, engaged and documented relationships between researchers and communities.
- When necessary, global health research should allow for retrospective registration, with full fee waivers for researchers from CBOs and low-income and middle-income settings.

CBOs serve as a crucial link between academic institutions and the community and offer opportunities for qualitative and participatory elements to research. Involving a broad range of perspectives beyond academia increases the impact potential of research, with evidence showing such research is relevant, facilitates adoption of innovations, drives change, reduces waste of resources and improves recruitment of participants.[9] The value of coproduced knowledge, validation against local needs and community-led research agenda setting, implementation

Box 1 Case study of CBO attempts to retrospectively register a public health intervention trial

In a recent example, one of us conducted research within the communities where we work. The research examined mental health outcomes among 297 people with psychosocial disability, following them over 2 years. While this study had received no research grant, we had completed ethics approval and implemented a 'real-world' intervention that had a core, with bespoke adaptation on the periphery for different contexts and needs of clients. Friends with experience in research and analysis from Indian academia, as well as in high-income countries gave their time pro bono to support data analysis and writing. However, when the paper was complete, we were unable to submit to numerous journals for publication due to the requirement for priori trial registration, something we had not heard or thought of for a community-based non-pharmaceutical study at the project's inception.

We wrote to five journal editors requesting that they waive this requirement, as this was a study developed and conducted by grassroots researchers. However, journal editors either declined to respond or stated that this was the journal policy. Eventually, we sought and found a registry that permitted retrospective registration, but the cost for this was GBP400, which would pay for 4 months of salary for one of our community health workers. Ethically, we felt that these funds were better used to keep a trained team member employed and we did not retrospectively register this study. This study was eventually accepted for publication by the open access peer-reviewed journal *International Journal of Health Policy and Management*, which is based in the Global South which to date does not charge an article processing fee.[12]

and translation has been identified over and over in diverse low-income and high-income settings;[5 10 11] it is commended by ethics guidelines and experts, and often required by funders.[12]

As researchers and practitioners working primarily with organisations that are not tertiary academic institutions, but who publish in peer-reviewed academic journals, we have faced several challenges which are illustrated in the case study in box 1. These are as follows:

First, CBOs often lack the resources (human and financial) which are typically available to tertiary institutions and linked research grants. While many non-profits and CBOs obtain ethics approval, and document their programmes attentively, observational learning and real-world community-level interventions are often not registered a priori in the way required for clinical trials. Registration for such studies retrospectively is difficult, expensive, time-consuming and unnecessary. Given the power imbalances within global health research,[2–5] which mean that LMIC researchers are greatly under-represented as authors, why add one more barrier? Academic conventions purporting to promote accountability can further limit communities and CBOs from joining the global conversation.[7] While prior registration for clinical (not public health) trials may be required, registries which include global health research should allow for retrospective registration on the basis of a valid rationale for such registration being provided, with full fee waivers for authors from CBOs and LMICs.

Second, CBOs conduct 'real-world' research that seek to be contextually and culturally relevant, responding to community priorities and ongoing learning. Yet the biomedical evidence ladder (which continues to be dominant in global health) values large multisite and quantitative studies instead, even though they often over-simplify complex realities.[7 13] The COVID-19 pandemic has underlined many evidence-gaps that were broad and complex and could not be addressed with population–intervention–comparison–outcome type questions.[14] Recognising the value of studies which are small, specific, local, descriptive, observational or which focus on process and implementation (ie, studies that are less positivist) can reorder the current unbalanced hierarchies of rigour and contribute to decolonising global health. Recognising their value will also lead to including such evidence in conventional policy discourse rather than relegating them to CBO reports or grey literature. Training in research methods should include content on the value of textured community-based and community-oriented studies, especially those by CBOs. Their peculiarities must be flagged and explained. This does not take away the need to focus on scientific and ethical issues involved in the design and the need to have oversight mechanisms (including from the community). In addition, the role of independent ethics review and oversight needs to be recognised, as observed in the past three decades which has seen widespread adoption of ethics review and consent requirements.

Third, there are multiple ways for researchers to be held accountable. While trial registration offers one type of public accountability, long-term relationships with communities and 'experts by experience' groups have required us in our research to hold ourselves to a perhaps more exacting form of accountability. In frequent dialogue with community advisory groups and leaders, we discuss our research questions, methods and findings. With engaged and non-hierarchical discussions and relationships, a community can assess whether research questions are relevant, whether research funding is used appropriately, whether findings of studies are shared with participants and affected groups and whether this leads to changes in government policy and services. Rather than requiring trial registration in global health, perhaps we should follow the examples set by indigenous health researchers where the requirement is for researchers to document long-term, accountable relationships between researchers and the communities being 'researched' as best-practice?[15]

Now more than ever, global health research needs clarity, planning, transparency, community-responsiveness and ethics. Decolonising global health requires us to review the ways that research is conducted and disseminated so that the priorities of communities, knowledge users and other actors in low-income settings are elevated. To be relevant, holistic and representative, global health research must include voices and methods of research that are developed by communities and CBOs. It therefore requires publication policies that welcome studies coproduced by communities.

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