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Privilege and prejudice must be recognized for equitable research partnerships

By Doris Schroeder

Not involving communities throughout the research process may be attributable to prejudice and a failure to recognize privilege. The result is a loss for all involved.

Funders and publishers are at the forefront of promoting equitable research partnerships. In 2018, Europe's biggest research funder addressed unfair research practices¹ by adopting the TRUST Code², a short, jargon-free code focused on building equitable research partnerships. In 2022, NATURE addressed helicopter research and ethics dumping³ by encouraging transparency of potential inequities in international research through a short list of questions based on the code. These are great leaps forward in the fight against systemic exclusion and injustice in international research, but are they enough? No. Not yet. There is a need for further improvements, especially in conducting research more equitably with communities.

In June 2018, when the TRUST Code was launched in the European Parliament, a community researcher was the star of the event. Joyce Adhiambo Odhiambo, a sex worker from Nairobi, ended her speech by saying: "We want to be treated with fairness, respect, care and honesty. Is that too much to ask?" The applause was thunderous and the moderator, a BBC journalist, said: "And this is why African women will one day rule the world".

Fifteen years earlier, I wanted to invite two speakers from the indigenous San community to the first ever conference I organised. The topic was benefit sharing with indigenous peoples according to the Convention on Biodiversity. I hit a wall of prejudice. "You can't invite them to an academic conference!", was the consensus amongst those I asked for advice. The reasons given were manifold. None of them are worth repeating and none of them materialized at the conference. Instead, South African San leaders Andries Steenkamp (1960-2016) and Collin Louw presented to a rapt audience, in Afrikaans with interpretation, and I was congratulated heartily on my decision to invite them. We have collaborated ever since.

Fast-forward to 2016. Five sex workers and four San representatives are involved in the development of the TRUST Code. During a meeting, a San leader explains why they need their own research ethics code to cope with the level of exploitation experienced by the community. There was no funding other than the TRUST budget. "If we run our consultations in low-cost venues and stay in unrated accommodation, the South African share of the TRUST budget will suffice for the development of two ethics codes" was the response. Uncounted confrontations with various cockroaches later, the community-driven research and consultations were a major success. The San were the first indigenous community in Africa to issue their own research ethics code⁴.

In my experience, as the lead author of the TRUST Code, the benefits of involving community members in research from planning to dissemination, including publication, and evaluation are so considerable that I cannot understand why it is still quite rare. Other researchers, like Ana Bracic, seem to agree when she argues that: "... engaging with the community ... is the right thing to do ... But we would be remiss to not recognize that doing so also makes our science better."⁵ Who would not want to do the right thing *and* improve scientific output?

The main argument I have heard informally is that it is difficult to get funding for engagement and particularly for appointing community researchers. That has not been the case for me. For instance, the Wellcome Trust is especially keen on promoting engaged research, encouraging applicants to embed engagement throughout the design and implementation of their research with appropriate costs and staff being built into research proposals⁶. Other funders, like the European Commission, are agnostic on the topic and will leave the decision which researchers to involve in a project to the budget holders.

It is true that the scientific process gets more challenging when involving communities throughout the research cycle. Communication can be difficult due to language barriers and unreliable e-infrastructure and time is required for training and team integration, to name just a few topics. However, the benefits are exceptionally rewarding and if you think you do not have the energy or the time for engaged research, think: Privilege. Warren Buffett, one of the richest people in the world, famously attributed his wealth to lucky privilege⁷, and pledged 99% of it to charity⁸. Researchers who are aware of their privileges can make their research more meaningful and equitable by taking every opportunity to involve members of local communities for better science.

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¹ Nordling, L (2018) Europe's biggest research fund cracks down on 'ethics dumping', Nature 559, 17-18, doi: <https://doi.org/10.1038/d41586-018-05616-w>.

² TRUST (2018) The TRUST Code – A Global Code of Conduct for Equitable Research Partnerships, doi: <https://doi.org/10.48508/GCC/2018.05>.

³ Nature Editorial (2022) Nature addresses helicopter research and ethics dumping, Nature 606, 7, doi: <https://doi.org/10.1038/d41586-022-01423-6>.

⁴ Callaway, E. (2017) South Africa's San people issue ethics code to scientists, Nature 543, 475–476, doi: <https://doi.org/10.1038/543475a>.

⁵ Bracic, A. (2018) For Better Science: The Benefits of Community Engagement in Research. PS: Political Science & Politics, 51(3), 550-553, doi: <https://doi.org/10.1017/S1049096518000446>.

⁶ <https://wellcome.org/grant-funding/guidance/using-engaged-research-approach#what-is-an-engaged-research-approach>

⁷ <https://www.businessinsider.com/warren-buffett-on-the-ovarian-lottery-2013-12>

⁸ <https://givingpledge.org/pledger?pledgerId=177>