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Research participants as hidden contributors: On the epistemic price of anonymity

Significance:

Research participants are the largest and most structurally erased category of hidden contributors in health research. Anonymisation, the passive grammar of reporting guidelines, and institutional reward structures converge to render them invisible at the point of publication. In this Commentary, we argue that protection and erasure are not the same thing, and we propose four practical inclusions: contributorship statements that name participants' contributions, ethical review that requires recognition alongside protection, reporting guidelines that require substantive accounts of participant contributions, and reformed promotion criteria to close the gap between ethical conduct and conventional reporting.

Introduction

The hidden contributors so far foregrounded in this series – technicians, preparators and fieldworkers – share a feature that makes their visibility achievable in principle: they can be named.[1] The tribute to Abel Molepolle and the Sterkfontein Caves technicians demonstrates what that looks like in practice. There remains one category of contributor for whom even this is structurally foreclosed: the research participant, whose anonymity is not a side effect of reporting conventions but a condition of ethical approval.

We argue that the architecture protecting participants also erases them as contributors, and that the two functions cannot be separated by editorial tweaks alone. Anonymisation, standardised reporting, and the grammar of "subjects" acted upon rather than contributors acting were each built for defensible reasons; cumulatively, they render the people whose bodies and cooperation make health research possible, invisible in the final record. Making participants visible is therefore not a matter of adding acknowledgements: it requires reconsidering what contribution means when the ethical architecture itself is designed to prevent its recognition.

Our argument proceeds in four parts: the nature of participant contribution in health research, anchored in a clinical trial example; the three mechanisms through which that contribution becomes invisible; the South African dimension, in which invisibility carries the additional weight of a colonial research history; and what a different approach to recognition would look like.

The nature of participant contribution

Consider the Immediate Kangaroo Mother Care (KMC) Study, the multi-country randomised trial that established that continuous skin-to-skin contact, initiated immediately after birth for infants with low birthweight, reduces neonatal mortality.[2] The finding was practice-changing. The intervention is now recommended by the World Health Organization. The paper carries dozens of authors: principal investigators, site leads, trial statisticians and the data safety monitoring board.

The intervention itself was delivered by mothers. It was their bodies, for 16 or more hours a day, across weeks, under conditions of acute neonatal vulnerability, that constituted the exposure arm of the trial. No machine delivered this intervention; no study nurse could substitute for it. The mothers were not only enrolled but were the active administrators of the intervention being tested. They appear in the paper as a study sample size (*N*), disaggregated by site and outcome, their contribution recorded in the aggregate survival curves that made the trial's conclusions defensible.

This is not a failure of the KMC trial specifically. The study was conducted with substantial community engagement and is widely regarded as a model of well-executed pragmatic research. It is an illustration of what even careful studies produce at the point of publication: a record in which the people who performed the intervention appear only as data. The asymmetry is structural. The researcher who conceived the study, the statistician who analysed it, the clinician who screened eligible participants, and the research nurse who coordinated the visits, including the data safety monitoring board team that monitored safety, all appear as named contributors. The mothers who actually did the thing the trial was testing do not.

The KMC example is unusually stark because the intervention and the participant are so closely identified. In most clinical trials investigating effects of drug treatments, the contribution is less visible because it is less active: a patient swallows a tablet, provides a blood sample, returns for a follow-up visit, and tolerates uncertainty about which arm they have been allocated to. But the logic is the same. Without those contributions, the study cannot exist. What participants receive in exchange is well rehearsed in the ethics literature: information to provide consent, the right to withdraw, protection from harm, compliance with the *Protection of Personal Information Act*[3], and sometimes access to interventions they would not otherwise receive. These are genuine goods, but they are framed in the protective register. They describe what participants must not be subjected to; they say nothing about what participants actually do to advance knowledge for the collective good.

The architecture of invisibility

Participant invisibility is produced by three reinforcing mechanisms. Each was developed for defensible reasons. Each continues to serve a legitimate function. Their combined effect is cumulative erasure. Firstly, the ethical mechanism is anonymisation. Participants in health research are typically anonymised or pseudonymised in publications and in the data archives on which the publications draw. This protects participants' privacy, prevents the inadvertent disclosure

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of sensitive health information, and safeguards participants against social, economic or legal consequences that might follow from identification. Ethics committees operating under South Africa's *National Health Act* and the Department of Health's research ethics guidelines build anonymity into the approval process at a foundational level: protocols that do not adequately protect participant identity are returned for revision, and studies that would require identification face serious scrutiny and a substantially higher evidentiary burden.[4] The default position of the research ecosystem is that participants must not be named, and naming them requires affirmative justification that is rarely straightforward to construct.

Secondly, the methodological mechanism is the grammar of scientific writing, codified in the reporting guidelines that now govern publication of health research. The Consolidated Standards of Reporting Trials (CONSORT)[5], Strengthening the Reporting of Observational Studies in Epidemiology (STROBE)[6], and Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT)[7] specify in detail how participants should be described: their number, selection criteria, demographics and outcomes. The guidelines say nothing about how participants might be acknowledged as contributors. The prose is almost entirely passive and aggregate. Participants are enrolled, randomised, followed up, analysed, lost to follow-up and excluded. They do not act; they are acted upon. The shift in terminology from "subjects" to "participants", adopted in response to exactly the critique this essay offers, was lexical rather than grammatical.[8] The word changed; the syntactic position did not. A paper may use "participant" throughout and still describe a set of people to whom things happen rather than a set of people who do things contributing to knowledge creation.

Thirdly, the institutional mechanism is the reward structure. Contemporary universities attach value to publications, citations and grant income.[9,10] They do not attach value to cultivating relationships with research communities, developing communication materials in languages communities actually read, or returning findings to the people whose contributions made the research possible. A researcher who spends time on these activities is engaged in work that is professionally invisible. A researcher who does not lose anything in career terms. The structure incentivises ending the researcher–participant relationship immediately after enrolment, as any further investment yields no reward.

These three mechanisms do different work and draw on different rationales. Their convergence is not a conspiracy but a consequence. The ethical mechanism makes naming impossible; the methodological mechanism makes recognition grammatically unnatural; the institutional mechanism makes the labour of working around both of these professionally unviable. What appears to be an accidental silence is in fact structured and universally accepted as the norm.

The South African dimension

It is important to recognise that this invisibility of research participants in the research ecosystem is universal across the globe. However, in the South African context, this invisibility carries weight it does not carry everywhere. The history of health research in South Africa reflects a legacy of medical practices during apartheid and colonialism that often compromised the dignity of non-white populations.[11] Medical institutions frequently engaged in research and clinical activities with limited regard for the social and ethical considerations of non-white patients.[11,12] Concerns have been raised about clinical trials in poor communities, where the risks borne by these populations have not been matched by equitable access to the benefits of such research.[13,14] Against this history, the contemporary architecture of informed consent, ethics review and anonymisation represents genuine progress, and this essay does not suggest otherwise.

But the history also means that when a rural community contributes substantial numbers of participants to a study whose findings appear in a high-impact journal, affiliated with a well-resourced institution, and cited primarily within Western scholarly networks, the question of how that community is recognised is political as well as ethical. The structural invisibility of participants at the point of publication mirrors, at the level of credit, the broader pattern in which knowledge is generated from Southern bodies and disseminated within Western networks.

This is not a new observation: patient and community groups, rare disease communities, HIV/Aids activism and Indigenous data sovereignty movements have articulated versions of it for decades.[15-17] Decolonial scholarship has likewise argued, for over a decade, that the extraction of data from Southern populations without meaningful reciprocity reproduces colonial science in a new form.[18-20] The response has largely taken the form of improved community engagement practices, benefit-sharing frameworks and attention to building research capacity within the communities studied.[21-23] These are valuable responses. But they address research conduct, not its reporting or named recognition of the communities that made the research possible. A study may be conducted with exemplary community engagement and, at the point of publication, still render its participants invisible in entirely conventional ways. The ethical advances during the study do not carry through to the final record, and the final record is what enters the citation networks, the policy documents and the training curricula that shape the next generation of research.

What recognition requires

The purpose of this final section is not to advocate for participant authorship. Authorship carries specific responsibilities for data integrity, for manuscript approval and for accountability. These cannot reasonably be borne by someone who contributed a blood sample or completed a symptom questionnaire. The International Committee of Medical Journal Editors' criteria exclude such contributions from authorship for good reason.[24] The space between authorship and a line of acknowledgement is much larger than current conventions treat it as being, and it is in that space that recognition can meaningfully be done. What follows is a reform of the reporting layer, not of the deeper political research economy. Four changes would begin to close the gap.

Firstly, contributorship statements (see the supplementary material for an example) should name participant contribution as a distinct category, described in terms specific to the study rather than in generic language. Where community advisory boards, patient representatives, or peer-researcher structures have been part of the work, they should be credited in a manner analogous to consortium authorship in multi-centre trials. The KMC mothers, in the earlier example, could have appeared in a contributorship statement as the deliverers of the intervention being tested. That statement would not name any individual and would therefore not compromise anonymity. It would name the contribution.

Secondly, ethical review should require a participant recognition plan alongside a protection plan. The current ethical review structure asks how participants will be kept safe. It rarely asks how they will be recognised in the research output or how findings will be returned to them. Adding a recognition question to standard ethics protocols, with the answer subject to the same review as the rest of the study, would ensure the issue is addressed from the outset rather than as an afterthought at publication. Different studies require different answers, and the review process should treat the question as substantive rather than formulaic.

Thirdly, existing reporting standards for clinical and observational research should be expanded to include participant contribution statements. Explicitly documenting participant involvement and the dissemination of results to them would redefine the standard for ethical editorial oversight. Journals should treat the absence of such a statement, or its reduction to generic thanks, as grounds for editorial query rather than as acceptable standard practice.

Fourthly, institutional reward structures should consistently attach value to community engagement and the return of findings. This is arguably the most difficult and consequential change. If promotion and evaluation continue to attach value mostly to publications, citations and grant income[9,25,26], the work of recognising participants as contributors will remain professionally invisible, and rational researchers will continue to allocate their time accordingly. Reweighting promotion criteria to include substantive community engagement and the return of findings to study communities is a statement on what a South African university considers as its purpose. The current metric regime answers that question one way. A university that takes participants seriously as contributors would answer it differently.

Conclusion

Research participants are hidden contributors in a particularly structured way. The architecture that renders them invisible was built into each of its components for reasons that can be defended. The cumulative effect is that the people at the centre of health research appear in the final record as only an anonymous aggregate, and the labour of making their contribution visible is, under current conditions, professionally unrewarded.

Protection and erasure are not the same thing, and the first does not require the second. We propose: contributorship statements that name participants' contributions, ethical review that requires recognition alongside protection, reporting guidelines that require substantive accounts of participants' contributions, and institutional reward structures that value community engagement. These would hopefully begin to close the gap between the ethical advances that now characterise the conduct of research and the conventions that still govern its reporting.

What is at stake is not just a question of credit. The invisibility of participants in the final record shapes how researchers think about the people whose work their work depends on, how students are trained to understand the research enterprise, how communities experience their involvement in science, and how knowledge generated by Southern bodies is used. The mothers who carried the KMC intervention, and the patients, community members and research volunteers whose contributions make health research possible more generally, are the largest and most structurally erased category of hidden contributors the field has. Bringing them into view without compromising the protections they are owed, and with attention to the historical weight the question carries in South Africa, is both overdue and, in the most practical sense, a step toward a health sciences field that is more honest about how its knowledge is actually created.

Declarations

We have no competing interests to declare. We have no AI or LLM use to declare. Both authors read and approved the final manuscript.

References

1. Swartz L. Making the hidden visible: A challenge and call for submissions. S Afr J Sci. 2026;122(3/4), Art. #2560. https://doi.org/10.17159/sajs.2026/25640
2. World Health Organization Immediate KMC Study Group. Immediate "kangaroo mother care" and survival of infants with low birth weight. N Engl J Med. 2021;384:2028–2038. https://doi.org/10.1056/NEJMoa2026486
3. Republic of South Africa. Protection of Personal Information Act, No. 4 of 2013. Available from: https://www.gov.za/sites/default/files/gcis_document/201409/3706726-11act4of2013protectionofpersonalinforcorrect.pdf
4. Mahomed S, Labuschaigne M. The role of research ethics committees in South Africa when human biological materials are transferred between institutions. S Afr J Bioeth Law. 2019;12(2):79–83. https://doi.org/10.7196/SAJBL.2019.v12i2.685
5. Hopewell S, Chan AW, Collins GS, Hróbjartsson A, Moher D, Schulz KF, et al. CONSORT 2025 statement: Updated guideline for reporting randomised trials. BMJ. 2025;389, e081123. https://doi.org/10.1136/bmj-2024-081123
6. Cuschieri S. The STROBE guidelines. Saudi J Anaesth. 2019;13:S31–S34. https://doi.org/10.4103/sja.SJA_543_18
7. Chan AW, Boutron I, Hopewell S, Moher D, Schulz KF, Collins GS, et al. SPIRIT 2025 statement: Updated guideline for protocols of randomised trials. BMJ. 2025;389, e081477. https://doi.org/10.1136/bmj-2024-081477
8. Bromley E, Mikesell L, Jones F, Khodyakov D. From subject to participant: Ethics and the evolving role of community in health research. Am J Public Health. 2015;105(5):900–908. https://doi.org/10.2105/AJPH.2014.302403
9. Mfengu A, Raju J. Challenges with measures used for assessing research impact in higher education institutions. S Afr J Sci. 2024;120(7/8), Art. #14934. https://doi.org/10.17159/sajs.2024/14934
10. McKenna S. The resilience of rankings in the neoliberal academy. Transform High Educ. 2024;9, Art. #415. https://doi.org/10.4102/the.v9i0.415
11. Braude HD. Colonialism, Biko and AIDS: Reflections on the principle of beneficence in South African medical ethics. Soc Sci Med. 2009;68(11):2053–2060. https://doi.org/10.1016/j.socscimed.2009.03.019
12. Tilley H. Medicine, empires, and ethics in colonial Africa. AMA J Ethics. 2016;18(7):743–753. https://doi.org/10.1001/journalofethics.2016.18.7.mhst1-1607
13. Gedela K, Wong R, Balendra S, Chita S, Jones H, Golombek R, et al. Embedding equity, diversity and inclusion processes within clinical trials and health and social care research. BMJ Open. 2025;15, e091807. https://doi.org/10.1136/bmjopen-2024-091807
14. Denny CC, Grady C. Clinical research with economically disadvantaged populations. J Med Ethics. 2007;33(7):382–385. https://doi.org/10.1136/jme.2006.017681
15. Schnarch B. Ownership, control, access, and possession (OCAP) or self-determination applied to research: A critical analysis of contemporary First Nations research and some options for First Nations communities. Int J Indig Health. 2004;1:80–95.
16. Hansson MG, Lochmüller H, Riess O, Schaefer F, Orth M, Rubinstein Y, et al. The risk of re-identification versus the need to identify individuals in rare disease research. Eur J Hum Genet. 2016;24(11):1553–1558. https://doi.org/10.1038/ejhg.2016.52
17. Epstein S. Impure science: AIDS, activism, and the politics of knowledge. Berkeley, CA: University of California Press; 1997. https://doi.org/10.1525/9780520921252
18. Hedt-Gauthier BL, Jeufack HM, Neufeld NH, Alem A, Sauer S, Odhiambo J, et al. Stuck in the middle: A systematic review of authorship in collaborative health research in Africa, 2014-2016. BMJ Glob Health. 2019;4, e001853. https://doi.org/10.1136/bmjgh-2019-001853
19. Abimbola S. The foreign gaze: Authorship in academic global health. BMJ Glob Health. 2019;4, e002068. https://doi.org/10.1136/bmjgh-2019-002068
20. Naidu T. Modern medicine is a colonial artifact: Introducing decoloniality to medical education research. Acad Med. 2021;96(11S):S9–S12. https://doi.org/10.1097/ACM.0000000000004339
21. Clayton JL, Utz RL, Aruscavage N, Bybee SG, Bigger SE, Iacob E, et al. Using community engagement with FRAME: Framework for reporting adaptations and modifications to evidence-based interventions. Contemp Clin Trials Commun. 2024;42, Art. #101398. https://doi.org/10.1016/j.conctc.2024.101398
22. Nabukenya S, Kyaddondo D, Munabi IG, Waitt C, Twimukye A, Mwaka ES. The role of community engagement in promoting research participants' understanding of pharmacogenomic research results: Perspectives of stakeholders involved in HIV/AIDS research and treatment. PLoS One. 2024;19(4), e0299081. https://doi.org/10.1371/journal.pone.0299081
23. Kelly WB, Given LM. The *community engagement for impact (CEFI) framework*: An evidence-based strategy to facilitate social change. Stud High Educ. 2024;49(3):441–459. https://doi.org/10.1080/03075079.2023.2238762
24. Ali MJ. ICMJE criteria for authorship: Why the criticisms are not justified? Graefes Arch Clin Exp Ophthalmol. 2021;259:289–290. https://doi.org/10.1007/s00417-020-04825-2
25. Harley A. Alienating academic work. Educ Change. 2017;21(3), Art. #3489. https://doi.org/10.17159/1947-9417/2017/3489
26. Magoqwana B, Maqabuka Q, Tshoaedi M. "Forced to care" at the Neoliberal University: Invisible labour as academic labour performed by black women academics in the South African university. S Afr Rev Sociol. 2019;50(3–4):6–21. https://doi.org/10.1080/21528586.2020.1730947