

EDITORIAL

Researching 'others'

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FULL ARTICLE:

The Conference Declaration at the end of the 17th World Rural Health Conference 2021, hosted virtually from Bangladesh, calls for research that is guided by communities to foster and enhance rural services, noting that for rural communities there should be 'nothing about us, without us'¹. This is an important call that *Rural and Remote Health* should consider seriously. The slogan 'nothing about us, without us', rendered from the Latin *nihil de nobis, sine nobis*, apparently originated in central European politics and demands that no policy should be decided without the

participation of people who are or will be affected by a policy or action². It has been used widely by different activist groups to campaign for a place at the decision-making table, and in essence lies behind rural-proofing, a concept with which readers of this journal are likely to be familiar^{3,4}.

Despite extensive research ethics committees and review board processes being in place for research to be conducted, the notion of what it means to be a research participant, and for a person or

group to be researched, has not been widely discussed in terms of health research ethics, beyond ensuring fully informed consent. In contrast, there is an extensive social science literature around alternative approaches to research that are more inclusive and participatory⁵⁻⁹.

This silence is concerning, particularly given the exploitation of study participants throughout the history of medical research, even post-Nuremberg, particularly well documented in the story of Henrietta Lacks¹⁰. Is there a failure to see the power and hierarchy that may prevent participation from being seen as anything more than giving consent?

As a result, perhaps, the medical literature is replete with examples of studies about groups in which researchers from the 'outside' present and discuss their findings without any reflection of the views of those who have been researched. This can be seen at an international level where, on a regular basis, articles about people in the Global South are written by researchers from high-income countries, without participation of researchers in low-to-middle-income countries (LMICs), which is a manifestation of ongoing research colonialism in Africa¹¹. For example, an article about COVID-19 was published last year in *Science*, in which authors affiliated to institutions in high-income countries discussed mitigation and suppression strategies in LMICs¹²; the nature of the authorship was raised in two letters published in the journal^{13,14}, which apparently did not receive any response, either from authors or from editors. More recently, *BMJ Global Health* published an analysis of global health research that noted the uneven progress in improving representation of LMIC-affiliated authors in studies about LMICs, but the authors of the review were all affiliated with institutions in a higher income country, the irony of which was not even mentioned in the article¹⁵.

A related issue may arise in relation to the moral rights in written work for memorable quotations in qualitative research. When a researcher identifies a pattern or relationship in participant responses, it appears entirely appropriate to claim this as the intellectual property of the researcher. However, when a direct quotation is used to illustrate this finding, when should the participant be given the opportunity to be recognised as the author of the quote? What if the quote is used in the title of the paper, as is done in an excellent article from New Zealand, recently published in this journal?¹⁶ How could this be done while ensuring the rights of participants to confidentiality and privacy are protected? Or could this be what restrains authors from considering this?

Is this just an ethical issue? 'Nothing about us without us' in health research is mirrored in the debates on value-based health care around moving from informed patient consent to informed patient choice¹⁷. Key to this improvement is the patient having an active voice in determining the care provided to them as compared to a more passive assent to care options decided by clinicians. If the evidence is that clinical outcomes, cost and reduction in unintended harms are all improved by this active patient participation in care choices¹⁸, could more active participation in research by study participants lead to similar improvements in

research outcomes such as improved analysis of data, reduced harm to participants and swifter translation of findings into practice?

This journal has taken the decision that, as far as it can be determined, an article about people in any country or region without authors from that country or region will not be published. A few other journals, notably including *Global Health Action Journal*, have similar stances. An article published by *Human Resources for Health* in 2020, on barriers to performing surgery among associate clinicians in sub-Saharan Africa, had no authors affiliated to sub-Saharan African institutions¹⁹. After this was raised by one of us (IC), an addition was made to that journal's aims, indicating that it 'encourages collaboration with colleagues in the locations where the research is conducted, and expects their inclusion as co-authors when they fulfill all authorship criteria'²⁰.

It is recognised, however, that as an editor it is more difficult to assess this at a community level, where outsiders cannot easily tell who might be representing a particular community in an author team. This would require more specific screening. In response to discussions about the requirement for meaningful engagement of Indigenous peoples in publications about them, the *Canadian Journal of Public Health* has introduced specific questions to address this issue²¹: whether Indigenous peoples are a focus of the manuscript; if yes, whether they were engaged in the study and/or preparation of the manuscript; and, if yes, what the nature of the involvement was. These provide a very useful template, which could serve as a basis for further policy development in *Rural and Remote Health*.

An article just published in this journal²² provides an excellent example of how communities can be meaningfully engaged in research. When this article, about a project in Uganda, was submitted, in addition to a named author from a Batwa community, the Batwa communities as a whole were listed among the authors. The responsible editor (IC) raised concern about how a community could fulfil the requirements of authorship set out in the guidelines of the International Committee of Medical Journal Editors (ICMJE)²³. The response of the authorship team was unequivocal, showing how each of the four ICMJE criteria were clearly met by the Batwa communities, because:

- given the community-based research design, Batwa communities were central in developing the research question and methodology for the manuscript
- several follow-up research sessions were held in Batwa communities in 2016 and 2017 to critically revise the manuscript draft
- the main findings included in the manuscript were reviewed by Batwa community members during follow-up research sessions
- Batwa community representatives were accountable and ensured that the work presented was accurate.

On that basis, *Rural and Remote Health* was pleased to accept the article and acknowledge the Batwa communities as co-authors in this publication, and we wish through this editorial to both

commend the authors for this and hold them up as possible examples for others to follow.

We recognise as a journal that we need to get our own house in order and to have clearer policies in this regard. We also recognise as individual authors that we have personally been involved in research approaches that we may now frame differently on the basis of reflecting on these issues as editors. One step for us was having this editorial reviewed by authors of the two 2021 *Rural and Remote Health* articles we have referred to^{16,22}: Fiona Doolan-

Noble, Vivienne Steele, Kaitlin Patterson, Nia King and Sherilee Harper.

Science is not static; nor are we, as researchers or individuals. We argue that, as an international health science community, we should be developing and adopting such research and publication policies so that there is indeed 'nothing about us, without us'. We welcome input from readers as to the approach we should be taking in *Rural and Remote Health* going forward.

REFERENCES:

- 1 The WONCA Working Party on Rural Practice. *17th World Rural Health Conference Declaration, Bangladesh*. 2021. Available: [web link](#) (Accessed 20 May 2021).
- 2 Wikipedia. *Nothing About Us Without Us*. 2020. Available: [web link](#) (Accessed 26 March 2021).
- 3 Sherry E, Shortall S. Methodological fallacies and perceptions of rural disparity: how rural proofing addresses real versus abstract needs. *Journal of Rural Studies* 2019; **68**: 336-343. DOI link
- 4 Swindlehurst HF, Deaville JA, Wynn-Jones J, Mitchinson KM. Rural proofing for health: a commentary. *Rural and Remote Health* 2005; **5(2)**: 411. Available: [web link](#) (Accessed 25 May 2021). DOI link, PMID:15885027
- 5 Sarna-Wojcicki D, Perret M, Eitzel MV, Fortmann L. Where are the missing coauthors? Authorship practices in participatory research. *Rural Sociology* 2017; **82**: 713-746. DOI link
- 6 Tobias JK, Richmond CA, Luginaah I. Community-based participatory research (CBPR) with indigenous communities: producing respectful and reciprocal research. *Journal of Empirical Research on Human Research Ethics* 2013; **8(2)**: 129-140. DOI link, PMID:23651937
- 7 Castleden H, Mulrennan M, Godlewska A. Community-based participatory research involving Indigenous peoples in Canadian geography: Progress? An editorial introduction. *The Canadian Geographer/Le Géographe canadien* 2012; **56**: 155-159. DOI link
- 8 Koster R, Baccar K, Lemelin RH. Moving from research ON, to research WITH and FOR Indigenous communities: a critical reflection on community-based participatory research. *The Canadian Geographer/Le Géographe canadien* 2012; **56(2)**: 195-210. DOI link
- 9 Castleden H, Morgan VS, Neimanis A. Researchers' perspectives on collective/community co-authorship in community-based participatory indigenous research. *Journal of Empirical Research on Human Research Ethics* 2010; **5(4)**: 23-32. DOI link, PMID:21133784
- 10 Skloot R. *The immortal life of Henrietta Lacks*. New York: Crown Publishers, 2010.
- 11 Owings L. Research colonialism still plagues Africa. *SciDevNet* 2021; 30 March. Available: [web link](#) (Accessed 6 April 2021).
- 12 Walker PGT, Whittaker C, Watson OJ, Baguelin M, Winskill P, Hamlet A, et al. The impact of COVID-19 and strategies for mitigation and suppression in low- and middle-income countries. *Science* 2020; **369(6502)**: 413-422. DOI link, PMID:32532802
- 13 Tomlinson M, Volmink J. 'Speaking for and about others': we need to do better. *Science* 2020; **369(6502)**: 413-422. Available: [web link](#) (Accessed 28 March 2021).
- 14 Dartnall E, Pino A. Nothing about us without us...We must decolonize research and democratize knowledge for better science [Letter]. *Science* 2020; 2 September. Available: [web link](#) (Accessed 28 March 2021).
- 15 Dimitris MC, Gittings M, King NB. How global is global health research? A large-scale analysis of trends in authorship. *BMJ Global Health* 2021; **6**: e003758. DOI link, PMID:33500263
- 16 Doolan-Noble F, Noller G, Nixon G, Stokes T. 'I'm still here, that's probably the best part'. Lives of those living rurally with an implantable cardioverter defibrillator: a qualitative study. *Rural and Remote Health* 2021; **21(1)**: 5659. Available: [web link](#) (Accessed 25 May 2021). DOI link, PMID:33751896
- 17 Institute of Medicine (US) Committee on Quality of Health Care in America. *Crossing the quality chasm: a new health system for the 21st century*. Washington, DC: National Academies Press (US), 2001.
- 18 Wennberg J. *Tracking medicine: a researcher's quest to understand health care*. New York, NY: Oxford University Press, 2010.
- 19 van Heemskerken P, Broekhuizen H, Gajewski J, Brugha R, Bijlmakers L. Barriers to surgery performed by non-physician clinicians in sub-Saharan Africa – a scoping review. *Human Resources for Health* 2020; **18(1)**. (51) DOI link, PMID:32680526
- 20 Biomed Central. *Human Resources for Health: Aims and scope*. Available: [web link](#) (Accessed 25 May 2021).
- 21 Marsden N, Star L, Smylie J. Nothing about us without us in writing: aligning the editorial policies of the Canadian Journal of Public Health with the inherent rights of Indigenous Peoples. *Canadian Journal of Public Health* 2020; **111(6)**: 822-825. DOI link, PMID:33289058
- 22 Steele V, Patterson K, Berrang-Ford L, King N, Kulkarni M, Namanya D, et al. Factors influencing antenatal care attendance for Bakiga and Indigenous Batwa women in Kanungu District, Southwestern Uganda. *Rural and Remote Health* 2021; **21(2)**: 6510. Available: [web link](#) (Accessed 28 May 2021). DOI link
- 23 International Committee of Medical Journal Editors. *Defining the role of authors and contributors*. 2021. Available: [web link](#)

(Accessed 25 May 2021).

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