Available online at www.sciencedirect.com

Public Health

journal homepage: www.elsevier.com/puhe

Themed Paper – Short Communication

Indigenous data and health: critical approaches to 'race'/ethnicity and Indigenous data governance

D. Cormack [a,*], P. Reid [a], T. Kukutai [b]

[a] University of Auckland, New Zealand
[b] University of Waikato, New Zealand

ARTICLE INFO

Article history:
Received 25 September 2018
Received in revised form
16 March 2019
Accepted 27 March 2019
Available online 23 May 2019

Keywords:
Racism
Race
Ethnicity
Indigenous
Data sovereignty

ABSTRACT

'Race'/ethnicity data have become increasingly institutionalised within research on Indigenous health. While these data are important to monitoring the differential distribution of health risks and benefits in racialised societies, their uncritical and undertheorised use can perpetuate harmful biologically deterministic and essentialist approaches to Indigenous health. In addition, narratives of Indigenous health are often still shaped by colonial logics, with Indigenous data rights, priorities and governance overlooked or ignored. Researchers need to critique the use of 'race'/ethnicity concepts and data in Indigenous health research. This requires an explicit shift away from describing 'race'/ethnicity as 'risk factors' to examining processes by which 'race'/ethnicity become meaningful in relation to health outcomes for Indigenous communities. In addition, researchers need to consider how Indigenous rights to health data are recognised, including the application of frameworks or principles of Indigenous data sovereignty.

Introduction

Data for Indigenous peoples continues to be absent or limited in many countries, and Indigenous communities have articulated the importance of data to support fundamental Indigenous rights to self-determination and identify Indigenous priorities for health and well-being.[1,2] While constructs of 'race'/ethnicity are not synonymous with Indigenous status, they have become increasingly institutionalised as variables in health data in both administrative and research contexts in many countries. As analytical categories, they can be useful as one way in which Indigenous peoples can measure the impact of state policies and (in)actions on Indigenous health and well-being, assess state obligations to Indigenous peoples and monitor the alignment of health services and health policies with rights under the United Nations Declaration on the Rights of Indigenous Peoples.

However, constructs of 'race'/ethnicity continue to be undertheorised and used uncritically in health research, particularly research that is undertaken about, but not by, Indigenous peoples. This leaves the historical and political contexts of these constructs unexamined, and risks perpetuating harmful deterministic, deficit and essentialist approaches to Indigenous health.[2] This paper briefly considers the importance of critical approaches to 'race'/ethnicity in Indigenous

* *Corresponding author*. Te Kupenga Hauora Māori Faculty of Medical and Health Sciences University of Auckland, Private Bag 92019, Auckland 1142, New Zealand. Tel.: +64 21 844 620.
E-mail address: d.cormack@auckland.ac.nz (D. Cormack).

https://doi.org/10.1016/j.puhe.2019.03.026
0033-3506/

health, drawing on our experiences as Māori scholars in the health and social sciences from Aotearoa New Zealand.

'Race'/ethnicity in colonial spaces

Colonialism has material impacts on the lives of Indigenous peoples through structuring access to resources, power and privilege in colonial settler states such as Aotearoa New Zealand.[3,4] The constructs of 'race'/ethnicity are key imaginaries of colonialism and represent what decolonial scholars have referred to as the central dividing line between those understood as human and those seen to be less, or non, human.[5] Racial categorisations reflect settler colonial logics and values and have become a primary way of defining Indigenous populations in many contexts, although they often are in conflict with the ways in which Indigenous peoples define themselves. These categorisations shift over time, reflecting their historically, socially and politically contingent nature. In the Aotearoa New Zealand context, this is evident in a move in official statistics away from biological, proportion of descent approaches to 'race'/ethnicity for Māori (Indigenous peoples of Aotearoa New Zealand) to measuring ethnicity as self-defined cultural affiliation.[6] Internationally, there have also been shifts away from conceptualising 'race'/ethnicity as a static, biological variable in health research, although this has not been universal and we continue to see a conflation of constructs of 'race'/ethnicity with biology or ancestry.[7]

Continuities with colonial logics of 'race'/ethnicity are also reflected in how Indigenous peoples have been (re)presented in health research as deficient.[2] At times, this deficiency is constructed as one of biological deficit and at other times as cultural deficit. More recently, for Māori in Aotearoa New Zealand, this deficiency is represented in health research through languages, whereby Indigenous peoples are positioned as 'vulnerable'. This narrative retains the colonial frame on perceived failings by Indigenous peoples—bodies, genes, cultures, knowledge—and obscures the fundamental determinants of Indigenous health that are the structural drivers of colonialism and racism.[4]

A move to a critical use of 'race'/ethnicity in Indigenous health

Research needs to engage with critical approaches to the use of constructs of 'race'/ethnicity in Indigenous health. This requires an explicit move away from a tendency to explore and describe 'race'/ethnicity as 'risk factors' in and of themselves to examining the processes by which 'race'/ethnicity become meaningful in relation to health outcomes.[8,9] For Indigenous peoples, these processes include the colonialism and racism that continues to structure social experiences and lived realities, evident in racially stratified health outcomes and access to health determinants. Czyzewski (2011), in discussing the importance of colonialism and racism as fundamental drivers of Indigenous health, notes that colonialism is:

> … the guiding force that manipulated the historic, political, social, and economic contexts shaping Indigenous/state/non-Indigenous relations and account for the public erasure of political and economic marginalization, and racism today. These combined components shape the health of Indigenous peoples.[4]

In order to better understand colonialism and racism as structural drivers of Indigenous health, we need to pay critical attention to what 'race'/ethnicity are understood to be representing as variables in health research. Much health research continues to fail to be explicit about the researchers' theoretical assumptions underpinning their approach to 'race'/ethnicity. There is often a focus on measuring 'race' as what Roth[10] (2016) has termed, a 'single dimension' of self-reported 'race' or of viewing the variables of 'race'/ethnicity in isolation from broader systems and structures of racism, limiting our ability to examine how these constructs becomes meaningful in relation to health outcomes.[8,9] In recent years, some attention has turned to looking at other dimensions of 'race' outside of self-reported variables, including interrogation of 'socially assigned' ethnicity, or how one's race or ethnicity is assigned by others in a racialised society, as part of a move towards understanding the mechanisms by which racism drives health outcomes. As an example, Jones et al.[11] (2018) found that being socially assigned as white in the United States was associated with health advantage, irrespective of how an individual self-identified. Similarly, in Aotearoa New Zealand, Māori who were socially assigned as belonging to the dominant European grouping had a significant health advantage compared with other Māori, in part, due to less exposure to racial discrimination and better socio-economic position, a marker of structural racism.[12] This approach to conceptualising 'race'/ethnicity, alongside self-identification, allows for explicit consideration of the processes of racialisation by which people are racially identified and placed in racial hierarchies and one's 'race'/ethnicity becomes salient in racialised societies.[13] Racialisation occurs through structural processes, such as racial classification and state policies, as well as through more informal practices and everyday interactions. In health, this can influence health service interactions and be expressed in health provider decision-making.[14] As researchers, we need to be overt about the theories underpinning our approach to the use of these constructs in health research and direct attention to interrogating 'race'/ethnicity as markers of exposure to racism for Indigenous peoples.

Indigenous data sovereignty and data governance

Part of a critical approach to Indigenous health research requires attention not only to variables and constructs used in Indigenous health research but also meaningful consideration of Indigenous rights in data, including questions of Indigenous data sovereignty, recognising the ways in which colonial hierarchies and power relations are (re)produced in many contemporary data practices. Indigenous data sovereignty refers to "… the right to determine the means of collection, access, analysis, interpretation, management, dissemination and reuse of data pertaining to the Indigenous peoples from whom they have been derived, or to whom they

relate".[2] In Aotearoa New Zealand, this requires researchers to consider how these rights can be realised for Māori and how any proposed research engages meaningfully with Indigenous data governance at local levels. This includes consideration of data governance arrangements, policies, processes and models for both individual and collective consent. In addition, researchers need to assess whether any research will provide real, meaningful benefits in line with Indigenous community priorities and what safeguards and protective mechanisms are in place to minimise the likelihood of harm to Indigenous peoples and to restore balance where harm occurs.

Māori and other Indigenous peoples are working within and across nations to realise data sovereignty and operationalise data governance.[1,2,15] There is also a focus on building statistical and research capacity in Indigenous communities to facilitate self-determined approaches to health research, as well as re-orienting data systems and practices to properly engage with Indigenous worldviews, colonial contexts and research principles.[1]

Conclusion

Indigenous health research is critical to realising Indigenous aspirations for health and well-being. However, there is a need for a turn away from research that frames 'race'/ethnicity as a risk factor in and of itself, towards an examination of the racialising processes by which it becomes meaningful for Indigenous health. This requires researchers to be explicit about theories underpinning their use of 'race'/ethnicity and to commit to deep thinking, power sharing and meaningful engagement with principles of Indigenous data sovereignty. Anything else risks reproducing colonialism and racism in Indigenous health research. Indigenous peoples need to be leading in this space in terms of determining the types of research and data practices that are meaningful, useful and productive for Indigenous communities.

Author statements

Ethical approval

None sought.

Funding

None declared.

Competing interests

None declared.

REFERENCES

1. Walker J, Lovett R, Kukutai T, Jones C, Henry D. Indigenous health data and the path to healing. *Lancet* 2017;**390**(10107):2022–3.
2. Walter M. Data politics and Indigenous representation in Australian statistics. In: Kukutai T, Taylor J, editors. *Indigenous data sovereignty: toward an agenda*. Canberra: ANU; 2016. p. 79–98.
3. Paradies Y. Colonisation, racism and indigenous health. *J Popul Res* 2016;**33**(1):83–96.
4. Czyzewski K. Colonialism as a broader social determinant of health. *Int Indigenous Policy J* 2011;**2**(1). https://doi.org/10.18584/iipj.2011.2.1.5.
5. Grosfoguel R. What is racism? *J World Syst Res* 2016;**22**(1):9–15.
6. Cormack D. *The politics and practice of counting: ethnicity in official statistics in Aotearoa/New Zealand*. Wellington: Te Rōpū Rangahau Hauora a Eru Pomare; 2010.
7. Yudell M, Roberts D, DeSalle R, Tishkoff S. Taking race out of human genetics. *Science* 2016;**351**(6273):564–5.
8. Garner S. *Racisms: an introduction*. London: Sage Publications; 2010.
9. Gomez L. Introduction: taking the social construction of race seriously in health disparities research. In: Gomez L, Lopez N, editors. *Mapping "race": critical approaches to health disparities research*. New Brunswick, US: Rutgers University Press; 2013. p. 7–22.
10. Roth W. The multiple dimensions of race. *Ethn Racial Stud* 2016. https://doi.org/10.1080/01419870.2016.1140793.
11. Jones C, Truman B, Elam-Evans L, Jones C, Jiles R, et al. Using "socially assigned race: to prove white advantages in health status. *Ethn Dis* 2008;**18**:496–504.
12. Harris R, Cormack D, Stanley J. The relationship between socially-assigned ethnicity, health and experience of racial discrimination for Māori: analysis of the 2006/07 New Zealand Health Survey. *BMC Public Health* 2013;**13**:844.
13. Garner S. The racialisation of asylum in provincial England: class, place and whiteness. *Identities* 2013;**20**(5):503–21. https://doi.org/10.1080/1070289X.2013.827577.
14. van Ryn M, Burgess DJ, Dovidio JF, Phelan SM, Saha S, Malat J, et al. The impact of racism on clinician cognition, behavior, and clinical decision making. *Du Bois Rev: Soc Sci Res Race* 2011;**8**(1):199–218.
15. Lovett R, Lee V, Kukutai T, Cormack D, Carroll Rainie S, Walker J. Good data practices for Indigenous data sovereignty. In: Daly A, Devitt K, Mann M, editors. *Good data*. Amsterdam: Institute of Network Cultures; 2019.