Research, information and consent for the Australian Health Survey: a separate standard for Indigenous people?

Kevin G Rowley and Alister H Thorpe

To the Editor: Recently, Professor Hoy argued for the full inclusion of Aboriginal and Torres Strait Islander people in the Australian Health Survey (AHS), including the measurement of clinical variables and the proposed sample repository.[1] Although much of the argument is plausible, several points were overlooked that make it untenable overall.

First, the current study design arose with input from at least five Indigenous representative bodies, including the National Aboriginal Community Controlled Health Organisation.[2] They identified social and cultural issues as priority areas to be addressed — correctly so, as the underlying causes of health disparity are located in these domains, not primarily in the clinical and biomedical aspects of the AHS. The input from these major national bodies cannot be ignored.

Second, yes — there are concerns that "the stored samples and their results might be somehow misused".[1] These concerns are legitimate and well founded in historical and contemporary experiences of Indigenous people. The argument for applying “current scientific and epidemiological knowledge, methods and safeguards”[1] to the use of information held in the AHS is correct as far as it goes, but ignores equally important Indigenous knowledge and methodologies, Indigenous intellectual property issues, the principles of “ownership, control, access and possession” of Indigenous information,[3] and certain aspects of the United Nations Declaration on the Rights of Indigenous Peoples. This position is therefore inconsistent with the National Health and Medical Research Council guidelines on values and ethics in Aboriginal and Torres Strait Islander health research, particularly as they relate to “survival and protection”.[4]

Third, denying Indigenous people control over how their health information is used by mainstream research institutions prevents accountability of researchers to communities. Using and publishing this information requires review by relevant experts, in this case Aboriginal and Torres Strait Islander community representatives. Biomedical expertise alone is insufficient to enable effective peer review and, at worst, it risks promoting destructive policies that ignore social, cultural and political realities for Aboriginal people and Torres Strait Islanders.

Aboriginal people and Torres Strait Islanders rightly feel that they have been one of the most researched groups in history. And yet, even with this background of decades of being constantly studied, researched and examined, it seems that there is still not enough information being collected. Wellbeing is “grounded in the respect given to people, and the control afforded to them, in their daily lives”.[5] Sometimes it’s up to Aboriginal and Torres Strait Islander people to identify what is important in Aboriginal and Torres Strait Islander health: it’s our health!

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2 Jelfs PL. Indigenous participation in the Australian Health Survey: a response. *Med J Aust* 2011; 194: 511.
3 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. *J Aboriginal Health* 2004; 1: 80-95.
4 National Health and Medical Research Council. Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander Health Research. Canberra: NHMRC, 2003. http://www.nhmrc.gov.au/publications/synopses/e52syn.htm (accessed Jul 2011).
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Wendy E Hoy

IN REPLY: I thank Dr Rowley and Mr Thorpe for their response.[1] It is hard to justify exclusion of any Australian from opportunities to participate fully in important initiatives on the recommendation of bodies whose membership sometimes has no direct link to the persons affected. There is no other population group in Australia to whom this applies.

Medical and clinical approaches should complement initiatives to address critical social and cultural issues; they are not in competition nor mutually exclusive. The inclusion of health measures in the adult (but not youth) components of the Australian Health Survey (AHS) acknowledges that there is much to be learned and remediated clinically.

Any interpretation of the deliberate exclusion of Indigenous youth from the “measures” elements of the survey is unsettling. There is more, not less, to be learned from this group. Their exclusion deprives policymakers of robust evidence that could improve health status. It condemns enquiry to the current sidestream method of short-term research projects on small pockets of people. These sometimes yield results of dubious generalisability and cause ongoing competition for the impossibly stretched research dollar. Alternatively, is it implied that Indigenous parents are less able to make sound decisions on their child’s participation or that the minors are less likely to cooperate?

I suggest that the matter of participation in the AHS be aired through general media channels, as well as those with an Indigenous focus, such as “Living Black” (SBS television) and Imparja television, and through local Indigenous radio stations and community networks. With a developed sampling frame for Indigenous people, dialogue about elements of the examination should at least be conducted with the specific individual tribal groups or communities, if not with the targeted individuals (the preferred option). Subsequently, the whole issue of representation to policymakers in Indigenous health matters might be re-examined on a national basis.

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1 Rowley KG, Thorpe AH. Research, information and consent for the Australian Health Survey: a separate standard for Indigenous people [letter]? *Med J Aust* 2011; 195: 000. ❑