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

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ABSTRACT

- In the next Australian Health Survey, Indigenous people under 18 years of age will be excluded from direct clinical measurements and laboratory tests.
- Indigenous people of all ages were to be excluded from the opportunity, offered to other Australians, to donate blood and urine samples to a national repository. This component has now been abandoned for the whole cohort.
- This sets perilous precedents of exclusion from opportunities available to all other Australians, and deprives the medical community of information that could inform strategies to improve health profiles and outcomes in this seriously disadvantaged group.

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The next survey of Australia's health, the newly named Australian Health Survey 2011–13 (AHS), will unroll this year for the "mainstream" component, and in 2012 for the separate Aboriginal and Torres Strait Islander "wave".[1] The intent is to repeat the Survey every 6 years. The objectives are to:

- estimate the prevalence of certain chronic conditions and selected biomedical and behavioural risk factors;
- enable monitoring and reporting against national food, nutrition and physical activity guidelines;
- inform development and evaluation of food regulatory standards; and
- compare health outcomes across different population subgroups.

The AHS incorporates the elements of the previous National Health Survey and, in its application to Indigenous people, replaces the previous National Aboriginal and Torres Strait Islander Health Survey.[2] Participants in the AHS will include informed consenting adults and (presumably with the consent of their parent or guardian) children, perhaps aged 5 years and over, from a representative household-based sample of the population. In addition to answering questions about their health, participants will, for the first time, have their height, weight, waist circumference and blood pressure measured. They will also be asked to give blood and urine samples for specific tests, including measuring markers of chronic disease, nutritional status and inflammation. Originally, it was also planned to invite participants to donate blood and urine samples to a national repository, which would have required additional information and a separate consent process.

The inclusion in the AHS of some direct measures of health status and some laboratory tests is a great advance. Australia now joins other nations with detailed national health surveys, such as the United States National Health and Nutrition Examination Survey.[3] The planned (but now deferred) sample-storage repository option would also have provided opportunities for validation of tests at a later date, performance of improved and new assays, and, with proper protocols and approvals, probing questions, which have not yet been formulated.

However, on advice from various bodies, including an Aboriginal and Torres Strait Islander technical panel, the Indigenous wave of the AHS was planned to be different from the mainstream wave in two important ways. Indigenous children up to the age of 18 years would not be included in the health measures component of the Survey, and the sample-storage option would not be offered to Indigenous participants. Both decisions provoke questions.

The need for a specific Indigenous wave of the Survey is arguable, although additional logistics will certainly be needed to access people in remote and very remote areas. The issue of what constitutes "Indigenous status", and therefore inclusion in the mainstream wave versus the Indigenous wave, is too complex for discussion here. Detailed questions on ancestry should be standard for all participants in the AHS, and self-assignment of ethnicity (which derives as much from a sense of belonging as from other factors) should be one of many data items. Furthermore, although many groups of Indigenous people have high levels of disadvantage, poor education, poor health, different languages and alternative world views, so, too, do some other members of Australian society.

This is the best opportunity yet to build the evidence base for strategies aiming to "close the gap" between Indigenous and non-Indigenous health.[4] For Indigenous people, an examination of greater scope and depth might be supported, but one that is less inclusive and less detailed is hard to justify. By current estimates, about half of Australia's Indigenous people are under 20 to 22 years of age.[5,6] Exclusion of most of these people from the health measures component of the AHS will leave a large information vacuum, precisely in the age group for whom interventions are most likely to have long-term benefit. Concerns about "truly informed" consent for children apply to all population groups, and are handled through delegation of consent to parents or guardians, who also decide about participation on their own behalf.

The exclusion of young people from parts of the AHS directly contravenes the emphasis on the "life course" view of health, which has a relevance to Indigenous people that is increasingly appreciated. Tests for the levels of some nutrients, including iron, iodine, vitamin D and folic acid, are included in the menu of proposed measurements.[7,8] The opportunity is being waived to identify, in younger Indigenous people, some remediable deficiencies in these nutrients, which variously and together restrict intrauterine growth and nervous system and somatic organ development, impair immunity and contribute to cardiovascular, kidney and related chronic diseases. We deplore the appearance of the metabolic syndrome, diabetes and kidney disease in children, but fail to seize the opportunity to assess their extent. Documentation of the scope of the fetal alcohol effect, through indicators in the survey, might stimulate more effective action. Overall, it seems that, by elimination of the "measures" component, none of the objectives of the AHS will be fully realised for Indigenous children and youth.

The recent decision to abandon the sample-storage option for the 2011–13 AHS, due to cost and logistical constraints, is regrettable. It does, however, allow rethinking of exclusion of Indigenous people from this component. That exclusion would have been scientifically and ethically unsound. New-generation tests might be most revealing for the sickest section of the population. Any concerns about threats to privacy through potential identification of people (by age and date of birth) from sparsely populated, very remote areas would apply equally in the main phase of the study, to which the same participants will have already consented. Privacy arguments also imply that survey results are likely to be a source of shame or demonstrate inferiority in some way. Is there concern that the stored samples and their results might be somehow misused? These poorly articulated fears need to be revisited openly in the light of current scientific and epidemiological knowledge, methods and safeguards.

The Australian Bureau of Statistics has apparently consulted widely on these matters, and its stance reflects the best assessment of the advice received. What, then, is the provenance of this advice? It is likely that it originated in processes initially intended to minimise the potential for exploitation of Indigenous people in research. With transmutations over time and multiple representations through myriad agencies, regions, health services and communities, some expressions of this intent have become counter-productive. They can impede rigorous studies and analyses, block access to data, impair transparency of processes and reduce accountability. Misdirected intentions to minimise exploitation have also fostered the notion that determinants of health and responses to interventions are somehow different in Indigenous people.

It is difficult to see how the opportunity to participate fully, with proper safeguards, in a survey available to all other Australians poses specific threats to Indigenous people. On the contrary: the exclusion of young people from the health measures component, and denial to any Indigenous person of the opportunity to consider the sample-storage option offered to other Australians constitute exclusion from the right to know, to participate, and to benefit from application of new knowledge.

I hope the AHS planning group will rethink its position on Indigenous participation in the Survey. Over the longer term, and in a broader national debate, the intent and mechanisms of protectionism in Indigenous health matters should be also reconsidered. That debate should include the question of whether any advisory group can speak on behalf of individuals in a population as heterogeneous as today's Indigenous Australians, and, if so, whether other minority groups deserve similar representation at the national level.

Competing interests

None identified.

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