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**Title:**

Widening the Health Information Gap between Indigenous and non-Indigenous Australians.  
Exclusion of Indigenous youth from important components of the Australian Health Survey.

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## Abstract

The selective exclusion of Indigenous youth from the “measures” component of the unfolding Australian Health Survey is inconsistent with an evidence-based approach to health and health policies, with the acknowledged importance of early determinants of lifelong health and the benefits of early interventions, and with well publicised commitments to “Close the Gap” between Indigenous and non-Indigenous health and life expectancy. The grounds for this decision have not been adequately explained and, despite widespread protest, suggestions to restore full participation of Indigenous youth have been rejected. Health considerations aside, rights of Indigenous people to participate as Australian citizens in nationwide programs for the common good must be defended. Furthermore, the legitimacy and functions of Advisory Bodies who influence such decisions need to be re-evaluated.

In Australia, as in other westernised environments, it is accepted that clinical care and health service delivery should be based on the best available evidence of needs, options, outcomes and cost-effectiveness. There is also increasing appreciation of the early-life determinants of life-long health, early risk markers, and the potential for early prevention and remediation to mitigate adverse outcomes.

The strategies required to “Close the Gap” in health and life expectancy between indigenous and non-Indigenous Australians (1), or more realistically, to minimise that Gap (2), depend on knowledge of determinants and markers of conditions driving the health disparities. They also require appreciation of the great heterogeneity of Indigenous health by region, remoteness and socioeconomic status, which, in turn, will drive resource allocation for targeted, needs-based interventions. Any systematic initiative to gather data on these matters must be applauded. That opportunity has been waived in the Indigenous component of the unfolding Australian Health Survey (AHS) (3,4)

That survey (3), designed by the Australian Bureau of Statistics (ABS), is the first-ever attempt to gain a snapshot of the nation’s health in an examination that includes some direct measures. Using a family-based sampling design, consenting volunteers will be offered a questionnaire, measurement of body size and blood pressure, and testing of blood and urine samples for markers of nutrition and risk for, or presence of, common diseases. These include chronic conditions like diabetes, kidney disease and cardiovascular risk, which constitute the most pressing health problems in the Western world, are appearing in epidemic proportion in Indigenous people, and have their origins early life. The non-Indigenous component of the AHS is already underway, while the Indigenous wave, examining 13,500 people, will begin in April 2012.

On the advice from several external bodies, cited by the ABS and others (5,6) Indigenous Australians (and what defines “Indigenous” for the purpose of this exclusion?) under the age of 18 years, who constitute up to half the Indigenous population, will, unlike non-Indigenous youth, not be offered the “measures” or sample collection components of that examination. Thus we will gather no data in Indigenous youth on global or specific nutritional deficiencies, congenital abnormalities (including fetal alcohol spectrum disorder), toxicities, burden of infections or chronic disease risk. Furthermore, in an earlier phase of the design of the AHS, all Indigenous people (adults and children) were to be selectively excluded from (not told of) the opportunity to voluntarily contribute samples of blood and urine to a national repository, available, with due process, for future testing as new questions arose. This “sample storage” component of the survey has now been abandoned for the entire population, due to logistic and cost issues, but this does not mitigate the illegitimacy of the decision itself.

What are the grounds for the decision to exclude? Is it based on reluctance to expose the scope and nature of the problems? Is it the potential impact on health services of the findings? Does it reflect concerns about truly informed consent, which, as for non-Indigenous children, would be given by parents or guardians, and what might that imply about the ability of Indigenous parents to comprehend and decide? Does it stem from the costs and logistics of screening in remote areas, concerns about confidentiality, or about potential misuse of data and of stored biologic samples? The variable needs for interpreters, extended explanations and decision supports apply to many other minority and

disadvantaged groups and individuals, none of whom are excluded from the opportunity to participate (7). What has been the role of those with vested interests in current processes and advisory structures or in propagating the myth of homogeneous Indigenous health profiles and health service needs?

Are we serious about better understanding and improvement of Indigenous health? Are we caught in a medieval conflict between proponents of social and clinical approaches to health improvement in Indigenous people? More fundamentally, does not this exclusion of the right to participate and even the right to know about national campaigns for the common good constitute a violation of human rights for these citizens of Australia?

These questions have been raised with the ABS, the Department of Health and Ageing, the Health Minister, the Minister for Remote Health, the Prime Minister, the Human Rights Commission and in the media (8, 9), and the issues discussed in the *Medical Journal of Australia* (6,4,5,7), and on a scientific chat site (10,11). The Shadow Minister for Health, Dr Andrew Laming, has helped fuel the debate. Proffered explanations have been various, guarded and unsatisfactory, citing needs for extended consultation, difficult logistics, fears that samples would be misused, and doubts that children would comply with sample collection, although researchers with long experience in remote Aboriginal health cite refusal rates among children of less than 1%. Respondents concede that children will be fully included in the next survey, but this will unfold in 2018, and the findings scarcely actioned before the target date for Closing the Gap (2030). Some specifically nominated advisers have denied being consulted. The National Health and Medical Research Council of Australia advised against exclusion (personal communication). The Human Rights Commission declined to pursue the matter, but conceded the need for full Indigenous participation on the next survey. Suggestions to restore to the current survey, and to assist with, the full measures component for Indigenous youth, who will already be participating in the more restricted version of the examination, have been rejected.

But let us not leave it there. This is the occasion to revisit the notion that nonelected persons or groups can speak for indigenous people in all their diversity, most especially in matters which restrict, rather than promote their rights (7)

### References.

1. Indigenous Health Equality Summit. Close The Gap, Statement of intent, March 20 2008; Australian Human Rights Commission; [http://www.hreoc.gov.au/social\\_justice/health/statement\\_intent.html](http://www.hreoc.gov.au/social_justice/health/statement_intent.html); accessed Nov 24 2011.
2. Hoy WE. Closing the Gap by 2030: Aspiration vs Reality in Indigenous health. *Med J Aust.* 2009;190:542-544.
3. Australian Bureau of Statistics. Australia Health Survey; ABS; <http://www.abs.gov.au/websitedbs/D3310114.nsf/Home/Australian+Health+Survey>, updated September 14 2011; accessed Nov 24 2011.
4. Hoy WE. Research, information and consent for the Australian Health Survey: a separate standard for Indigenous people. *MJA.* 2011;194:509-510.
5. Jelfs PL. Indigenous participation in the Australian Health Survey: A response. *MJA.* 2011;194: 511.

6. Rowley KG, Thorpe AH. Research, information and consent for the Australian Health Survey: a separate standard for Indigenous people? *MJA*. 2011; 195(3):158-159.
7. Hoy WE. Research, information and consent for the Australian Health Survey: a separate standard for Indigenous people? *MJA*. 2011; 195(3):158-159.
8. Martin L. National health survey under race cloud. Australian Associated Press; *Sydney Morning Herald*, October 21 2011; <http://news.smh.com.au/breaking-news-national/national-health-survey-under-race-cloud-20111021-1mbfp.html?skin=text-only>; accessed November 24 2011.
9. Martin L. Indigenous kids 'tail end' of survey:ABS. Australian Associated Press; *Sydney Morning Herald*, November 1 2011;<http://news.smh.com.au/breaking-news-national/indigenous-kids-tail-end-of-survey-abs-20111101-1mtus.html>; accessed November 24 2011.
10. Hoy WE. Failing to close the Indigenous data gap with the Australian health Survey, November 15 2011; The Conversation media Group; <http://theconversation.edu.au/failing-to-close-the-indigenous-data-gap-with-the-australian-health-survey-4041>; accessed November 24 2011.
11. Altman J. Comment, November 16 2011; The Conversation media Group; <http://theconversation.edu.au/failing-to-close-the-indigenous-data-gap-with-the-australian-health-survey-4041>; accessed November 24 2011.