Genetic research in Indigenous health: significant progress, substantial challenges

Final post-refereed submission of a letter/comments on a published MJA article, published in the MJA:


The NHMRC has supported genetic testing in Indigenous Australians for longer than cited by Dr Kowal (1). Through a 1995-1997 project grant, (Mathews et al), a 1997 PhD scholarship (McDonald) (2,3), a 2006 program grant (Foote et al) and an Australia Fellowship (2008-Hoy), it has supported work on kidney and related chronic disease, in protocols endorsed by the specific community, and approved by appropriate agencies. Important findings from family mapping, phenotyping, and DNA profiling underpin the validation study in the current project grant (Thompson et al, 2011). However progress has been agonisingly slow, with much interference, as Dr Kowal describes, that creates paranoia and trepidation about publishing (4). In one ongoing project, with DNA already stored, approval of NIH testing for a vital kidney-disease candidate gene took two years, a stalemate resolved only through heated protest by the community itself. Aboriginal people must marvel at the collaborative disarray among non- Indigenous agencies supposedly acting in their interests. The waste of precious NHMRC funds and obstruction of scientific progress are very serious.

We must question the probity of obstruction of projects, genetic or otherwise, which are requested by specific communities, and approved through traditional channels, by intermediary bodies with whom those communities have no direct connection. Non-Indigenous people might not tolerate such interference. Aboriginal people should be alerted to these issues through the media, including Imparja TV and in “Living Black”, and invited into the discussion, through the media, e-mail, Twitter and Facebook, and, indeed within the pages of the MJA itself.

