









"Dynamic consent as a new approach for engaging people in health research and upholding data sovereignty – Victorian Aboriginal perspectives."

Authors: A/Professor Luke Burchill, Dr Aneta Kotevski, Daniel Duke

Abstract

Introduction:

Clinical research carries unique risks for Aboriginal people, particularly those providing broad consent for their data and material to be shared widely. In pursuit of self-determination, Indigenous communities are seeking new approaches to consent that support data sovereignty, decisional autonomy and research engagement. Dynamic consent is a new approach with potential for improving the research experience of Indigenous Australians. Compared to traditional or broad consent, which is typically undertaken once at study entry, dynamic consent is active, allowing for ongoing engagement and control over research involvement over time.

Method:

A thorough literature review of existing attitudes to Indigenous health research engagement as well as current limitations in existing frameworks of consent, has identified major shortcomings in the way medical research is conducted with Indigenous communities. As an emerging contemporary framework, dynamic consent has been identified as having potential to put the principles of 'community controlled' and 'culturally safe' into formalised frameworks of medical research engagement. A survey has been developed to assess community attitudes towards both existing frameworks of consent and the dynamic consent process.

Results:

Based on review of existing Community attitudes and identified limitations of broad consent in the literature, consultation that gives voice to First Nations peoples experiences of research and consent is required to assess the viability of establishing a new framework around dynamic consent for medical research.

Conclusion:

The output of this project will support improved research practices and participant experiences of health research. For Indigenous Australians, dynamic consent may offer more meaningful and culturally-sensitive consent processes and enhance participant control over data.