

Aboriginal health research in the remote Kimberley: An exploration of perceptions, attitudes and concerns of stakeholders

What is the KAHPF Research Subcommittee?

- In late 2006 a local research review panel – the Kimberley Aboriginal Health Planning Forum (KAHPF) Research Subcommittee – was formed to improve research processes and encourage appropriate research. This was in response to concerns raised across the Kimberley, particularly from Aboriginal people and health services, about the health research being carried out here.
- The Research Subcommittee aims to encourage a coordinated approach to health research and promote research that is meaningful, useful and results in practical change and development within the region.

Why did we review the Research Subcommittee and its processes?

- As the number of applications to the Research Subcommittee increased, concerns were raised by Kimberley organisations about the burden of research. Also some researchers criticised the processes of getting approval for their projects.
- The Research Subcommittee reported this to KAHPF and proposed to review its own activities.

How did we review the Research Subcommittee and its processes?

- We conducted a retrospective audit of all the data from the Research Subcommittee from 1 January 2007 to 31 October 2013.
- All data used in the review of the Subcommittee were collected as part of the Subcommittee's normal procedures.
- We analysed text in the data collected to identify broad themes related to research in the region that reflected opinions, attitudes or insights of stakeholders.
- We then compared the perceptions, attitudes and concerns of local stakeholders connected to the Research Subcommittee with external stakeholders' (researchers based outside the region) perspectives on the issues they faced conducting research in the Kimberley.

What did we find?

- From 1 January 2007 to 30 June 2013 the Subcommittee received 95 proposals:
 - 60% were driven by researchers based outside the region (external researchers).
 - Local stakeholders raised concerns about 40% of all projects – most of these projects were driven by external researchers.
- The major concerns of local stakeholders (22 people from 12 different Kimberley organisations) were:
 - Inadequate community consultation and engagement;
 - Burden of research on the region;
 - Negative impact of research practices;
 - Lack of demonstrable community benefit; and
 - Power and control of research in the region.

- The major themes identified by external stakeholders (25 external researchers who completed the review form in mid-2013) were:
 - Unanticipated difficulties with consultation processes;
 - Conflict between importance of face-to-face visits and barriers to travel;
 - Perceiving research as a competing priority for health services; and
 - Time-consuming ethics processes.
- External stakeholders also identified strategies for improving research practices in the Kimberley:
 - Importance of community support in building good relationships;
 - Employing local people;
 - Being flexible in approaches to research; and
 - Importance of allocating sufficient time for consultation and data collection.

What does this mean?

- Health research in the Kimberley has improved in recent years, however significant problems remain.
- Prioritising research addressing genuine local needs is essential in closing the gap in Aboriginal health outcomes and life expectancy.
- The long-term aim is for Kimberley health service connected researchers to identify priorities, lead, conduct and participate in the majority of Kimberley health research.
- For this to occur, a more radical move involving changing the research process is needed. Changes to funding processes (e.g. government research funding to go directly to health services rather than universities and giving researchers extra time for community consultation and feedback of results) could improve remote area Aboriginal health research.

What changes to the Research Subcommittee processes have resulted from this review?

- Kimberley communities and organisations expect to be involved in the development of research proposals and for research to be based on local priorities. They have the right to be informed of the results of any project in which they were involved.
- The Research Subcommittee wants to ensure that research conducted in the Kimberley is in line with local priorities and is supported by local communities and organisations. The Research Subcommittee encourages Kimberley communities and organisations to get in touch if they have any questions or concerns about research that is occurring / planning to occur in the Kimberley. Contact details are available on the Research Subcommittee website: http://www.kamsc.org.au/research/KAHPF_Research_Process.html
- We have updated the advice that we give researchers on the processes of conducting research in the Kimberley. This is available on the Research Subcommittee website.
- To hold researchers accountable we have also updated the Research Subcommittee Project Form. Researchers will need to list any Kimberley projects that they have been involved in and if these have finished they will need to describe the feedback provided to the communities and organisations involved in their research.
- We will continue to streamline processes (e.g. reporting requirements) with the WA Aboriginal Health Ethics Committee.

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