

## **Kimberley Aboriginal Health Planning Forum Research Sub-committee Terms of Reference**

### **Background**

The Kimberley Aboriginal Health Planning Forum (KAHPF), originally called the Kimberley Aboriginal Health Plan Steering Committee, was formed in 1998 with the task of developing a Kimberley Regional Aboriginal Health Plan. Over time, the role of the KAHPF has subsequently expanded. The KAHPF is now the peak regional health forum for improving health outcomes for Aboriginal people in the Kimberley, with a particular focus on high quality, culturally responsive comprehensive primary health care that considers the impact of social determinants on health outcomes, including environmental health.

In October 2018 the KAHPF Strategic Plan 2018–2028 was developed and endorsed by the KAHPF. This Plan outlines the key priorities to drive improvements in health outcomes for Aboriginal people in the Kimberley and was developed by KAHPF members in consultation with sub-committees and a time-limited working group of KAHPF. KAHPF takes ultimate responsibility for overseeing its implementation through its members and sub-committees.

### **Rationale and objectives of the KAHPF Research Sub-committee**

The KAHPF Research Sub-committee was established in 2006 to guide research in the region. Projects need to be assessed by this sub-committee before being reviewed by the Western Australian Aboriginal Health Ethics Committee (WAAHEC).

Key priorities in the KAHPF Strategic Plan include “Ensuring health research, evaluation and evidence transfer is designed, collected and utilised in a culturally secure manner”. The primary objective of the KAHPF Research Sub-committee is to support high standards of research in the Kimberley by reviewing project applications for cultural security, benefit, and burden.

The KAHPF Research Sub-committee has a close relationship with the Kimberley Aboriginal Health Research Alliance (KAHRA), which was established in 2020. The KAHRA Team administers the research review and secretariat function of the KAHPF Research Sub-committee in collaboration with relevant KAHPF representatives, and provides advice and recommendations to KAHPF on matters of health research in the region.

### **Responsibilities of the Research Sub-committee**

The Research Sub-committee is responsible for determining whether support should be provided at the regional level for proposed research projects, or research projects occurring elsewhere that are seeking to add the Kimberley region as a site. Projects are required to meet the following conditions:

- There is consultation with each individual organisation that is involved in the project (noting that Kimberley Aboriginal Medical Services does not provide region-wide support). An outcome of this would be a detailed letter/s of support from the relevant organisation/s.
- If organisations do not have capacity to be involved in a proposed project, they will say no. If an organisation approached for involvement in research does not respond, this should be taken as declining involvement. KAHPF member organisations can be approached directly using the Research Engagement Request form that is on the KAHPF Research Sub-committee website.

- Aboriginal health research projects in the Kimberley require the meaningful and informed involvement of Kimberley Aboriginal people. It is expected that local Aboriginal people will be included as Investigators on projects.
- Any costs incurred by organisations in support of the research (e.g. clinic space, transport, human resources, participation in research) are budgeted for, and reimbursed to the organisation if required.
- Researchers commit to providing updates, research findings and practical implications to the involved organisations, communities, and individuals throughout the project. This could form part of the organisation's letter of support, or a written research agreement.
- Researchers commit to working with the involved organisations at the end of the project to help make use of the findings, including advocacy for funding or resources where relevant.

As part of assessing projects for cultural security, benefit and burden, the following requirements will also be considered:

- Methods that are appropriate for the Kimberley setting.
- Lack of duplication of current or previous research.
- Availability of sufficient resources.
- Useful outcomes for Kimberley Aboriginal people.
- Consistency with the Principles of KAHRA that have been endorsed by representatives of Aboriginal Community Controlled Health Services (ACCHS) and WA Country Health Service (WACHS).

If the KAHPF Research Sub-committee does not support an application on the basis of regional requirements, but there is confirmed support from an Aboriginal community or organisation, this will be communicated to the WAAHEC Ethics Officer by the Research Sub-committee Secretariat for consideration by WAAHEC.

It is a condition of support that the lead investigator will provide progress reports to the KAHPF Research Sub-committee by June 30 each year, and a final report at the conclusion of the project. The KAHPF Research Sub-committee will ensure that lead investigators are up-to-date with KAHPF Research Sub-committee reporting for any other projects before providing support for a new project.

The Research Sub-committee is also responsible for collecting and maintaining relevant data on KAMS IT systems, including the following information:

- Provision of regional indicators based on those specified in the KAHPF Strategic Plan:
  - Number and proportion of lead investigators and total investigators listed on new project applications during the 12 month reporting period who reside in the Kimberley.
  - Number and proportion of lead investigators and total investigators listed on new project applications during the 12 month reporting period who are Aboriginal.
- An annual KAHPF Kimberley research and evaluation overview report, utilising information provided by researchers in application forms, annual progress reports and final reports. Reporting will be provided to KAHPF at additional intervals as directed by KAHPF.
- Progress against the Research Sub-committee Action Plan.

This information will be presented to KAHPF and shared with the KAHRA Board of Directors.

## **Powers of the Research Sub-committee**

Sub-committees may not speak or act on behalf of KAHPF without prior permission of the KAHPF. The Research Sub-committee does not have any decision-making powers as an entity which cut across the authority of individual health service governance and management bodies.

The Research Sub-committee advises WAAHEC about whether proposed research is supported at the regional level. The decision to grant or deny ethics approval rests with WAAHEC.

WAAHEC is a Human Research Ethics Committee (HREC) registered with the National Health and Medical Research Council (NHMRC). It was established to promote and support quality research that is reflective of the needs of the community. As part of achieving this, WAAHEC has partnerships with various research sub-committees and planning forums throughout Western Australia, and requires that proposed projects have been through regional processes before undergoing ethical review by WAAHEC. In addition to the letters of support from the relevant Aboriginal community controlled organisations and communities that are required by WAAHEC, support from the KAHPF Research Sub-committee ensures that the overall project meets regional needs and expectations including engagement with all relevant organisations and involvement of local investigators including Aboriginal people. Relevant information regarding projects in the Kimberley may be shared between the KAHPF Research Sub-committee and WAAHEC for cross checking and clarification purposes at any stage of a project.

## **Membership**

The KAHPF Research Sub-committee consists of up to 8 individuals who are Kimberley-based, employed by a KAHPF core member organisation, have interest and/or experience in research, and will include representation from the ACCHS sector and WACHS. Any Sub-committee member who has additional employment with a non-KAHPF organisation will participate in the Sub-committee as a KAHPF member organisation representative only.

The Research Sub-committee requires expertise across research, regional health service provision and Kimberley Aboriginal cultures.

KAHPF will call for expressions of interest for membership when required, and will decide the composition of the Research Sub-committee with consideration to the organisations, areas of expertise, location, and inclusion of Aboriginal people.

In addition to the Research Sub-committee, the CEOs of ACCHS (or their delegate) will be included in the review process when a proposed project is located in their area. For projects covering the entire region, all CEOs of ACCHS (or delegates) will be invited to participate in the review process. Other representatives from KAHPF member organisations will also be called upon to participate when a proposed research project is relevant to their expertise or organisation's area of focus. This may include distribution to other KAHPF sub-committees for feedback.

## **Operation of the Research Sub-committee**

### ***Chair***

The KAHRA Team is responsible for chairing the KAHPF Research Sub-committee. In particular, the KAHRA Team administers the research review function of the KAHPF Research Sub-committee in collaboration with relevant KAHPF representatives (see 'Research review process' below).

### ***Secretariat***

The Research Sub-committee has its own Secretariat. From 2021, this role has been performed by KAHRA team members. The responsibilities of the Secretariat include:

- Providing advice to researchers about Kimberley research requirements and KAHPF Research Sub-committee processes, primarily through maintaining and promoting the Research Sub-committee website.
- Acknowledging applications received.
- Sending notification of decision to support, or otherwise, to researchers on behalf of the Research Sub-committee.
- Communicating with KAHPF as required.
- Collating and distributing summaries of research project progress reports and final reports to Research Sub-committee members and other relevant KAHPF sub-committees.
- Maintaining a record of applications and the status of supported projects.
- Assisting in ensuring accountability of researchers to translate knowledge acquired through research with the communities they are designed to benefit.
- Collating and reporting KAHPF regional indicators.
- Preparing an annual Kimberley research and evaluation overview report for KAHPF.
- Facilitating any Research Sub-committee meetings.

### ***Research review process***

- The KAHRA Project Coordinator will confirm that the application meets KAHPF's conditions.
- If so, the KAHRA Project Coordinator will correspond with involved organisations and listed investigators, to check that they are aware of the details and are supportive. If there are concerns at this stage, the researcher will be contacted by email and the application will not progress further.
- The KAHRA Project Coordinator will coordinate review and discussion of proposed projects within the KAHRA Team, which includes academic research expertise, Aboriginal people with knowledge about Aboriginal research methodologies, Indigenous Data Sovereignty expertise, and Aboriginal men and women with community understanding and connections.
- If there are significant concerns at this stage, the KAHRA Project Coordinator will respond to the lead investigator by email, noting that the application can be resubmitted after concerns are addressed.
- If there are not significant concerns at this stage, the KAHRA Project Coordinator will contact subject matter experts and other representatives of relevant organisations. The KAHRA Project Coordinator will then engage with the researcher by phone to talk through any concerns, noting anything that can be improved, and follow up with an email summary. Any overdue KAHPF Research Sub-committee reports involving the lead investigator will also be followed up at this time. The application can be resubmitted or additional information can be provided by email in response to this feedback.
- The application, summary and recommendation will then be sent by email to the KAHPF Research Sub-committee for final decision.

### ***Decision making and timeframes***

All applications will be reviewed as expediently as possible in the context of competing demands for all involved in the process, noting that there is a high volume of research applications and finite human resources to manage these.

Researchers will be encouraged to submit their application as soon as it is ready, and before submitting to WAAHEC. Where there is sufficient time and the application is of the required standard, the Research Sub-committee will notify researchers and WAAHEC about whether a project is supported by the Sub-committee before the corresponding WAAHEC submission deadline.

The Research Sub-committee's decision to support or not support a proposed project is by consensus. If a Sub-committee member is listed as an investigator on an application, they will not participate in the

decision-making process but can provide information to other Sub-committee members about why they decided to be involved in the project. If a Sub-committee member is employed by an organisation which is listed on an application, they should also note a duality of interest. All Sub-committee members are expected to respond to each application within two weeks, or advise that they will abstain. A quorum is at least half the core members of the Sub-committee, including at least one representative from the ACCHS sector.

On rare occasion, when consensus cannot be reached, the Research Sub-committee may request that the researchers present their proposed project at a KAHPF meeting. The Research Sub-committee Secretariat will brief KAHPF on the relevant issues prior to the presentation. KAHPF will make a decision about whether to provide support for the project at the KAHPF meeting, and advise the Research Sub-committee.

Once a decision has been reached, the Secretariat will email the lead investigator with a letter that advises of one of the following outcomes. The WAAHEC Ethics Officer will be copied into the email where appropriate.

1. The project is supported by the KAHPF Research Sub-committee.
2. The KAHPF Research Sub-committee has concerns with the project but acknowledges that the project has confirmed support from relevant individual organisation/s.
3. The KAHPF Research Sub-committee requires clarification or modifications to a proposed project before it can provide support. Any subsequent correspondence between the investigator and the Sub-committee will occur by email via the Research Sub-committee Secretariat. If the Sub-committee then supports the project, the investigator will be notified as soon as possible as per point 1 above. If the Sub-committee does not support the project after sufficient correspondence with the researcher, the researcher will be notified as per point 4 below.
4. The project is not supported by the KAHPF Research Sub-committee. Reasons will be provided. The investigator may re-apply.

### ***Confidentiality***

Applications to the Research Sub-committee, including details of proposed projects, will remain confidential within the Sub-committee, KAHRA, relevant Kimberley organisations for each project, and WAAHEC.

If a project is supported by the Research Sub-committee, the project summary from the application form may be included on the Sub-committee website, as noted on the application form.

### **Review and assessment of the Research Sub-committee**

A representative of the Research Sub-committee will meet face-to-face with the KAHPF annually, to discuss achievements and challenges regarding Sub-committee processes and outcomes, and seek feedback.

The terms of reference will be reviewed and ratified annually in consultation with relevant KAHPF representatives, including at least one representative from the ACCHS sector and one from WACHS. A copy of the updated terms of reference will be provided to the KAHPF Secretariat for endorsement by KAHPF. A copy of the endorsed terms of reference will be provided to WAAHEC and placed on the KAHPF Research Sub-committee website.