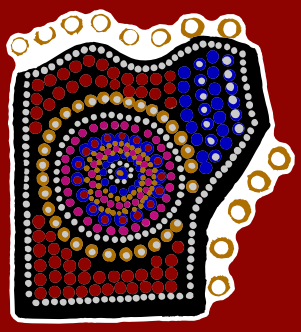
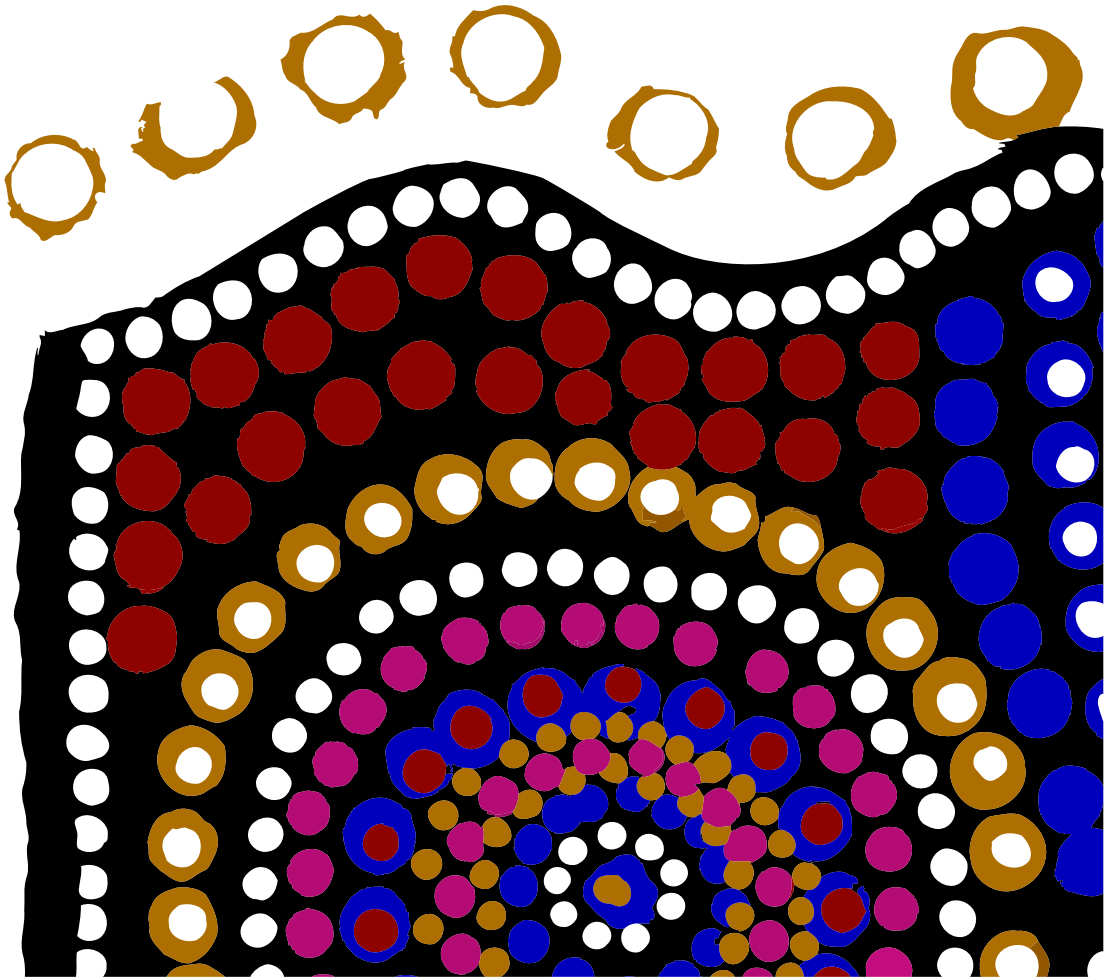


Aboriginal Health & Medical Research Council of New South Wales

AH&MRC

Research Assessment Tools

Tools for Aboriginal Community Controlled Health Services to support decision making about research requests



ACKNOWLEDGEMENTS

The AH&MRC appreciates and wishes to acknowledge the thoughtful contributions and expertise of the members of the Research Assessment Tools Working Group: Debbie McCowen (CEO Armajun Aboriginal Health Service), Hellen Mannix (Practice Manager, Brewarrina Aboriginal Medical Service), Jamie Newman (CEO Orange Aboriginal Medical Service and Julie Calleja (CEO Viney Morgan Aboriginal Medical Service, Cummeragunja).

The following AH&MRC staff contributed to the development of these tools:

Kylie Haywood | Senior Project Officer, Research Support Program

Dr Jenny Hunt | Public Health Medical Officer

Lucy McGarry | Senior Project Officer, Social and Emotional Wellbeing Workforce Support Unit

If you ever have concerns about a research project, you are encouraged to make contact with the AH&MRC Ethics Committee secretariat:

Telephone: (02) 9212 4777

or email: ethics@ahmrc.org.au

The AH&MRC plans to continue to support ACCHSs in their research related roles, and would appreciate feedback from ACCHSs about these tools and their support needs at any time.

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Location
Level 3, 66 Wentworth Avenue
Surry Hills NSW 2010

Postal Address
PO Box 1565
Strawberry Hills NSW 2012

Contact
Phone: (02) 9212 4777
Fax: (02) 9212 7211
e-Mail: ahmrc@ahmrc.org.au
web: www.ahmrc.org.au

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of New South Wales

INTRODUCTION

The AH&MRC Research Assessment Tools are designed to help the staff and board of an Aboriginal Community Controlled Health Service (ACCHS), identify and clarify the risks and benefits of supporting or getting involved in research. The tools are intended to enable ACCHS to make the most of opportunities which involvement in research may present, while reducing the potential burden and risk of adverse impacts.

The tools can be adapted for local use. We have identified a range of key questions which you can select from and use in different ways according to both your needs, and the type of research project in which you are engaging.

These tools were developed in response to a survey conducted by AH&MRC in 2010-2012, investigating the experiences and engagement of NSW ACCHSs with research. A report on the survey is attached to this package as an appendix.

This package includes:

- Tool One: Questions to ask researchers
- Tool Two: Checklist for internal ACCHS discussion and decision making

How to use the tools

The two tools are designed to be used together, to inform, guide and support ACCHS decision making about:

- Providing researchers with a letter of support for their project
- Being involved in the conduct of the project, and to what extent

Tool One: Questions to ask researchers

This tool is for gathering information from researchers. It is a range of questions which an ACCHS might ask of researchers who request that the ACCHS support or participate in research. The information gathered from these questions will help an ACCHS make an informed assessment of the request.

Tool Two: Checklist for internal ACCHS discussion and decision-making

This tool is a checklist designed for use by an ACCHS, to discuss and consider the information gathered from researchers. The checklist identifies issues which the ACCHS may want to consider in order to assess the risks and benefits of supporting or getting involved in the research, and ultimately whether they will do so or not, or to what extent.

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web: www.ahmrc.org.au

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TOOL ONE: QUESTIONS TO ASK RESEARCHERS

This tool is for gathering information from researchers. It is a range of questions which an ACCHS might ask of researchers who request that the ACCHS support or participate in research. The information gathered from researchers in response to these questions will help an ACCHS make an informed assessment of the request.

Questions about the research

1. What are the timelines for your project, including time for us to respond and provide feedback to you on the proposal?
2. Has or will an application be made to the AH&MRC Ethics Committee?
3. What are the benefits of the research to all or any of the following groups?
    a. To the ACCHS
    b. To the local Aboriginal community
    c. To the wider Aboriginal community
4. Have you discussed the proposal with other Aboriginal community groups or Aboriginal people?
5. What is expected of the ACCHS and or community members in terms of support, involvement, commitment and/or resources?
6. Please estimate the amount of ACCHS staff time required for the project e.g.) in hours, days weeks.
7. If ACCHS staff are going to be recruited for the project, please detail plans for reimbursement to the ACCHS e.g. resources/financial support.
8. If appropriate, are ACCHS staff being offered any research related training or up skilling to enable their participation in the research process and how will their involvement be acknowledged e.g. formal letter, individual certificate of participation, in documents regarding the project.
9. How might your research findings inform ACCHS service delivery, program development, policy formation and/or community experience of health care?
10. Have or will ACCHSs/Aboriginal people or communities be involved in decision making regarding the project, including its design, implementation, monitoring, interpretation of findings and evaluation?
11. What are your plans about arrangements for ownership of data and intellectual property?
12. How do you plan to acknowledge ACCHSs, and Aboriginal people or communities contributions to any publications?
13. Are there opportunities for ACCHS staff, Aboriginal people or community members involved in your project to be authors or co presenters in outputs from the project?
14. What are the arrangements for the dissemination of information back to the ACCHS, Aboriginal people and communities during the project? What are the arrangements for feeding back final outcomes of the project to these groups?

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TOOL TWO: CHECKLIST FOR INTERNAL DISCUSSION AND DECISION MAKING

This tool is a checklist designed for use by an ACCHS, to discuss and consider the information gathered from researchers. The checklist identifies issues which the ACCHS may want to consider in order to assess the risks and benefits of supporting or getting involved in the research, and ultimately whether they will do so or not, or to what extent.

Questions for internal discussion

1. Has the researcher provided enough information about the project for the ACCHS to make an assessment?
2. Have the researchers provided enough time for the ACCHS to make an assessment and to consult adequately within the ACCHS and/or your local community?
3. Has or will an application be made by the researchers to the AH&MRC Ethics Committee?
4. Will the research lead to benefits for the ACCHS, the local Aboriginal community, and/or Aboriginal communities elsewhere?
5. Does the project align with the current goals and health priorities of the ACCHS?
6. Are any resources being provided to the ACCHS to assist support its involvement?
7. Does the ACCHS have the time/resources to be involved in the project?
8. Are the arrangements for Aboriginal people to be involved in the project satisfactory to the ACCHS in terms of:
    - Decision-making?
    - Membership on the research team?
    - Ownership of data?
    - Participation in writing of documents for publication?
    - Authorship and acknowledgement?
9. Are the arrangements for the dissemination of information about the project back to the ACCHS and local community satisfactory to the ACCHS?
10. Based on the above, and information provided by the researchers, is the ACCHS prepared to provide a letter of support for the research?
11. Based on the above, and information provided by the researchers, is the ACCHS prepared to become involved in the project?

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APPENDIX: REPORT ABOUT NSW ACCHSs EXPERIENCE WITH RESEARCH

Background

Between 2010 and 2012 the AH&MRC received funding through a Research Capacity Building Grant from the National Health and Medical Research Council to develop and implement several small scale projects to build research capacity within the AH&MRC, Member ACCHSs and with researchers interested and active in Aboriginal health research.

AH&MRC Member ACCHS had indicated that they had concerns around their involvement in research and had expressed the need for support in responding to the requests that they received to support or participate in research.

In response the AH&MRC conducted a survey exploring ACCHS views and experiences of research, to inform the development of research assessment tools for ACCHSs to use when receiving a research request and to identify research concerns and needs more generally.

This report has been developed to describe the methods and key findings of the survey, and how its results have been used to inform the development of tools for ACCHSs to support decision-making about research involvement.

Methods

Invitations to participate in the project were sent to the Chief Executive Officers of all AH&MRC Member Services. Follow up aimed to encourage ACCHS participation, and capture the views of ACCHSs with varying levels of research experience, and of different sizes and geographical locations. Nineteen ACCHSs agreed to participate, all of which were located in rural and remote NSW. A semi structured interview guide was developed to explore the ACCHS views and experience of involvement in research over the previous two years. The questions also explored the ACCHS perspectives on the pros and cons of research involvement and associated barriers and enablers. Finally, the interview guide included questions about research assessment tools that would be useful and of value to ACCHS.

Participating ACCHS CEOS nominated one or more staff members to interview. The interviews were conducted over the phone or face to face and took about 30-45 minutes to complete, with opportunities for further input if required. . The interview responses were collated into themes and a number of key findings identified.

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KEY FINDINGS

ACCHSs were engaged in and supporting research

It was clear that participating ACCHSs were engaged in and supporting research. Individual ACCHSs described being involved in up to 13 different research projects during this time, with an average of four projects per ACCHS. The average for the 19 ACCHS interviewed was 4. ACCHS involvement and support commonly included:

- acting as facilitators to engage the local Aboriginal community and identifying appropriate people to be involved in the conduct of the research
- identifying and assisting with the recruitment of participants for the research
- interviewing ACCHS clients and or supporting clients during research interviews
- providing access to de identified information/data
- being interviewed as part of a stakeholder or consultative process

ACCHSs were positive about Aboriginal health research

ACCHSs interviewed said that Aboriginal health research was important because of its potential to lead to improvement in Aboriginal health outcomes. Research was viewed as beneficial to the broader Aboriginal community, as well as having potential benefit for the local community. Research was considered potentially useful in identifying gaps in ACCHS service delivery and for making improvements at the local and service level. The role of research in building the evidence base for advocacy in Aboriginal health in general was noted.

ACCHSs understood Aboriginal health research protocols

ACCHSs understood that Aboriginal health research conducted in NSW requires the approval of the AH&MRC Ethics Committee. ACCHS were aware that their participation in research was required for researchers to demonstrate that they had engaged in appropriate Aboriginal health research protocols by seeking Aboriginal community support and involvement. This included demonstrating to the AH&MRC Ethics Committee that the researchers had spoken to the local ACCHS about the research by producing a letter of support.

ACCHSs were enthusiastic about projects that involved a collaborative approach

ACCHS staff interviewed had positive experiences of research and were enthusiastic about projects where there was strong engagement and genuine partnership between the researchers and the ACCHS as well as the local Aboriginal community. The key features of these projects were that they were relevant to local needs and had a direct observable benefit to the local Aboriginal community.

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These collaborative projects were characterised by ACCHSs as having;

- early involvement of the ACCHS in the design phase of the project
- long standing relationships built over time
- adequate remuneration for ACCHS time and resources
- good communication and dispute resolution processes
- formal agreements or MOUs
- opportunities to be acknowledged and included as authors and co present the research at conferences etc.

Research involvement can be experienced as an additional burden on ACCHSs resources

Participants commented that ACCHSs are not funded to do research and that it is not their core business. If the ACCHS is not sufficiently remunerated by researchers to do this additional work, a strain is placed on ACCHS resources. As one participant noted, "***research asks a lot of us***".

Participants spoke of the feeling of individual responsibility for the research their ACCHSs supported and become involved in. They noted that they are accountable to their community for how that research is conducted and for any outcomes.

Participants said that research projects being linked to ACCHS funding could make it difficult for the ACCHS say no to involvement. As one participant noted, "***sometimes there is a pressure to participate in projects from (funding body) and this can involve taking staff off line***".

Researchers are not always doing the right thing

Participants discussed research projects where they did not feel that the ACCHS was sufficiently involved or consulted regarding the conduct of the research.

Participants noted that there were projects where they did not have adequate input into the design of the research. In these cases, researchers did not make contact with the ACCHS until well after the area to be investigated and the design and methodological components of the research project had been decided. This causes problems when the project design was inappropriate and did not take into account the daily operations of the ACCHS or the needs of the local Aboriginal community.

In terms of publications and presentations ACCHS were not always provided with the opportunity to review documents; and sometimes when they were provided with draft documents, not enough time was allowed for them to give feedback. Participating ACCHSs reported cases where they were not provided with the opportunity to participate in research outputs as authors or to present the research.

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Participants expressed concern that research results were not always disseminated back to the community. As one comment reflects, "***there is a lack of feedback on the outcomes - it would be good to get more feedback.***" It was explained that feedback on the research results were sometimes received late, in the form of a written report only, without specific attention to providing information that would be locally relevant or useful.

ACCHSs research assessment tools

A key aim of the survey was to identify if research assessment tools would assist ACCHS in addressing some of the issues they faced in responding to research requests and participating in research. The survey findings suggested that ACCHS are supporting and participating in research and experiences both constraints and enablers to meaningful and rewarding research participation and outcomes.

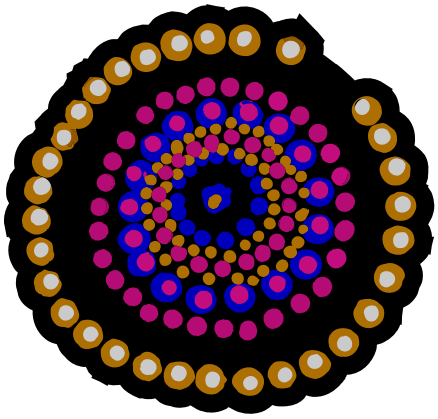
All participating ACCHSs agreed that research assessment tools could improve their current processes for reviewing and engaging in research, and were enthusiastic about tools being developed to formalise and enhance their existing research assessment processes.

It was noted by participants that tools could encourage researchers to communicate and engage with the ACCHSs in a more collaborative way and enable the ACCHS to respond more proactively to requests.

Participants made a range of specific suggestions about the kinds of questions and information that it would be good to include in the proposed research assessment tools.

What happened next?

The AH&MRC established a working group of ACCHS representatives and worked with the group to collate and build on the feedback provided by member ACCHSs in the survey. The group then developed the research assessment tools in this package, to respond to the key issues identified in the survey.



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