Supplement A: Ethics Documents

The University of Melbourne Human Research Ethics Committee application

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THE UNIVERSITY OF MELBOURNE

HUMAN RESEARCH ETHICS COMMITTEE

APPLICATION FOR APPROVAL OF A PROJECT INVOLVING HUMAN PARTICIPANTS

PROJECT REFERENCE DETAILS

Enter the Ethics ID number assigned by Themis Research to this ethics application.	1034282.1
Enter the title of the Project as recorded in Themis Research	Barriers to the provision and utilisation of eye health services for Indigenous Australians
Enter the name of the Responsible Researcher as recorded in Themis Research	TAYLOR, PROF HUGH RINGLAND

1. PROJECT DETAILS

1.1 EXECUTIVE SUMMARY IN PLAIN ENGLISH: PROVIDE A BRIEF SUMMARY OF THE PROJECT OUTLINING THE BROAD AIMS, BACKGROUND, KEY QUESTIONS, RESEARCH DESIGN/APPROACH, THE PARTICIPANTS IN THE STUDY AND WHAT THEY WILL BE ASKED TO DO, AND THE IMPORTANCE OR RELEVANCE OF THE PROJECT. *[THIS DESCRIPTION MUST BE IN EVERYDAY LANGUAGE, FREE FROM JARGON, TECHNICAL TERMS OR DISCIPLINE-SPECIFIC PHRASES. (NO MORE THAN 300 WORDS).]*

Although Aboriginal and Torres Strait Islander children start life with much better vision than the average Australian, Indigenous people over the age of 40 have six times more blindness than other Australians. Almost all this vision loss is unnecessary and could be stopped if adequate eye care services were available and used. We are going to find out what needs to be fixed in the Government support programs for visiting eye specialists by talking to people who work in that area. We will talk to Indigenous people and find out why they have trouble using eye services that already exist. And we will find out what needs to happen so Indigenous people with eye problems get proper care and referrals for further treatment. With this information we will develop a model of care, work out what it would cost and present it to Government to change the way eye care is provided to Indigenous people to close the gap for vision.

1.2 AIMS OF AND JUSTIFICATION FOR THE RESEARCH: STATE THE AIMS AND SIGNIFICANCE OF THE PROJECT. WHERE RELEVANT, STATE THE SPECIFIC HYPOTHESIS TO BE TESTED. ALSO PROVIDE A BRIEF DESCRIPTION OF CURRENT RESEARCH/LITERATURE REVIEW, A JUSTIFICATION AS TO WHY THIS RESEARCH SHOULD PROCEED AND AN EXPLANATION OF ANY EXPECTED BENEFITS TO THE COMMUNITY. *[NO MORE THAN 500 WORDS]*

Project Aims:

The overall aim of this review of health service provision is to develop a model of eye care for Indigenous Australians for presentation to Australian Governments.

1. Identify the specific limitations and restrictions of the current funding mechanisms that support visiting eye care services to remote areas (Medical Specialist Outreach Assistance program-MSOAP and Visiting Optometrist Scheme-VOS).

2. Identify barriers to access for Aboriginal people to existing eye care services in urban and rural areas and ways to overcome them.

3. Identify key components in enhancing the pathway of care for the provision of eye services through Aboriginal Health Services.

4. Identify the economic implications of the proposed policy changes.

Significance of the project:

Our overall aim is to "close the gap for vision" by developing evidence-based recommendations for policy change. The National Indigenous Eye Health Survey showed that although Indigenous children have better vision than mainstream children, Indigenous Australians aged 40 and above have six times the rate of blindness compared to mainstream (1). Ninety four per cent of their vision loss is preventable or treatable, but a third of adults have never had an eye exam. There is a significant shortfall in the provision of eye care services in outback Australia (2). Well co-ordinated and organised services provide a measurably better service and save money (3). Urban ophthalmologists and optometrists are prepared to provide these outreach services if the services are well organised.

In addition, Indigenous people in urban and rural areas have similar rates of vision loss to those in more remote areas, even though eye care services are readily available in the more populated areas (1). An understanding of the real and perceived barriers to accessing these services and solutions to them are important to improve utilisation.

To improve the regional co-ordination of eye care, Regional Eye Health Co-ordinators (REHCs) are based in Aboriginal Medical Services (AMS). However, only 23 of some 34 regions currently have a Co-ordinator. Many deficiencies and inconsistencies in the role and function of these Co-ordinators have been recently documented (4, 5). Their responsibilities have expanded enormously which makes it impossible for one person to cover all these expectations leaving many gaps in the pathway of care (6). We will map out the key steps in the patient journey and define the functions required in the pathway of eye care.

Information from these three areas will be combined with health economic assessments of a new model of care to recommend policy change for the delivery of appropriate and acceptable eye care to Indigenous Australians.

Specific Hypothesis tested:

Specific hypotheses to be tested:

1. Gaps and shortcomings can be identified in the current funding mechanisms for outreach eye services, MSOAP and VOS

2. Barriers to the utilisation of existing eye services can be identified and solutions designed

3. The critical steps and functions in the pathway of care for eye services can be identified

4. This information can be developed into a model of care

5. Additional costs and savings can be identified and quantified

Description of current research/literature review:

We have shown the very high unmet need for eye care services amongst Indigenous Australians (1). In more remote areas this is due to a lack of eye care services (2). In areas where eye care services are available, they are under utilised. Eye care services used by Indigenous Australians are predominantly funded by the Federal or State Governments and evidence-based models are required to influence the development and implementation of new policy. This health services audit and research will assist in this process.

Justification of why research should proceed

See above

Explanation of any expected benefits to the community

The project will lead to a series of recommendations for federal and State government departments that are anticipated to lead to improved provision of eye care to Indigenous communities Australia wide.

References

1. Taylor HR, Xie J, Fox SS, Dunn RA, Arnold A-L, Keeffe JE. The prevalence and causes of vision loss in Indigenous Australians: the National Indigenous Eye Health Survey. Med J Aust. 2010;192:312-18.

2. Kelaher M, Ferdinand A, Ngo S, Tambuwla N, Taylor HR. Access to Eye Health Services Among Indigenous Australians. An Area Level Analysis. Melbourne: Indigenous Eye Health Unit, Melbourne School of Population Health, The University of Melbourne 2010.

3. Turner A, Mulholland W, Taylor HR. Outreach Eye Services in Australia. Melbourne: Indigenous Eye Health Unit, Melbourne School of Population Health, The University of Melbourne; 2009.

4. Siggins Miller. An options paper on the current and future role of the Regional Eye Health Coordinator - A report to the Department of Health and Ageing. 2010.

5. Vision 2020 Australia, Regional Eye Health Coordination Workshop; 2010; Adelaide, South Australia.

6. Taylor HR, Stanford E. Provision of Indigenous Eye Health Services. Melbourne: Indigenous Eye Health Unit, Melbourne School of Population Health, The University of Melbourne; 2010

1.3 METHOD *Provide an outline of the proposed method, including details of the recruitment strategy and data collection techniques, the tasks participants will be asked to do, the estimated time commitment involved, and how data will be analysed*. [No more than 500 words]

Recruitment Strategy

The project will involve health services research through a series of semi-structured face to face interviews with eye health service providers and eye health support and coordination staff across 17-18 different sites. From previous research, networks and partnerships, existing relationships between the Indigenous Eye Health Unit (IEHU) and key informants have been established.

Key Informants include REHCs, visiting eye health teams, regional hospital staff, and AMS staff.

Additional key informants that are recommended by interviewees throughout the consultation will also be invited to participate in interviews.

Invitation to participate in the semi structured interviews will be undertaken by the research team by telephone, email or via face to face meetings.

All participants will be required to complete the written consent form.

Consultations with the NACCHO Chairman were undertaken to establish a collaborative relationship and determine the most appropriate approach to partner with AMSs. Ongoing consultation with NACCHO, VACCHO and the selected AMS's and/or elected community councils, will be undertaken to facilitate recruitment of focus group participants and ensure that all research protocols are in accordance with the NHMRC Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research.

Participants for focus groups will be AMS clients identified by AMS staff.

AMS staff will distribute a focus group discussion information sheet (flyer). The flyer will include details about the project, what would be discussed in focus groups and instructions for how to register.

Clients interested in participating can contact the research team directly via telephone or email to register.

If required additional semi structured interviews with AMS staff will be conducted to clarify issues raised in focus groups and provide suggestions to address these issues. These participants will be contacted and invited to participate by the research team, by telephone or email.

Data Collection techniques

Semi structured interviews will be carried out to collect information about questions related eye health services, pathway of care and coordination of visiting services.

Focus groups will be used to gather information from Aboriginal clients of AMS services relating to barriers that impact on client's utilisation of eye health services in their area. Additional interviews with eye specialists or health care staff will be conducted to clarify issues raised and provide suggestions to address issues.

Interviews and focus groups will be recorded with the consent of the participants.

Tasks participants will be asked to do

Participants involved in semi-structured interviews will be asked a series of questions related to their experiences in the delivery of eye health services in different regions. Follow up interviews may be required to obtain additional feedback on findings and suggested recommendations.

Focus group participants will be asked to discuss barriers that impact on their access to eye health services and suggestions to improve their access to current eye health services. Additional semi structured interviews with AMS staff will be conducted to clarify issues raised in focus groups and provide suggestions to address issues.

Estimated time commitment

Semi structured interviews will vary from thirty minutes to two hours long

Focus groups will be two hours long.

Additional follow up interviews will be thirty to sixty minutes in duration.

Data analysis

Interview and focus group data will be examined by thematic analysis to determine general themes and identify specific issues. Qualitative data will be analysed and stored using NVIVO Qualitative software.

1.4 USE OF INDEPENDENT CONTRACTORS *Will parts of this project be carried out by independent contractors? (e.g. interviewing, questionnaire design and analysis, sample testing, etc)*

☐ YES ☒ NO *If YES, confirm that the independent contractor will be engaged on the basis of relevant qualifications and experience and will receive from the Responsible Researcher, a copy of the approved ethics protocol and be made aware of their responsibilities arising from it.* [The responsibility for effective oversight and proper conduct of the project remains with the Responsible Researcher]

1.5 MONITORING

(a) *How will researchers monitor the conduct of the project to ensure that it complies with the protocols set out in this application, the University's human ethics guidelines and the National Statement on Ethical Conduct in Human Research?* [Address, in particular, cases where several people are involved in recruiting, interviewing or administering procedures, or when the research is being carried out at some distance from the Principal Researcher (i.e. interstate or overseas)]

The research will be carried out in its entirety by the researchers on this application who have read and are familiar with the protocols set out in this application, the Universities Human Ethics Guidelines, and the National Statement on Ethical Conduct in Human Research, as well as the NHMRC Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research.

A discussion group that works as an advisory body for the project has been formed that consists of a number of key stakeholders including:

- *Australian College of Optometry*
- *International Centre for Eye Education*
- *Office for Aboriginal and Torres Strait Islander Health (Department of Health and Ageing)*
- *Optometry Association of Australia*
- *Royal Australian and New Zealand College of Ophthalmologists*
- *Victorian Aboriginal Community Controlled Health Organisation*
- *Victorian Department of Health*
- *Vision CRC*
- *Vision2020 Australia*

This advisory body has met to review research plans and will meet approximately six monthly to review progress and provide input and advice for the research project.

Separate discussions have occurred with the chairman of the National Aboriginal Community Controlled Health Organisation (NACCHO) to advise them of the project. Further meetings with the chair and CEO to discuss collaboration are scheduled. Meetings will be held with the state affiliates to discuss the proposed work and processes, discussions have already been held with the Aboriginal Medical Services Alliance Northern Territory (AMSANT), Aboriginal Health Council Western Australia (AHCWA) and the aboriginal Health Council of South Australia (AHCSA).

Once ethics approval has been granted state/territory affiliations and relevant Aboriginal Medical Services and/or where applicable; elected community councils; will be contacted to explain the research project and request permission to visit and collaborate in the study.

It is anticipated that at each site, AMS staff and/or elected community councils will further inform the research team of the most appropriate way to work with their community

(b) *For student research projects how will the student be supervised to ensure they comply with the protocols? If the student is working overseas, provide additional details of any local supervision arrangements.*

2. PARTICIPANT DETAILS

2.1 *DOES THE RESEARCH* SPECIFICALLY TARGET*: [TICK AS MANY AS APPLICABLE]*

		YES	NO
a.	students or staff of this University	☐	☒
b.	adults (over the age of 18 years and competent to give consent)	☒	☐
c.	children/legal minors (anyone under the age of 18 years)	☐	☒
d.	the elderly	☐	☒
e.	people from non-English speaking backgrounds	☐	☒
f.	pensioners or welfare recipients	☐	☒
g.	anyone intellectually or mentally impaired who cannot provide consent	☐	☒
h.	anyone who has a physical disability	☐	☒
i.	patients or clients of professionals	☒	☐
j.	anyone who is a prisoner or parolee	☐	☒
k.	a ward of the state	☐	☒
l.	any other person whose capacity to give informed consent may be compromised	☐	☒
m.	Aboriginal and/or Torres Strait Islander people and/or communities	☒	☐
n.	other collectives where a leader or council of elders may need to give consent	☐	☒

2.2 NUMBER, AGE RANGE AND SOURCE OF PARTICIPANTS

Provide number, age range and source of participants.

Participants will be sourced from eye health care services, visiting eye health teams, public hospitals/clinics, Aboriginal Medical Services and Community Controlled Health Organisations. There will be approximately 100-140 people interviewed for this project and approximately 60 people that will participate in focus group discussions.

Eye health service providers, Regional Eye Health Co-ordinators and other support staff will be selected from across the country to participate in semi-structured interviews.

In Victoria, further consultations are planned with Aboriginal clients of selected AMS's via focus group discussions. Consultations around site selection will be conducted with VACCHO prior to commencement of recruitment for focus group discussions. Participants for the focus group discussions in Victoria will be recruited by the research team in consultation with AMS staff. The five to six proposed sites for the focus group discussions have been identified by previous research as well as preliminary consultations with key eye health service providers and stakeholders in Victoria. It is anticipated that there will be five to six focus groups, each with six to ten participants.

Participants will be 18 years or older.

2.3 JUSTIFICATION OF PARTICIPANT NUMBERS [The quality and validity of research is an essential condition of its ethical acceptability (refer National Statement)]. *Where applicable, provide a justification of sample size (including details of statistical power of the sample, where appropriate), explaining how this sample size will allow the aims of the study to be achieved.*

Regional Eye Health Coordinators and peak bodies for Indigenous Eye Health participated in a National workshop hosted by Vision 2020 Australia, in May 20101. Through this workshop and previous research on the provision of eye health services in Australia2, 17-18 proposed key sites across Australia have been identified to be of primary interest for research. *Please see Appendix I for a list of the sites.* Sites have been selected to obtain information about barriers to access for eye health that will inform National policy recommendations. Participants will be selected from these sites and will be contacted directly by the researchers. At each site a number of key informants will be consulted via face to face interviews. These include:

- Regional Eye Health Coordinators (where applicable)
- Visiting Optometrist(s)
- Visiting Ophthalmologist(s),
- AMS administration, coordination staff and/or clinical personnel
- Regional hospital administration, coordination staff and/or clinical personnel such as Aboriginal Health Workers

The project will predominately involve qualitative research methods to assess current health system function and will engage with a range of different stakeholders involved in the client care pathway for eye health as outlined above. This involves face to face interviews with approximately eight individual key stakeholders at each of the 17-18 sites selected.

It is anticipated that at each site, consultations with key informants may identify other people who should be included in subsequent interviews. In addition researchers may consult with federal government, state government and NGO personnel

In addition, in the more settled areas in Victoria, six focus groups (three urban sites and three rural sites), each involving six to ten people are planned. The number and distribution of these focus groups have been decided to provide an understanding of barriers to accessing eye health care from the client's perspective in urban and rural areas where services currently exist.

It is anticipated that the number of focus groups and interviews will provide an appropriate data set for thematic qualitative research of the issues currently affecting provision and utilisation of eye health services for indigenous Australians. As the project is a qualitative research proposal, we cannot provide a statistical estimate of power and precision of the sample size.

2.4 PARTICIPANT RECRUITMENT

1 Vision 2020 Australia, Regional Eye Health Coordination Workshop; 2010; Adelaide, South
2 Turner A, Mulholland W, Taylor HR. Outreach Eye Services in Australia. Melbourne: Indigenous Eye

(a) *Please indicate the method of recruitment by ticking the appropriate boxes. Tick all that apply.*

Mail out - *see below*	☐	**Email -** *see below*	☐	**Telephone**	☐
Advertisement - *see below*	☐	**Recruitment carried out by third party** (eg. employer, doctor) – *see below*	☒	**Recruitment carried out by researcher/s**	☒
Contact details obtained from public documents (eg. phone book)	☐	**Contact details obtained from private sources** (eg. employee list, membership database) – *see below*	☐	**Personal contacts**	☐
Participants from a previous study	☐	**Snowball** (participants suggest other potential participants)	☒	**Other** *(Please explain in no more than 50 words)*:	☐

- *If using a **mail out** or **email** who will be distributing it?*
- *If using an **advertisement**:*
  - *explain where will it be placed?*[e.g. on waiting room wall, in newspaper, in newsletter]
  - *have you attached a copy?*

    Yes ☐ No ☐ NA ☒ *If "No" please explain (no more than 50 words):*
- *If recruitment is to be conducted by a **third party**, (eg employer, doctor) have you attached an approval letter?*

  - requesting their assistance?[yes, no or not applicable]

  Yes ☐ No ☐ NA ☒ *If "No" please explain (no more than 50 words):*

  - confirming their willingness to assist?

  Yes ☐ No ☐ NA ☒ *If "No" please explain (no more than 50 words):*

  - that has been drafted for the third party to send to potential participants?

  Yes ☒ No ☐ NA ☐ *If "No" please explain (no more than 50 words):*

  Attachment is focus group information sheet (focus group flyer)
- *If contact details are to be obtained from **private sources**, have you attached an approval letter?*

  Yes ☐ No ☐ *If "No" please explain (no more than 50 words):*

(b) *Describe how, by whom, where potential participants are to be identified or selected for this research*.

Our ongoing research on eye health care for Indigenous Australians has identified a number of issues relating to the availability, accessibility and utilisation of eye health services. This research has also identified potential key informants from the eye health service system, the public health system and from Aboriginal Medical Services, who will be able to inform the new proposed research.

These key stakeholders will serve as participants in the research, but they may also identify further people of interest for the research project.

Aboriginal persons who access AMS services will be potential participants in the research to provide information regarding barriers to accessing eye health care. These potential participants will be identified by collaborating AMS staff.

(c) *Describe how, by whom, where potential participants are to be approached or invited to take part in this research*.

Face to face interviews
Key informants that are involved in the eye health service system, the public health system as well as from Aboriginal Medical Services will be approached by the research team directly either by telephone, email or in person and will be invited to be involved in the research.

Focus Group discussion
Collaborating AMSs in Victoria will be informed of the project via direct contact with the research team. The staff of the AMS will be provided with printed information (focus group flyer) regarding the project and requirements of focus group participants, which they can distribute and discuss with clients that the AMS staff will identify as potential participants. If clients are interested in being involved in the research they will contact the research team directly via telephone of email to register their interest. Research team contact details will be provided in the focus group flyer.

2.5 DEPENDENT RELATIONSHIPS

[The issue of research involving persons in dependent or unequal relationships (e.g. teacher/student, doctor/patient, student/lecturer, client/counsellor, warder/prisoner, and employer/employee) is discussed in Sections 2 and 4.3 of the National Statement. Such a relationship may compromise a participant's ability to give consent which is free from any form of pressure (real or implied)]. *Are any of the participants in a dependent relationship with any of the researchers, particularly those involved in recruiting for or conducting the project?*

☒ YES ☐ NO *(If YES, explain the dependent relationship and the steps to be taken by the researchers to ensure that participation is purely voluntary and not influenced by the relationship in any way)*

Doctors and AMS clinical staff will be approaching the clients to seek their participation in the research project.

Clients will be advised both verbally by the staff as well as in project information material distributed that participation in the research is voluntary, confidential; and information given by clients will not be identifiable. Clients will also be informed of the option to withdraw from research at any time.

In addition clients will be informed both verbally and in writing that by the decision to decline to participate in the research will not have any impact on further care provided by the staff and will not have any impact on the relationship that client has with AMS personnel.

2.6 PAYMENT OR INCENTIVES OFFERED TO PARTICIPANTS

Do you propose to pay, reimburse or reward participants?

☒ YES ☐ NO *(If YES, how, how much and for what purpose? Please justify the approach)*

Reimbursements will be provided to participants involved in focus group discussions to recognize their contributions to the research and as reciprocity for their time.

Consultation with VACCHO will be undertaken in the first instance to determine what is appropriate and the best approach for making reimbursements to participants. Reciprocity will be determined at each site in consultation with AMS staff, and where applicable, elected community councils, regarding what is determined as appropriate and valuable for the community. Reimbursements will not include cash payments to participants. Examples of appropriate reimbursements could include vouchers, transport to attend focus group discussions and refreshments which will be served at the time of their involvement in focus group discussions.

The process of reciprocity will strictly adhere to NHMRC Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research and the National Statement on Ethical Conduct in Human Research.

2.7 DECEPTION OR CONCEALMENT

[LIMITED DISCLOSURE, DECEPTION AND ACTIVE CONCEALMENT ARE DISCUSSED IN SECTION 2.3 OF THE NATIONAL STATEMENT. ESSENTIALLY THE PRACTICE IS NOT CONSIDERED ETHICAL UNLESS THERE ARE COMPELLING REASONS GIVEN FOR ITS USE] WILL THE TRUE PURPOSE OF THE RESEARCH, OR THE COLLECTION OF DATA ITSELF, BE CONCEALED FROM PARTICIPANTS OR WILL PARTICIPANTS IN ANY WAY BE DECEIVED?

☐ YES ☒ NO

If you answered YES, provide a clear justification. [You will also need to provide participants with details of the deception in a debriefing (refer 3.4) and give them the opportunity to withdraw their data if they wish to do so.]

3. RISK AND RISK MANAGEMENT

3.1 STUDY PROFILE –DOES THE RESEARCH INVOLVE THE FOLLOWING:

[Tick as many as apply. Provide details in methodology –section 1.5 and attach information where indicated]

	YES	NO
• use of questionnaires designed by the researcher ***(attach a copy)***	☐	☒
• use of standard survey instruments ***(attach a copy)***	☐	☒
• use of on-line surveys ***(attach printout of screen information)***	☐	☒
• use of interviews ***(attach the list of interview questions)***	☒	☐
• use of focus groups ***(attach the list of focus group topics/questions)***	☒	☐
• observation of participants without their knowledge	☐	☒
• covert observation	☐	☒

• audio-taping interviewees or events	☒	☐
• video-taping interviewees or events	☐	☒
• access to personal and/or confidential data (including student, patient or client data) without the participant's specific consent	☐	☒
• administration of any stimuli, tasks, investigations or procedures which may be experienced by participants as physically or mentally painful, stressful or unpleasant during or after the research process	☐	☒
• performance of any acts which might diminish the self-esteem of participants or cause them to experience embarrassment, regret or depression	☐	☒
• research about participants involved in illegal activities	☐	☒
• research conducted in an overseas setting	☐	☒
• administration of any substance or agent	☐	☒
• use of non-treatment or placebo control conditions	☐	☒
• collection of body tissues or fluid samples	☐	☒
• collection and/or testing of DNA samples	☐	☒

3.2 POTENTIAL RISKS TO PARTICIPANTS

Identify, as far as possible, all potential risks to participants (e.g. physical, psychological, social, legal or economic etc.), associated with the project and the setting (e.g. overseas) in which the project is conducted. It may be useful to consider the study profile above and your response to participant details in section 2

It is anticipated that there are no potential risks to participants.

All participants will be required to provide informed consent indicating they understand the project and what is required and how the data will be used regarding their participation in the research. Further to this, participants will be free to excuse themselves from participating in the research if they wish.

No participant will be identified by the research and all comments will be treated confidentially.
Clients of AMS's who choose not to be involved in the research will be informed both verbally and in writing that the decision to decline to participate in the research will not have any impact on care provided by the staff and will not have any impact on the relationship that client has with AMS personnel.

3.3 MANAGING POTENTIAL RISKS

Describe what measures you have in place to minimize these potential risks to participants and to ensure that support is available if needed. [Depending on risks, participants may need additional support (e.g. external counselling) during or after the study]

We do not anticipate any risks in this type of study

3.4 DEBRIEFING (if applicable)

What debriefing will participants receive following the study and when? (Attach a copy of any written material or statement to be used in such a debriefing, if applicable). [Participants may need to talk about the experience of being involved in the study with the researchers, as well as learn more about the aims of the research]

Not applicable

3.5 BENEFITS COMPARED TO POTENTIAL RISKS

Outline the benefits of the study to the community (and participants, if applicable), relative to the potential risks to participants

They key benefit to Australian Indigenous populations from this research will be improved eye health care and eye health outcomes in the medium to long term.

We do not recognize any potential risks to the participants, whilst benefits of contributing towards future improved eye health for Indigenous people may provide personal satisfaction.

3.6 MANAGING ADVERSE / UNEXPECTED OUTCOMES

Describe what measures you have in place in the event that participants experience adverse effects arising from their involvement in the project (e.g. adverse drug reaction, revelation of illegal activity, or unexpected distress due to questioning)

We anticipate there will be no unexpected or adverse outcomes from this research

3.7 POTENTIAL RISKS TO RESEARCHERS

Will there be any significant risks to researchers associated with the project and the setting (e.g. overseas) in which the project is conducted. (e.g. personal safety, health, emotional well being)? [Refer to the University's Environmental Health & Safety Manual for more information]

☐ YES ☒ NO *(If YES, how will such risks be addressed)*

4. INFORMATION FOR PARTICIPANTS AND INFORMED CONSENT

Before research is undertaken, the informed and voluntary consent of participants (and other properly interested parties) is generally required (refer Section 2 of the National Statement for more details). Information needs to be provided to participants at their level of comprehension about the purpose, methods, demands, risks, inconveniences, discomforts and possible outcomes of the research. Such information is often provided in a written **Plain Language Statement**. Each participant's consent needs to be clearly established (e.g. by using a signed **Consent Form**, returning an anonymous survey or recording an agreement for interview).

4.1 PROVIDING INFORMATION FOR PARTICIPANTS

(a) *Will you be providing participants with information in a written Plain Language Statement?*

☒ YES ☐ NO *(If NO, provide details of the protocol you will use to explain the research project to participants and invite their participation?)*

(b) *Will arrangements be made to ensure that participants who have difficulty understanding English can comprehend the information provided about the research project?*

☐ YES ☒ NO *(If YES, what arrangements have been made? If NO, give reasons.*

It is anticipated that participants involved in the semi structured interviews and focus group discussions will be able to understand English and will not require translation services.

4.2 PLAIN LANGUAGE STATEMENT (IF APPLICABLE)

CONFIRM THAT THE PLAIN LANGUAGE STATEMENT WILL:

		YES	NOT APPLICABLE
1.	be printed on University of Melbourne letterhead	☒	
2.	include clear identification of the University, the Department(s) involved, the project title, the Principal and Other Researchers (including contact details), and the study level if it is a student research project.	☒	
3.	provide details of the purpose of the research project	☒	
4.	provide details of what involvement in the project will require (e.g., involvement in interviews, completion of questionnaire, audio/video-taping of events), and estimated time commitment	☒	
5.	provide details of any risks involved and the procedures in place to minimise these.	☒	☐
6.	advise that the project has received clearance by the HREC	☒	
7.	(if the sample size is small), confirm that this may have implications for protecting the identity of the participants	☐	☒
8.	include a clear statement that if participants are in a dependent relationship with any of the researchers that involvement in the project will not affect ongoing assessment/grades/management or treatment of health (if relevant)	☒	☐
9.	state that involvement in the project is voluntary and that participants are free to withdraw consent at any time, and to withdraw any unprocessed data previously supplied	☒	
10.	provide advice as to arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations (see ** below)	☒	
11.	provide advice as to whether or not data is to be destroyed after a minimum period (if relevant)	☒	☐
12.	provide in the footer, the project HREC number, date and version of the PLS	☒	
13.	provide advice that if participants have any concerns about the conduct of this research project that they can contact the Executive Officer, Human Research Ethics, The University of Melbourne, ph: 8344 2073; fax 9347 6739	☒	

[**Re 10 – it is possible for data to be subject to subpoena, freedom of information request or mandated reporting by some professions. Depending on the research proposal you may need to specifically state these limitations]

PLEASE ATTACH A COPY OF THE PLAIN LANGUAGE STATEMENT TO YOUR APPLICATION

4.3 OBTAINING CONSENT

(a) *How will each participant's consent be established*?

By signing and returning a Consent Form – *see 4.4 below*	☒	**By returning an anonymous survey**	☐
Via a verbal agreement	☒	**Via a person with lawful authority to consent** (eg. parent, doctor) – *see 4.3(b) below*	☐
Via a recorded agreement for interview	☒	**Other** *(Please describe in no more than 50 words)*:	☐

(b) *If participants are unable to give informed consent, explain who will consent on their behalf and how such consent will be obtained.*

Not applicable

4.4 CONSENT FORM (IF APPLICABLE)

CONFIRM THAT THE CONSENT FORM WILL:

		YES	NOT APPLICABLE
1.	be printed on University of Melbourne letterhead	☒	
2.	include the title of the project and names of researchers	☒	
3.	state that the project is for research purposes	☒	
4.	state that involvement in the project is voluntary and that participants are free to withdraw at any time, and free to withdraw any unprocessed identifiable data previously supplied	☒	
5.	outline particular requirements of participants including, for example, whether interviews are to be audio and/or video-taped	☒	☐
6.	include arrangements to protect the confidentiality of data	☒	
7.	include advice that there are legal limitations to data confidentiality (see below)**	☒	
8.	(if the sample size is small) confirm that this may have implications for protecting the identity of the participants	☐	☒
9.	(once signed and returned) be retained by the researcher	☒	

[**Re 7 – it is possible for data to be subject to subpoena, freedom of information request or mandated reporting by some professions. Depending on the research proposal you may need to specifically state and explain these limitations]

PLEASE ATTACH A COPY OF THE CONSENT FORM TO YOUR APPLICATION

5. PRIVACY AND CONFIDENTIALITY

Privacy can be described as "…a complex concept that stems from a core idea that individuals have a sphere of life from which they should be able to exclude any intrusion." A major application of the concept of privacy is information privacy: the interest of a person in controlling access to and use of any information personal to that person. 'Confidentiality', a narrower more specific term than 'privacy' refers to the legal and ethical obligation that arises from a relationship in which a person receives information from or about another.

At the Commonwealth level, the collection, storage, use and disclosure of personal information by Commonwealth agencies is regulated by the *Privacy Act 1988*. Sections 95 and 95A of the Act are of particular relevance to researchers. There is regulation at State and Territory level in the form of legislation related to privacy generally or the administration of agencies, or administrative codes of practice. In Victoria, the *Health Records Act 2001* regulates health information handled by the Victorian public sector and private sector, while the Information Privacy Act 2000 regulates the collection and handling of non-health-related personal information. The National Statement states that an HREC must be satisfied that a research proposal conforms to all relevant Commonwealth, State or Territory privacy legislation or codes of practice]

5.1 ACCESSING PERSONAL INFORMATION

[Personal Information' includes names, addresses, or information/opinion about an individual whose identity is apparent, or can reasonably be ascertained, from the information/opinion. It also includes Health Information (e.g. health opinions, organ donation or genetic information) and Sensitive Information (e.g. political views, sexual preferences, criminal records)]

*Is there a requirement for the researchers to obtain **Personal Information** (either identifiable or potentially identifiable) about individuals **without their consent**?*

		YES	**NO**
a)	from Commonwealth departments or agencies?	☐	☒
b)	from State departments or agencies?	☐	☒
c)	from Other Third Parties, such as non-government organisations?	☐	☒

IF YOU ANSWERED YES TO (A), (B) OR (C), YOU WILL NEED TO COMPLETE MODULE P AND ATTACH IT TO THIS APPLICATION

5.2 REPORTING PROJECT OUTCOMES

(a) *Will the project outcomes be made public at the end of the project?*

☒ YES ☐ NO *(If YES, give details of how the results will be made public (eg in journal articles book, conference paper, the media, working paper or other). If NO, explain why not*

It is anticipated that the research will result in a policy document as well as the option for journal articles and conference presentations.

☒ YES ☐ NO *(If YES, give details of how the results will be made public (eg in journal articles book, conference paper, the media, working paper or other). If NO, explain why not*

It is anticipated that the research will result in a policy document as well as the option for journal articles and conference presentations.

(b) *Will a report of the project outcomes be made available to participants at the end of the project?*

☒ YES ☐ NO *(If Yes, give details of the type of report and how it will be made available. If No, explain why not.*

A summary document will be prepared and circulated widely amongst interviewed participants.

Information regarding the findings will be sent to the collaborating AMS's involved in the consultation, for distribution to focus group participants as the AMS's and, where appropriate, elected community councils, see fit.

5.3 WILL THE RESEARCH INVOLVE:

	YES	NO
• complete anonymity of participants (i.e., researchers will not know the identity of participants as participants are part of a random sample and are required to return responses with no form of personal identification)?	☐	☒
• de-identified samples or data (i.e., an irreversible process whereby identifiers are removed from data and replaced by a code, with no record retained of how the code relates to the identifiers. It is then impossible to identify the individual to whom the sample of information relates)?	☐	☒
• potentially identifiable samples or data (i.e., a reversible process in which the identifiers are removed and replaced by a code. Those handling the data subsequently do so using the code. If necessary, it is possible to link the code to the original identifiers and identify the individual to whom the sample or information relates)?	☒	☐
• participants having the option of being identified in any publication arising from the research?	☐	☒
• participants being referred to by pseudonym in any publication arising from the research?	☐	☒
• any other method of protecting the privacy of participants? *Please describe:*		

Note that where the sample size is very small, it may be impossible to guarantee anonymity/confidentiality of participant identity. Participants involved in such projects need to be clearly advised of this limitation in the Plain Language Statement.

6. DATA STORAGE, SECURITY AND DISPOSAL

6.1 DATA STORAGE

Does data storage comply with the University policy? [University of Melbourne Policy on the Management of Research Data and Records is available at: http://www.unimelb.edu.au/records/research.html The Joint NHMRC/AVCC Statement and Guidelines on Research Practice is available at: http://www.nhmrc.gov.au/funding/policy/researchprac.htm]

☒ YES ☐ NO *(If NO, please explain.)*

6.2 DATA SECURITY

(a) *Will the Principal Researcher be responsible for security of data collected?*

☒ YES ☐ NO *(If NO, please provide further details. You may also use this space to explain any differences between arrangements in the field, and on return to campus.)*

(b) *Will data be kept in locked facilities in the Department through which the project is being conducted?*

☒ YES ☐ NO *(If NO, please explain how and where data will be held, including any arrangements for data security during fieldwork.)*

(c) WHICH OF THE FOLLOWING METHODS WILL BE USED TO ENSURE CONFIDENTIALITY OF DATA? (SELECT ALL OPTIONS THAT ARE RELEVANT)

- data and codes and all identifying information to be kept in separate locked filing cabinets ☐
- access to computer files to be available by password only ☒
- access by named researcher(s) only ☒
- other *(please describe)* ☐

(d) *Will others besides the researchers associated with this project have access to the raw data?*

☐ YES ☒ NO *(If YES, please explain who and for what purpose? What is their connection to the project?)*

6.3 DATA RETENTION AND DISPOSAL

[Research data and records should be maintained for as long as they are of *continuing value* to the researcher and as long as recordkeeping requirements such as patent requirements, legislative and other regulatory requirements exist. The minimum retention period for research data and records is five years after publication, or public release, of the work of the research as stated in the University of Melbourne *Code of Conduct for Research*. If the project involves clinical trial(s), the data should be kept for a minimum of 15 years (refer to Section 3.3 of the National Statement for further details)]

Specify how long materials (e.g. files, audiotapes, questionnaires, videotapes, photographs) collected during the study will be retained after the study and how they will ultimately be disposed of.

Material such as audio files and transcripts from interviews and focus group sessions will be kept for a period of five years following the completion of publication or public release of the work or the research.
Disposal of audio files will involve deleting digital files. Disposal of transcript will involve deleting of computer files as well as shredding of any paper files.

7. POTENTIAL CONFLICT OF INTEREST

7.1 POTENTIAL CONFLICT OF INTEREST

Is there any affiliation or financial interest for researchers in this research or its outcomes or any circumstances which might represent a perceived, potential or actual conflict of interest?

☐ YES ☒ NO *(If YES, give brief details?)*

[If you have declared a potential conflict of interest, you should include an appropriate comment on the Plain Language Statement and Consent Form]

7.2 COMPLIANCE WITH THE CODE OF CONDUCT FOR RESEARCH

[University researchers must disclose and manage Conflict of Interest in accord with the provisions of the University's *Code of Conduct for Research*. See http://www.unimelb.edu.au/ExecServ/Statutes/r171r8.html]

Is the Conflict of Interest noted above in section 7.1 being managed in accordance with the Code of Conduct?

☐ YES ☐ NO ☒ Not Applicable

8. DECLARATION BY RESEARCHERS

The information contained herein is, to the best of our knowledge and belief, accurate.

We have read the University's current human ethics guidelines, and accept responsibility for the conduct of the procedures set out in the attached application in accordance with the guidelines, the University's Code of Conduct for Research and any other condition laid down by the University of Melbourne's Human Research Ethics Committee or its Sub-Committees. We have attempted to identify all risks related to the research that may arise in conducting this research and acknowledge our obligations and the rights of the participants. We have the appropriate qualifications, experience and facilities to conduct the research set out in the attached application and to deal with any emergencies and contingencies related to the research that may arise.

If approval is granted, the project will be undertaken in strict accordance with the approved protocol and relevant laws, regulations and guidelines.

We, the researcher(s) agree:

- *To only start this research project after obtaining final approval from the Human Research Ethics Committee (HREC);*
- *To only carry out this research project where adequate funding is available to enable the project to be carried out according to good research practice and in an ethical manner;*
- *To provide additional information as requested by the HREC;*
- *To provide progress reports to the HREC as requested, including annual and final reports;*
- *To maintain the confidentiality of all data collected from or about project participants, and maintain security procedures for the protection of privacy;*
- *To notify the HREC in writing immediately if any change to the project is proposed and await approval before proceeding with the proposed change;*
- *To notify the HREC in writing immediately if any adverse event occurs after the approval of the HREC has been obtained;*
- *To agree to an audit if requested by the HREC;*
- *To only use data and any tissue samples collected for the study for which approval has been given;*

We have read the National Statement on Ethical Conduct in Human Research and agree to comply with its provisions.

9. *DECLARATION BY DEPARTMENTAL HUMAN ETHICS ADVISORY GROUP (HEAG)*

DATE APPLICATION RECEIVED: / / **HEAG NO:**

TECHNICAL REVIEW COMPLETED ***ETHICAL REVIEW COMPLETED***

The HEAG has reviewed this project and considers the methodological/technical and ethical aspects of the proposal to be appropriate to the tasks proposed and recommends approval of the project. The HEAG considers that the researcher(s) has/have the necessary qualifications, experience and facilities to conduct the research set out in the attached application, and to deal with any emergencies and contingencies that may arise. [Note: If the HEAG Chair is also a principal researcher for this project, the declaration should be signed by another authorised member of the HEAG]

Comments/Provisos:

Name of HEAG Chair (in BLOCK LETTERS)	
Signature	
Date	

10. *DECLARATION BY HEAD OF DEPARTMENT*

DATE APPLICATION RECEIVED: / / **HEAG NO:**

TECHNICAL REVIEW COMPLETED ***ETHICAL REVIEW COMPLETED***

I have reviewed this project and consider the methodological, technical and ethical aspects of the proposal to be appropriate to the tasks proposed and recommend approval of the project. I consider that the researcher(s) has/have the necessary qualifications, experience and facilities to conduct the research set out in the attached application, and to deal with any emergencies and contingencies that may arise. [Note: If the Head of Department is also a principal researcher for this project, the declaration should be signed by another authorised member of the Department]

This project has the approval and support of this Department/School/Centre.

Name of Head (in BLOCK LETTERS)	
Signature	
Date	

11. WHEN COMPLETE

When this form has been completed and finalised it should be attached to the coversheet section of the application completed in Themis Research and then submitted to the nominated Human Ethics Advisory Group for review.

Plain language statement

Professor Hugh R. Taylor AC
MD FRANZCO FRACS
Harold Mitchell Chair of Indigenous Eye Health
Indigenous Eye Health Unit

THE UNIVERSITY OF MELBOURNE

Plain Language Statement

Research Project:	Barriers to the provision and utilization of eye health services for Indigenous Australians
Research Unit:	Indigenous Eye Health Unit Melbourne School of Population Health The University of Melbourne
Researchers:	Professor Hugh R Taylor AC Ms Emma Stanford Mr Colin Garlett Mr Longyun (Alex) Zhang Professor David Dunt Ms Andrea Boudville Ms Robyn McNeil Dr Ya Seng (Arthur) Hsueh Ms Helen Jordan
Contact:	Professor Hugh R Taylor AC Ph: (03) 8344 9320 Email: h.taylor@unimelb.edu.au

Description:

Project Aims: The aim of the Indigenous Eye Health Unit is to 'close the gap for vision'. This project forms the policy development phase of this work to improve access to eye care for Aboriginal and Torres Strait Islander peoples.

Participants will be asked a series of questions in either face to face interviews or focus groups discussion relating to eye health in Indigenous Australians.
Interviews will be from thirty minutes to two hours in duration.
Focus Group discussions will be approximately two hours in duration.
Researchers will make audio recordings of the consultations.

This project presents no risk to the participants and has been approved by The University of Melbourne Human Research Ethics Committee.

There will be about 200 participants. The confidentiality and privacy of the interviewees and focus group participants will be protected by the researchers. Some or all participants (senior and highly experienced or professionals) may wish to be identified.

Involvement in the project is voluntary and participants are free to withdraw consent at any time and to withdraw any unprocessed data previously supplied. Declining to participate in the research project will not impact on the quality of care or services received or accessed by participants.

All data and records collected from interviews and focus group sessions will be destroyed after a period of five years following the completion of publication or public release of the work or the research.

If participants have any concerns about the conduct of this research project, they can contact:
The Executive Officer
Human Research Ethics
The University of Melbourne
Ph: (03) 83442073; fax (03) 93476739

Ethics Application Number: 1034282.1
2 August 2010
Document Version Number: 3

Melbourne School of Population Health
The University of Melbourne, Victoria 3010 Australia
T: +61 3 8344 9320 **F:** +61 3 9348 1827 **E:** h.taylor@unimelb.edu.au
W: www.iehu.unimelb.edu.au

unimelb.edu.au

Consent form

Research Project: Barriers to the provision and utilisation of eye health services for Indigenous Australians

Research Unit: Indigenous Eye Health Unit Melbourne School of Population Health The University of Melbourne

Researchers: Professor Hugh R Taylor AC
Ms Emma Stanford
Ms Robyn McNeil
Ms Andrea Boudville
Mr Colin Garlett
Dr Ya Seng (Arthur) Hsueh
Mr Alex Zhang
Prof David Dunt
Ms Helen Jordan
Mr Mitchell Anjou

Contact: Professor Hugh R Taylor AC

Ph: (03) 8344 9320 Email: h.taylor@unimelb.edu.au

Description: This signed consent form will be retained by the Researchers

I confirm I have received and read a copy of the Plain Language Statement

I understand participation is voluntary and that I have the right to withdraw at any time, and that I may withdraw any data I have supplied.

□ I understand I will not be identified in any publication arising from the research

□ I elect to be identified if necessary

□ I consent to having my interview/focus group discussion audio taped

Participant Signature ……..

NAME …….

Date …….

Researcher ……..

NAME ……..

Date ……

Verbal consent script

Some participants may not be able to participate in face-to-face interviews and may be interviewed by telephone. Participants interviewed by telephone will be required to give verbal consent for their participation. To obtain verbal consent the researcher will read the verbal consent script to the participant and ask for their verbal consent to participate in place of written signature. Telephone interview participants will be provided with a copy (hard copy or electronic) of the plain language statement prior to the interview.

The following script will be read to the participant at the beginning of telephone interview.

"*The title of this research project is Barriers to the provision and utilisation of eye health services for Indigenous Australians. This research is being conducted by the Indigenous Eye Health Unit from the Melbourne School of Population Health at The University of Melbourne.*

The names of Researchers involved in this project are: Professor Hugh R Taylor AC; Ms Emma Stanford; Ms Robyn McNeil; Ms Andrea Boudville; Mr. Colin Garlett; Dr Ya Seng (Arthur) Hsueh; Mr. Longyun (Alex) Zhang; Ms Helen Jordan and Professor David Dunt.

The primary contact person for this research project is: Professor Hugh R Taylor AC. If you wish to contact Prof Taylor regarding this research project, telephone (03) 8344 9320 or send email to h.taylor@unimelb.edu.au

Participation in this research project is voluntary and you have the right to withdraw at any time, you may also withdraw any data you have supplied. You will not be identified in any publication arising from the research.

A record of verbal consent will be retained by the Researchers. By answering yes to the following statements you will be giving verbal consent in place of written consent:

- *Do you agree to give verbal consent to participate in the research?*
- *Do you confirm that you have received and read a copy of the Plain Language Statement and understand that this project is for research purposes?*
- *Do you consent to having this interview recorded and or audio taped?"*

NAME ……

Date ……

Researcher ……..

NAME ……..

Date ……

Sample questions for semi structured interviews

Questions for Outreach and Visiting Eye Health Services:

1. What are the critical elements of a visiting outreach service?
    a. In your experience what are the challenges or barriers encountered when using the VOS and MSOAP schemes to deliver outreach services?
    b. What could be done to addresses these barriers?
    c. Logistics – constraints and limitations around logistical requirements to deliver outreach services. Which elements of the planning, organizing and coordination for logistics need to be changed and how should these be revised?
        i. Equipment for clinics and surgery
        ii. Scheduling for eye health specialists, support staff including coordination and administration staff, surgical teams and other support staff
        iii. Planning and booking transport and travel
        iv. Booking accommodation
        v. Coordination with Primary Health Care clinics (AMSs) and regional hospitals
        vi. Coordination between visiting optometry and ophthalmology services
        vii. Booking theatres, equipment and staff for surgery
    d. What are the critical blocks or gaps in the service delivery system (logistics or systematic blocks) and what could be done to address these?
    e. What are the limitations for patient logistics and support required for patients to attend services i.e. organizing transport and accommodation, allowances for meals, follow up appointments including return visits to collect glasses and other support requirements
    f. What are the key factors for successful delivery of services and factors impacting on the sustainability of outreach services?

2. Cost of the projected recommendations
    g. What is the cost of the projected recommendations for systems improvements as suggested by participants?
    h. What are the cost savings related to the proposed recommendations and addressing the systematic blocks or critical elements creating gaps in visiting outreach services?

Pathway of Eye Care Questions:

To establish the necessary components in the pathway of care to ensure a safe and efficient patient journey the following issues will be discussed initially with Regional Eye Health Coordinators and then with other personnel involved as appropriate

Community Liaison

1. Who does community liaison and provides a vital link between individual community members and their families to clinics? When and How is this done?
2. Who identifies patients for referrals to eye health care services within your service?
3. Do you offer a transport service for clients accessing your health care service or other specialists services?
4. Do you have an interpreter service? If so, who provides interpreter/translation services within your clinic?
5. Who offers moral support to clients when attending appointments or undergoing treatment?

Clinic (Primary Health Care = Clinic Staff)

1. Who in your clinic has the skills in primary health care that has the necessary skills to diagnose and treat simple cases and have referral options for more complex cases?
2. Who makes referral's for more complex cases to the visiting eye team?
3. Who maintains patient records and the referral lists for visiting team?
4. Who schedules visits for the visiting eye team?
5. Who is responsible for coordinating multiple visiting specialists that may visit your clinic?
6. Who coordinates booking of exam rooms, accommodation, equipment and local staff?
7. Who makes arrangements for referrals for surgery appointments at Regional Hospitals?
8. Who does follow up visits with patients, if/when required?

Visiting Eye Team (Secondary Eye Care = Visiting Eye Team)

1. How are visits coordinated with clinic and community?
2. Who coordinates these visits?
3. Who updates patient records after visit/s?
4. Who is responsible for all communication and coordination between visiting optometrists and ophthalmologists?
5. Who is responsible for providing specific equipment items for clinics?
6. Who is responsible for providing a list or information about patients waiting to be seen?
7. When the visiting team arrives, who is responsible for assistance with patient identification, transport, translation, explanation and support?
8. Who provides clerical support for forms and paper work?
9. Who manages and maintains Referral System for further management or surgery?

Regional/Hospital (Tertiary Eye Care = Hospital)

1. Who organizes clinic space, theatre time, staff, accommodation, travel and surgical supplies for the visiting eye teams?
2. Who coordinates between other visiting specialists?
3. Who is responsible for the supply of surgical equipment?
4. Who is responsible for coordinating with community and the clinic when patients require surgery?
5. Who is responsible for organizing travel and other arrangement for patients, when attending the Regional Hospital?

State/Territory

1. Who coordinates other specialists and allied health visits with the visiting eye team.
2. Who oversights coordination performed at different levels, recruitment, training and support?
3. Who oversights distribution of visiting eye team (other specialists) including ration of optometric and ophthalmic visits and frequency of visits.

Focus group discussion process

Consultations with Justin Mohamed the Chairman of National Aboriginal Community Controlled Health Organisation (NACCHO) were undertaken to establish a collaborative relationship and determine the most appropriate approach to partner with AMSs. Ongoing consultation with NACCHO, VACCHO and the selected AMS's and/or elected community councils, will be undertaken to facilitate recruitment of focus group participants and ensure that all research protocols are in accordance with the NHMRC Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research.

It is anticipated that there will be five to six focus groups, three urban sites and three rural sites. The number and distribution of these focus groups have been decided to provide an understanding of barriers to accessing eye health care from the client's perspective in urban and rural areas where services currently exist. The five to six proposed sites for the focus group discussions have been identified by previous research as well as preliminary consultations with key eye health service providers and stakeholders in Victoria. Consultations to finalise site selection will be conducted with VACCHO prior to commencement of recruitment for focus group discussions.

Each focus group discussion is intended to have six to ten participants.

Participants for focus group discussions will be 18 years or older.

Participants for the focus group discussions will be recruited by the research team in consultation with AMS staff.

AMS staff will distribute a focus group discussion information sheet (flyer). The flyer will include details about the project, what would be discussed in focus groups, the time, date and venue where the discussion will be held, and instructions for how to register. Clients interested in participating can contact the research team directly via telephone or email to register.

Upon arrival at the focus group discussion session, participants will be given the Focus Group Plain Language Statement to read and keep. Participants will then be asked to sign the consent form. In any cases where people were hesitant to sign a consent form, verbal recorded consent will be obtained.

Focus group participants will be asked to discuss barriers that impact on their access to eye health services and suggestions to improve their access to current eye health services.

Focus groups will be two hours long. Food and refreshments will be provided during the focus group. Participants will be provided with transport to and from the focus group discussion where required, and provided with other reimbursement where determined appropriate. Other types of reimbursements will be provided to participants if determined appropriate, this decision will be made in consultation with AMS staff.

Focus group information sheet

Do you have any problems seeing?

Have you or someone in your family had any problems in getting help for your eyes?

Do you feel that there are things that prevent you or someone in your family getting good quality care for your eyes?

If you answered yes to the any of the above questions-we would like to talk to you.

The University of Melbourne Indigenous Eye Health Unit is conducting research into barriers to accessing eye health care for Aboriginal people in Victoria. We are seeking people for a group discussion to explore issues such as where people go to get help with their eyes, how and why you use the services that you do, the problems you may have faced and your experiences of getting eye health care.

A meeting of a small number of 6-10 people (called a focus group) is being held to discuss some of the issues relating to accessing eye care in your community.

Where:

Date:

Time:

- The focus group usually takes about two hours of your time
- Refreshments will be provided in the meeting and transport assistance can be provided if required.

If you are interested in this opportunity to help improve eye health services for Aboriginal people, we would be very interested and grateful to hear from you.

To register your interest or for further information, please contact the research team on the details below.

Robyn McNeil
Research Fellow
Indigenous Eye health unit
Melbourne School of Population health
Phone: (03) 8344 0752
Email: rmcneil@unimelb.edu.au

Mitchell Anjou
Senior Research Fellow
Indigenous Eye health unit
Melbourne School of Population health
Phone: (03) 8344 0752
Email: manjou@unimelb.edu.au

Participation in the focus group is voluntary. All information provided in the focus group is confidential..

If you choose to not continue with your involvement in the research, this is your right which will be respected.

Choosing not to be involved in this research will not have any impact on the quality of care you receive at your AMS/CCHO or have any impact on your relationship with staff at the AMS/CCHO.

Focus group questions

Barriers to the provision and utilization of eye health services for Indigenous Australians

1. Have you thought about how important vision is?
    - Have you ever had your eyes checked?
    - When was the last time you had your eyes checked?
    - How often do you think you need to get your eyes checked?

2. Can we discuss some of the problems you may have with your eyes?
   (understanding range of issues in the room that we want to explore in terms of care pathway context)

3. What do you do if you have a problem with your eyes and need help? Who would you see/where would you go?
    - Do you use eye services in your local community?
        - If not, why not?
    - Why do you use the service(s)? Why do you go to that person/s?
      (enablers-contextual and cultural)
        - What do you like about this service(s)?
          (enablers- contextual and cultural)
        - What don't you like about this service(s)?
          (gaps/challenges/barriers)
        - How could this service(s) be better?
          (gap identification)

4. What are some of the issues that affect you and your family getting good eye health care?

5. How could it be easier for you to get what you need for your eyes in general?
   (barriers-prompts around costs of glasses, transport schemes, availability of specialist services locally. Important to include here what do you think you should pay/what would you pay for a pair of glasses)

6. Has anyone you know needed to have some surgery for their eyes (cataracts, DR). Can you discuss what and how happened? *(process relating to pathway)*
        - What was their experience like?

7. Do you have any other ideas about what could be done to improve access to eye health care services for Aboriginal people?