



Government of **Western Australia**
Department of **Health**
Public Health

Aboriginal Sexual Health and Blood-borne Virus Research Meeting

23 February 2011

Sexual Health and Blood-borne Virus Program
and Aboriginal Health Council of WA

Acronyms

ACCHS	Aboriginal Community Controlled Health Service
AHCWA	Aboriginal Health Council of Western Australia
AHERU	Aboriginal Health Education Research Unit
A/p	Associate Professor
BBV	Blood-borne Virus
CHIRI	Curtin Health Innovation Research Institute
CDCD	Communicable Disease Control Directorate
DoH	Department of Health, Western Australia
FPWA	Family Planning Association of WA
GRAMS	Geraldton Regional Aboriginal Medical Service
IDU	Injecting Drug Use
NDRI	National Drug Research Institute
SHBBVP	Sexual Health and Blood-borne Virus Program
SiREN	Sexual Health and Blood-borne Virus Applied Research and Evaluation Network
WACHPR	Western Australian Centre Health Promotion Research
WACHS	Western Australian Country Health Service
WAISHAC	Western Australian Indigenous Sexual Health Advisory Committee

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Executive Summary

On 23 February 2011 an Aboriginal Sexual Health and Blood-borne Virus (BBV) Research Meeting was held in Perth, Western Australia (WA) with the aim of identifying priority research areas. The meeting was a cooperative approach between the Sexual Health and Blood-borne Virus Program (SHBBVP), of the Public Health Division, Department of Health (DoH), and the Aboriginal Health Council of WA (AHCWA).

The meeting was successful in bringing together people from Aboriginal Community Controlled Health Services (ACCHS), other non government health service providers, Department of Health (DoH), researchers and other agencies with experience in working with Aboriginal people.

Many priorities for research were identified. Importantly there was also an emphasis on the process of research and the need for engagement of Aboriginal people as the drivers, owners and active participants in their own research. Participants identified the highest priority for further research as screening and testing for sexually transmitted infections (STIs) and BBVs in Aboriginal people, particularly in engaging with and accessing young people. The greatest need for carrying out evaluation and research was thought to be data collection and patient information systems that can facilitate good quality information.

The meeting participants saw the way forward as building and improving partnerships between stakeholders, service providers and research institutions to work together to better meet the research needs of Aboriginal people in WA.

Recommendations

It is recommended that:

1. The priorities and processes identified in this meeting are used by national and state based research agencies and local WA stakeholders to inform future planning in WA Aboriginal sexual health and BBV.
2. Mechanisms for engaging Aboriginal people as the owners and active participants in their own research should be a component of any research carried out with Aboriginal communities in WA.
3. The research priorities relating to access and engagement of youth in sexual health services and programs, and quality improvement in patient management and program evaluation systems, are considered in the context of comprehensive and systemic change in health service and program delivery.
4. This report provide a guide to Sexual Health and Blood-borne Virus Applied Research and Evaluation Network (SiREN) relating to sexual health and BBV and WA Aboriginal communities.

Background

In early 2010, the SHBBVP, DoH facilitated a meeting that reviewed sexual health and BBV research relevant to WA service providers and policy makers. The meeting consisted of several presentations on current WA and national research projects and concluded with a discussion about future research in WA. The end result was the formation of the Sexual Health and Blood-borne Virus Applied Research and Evaluation Network (SiREN). The aim of SiREN is to enable better networking, strengthen existing and create new partnerships between researchers and primary health services by promoting and facilitating WA-based applied research and evaluation relating to the prevention and control of STIs and BBVs. The Terms of Reference for SiREN are in Appendix One.

The objective of SiREN is to identify sexual health and BBV public health research priorities for priority populations within WA which includes Aboriginal communities. The Chair of the West Australian Indigenous Sexual Health Advisory Committee (WAISHAC) approached SHBBVP and recommended that a research meeting be held, which was then further developed in discussion between AHCWA and the SHBBVP. As a result of discussions in late 2010, it was agreed that a partnership between the two agencies be formed to work on a one day Aboriginal Sexual Health and BBV Research Meeting/Workshop in February. The planning for the Research Meeting was to be informed by a Working Party with representatives from SHBBVP, AHCWA, WA Country Health Service (WACHS), WAISHAC, Derbarl Yerrigan Health Service and Hepatitis WA. The process to develop the workshop involved engaging the services of two senior Indigenous researchers; Associate Professor (A/P) Dawn Bessarab and Marion Kickett from the Aboriginal Health Education Research Unit (AHERU) located in the Curtin Health Innovation Research Institute (CHIRI). Two meetings were arranged between A/P Bessarab and Ms Kickett and the working party to develop the content and process for the workshop.

The meeting was the first time since 2003 where people from across WA had gathered to discuss Aboriginal sexual health and BBV issues. The content of the workshop was informed not only by SiREN priorities but by the Second Western Australian Aboriginal Sexual Health and BBV Strategy 2010-2014 which has research as a priority area for action.

Purpose of the Aboriginal Research Meeting

On 23 February 2011 a one day meeting was held to discuss research priorities in sexual health. The main purpose of the Research Meeting was for Aboriginal people and their colleagues to have an opportunity to inform and guide the future direction of research in sexual health and BBVs. In addition it was hoped that:

- Potential research partnerships would be formed between researchers and primary health care service providers; and
- Sexual health and BBV research priorities would be identified.

Meeting Proceedings

Introductory session

The research workshop commenced with a welcome to country by Ingrid Cumming followed by an opening address from Lisa Bastian, Manager of SHBBVP at the DoH; Michael Doyle, WAISHAC Chairperson; and Sharon Bushby, Manager Workforce Development Unit, AHCWA. The agenda for the Research Meeting is available at Appendix Two.

Lisa Bastian spoke on the background to SiREN and the link to this meeting. She talked about the importance of evidence and research to support clinical practice, with the possible outcomes of day being the identification of research priorities from a WA service provider perspective which can feed into the national research agenda. She also discussed the need to build and strengthen partnerships between service providers and researchers.

Michael Doyle spoke on the benefits of research to the Aboriginal community and the importance of Aboriginal researchers being involved in all aspects of research. He stated that, ultimately, research is science and Aboriginal people need to embrace science. Whilst Aboriginal people have, for good reason, been nervous and sceptical of research, it is important that Aboriginal people use research to improve the lives of their community.



Michael Doyle, Sharon Bushby and Lisa Bastian

Sharon Bushby spoke of the ongoing partnership with the SHBBVP and the opportunities this presents to bring positive impacts on Aboriginal health. She then highlighted three areas that were important to consider:

1. Meaningful partnerships – partnerships between research bodies and community controlled organisations are essential if any progress is to be made. Community controlled organisations have the ability to bring the voice of grassroots people and those of greatest risk are those with the smallest voice. Research bodies have knowledge, expertise and ability to influence policy directions and clinical practice. The challenge is how to establish equitable partnerships that are able to effectively utilise the combination of these attributes.
2. Leadership – A good leader is a person who is able to assist those they interact with to reach their full potential. They have an important role in working with a whole industry in partnership with the community to change Aboriginal health. The challenge for leaders in this field is how to assist those they work with or work for to reach their potential.
3. Moving away from the deficit model – Research historically has painted a picture of Aboriginal health that is strongly focused on the deficit model. Future research should promote opportunities for strength based research that celebrates successful ways of working and establish a platform of hope and belief in the ability of the community to bring about change.

Kellie Kwan, Senior Research officer, DoH then provided an overview of the epidemiology of Aboriginal sexually transmitted diseases and blood-borne viruses, which highlighted the very high rates within the Aboriginal population when compared with non-Aboriginal people in Western Australia.

James Ward, Head of the Aboriginal and Torres Strait Islander Research Program, National Centre in HIV Epidemiology and Clinical Research (NCHECR), now the Kirby Institute, gave an overview of the principles which should guide Aboriginal Health Research. He then gave an update on several Aboriginal research projects that the Institute is currently involved in.



James Ward

Lastly, Sherry Saggars spoke about a research study she is involved in called 'Our Lives: Culture, Context and Risk', which is investigating sexual behaviour and sexual decision making in the context of everyday life experience and aspirations of Aboriginal young people under 25 years of age in the Northern Territory, Western Australia and South Australia.

Group Session One

Following the speakers who set the scene for group discussions, the workshop broke into its first group discussion on sexual health and BBV research priorities in WA.

In this session there were six groups formed where the participants were asked to discuss and *identify research sexual health and BBV research priorities in the Aboriginal population in Western Australia*. The following broad priority themes were identified across the six groups:

- Screening and testing, particularly targeting young people
- Workforce training and education
- Program and service issues for target groups of young people, injecting drug users and gay men
- Access to services
- Cultural issues

- Specific infections
- Data related issues
- A variety of single issues which included process issues around the mechanisms for engaging Aboriginal people as the drivers and owners of their own research.

To identify priorities each participant was given four different coloured dots that were given different ratings of importance. People were asked to place them next to the priority they rated as the highest to the least important.



The following lists of issues have been grouped under a priority theme with an indication of the priority as voted by the participants.

Screening and testing particularly targeting young people

This theme had the most ideas for research and was given the highest rating of priority by the participants.

Specific priorities for research raised under this theme included:

- Appropriate models and processes which will increase STI/BBV testing particularly in young people
- Ways of engaging and involving communities in screening and testing
- Components of effective screening programs including cost
- Appropriate use and ethics of involvement of health and non-health personnel in screening and follow up programs
- Effectiveness of point of care STI/BBV testing particularly in remote settings.

Engagement of Aboriginal people in the research process

The issue identified as the second highest priority by participants was that *“people in communities know what they need but support is needed for training and data gathering”*.

The *third* highest priority also was associated with this theme and was related to involving Aboriginal communities in setting the research agenda and priorities for health and community services; particularly the need to include young people in the development and evaluation of appropriate clinical and education services. The need to define research in a way that is acceptable to communities was noted, for example, *“sharing stories to make change”*.

Youth and Access to Services

Youth were also highlighted as the *fourth* priority under the theme of **access to services** with a particular emphasis on the need to better understand what is needed for services to be acceptable to them. Questions were raised such as: how to overcome the ‘shame’ associated with accessing services for sexual health; gaining better youth participation and awareness in programs and services; and how to build up trust and confidence in this group.

There were a range of other ideas for research under the theme ‘youth/injecting drug users and gay men’ but with the predominant focus on young people. These included;

- Effective engagement and active participation by youth in services and programs
- Effective peer based strategies
- The best environment for sex education; is it schools?
- Development and evaluation of models for needle and syringe programs that will engage Aboriginal injecting drug users
- Preferred service models for young people; Aboriginal or non-Aboriginal services?
- Methods for educating gay men in rural areas
- Engaging with men in general.

Workforce

The next highest priority theme was workforce issues. Under this theme the highest priority was *interventions with workers on cultural awareness*. The other issues were:

- Appropriate training for Aboriginal health workers to offer screening and testing
- Required skills, attributes and qualities for health professionals to work effectively with young people and injecting drug users
- Identification of barriers to health providers in making screening part of routine practice.

Other research questions

The following questions and statements relating to the research priorities for Aboriginal communities were raised by the groups but were not prioritised as highly as those noted above. However the statement prioritised highest in the remaining issues was that the *“research framework needs to include translation into practice/policy therefore accessible to people on the ground; a step beyond journal publication”*.

Other issues around the *process of research* included comments relating to the need for research to be sustainable and supportive, with a long term commitment to the community which becomes part of the research and its outcomes. The need for a collaborative environment for discussion and the importance of feeding information from the research back to the community in appropriate and timely ways was highlighted.

The following is a list of other questions that were raised:

- What are the cultural norms when learning or talking about sexual health
- The need for a better understanding of the impact on stigma and discrimination within communities on sexual health and BBVs
- Investigate the reasons for a reduction in gonorrhoea
- What needs to be done to increase treatment uptake for hepatitis C
- The impact of alcohol restrictions on STIs; does it shift the problem from one area to another
- The need for user friendly data and client record systems
- The impact of mining and other industries such as fishing on transmission trends and service provision for STIs and injecting drug use (IDU)
- The need to evaluate what is being done now in clinical practice and contact tracing and identify areas of improvement
- How best to increase awareness of STIs
- How to turn knowledge into action, resulting in behaviour change.



Marion Kickett, Dawn Bessarab and Trish Langdon

Group Session Two

In session two participants were asked to focus on identifying evaluation and audit needs within their health service or region. The following three tasks were asked of participants:

1. Identify evaluation and audit needs in your service or region?
2. What mechanisms are in place to achieve this?
3. How can evaluation/audits add value to service delivery of sexual health/BBV?

The main themes that were identified for evaluation and audit needs within health service or region were:

- Data collection and patient information systems
- Program evaluation
- Health service evaluation
- Health promotion.

Data collection and patient information systems

This theme was consistently mentioned throughout the day and was the highest priority. Specific priorities for further research that were raised in this area included:

- Appropriate entry of data that will ensure better quality data
- Issues and concerns around the current patient information systems
- Sharing of electronic patient records across health services
- Quality of data (entry of data)
- How can data collection systems be modified for better targeted screening/testing?
- Dedicated person needed to ensure data collection is adequate and evaluation occurs.

Health service evaluation

The next theme was health service evaluation and the following issues were raised:

- Do health services have capacity to undertake audits/evaluations?
 - How can capacity be increased?
 - Share successful work in this area –communication
 - Consult with various service providers
- Working together to implement research outcomes
- Evaluation needs to include the impact/value of after hours work of staff e.g. family referrals and community leadership
- Evaluate community engagement
- Evaluate workforce and workforce needs (support Aboriginal staff)

Program evaluation

The evaluation of programs within health services was considered important. Issues raised were:

- Audit tool required that outlines what is required to make a program effective
- Do education programs have an impact on people's behaviour? Is this change sustainable over time?
- Allowing a program budget for evaluation
- Clinical aspects of STI testing and management
- Aspects of comprehensive STI/BBVs program e.g. clinical, health hardware, youth friendly, health education, gender, workforce, education
- Impact evaluation of training run through FPWA etc i.e. has it changed /influenced practice? For how long?
 - Mooditj leaders
 - Nurse training
- Evaluate peer education programs
- Clinical audits which include:
 - Protocols best practice
 - Testing
 - Regular and systematic
 - Adult health checks.

Health Promotion

The need to evaluate health promotion activities was another theme. Issues that related to this theme were:

- Evaluation of all health promotion activities within a health service, particularly impact evaluation
- The length of time before an evaluation is conducted on a program/project
- Health promotion activities and resources.

The second question asked what mechanisms are in place to achieve this? In answering this question groups focused more on the lack of mechanisms and barriers to conducting evaluation and audits in their health service, and identified current gaps.

Current Gaps

- Baseline data must be adequate to be able to work from
- Better reporting and availability of pathology
- Need to be able to compare and collate different data collections systems
- Need standardised high quality data collection systems
- Audit tool/monitoring tool for health promotion program is needed
- Greater administrative support within health services for evaluation and audit

- Qualitative evaluation as a 'feel good' measure but what is the impact short and long term? And how does it translate into behaviour change?
- Need a shared data platform for:
 - Doctors
 - Other clinicians
 - Health promotion staff.

The final question in session two asked *how can evaluation and audits add value to service delivery of sexual health and BBV programs?* In response it was noted that evaluation and audits can:

- Inform knowledge base
- Inform funding applications
- Identify efficacy of program/activities
- Guide clinical practice
- Assist in service responses to improve and enhance service delivery
- Link program indicator/outcomes to funding/reporting; they need to match
- Help to identify the strengths and weaknesses in programs
- Aid self reflection of a service
- Orientate services as to what works best.

Panel Discussion



*Left to Right front row: Dr Sherry Siggers, James Ward, Marion Kickett
Back row: Michael Doyle and Deborah Woods*

The session after lunch was a panel discussion with the theme *Sexual Health Research in Aboriginal Communities*. The five speakers for the session were Marion Kickett, Debbie Woods, James Ward, Sherry Saggars and Michael Doyle.

Marion spoke of being involved in qualitative research as an Aboriginal person. She spoke of the importance of this form of research and the use of 'yarning' to collect data as a legitimate Aboriginal methodology. She spoke about being an Aboriginal researcher and how credibility within her own community was important, including adhering to community protocols. Seeking permission from Aboriginal elders is one very important protocol. Therefore, she interviewed elders from her community and family prior to commencing her PhD. She also had an Aboriginal advisory committee who gave advice on aspects of her research.

Marion spoke of issues of power and told of how after selecting participants for her research she found some that were, or had been, her students. They still saw her as their lecturer which raised her awareness of power relationships in research. This needed to be dealt with prior to conducting the research.

Debbie Woods talked about projects at Geraldton Regional Aboriginal Medical Service (GRAMS) which the local community had developed and implemented based on an action research approach. Debbie discussed the process of development of the *Youth Health Manual; An Education Program for Indigenous Youth*. The Aboriginal young people contributed to the development of the manual by talking about the issues relevant to them. This project was completed with support from students from Curtin University.

James Ward discussed the process of how to conduct research in Aboriginal communities. These should include:

- Identifying the right people
- Being driven by Aboriginal community
- Defining the research question(s)
 - Broad research question need to tailor to communities
 - How will we test it?
 - How will we measure it?
 - What do we want to do?
- Consultation and engagement
- Appropriate methodology
- Identifying how it will influence the policy agenda.

Sherry spoke about the need to have strong team when conducting research to build long term relationships and the importance of using local Aboriginal people to work on research projects and to provide good quality rather than 'quick and dirty' training. She emphasized the need to acknowledge that often Aboriginal people have a different set of skills.

Michael talked of how Aboriginal people have helped to define good ethical research practice in Australia. Researchers need to meet and consult with Aboriginal people and their organisations and priorities for research should be defined by Aboriginal people. Aboriginal involvement in research should not be tokenistic and only involve Aboriginal people at the data collection stage. Aboriginal people need knowledge and information about current issues and consent for research needs to be fully explained to participants and community.

Where to from here?

The final session of the day included recommendations from participants on *where do we go from here?* The following points were made:

1. Access needed to a list of research projects & programs in STIs & BBVs. Possible avenues suggested included:
 - FPWA -Sexual Health Network
 - Monthly network meetings
 - West Australian Centre for Health Promotion Research (WACHPR) support
2. Build relationships between with WACHS (Population Health Units) and ACCHSs to understand community control
3. Build relationships with workforce in DoH
4. Collaborate across the university and primary health care sectors, such as;
 - NCHECR (Kirby Institute) – to work collaboratively in WA on research relating to STIs & BBVs
 - WACHPR– training to provide advice on building evaluation into programs
 - National Drug Research Institute (NDRI)
5. Ensure research conducted in Aboriginal communities is carried out by researchers with relevant experience in working in Aboriginal communities
6. Mentor primary health service providers to enable them to build capacity in research evaluation
7. Build program logic into research process
8. Build evaluation, capacity building and training into contracts
9. Management support for Aboriginal Health Workers to attend Sexual Health & BBV Forums

10. Refine priorities

- Questions
- Methodologies
- Research pathways in WA
- SiREN to facilitate ongoing discussion.

Recommendations

It is recommended that:

1. The priorities and processes identified in this meeting are used by national and state based research agencies and local WA stakeholders to inform future planning in WA Aboriginal sexual health and BBV.
2. Mechanisms for engaging Aboriginal people as the owners and active participants in their own research should be a component of any research carried out with Aboriginal communities in WA.
3. The research priorities relating to access and engagement of youth in sexual health services and programs, and quality improvement in patient management and program evaluation systems are considered in the context of comprehensive and systemic change in health service and program delivery.
4. This report provide a guide to SiREN relating to sexual health and BBV and WA Aboriginal communities.

Conclusion

The Aboriginal Sexual Health and BBV Research Meeting was a significant gathering of health services providers and researchers. The meeting provided a forum in which health service providers and researchers could begin to develop and enhance meaningful partnerships in research and evaluation and where Aboriginal sexual health and blood-borne virus priorities for research were identified through a collaborative process. The meeting was a positive forum in which participants engaged in robust discussion and worked together to agree on issues of importance.

The information from this report will be distributed to all participants and key agencies with an interest in improving sexual health and blood borne service programs and services for Aboriginal people in WA. It will provide information to guide future research both in respect of process and priorities.

The SiREN meeting on 6 May will be an opportunity to bring this information forward for consideration of 'where to from here'.

Appendix One SiREN Terms of Reference

Terms of reference for WA Sexually Health and Blood-borne Viruses Applied Research and Evaluation Network

Partnerships between government, policy makers, service providers, affected communities, researchers and educators are the cornerstone of Australia's public health response to HIV/AIDS, hepatitis C and sexually transmitted infections (STIs). The partnership approach is reflected nationally in the *Sixth National HIV Strategy 2009-2013*, *Second National Sexually Transmissible Infections Strategy 2010-2013*, *Third National Hepatitis C Strategy 2009-2013*, *National Hepatitis B Strategy 2009-13* and *Third National Aboriginal and Torres Strait Islander Sexually Transmissible Infections and Blood-borne Viruses Strategy 2009-2013* and in Western Australia's (WA) HIV, Hepatitis C and STI Models of Care.

The **WA Sexual Health and Blood-borne Virus Applied Research and Evaluation Network (WA SiREN)** is an applied research network that aims to strengthen existing, and create new, partnerships by promoting and facilitating WA-based applied research and evaluation relating to the prevention and control of STIs and blood borne viruses (BBVs).

Applied research and evaluation may include social research or evaluation of non-government organisation and the Department of Health, Western Australia (WA Health) programs, such as, evaluation of the WA Hepatitis C, STI and HIV Actions Plans; an intervention to improve clinical management of chlamydia in general practice; evaluation of mass media campaigns; review of the WA needle and syringe program or a survey of sexual health knowledge in migrants from West Africa.

The objectives of SiREN are to:

1. Identify sexual health and blood-borne virus (BBV) public health research priorities for priority populations within WA as specified in the national STI, hepatitis and HIV strategies; and the WA Model of Care implementation plans. The priority populations include:
 - a. Gay men and other men who have sex with men
 - b. injecting drug users
 - c. young people
 - d. Aboriginal population
 - e. sex workers
 - f. people living with HIV and/or other BBVs
 - g. people within custodial settings
 - h. priority culturally and linguistically diverse populations
 - i. migrants and new refugees
 - j. travellers to and from high prevalence regions
 - k. health professionals

2. Develop partnerships between WA-based researchers, WA Health's Sexual Health and Blood-borne Virus Program and the national centres for sexual health and BBV research.
3. develop and enhance partnerships between government and non-government service providers, researchers and policy makers working towards the prevention and control of STIs and BBVs
4. Enhance the capacity of the WA workforce to translate research findings into policy and research findings into practice.
5. contribute to an evidence-base to inform WA Health's policy and decision making for the prevention and control of STIs and BBVs within WA
6. Contribute to the national sexual health and BBV research agenda.

SiREN does not aim to address sexual health issues (such as sexual assault, infertility, gender identity, sexual dysfunction) that are not directly related to the public health priorities detailed in the aforementioned national strategies and model of care implementation plans.

Operations

SiREN is supported by WA Health's Sexual Health and Blood-borne Virus Program (SHBBVP). SHBBVP's mission is to coordinate and plan the public health response to HIV/AIDS, hepatitis B and C, and STIs within WA.

Within this role, SHBBVP will:

1. Establish a SiREN web-page on WA Health's web-site to promote the aim, objectives and function of SiREN.
2. Coordinate and provide secretariat support for an annual round table meeting to identify research questions and gaps in the evidence base to inform policy decisions. This information will be published on WA Health's SiREN web-page.
3. Coordinate and provide secretariat for an annual symposium focused on public health applied research and evaluation on the prevention and control of STIs and BBVs.
4. Facilitate formal linkage between SiREN and the WA Committee for BBVs and STIs.
5. Promote SiREN at the WA Sexual Health and BBV Quarterly Forums and other forums and among service providers.
6. Provide two grants each year for post-graduate students undertaking research projects that address the identified priority populations and aim and objectives of SiREN. The grants will be advertised annually and funded on an on-going basis.
7. Distribute notices and/or relevant reports, as arising and on request, to the SiREN email distribution list.

SHBBVP is regularly called upon to contribute to national or cross-jurisdictional research projects, along with other states and territories. Occasionally, SHBBVP will tender or commission research or an evaluation to meet a specific requirement for program or service planning. However, SHBBVP is not a primary source of funding for research projects identified by SiREN.

Researchers are advised to apply to standard funding sources such as the National Health and Medical Research Council and ARC Linkage Grants for research funding.

Governance

The aim of the SiREN Working Group is to provide a forum for the development and support of SiREN and to plan the inaugural SiREN symposium for 2011.

The SiREN working group will include a maximum of 8 representatives from:

- Non-government organisations
- WA-based universities
- WA Health

Election of these 8 working group members will take place at the 2010 Annual Research Round Table meeting.

Ex-officio members will include representatives from the National Centre in HIV Social Research, National Centre in HIV Epidemiology and Clinical Research and Australian Research Centre in Sex, Health and Society. The secretariat, also an ex-officio member, will be provided by the Sexual Health and Blood-borne Virus Program.

Specific working groups, that may include private consultants co-opted for specific events or projects, may be established as required.

SiREN working group members are responsible for the following tasks:

1. participate in the annual research round table meeting and plan and organise the annual symposium
2. monitor the purpose and function of the research and evaluation network
3. review the network's term of reference after 12-months initially and at regular intervals, as determined by the network members, thereafter
4. assume tasks as delegated by the Chairperson and Deputy Chairperson.

SiREN Chairperson and Deputy Chairperson will be elected by network members at the annual research round table meetings.

The elected Chairperson and Deputy Chairperson will be required to assume duties for up to but not exceeding a 2-year term. Duties will include:

1. chair the annual round table meetings and symposium.
2. review and approve all meeting documents and public relations drafted by the secretariat on behalf of SiREN.
3. represent or assign a delegate to represent SiREN at relevant meetings or committees, such as the WA Committee for BBVs and STIs and the Infections and Immunology Health Network research forums
4. attend or assign a delegate to attend and/or provide an update at the Sexual Health and BBV Quarterly Forum, as requested.

NOTE: WA Health will appoint an interim Chairperson and Deputy Chairperson for an initial 6-month period, while SiREN is being established. Thereafter, it will be the responsibility of members to elect the office bearers. The secretariat will not participate in the election of the Chairperson or Deputy Chairperson.

Appendix Two: Agenda

Aboriginal Research Meeting February 23rd

8.15am – 9.00am	Registration: Arrival Tea & Coffee
9.00am – 9.15am	Welcome to Country
9.15am – 9.30am	Opening address <i>Lisa Bastian SHBBVP, Sharon Bushby AHCWA, Michael Doyle NDRI</i>
9.30am – 9.45am	House Keeping Introduction: Overview of the Agenda, Purpose and aims of the day & Ground Rules
9.45am – 10.30am	Setting the Scene for WA, Showcase of National Research Projects & WA Research <i>Kellie Kwan (SHBBVP) , James Ward (NCHECR) & Sherry Saggars (NDRI)</i>
10.30am – 10.45am	Morning Tea
10.45am – 11.30am	Session 1: Sexual Health and BBV Research priorities Group Discussion
Feedback from Groups	
11.30am – 12.15pm	Session 2: Identifying evaluation and audit needs Group Discussion
Feedback from Groups	
12.15pm – 1.00pm	Lunch
1.00pm – 1.40pm	Panel Discussion: INSIGHT Sexual Health Research in Aboriginal Communities <i>Marion Kickett, James Ward, Debbie Woods, Sherry Saggars & Michael Doyle</i>
1.40pm – 1.50pm	Sexual Health & Blood Borne Virus Program (SHBBVP) <i>Sharon Clews</i>
1.50pm – 2.45pm	Session 3: Enablers and barriers in research participation Group Discussion
Feedback from Groups	
2.45pm – 3.00pm	Afternoon Tea
3.00pm – 3.30pm	Where to from here? <i>Building research partnerships, Collaborations and SIREN</i>
3.30pm – 3.45pm	Feedback
3.45pm – 4.00pm	Evaluation: Close

Appendix Three: List of participants

Sharon Bushby	Aboriginal Health Council of WA
Sue Cristopoulos	Aboriginal Health Council of WA
Katherine Dann	Aboriginal Health Council of WA
Rekisha Eades	Aboriginal Health Council of WA
Tash Nannup	Aboriginal Health Council of WA
Neil Thomson	Australian Indigenous HealthInfoNet
Chris Johnston	Bega Garnbirringu Health Service
Corrina Ryder	Bega Garnbirringu Health Service
Christopher Bin Kali	Broome Regional Aboriginal Medical Service
Troy Edwards	Broome Regional Aboriginal Medical Service
Ganthi Kuppusamy	Carnarvon Medical Service Aboriginal Corporation
Aileen Mitchell	Carnarvon Medical Service Aboriginal Corporation
Heath Greville	Centre for International Health
Michael Borenstein	Centre for Sexual Health
Robyn Davis	Derbarl Yerrigan Health Service
Matt Tilley	Department of Sexology
Stanley Ozies	Derby Aboriginal Health Service
Ursula Swan	Drug & Alcohol Office
Kellie Kwan	Epidemiology & Surveillance Program
Lewis Marshall	Fremantle Hospital
Debbie Woods	Geraldton Regional Aboriginal Medical Service
Rae Peel	Geraldton Regional Aboriginal Medical Service
Kay Morton	FPWA Sexual Health Services
Charmaine Dershow	FPWA Sexual Health Services
Lyn Tolliday	Hepatitis WA
Lynda O'Connor	Mawarnkarra Health Service
James Ward	National Centre in HIV Epidemiology and Clinical Research
Rebecca Guy	National Centre in HIV Epidemiology and Clinical Research
Sherry Saggars	National Drug Research Institute
Ann Tangey	Ngaanyatjarra Health Service
Susan Bray	Ngaanyatjarra Health Service


Veronica Hoad	North Metro-Public Health and Ambulatory Care
Sue Parker	Puntukurnu Aboriginal Medical Service
Lisa Bastian	Sexual Health & Blood-borne Virus Program
Jude Bevan	Sexual Health & Blood-borne Virus Program
Sharon Clews	Sexual Health & Blood-borne Virus Program
Trinity Fredericks	Sexual Health & Blood-borne Virus Program
Kathryn Kerry	Sexual Health & Blood-borne Virus Program
Suzanne Mc Evoy	South Metro Area Health Service
Trish Langdon	WA Aids Council
Keile Robinson	WACHS Goldfields Population Health
Claire Mutton	WACHS Goldfields Population Health
Naru Pal	WACHS South West
Phillipa Rose	WACHS Pilbara Population Health
Jane Gilmour	WACHS Wheatbelt Aboriginal Health Service
Margaret Drummond	Yura Yungi Aboriginal Medical Service
Angela McDonald	Yura Yungi Aboriginal Medical Service

Appendix Four: Presentations


Kellie Kwan –WA Aboriginal Sexual Health and BBV Research Meeting Epidemiology Update

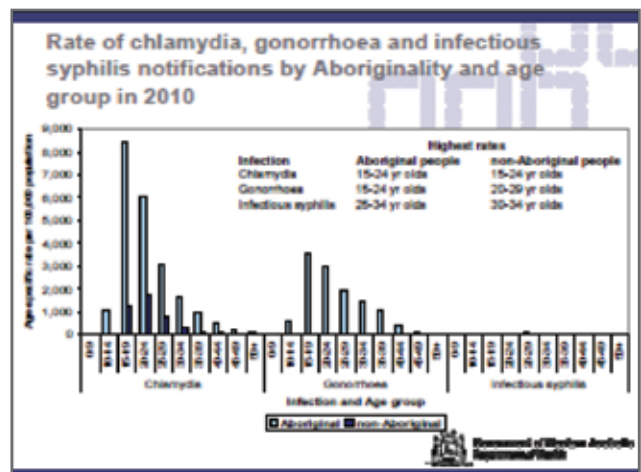
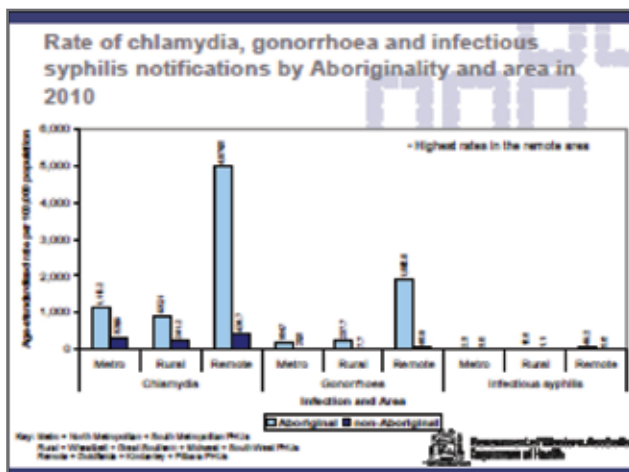
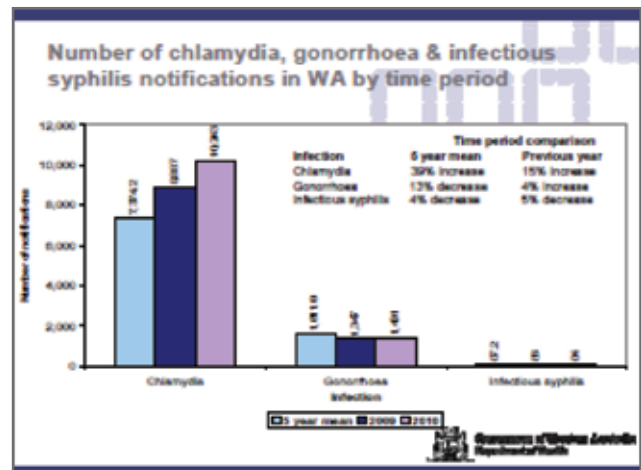
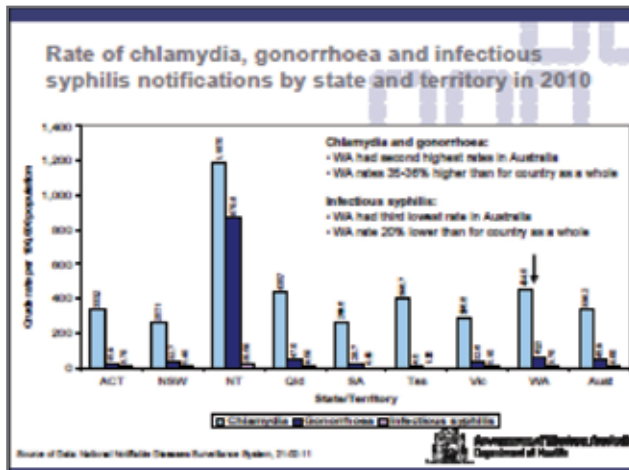
WA Aboriginal Sexual Health & Blood-Borne Virus Research Meeting: Epidemiology Update

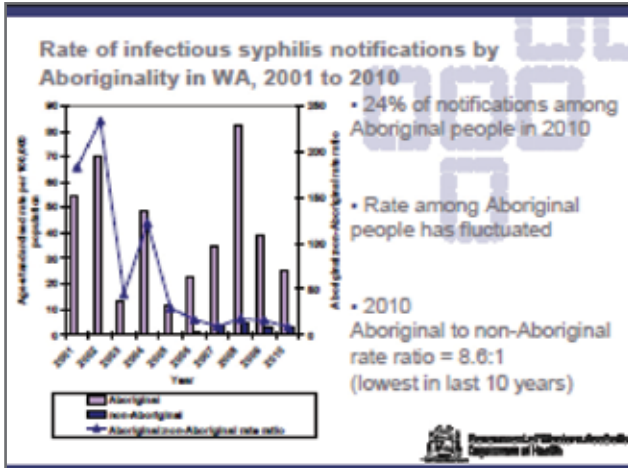
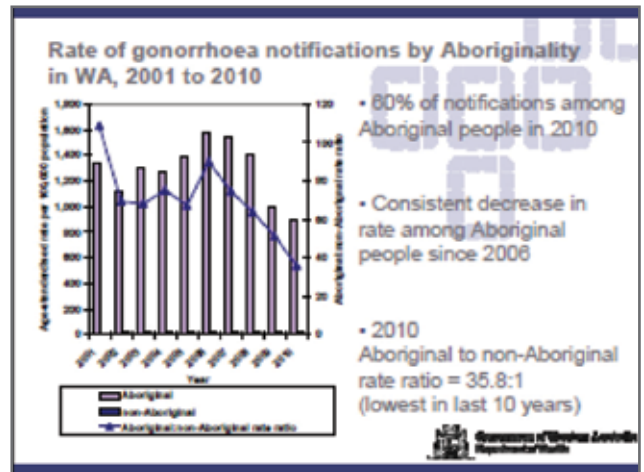
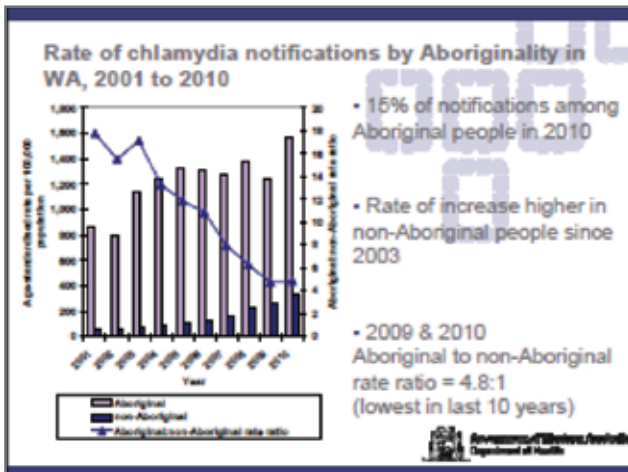
Kellie Kwan
Epidemiology and Surveillance Program
Department of Health

Delivering a Healthy WA. 

Sexually Transmitted Infections in WA

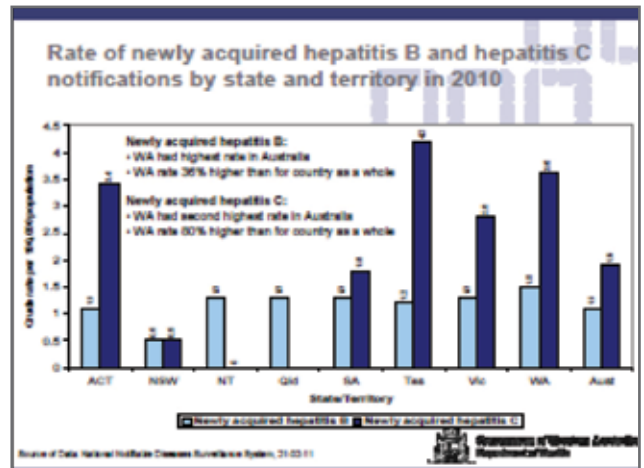
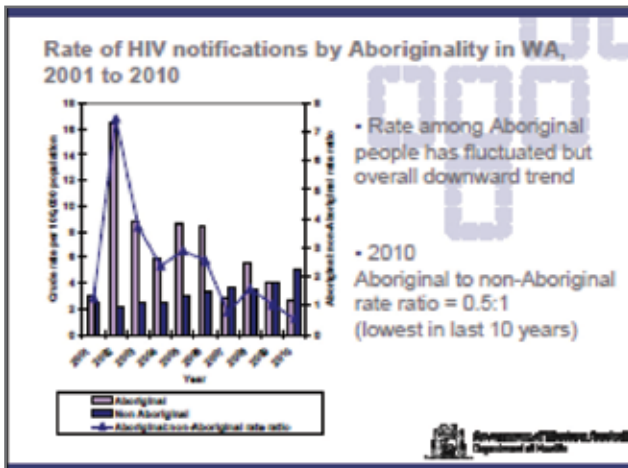


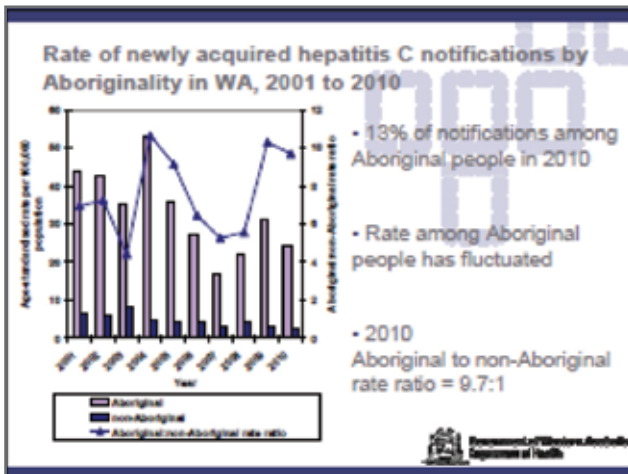




Blood-borne Viruses in WA

Government of Western Australia Department of Health





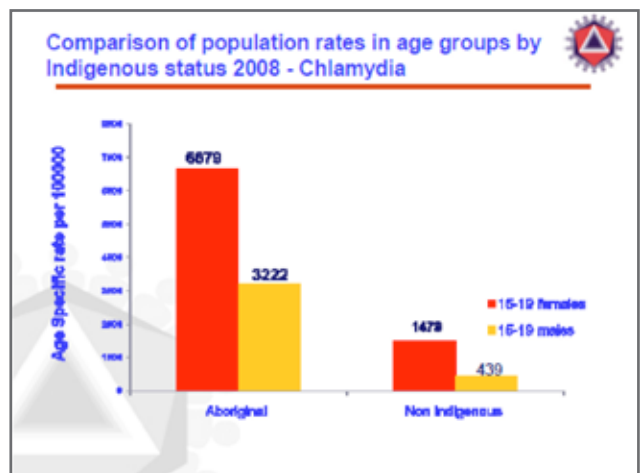
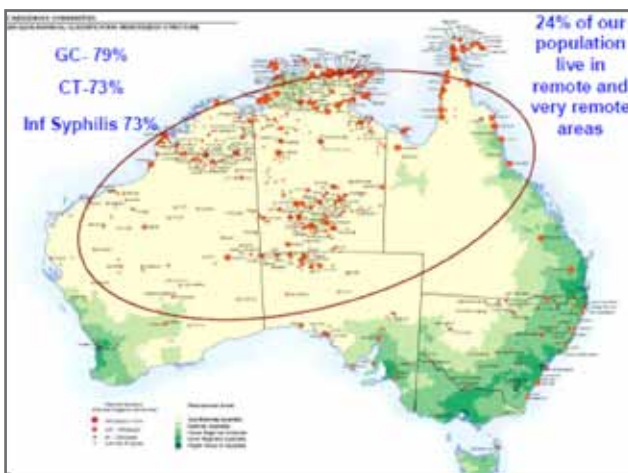
James Ward – Aboriginal STI and BBV Research

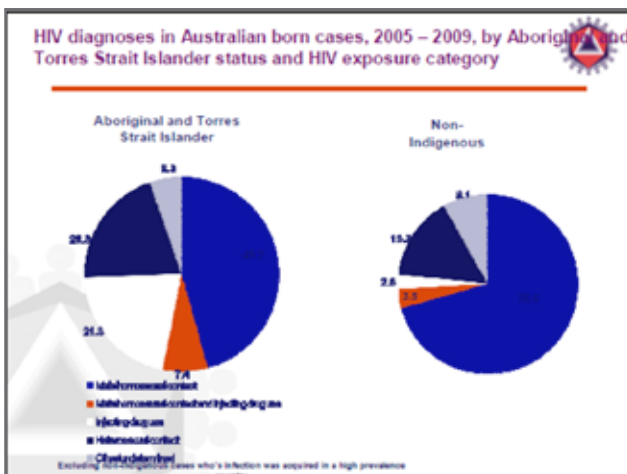
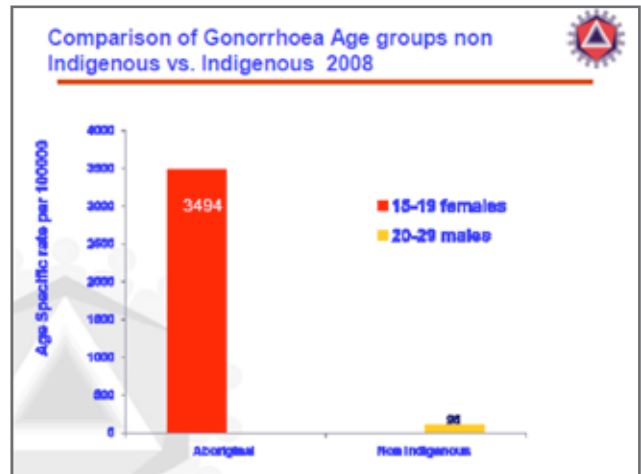
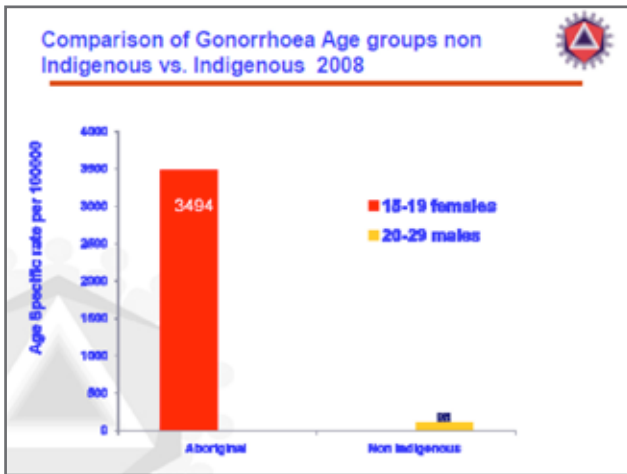
Aboriginal STI and BBV Research

James Ward
 Head Aboriginal and Torres Strait Islander Health Research Program
 National Centre in HIV Epidemiology and Clinical Research UNSW

What difference will research make anyway.....

-when we already know what the problems are in our communities?





- ### Why Communities Resist Participating in Research
- Research is historically a "dirty word"
 - Feeling researched to death
 - Academic interest driven vs. community relevance
 - Capacity to participate meaningfully in research
 - Treated as a convenient data source
 - "Helicopter" or Fly in fly out Research methodologies
 - Research jargon
 - Tension between program \$\$ and research \$\$

- ### What constitutes good Aboriginal Health Research?
- NHMRC say:
 - **Capacity building**- are we building the capacity of Aboriginal people and communities
 - **Community engagement** in planning and will be involved at all stages of research
 - **Sustainable**- after the research is completed what will be left...
 - **Priority**- is this a priority in Aboriginal health, for the community involved
 - **Benefit**- will the answers to this research benefit the community?

- ### Indigenous Research Reform Agenda (IRRA) Ref: Lowitja Institute
- **Involvement of Aboriginal communities** in the design, execution and evaluation of research; including roles for Aboriginal community controlled organisations
 - **Ongoing consultation/negotiation and surveillance** with Indigenous organisations throughout the life of a research project;
 - **ownership and control of research findings** by participating Aboriginal communities/orgs;
 - **processes to determine research priorities and benefit** to the Indigenous communities involved;

Indigenous Research Reform Agenda (IRRA) Ref: Lowitja Institute



- determination of **ethical processes** for the conduct of research;
- transformation of research practices **from 'investigator-driven' to an adoption of a needs-based approach to research;**
- **linkage between research and community development and social change;**
- the adoption of effective mechanisms for the **dissemination and transfer of research findings**

Aboriginal Human Research Ethics Committees



- **Personnel**-Are the right Aboriginal and non Aboriginal people involved in proposed research, ideally led by Aboriginal people
- **Respect** -Acknowledgement of individual and collective contribution, interests and aspirations; Acknowledgement and affirmation of the rights to have different values, norms and aspirations.
- **Equality** -Acknowledgement that all partners are equal, regardless that they may be different; The distribution of benefit;

Other written principles of good Indigenous research



Responsibility -To do no harm to individuals or communities, or to those things that they value; Establishment of processes to ensure researcher accountability to individuals and communities, particularly with respect to cultural and social dimensions of community life.

Survival & Protection -Protection against assimilation, integration and/or subjugation of values; Respect for social cohesion; Involvement that does not diminish the right to assertion or enjoyment of cultural distinctiveness.

Spirit & Integrity -Demonstration of credibility in intent and process; An approach that does not impede upon the richness and integrity of cultural inheritance

Principles of Research in Aboriginal and Torres Strait Islander communities



- Where possible **ensure research is embedded in service delivery** and have potential to make improvements in population health and/or service delivery.

Benefits of Aboriginal Self-Determination in Research



- Helps rebuild community trust
- Increases participation rates
- Improves quality and accuracy of research
 - Promotes Indigenous analyses and perspectives
 - Produces more relevant and useful results
- Contributes to community empowerment, self-determination and healing activities
- Encourages meaningful capacity building

Potential of research in Aboriginal Health?



- "Evidence based decision making"- growing recognition that traditional research methods have failed to address the complex health needs and disparities common in Aboriginal health
- Responsive to issues- communities are demanding research address their local needs
- Community voices can lead to sound scientific research which can influence policy and social change

Potential of research in Aboriginal Health?

- Provides resources to sector that may be difficult otherwise
- Can leave sustainable products post research
- Everyone learns something- potential to build greater trust between researchers and communities
- Change is an inevitable outcome – small or large

Current NCHECR Aboriginal Health Research

- **Surveillance projects**
 - Networks of ACCHS and other services combining data to enable benchmarking, understanding of sector, providing context to passive surveillance outcome of improving service delivery

Health Service research projects

- **STRIVE- clustered community randomised trial...**
- to test whether a Sexual Health Quality Improvement Program can achieve best practice targets in clinical sexual health service delivery, and if so...
- Can it reduce community STI prevalence?
- Involving 68 remote communities NT WA and FNQ

Health Service research projects

- **REACCH- Research in 5 urban ACCHS**
- Outcomes to influence clinical guidelines in STIs and BBVs for this sector
- Projects include- antenatal, evaluations, baseline data extraction and CQI projects, youth projects
- Other CQI Projects
- Evaluations of interventions CTG NPA

Health Service Research Projects

- Trial of Point of Care Tests in remote communities for STIs (WA and QLD)
- Reduce testing results and treatment times and potentially increase contacts treated
- Test feasibility and acceptability of POC tests in high prevalence settings
- Chlamydia and gonorrhoea

First national study of young Indigenous people: Sexual health and relationships

- ARC Linkage Grant
- Cross sectional survey – cultural events
- Survey administered by PDAs
 - 5 consecutive events in each State/Territory 2011-2013
 - Sexual health and BBV knowledge
 - Risk Behaviours
 - Access to health services
 - Aim of 4000-5000 surveys across jurisdictions
 - 5/40 events completed (500 surveys)

Other Research Projects

- Data Linkage projects NSW and potentially WA
- IDU Survey QLD
- Hepatitis B Qualitative research project Clinicians TSI
- Modelling Projects STIs and clinical care and HIV interaction IDU and STIs

Summary

- We have a long way to go in addressing complex health needs of Aboriginal people
- Principles of good Aboriginal Health research are well documented
- Potential for further research will remain
- Challenge is what is feasible and acceptable and do-able for communities.

Contact Details

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Dr Sherry Siggers – Our Lives: Culture, context and risk; socio-cultural influences on the sexual health of Indigenous young people

Our lives : Culture, context and risk; socio-cultural influences on the sexual health of Indigenous young people.


Australian Research Council
Linkage Grant – 2009-2013

Aims

- To investigate sexual behaviour and sexual decision making in the context of the everyday life experience and aspirations of Indigenous young people under 25 in the NT, WA and SA;
- Understand young people's decisions about their sexual health and required health services; and
- To increase the capacity of service providers to deliver effective services for young people.

Background 


- Indigenous youth are the target of many interventions to address their sexual health.
- But, there is little evidence for improvement.
- New approach is needed to obtain a detailed understanding of the lives of Indigenous young people.
- Requires significant input of young people themselves.

Outcomes 

- Evidence base from which interventions can be developed
- Appropriate ways to engage with young Indigenous people about their sexuality
- Increasing knowledge about youth perceptions of sexuality, relationships and risk
- Development of appropriate resources


Chief investigators 

- **Menzies School of Health Research (CDU)**
 - Dr Kate Senior
 - Associate Professor Tricia Nagel
 - Dr Richard Chenhall
- **National Drug Research Institute (Curtin University)**
 - Professor Sherry Siggers
- **Latrobe University**
 - Professor Marion Pitts
- **The University of Western Australia**
 - Professor Victoria Burbank


Communities involved 

- Case study approach, with one long term ethnographic study
- Communities are yet to be determined.

Will include: 5 communities
 1 top end NT
 1 central Australia
 Alice Springs (possible location of long term study)
 1 South Australia
 1 Western Australia


Why Alice Springs? 

- Strong support and investment in the project from Congress.
- Interested in the relationships between Indigenous and non-Indigenous youth.
- Interested in young people who move between remote and urban settings.
- Interested in the tensions that arise between traditional values and an emerging globalised youth culture.

Approach- qualitative 


- Ethnographic approach- contextualised in depth understanding of motivations which guide behaviour.
- Observations, in depth interviews, focus groups with key informants.
- Participatory action framework

Youth friendly methods




- Trialled through the "Risky Business" project run by Save the Children in Kununurra, WA.
- Interactive methods
- Group focussed
- Encouraged discussion

Body Mapping




" you can get sickness when boys touch girls. Some boys you have to run away from because they grab you"


(Kununurra participant aged 14)




Risk mapping



- "Most of the problems are where the drunk mob are. They are always hanging around the pub. That's where the trouble is. The council should close up the pub early or shut it all up" Halls Creek participant aged 16
- We go there. But sometimes we get scared because the boys might come and grab us. So lots of times we go here instead or walk where there are lights" Kununurra participant aged 13




Approach- quantitative



- Survey- peer interview approach, using the SEIQOI. "What things are important in young peoples' lives"
- Clinical file audit to assess number of people accessing the service.
- STI data from service provider data bases will provide base line and ongoing contextual information.

Overview of project



Four parts:

- Part 1: set up- consultation and establishment
- Part 2: An in depth study of one community project
- Part 3: medium-depth case studies of 4 communities
- Part 4: Development of a series of resources and responses applicable to the NT, WA and SA.

Current status




- Research has begun in Alice Springs (January 2011).
- PhD student will begin field work in Borroloola in March 2011.
- Ongoing discussions about possible WA and SA sites.
- Ethics applications for WA and SA

Sharon Clews – WA Sexual Health and BBV Program Overview


WA Sexual Health and Blood Borne Virus Program Overview

Sharon Clews – Policy Officer
Sexual Health and Blood Borne Virus Program (SHBBVP)
Department of Health, WA
February 2011

Delivering a Healthy WA 

SHBBV Program Responsibilities

- Develop and implement statewide policy
- Fund NGO and government services and programs to build capacity and improve access to services
- Provide and fund education and training of health and non health professionals

22 March 2011 Slide 2 


Program Responsibilities (cont.)

- Manage various BBV and sexual health programs including the Aboriginal Sexual Health and NSP Programs
- Develop and support campaigns and health promotion strategies including resource development
- Support improvement of quality of evaluation, data collection analysis and dissemination and research

22 March 2011 Slide 3 

Examples of SHBBVP Activities Policy Development

- Models of Care
 - STI
 - HIV,
 - Hepatitis B & C
- 2nd WA Aboriginal Sexual Health and Blood Borne Strategy 2010-2014

22 March 2011 Slide 4 


Examples of SHBBVP Activities Service and program funding

- For programs and services that:
 - Conduct sexual health promotion, STI and BBV prevention programs for general and high risk groups
 - Improve access to prevention and treatment services e.g.
 - STI Clinical management support through services of Dr Janet Knox conducting audits within ACCHOS
 - Additional staff for clinical and prevention services
 - Specific programs e.g. David Wirrpanda, FPWA IEP, RUAH.
 - Limited research funding support

22 March 2011 Slide 5 

Examples of SHBBVP Activities Individual and Agency Grants

- Provide Organisation Development Grants to improve or develop sexual health or blood borne virus related workforce training or services.
- Bursaries, scholarships and clinical placements to assist individuals to attend sexual health & blood borne virus (BBV) related training and education

22 March 2011 Slide 6 

Examples of SHBBV Program Activities

STI & BBV Quarterly Forum


- Facilitation of a quarterly forum on sexual health, Sexually Transmitted Infections (STI) and BBV
- Participants include clinical, health promotion, disease control, education and research professionals from a wide range of government, non government and private organisations.
- The forum is designed to provide STI and BBV updates, professional development and networking opportunities.

22 March 2011 Slide 7 

Examples of SHBBV Program Activities

Clinical and Prevention Resources


- Silver Booklet <http://silverbook.health.wa.gov.au/>
- Sexual Health Orientation Package for Endemic Regions 2nd Edition
- and other clinical and health promotion resources including:
- Aboriginal specific resources

22 March 2011 Slide 8 

Examples of SHBBV Program Activities

Support for Workforce in Regions

- Ongoing support for the Regional Sexual Health Teams in STI endemic regions of WA
- Provision of access to professional development and training
- Monthly teleconferences and ongoing support
- Bi-annual face-to-face meetings
- Provision of quarterly testing data for each endemic region

22 March 2011 Slide 9 

WA Sexual Health and Blood-borne Virus Applied Research and Evaluation Network (WA SiREN)

- Creating new partnerships by promoting and facilitating WA-based applied research and evaluation relating to the prevention and control of Sexually Transmitted Infections (STIs) and Blood Borne Viruses (BBVs)
- **WA SiREN Research Symposium - Friday 6th May 2011 'Found or Lost in Translation' – Putting research into practice**

22 March 2011 Slide 10 

Contact

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22 March 2011 Slide 11 

Appendix Five: Feedback from Evaluations

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
The Research Meeting lived up to my expectations			3	25	5
The event increased my understanding of the Sexual Health and Blood -borne Virus issues		3	12	9	9
Sufficient time was allocated to each presentation		4	1	24	4
The presentations were informative				26	7
I was given the opportunity to actively contribute during the Research Meeting			2	18	13
The venue was satisfactory			1	18	14
Parking was accessible		1	14	7	3
The catering was satisfactory		1	6	17	9
Session 1: Sexual Health and BBV Research Priorities					
Sufficient time was allocated to Session	1	5	1	23	3
The group discussion was useful and productive			1	26	9

Session 2: Identifying evaluation and audit needs					
Sufficient time was allocated to Session 2		2	4	24	3
The group discussion was useful and productive		1	2	25	4
Insight Forum: Sexual Health Research in Aboriginal Communities					
Sufficient time was allocated for the discussion		2	4	27	5
The discussion was informative and useful		1	2	25	4
Enablers and barriers in research participation					
Sufficient time was allocated to Session 3	1	1	7	8	1
The group discussion was useful and productive		1	3	16	4

What was most valuable about the Research Meeting?

- Range of participants was excellent
- Hearing the perspective of the sector and priorities
- Networking
- Exposure to different perspectives
- Seeing how different groups had common areas of concern
- Understanding other passion for research
- Participants having input
- Learning about research priorities from each region
- The discussions and hearing peoples experience
- Panel discussions
- Hearing current research projects
- meeting with health professionals in the region
- Research priorities
- Cooperation from staff from ACCHOs and Government organisations
- Good to meet others working in this field

- Discussions and interacting
- Different ideas
- Views from different experts
- Facilitators were good
- People attending were a good mix and were able to contribute meaningfully
- Group discussions
- Beginning to discuss the issues specific to research
- Evaluation relating to Aboriginal sexual health and BBV programs
- Researchers, practitioners and Managers in the same room
- Hearing from Aboriginal view points and gaining form Aboriginal expertise in research
- James talk about steps for completing research and listening to Debs programs that provided capacity building for community
- James Ward information on projects that are happening
- I think priorities were made and I look forward to further updates
- Cross organisation discussion

What was least valuable about the Research Meeting?

- Not enough time developing research agenda
- Not enough time in group discussion
- The statistics
- Lunch
- There was some confusion with some health workers regarding audits and evaluation
- Need a explanation prior to group discussion
- I think research and evaluation were confused they really are too different things
- Topics or possible research topics
- Research ideas not long enough
- Not enough clarity of difference between research and evaluation/audits
- It would have been better to break up into regional /remote areas as Hepatitis C was a priority
- Combining the audit and the research question into the same dot prioritising became confusing
- The smell in the room
- Perhaps lost a bit of steam towards the end but this was attended to
- Agenda of particular individuals overtaking discussion
- Afternoon tea

Was anything missed in the discussions or in the overall agenda?

- Themes of research e.g. Health service research, qualitative
- Types of research
- Explanation of research methodology
- Focused research questions
- Example of failed research or inappropriate research done in the past would be good
- We need to keep the emphasis on all this being meaningful to communities (Aboriginal) –all research, all program evaluation and to workers on the ground
- Perhaps identifying research training needs for services/ workers
- Youth consultation

Any comments/suggestions for future network events?

- Video conferencing
- Presentation of Success stories
- Networking and clarifying research priorities
- Great planning would be good to have more Aboriginal sexual health workers
- Share list of participants so we can continue networking
- This should be a regular event
- Sharing best practice examples of small/ medium /large projects
- Training in program logic/evaluation
- Research proposals should only be approved/tried where there is no duplication
- Researchers must work in close collaboration with health services where appropriate
- Well done on getting this off the ground its invaluable
- Keep them coming
- Involve more Aboriginal workers and on the ground health workers
- The butcher's paper comment maybe should have been clustered to make the placing of dots more meaningful to participants. Besides from that well done everyone
- Regular V/C on upcoming opportunities for research projects
- Bar research institutes



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in alternative formats on request for
a person with a disability.