Indigenous Health at the Doherty Institute

2017 Report

Doherty Institute

THE UNIVERSITY OF MELBOURNE

The Royal Melbourne Hospital

A joint venture between The University of Melbourne and The Royal Melbourne Hospital

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Contents

Foreword

With its mission to prevent, treat and cure infectious diseases, the health of Australia's first people is of critical importance to the team at the Peter Doherty Institute for Infection and Immunity. We aim to play an increasingly meaningful role in reducing the unacceptable burden of infectious disease on Aboriginal and Torres Strait Islander Australians, and we are enthusiastic to train the next generation of exceptional Indigenous researchers specialising in Infection and Immunity.

On 6 September 2017, the Doherty Institute hosted its inaugural Indigenous Health at the Doherty Institute forum and dinner. Our objectives were to:

1. Showcase and raise awareness of Aboriginal and Torres Strait Islander health research programs at the Doherty Institute.
2. Deepen our conversations with leaders in Indigenous health about how we can best partner with their communities.
3. Build on the growing community of practice advancing Indigenous health in the Melbourne Biomedical Precinct.

We invited leaders in Aboriginal and Torres Strait Islander health from across Australia to share their insights on how we can grow our capacity as an Institute.

'The Doherty Institute is grateful to all who participated in this forum, for their intellect and generosity of spirit.'

What transpired was an incredibly meaningful day that will shape the practice of our Institute in the years ahead.

We'll keep listening, we'll strive to build and maintain enduring relationships, we'll encourage communities to set the agenda and we'll focus on delivering impact – not just conducting research.

Proceedings and key learnings are summarised on the following pages so our Institute and others can draw on them for years to come. The insights are relevant to all researchers wishing to undertake research that aims to improve health outcomes for Aboriginal and Torres Strait Islander people. But more than this, the insights shared are simply good practice for any researcher wishing to collaborate beyond their institution.

The Doherty Institute is grateful to all who participated in this forum, for their intellect and generosity of spirit, and for all who made time to attend this inaugural forum.

(L-R) Professor Adrian Miller, Charles Darwin University; Professor Katherine Kedzierska, Professor Jodie McVernon, Associate Professor Steven Tong, Doherty Institute

Guiding principles that will shape our practice

We're grateful to **Professors Adrian Miller** and **Marcia Langton** for sharing the recent history of Aboriginal and Torres Strait Islander people with us. We'll be respectful of the history and context of the communities with whom we work.

As **Adrian Miller** has encouraged us: we will not only build, but strive to maintain relationships with communities and leaders in health. We'll undertake research 'with' rather than 'on' communities.

We'll work with communities in partnership. **Professor Shaun Ewen** talked to us about place-based research and the communities the University works with: Melbourne, Goulburn Valley, East Arnhem and Cape York.

We'll listen to the health needs of communities to ensure we're undertaking the most critical research.

We'll strive to ensure our research translates into clear and immediate benefits. **Dr Lucas de Toca** shared with us the way in which Miwatj Health assesses research proposals. Within this community, research is not progressed unless it is deemed there is an immediate benefit to the community, not just a contribution to the 'body of knowledge'.

We will also work with **Leila Smith** and understand how we integrate the Lowitja Institute's Impact Assessment Tool as a framework for our work – letting their principles further guide the development of our research projects.

We look forward to working with **Louise Lyons** and the team at VACCHO to explore how we might contribute as they develop their research priorities with both local urban and remote communities.

We shall be mindful of the enormous burden, described by **Marcia Langton**, on researchers and the need for their institutions to undertake capability building work: dividing responsibilities so that researchers can benefit from long-standing relationships. It's up to institutions to help overcome some of the hurdles so researchers have a greater chance of success and impact – 'learning from scale', as **Lucas de Toca** described.

The Doherty Institute is fortunate to have strong Aboriginal and Torres Strait Islander leadership in the University and we will work closely with this leadership group, so that our researchers can benefit from relationships developed over generations.

We understand the need to structure our PhD scholarship program for Aboriginal and Torres Strait Islander people in a way that it is accessible and supportive and that sets up candidates for success – with supportive career paths available.

As **Associate Professor Steven Tong** summarised, these are great lessons, not only for our work with Aboriginal and Torres Strait Islander people but great principles for all research work.

Professor Shaun Ewen, University of Melbourne

Program

Wednesday 30th August
2-30 pm - 5:30 pm

The Doherty Institute

792 Elizabeth Street, Melbourne 3010

2:30pm	**Acknowledgement of Country by Professor Marcia Langton**
2:35pm	**Opening by Professor Sharon Lewin**
2:40pm	**Presentations by Doherty Researchers** Professor Katherine Kedzierska - Influenza Associate Professor Steven Tong - Hepatitis B Professor Damian Purcell - HTLV1 in Australia Professor Jodie McVernon - Skin infections
3:45pm	**Developing networks and partnerships** Professor Adrian Miller (*Charles Darwin University*) Professor Shaun Ewen (*University of Melbourne*) Dr Lucas de Toca (*Miwatj Health*)
4:40pm	**Panel discussion: A conversation with leaders in Indigenous health** Professor Adrian Miller (*Charles Darwin University*) Professor Beverley Biggs (*Doherty Institute*) Leila Smith (*Lowitja Institute*) Louise Lyons (*VACHHO*) Dr Lucas de Toca (*Miwatj Health*) Professor Marcia Langton (*University of Melbourne*) Chairperson: Associate Professor Steven Tong (*Doherty Institute*)
5:30pm	**Summary by Indigenous Health Cross-Cutting Discipline leaders** Professor Katherine Kedzierska and Associate Professor Steven Tong
5:35pm	**Forum drinks**
6:00pm	**Conclude**

Opening speech

Delivered by **Professor Sharon Lewin**, Director of the Doherty Institute

Wominjeka – Welcome in the language of the Wurundjeri people of the Kulin Nations, the custodians of this land where we meet. I pay my respects to elders past and present and welcome all Indigenous people here today.

Welcome to each of you here today. It's quite an extraordinary collection of leaders in Aboriginal and Torres Strait Islander health from across the country.

We are very grateful that you have made the time to be here to share your knowledge to help us grow the capacity of this Institute to play a more meaningful role achieving better health outcomes for Aboriginal and Torres Strait Islander Australians.

Let me rewind a moment to explain how we came to be here.

'What will this Institute do to improve the health of Aboriginal people?'

In September 2014, as the Doherty Institute was formally opened, Aunty Joy Murphy Wandin visited us for the first time and welcomed us to the land where her people, the Wurundjeri people, have lived for time immemorial.

But wisely, the Welcome came with a challenge to Peter Doherty – 'What will this Institute do to improve the health of Aboriginal people?'

Aunty – we heard you and we are responding.

Each of us in this room knows only too well that Australia's First People carry an unacceptable burden of infectious diseases. White colonisation of this land brought with it myriad challenges for Aboriginal Australians, not the least of which were the raft of infectious diseases still wreaking havoc today.

What brings us together today is a mutual desire to explore how we, the researchers and clinicians at the Doherty Institute, as well as our colleagues in the University, Royal Melbourne Hospital and across this Melbourne Biomedical Precinct, can work together with Indigenous communities to deliver better health outcomes.

To give some context to the Doherty Institute. This institute is a joint venture between the University of Melbourne and the Royal Melbourne Hospital. We exist to prevent, treat and cure infectious diseases. We have

around 700 researchers and clinicians in our team.

Our work is structured into themes:

- Immunology
- Viral infectious diseases
- Antimicrobial resistance and healthcare associated infections
- Host-pathogen interactions

We then have a series of cross cutting disciplines that intersect with each of those themes. Indigenous health is a cross cutting discipline – this means improving health outcomes for Aboriginal Australians should cut across everything we do.

To the Doherty researchers here today, as members of this Institute you are encouraged to pursue research that can improve Indigenous health outcomes. It's critical our practice is informed by the communities we wish to serve.

To the structure of today – you have programs available. Firstly, we'll share highlights of the Doherty research capacity to provide some context.

But then it's our turn to listen… Tell us about the role you want us to play. How you want to work together. Please share with us your challenges, the frustrations you have experienced with research as well as examples of success. This Institute strives for excellence in all we do – and our engagement with you should be no exception.

'This is a chance for you to shape the direction the Doherty might take in Indigenous health research.'

We are a young institute just shaping our research agenda. This is a chance for you to shape the direction the Doherty might take in Indigenous health research. In this conversation, we hope that the community priorities will help to shape our research priorities.

This is just the beginning. The profound Uluru Statement from the Heart invites us to walk together in a movement of the Australian people for a better future. We are committed to walking with you. Together we have much to do.

I'd now like to invite some of our Doherty researchers to share their research with you. The first two presenters are Professor Katherine Kedzierska and Associate Professor Steven Tong, the leaders of our Indigenous health cross cutting discipline.

Steven and Katherine have agreed to act as custodians of this work but would like to see a time when this discipline can be led by Indigenous researchers.

With workforce development in mind, I'm very pleased to announce that following a generous donation to the Doherty Institute, and with support from the University, that today we launch our first scholarship – to recruit an Aboriginal or Torres Strait Islander PhD scholar of the highest merit, wishing to work in infection and immunity. If there is anyone in the audience today who would like to discuss this opportunity please do reach out to one of our team.

List of attendees

Allity
Liliana Espindola

APPRISE
Julie Milland
Miranda Smith

Australian Catholic University
Obrie Rugube

BrainLink Services
Suzanne Shaw

Burnet Institute
Shuli Rawson

Charles Darwin University
Adrian Miller

Department of Health and Human Services
Ee Laine Tay
Jasmine Lyons

Doherty Institute
Andrea Fischer
Ashley Hirons
Bridie Clemens
Chelsea Brown
Jennifer MacLachlan
Katherine Gibney
Laura Thomas
Luca Hensen
Matthew Nguyen
Natalia Evertsz
Phyo Aung
Sarah Londrigan
Sheilajen Vinca Alcantara
Trish Campbell
Louise Randall
Ashleigh Qama
Beverley Biggs
Charlene Mackenzie
Damian Purcell
Jodie McVernon
Katherine Kedzierska
Liyen Loh
Mark Davies
Natalia Evertsz
Peter Doherty
Sarah Hanieh
Sharon Lewin
Steven Tong
Will Cuningham

Global Health Alliance Melbourne
Misha Coleman

Inner West Mental Health Service
David Pruden

Lowitja Institute
Bronte Spiteri
Fiona Walls
Lowanna Norris
Mary Guthrie
Tahlia Eastman
Catherine Richards
Leila Smith
Mark Glazebrook
Shayne Bellingham

Melbourne Health
Sarah Cahir
Amy Ross-Edwards

Melbourne Poche Centre for Indigenous Health
Jennifer Johnston
Shaun Ewen
Warwick Padgham
Karyn Ferguson
Tui Crumpen

Menzies School of Health Research
Colin Baillie
Vijaya Joshi
Ella Meumann

Miwatj Health
Lucas de Toca

Murdoch Children's Research Institute
Emily Moroney
Rosie Stoke
Jordan Nathanielsz
Ashani Lecamwasam

Productivity Commission
David Garner

Red Dust Role Models
Martin Hirons
Scott Stirling

Trinity College
Ken Hinchcliff

University of Melbourne
Aaron Weinman
Alex Leeder
Angeline Ferdinand
April Valle
Bridget Pratt
Caroline Park
Emerald Chang
Francesca Mercuri
Giska Raissa
Hans Baer
Hugh Taylor
Janice Thomas
Jim McCluskey
Jingyi Dong
John Mathews
Juliana Betts
Karen McCulloch
Ken Winkel
Kristen Smith
Lindsey Pettifer
Louise Harms
Marcia Langton
Mariam Hachem
Megan Prictor
Nikki Moodie
Phuong Anh Phung
Rachel Nordlinger
Rebecca Chisholm
Shane Bawden
Stephanie McMahon
Thiripura Vino
Xianan Yin
Yu Bai
Alana Robinson
Alison Langley
Anne Donegan
Austin Kurne
Callum McBride
Daniel Lindholm
Felix Davis
Geoff Browne
Guillermo Gomez
Hillary Vanderven
Iderlina Mateo-Babiano
Jialing He
Jing Wu
Joaquin Lopez-Tan
Jonathan Law
Julie Satur
Kate Naish
Kit Crane
Liam Finlay
Liz Brentnall
Mandy Tsai
Maria Auladell
Mark Foresi
Nathan Fioritti
Oanh Nguyen
Quan Li
Raelene Nixon
Robyn May
Shiting Wang
Stephen Leslie
Vikram Kumar
Yiran Wang
Zara La Roche

Telethon Kids Institute, University of Western Australia
Fiona Stanley

Victorian Aboriginal Community Controlled Health Organisation (VACCHO)
Louise Lyons

Victorian Infectious Disease Service
Mike Richards
Sally Watkinson

Victorian Infectious Diseases Reference Laboratory
Lilly Yuen
Ros Edwards
Margaret Littlejohn

Walter and Eliza Hall Institute
Jason Brouwer
Louise Johansson
Leonard Harrison

WHO Collaborating Centre for Influenza
Aeron Hurt

Speakers and Panellists

In order of appearance

Professor Marcia Langton

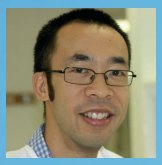
Professor Marcia Langton AM PhD Macq U, BA (Hons) ANU, FASSA, has held the Foundation Chair of Australian Indigenous Studies at the University of Melbourne since February 2000. As an anthropologist and geographer, Marcia has made a significant contribution to government and non-government policy as well as to Indigenous studies at three universities. In 2016 Professor Langton was honoured as a University of Melbourne Redmond Barry Distinguished Professor. As further recognition as one of Australia's most respected Indigenous academics, in 2017 Marcia was appointed as the first Associate Provost at the University of Melbourne.

Professor Sharon Lewin

Professor Sharon Lewin is an infectious diseases physician and scientist who is internationally renowned for her research into all aspects of HIV disease and pathogenesis. She is the inaugural Director of the Doherty Institute for Infection and Immunity at the University of Melbourne; consultant physician at the Alfred Hospital; and an Australian National Health and Medical Research Council (NHMRC) Practitioner Fellow. She was previously Head, Department of Infectious Diseases, The Alfred Hospital and Monash University (2003 – 2014) and Co-head, Centre for Biomedical Research, Burnet Institute (2010-2014). Her laboratory focuses on strategies to cure HIV infection, immune reconstitution following antiviral therapy, and pathogenesis of HIV-Hepatitis B co-infection. Sharon was the local Co-chair of the 20th International AIDS Conference (AIDS 2014), which was the largest health conference ever held in Australia. She is on the leadership team of the International AIDS Society's Strategy Towards an HIV Cure and a member of the Australian Government Ministerial Advisory Committee on Blood Borne Viruses and Sexually Transmitted Infections.

Professor Katherine Kedzierska

Professor Katherine Kedzierska is a laboratory head in Department of Microbiology and Immunology, University of Melbourne, at the Peter Doherty Institute for Infection and Immunity as well as one of our cross cutting discipline leaders for Indigenous health. Her research interests include human T cell immunity to pandemic, seasonal and newly emerged influenza viruses, anti-viral immunity in the young, the elderly and Indigenous Australians, viral escape and generation of immunological memory in human influenza infection.



Associate Professor Steven Tong

Associate Professor Steven Tong is an infectious diseases clinician who has spent 10 years working in Darwin. His research has focused on infections that affect Indigenous Australians, and includes influenza, hepatitis B, skin infections, and rheumatic heart disease. He moved to Melbourne in 2016 and now co-leads the Indigenous health cross cutting discipline at the Doherty Institute.

Professor Damian Purcell

Professor Damian Purcell is head of the molecular virology laboratory in the Department of Microbiology and Immunology at the Doherty Institute, University of Melbourne. After receiving a PhD from the University of Melbourne in 1987 he was a CJ Martin travelling fellow with Dr Malcolm Martin at the Laboratory for Molecular Microbiology of the NIAID, at the NIH in Bethesda, Maryland. He returned to Melbourne's Burnet Institute in 1995 before moving to a tenured teaching and research position at the University of Melbourne in 2001. He is the Virology Division Chair for the Australian Society of Microbiology, the immediate past President of the Australasian Virology Society, and Executive member of the Australian Centre for HIV and Hepatitis Virology. He studies RNA-mediated control of retrovirus gene expression during productive and the latent phase of infection. He seeks to translate his insights into the molecular mechanisms governing viral replication and the innate and adaptive antiviral responses into new antiviral drugs, vaccines and biomedical preventions.

Professor Jodie McVernon

Professor Jodie McVernon is Director of Epidemiology at the Peter Doherty Institute for Infection and Immunity. Jodie's research group uses mathematical models to understand the spread and burden of infectious diseases with a view to identifying the most efficient and effective strategies for their control. These methods provide useful frameworks for incorporating the influence of complex social determinants on the extremely high levels of infection spread observed in settings of poverty. This approach assists in defining the multiple layers of social and medical interventions most likely to result in sustained improvements in health.

Professor Adrian Miller

Professor Adrian Miller is of the Jirrbal people of North Queensland and is the Pro Vice-Chancellor Indigenous Leadership at Charles Darwin University. His previous appointments include Academic Director of Indigenous Education and Research and Professor of Indigenous Research at Griffith University, Professor and Head of School at Southern Cross University, Founding Head of the Department of Indigenous Studies at Macquarie University and Deputy Head of School at James Cook University. During the past 22 years in higher education, his experience has been in management, leadership, academic program development, teaching and research. He has held Professorial adjunct appointments at three Australian universities and has made significant contributions to Indigenous health and education. Adrian has a research track record in competitive grants with both the Australian Research Council and National Health and Medical Research Council grant schemes totalling over $10M. He has a strong interest in applied and translational research and twice been awarded Australian College of Educators Teaching Award.

Professor Shaun Ewen

Professor Ewen is Pro Vice-Chancellor (Indigenous) at the University of Melbourne and Foundation Director of the Melbourne Poche Centre for Indigenous Health in the Faculty of Medicine, Dentistry and Health Sciences at the University of Melbourne. In his role as PVC Professor Ewen has responsibility for institutional policy, strategy and advice in relation to all aspects of Indigenous higher education. As Foundation Director of the Melbourne Poche Centre he provides academic leadership to the Centre and maintains a strong sense of Indigenous leadership in the health and higher education sectors. Shaun held the position of Associate Dean (Indigenous Development) from its inception in 2010 until his recent appointment to Pro Vice-Chancellor in 2017.

Dr Lucas de Toca

Dr Lucas de Toca is the Chief Health Officer at Miwatj Health, the regional Aboriginal Community-Controlled Health Service for East Arnhem Land, where he is in charge of public health systems and programs and the management of Aboriginal Primary Health. He went to medical school in Spain and Sydney and completed further training in Public Health at Harvard where he focused on health system and leadership in health and human rights.

Professor Beverley Biggs

Professor Beverley Biggs heads the International and Immigrant Health Group in the Department of Medicine at the Doherty Institute, University of Melbourne. She has a joint appointment as Consultant Infectious Diseases Physician in the Victorian Infectious Diseases Service at the Royal Melbourne Hospital. Her research focuses on maternal and child health, nutrition and infectious diseases. Research projects include the role of the microbiome and other predictors of stunting in disadvantaged children, the causes of anaemia and benefits and costs of iron supplementation in infants, integrated approaches to improve women's health and child development in Vietnam and the prevention and early diagnosis of illness in refugees and immigrants. In 2016, Beverley and Dr Sarah Hanieh, with collaborators from the Menzies Institute, commenced the Elcho Island Child Health and Nutrition project to determine major contributors to child growth and development in early childhood, with a focus on gut health. The project has received excellent support from local organisations and fieldwork continues. Results will be disseminated to the community in early 2018.

Leila Smith

Leila Smith is a Wiradjuri woman, whose family is from Erambi Mission, outside Cowra in central NSW. She is currently Knowledge Translation Manager at the Lowitja Institute. Prior to the Lowijta Institute, Leila was a Senior Consultant at Nous Group where she managed the development of a change plan for the Commonwealth Department of Prime Minister and Cabinet to adjust practices, process and expectations to better value and maximise the expertise and experiences of Aboriginal and Torres Strait Islander staff. Leila also led the Policy and Programs Team at the Australian Indigenous Doctors' Association, facilitated the establishment of the first Aboriginal and Torres Strait Islander Data Archive with the Australian Institute of Health and Welfare, and managed the Fred Hollows Foundation's project to write and publish an Aboriginal history of the National Trachoma and Eye Health Project while at the Australian Institute of Aboriginal and Torres Strait Islander Studies.

Louise Lyons

Louise Lyons is a proud Jaadwa woman from the Western District of Victoria, and the Director of Public Health and Research at VACCHO where she has managed 15 programmes and 24 staff over the past three and a half years. Louise has had extensive experience working in the health and social justice sectors. Her academic qualifications include: MBA (Health Services), MLA (International and Comparative Law), Grad. Dip. International Health, and Assoc. Dip. Business (Computing). She is a member of the Barengi Gadjin Land Council (BGLC), and a member of the BGLC Negotiating team. She is passionate about improving the health and wellbeing outcomes of Aboriginal people living in Victoria, engendering a culture of community-led Aboriginal translational research programs and developing an Aboriginal HREC in Victoria. While at VACCHO, she has established a Health Evidence team within the PHR, and implemented a data platform and health information system that enables the collection, analyses and reporting of clinical data from every Aboriginal Community Controlled Health Organisation (that has a clinical service) in Victoria.

Summary of presentations

1st Session

Indigenous Health Research

Professor Katherine Kedzierska - Influenza

• There is evidence to show that Indigenous people are at higher risk of hospitalisation, morbidity, and mortality from influenza infection, especially when new a new virus enters human circulation.

• During the Spanish influenza pandemic, 10-20% of Indigenous Australians died compared to <1% of non-Indigenous Australians. There was similar inequity during the Swine influenza pandemic. We also see this in Canada, New Zealand, and the US.

• Factors for higher hospitalisation and morbidity rate can be due to nutrition, living conditions, co-morbidities, or a lack of immunity against the influenza virus.

• Studies on CD8+ T cells from 140 healthy Indigenous donors. Some of the HLAs identified were unique to Indigenous Australians. HLA-A24, which is associated with higher mortality during influenza, was found to be enriched in Indigenous Australians.

• Five HLAs have been identified that are universal for influenza. People with these HLAs have robust influenza immunity. For HLA-A24, computational studies show that the peptides do not bind, so the T cells do not respond.

• We want to understand how we can generate protective immunity, specifically T cell immunity, to influenza in Indigenous Australians. The cohort of 140 donors, recruited with the help of an Indigenous research assistant, are helping us do that.

• We have characterised four main HLA-A types and four main HLA-B types, and believe that characterisation of the HLA variants in Indigenous populations is not only beneficial for influenza but also for other infectious diseases and tumours.

• We are discovering novel T cell targets to provide cross-protective immunity against different influenza strains among Indigenous and non-Indigenous people.

Associate Professor Steven Tong - Hepatitis B

• Prevalence rates of Hepatitis B are up to 5-10% in some Indigenous Australian communities. This is significantly higher than the <1% prevalence across Australia.

• The higher rates of Hepatitis B lead to increased risk of end stage liver disease (cirrhosis) and liver cancer.

• We have an effective vaccine and anti-viral treatments for Hepatitis B. However, there continues to be therapeutic nihilism about providing standard of care to Indigenous Australians.

• In the Northern Territory, Indigenous Australians have been found to be infected with a unique genotype of Hepatitis B – called HBV/C4.

• Ongoing research is seeking to understand the natural history of HBV/C4 infections and whether it has an impact on the efficacy of the vaccine.

• In partnership with primary care, public health providers, and communities, Doherty and Menzies researchers hope to ensure all Northern Territory Indigenous Australians are tested for Hepatitis B, and for those infected, to receive appropriate care.

• We highlighted the importance of capacity building and community involvement. Community based workers have completed a Certificate II in Research Methodologies with a focus on Hepatitis B and three were supported to present their work at the World Indigenous Peoples' Conference on Viral Hepatitis in Alaska in 2017.

Professor Jodie McVernon - Skin infections

• Aboriginal children living in remote communities in the Northern Territory experience an extremely high burden of skin sores, with more than a third affected at any one time.

• The majority of these sores are caused by group A streptococcus (GAS), and can lead to serious consequences including acute life-threatening infections, and chronic diseases caused by abnormal immune responses.

• The most serious immune disease causes by GAS is acute rheumatic fever – Indigenous Australian children experience the highest rates of this condition in the world.

• Untreated, rheumatic fever can recur and cause permanent heart damage, known as Rheumatic Heart Disease (RHD) which is associated with poor health and early death.

• In the early 2000s, the Menzies School of Health Research and the CRC for Aboriginal Health partnered with communities to design and implement the East Arnhem healthy skin project, which identified effective strategies to reduce disease, but benefits have not been sustained.

• Doherty researchers are working with Menzies researchers to re-evaluate findings from that study, to help identify the key drivers of high disease burden, and recurrent infection.

• We are doing additional research funded by the NHMRC to better understand the way household living conditions and community mixing contribute to the spread of skin infections.

• Our aim is to put all this information together to identify the best combination of approaches for skin sore prevention, including housing measures, antibiotic treatments and future vaccines.

Professor Damian Purcell - HTLV1 in Australia

• HTLV1 is a virus and therefore an evolution machine. It has genetic information that it passes into the cell. HIV1 has some similarities but also differences.

• HTLV1 and HIV both stitch their information into the target cell DNA and become part of your genetic makeup. The cell then produces virus particles.

• No one is born with infections like these. Once you are infected the virus stays for a lifetime; we can treat it, but we cannot get rid of the virus information in the cell at the moment.

• HTLV1 primarily infects by cell to cell transfer, unlike HIV. It targets the same cells as HIV though: the important CD4 T cells – which are essentially the 'Facebook' of the immune system, telling everyone what's going on. HTLV1 also infects other immune system cell types – more than HIV.

• For diagnosis, we measure the amount of DNA that is present within infected cells.

• There is no vaccine against HTLV1 internationally.

• It is thought that most are infected through a blood transfer. Globally, breast feeding is the highest vertical transmission. It is like HIV – usually asymptomatic during the initial infection.

• Around 50 million people are infected globally. It is highly concentrated in Indigenous communities around the world. We know a lot about it in communities in Northern Japan, Africa, Peru, and other countries in South America. But we have recently realised there is a significant burden of infection in Australia.

• The virus has been endemic in communities in Australia for at least 40,000 years – the subtype of virus found here is called HTLV1 Subtype C.

• Highly prevalence in remote communities in central Australia. In these communities we have the highest prevalence measured anywhere in the world.

• Transmission rates are low in children and increase in 15-34-year-old Indigenous people. It is highest in older people.

• Internationally, HTLV1 is linked with other diseases including Adult T cell leukemia and infections leading to myelopathy around the spinal cord; but only 5% develop these severe forms.

• There is a lot of work to do in this area around disease associations and the potential to control the virus. There are no current community prevention strategies, no specific drugs, no vaccines.

2nd Session

Developing networks and partnerships

Professor Adrian Miller

• In order to begin thinking about Indigenous research, some things need to be understood first.

• The history of Indigenous Australia – the socio-political environment – and how communities have responded to the colonial effects of white presence.

• The history of research in Indigenous communities – it has not been very positive and there has been a lack of translation.

• It has been harmful and exploitative at times and has not been to the benefit of Indigenous communities, which has led to distrust.

• The problem of being subjects of research rather than partners.

• Highly recommended a new impact assessment tool developed for researchers by the Lowitja Institute.

• Research is commonly researcher driven in this country (confident that nearly 98% is) and there is also the government or public driver.

• When is it ever community-driven? Research is conducted *on* rather than *with* Indigenous Australians.

• How can we make it better? Indigenous people should be part of research decision making processes. Communities should be able to communicate their needs and have active involvement throughout the entire process.

• How do we start to translate and disseminate our research when there are barriers such as low literacy levels that need to be addressed?

• Building relationships is important but maintaining the relationships is even more important.

• People want ways to be able to say 'no' to research or ask for researchers to address their concerns.

• Researchers need a focus on capacity development so the knowledge and benefits remain within the community.

Professor Shaun Ewen

• Spoke about reprioritising Indigenous employment across the University. However this has been mostly entry-level and there has been little growth in the academic space.

• We need to get Indigenous people involved in knowledge creation, teaching, learning and research. To do this Indigenous academics need to be well-trained and supported.

• Which communities can we engage deeply?

• The University is working on developing relationships with communities before commencing research. Engagement comes first. Then, based on community priorities and health needs (addressing housing as a barrier for improved health, for example).

• Partnerships are about doing things that we can't do on our own.

• We need to consider how other people see us. What does the Doherty Institute represent to people outside? How does it want to be seen?

• Historically we can learn from mistakes that have been made over the last couple of hundreds of years. What do we need to put in place to make sure these mistakes aren't repeated?

• Referred to the deliberate program of the Poche Centre in recruiting PhD students – building slow, sustainable success.

Dr Lucas de Toca

• Works and lives in East Arnhem Land for an Aboriginal-led community control health service, Miwatj – the largest remote ACCHS in Australia.

• Thriving political environment, especially around land rights, in this area.

• Within the next two years, regional health services here will be completely community-driven.

• Career pathways as a whole are important to Miwatj – not just looking at representation but also areas such as median income of Indigenous workers.

• The importance of addressing the social determinants of health in the area – particularly housing and drug and alcohol in this community.

• Research needs to meet the interests of the community it engages with. The communities want something that is beneficial to them. Both immediate and ongoing impact of research is important.

• The Miwatj board assesses research proposals for the area and can reject them if they do not meet the expectations for the community. They are currently working on transitioning to only community-instigated research – setting up a set of research priorities the communities want addressed.

• True effective community research partnership is a safeguard for the community but is also something that can facilitate the ability of researchers to engage effectively and responsibly with the community.

Summary of panel discussion

Chairperson:

Associate Professor Steven Tong (**ST**)

Participants:

Professor Adrian Miller (**AM**)

Professor Beverley Biggs (**BB**)

Leila Smith (**LS**)

Louise Lyons (**LL**)

Dr Lucas de Toca (**LT**)

Professor Marcia Langton (**ML**)

Please note that the following summary has been abridged and paraphrased in parts and is not a word-for-word transcript of the panel discussion. A full recording is available on the Doherty Institute website.

ST begins the panel discussion, stating it will continue with the forum themes of understanding more about community-driven research and how an institute like the Doherty can enter into long-term trusting partnerships with communities. What are the priorities of communities and how might they dovetail with the strengths of the Doherty Institute? As a researcher at the Doherty, how can I get involved? In reflection, so many of the principles that we have been hearing about today are actually great principles for research in general – my hope is that what we learn from Indigenous health research can be applied to our other research as well.

Introduction of panel members

ST: I want to take us back 20 years, Marcia, to when the Lowitja Institute started as the cooperative research centre for Aboriginal and Tropical health research, which was a partnership between the Menzies School of Health Research, Danila Dilba, and Congress – an Aboriginal community controlled health organisations in Darwin and Alice Springs. I understand you were pivotal to that starting. Could you take us back in time and tell us what the research landscape was like then and what happened around that period?

ML: The key person who initiated the cooperative research centre in Aboriginal and Tropical health was Professor John Mathews. He came to see me in Darwin with the proposal and I said that it is a great idea. We then went to see Pat Anderson who was then Director of the Danila Dilba community controlled health service. He then drove the socialisation of the Centre across the sector, which led to a very successful cooperative research centre. I think there were three iterations of it, which is a huge success in research terms. There is a

limit to how many cooperative research centres are funded, so the Lowitja Institute was established as an autonomous research institute as a result of the 20 years of work. The idea of the cooperative research centre, as Professor Mathews envisaged it, was precisely to overcome the problems of community engagement in research.

There was an absence of trust altogether back then and very few Indigenous research graduates as well as very little funding for Indigenous researchers. At the time I was involved in the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS). Most of the AIATSIS money back then, 30-40 years ago, was going to archaeologists, anthropologists, and historians and almost none of it was going to Indigenous researchers. There was a push at this time for Indigenous researchers, but the academy refused to involve people who didn't come through the PhD program. We broke with tradition once we got control of the Institute, and it then became a more relevant research body for Indigenous Australia. That took at least ten years and Robert Tickner was the minister who changed the act. The Institute developed ethics guidelines and I'm sad to say that not much has changed in building up those ethics guidelines to be relevant for research today. How do they translate research in the Indigenous health sector so it is relevant to people? Well, that's not research, that's a translation job and I think far too much of the burden of history, of poverty, of disadvantage, and of educational disparity is put on the researcher.

You might notice that our funding has been cut, quite radically. The entire university sector's funding is being cut and more and more pressure is being put on researchers. Researchers can't bear the burden that the entire Indigenous world is putting on researchers. Researchers can't get enough money to do capability building – it's impossible. We can barely even fund our research projects. So the capability needs to be done in collaboration with our institutions. And that's what we are trying to do here at the University, to divide the job up into its correct parts. There's research, capability building, partnership building – they're separate things. A small example of the problems researchers face is permission to do their research before they get funding. If they have no money how can they go and get permission from a community? They can't. They don't know how to wrangle the remote world, the community world, wherever it might be, in the city or remote areas. There is no money to get the permission and it can take months to go through the process. The burden is on researchers already before they have even started their research. Here in our Indigenous leadership group we are trying to solve the problem by finding funding for researchers to go and get permission.

ST: Marcia, we might come back to that capacity building. I want to give Professor John Mathews (in the audience) an opportunity to reflect on that period 20 years ago and also share with us where you think things have gone since then? What led to you approaching Marcia and Pat?

John (from the audience): I'll go back 31 years ago to 1986. I went to Darwin to start the Menzies School of Health Research and all the issues we have heard about were very salient. We organised a meeting in Alice Springs in 1986 to try to bring Aboriginal leaders and researchers together to talk about the issues. There were maybe one or two other people in the room who were at that meeting but it was famously taken over by Aboriginal activists and the program was altered unilaterally. That was a very important signal to NHMRC, who were represented at the meeting. It was really a turning point when the anxiety that Aboriginals had about research was understood by people who hadn't tried to understand the issues. There was the tension between the social and medical models of health, when you needed both. The issue of Aboriginal control of health services versus government control, and we had issues around the ethical processes not being established. It was all very rudimentary at the time and it is very gratifying to see what progress has been made but some of the problems are still with us. But there is a huge amount of good will these days, a huge amount of understanding. People understand why they did not understand before, which is a great relief.

ST: Leila, in terms of the Lowitja, what do you do now and what do you see your role as in the research landscape in Australia?

LS: When we think of partnership we're thinking about Aboriginal and Torres Strait Islander leadership. We heard earlier from Lucas that their Board often says no to research projects. That's partnership that is led by Aboriginal and Torres Strait Islander people and that's partnership where the power is held by the communities. Our research is guided by five principals that sum up all of these things we've talked about today: leadership, community beneficence, engagement of end-users in the research design, capacity development of Aboriginal and Torres Strait Islander researchers, and impact. These are the five things that need to guide the way forward. And for us, that means processes that are led, designed, and evaluated by, Aboriginal and Torres Strait Islander people at any level, whether that be at the University of Melbourne, community-controlled health organisations, research institutes, and for the Doherty Institute that could be an employment strategy as well, it could be ways of building that into collaboration agreements, but I think those five themes are recurring because those are the solutions that are going to last.

LT: It's really interesting because we normally see research at our end, but it is also important to think about

how it is on your end, and I completely concur with Marcia that the burden on researchers to do all of that can be quite unrealistic and might discourage people from engaging in Indigenous research altogether. We have some examples of that bureaucratic impossibility in which we require ethics approval to give consent to participate in the community and the ethics committee requires community consent to grant ethics approval, and the same happens with the funding and a lot of other areas. We do find ways around it but the system in itself is not particularly accessible or pragmatic. This is why we insist on the importance of solid, long-term, and structured partnerships. What we have with Menzies and with Melbourne are good examples. Even in these early stages of our partnership with Melbourne and the engagement strategy we have tried to capitalise on the pooling of resources and initiatives across a large institution. We can then build an economy of scale, allowing us to address all these important principles without asking for the impossible from individual researchers.

ST: Perhaps I can then ask you, Bev, as someone who recently started a project with Miwatj and in East Arnhem, what that process has been like for you? What have been the difficulties, how long has it taken, what are some of the practical issues that have arisen for you?

BB: It has taken two years, possibly a little bit longer, to have a research project that we and the community want to do with approval from the Miwatj Health Board, as well as approval from the local shire authority. There have been some things that have been real enablers including the relationship with Miwatj. I have to say I didn't know about the University's relationship to Miwatj until I met Lucas and I didn't know one of our key collaborators, the Graduate School of Education, had a relationship until I was in a school in Galiwin'ku and saw a University of Melbourne poster up. Help was the key. Another key enabler has been our relationship with the Menzies School, working with researchers, Indigenous and non-Indigenous, who were well-known in the community and were trusted and respected, really opened the door for us. One big pitfall that I have to mention was that we underestimated the time it would take to set up the project and also the cost. It's really expensive doing research in a remote community. You can take the budget of your project and double or triple it.

ST: How much does it cost?

BB: We've completely spent our budget and we're about halfway through. Luckily we have some reserve funds to use and we're applying for other project grants. Even accommodation and a car costs around $2000 a week, and if you add the salaries of local community health workers it's probably around $5000 a week to run the project without the cost of any flights. The other thing I think is the communication challenge. The Yolngu people are very proficient in language, they speak five or six languages, but English is only one of those, and the other problem, even for people who speak English is the conceptual differences in how they see the world and we see the world and our understanding of various technical aspects of the biology that we're all interested in. We've now translated all our material into language to help our Aboriginal health workers understand the story and help engage the community.

ST: Louise, the Doherty is a Victorian-based institute. We obviously have both a national and international reputation, but I think we have a great responsibility to the traditional owners of the land we're actually at. What are some ways we can partner with VACCHO and the communities that are members of VACCHO?

LL: There's a lot that has to be done in Victoria. For a start we don't have an Aboriginal research ethics committee so we get a lot of requests to review research proposals. St Vincent's Public Hospital reviews quite a number of the Aboriginal research proposals from a whole range of different groups. So I think we need to work closer together with key partners to get a committee down here. I would recommend taking a look at the South Australian Aboriginal Health Research Accord. What they did was an extensive consultation that took well over 18 months where the staff went to all of the Aboriginal communities within South Australia and sat down with them and consulted quite extensively about their principles for engaging in research and what they wanted to see researchers do. That Research Accord really embodies the voices of South Australian Aboriginal people and goes to much greater lengths than any of the other NHMRC documents. I think what is embodied within that Accord is not just the process but the acknowledgement of the two-way learnings that occur with research and whether researchers have identified the value in the intellectual property that sits with the communities that they're researching. If you've undertaken any of this research you'll come away with a much greater knowledge base yourself than what you ever give into a community. Recognising that is very important. Within Victoria I'd like to model a similar consultation process within our communities and truly understand what Aboriginal communities and people see as their research priorities and if VACCHO can, play a role in identifying those research priorities, brokering the funding and partnerships and working with academic organisations to bring the right people together to deliver on that research. We can do better than what's being done at the moment. Even in Victoria, I don't think we've got it right. Those are some of the ideas for how we can work together, and VACCHO has only just started in this space.

ST: If priorities arise that do link with the strengths of the Doherty, come to us, and let's talk and have that longer-term relationship.

LL: Because there is a relatively small proportion of Aboriginal people in Victoria – I think it's around 55,000 people – the ABS doesn't really do any granular analysis of the health data that exists here. So VACCHO embarked on the extensive process of developing a data repository from all of our health services over the past two years and I think we've got quite unique data sets that would be of extreme benefit to researchers. One example is that the national smoking rate for Aboriginal people is around 39%, and that's pretty much what we thought the rate was in Victoria, but what the data has shown us is that the rate here is actually 58%, consistently over the last two years. If you're an Aboriginal man aged between 35 and 44, it's 77%. That presents a huge problem and also an opportunity for partnering and looking at ways to find what unique research priorities exist in Victoria.

AM: Quite often we focus on rural and remote communities because that is where the need is and where the severity is in terms of disease burden, but we often neglect urban Aboriginal communities. I'd also just like to echo, and this is not my own thought by any means, but retired Professor Cindy Shannon constantly advocated for the fact that we don't do enough urban Indigenous research because quite often the disease profile is similar but less severe.

Professor Hugh Taylor (question from the audience): There are two points I would like to make. One is the difficulty in doing national research on Aboriginal and Torres Strait Islander people. We had a random sample of 30 communities that we needed to get 72 ethical clearances for. So that point that Marcia and Beverley were making about the difficulty of it is real, but it's an even bigger impediment if you're trying to look at the broader picture across the country. Second thing, to absolutely reinforce what Louise was saying, I think it is fabulous that VACCHO is here. We found in a survey that the unmet need around eye disease in Fitzroy is the same as in Fitzroy Crossing. In Fitzroy Crossing you need more optometrists and services and so on and in Fitzroy the Royal Victorian Eye and Ear, the largest eye hospital in the southern hemisphere, is right there. It's not a shortage of manpower but it is all the other things that need to be looked at, and as three quarters of Aboriginal and Torres Strait Islander people live in towns and cities, we really do need to look at what we are doing around their health in addition to people in remote areas. I think Bev brought up the point of the expense and difficulty of communicating back and forth over 3,000 km, which is true, but I think we should really, in addition, be looking at what we can do in the communities nearby that we can get to easily and whose unmet need is probably similar to those in the most remote places.

ST: And if we're not going to do it, people in NSW aren't going to do it for Victorians, are they? So I think we do have a great responsibility there.

Natalia Evertsz (question from Doherty Institute Research Assistant and student): There have been some really great examples of community engagement given today, and some really great thoughts on how Aboriginal communities can set some of the research priorities moving forward with a more bottom up approach. From what I'm hearing a lot of the organisations might then represent some of those priorities to institutes like the Doherty. Now I don't have any experience in Aboriginal communities but what I could imagine is that there might be some local knowledge about what some of the health burdens they would like to be addressed are, and as that filters up through those organisations to the Doherty, some of that might get lost. Is that an issue? If so what are some of the things that we can do to make sure those get through.

LS: I might just give one example of how we do that. Before we put a call out for research funding at the Lowitja Institute, we begin with a process where the first step is looking at the community priorities. And we hold a range of different forums, workshops, or roundtables, where we bring in different experts from different levels so it starts with conversations and understanding. This might include community members experiencing these issues or service users, in with organisations, government and policy makers. Following that we have three program committees. One is the social determinants of health committee, a committee of Aboriginal and Torres Strait Islander people, who look at the outcomes of these dialogues and following that they approve research questions that have emerged from that process. Those research questions then go out for funding, so it is a clear line that is drawn back to conversations and then the research is funded and assessed by experts and Aboriginal and Torres Strait Islander people, so it's by, for and with the whole way. As soon as the contract is signed they undertake a knowledge translation plan where they map out their processes about how that research will deliver benefits to the community and impact in whichever way is most relevant and appropriate with their research methodology. Then the research is also conducted in a way that builds the capacity of researchers too. So there are ways to do that. We have inbuilt processes as well to look at the research that is happening and get updates from them to feed into discussions that we might be having at the Institute with governments and on committees we might be on – such as the Close the Gap Campaign Steering Committee and the National Health Leadership Forum. It is people-based and it is about talking to people and sharing your knowledge and creating understandings. It might be messy and all over the place but we need some kind of structure under that and I'm not saying that our way is the way, but we are learning and continually improving as we go.

Notes

A joint venture between The University of Melbourne and The Royal Melbourne Hospital