



**NCIG**

NATIONAL CENTRE  
FOR INDIGENOUS  
GENOMICS

Annual Report 2022

# JUSTICE. EQUITY. ENGAGEMENT.

The Power  
of Indigenous  
Genomics

“

*...we must ‘bend the will’  
of genomics to deal with  
the fundamental drivers  
of health inequality among  
Indigenous Australians.*

”

Prof Alex Brown

The Australian National University acknowledges, celebrates and pays respects to the Ngunnawal and Ngambri people of the Canberra region, and to all First Nations Australians upon whose traditional lands we meet and work, and whose cultures are among the oldest continuing cultures in human history. We acknowledge that Aboriginal sovereignty was never ceded. It always was and always will be, Aboriginal land.

## Our Purpose

The role of the National Centre for Indigenous Genomics (NCIG) is to ensure Indigenous Australians are at the forefront of health benefits that will flow into the national health system from the integration of genomic knowledge and technology.

## Our Values

- **Integrity, Trust, Respect** – NCIG acts with integrity, builds trust and behaves ethically. NCIG gives respect and strives to earn it in return.
- **Confidentiality, Privacy and Security** – NCIG protects the privacy of participants and the confidentiality and security of data and information about participants.

Burial Poles at the John Curtin School of Medical Research, ANU were unveiled in a ceremony hosted by ANU Chancellor The Hon Julie Bishop and Vice-Chancellor Prof Brian Schmidt with Galiwin'ku Community leaders and guests during Reconciliation Week in May 2021. These duplicate Burial Poles mirror poles erected in Galiwin'ku and acknowledge the 2019 repatriation of samples collected from now-deceased Galiwin'ku people. They serve to mark the ongoing connection and commitment to a partnership between NCIG and the Community. *Photo: ANU*

Cover image: The grand, scarred Yellowbox tree on the ANU campus, near the Chancelry building. This symbolic tree is believed to be some 300 years old and features a large Indigenous cultural scar, likely for a canoe or raft and another, smaller scar on its opposite side. *Photo: ANU*



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# CHAIR NCIG GOVERNANCE BOARD

Assoc Prof Glenn Pearson

I've had the pleasure to have travelled this beautiful place and to meet with different people and communities and never failed "to be completely inspired and captivated – and excited that has it always been Aboriginal and Torres Strait Islander Country. This work of the National Centre for Indigenous Genomics (NCIG) brings together the best of both worlds, for wherever we are, we acknowledge we are meeting on Sacred Country".



We acknowledge also, this unique opportunity as members of this NCIG Governance Board, to bring a number of worlds together for a conversation - to break bread around the table is a really sacred thing - it's a ritual - it's when people come together to check in and let the world sit back - to connect and have conversations is really important in a world that seems pretty busy pulling us left, right and centre.

What an amazing opportunity to be a part of this journey – contributing the best of all of our worlds to ensure that our families and communities get the best health outcomes that we can possibly provide. I believe this Annual Report for 2022 really does reflect a lot of effort over a whole lot of time by a lot of people around our core objectives for NCIG. So, I honour our NCIG team and our Board members, who over the last couple of years in particular, have got us to where we are today - you are totally amazing.

On behalf of our Board, I especially acknowledge the leadership and commitment of our outgoing NCIG director, Prof Graham Mann, whose guidance and journey with us is embedded in the Centre's continuing development and vision.



- ▲ ANU Vice-Chancellor Prof Brian Schmidt and Professor Graham Mann, NCIG Director, carry boxes containing biological samples to be returned to Country, during a ceremony at the John Curtin School of Medical Research, ANU, 11 November 2019. *Photo: ANU*

# NCIG DIRECTOR

Prof Graham Mann

It's a special pleasure to present this 2022 Annual Report after a truly transformative year for NCIG.



Most significant has been the support attracted from the Australian human genetics community, through NHMRC and the Medical Research Future Fund, for our ambitious, determined plans to deliver benefit from genomic medicine to Indigenous people. Led by our new ANU Professor of Indigenous Genomics, Dr Alex Brown, we launched two major initiatives. The CONNECT collaboration aims to lay out the necessary cultural, legal, genetic, data science and health system conditions for those benefits to be realised. The National Indigenous Genomic Network has the task of building the roadmap that will get Australia there in the right way. These successes were bracketed by a brace of other research grants.

We have much to do, and more work in front of us to ensure NCIG can fulfil its mission, through ANU, on behalf of Indigenous Australians. I am delighted to wish Alex well as incoming Director, thank him, Deputy Director Azure Hermes and all the team here at NCIG and its extended family around the country for their drive and talents. I especially thank Chairman Glenn Pearson, all members of the NCIG Board, and the ANU leadership under Chancellor Julie Bishop and Vice-Chancellor Brian Schmidt for their constant support. It was wonderful to have had the opportunity to showcase these achievements and this community at our inaugural gala annual event, the NCIG Summer Oration, in December.

I encourage anyone committed to Indigenous health and wellbeing to walk with NCIG and shape this journey.



◀ ANU Vice-Chancellor Prof Brian Schmidt acknowledging the leadership and contribution of outgoing NCIG Director Prof Graham Mann at the inaugural NCIG Summer Oration. Prof Schmidt also announced the appointment of Prof Alex Brown as the incoming NCIG Director.

“I want to thank Prof Graham Mann who has stewarded NCIG since his time starting here at the John Curtin School of Medical Research - and what we're seeing here is what actually happens when you empower people and let them have the agency to do what they want - that's the thing that I'm most proud of - and Graham has really embraced that philosophy. Graham, I do appreciate that it's a tireless job being the head of the John Curtin School of Medical Research, it requires a huge amount of dedication - and I do look forward to your reappointment on the NCIG Board as one of our two ANU representative members.”

# 1

# NCIG AT WORK 2022

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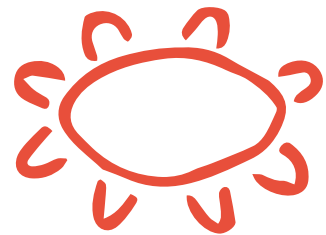
# NCIG – CARING FOR THE COLLECTION



DNA CHAIN



CELL



PEOPLE MEETING

## About the NCIG Collection

The **National Centre for Indigenous Genomics** (NCIG) was created in 2013 to manage and expand a collection of 7,000 historical Indigenous blood samples held at the John Curtin School of Medical Research (JCSMR), and to develop a research reference resource from the samples' DNA for genomic health and medical research.

Genomics is at the heart of new discoveries and technologies that are transforming medical practice. However, the lack of genomic data from Indigenous Australians means that research, data and the implementation of healthcare genomics are biased towards people of European ancestry.

The National Centre for Indigenous Genomics at the Australian National University (ANU), established as a federal statute is creating Australia's national Indigenous genomic data resource under a unique governance and research model placing Indigenous Australians in charge of their genomic data and its use.

NCIG is creating one of the first Indigenous Australian reference genomes, and when complete it will encompass a remarkable depth and breadth of information.

[See NCIG's collection sites here](#)



This is a very important story about our Mob's health

## Caring for the Collection

The NCIG Collection comprises 8,612 Indigenous donors whose materials are securely located within the John Curtin School of Medical Research (JCSMR) at the ANU under the governance of NCIG.

These samples are preserved at the JCSMR in -80°C freezers and liquid nitrogen tanks until their use is determined by donors and their families.

In 2022, JCSMR kindly supported the purchase of *FreezerWorks* software that enables biobank quality management of our samples. A new version of the software allows us to record donor consents through a web-based interface, reducing the need for manual data entry and paper-based records. This effort has led to the streamlined management of private information and the ability to link our document archive located at JCSMR with our genomic data repository housed at the NCI.

2022 also saw NCIG review its current freezer storage facilities. This partial audit identified an alternative option for increasing redundancy to store NCIG samples, while potentially reducing risk of sample loss due to unforeseen circumstances. Implementation of best practice risk management strategies remain an ongoing priority for NCIG.

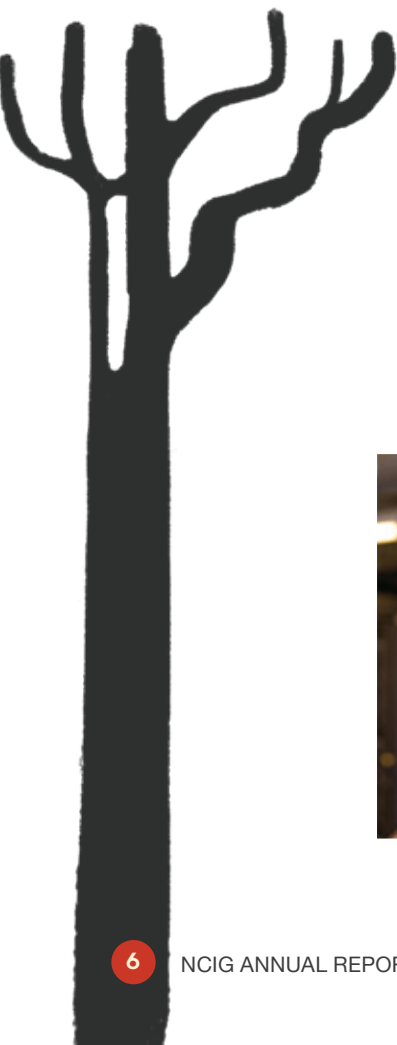


▲ NCIG Data Manager, Ms Jiaxin Yuan is responsible for overseeing the NCIG Collection, preprocessing the data and managing the storage and resources required for the data pipeline workflow.

## NCIG Collection – Managing Research Access

Access to the NCIG Collection is controlled by the NCIG Indigenous majority Governance Board with the assistance and expertise of the NCIG Collection Access and Research Advisory Committee (CARAC).

[Read more about the NCIG Collection](#)



▲ Dr Hardip Patel – NCIG Bioinformatics Lead



# GENOMICS – TRANSFORMATION IN HEALTHCARE

Genomics has become the core of modern biomedical science. High throughput sequencing technologies, and novel computational and statistical methods have enabled the documentation of rich libraries of human genetic variation, driving examination of the structure and function of the human genome and the molecular basis of disease.

Integration of genomics into health care has delivered key success in areas such as precision cancer therapies, and the diagnosis and treatment of rare diseases.

According to Prof Alex Brown, incoming NCIG Director “An Indigenous Australian reference genome resource will be the foundation of genomics research, clinical genomics and precision medicine in Indigenous communities.”



## NCIG is driving the development of the National Indigenous Genomics Network

The National Centre for Indigenous Genomics at the Australian National University is driving the development of Australia’s national Indigenous genomic data resource under a unique Indigenous governance and research model placing First Nations Australians in charge of their genomic data and its use.

Now, with the support of the Medical Research Future Fund (MRFF), a multi-disciplinary and unique program will establish a **National Indigenous Genomics Network** that synergistically builds and extends Indigenous leadership and involvement in genomic science, research, precision health care, data sciences, ethics and Indigenous knowledge systems to reduce health inequality among Australia’s First Peoples.

Prof Brown believes “Australia has a national responsibility to place Indigenous people at the centre of these developments as this will ensure clinical genomics fulfils its promise to not only improve health outcomes but does so in a way that is equitable for all.”

“First Nations Australians must be given access to the power and potential of genomics and the health benefits it delivers.”



▲ ANU Chancellor *The Hon Julie Bishop* with internationally acclaimed Aboriginal researcher and clinician *Professor Alex Brown*, who has been named the incoming director of the ANU National Centre for Indigenous Genomics, says genomics offered “a new frontier” for improving health outcomes among Indigenous Australians as well as addressing other major inequities.

Professor Brown delivered the inaugural NCIG Summer Oration with Pat Anderson AO, Co-chair of the Voice to Parliament and Chair of the Lowitja Institute, at ANU 13 December 2022.

# THE POWER AND POTENTIAL OF INDIGENOUS GENOMICS

## PROF ALEX BROWN\*

*\*The inaugural Summer Oration the Power and Potential of Indigenous Genomics was delivered by Prof Alex Brown on 13 December.*

First Nations Australians must be given access to the power and potential of genomics and the health benefits it delivers, says Professor Alex Brown.

Genomics unlocks the information in our DNA to enable personalised and targeted prevention and treatment of a range of health conditions including cancer, diabetes and heart disease, as well as rare diseases among Indigenous children.

Internationally acclaimed Aboriginal researcher and clinician Professor Alex Brown, who has been named the new director of the ANU National Centre for Indigenous Genomics (NCIG), said genomics offered “a new frontier” for improving health outcomes among Indigenous Australians as well as addressing other major inequities.

“Genomics represents a step change in biomedical science which will be fundamental to the future of research and medical care,” Professor Brown said.

“It drives precision medicine and underpins new diagnostics, therapeutics and treatments. But if we are to ensure direct benefit, and the hope of reducing inequalities, we have to bend it to prevention, prognosis and monitoring response as well.

“And we must ‘bend the will’ of genomics to deal with the fundamental drivers of health inequality among Indigenous Australians - including cardiovascular disease and cancer.

“Australia has a national responsibility to place Indigenous people at the centre of these developments as this will ensure genomics fulfils its promise to not only improve health outcomes but does so in a way that is equitable for all.”

Professor Brown said genomics also offered the chance for First Nations people to have greater say and oversight on health research “undertaken in our name and on us for centuries”.

“Science has a painful relationship with indigenous people. In the machine of colonisation, science — often pseudo-science — was used as a vehicle for oppression, marginalisation, and cover for the atrocities carried out against my ancestors,” Professor Brown said.

“But change has arrived. Indigenous people are no longer simply the subjects of research. We must become the architects of our own future in research.

“At ANU we are driving the development of Australia’s national Indigenous genomic data resource under a unique Indigenous governance and research model placing First Nations Australians in charge of their genomic data and its use.

“And we must ensure that science does not ignore all that Indigenous people have to offer, including ethics and ancient wisdom.”

As part of his work at ANU, Professor Brown is leading the National Indigenous Genomics Network, which aims to develop a responsible, culturally appropriate, nationally consistent and internationally relevant Indigenous genomics ecosystem.

Professor Brown said the national network, which consists of six nodes across Australia, will advance the benefits of genomic medicine for Aboriginal and Torres Strait Islander patients, who have to date been excluded from national genomics efforts.

“Indigenous populations are not appropriately represented in genomic medicine, nor do they have equitable access to its benefits,” Professor Brown said.

“Little attention has been paid to the steps required to ensure Indigenous Australians can and do benefit from all that genomics has to offer.”

“NCIG, and the growing national network represents this new way forward.”

# NCIG RESEARCH PROJECTS

## Telomere-2-Telomere (T2T) Genome Assemblies for Indigenous Australians

**Project lead: Dr Hardip Patel, NCIG**

The human reference genome is the vital resource underpinning genomics driven biomedical research and clinical services. The reference genome is essential because (a) it provides the coordinate system to anchor information about the function, clinical significance, and population variation, and (b) it is the substrate used to align sequence reads. However, the reference genome is incomplete, inaccurate and lacks ancestral diversity representation making it a limiting resource for diagnosis of genetic diseases, especially for ancestrally diverse populations, including Indigenous Australians.

This project will generate 10 telomere-2-telomere (T2T) reference genomes to represent distinct Indigenous

communities using long (PacBio HiFi, ONT) and linked read (HiC) DNA sequencing technologies. We will develop innovative software for reference guided *de novo* genome assemblies for improved accuracy and the graph-based representation for variant discovery and multi-omic analysis (transcriptomics and epigenetics). We will discover mutational processes of complex structural variations and sex-chromosomes to understand their roles in disease and health using Indigenous T2T genomes. We will demonstrate the clinical utility and translation benefits of Indigenous T2T genomes by performing genomic analysis of patients enrolled in the Australian Undiagnosed Diseases Network.



## Using Graph Pangenomics to Reduce Reference Bias and Improve Variant Genotyping and Discovery

**Project leads: Dr Yassine Souilimi, Uni of Adelaide; Assoc Prof Bastien Llamas, Uni of Adelaide**

The current linear reference genomes are used as a scaffold to map DNA sequencing data; however, they capture no genetic diversity, introducing biases when the studied genomes diverge sufficiently, such as Australian First Nation genomes. In this project, we are building a pangenome that captures Indigenous Australian genomic diversity, helping reduce reference biases and improve Indigenous genomic research.

Building an Indigenous Australian pangenome reference, we capture several known Indigenous genomic variations (from the NCIG cohort), represent structural differences absent in the linear reference – resolving complex regions (e.g., HLA) in the process and represent unique additional sequences missing in the reference genome.

Pangenomes, particularly graph pangenomes, are perceived as the future of reference genomes.

Several international efforts are underway to produce a global pangenome reference to replace the existing linear reference (GRCh38.p13). By researching and building an Indigenous Australian pangenome graph, we are future-proofing Indigenous genomics in Australia, thus offering a near-bias-free reference that dramatically improves our understanding of genetic variation in the continent. This unlocks our ability to study medically relevant Structural Variations and enables association studies of additional sequences absent in the reference genome.

An Indigenous pangenome graph will enable a near-bias-free variant detection and genotyping, resulting in improved diagnosis and study of genetic conditions of interest to Australia's First Nations. Thus, this project provides an essential tool in the genomic toolkit to empower Indigenous genomics in Australia.

## Building Genomic Knowledge in Partnership with Indigenous Communities and Health Services

**Project Lead: Ms Azure Hermes, NCIG**

This public health program is designed to complement the Indigenous Genomics Ecosystem research platform funded through the Synergy grant awarded to Prof Alex Brown and through existing Australian Genomics (“AG”) funding support. Designed in partnership with Aboriginal Controlled Community Health Organisations (ACCHOs) and Communities, this work will build shared genomic

knowledge and create opportunities for better informed consultations and engagement as Indigenous genomic research is developed and implemented. ACCHOs and Community leaders will be invited to work with an experienced community engagement team headed by the Deputy Director of NCIG, and supported by NCIG’s research partners.



## Tiwi Islanders - Kidney Disease Project ANU Indigenous Health and Wellbeing Grand Challenge (IHWGC) 2020–2025

**Project leads: Assoc Prof Brendan McMorran, ANU; Dr Simon Jiang, ANU, Dr Hardip Patel NCIG; Ms Azure Hermes, NCIG**

The Tiwi people suffer one of the highest known rates of Chronic Kidney Disease (CKD) worldwide, and effective treatment and disease management strategies are limited by poor understanding of how and why it develops.

The mission of the ANU Indigenous Health and Wellbeing Grand Challenge 2020 to 2025 is to:

1. Enable improvements in health and wellbeing outcomes among Aboriginal and Torres Strait Islander peoples in the areas of: Truth-Telling, improving kidney disease outcomes, mapping culture and Country, sovereign walks/actions on Country, cultural actions through art, Country, language and music, Indigenous community and research partnerships.
2. Build and maintain genuine partnerships with communities, stakeholders, and funders.
3. Utilise best practice principles and novel research approaches, informed by IHWGC research priorities.
4. Create research leadership opportunities and build Indigenous early career researcher (ECR) capacity.

5. Develop and implement an effective research communication strategy that adequately captures and communicates benefit resulting from IHWGC.

This project seeks to understand how to prevent a serious health problems experienced by a large proportion of Tiwi Islanders, in particular, chronic kidney disease (CKD). The project is applying genetic and genomic methods to investigate the causes of the disease, underpinned by large scale genome sequencing, laboratory-based studies using molecular and biochemical methods, and research and education activities in the Tiwi community. It represents a long-standing and Community driven collaboration between NCIG and researchers based at the John Curtin School of Medical Research, Menzies School of Health, Royal Darwin Hospital, University of Queensland and Queensland University of Technology.

This project received seed funding as part of the ANU Indigenous Health and Wellbeing Grand Challenge (IHWGC) and additional funding was granted from the National Health and Medical Research Council (NHMRC).

## Respecting the Gift: Empowering Indigenous Communities in Genomics Medicine

Professor Alex Brown is leading a consortium which was awarded \$5 million under the National Health and Medical Research Council's Synergy Grant program (2022–2026). The ambitious multi-institutional program of work planned under the grant is spread across five research domains and eight research nodes across Australia.

**Chief Investigators: Prof Alex Brown, ANU, Telethon Kids Institute; Ms Azure Hermes, NCIG**

**Project Leads – ANU and NCIG:  
Prof Graham Mann; Emer Prof Simon Easteal;  
Dr Sharon Heubner; Dr Hardip Patel**

### Domain 1

In partnership with Indigenous Communities, Domain 1 will explore the cultural, ethical, social and legal issues (C+ELSI) relating to genomics research and provide a roadmap for Indigenous leadership and inclusion in genomics. Domain 1 includes the evaluation of

community engagement and governance strategies with the aim of supporting communities in decision making processes relating to consent and data sovereignty.

### Domain 2

Domain 2 will examine how genomic information is interpreted, incorporated and translated meaningfully into the lives, experiences and healthcare of individuals and communities. It will produce a national Indigenous data governance framework aligned with international best practice to strengthen public trust, ensure appropriate data collection and sharing that reflects Indigenous principles; and develop standards for data collection, sharing, analysis, and reporting.

### Domain 3

Domain 3 will create high-quality reference genome sequences that represent Indigenous Australian diversity; create a variant reference database to improve the diagnosis of rare diseases; and functionally annotate novel variants for further study.

## Acknowledgements

### Research Collaborators

- Dr Alex Brown – Australian National University, Telethon Kids Institute
- Assoc Prof Glenn Pearson – Telethon Kids Institute
- Prof Gareth Baynam – University of Western Australia
- Dr Simon Jiang – Australian National University
- Assoc Prof Brendan McMorran – Australian National University
- Dr Ashley Farlow – Australian National University, University of Melbourne
- Assoc Prof Bastien Llamas – University of Adelaide
- Dr Yassine Souilmi – University of Adelaide
- Dr Ira Deveson – Garvan Institute of Medical Research
- Dr Daniel MacArthur – Garvan Institute of Medical Research
- Dr Andre Martin-Reis – Garvan Institute of Medical Research
- Assoc Prof Misty Jenkins – Walter & Eliza Hall Institute of Medical Research
- Dr Rebekah McWhirter – Deakin University
- Ms Louise Lyons – South Australian Health & Medical Research Institute
- Dr Kalinda Griffiths – University of NSW
- Dr Michelle Bootcov – University of NSW
- Mr Yarlalu Thomas – King Edward Memorial Hospital for Women
- Dr Rebekah McWhirter – Deakin University
- Assoc Prof Maree Toombs – University of Queensland

- Dr Kristen Nowak – Department of Health, WA
- Mr Gregory Pratt – Council of the Queensland Institute of Medical Research

### Indigenous Communities and Organisations

- Anindilyakwa Land Council
- Kimberley Aboriginal Law and Culture Centre, WA
- Kimberley Aboriginal Medical Service, WA
- Ninti One, NT
- SING Australia
- Tiwi Land Council, NT
- Top End Human Research Ethics Committee, NT
- Yalu Aboriginal Corporation
- Yarrabah Community
- The Walpiri people of Yuendumu and Lajamanu

### Technical service providers

- The Australian Phenomics Facilities – Australian National University
- Biomolecular Resource Facility – Australian National University
- Information Technology Services – Australian National University
- Kinghorn Centre for Clinical Genomics – Garvan Institute of Medical Research
- National Computational Infrastructure – Australian National University
- Ramaciotti Centre for Genomics – University of NSW

# NCIG RESEARCH GRANTS AWARDED 2022 | PROJECTS COMMENCING 2023

## Pathways to benefit Indigenous Australians in Genomic Medicine Medical Research Future Fund (MRFF): Genomic Health Future Mission: Streams 3, 4, 5, 6

**Stream 3 – Project Leads:** Prof Ainsley Newson, Uni Sydney; Prof Alex Brown, ANU; Ms Azure Hermes, NCIG

### **Ethical governance for clinical and genomic data:**

Rapid advances in genetic sequencing technologies are enabling large collections of genetic information, “genomic datasets” to be set up and used to benefit human health. *But what risks are there? Who should access them? How can we harness their benefits while maintaining public trust?*

This project will address the pressing ethical, legal and social aspects of these questions. It will develop and put into practice systems and processes to ensure genomic datasets are developed and used well. *Stream 3*

**Stream 4 – Project Leads:** Prof Alex Brown, ANU; Ms Azure Hermes, NCIG; Dr Hardip Patel, NCIG; Dr Sharon Huebner, NCIG; Professor Graham Mann, ANU/JCSMR

### **Pathways to benefit for Indigenous Australians in**

**Genomic Medicine:** Indigenous populations are not yet appropriately represented in genomic research. We have assembled a national consortium of Indigenous researchers, health services, institutions and industry to empower Indigenous leadership in genomics with a focus on 1) Governance; 2) Data Systems and Sovereignty; 3) Genomics Policy; and 4) Indigenous Genomics Capacity Development.

Our network will enable equitable, culturally safe and responsive access to the benefits of genomic medicine for all Australians. *Read more on the National Indigenous Genomics Network.*

**Stream 5 – Project Leads:** Prof Daniel MacArthur, Uni of NSW; Prof Alex Brown, ANU; Ms Azure Hermes, NCIG; Multi-institutional

### **The Australian Genetic Diversity Database:**

Many severe diseases are caused by DNA changes that are very rare in the general population. Clinical

laboratories thus need DNA data from many people to identify the specific cause(s) of each person’s condition. Unfortunately, current DNA databases include mostly people from Europe, making it harder to diagnose patients from other ancestries. We propose a new DNA database of over 20,000 Australians that better reflects our diversity, ensuring more accurate diagnosis for all Australians.

**Stream 6 – Project Leads:** Dr Simon Jiang, ANU; Ms Azure Hermes, NCIG

**High throughput validation of genomic variants in Indigenous Australians and their contribution to kidney and immune disease:** Indigenous Australians have some of the highest rates of chronic kidney disease (CKD) in the world. It has been estimated that one of the greatest risks for the development of CKD in these communities is genetics. This project is a national collaboration to understand and prove the genetic basis contributing to high rates of CKD. Through understanding the unique and shared basis for CKD in Indigenous communities across Australia, we can improve detection and treatment for these groups.

**Stream 6 – Project Leads:** Dr Ira Deveson, Garvan Institute; Dr Hardip Patel, NCIG

### **Description of Genomic Structural Variation**

**in Indigenous Australian Populations with Nanopore Sequencing:** Long-read nanopore sequencing is an emerging technology that promises to advance our understanding of genetic variation by resolving repetitive genome regions and structural variation, which are intractable with established short-read sequencing platforms. We are applying nanopore sequencing to NCIG-partnered communities in order to explore the landscape of Indigenous structural variation and create reference catalogues and analysis frameworks for future use in genomic medicine. This approach will help resolve a diversity of repetitive variation, much of which is unique to Indigenous people and/or specific communities.

## Indigenous Telomere-2-Telomere Human Reference Genomes to Enable Discovery, Translation and Innovations

**Project Leads: Dr Hardip Patel, NCIG; Ms Azure Hermes, NCIG**

This project will use the latest DNA sequencing technologies to generate, for the first time, Indigenous telomere-2-telomere reference genomes. These genomes will account for ancestral diversity and underpin the implementation of precision medicine, enable discoveries and drive innovations using genomics.

Critically, this NCIG project will foster both existing and new partnerships with Indigenous communities through mutually agreed benefits of the genomics revolution. This project is funded by a National Health and Medical Research Council (NHMRC) Ideas Grant.



## Genomic Medicine for Indigenous Australians

**Project leads: Dr Ashley Farlow, NCIG; Ms Azure Hermes, NCIG; Assoc Prof Brendan McMorran, ANU**

Study of renal disease in the Tiwi Islands has been a multi-decade endeavour that has collected clinical data from more than 80% of the community and genetic data from approximately 40% of the community (although much of this data is currently not available to this project). Results from the “Characterising genetic variation”

project identified a potentially significant shortcoming in previous efforts to map this disease. This project is funded by a NHMRC Ideas Grant “Accounting for the demographic history of Indigenous Australians in genomic medicine” to enable re-analysis of this data.





# NCIG PARTICIPATION AND OUTREACH

## Dr Hardip Patel, Bioinformatics Lead NCG

- Enabling the Inclusion of Indigenous Australians in Precision Medicine, Lorne Genome Conference, 13–15 February 2022
- Microchromosomes are Building Blocks of Bird, Reptile and Mammal Chromosomes: Lorne Genome Conference, 13–15 February 2022
- The Canberra Health Annual Research Meeting, 27 July 2022, *virtual*
- Enabling the Inclusion of Indigenous Australians in Precision Medicine, The Asia Pacific Advanced Network, 25 August 2022
- BioChats by Australian BioCommons – monthly event, 6 September 2022
- Enabling the Inclusion of Indigenous Australians in Precision Medicine: ComBio, 27–30 September 2022
- Enabling the Inclusion of Indigenous Australians in Precision Medicine, Human PanGenome Reference Consortium Annual Meeting, 11 October 2022, USA
- Enabling the Inclusion of Indigenous Australians in Precision Medicine: American Society of Human Genetics, featured plenary presentation, 25–29 October 2022, USA
- Enabling the Inclusion of Indigenous Australians in Precision Medicine: Human Genetics Society of Australasia, 24–27 November 2022

## Ms Azure Hermes, Deputy Director NCIG

- Introduction to NCIG, – Marramarra Murumbang Mawambul, 11 May 2022
- What Does Winning Look Like? Australian Genomics, 30 May 2022
- Introduction to NCIG, Sing Workshop, 14 June 2022
- Presentation to group attending the Genetic Counselling Course, University of Technology Sydney 12 August 2022
- Panel Member, National Member Conference – Aboriginal Community Controlled Health Organisation (AACHO) 17–20 October 2022
- Indigenous Community Perspectives on Genomic Data Sharing, Genomic Data Sharing Workshop, 15–17 November, Hobart

## Committees

- Multi Stakeholder Advisory Group – University of Queensland
- Global Alliance for Genomics & Health (GA4GH) – Advisory Group
- Undiagnosed Disease Network – Australia Steering Committee
- UDN–Aus – Indigenous Advisory Committee
- Australian Genomics Policy Network
- Human Genetics Society of Australasia – Indigenous Genomics Steering Group
- Yalu Research Committee
- Sing Australia Working Group
- Human Cell Atlas Outreach Australia
- Indigenous Health and Wellbeing Grand Challenge Executive Committee
- Connect Executive committee
- Aboriginal and Torres Strait Islander Advisory Group on Health Genomics

# JUSTICE, EQUITY AND ENGAGEMENT WITH INDIGENOUS COMMUNITIES

“This moral right of Indigenous peoples to retain control over their life stories by controlling what is done with their DNA, in some ways gives ultimate meaning to the slogan “Nothing about us without us”. Because there’s nothing that’s more definitively “about us” than our DNA and the genomic sequence it’s arranged into, to give us life and make us who we are.”

Prof Megan Davis



▲ *Professor Megan Davis is an Aboriginal woman (Cobble Cobble) from southeast Queensland and of south-sea Islander descent (Vanuatu). She is a constitutional and human rights lawyer and professor of Law, and Pro Vice-Chancellor Indigenous at UNSW.*

Prof Davis was a co-architect of the Uluru Statement from the Heart and is Co-Chair of the working group to progress the Referendum on the First Nations Voice to Parliament. Prof Davis served on the NCIG Governance Board from July 2019 to December 2022. Her Summer Oration – Life Story was kindly delivered by Assoc Prof Pat Anderson AO.



▲  
 Assoc Prof Pat Anderson AO, Co-Chair of the Voice to Parliament and Chair of the Lowitja Institute, delivered the inaugural NCIG Summer Oration on behalf of Prof Megan Davis, with Prof Alex Brown, at ANU 13 December 2022. Assoc Prof Anderson is an Alyawarre woman known nationally and internationally as an advocate for the rights and health of Aboriginal and Torres Strait Islander people.

# LIFE STORY

## BY PROF MEGAN DAVIS

*\*This excerpt of the inaugural Summer Oration Life Story by Prof Megan Davis, was delivered on behalf of Prof Davis, by Assoc Prof Pat Anderson AO, at the ANU on 13 December 2022.*

**Controlling our own DNA** allows us to take control of our genetic story and therefore gain control over the building blocks of our own lives.

What's our life story? How do we take back control of it?

It's a central question of all Black and First Nations survival.

And when you possess very little, sometimes that life story can be the only thing of value you have to hand down to your children and grandchildren and community.

This moral right of Indigenous peoples to retain control over their life stories by controlling what is done with their DNA, in some ways gives ultimate meaning to the slogan "Nothing about us without us". Because there's nothing that's more definitively

"about us" than our DNA and the genomic sequence it's arranged into, to give us life and make us who we are.

The fact that we can use science to tell the story of life is an incredible human achievement.

The men and women who began this amazing scientific journey by unlocking the double helical structure of DNA – James Watson, Francis Crick, Rosalind Franklin, Maurice Wilkins and others – were brilliant scientists. Their discovery laid the basis for today's genomic research, with its almost limitless possibilities for medical advances.

I wonder if they knew they were creating not just the story of life... but the life stories of individuals? Of communities? Of mobs? Providing precise answers to the big, personal questions.

**Who am I?**

**Where did I come from?**

**What might become of me?**

For many, these questions are incredibly important. And sometimes incredibly painful.

Finding the answer, and therefore someone's life story, can be a source of pride and self-confidence and therefore of strength and survival for them.

This is the broad moral basis behind the creation of the National Centre for Indigenous Genomics back in 2013 chaired by the Aboriginal and Torres Strait Islander Social Justice Commissioner, Mick Gooda.

Its practical task is to bring to Indigenous communities the health benefits made possible by genomics and precision medicine.

These potential health benefits are enormous. Only the future of science will determine just how enormous they will be.

Scientists are creating rich libraries of human genetic variation, allowing us to gain greater understanding of the human genome and the molecular basis of disease.

It is being used to help treat cancers, in prenatal screening and in treating rare diseases.

With the creation of the Centre, which oversees some 7,000 Indigenous genetic samples in the NCIG Collection, we can ensure Indigenous Australians can also enjoy the benefits of this age of genomic medicine.

Currently these genomic databases are biased towards people of European ancestry. Indigenous Australians, like Indigenous peoples worldwide, are not adequately represented.



▲ Assoc Prof Pat Anderson AO and ANU Chancellor The Hon Julie Bishop and guests enjoy the opening of the inaugural NCIG Summer Oration.

This has to be rectified. If it isn't, Indigenous people around the world, including here, will be excluded from the benefits of modern genomic medicine.

And that would widen further the already far too wide inequalities in health and life expectancy. Turning tragedy into further injustice.

With a sufficient knowledge base, the scientific power of genomics can be used to better understand and combat diseases that are all too frequent among Australian First Nations peoples.

Diseases we are sadly all too familiar with, like kidney disease, rheumatic heart disease, diabetes, mental health problems.

According to the Australian Institute for Health and Welfare, today an Indigenous Australian is almost four times more likely than other Australians to have diabetes or pre-diabetes. And twice as likely to

have signs of chronic kidney disease. Almost 1-in-5 Indigenous Australians suffer from it. It's terrible. And the risks increase quite dramatically if you live in a remote community.

Now we already know that many health conditions that afflict Indigenous Australians are driven by socio-economic inequality, diet, unemployment, poor housing, the mental by-products of historical and contemporary injustice. The answers don't just lie in medical science.

But we also know that when those other factors are controlled, some Indigenous people are genetically disposed to higher incidence to some chronic diseases. And these diseases are sometimes less responsive to treatments developed for non-Indigenous people.

***We need to know why.***

***We have a duty to find out the answers why.***

***Genomics can help tell us.***

## Engaging and Building Partnerships with Communities

NCIG's Community Engagement remains altered in the ongoing wake of COVID-19. However, NCIG has continued to prioritise, engage and build relationships with communities, in innovative ways where necessary.

This year's highlights include:

### The visit of the Walpiri people of Yuendumu and Lajamanu to NCIG at ANU

- NCIG was delighted to welcome representatives to the Center and grateful that they made the trip to meet our team and learn about the NCIG Collection.

### Working with the Anindilyakwa Land Council

- NCIG held initial discussions with the Anindilyakwa Land Council of Groote Eylandt to begin engagement with the community. Members of Anindilyakwa Arts, an initiative of the Anindilyakwa Land Council, visited NCIG in December.



- ▲ NCIG's Director Prof Graham Mann and Deputy Director Ms Azure Hermes welcomed the Walpiri people of Yuendumu and Lajamanu to John Curtin School of Medial Research, ANU, Canberra in October.

### Building our partnerships

- The importance of our community partners and the trusted relationships that we share was evident again this year. NCIG has been discussing new ways of working together with community partners like Yalu Aboriginal Corporation (Galiwin'ku and Milingimbi, NT), Ninti One (Alice Springs, NT), and KALACC (in the Kimberley, WA) to undertake respectful, appropriate community engagement in their regions.

### Investing in future leaders

- NCIG hosted two events this year where the focus was on engaging Indigenous students, our future leaders. Each session involved an introduction to NCIG and the work we undertake, plus a laboratory exercise designed to contextualise and engage the students in the science. As always, the diversity and energy in these groups is an exciting indication of our future.
- In September NCIG hosted around 30 young women in Years 8 and 9 who were participating in the **CSIRO Young Indigenous Women's STEM Academy**.
- In December NCIG also hosted the **2022 cohort of the National Indigenous Summer School** (photo below).





**Podcast: Community Engagement and Consent: \*Collaboratory conversations series, released 2 December 2022**

*\*Collaboratory is produced by the Scaffolding Cultural Co-creativity Project hosted by the Centre for Heritage and Museum Studies in the College of Arts and Social Sciences at the Australian National University*



NCIG's Deputy Director & Community Engagement Coordinator Azure Hermes, a Gimuy Walubara Yidinji woman, helps to build the Galiwin'ku Memorial Garden on Elcho Island. Samples held in the historic NCIG Collection were repatriated to the Galiwin'ku Community in 2019 with a moving ceremony and unveiling of burial poles in the community's centre. The community and individuals gave permission for these samples to be sequenced and the data to be retained in the NCIG Collection.

In May 2021 duplicate burial poles were unveiled during a similar ceremonial event with community Elders and members at the John Curtin School of Medical Research to mark the Galiwin'ku community's strong connection with the ANU and their ongoing commitment to research in collaboration with NCIG and the University.





# 2 NCIG BY 2027

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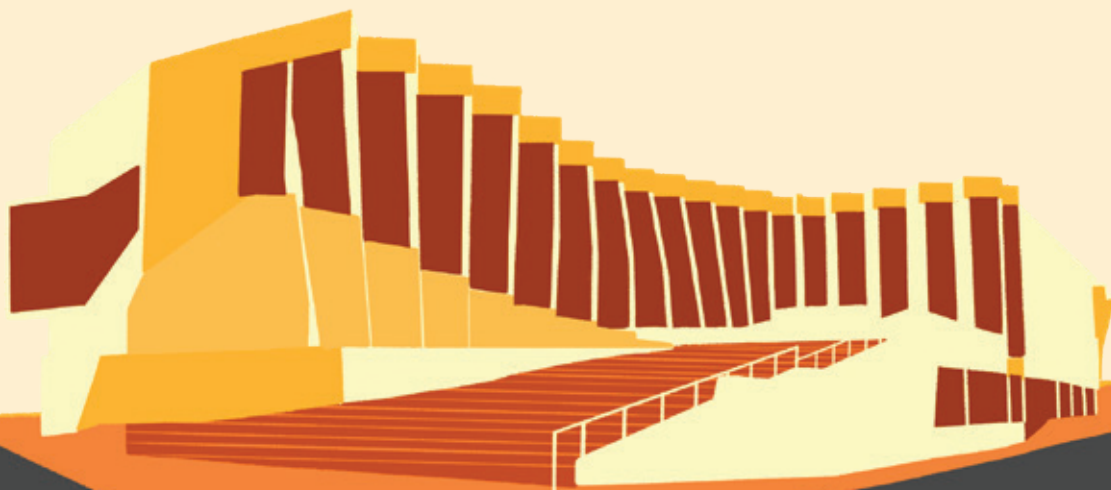
# OUR VISION

Under Indigenous governance, the unique historic, and growing NCIG Collection of biospecimens, genomic data and document archive is a national Indigenous genomic data resource of international significance. This NCIG Collection is enabling Australia's First Peoples to directly benefit from genomics-led precision and personalised medicine.

# OUR MISSION

Under best-practice Indigenous governance and in partnership with Australian Indigenous communities, NCIG:

- develops and manages Australia's Indigenous genomic data resource;
- uses a research model that places Indigenous Australians in charge of their genomic data and its use. Through consultation and engagement with Indigenous communities, individuals will determine if, for what, and how their data and records may be accessed and used for research;
- provides a safe, permanent, national keeping place for the historic and growing Collection comprising biospecimens, genomic data and historical and contemporary records.





# OVER THE NEXT 5 YEARS OUR CENTRE WILL FOCUS UPON –

## Building a sustainable future – caring for the collection

**Sustainability, Resource and Capacity Building** – securing sustainable funding for core infrastructure and personnel resources. This will ensure NCIG’s capacity to meet custodial, community engagement, research and ethical responsibilities; minimise risk, and to realise the Centre’s vision and mission to advance Indigenous genomics and deliver health benefits to Indigenous Australians.

## Driving a research agenda to benefit Indigenous Australians

**Leading, Participating, Supporting Research** – implementing a research strategy comprising three objectives - *to Lead, to Participate and to Support* high quality research that benefits Indigenous people in accordance with their priorities. During the next five years NCIG will determine key steppingstones - *the core people, the core science and the research agenda* to drive both the work of NCIG and support the national Indigenous genomic scientific agenda within this five-to-ten-year timeframe.



## Growing our community engagement capacity and outreach

**Indigenous Partnerships, Fulfilling Obligations and Commitments** – building team capacity and financial resources to enable the Centre to fulfill its obligations and commitments *to engage with and consult* Indigenous Australians. Our Centre’s engagement objectives will align with Community needs and benefits, and research priorities. Incorporating Community Engagement in grant funding and forging research partnerships will enhance the Centre’s capacity and open opportunities for consultation with Communities. NCIG will deliver targeted, engaging digital communications and compelling philanthropic programmes to support and fund NCIG’s Community engagement objectives.

### NCIG Governance Board

The primary function of the NCIG Governance Board is to be the custodian of the Collection.

As a custodian of the Collection, the Board is responsible for the management and use of the Collection, and for the appropriate addition of material to the Collection, in accordance with international standards. *ANU NCIG Statute 2021*



# 3 NCIG INDIGENOUS GOVERNANCE AND FINANCIAL REPORTS

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# NCIG INDIGENOUS GOVERNANCE

**The NCIG Governance Board** meets four times per annum. The role of the Indigenous-majority Board is constituted under the ANU NCIG Statute 2021.

The Statute commits the Australian National University (ANU) to ensuring that:

- the Collection is under Indigenous custodianship
- there is proper engagement with Indigenous people and the communities from which samples, records and data are collected
- appropriate consents are obtained for research using the Collection
- in accordance with the Statute, the ANU Council delegates the custodianship of the NCIG Collection to the NCIG Indigenous-majority Board. As custodian, the Board is responsible and accountable for the management, use, and appropriate addition of material to the Collection.

[Read more about the NCIG Governance Framework](#)



▲ ANU Chancellor *The Hon Julie Bishop* introducing Assoc Prof *Pat Anderson AO* who delivered the inaugural NCIG Summer Oration.

On behalf of Vice-Chancellor Prof Brian Schmidt, NCIG and the University, Chancellor Bishop welcomed guests to the inaugural NCIG Summer Oration.

Chancellor Bishop began by saying,

“Over the last 76 years, ANU has met its mission through its people – for our students - our academics are among the best and brightest - they have become public and private sector leaders. We have Nobel laureates, ministers, business leaders, community leaders - people who are dedicated to changing the life of their times for the better.

“We have met our mission through our research from physics to philosophy – we have met our mission through our values – our culture, not just what we say, but what we do as an institution, and the exemplar of all that is the National Centre for Indigenous Genomics.”

## Governance Board Meetings and Attendance 2022

Board Member	Meeting 1 28 March Online	Meeting 2 15 June 2022 Online	Meeting 3 26 Sept 2022 Online	Meeting 4 13 Dec 2022 ANU/JCSMR
Assoc Prof Glenn Pearson – Chair	Apologies	✓	✓	✓
Professor Megan Davis	✓	Apologies	Apologies	Apologies
Dr Lyndon Ormond-Parker	✓	✓	✓	✓
Prof Marcel Dinger		✓	✓	✓
Prof Gareth Baynam	✓	✓	✓	✓
Professor Keith Nugent	✓	✓	Apologies	✓
Ms Erica Kneipp	✓	Apologies	Apologies	✓
Prof Yvette Roe	✓	Apologies	Apologies	✓
Mr Benjamin Murray	✓	✓	✓	✓
Ms Janine Mohamed – Deputy Chair		First meeting	✓	✓

## Retirements

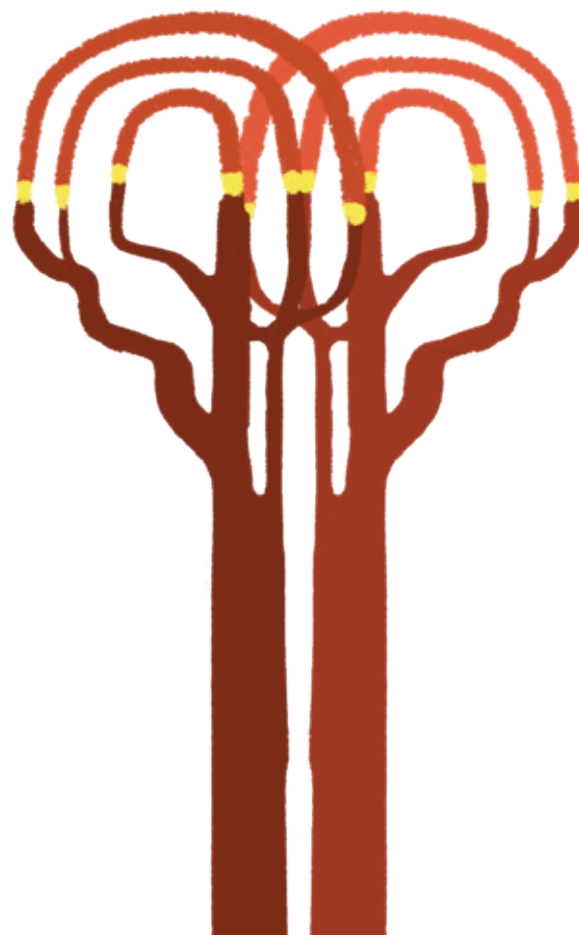
- Ms Jackie Stenhouse retired as NCIG Board Secretariat in March 2022. Jackie's involvement in NCIG extends from 2012 when the Consultative Committee on the Indigenous Collection was convened which led to the recommendation to establish NCIG in 2013. The Board conveyed its sincere thanks to Jackie and acknowledged her outstanding 10-year contribution and commitment.
- Board members Prof Megan Davis and Prof Marcel Dinger retired from the Board 31 December 2022.

Acknowledging Prof Dinger's scientific contribution Chair Glenn Pearson said "your role to help us in terms of the science has been immeasurable – an incredible comfort and security that you've been on the journey with us".

Glenn Pearson expressed his gratitude to Prof Megan Davis upon her retirement from the board especially paying respect to her commitment to The Voice "– we have been discussing this work she is doing around The Voice – it's a tough journey – taking this story back out to our communities to put a proposition out for them to think deeply and consider having this constitutional voice in recognition of the unique relationship that Aboriginal and Torres Strait Australians have with white Australia".

## Appointments

- Ms Janine Mohamed joined the board in 2022, attending her first meeting in June 2022. Ms Mohamed was elected Deputy Chair of the Board at the Board meeting held 24 September 2022.



## Fundraising Committee

*The Fundraising Committee comprises Board members including: Assoc Prof Glenn Pearson (Chair), Prof Megan Davis, Mr Ben Murray, Ms Erica Kneipp.*

- This Committee met on Friday, 16 September 2022. Attendance: Glenn Pearson (Chair), Ben Murray, Erica Kneipp. The Chair issued an apology on behalf of Megan Davis. NCIG Team: Ms Azure Hermes and Ms Prue Beckett.
- **Fundraising Priorities and Strategy:** The committee, in consultation with the NCIG team, agreed specific, targeted funding priorities would lead the development of NCIG's annual fundraising and PR/communications strategy. Committee agreed fundraising and communications would be included in the new five-year Strategic Plan – NCIG by 2027.
- **NCIG inaugural Summer Oration 2022:** The Committee unanimously endorsed the proposed inaugural Summer Oration, held 13 December 2022 at the John Curtin School of Medical Research, ANU. The aim of this high-profile annual event is to build awareness, connections and support of NCIG.



- ◀ NCIG Governance Board Chair, Assoc Prof Glenn Pearson introducing musician and composer, and Queensland Australian of the Year 2023, Mr William Barton at the Inaugural Summer Oration held at the ANU John Curtin School of Medical Research on 13 December.

- ▼ William Barton, composer, vocalist and multi-instrumentalist, and Queensland Australian of the Year 2023, gave a moving, dramatic performance for guests at NCIG's Summer Oration.



- ▲ Aunty Matilda House welcomes guests to Country at the NCIG inaugural Summer Oration. Aunty Matilda is a proud Ngambri-Ngunnawal woman who has a long and respected association with the ANU.



# 2022 NCIG FINANCIAL REPORTS

## 2022 Financial Statement

	ANU NCIG Operational Funding	External Grant Funding	Philanthropic Donations
<b>Open Balance</b>	\$-	\$146,557.85	\$54,860.38
<b>Income</b>			
Operating & Project Grants	\$734,176.00	\$643,125.12	
<b>Operating Expenses</b>			
Salaries	\$565,847.99	\$130,704.74	
Equipment	\$5,425.09	\$72,297.18	
Scholars' expenses			
Travel and fieldwork	\$47,587.44	\$5,602.59	
Expendable research materials	\$16,387.98	\$237,395.71	
Contributions			
Consultancies	\$25,970.50	\$240.00	
Consumables	\$21,927.46	\$1,337.57	
Internal purchases			
Other expenses	\$15,056.73	\$2,755.45	
<b>Net result</b>	<b>\$35,972.81</b>	<b>\$339,349.73</b>	<b>\$54,860.38</b>

## ANU NCIG Operational Funding and Grant Funding Awarded 2022/2023

*Grant/Funding Source	Funding 2023	Remaining Period	Total Remaining Funding
ARC DECRA	\$123,333.00	2 Years	\$246,666.00
NHMRC Aust Genomics	\$239,327.00	1 Year	\$239,327.00
MRFF Synergy - Domain 1	\$ 200,000.00	5 Years	\$1,000,000.00
MRFF Synergy - Domain 2	\$65,680.00	5 Years	\$328,400.00
MRFF Synergy - Domain 3	\$51,000.00	5 Years	\$255,000.00
MRFF GHFM S4 (Brown)	\$180,000.00	5 Years	\$ 900,000.00
MRFF GHFM S6 (Jiang)	\$90,000.00	2 Years	\$180,000.00
ANU Grand Challenge	\$150,000.00	3 Years	\$450,000.00
MRFF GHFM S3 (Newson)	\$ 80,000.00	5 Years	\$400,000.00
MRFF GHFM S6 (Deveson)	\$ 149,000.00	2 Years	\$298,000.00
MRFF GHFM S5 (Brown)	\$1,600.00	5 Years	\$8,000.00
NHMRC Idea Grant - (Patel)	\$630,246.00	3 Years	\$2,044,098.00
NHMRC Idea Grant - (Farlow)	\$ 293,333.33	3 Years	\$879,999.99
ANU JCSMR Operational Funding	\$320,000.00	3 Years	\$960,000.00
ANU DVCRI Operational Funding	\$ 150,000.00	3 Years	\$450,000.00
<b>Grand Total</b>	<b>\$2,723,519.33</b>		<b>\$8,649,164.99</b>

### \*Glossary of funding Bodies

Commonwealth Government – Australian Research Council (ARC) – Discovery Early Career Research Award (DECRA)  
 Commonwealth Government – Medical Research Future Fund (MRFF)  
 Commonwealth Government – National Health & Medical Research Council (NHMRC)  
 Australian National University (ANU) - John Curtin School of Medical Research (JCSMR)  
 Australian National University (ANU) - Deputy Vice Chancellor Research & Innovation (DVCRI)

NCIG acknowledges the financial support of these organisations:

- The Australian National University
- Bioplatforms Australia
- National Computational Infrastructure
- National Health & Medical Research Council (NHMRC)
- Medical Research Future Fund (MRFF)
- The Kinghorn Foundation, Garvan Institute of Medical Research

# OUR TEAM

## Director

Professor Graham Mann

## Deputy Director & Indigenous Community Engagement coordinator

Ms Azure Hermes

## Bioinformatics Lead

Dr Hardip Patel

## Project Manager/Board Secretariat

Ms Prue Beckett *(from July 2022)*

## Community Engagement Officer

Ms Alice McCarthy *(from Nov 2022)*

## ELSI Lead/Research Manager

Dr Sharon Huebner

## Data Manager

Ms Jiaxin Yuan

## Research Officer

Mr Duminda Dissanayake *(to Sept 2022)*

## Administration/Board Secretariat

Ms Jackie Stenhouse *(retired March 2022)*



▲ Pictured L to R: Alice McCarthy, Rubijayne Cohen, Jiaxin Yuan, Bridie Moy enjoying the NCIG Christmas dinner held on 12 December with NCIG and TKI board members, and our NCIG Canberra and interstate research team. NCIG was delighted to welcome ANU Chancellor The Hon Julie Bishop, ANU Vice Chancellor Prof Brian Schmidt and Prof Alex Brown who also joined the end of year festivities.

## 2022 Team Appointments



**Ms Alice McCarthy – Community Engagement Officer:** Alice first connected with NCIG as an intern in 2017, and subsequently worked with NCIG in 2018 and 2019. Alice has returned to NCIG in November 2022 in a Community Engagement role after three years working in Galiwin’ku as the

Program Manager at Yalu Aboriginal Corporation; a Yolŋu organisation delivering community development programs and supporting research for the benefit of Yolŋu.

Alice’s current role will involve consultation with communities on NCIG’s historical Collection as well as working in partnership with Aboriginal and Torres Strait Islander Community Controlled Health Organisations to develop education and engagement resources that reflect community priorities through an Australian Genomics funded project *Building Genomic Knowledge in Partnership with Indigenous Communities and Health services*.



**Prue Beckett – Project Manager | Board Secretariat:** Prue joined the NCIG team in July following nine years in primary health care as general manager of large medical group on the south coast of NSW.

Prue is a management and communications professional with extensive experience working with federal and state government, prominent public institutions plus private sector companies and prestige global brands. In this new, broad role, Prue joins NCIG’s leadership team and manages the NCIG Governance Board secretariat. Prue is providing the leadership and management of key NCIG programmes and projects and is working with the Director, Deputy Director and Board to help guide NCIG strategic and operational planning and implementation.



## PhD Students

### Investigating the link between A20 variants and chronic kidney disease burden in the Tiwi Islands



**Ms Bridie Moy** is a Wiradjuri woman who grew up in Batemans Bay (Yuin country). She completed a Bachelor of Science at the ANU, majoring in human biology and specialising in biomedical science. In 2022, Bridie completed her Honours project with NCIG research collaborator, Dr Simon Jiang.

Her project focused on investigating rare variants in the Autoimmune Regulator gene (AIRE) that are found in the Tiwi Islander population, and how they might be associated with kidney disease.

During this time, Bridie developed a passion for Tiwi Islander health, and has decided to continue her research in this area during her PhD. However, during her PhD, she will be focusing on variants in the A20 gene commonly found in the Tiwi, and how they impact on molecular pathways contributing to kidney disease burden.

Bridie begins her PhD in 2023, and will again be supervised by Dr Simon Jiang. She hopes that one day, her research will lead to therapeutics being developed that will improve Tiwi Islanders' quality of life

### Benefit sharing genomic research: co-developing guidelines to communicate genomic science research to empower Indigenous communities

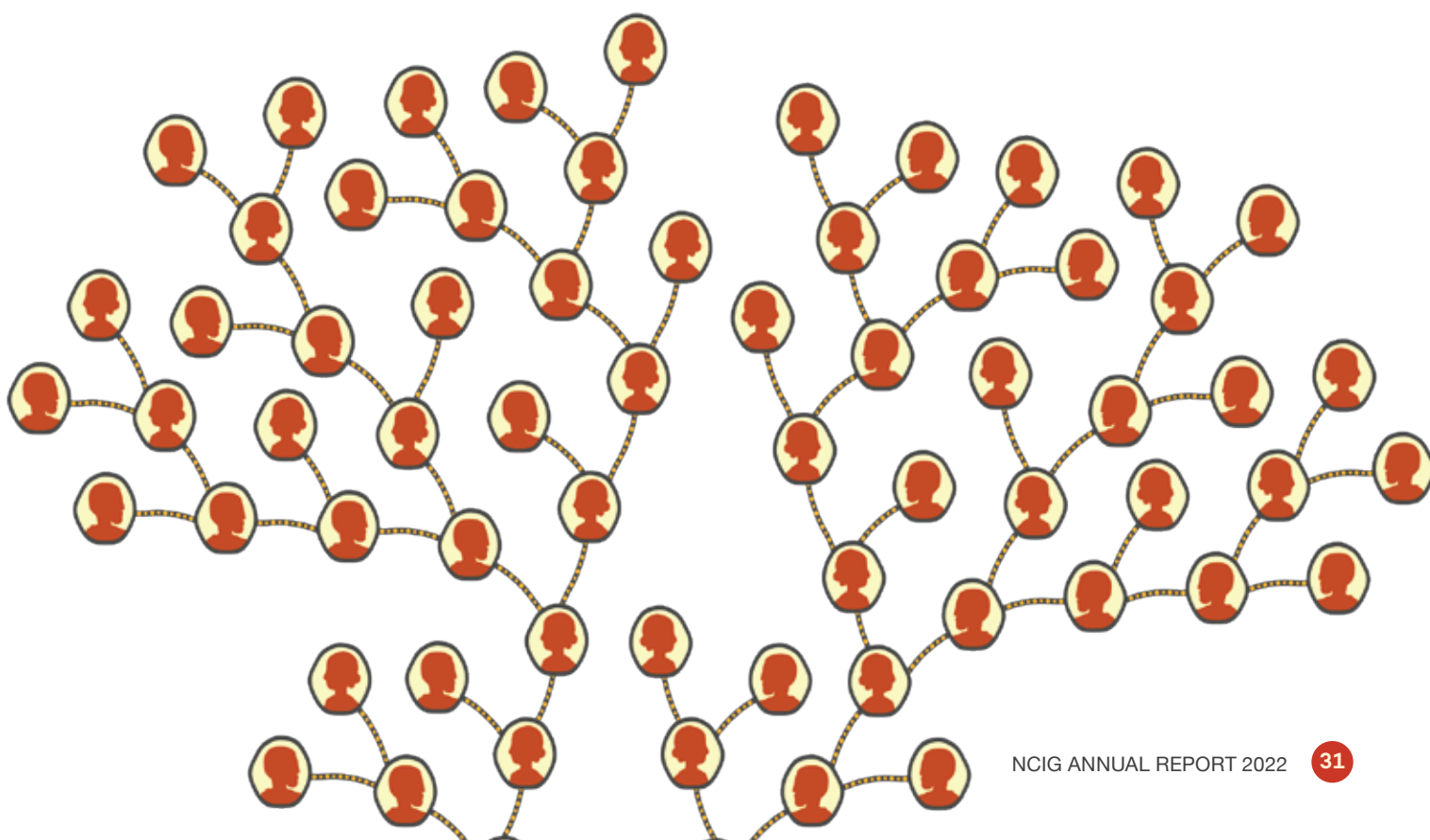


**Ms Rubijayne Cohen** is a Wiradjuri woman with familial ties to Peak Hill in the Central West of New South Wales. She completed a Bachelor of Science (Psychology) and Bachelor of Science, majoring in biology and minoring in molecular biology at ANU (2016) and a Graduate Diploma in Education Studies from the

University of New England (2021).

Rubijayne has four years' experience in Aboriginal and Torres Strait Islander health and wellbeing research with a focus on data management and creating resources to communicate tailored data back to Indigenous communities and service providers.

Rubijayne will begin her PhD in 2023, supervised by Dr Sharon Huebner. Rubi's project will detail the ethical and cultural considerations in communicating genomic research for Indigenous peoples and demonstrate how this can empower communities using a case study analysing genomic variation within four Indigenous communities in the Northern Territory.





**NCIG**

NATIONAL CENTRE  
FOR INDIGENOUS  
GENOMICS



Australian  
National  
University

## National Centre for Indigenous Genomics

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#### NCIG Governance Board - Secretariat

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