

ANNUAL REPORT 2024

Our DNA • Our people • Our stories • Our way

ACKNOWLEDGEMENT OF COUNTRY

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.

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DIRECTOR'S MESSAGE



The role of the National Centre for Indigenous Genomics (NCIG) is to ensure Indigenous Australians are at the forefront of benefits that flow into the national health system from the integration of genomic knowledge and technology. Established through federal statute under the ANU Act 1991, NCIG represents a significant milestone in advancing biomedical research and improving Indigenous health outcomes in Australia. By combining Indigenous decisionmaking, through an Indigenous-majority governance board, with high-value biomedical research and related infrastructure, NCIG ensures that Indigenous Australians lead the transformation of medical research and healthcare using genomic knowledge and technology.

NCIG's interdisciplinary framework bridges the gap between Humanities, Arts, and Social Sciences (HASS) and Science, Technology, Engineering, Mathematics, and Medicine (STEMM). This ensures that, beyond technical and scientific advancements, NCIG's work respects and incorporates the social, cultural, and ethical dimensions of Indigenous health research.

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At a time when global genomic science recognises the importance of ancestrally diverse populations, NCIG is poised to lead Australia's Indigenous genomics agenda.

Understanding under-represented populations is key to unlocking the next era of genomic discoveries breakthroughs that could reshape healthcare for all of humanity.

Guided by its 2023–2027 strategic plan, NCIG remains committed to strengthening operational sustainability and technical capacity while staying true to its core mission: generating new genomic data and pioneering an innovative research model that delivers real health and medical benefits to Indigenous Australians. The strategic goals of NCIG are:

- 1. Caring for the NCIG Collection
- 2. Advancing a research agenda to benefit Indigenous Australians
- 3. Enhancing community engagement and outreach capacity.

In every way, 2024 was a remarkable year. Through focused execution and unwavering dedication, NCIG made significant strides toward these goals. This success is a testament to the passion, creativity, and expertise of the NCIG team, whose achievements are recorded in this Annual Report.

Professor Alex Brown NCIG Director

STRATEGIC GOAL 1 BUILDING A SUSTAINABLE FUTURE - CARING FOR THE COLLECTION



Sustainability, Research 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.

The NCIG Collection comprises biospecimens, historical documents, genomics data, social science artefacts and audio-visual stories of Indigenous peoples securely located within The John Curtin School of Medical Research (JCSMR) at the Australian National University (ANU) under the custodianship of an Indigenous-majority governance board.

Caring for the Collection is a core NCIG responsibility, and we acknowledge the financial and in-kind support given by ANU to help sustain the Collection. Important initiatives to protect and improve the conditions of the biospecimens and data within the Collection were consolidated during the year.

Image: Carly Conlan (left) and Natasha Best (right) in the NCIG laboratory



1.1 Biospecimens

Over 7,000 biological samples are carefully preserved at JCSMR in –80°C freezers and liquid nitrogen tanks, awaiting decisions from participants and their families on their use. In recent years, significant progress has been made in cataloguing this biospecimen collection using advanced sample management software. This modernisation ensures that handling, processing, storage, and documentation meet both national and international standards.

Building on these improvements, 2024 saw further upgrades to the physical storage and security of the biospecimens. The first major step was consolidating samples from 67 boxes down to just 10 — freeing valuable freezer space for new donations and improving search efficiency and access. These samples are now securely housed in a new -80°C freezer, acquired in 2023 by NCIG and fully under its control. This move minimises the risk of sample loss due to equipment failure and uncontrolled relocations in emergencies. Additionally, following best practice for biorepositories, duplicate samples were strategically distributed between -80°C freezers and liquid nitrogen tanks. This ensures greater protection against mechanical failures, safeguarding the integrity of the collection.

Senior Technical Officer Ms Carly Conlan led these critical enhancements, reinforcing NCIG's commitment to maintaining world-class biospecimen management.

1.2 MediaFlux Data platform implementation

Mediaflux is a mature and rich software platform designed in Australia that can be used to curate, manage, protect and disseminate large volumes of structured and unstructured data. NCIG and the National Computational Infrastructure (NCI) have been collaborating for several years to develop the capability to securely manage genomic information using the MediaFlux platform. While the push to ethically handle sensitive genomic information is strong across all genomic research areas, for NCIG and its unique collection, it is an inarguable requirement. Along with the development of the required technologies and protocols, NCIG and NCI are exploring appropriate ways of representing the data. True to its values, NCIG's data collection protocols are developed in consultation with the Indigenous communities to whom the data belongs.

This collaboration has led to innovations with both national and global implications. Around the world, research institutions are tackling the challenge of controlled, ethical access to genomic data collections. The NCIG-NCI partnership represents a significant step forward, positioning NCIG as a leader in shaping best practice.

1.3 Collection Access and Research Advisory Committee (CARAC) platform

The Collection Access and Research Advisory Committee (CARAC) is a sub-committee of the NCIG governance board responsible for reviewing research proposals that seek access to materials in the NCIG Collection. It evaluates applications and provides recommendations to the Board on their suitability.

In 2024, a long-anticipated milestone was achieved—the digitisation of CARAC's workflow. Given the unique and diverse nature of the NCIG Collection, it has always been clear that researchers from a wide range of disciplines would find it valuable. To streamline access, assessment, and management of applications and approved projects, an online system was essential. To meet this need, a tailored digital service was developed within ANU using the Conduit platform. Originally designed for managing ANU Human Ethics research applications, Conduit is an enterprise-level system overseen by the Research Services Division. This ensures that NCIG's CARAC workflow remains up-to-date, sustainable and supported by robust technical resources.

Data Manager Ms Jiaxin Yuan was the NCIG lead on this project.

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1.4 Metadata

Jiaxin Yuan conducted a project to restructure the NCIG Collection metadata. This initiative involved creating a "unique identifier pair" to link all available genomic sequencing data in the NCIG Collection directly with corresponding source samples and participants' consents. With all data now correctly curated and stored, this metadata database will allow automated management of genomic information. Audit-tracked workflows have been developed for better reporting and presentation of information. Completion of this work will support the creation of variant databases in the future.



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STRATEGIC GOAL 2 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 stepping stones – 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 5–10 year timeframe.

NCIG's strategic vision aligns with a transformative moment in the era of genomics and precision medicine. As the Human Reference Genome Project marks 30 years since its inception, the global scientific community is increasingly recognising the critical role of diversity in genomic research. While much of this focus has been on integrating ancestrally diverse data into large-scale reference databases, NCIG and its partners—both in Australia and abroad—are advancing a more ambitious agenda.

This vision goes beyond inclusion; it acknowledges the distinctiveness of Indigenous peoples and their invaluable contributions to understanding human variation in all its complexity. Through advocacy, leadership, and groundbreaking research, NCIG is ensuring that Indigenous communities engage with genomics on their own terms. More importantly, we are working to ensure that the benefits of genomic research—and its role in modern science and society—are shaped and guided by Indigenous peoples themselves.

2.1 Research update

NCIG's research program leverages interdisciplinary expertise to reflect the strategic directions of NCIG. Rather than operating in isolation, our projects are designed to inform and support one another, creating a dynamic research ecosystem. This integrated approach accelerates the delivery of high-quality, impactful research and resources, all aligned with our strategic objectives.

- NCIG and its partners are **leading two large scale national programs,** both of which have sparked satellite projects, which iteratively enhance the value of our collective effort.
 - CONNECT, Consortium for National Indigenous Genomics Capacity, is a scientific program in Indigenous genomics focussing on improving genomic literacy; best practice data sovereignty; development of genomic reference datasets; the genomics of complex disease; translational research; and Indigenous genomics workforce capacity.

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• ALIGN, the Australian Alliance for Indigenous Genomics, is developing a national approach for the implementation of genomics benefits to Indigenous Australians.

These two large programs, and their associated projects, are concurrently creating:

- genomic data resources for health and medical research, and
- the knowledge and tools needed to ensure Indigenous Australians are in charge of their genomic data and its use.

Instead of describing each project individually, we present our research here through the following key themes:

- Indigenous consent, control, knowledge and capacity-building
- Data governance and systems
- Genomic reference resources
- Medical research

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Indigenous consent, control, knowledge and capacity-building.

Research and capacity-building projects create the knowledge and tools needed to ensure Indigenous Australians are in charge of their genomic data and its use. In 2024, a significant, innovative body of work was completed.

CONNECT is a grassroots foundationbuilding program that empowers Indigenous communities in genomic medicine. Headed by NCIG Director Professor Alex Brown, CONNECT is divided into five domains of work collaboratively distributed amongst Australian universities and medical research institutes. NCIG leads Domain 1, an ELSI (ethics, legal and social issues) program, and contributes to Domain 2 (data management and data sovereignty) and Domain 3 (genome biology), all discussed below and elsewhere in this report.

Aboriginal and Torres Strait Islander communities and health organisations need to have access to culturally appropriate and accurate information so they can make informed decisions about their engagement in genomic medicine and research.



Lyndsay Newett, Alice McCarthy and Deb Marburg near Darwin, for community consultation field work

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It is vital for this information to reflect community priorities and concerns. Collecting, analysing and actioning these views is one of NCIG's core activities.

In 2024 fifteen workshops were run in Yarrabah (Queensland), Groote Eylandt (Northern Territory) and Galiwin'ku (Northern Territory), bringing together groups of Aboriginal and Torres Strait Islander peoples with rich and diverse experiences of rare disease, the health system, and lived experiences of genetic conditions. At the workshops, foundational questions about consent and use and storage of genomic data were explored, and specific resources were identified by and for communities to help them navigate the day-to-day challenges of genetic diseases and conditions, and the genomic health

system. Dr Lyndsay Newett, a Research Fellow with NCIG, was funded in part through a LINEAGE Targeted Research Grant to lead the workshops.

NCIG successfully secured supplementary funding from Australian Genomics to implement insights gained from the workshops. An initial tranche of \$250,000 was allocated to develop culturally informed resources on genomic medicine for national use, in collaboration with community organisations and Aboriginal and Torres Strait Islander Community Controlled Health Organisations. These resources include:

- two videos and three animations
- a comprehensive 16-page FAQ guide

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• an interactive map of genetic services state-by-state

This collection represents a valuable, high-impact set of plain-language, culturally appropriate materials to be hosted on a dedicated website

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To build on this success, Australian Genomics committed a second tranche of \$250,000 to translate these resources into five Indigenous languages, with translation work set for completion in 2025.

Additionally, feedback from the workshops highlighted the need to enhance cultural competence among clinical practitioners and genetic/ genomic service providers. Drawing on findings from the CONNECT, LINEAGE, and Australian Genomics-funded initiatives, NCIG secured a \$1 million competitive grant from the Medical Research Future Fund (MRFF) at the end of 2024. This funding will support the development of training modules and tools to be embedded in tertiary genetic counselling and physician training programs, ensuring clinicians are better equipped to deliver culturally appropriate care to Indigenous Australians. Course design will commence in 2025.

This extensive program was the work of a large team under the leadership of NCIG's Deputy Director Associate Professor Azure Hermes, including Ms Alice McCarthy, Dr Lyndsay Newett, Ms Lynne El Hassan, Ms Rubi-Jayne Cohen, Dr Rebekah McWhirter and Ms Deb Marburg.

Data governance and systems

NCIG's commitment to building a robust ethical framework for genomic research and healthcare is matched by its dedication to implementing the best available technical solutions for the storage, management, and use of genomic data in the NCIG Collection. NCIG actively participates in projects aimed at improving architectures and systems that support the responsible stewardship of Indigenous genomic data, both within its own collection and in collaboration with others. This work brings together computer scientists, data specialists, bioinformaticians, and genomic scientists, ensuring an integrated approach to ethical data management.

At the core of NCIG's efforts is a participant-centred model that grants individuals fine-grained control over the use of their genomic data. At the local level, NCIG continues to advance its data management frameworks, as outlined in Caring for the Collection (pages 2-4), to enhance the security, accessibility, and ethical governance of the NCIG Collection.

On a national level, NCIG is contributing to research that establishes standards and operationalises Indigenous data sovereignty principles. This approach prioritises *controlled access* over *open access* to Indigenous genomic data, reinforcing the rights of Indigenous communities over their information. As part of this commitment, NCIG is currently reviewing its collection management practices to assess compliance with these principles, using standardised metrics developed by Indigenous scholars and experts.

Genomic reference resources

NCIG is creating Indigenous genomic reference resources for clinical and biomedical research applications. Work by NCIG, published in Nature in 2023, indicates Australian Indigenous communities are profoundly diverse amongst themselves, as well as with reference to genomes of non-Australian populations, as expected.

Years of preparation to lay the necessary ethical, technical, scientific and financial foundations have enabled NCIG to obtain consents for the inclusion of 815 individuals in the genomic data collection. Almost 800 historical and new samples have now been processed to extract DNA. In partnerships with the Kinghorn Centre for Clinical Genomics and the Garvan Institute of Medical Research's Genomics Technologies Group (GTG), whole genome sequence data for 532 individuals has been obtained using Illumina, PacBio HiFi and ONT sequencing platforms. These data are being analysed to produce an Indigenous population variant library and high-quality Indigenous ancestry representative reference genomes.

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	Census	Donors	Yes	No	New sample
Tiwi Islands	~2,350	442	298	28	233
Galiwin'ku	~2,000	1241	237	58	63
Titjikala	~200	105	51	7	11
Yarrabah	~4,000	136	96	14	50
Groote Eylandt	~950	362	133	40	5
Total	~9,500	2,286	815	147	362

Table showing the number of donors (by community) whose samples are held in the NCIG Collection, the number of consents given to use of the historical samples, and the number of new samples donated to NCIG, as at end of 2024.

A population variation library

Bioinformatics Officer Mr Kirat Alreja is working with NCI and Garvan's GTG to create genome data analyses workflows using the Nextflow platform. Nextflow is an opensource workflow language. It allows units of bioinformatic analysis work to be linked from one software platform or programming language to another in an integrated pipeline. The use of Nextflow will streamline the pipeline development process and create reproducible workflows for future use.

NCIG began developing workflows for analyses of Illumina and ONT data for variant discovery. It introduced the use of the complete CHM-T2T reference in preference to the GRCh38 version of the human reference, and replaced GATK software by DeepVariant2 software for accurate variant discovery. Preliminary benchmark analyses using the global standards for variant calls were completed satisfactorily. These workflows will be implemented for all NCIG samples in 2025 to produce a comprehensive variant library.



An ancestry-representative reference genome in pangenome format

At the heart of NCIG's genomic research agenda is the determination of the pathogenicity, or otherwise, of novel disease-associated variants among Indigenous Australians. To achieve this, accurate community-specific or Indigenous-specific reference genomes are essential. They ensure precise genomic data analysis, reducing errors in interpretations, whether for individual diagnoses or for understanding the role of genomics in health and disease within Indigenous communities.

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In a large-scale collaboration with Garvan's GTG, UNSW, and UniSA, NCIG began generating high-quality genome assemblies for nine individuals from four communities. Using long-read sequencing technologies, including PacBio HiFi and ONT-UL platforms, the team produced data suitable for genome assembly. As a result, they were able to assemble most genomes with exceptional accuracy-significantly outperforming the widely-used GRCh38 reference genome. This work is uncovering valuable insights into genomic biology, structural variations, and population-specific differences. A major publication detailing these findings is expected in 2025.

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Medical research

NCIG's genomic reference resources are in active use for approved medical research projects.

Kidney Disease

Chronic kidney disease (CKD) is a serious health problem. The people of the Tiwi Islands suffer one of the highest known rates of CKD worldwide, and effective treatment and disease management strategies are limited by poor understanding of how and why it develops.

Associate Professor Simon Jiang, Associate Professor Brendan McMorran, Dr Vicki Athanasopoulos and NCIG PhD student Ms Bridie Moy (all from JCSMR) are leading projects that apply genetic and genomic methods to investigate the causes of CKD, using large-scale genome sequencing, laboratory-based studies using molecular and biochemical methods, and research and education activities in the Tiwi community.

The research rests on a long-standing and community-driven collaboration between NCIG, JCSMR, Menzies School of Health, Royal Darwin Hospital, University of Queensland and Queensland University of Technology. Consideration is being given to extending the research to Alice Springs, where CKD is also a major health problem amongst Indigenous Australians.

Pharmacogenomics

Pharmacogenetics is a field of research that focuses on how a person's genes will affect their response to medications. Most medicines are prescribed in a 'one-size-fits-all' manner, even though an individual's genetic makeup can significantly impact the effectiveness of the medicine, or worse, cause adverse reactions. Studying variation in an individual's pharmacogenes can help clinicians prescribe drugs that are better tailored to each individual, and minimise adverse reactions.

NCIG is collaborating with Professor Klaus-Martin Schulte of JCSMR on a project to establish an end-to-end discovery pipeline to identify variations in pharmacogenes and assess the impact of these variations in medicine metabolisms for Indigenous Australians. Indigenous bioinformatician Mr Adam Heterick has been recruited to the project. Mr Heterick is analysing confidential anonymised data from the Therapeutic Goods Administration and Australian Institute of Health and Welfare to identify the prevalence of adverse drug reactions by medicine types and Indigenous status. This will generate a list of priority medicines that affect Indigenous populations the most. Postdoctoral researcher Dr Eli Niktab, who joined the project mid-year, will use genomic data to identify and prioritise genetic variants for functional testing and validations to improve drug prescriptions, treatment efficacy and eliminate adverse drug reactions.

NCIG Bioinformatics Lead, Associate Professor Hardip Patel at the Garvan Institute of Medical Research

2.2 NCIG advocacy and leadership

Through invited presentations, committee and advisory roles, advocacy and community engagement, and its publication output, NCIG is an active contributor to forums and debates that are shaping a genomics landscape that helps rather than inadvertently harms Indigenous Australians. New in 2024, NCIG established a presence on social media and began promoting its outreach, advocacy and leadership to a wider audience.

Advancing scientific conversations and public awareness

Collectively, NCIG team members spoke at more than 35 meetings, conferences, interviews and invited presentations, and published more than 60 times in 2024, advancing a conversation with scientific and general audiences that seeks to explain the significance of NCIG's findings, and to advocate for the potential of genomics to reduce health inequality experienced by Indigenous Australians.

The full list of talks and publications is provided on pages 15-20. Highlights include the following:

- In June 2024, Associate Professor Azure Hermes and Professor Alex Brown were featured in an article published by Australian Geographic. Titled 'Understanding Indigenous DNA,' the piece highlights NCIG's pioneering research uncovering the significant genetic diversity within Indigenous Australian populations. This genetic diversity mirrors the rich cultural, linguistic, and geographical variety found across Aboriginal and Torres Strait Islander communities. The article explores how NCIG's research is working to address health disparities by investigating the unique genetic factors behind conditions such as kidney disease, cardiovascular disease, and diabetes. It also emphasizes the importance of overcoming historical mistrust, focusing on ethical collaboration with Indigenous communities to ensure informed consent and mutual benefit throughout the research process. The article is available here: australiangeographic.com.au/topics/
- In June 2024, Associate Professor Hardip Patel hosted the Human Pangenome Project (HPP) meeting in Melbourne, at which global leaders came together to discuss the progress of pangenome creation worldwide. The HPP is rapidly evolving into a global collaboration focused on developing localised pangenomes. The consortium is working to establish policies and processes for evaluating the quality of these pangenomes, refining workflows, and addressing key considerations for their use in clinical settings.
- In July 2024, the NCIG team hosted Dr Eric Green, Director of National Human Genome Research Institute (NHGRI) at ANU, and follow-up talks occurred in October in the USA. Discussions focussed on the importance of ensuring that the emerging NHGRI agenda, which places an emphasis on diversity, has a strong focus on equity for Indigenous communities and Indigenous voices in leadership.

- In November 2024, Professor Alex Brown joined Professor Jason Kovacic, CEO of the Victor Chang Cardiovascular Research Institute, in conversation on stage at the Sohn Hearts & Minds event in Adelaide. The annual Sohn Hearts & Minds brings together top investment, scientific and philanthropic minds in support of medical research. Professors Brown and Kovacic explored the emergence of genomics and precision medicine, and the promise that this holds for improved diagnostics, treatments and preventions.
- Professor Alex Brown joined with others to successfully advocate the Australian Government to ban the use of genetic test results in life insurance underwriting.



Left to right: Professor Graham Mann, Professor Alex Brown, Professor Ross Hannan, Ms Tiffany Boughtwood, Professor Eric Green, Professor Kathryn North AC, Professor Daniel MacArthur, Associate Professor Azure Hermes, Dr Ira Deveson at JCSMR during the visit by Professor Eric Green, Director of NHGRI.

Committee and Academy membership

In 2024, Professor Alex Brown was made a Fellow of the Australian Academy of Technological Sciences and Engineering for contributions improving Indigenous health through genomics and data sciences, training the next generation of Indigenous researchers, and championing equity in healthcare. Professor Brown joined or continued his contributions to several other important thought-leading committees and panels.

- Member of Expert Advisory Group overseeing the establishment of Genomics Australia. A core priority of the new entity will be Indigenous genomics.
- Member of Expert Advisory Group for the refresh of the National Genomics Healthcare Framework.
- Member of Expert Advisory Group for Cancer Australia Genomics in Cancer Care Framework.
- Member of CSIRO board.

Communications and media

NCIG's strategic plan set a goal to deliver targeted, engaging digital communications. In 2024, the communication team expanded the organisation's digital footprint from a modest base of 300 Twitter followers to approximately 10,000 connections across eight major social media platforms.

This activity reflects NCIG's commitment to amplifying Indigenous voices in genomic research and bolstering transparency and ethical governance in biomedical science. The narrative aims to highlight NCIG as a dynamic and forward-thinking organisation, dedicated to fostering inclusivity, upholding ethical research practices, and continually improving health outcomes for Indigenous communities. The results achieved in the first year indicate there are opportunities for further growth.

Below is an overview of NCIG's social media presence.

Social Media Platform	Link	Follower Count (approximate)
Bluesky	<u>bsky.app/profile/ncig2013.</u> bsky.social	2564
LinkedIn Page	linkedin.com/company/ anu-national-centre-for- indigenous-genomics	2664
LinkedIn Account	linkedin.com/in/ncig2013/	2689
X (formerly Twitter)	x.com/NCIG2013	870
Instagram	instagram.com/ncig2013/	367
Facebook Page	facebook.com/NCIG2013/	279
Facebook Account	facebook.com/ANUNCIG2013/	124
Threads	threads.net/@ncig2013	17

Best-performing posts in 2024 included:

- A response to two ANU NCIG articles published in the Nature Portfolio in December 2023: <u>linkedin.com/feed/update</u>
- Promotion of an interview given to Australian Geographic by Alex Brown and Azure Hermes: <u>linkedin.com/feed/update</u>
- Coverage of a VIP visit to NCIG by Professor Eric Green of the National Human Genome Research Institute (NHGRI): <u>linkedin.com/feed/update</u>

Conferences, workshops, presentations, meetings

Mr Kirat Alreja

SCA2024 (Supercomputing Asia 2024), *Manual curation of genome assemblies for Australian reptiles and amphibians*, Sydney, 22 Feb 2024.

GSA2024 – AusARG, *Manual curation of genome assemblies for Australian reptiles and amphibians*, Sydney, 3 Jul 2024.

Professor Alex Brown

SCA2024 (Supercomputing Asia 2024), *The need for equality in a national Indigenous genomics ecosystem*, Sydney, 22 Feb 2024.

Aboriginal Health and Medical Research Council, *Indigenous Genomics*, keynote, Sydney, 5 Mar 2024.

World Indigenous Cancer Conference, *Towards an Indigenous genomics and precision medicine agenda* (invited plenary), Melbourne, 18 Mar 2024.

Beyond the Sequence – Wellcome Trust, *National Approaches to Indigenous Genomics*, invited London, 26-27 Mar 2024.

NHMRC – Speaking of Science Seminar Series, *Towards an Indigenous genomics and precision medicine agenda*, keynote, Canberra, 11 Apr 2024.

WHO Regional Expert Meeting on accelerating access to human genomics for public health, *Indigenous Genomics (Australian perspective)*, Manila, 29-30 Apr 2024.

The Hospital Research Foundation – Paul Flynn, *Empowering Indigenous Communities in Genomic Medicine*, Adelaide, 23 May 2024.

Public Health Association Australia, Communicable Diseases and Immunisation Conference *Indigenous genomics*, Brisbane, 11 Jun 2024.

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Winter Conversation Series – Government House, *Precision Medicine in addressing and preventing illness in Indigenous and non Indigenous Australians*, Adelaide, 5 Jul 2024.

Department of Industry, Science and Resources, *Recognising achievements in First Nations knowledges and knowledge systems*, Virtual, Canberra, 8 Jul 2024.

Cancer Australia, SA Cancer Consultation Presentation, Adelaide, 23 Jul 2024.

OurDNA Symposium (satellite of GA4GH 12th Plenary), *Indigenous genomics*, Melbourne, 17 Sep 2024.

Global Alliance for Genomics and Health (GA4GH) 12th Plenary, Keynote Address, *Genomic Equality*,

Melbourne, 8 Sep 2024.

Genetic Alliance Australia Annual Forum, *Increasing equitable access* to genomics for First Nations People, Canberra, 25 Sep 2024.

Indigenous Reference Genome Conference, *Indigenous genomics*, Banbury, New York, USA, 27-30 Oct 2024.

ATSE (Australian Academy of Technical Sciences & Engineering), *Keynote Fellowship Induction address*, Canberra, 8 Oct 2024.

SOHN's Hearts and Minds Investment Leaders Conference, *In conversation with Jason Kovacic*, Adelaide, 15 Nov 2024.

Professor Alex Brown & Associate Professor Azure Hermes

International Association of Privacy Professionals (IAPP) at ANZ24, *Indigenous genomic data*, Melbourne, 25-26 Nov 2024.

Dr Hyungtaek Jung

Black Ochre Data Labs, *Homecoming genomics for Indigenous Australian health*, Virtual, 21 Aug 2024.

ABACBS_2024, A Draft Pangenome Reference for Indigenous Australians, Sydney, 6 Nov 2024.

Associate Professor Hardip Patel

JCSMR Director's Seminar Series, NCIG Update, Canberra, 8 Mar 2024.

Human Pangenome Project Meeting, Meeting Host, *The Indigenous Australian pangenome*, Virtual, International, 26 Jun 2024.

International Graph Genome Symposium, *The Indigenous Australian pangenome*, Switzerland, 30 Jun to 4 Jul 2024.

PacBio Revio Workshop, *National Centre for Indigenous Genomics*, Canberra, 29 Jul 2024.

2024 WEHI Postgrad seminar series, *NCIG creating population variation maps and telomere-2-telomere reference genomes for enabling equitable healthcare for all,* Melbourne, 24 Sep 2024.

JCSMR 75th Anniversary Celebration Research Day, *National Centre for Indigenous Genomics*, Canberra, 24 Oct 2024.

Garvan Long-read Research Symposium, *Indigenous Australian pangenome resource*, Sydney, 7 Nov 2024.

International Conference on Research Infrastructure, *Nationally distributed collections infrastructure to solve global research challenges*, Brisbane, 6 Dec 2024.

Publications

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STRATEGIC GOAL 3 GROWING OUR COMMUNITY ENGAGEMENT CAPACITY AND OUTREACH



WELCOME TO UMBARUMBA

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 programs to support and fund NCIG's Community engagement objectives.

> Groote Eylandt, Umbakumba welcome sign

3.1 Connecting with communities

Community engagement is at the heart of NCIG's mission. It underpins our world-leading research and governance model, ensuring that our work aligns with the needs and priorities of Indigenous Australians. As NCIG continues to grow and refine its strategic vision, our engagement with communities extends beyond obtaining consent for samples. We are committed to fostering meaningful discussions that shape the future of genomic research and healthcare, guided by what Indigenous Australians want and need.

In 2024, NCIG community engagement personnel engaged with five communities, to pursue several streams of work. See also Research Updates (pages 6-11).

Since 2015 NCIG has established relationships with five Indigenous communities in far north Queensland, the central desert and the Northern Territory.

Map of participating communities

- 1. Yarrabah
- 2. Galiwin'ku
- 3. Titjikala
- 4. Tiwi Islands
- 5. Groote Eylandt





Natasha Best, Community Engagement Officer

1. Yarrabah

The Yarrabah community, located north of Cairns in Queensland, was the first to collaborate with NCIG. The historical samples taken from this community were the initial samples in the NCIG Collection to undergo re-consent. Since then, Yarrabah has remained a dedicated and active partner. The community offers candid advice and participates in trials that help NCIG refine and enhance messaging, information, and processes for the consent, management, and use of samples and data, as well as for understanding the genomic health ecosystem.

For the first time, NCIG has appointed a community-based engagement officer, Katrina Connolly, who joined the team in September to facilitate community engagement and research participation between Yarrabah and NCIG. In September, three workshops were held in Yarrabah further strengthening this collaboration.

2. Galiwin'ku (NT)

Return visits were conducted to Galiwin'ku in July and October to report on preliminary research findings, and to conduct workshops.

3. The Kimberley (WA)

COVID, serious flooding, and personnel changes had paused our work in the Kimberley in recent years. In 2024, it was a pleasure to begin re-establishing NCIG's relationship with our friends there. Ms Alice McCarthy, NCIG Community Engagement Coordinator led this work.

In September Ms Natasha Best joined the NCIG Community Engagement team, with her primary focus for the coming year to be the Kimberley.

NCIG has two major interests in the Kimberley: the Fitzroy Crossing Cemetery project, and the consent of historical samples held in the NCIG Collection.

The next stage of the Fitzroy Crossing Cemetery project was approved by the Western Australia Aboriginal Health Ethics Committee (WAAHEC) in September, with the support of the Kimberley Aboriginal Law and Culture Centre (KALACC). The initial stage of the Fitzroy cemetery project, described in the 2018 Annual Report was one of the most profoundly moving experiences yet for NCIG staff. In brief, at the request of KALACC, NCIG extracted DNA from unidentified Aboriginal

remains that had been saved from the eroding Old Fitzroy Crossing Cemetery.

Now, the next step is to identify the remains by DNA-matching with community members, so that the deceased can be re-laid to rest with dignity in a named grave.

> NCIG also began discussions with KALACC to request support for a program of community engagement throughout the Kimberley to connect with donors and their families about historical samples held in the NCIG Collection. It is planned to begin with Beagle Bay, One Arm Point and Lombadina. Initial meetings with the Prescribed Body Corporates (PBCs) of these communities and KALACC will inform the necessary ethics applications, which must be approved by both ANU and WAAHEC before NCIG commences formal community consultation later in 2025.

4. Tiwi Islands (NT)

NCIG has two major interests in the Tiwi Islands. The first is to obtain instructions and the consent of participants and their families for historical samples held in the NCIG Collection. This work was completed in 2018, and now, in accordance with NCIG's research model our task is to regularly report back to community on the use of their samples and outcomes of research.

NCIG's second responsibility in the Tiwi Islands is to provide expert assistance to legacy and new research projects into chronic kidney disease (CKD) by NCIG research partners and other researchers. Our collaboration with Dr Simon Jiang's CKD project is described in the Research Update (page 11). In addition, NCIG is helping to validate consents, and facilitate the storage of samples and data accrued from decades of kidney disease research from other institutions. The Tiwi Island Land Council has indicated its preference that 'old' research materials be placed with NCIG under Indigenous custodianship and governance. Several visits to the Tiwi Islands were conducted in 2024 to advance these matters.

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5. Groote Eylandt (NT)

The culmination of 18 months preparatory work saw Associate Professor Azure Hermes welcomed into the community several times during 2024, including for a 7-week visit commencing in May 2024. This enabled deep, effective consultation to occur at a productive pace. Consents were collected for the use of historical samples, and research interviews and workshops were run, described in Research Update (pages 6-8).

The repatriation of samples held in the NCIG Collection is an active discussion, with community consensus not yet reached.

Image: Azure Hermes during a community consultation visit on Groote Eylandt, with Hannah Moody, Anthropology Coordinator for Anindilyakwa Land Council, Groote Eylandt.

Anindilyakwa Land Council ASTRUCTURE INVESTMEN

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3.2 Growing workforce capacity: education & training programs

NCIG is committed to enhancing the capabilities of all students, researchers, and professionals within the Indigenous genomics ecosystem. A key focus is supporting Indigenous Australians in acquiring knowledge, qualifications, skills, and experience across all facets of genomics. NCIG achieves this through the activity described below.

- Educational Engagement: NCIG contributes to teaching in biology, medicine, genetics, genomics, and law/ethics courses at ANU and other institutions.
- Student Support and Mentorship: NCIG offers placements for Honours, Masters, and PhD students, and assists the academic supervision and mentorship of students placed with aligned researchers. It also contributes programming to ANU Tjabal's annual Indigenous STEM Summer School
- Resource Development for Indigenous Communities: NCIG creates and shares information and resources tailored for Indigenous communities and health organisations. (See also Research Update, pages 6-8)
- Curriculum Enhancement: NCIG contributes to the improvement of academic and professional course content, ensuring it reflects current advancements and Indigenous perspectives in genomics. (See also Research Update, pages 6-8)
- Staff development: NCIG endeavours to offer all staff and students the opportunity to visit Aboriginal and Torres Strait Islander communities to grow cultural competence, and each-way learning.

Images: students participating in the NCIG session at the Indigenous STEM Summer School. Top: constructing a DNA helix from lollies. Bottom: conducting an experiement in the NCIG laboratory. Photo credit: Tjabal Indigenous Higher Education Centre, ANU.

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In June, NCIG honours student Sarah Jackson and research officer Zahra Chew participated in a cultural exchange program with the ANU Research School of Biology and Charles Darwin University (CDU) in Darwin. The program, which included the course Indigenous Cultures and the Environment, explored the deep connections between Indigenous people, their culture, and the natural world. The course combined online modules with a week-long trip to Darwin and Kakadu.

The students visited Ubirr and Nourlangie rock art sites, explored Gunbalanya's art gallery, and participated in hands-on activities with a local artist, learning to craft paintbrushes and throw spears. A highlight was painting under the artist's guidance. The students also attended NAIDOC Week celebrations.

Teaching & Training

- Bioinformatics Lead Associate Professor Hardip Patel and Deputy Director Associate Professor Azure Hermes lectured at ANU in third year biology courses. BIOL3161 (3 lectures) and BIOL3204 (2 lectures).
- PhD Candidate Joel Keen spoke at the Indigenising University Mathematics 3 Conference at LaTrobe University in November on the topic of Computer-Assisted Research Mathematics and its applications.
- In December, NCIG hosted 30 secondary school students from across Australia who were at ANU
 participating in the National Indigenous Summer School, organised by the ANU Tjabal Indigenous
 Higher Education Centre.
- Associate Professor Azure Hermes gave a guest lecture at the University of Technology Sydney Master of Genetic Counselling course.

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Students

Sarah Jackson

Bachelor of Genetics (Hons) Supervised by Associate Professor Hardip Patel and Dr Hyungtaek Jung

Completed November 2024

Project: Description of Genetic Variability in Blood Group Genes for Indigenous Australians. Sarah's research highlighted that variations in these genes among different ancestries can lead to reactions during blood transfusions, posing unique health challenges. Notably, Indigenous Australians experience a higher prevalence of such reactions, potentially due to previously uncharacterised Indigenous-specific genetic variants.

Sarah's work demonstrated the complexity and structural differences in blood group genes across various ancestral groups, paving the way for future research to reduce these health risks. By better characterising Indigenous-specific genetic variants, her research has the potential to improve transfusion safety, enhance personalised healthcare, and strengthen health equity for Indigenous Australians.

Garrett Ball

Bachelor of Science/Bachelor of Laws, undergraduate Research Project Supervised by Associate Professor Hardip Patel

Completed July 2024

Project: Investigating the genetics of Chronic Kidney Disease in the Tiwi Islands. Structural variants present in this gene pool were analysed, with a particular focus on the relationship of these variants with loci associated with kidney function.

Olivia Dalton

MChD (Doctor of Medicine and Surgery) Research Project

Supervised by Associate Professor Azure Hermes, Dr Lyndsay Newett and Ms Alice McCarthy.

Completed October 2024

Project: An investigation of genomic healthcare services available to Aboriginal and Torres Strait Islander peoples in Australia. Results contributed to NCIG's 'Domain 1' work within the CONNECT project and 'Domain 5' work within the ALIGN project.

Joel Keen

PhD candidate Supervised by Dr Sarah Bourke and Professor Ted Maddess

Status: ongoing

Project: Indigenous Australia and Genomics: the intersection – A Gomeroi-Murri Perspective. An interrogation of the westernised relationship with knowledge. Utilising a sociological lens to examine Australia's contemporary hegemony from an Gomeroi-Murri standpoint, Joel's project will outline and analyse the intersections between Indigenous Australia and Genomics to better understand the shared historical, contemporary and potential landscape.

Bridie Moy

PhD candidate Supervised by Associate Professor Hardip Patel

Status: ongoing

Project: Understanding the functional consequences of Chronic Kidney Disease-associated structural variants in Indigenous Australians

Rubi-Jayne Cohen PhD candidate

Supervised by Dr Rebekah McWhirter, Professor Alex Brown, Associate Professor Azure Hermes and Dr Lyndsay Newett

Status: ongoing

Project: Benefit sharing in genomic research: co-developing recommendations for communicating genomic science research to empower Indigenous communities.

The proposed PhD project will contribute to the wider NHMRC Synergy project by contributing to the co-development of best-practice guidelines and recommendations for the effective communication of genomic science to First Nations people in Australia. The project will also detail the cultural, ethical, legal and social considerations that must be taken into account in communicating genomic research to First Nations people in Australia and demonstrate how this can empower communities.

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GOVERNANCE AND STATUTORY REPORTS



4.1 Governance

Board Membership

*	Chair – vacant in	2024
*	Professor Yvette	Roe

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* Mr Slade Sibosado
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* Mr Ben Murray

* Mr Mark Mayo (from 1 Feb 2024) * Mr Tim Brown (from 1 Feb 2024) Ms Julia Mansour (from 1 July 2024) Prof Gareth Baynam (until 5 December 2024) Ms Erica Kneipp (until 31 March 2024) Prof Graham Mann Prof Lachlan Blackhall (from 26 Feb 2024)

* Indigenous majority members.

Board Meetings

Board Member	#30—25 Mar	#31—24 Jun	#32—1 Oct	#33—4 Dec
Professor Yvette Roe	Yes	Yes	Yes	
Mr Slade Sibosado	Yes	Yes	Yes	
Mr Ben Murray	Yes	Yes	Yes	Yes
Mr Mark Mayo	Yes	Yes	Yes	Yes
Mr Tim Brown	Yes	Yes	Yes	
Professor Gareth Baynam	Yes	Yes	Yes	Yes
Ms Erica Kneipp	Yes	N/A	N/A	N/A
Ms Julia Mansour	N/A	N/A	Yes	Yes
Professor Graham Mann	Yes	Yes	Yes	Yes
Professor Lachlan Blackhall (DVCRI)		Yes		Yes
Professor Ute Roessner (acting DVCRI)			Yes	
Participants				
Professor Alex Brown NCIG Director		Yes	Yes	
Associate Professor Azure Hermes NCIG Deputy Director	Yes	Yes	Yes	Yes
Ms Deb Marburg Board Secretariat	Yes	Yes	Yes	Yes
Ms Jackie Stenhouse Board Secretariat (designate)				Observer

4.2 Financials

2024 Financial Statement

	ANU NCIG Operational Funding	External Grant Funding	Philanthropic donations
Open Balance	\$65,745.26	\$722,962.49	\$54,960.38
Income			
Operating & Project Grants	\$510,000.00	\$1,028,674.84	\$150.00
Operating Expenses			
Salaries	\$448,546.66	\$669,736.20	
Equipment	\$6,657.45	\$750.00	
Travel and fieldwork	\$28,569.06	\$26,369.45	
Expendable research materials	\$-	\$115,786.22	
Consultancies	\$5,636.54	\$52,940.00	
Consumables	\$2,261.92	\$174.67	
Other expenses	\$21,202.11	\$109,606.51	
Grant Share to Others	\$-	\$163,310.75	
Net result	\$62,871.52	\$612,963.53	\$55,110.38

Grants active in 2024

Grant/Funding Source	Funding received 2024	Remaining period	Total remaining funding
MRFF Synergy - Domain 1	\$200,000.00	2 Years	\$600,000.00
MRFF Synergy - Domain 2	\$65,680.00	2 Years	\$197,040.00
MRFF GHFM S4 (Brown)	\$131,216.00	2 Years	\$262,432.00
MRFF GHFM S6 (Jiang)	\$90,000.00	0 Year	\$-
ANU Grand Challenge	\$110,000.00	1 Year	\$-
ANU Grand Challenge	\$234,104.90	2 Years	\$594,594.58
MRFF GHFM S3 (Newson)	\$80,000.00	3 Years	\$240,000.00
MRFF GHFM S6 (Deveson)	\$149,410.00	0 Year	\$-
MRFF GHFM S5 (Brown)	\$1,600.00	3 Years	\$4,800.00
NHMRC Idea Grant - (Patel)	\$875,389.00	1 Year	\$875,389.00
ANU First Nationals Innovation Investment Program	\$12,500.00	1 Year	\$12,500.00
MRFF Genomics Health Futures (Schulte)	\$492,747.00	2 Years	\$-
NHMRC Genomics Grant Program (Brown)	\$150,000.00	1 Year	\$191,500.00
MRFF Indigenous Health Research (Hermes)	\$542,368.00	2 Years	\$453,067.00
ANU JCSMR Operational Funding	\$320,000.00	1 Year	\$320,000.00
ANU DVCRI Operational Funding	\$190,000.00	2 Years	\$190,000.00
Grand Total	\$3,645,014.90		\$3,941,322.58

4.3 NCIG Staff and Students

After rapid expansion the prior year to meet the responsibilities of the projects on hand, the NCIG team stabilised at around 20 staff and students.

We welcomed Ms Natasha Best to the role of Community Engagement Officer, Ms Katrina Connolly as Yarrabah Community Engagement Officer, Mr Adam Heterick as Bioinformatics Support Officer, Dr Eli Niktab, a postdoctoral fellow specialising in Applied Artificial Intelligence, and Ms Jackie Stenhouse as Acting Board Secretariat.



Back row left to right: Dr Lyndsay Newett, Natasha Best, Bridie Moy, Michael He, Carly Conlan, Associate Professor Azure Hermes, Professor Alex Brown, Associate Professor Hardip Patel, Dr Eli Niktab, Kirat Alreja, Dr Hyungtaek Jung, Dr Hadi Nazem-Bokaee, Alice McCarthy. Sitting left to right: Rubi-Jayne Cohen, Deb Marburg, Sarah Jackson, Lynne El-Hassan.

Role	Name	From/To (if applicable)	
Director	Professor Alex Brown		
Deputy Director	Assoc Prof Azure Hermes		
Senior Administration Officer & Board Secretariat	Ms Deb Marburg		
Project Manager	Dr Michael He		
Board Secretariat (acting)	Ms Jackie Stenhouse	From Dec 24	
Community Engagement Coordinator	Ms Alice McCarthy		
Community Engagement Officer	Ms Natasha Best	From Sept 24	
Community Engagement Officer (Yarrabah)	Ms Katrina Connolly	From Sept 24	

Role	Name	From/To (if applicable)
Research Fellow	Dr Lyndsay Newett	
Bioinformatics Lead	Assoc Prof Hardip Patel	
Bioinformatics Officer	Mr Kirat Alreja	
Bioinformatics Officer	Mr Adam Heterick	From May 24
Bioinformatics Officer	Dr Kosar Hooshmand	Until Apr 24
Data Manager	Ms Jiaxin Yuan	
Research Fellow	Dr Hyungtaek Jung	
Research Fellow	Dr Hadi Nazem-Bokaee	
Senior Technical Officer	Ms Carly Conlan	
Postdoctoral Fellow	Dr Eli Niktab	From Aug 24
Student (Research Project)	Mr Garrett Ball	Until June 24
Student (Research Project)	Ms Olivia Dalton	
Student (Honours)	Ms Sarah Jackson	
Student (PhD)	Mr Joel Keen	
Student (PhD)	Ms Rubi-Jayne Cohen	
Student (PhD)	Ms Bridie Moy	

ACKNOWLEDGEMENTS

ANU

ANU College of Science, Education Technology Section (resource evaluation) ANU First Nations Innovation Hub Gandaywarra (development of the app) ANU Research Services Division Biomolecular Resource Facility, ANU Genomics Technology Group, ANU Information Technology Services, ANU National Computational Infrastructure, ANU

Indigenous Communities and organisations

Anindilyakwa Land Council Groote Eylandt Language Centre Groote Eylandt's Preserving Culture Groote Eylandt Bickerton Island Primary College Aboriginal Corporation Gurriny Yealamucka Health Service Kimberley Aboriginal Law and Culture Centre, WA Kimberley Aboriginal Medical Service, WA SING Australia Tiwi Land Council, NT Top End Human Research Ethics Committee, NT (Menzies School of Health Research) Yalu Aboriginal Corporation Yarrabah Aboriginal Shire council

External technical service providers

Kinghorn Centre for Clinical Genomics (Garvan Institute of Medical Research) Ramaciotti Centre for Genomics, UN



