



ANNUAL REPORT 2018

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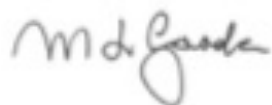
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CHAIRMAN'S LETTER

My term as Chair of the Board of the National Centre for Indigenous Genomics ends as 2018 draws to its close. I look back with pride on the achievements of the Centre. With ANU's commitment and its significant financial and in-kind support, a neglected but important collection of biospecimens has been transformed into the foundation for a substantial and long-lasting initiative of great national importance. Harnessing the power of genomics, NCIG is creating a resource with benefits that I have no doubt will contribute to an historic change in the trajectory of health and well-being outcomes of Aboriginal and Torres Strait Islander peoples. That is an undertaking worthy of one of the world's great universities, and it marks the ANU as an institution of national significance.

This year, the Centre completed a transition of operations to comply with the NCIG Statute, and is poised now to embrace a future focussed on research, both by the Centre and by others who may wish to use the important resource that is being created.

This report records the commitment and the hard work of the Centre's small team and its Board, and I commend the staff, my fellow Board members and the ANU for their achievements.



Mick Gooda
Chair
NCIG Governance Board

31 December 2018



Above: Professor Simon Eastal (R), Director of NCIG, presents Mr Mick Gooda (L) with a farewell gift at the December Board meeting. Photo by J. Stenhouse.

THE NCIG STORY

NCIG was formed when ANU put the future of a collection of Indigenous biospecimens in the hands of an Indigenous consultative committee, agreeing to abide by whatever it recommended.

The original samples were obtained from people in Aboriginal communities across northern and western Australia between the 1960s and 1990s for medical research.

In the 1990s, the ANU closed the collection to research until a meaningful dialogue could be established with the Indigenous community about the collection's management and use.

In 2012 the university established the Consultative Committee on the Indigenous Collection (CCIC), comprising seven eminent Indigenous Australians, to consider a range of options for the collection. After consulting independent experts in bioethics and genomics, and a range of stakeholders, the CCIC recommended the samples and associated archive material be developed into a managed collection as a national resource.

The CCIC regarded the collection as having 'immense cultural, historical and scientific importance' and it wanted a resource that would 'aim for high-quality research with substantial beneficial outcomes for the Indigenous peoples of Australia and...provide a model for the conduct of genetic research with Indigenous populations both in Australia and elsewhere in the world.'

NCIG was initially set up by the ANU in 2013 to manage the collection, under the custodianship of an Indigenous-majority Board, and formally established under a statute in 2016.

Creating a world-class research resource

Even before NCIG was formally established, the wise heads who formed the Consultative Committee on the Collection were adamant that Aboriginal and Torres Strait Islanders **must have agency**. NCIG operationalises Indigenous agency over Indigenous genomics. Distilled to its essence, the foundation stone of NCIG is the concept **it's our DNA, our people, our stories, our way**.

The challenge was to create an organisation that could:

find and properly consult with its many donors spread over the vastness of northern and western Australia;

empower donors to make decisions now, and provide mechanisms for those decisions to be amended over time;

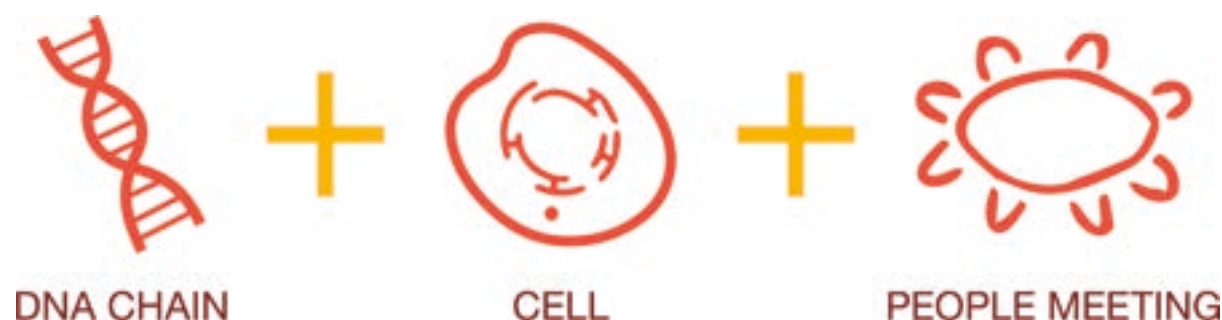
identify and accommodate different decision-making models from community to community;

face head-on questions of ownership and responsibility (do families have decision-making rights over the samples and DNA of their deceased forebears?)

How was the ANU to elevate the fundamental truths of a tagline to a sustainable, effective, scientific operation? How could the University move from a position of goodwill and best intentions, to generate not just new and interesting, but *useful* discovery? How could this be done in an era when the difficult ethical and technical questions intrinsic to genomic data remain daily challenges to scientists, government and the community in myriad ways?

NCIG was established to do nothing less than bring together the world's oldest living culture and its newest science. Each and every sample represents a person, living or deceased and has meaning to them or theirs. NCIG is finding ways to acknowledge the inherent *human-ness* of biospecimens and genomic data, within the high-tech settings of a major university, where the Collection surely must remain if it is to bring any good to world.

When NCIG was formally established in 2013, under an Indigenous-majority Board, and later with the further underpinning of a Statute, the ANU signalled its intention to tackle this endeavour with dedication.



The Centre has built its policies and processes to facilitate management and use of the Collection in ways that fully encompass Indigenous agency: *our DNA, our people, our stories, our way*. Consent is not a once-in-a-lifetime decision. Decision-making can be collective or individual. Decisions emerge in many ways, and each and every decision is valid. NCIG has engaged deeply with Indigenous people and communities whose samples are held in the Collection, and is forging a new style of partnership, wholly appropriate for the new era of genomic science, precision medicine and Indigenous engagement in research.

NCIG's **Governance Framework** is a plain English exposition of NCIG's principles and policies. Indigenous decision-making is at the centre of NCIG's practice.

Dynamic consent is built into NCIG's model. Donors, or those who speak for them, have full ongoing flexibility about the inclusion and use of their sample and data in the Collection.

The accepted **decision-making** structures and processes of each community are respected; no two places have been the same in their decision-making practices but the outcome is always consent that is free and informed.

From a standing start just a few short years ago, consultation with donors has been conducted for hundreds of samples from NCIG's vast biospecimen collection. In the process, many new donors have added their sample to the Collection, determined to contribute to improved medical and genealogical knowledge for their families and descendants.

Summary of Consultation and Consent Taking 2013-2018

Description	Number
Total number of samples with consent given for use, subject to Board approval	490
Consent given for DNA extraction from samples and use of data, with sample to be repatriated or respectfully disposed of	216
Total number of samples consented for use for research conducted under NCIG stewardship	706
Consent declined, disposal requested	79

Decision-making in Community A, Northern Territory

Consistently, we observed that families questioned NCIG staff thoroughly, conducted rigorous discussion, and then their nominated family leader completed consent forms on behalf of deceased donors, reflecting the family's decision.

'A particularly impressive example was the [*name withheld*] family meeting, led by their senior elder. There were 5 younger men at the family meeting. When it came time to decide who the next person would be to speak for this family's samples, there was a big discussion. It was such an amazing thing to witness. Once they made up their mind, the chosen young man stepped forward, and said, "That's me, I'm going to be the one responsible for these samples in the future". After we recorded their instructions, all 5 men stepped up and volunteered their samples, because they wanted to be included and kept with their elders. It was really an amazing process.'

Quoted from Daily Field Report by A. Hermes, Indigenous Community Engagement Officer.

Decision-making in Community B, Northern Territory

Faced with the question of who may speak for samples of deceased people with no known family, the community delegated their Elders to decide. Twelve Elders co-signed a letter giving their unanimous decision with regard to the samples.

Decisions regarding samples whose donors had passed away but for whom there were living family members in the community were taken by the person in the family with the cultural authority to speak and act on behalf of the deceased family member. The identity of each rightful decision-maker was known within families and throughout the community.

In a separate process, this community conducted a vigorous discussion and nomination process, led by its most senior and respected Elder, to choose the person who would donate blood *on behalf of the entire community* for a study by NCIG. The community was passionate that the individuals who participate in this study are representative of the people's deep roots on their Country.

2018 HIGHLIGHTS

- * 9 trips to remote communities
- * 706 consents obtained
- * 162 genomes sequenced from four communities
- * 4 long read genome assemblies completed or in progress
- * 25 students/interns
- * 3 visits (11 individuals) by Indigenous community members and Indigenous organisations to NCIG



Above: aerial view over north-east Arnhem Land. Photo by A. Hermes.

WORKING STRATEGICALLY

2018 was the second year of operation under the Centre's Five-Year Strategic Plan. Progress was achieved in each area of strategic priority.

Strategic Goal 1: caring for the Collection

Care for the Collection with the highest standards of governance, management and practice, guided by the Aboriginal and Torres Strait Islander community.

Completion of the Governance Framework

In June the Board completed and approved the NCIG Governance Framework after an extensive process of drafting by the staff and a subcommittee of the Board (Mr Gooda, Dr Jenkins, Mr Pearson), and review by ANU Legal Office and ANU Research Services Division. The Governance Framework encompasses the principles and policies by which NCIG undertakes its work, and is binding upon those who work with NCIG or use its resources.

The Governance Framework is essential to all aspects of the Centre's operation and to the fulfilment of the Centre's functions as described in the Statute. It forms the bedrock upon which the Centre's protocol for the ethical conduct of research rests.



Simon Eastea, Azure Hermes, Mick Gooda, Misty Jenkins, Glenn Pearson, Jackie Stenhouse at the end of a workshop to finalise the NCIG Governance Framework. Photo by H. Patel

Approval of Variation to the NCIG Ethics Protocol

NCIG's Ethics Protocol was first approved in 2016 by the ANU Human Research Ethics Committee. The subsequent introduction of the Statute and the Governance Framework necessitated changes to the Ethics Protocol.

The Variation to the Ethics Protocol was reviewed by the Chair of the ANU HREC, and approved by the NCIG Board in mid 2018.

First rotation of board members by retirement

Board members' initial appointments expired on 31 December 2018. The Board considered the process for retirement by rotation of a proportion of the Board, and developed a protocol for recruiting and appointing new members. A listing of retirements and new appointments is provided in Statutory Information section of this report.



Left to right: Glenn Pearson, Simone Reynolds, Don Chalmers, Simon Easteal, Mick Gooda, Misty Jenkins, Mick Cardew-Hall at the final Board meeting of 2018. Photo by J. Stenhouse.

The Board commissioned a review to consider the operation of the Statute, governance processes and strategy for future operations. The review was conducted by former ANU Counsel, Mr Ken Grime. Mr Grime found that the Board has governed the Centre in accordance with the Statute and there are no issues arising from the structure of the Statute. Mr Grime identified some operational areas in which NCIG and the ANU may better leverage each other to mutual benefit, and these recommendations will be pursued in 2019.

Terms of Reference approved for Collection Access and Research Advisory Committee

The Board approved the terms of reference for a new committee called the Collection Access and Research Advisory Committee. This milestone underpins the process of opening NCIG's collection of data and documents to researchers, upon application.

Strategic Goal 2: technical and research excellence

Apply the highest standards of technical and research excellence to maximise the value of the Collection.

Samples

Approval in principle was provided by the Board to transfer the biological samples to the NSW Health Statewide Biobank. This state-of-the-art facility provides the maintenance and accession control required by NCIG, in a fully automated system being sought to implement the transfer.

Right: DNA in a tube. This photo was one of a series taken to help explain to non-scientific audiences what DNA 'looks like'.

Photo by H. Patel.



Documents

Much work was undertaken in 2018 to establish the NCIG document collection in line with important principles of archival practice. The archive and the associated website remain under-utilised due to difficulties of access, both physical and digital, and searchability. Nevertheless, the archive has been a vital arm in the Centre's engagement with Indigenous communities, yielding essential preliminary information which has enabled the Indigenous Community Engagement Coordinator to find people represented in the Collection and talk to them about their potential ongoing relationship with the Collection and NCIG.



Above: The documents of the NCIG Collection. Photo by NCIG.

Data

NCIG greatly appreciates the technical advice and support, and the in-kind contribution of significant compute and storage capacity provided by the National Computational Infrastructure.



Above: One of many server racks at the National Computation Infrastructure, the site of NCIG computation and storage. Photo by J. Stenhouse

Research

Reference Assembly Project

(NHMRC funded, \$1.4m over 3 years, 2018-2020)

The human reference genome has been fundamental to the success of genomic medicine, however, the current release (GRCh38) is a mosaic from more than 80 individuals, with 70% coming from a single African-European donor. This ancestral bias impedes clinical research and medical advances for Indigenous populations, including Indigenous Australians. Worldwide, this problem is being addressed through locally relevant reference genomes, created using long-read genome sequencing technologies.

NCIG's project aims to:

- *de novo* assemble an Indigenous Australian reference genome from Indigenous participants across Australia;

- quantify the level and consequences of reference bias for genomic research and clinical genomics using genome sequence from panels of Indigenous and non-Indigenous participants; and
- establish best practice guidelines for implementing genomic tools for research and clinical practice in Aboriginal and Torres Strait Islander communities.

The project is progressing well.

Blood samples have been obtained from 10 consented individuals from 4 communities. High molecular weight DNA has been extracted from one individual from each community and sequenced using the PacBio SMRT system through the Ramaciotti Centre for Genomics at the University of New South Wales, and the Australian Genome Research Facility (AGRF) at the Walter and Eliza Hall Institute (WEHI).

Assemblies have been generated for three of these individuals. Assembly is in progress for the fourth individual. These assemblies are being improved by genome 'scaffolds' produced using the 10X Genomics Chromium System, with data produced through the Ramaciotti Centre and the Garvan Institute of Medical Research.

The completion of the first three genome assemblies is a landmark achievement for NCIG, although much work remains to improve these assemblies and complete the sequencing of additional genomes.

These assemblies have already identified substantial new information about the structure of the human genome that was not previously known. Importantly, initial analysis has confirmed that the genomic characteristics of these individuals are sufficiently different from the standard reference genome to demonstrate the need for Indigenous Australian genome assemblies to underpin medical research and precision medicine in Australia.

This work is being conducted by NCIG's Director Professor Simon Easteal, Bioinformatics Lead Dr Hardip Patel and PhD Students Mr Tim McNerney and Mr Renzo Balboa in collaboration with Associate Professor Stephen Leslie and Dr Ashley Farlow (University of Melbourne), Dr Misty Jenkins (Walter and Eliza Hall Institute), Associate Professor Gareth Baynam (University of Western Australia), and Dr Yu Lin (Computer Science, ANU).

Data storage, management and computation for this and the following project is carried out with the support of the National Computational Infrastructure and the ANU Bioinformatics Consultancy.

Population Variation Project

(Funded by ANU and Bioplatforms Australia)

This project aims to characterise genome variation within and among Indigenous Australian communities; to assess the importance of this variation in research and clinical investigation of disease; and to establish the resulting data as a resource for use by researchers and clinicians.

The short-read sequencing of many individuals serves to both inform the choice of samples for the NHMRC genome-assembly project and to understand the patterns of genetic variation in the population.

Initial analysis of short-read sequence data for 162 individuals from 4 communities has been completed. The results reveal substantial information about sequence variation within and between these populations, including variation at nearly 10 million sites in the genome that was not previously known.

This work is being conducted by NCIG's Director Professor Simon Easteal, Bioinformatics Lead Dr Hardip Patel and PhD Students Mr Tim McInerney and Mr Renzo Balboa in collaboration with Associate Professor Stephen Leslie and Dr Ashley Farlow (University of Melbourne).

Fitzroy Crossing Cemetery Project

The remains of 70 Aboriginal Australians were exhumed from the Old Pioneer Cemetery in Fitzroy Crossing, Western Australia, saved from loss caused by ongoing erosion of the site by the Fitzroy River. The names of those buried in the cemetery are known, but fewer than 20 of the remains can be individually identified.



Above: New graves ready for the reinterment of those recovered from the Old Pioneer Cemetery at Fitzroy Crossing, Western Australia. Photo by B. Llamas

The Kimberley Aboriginal Law and Cultural Centre (KALACC), has been working to save the remains for several years. KALACC requested NCIG to collect DNA from the unidentified remains and take it into safekeeping. In the future, funds permitting, the DNA from the remains can be compared with DNA from family. This will allow the new graves to be properly named, or for remains to be returned to Country, if that is the wish of the family.

This project came to NCIG at short notice and we were pleased and proud to assist KALACC pro bono. Azure Hermes, NCIG's Indigenous Community Engagement Coordinator, and Alice McCarthy, NCIG Research Assistant, spent over a week in Fitzroy Crossing. NCIG was able to secure the voluntary services of ancient DNA specialist Dr Bastien Llamas, ARC Fellow based at the University of Adelaide, to do the DNA extraction.

This project was challenging, technically and emotionally. Long, hot days of careful work concluded with a day of traditional ceremony and reinterment of the remains, attended by hundreds of people who travelled from the local and wider district. The staff of NCIG acknowledge the honour of being trusted to retrieve and to keep safe this DNA. NCIG will work with KALACC to source funding to complete the sequencing and analysis of the DNA.



Left to right: Neil Carter (KALACC), Azure Hermes, Bastien Llamas (University of Adelaide) and Alice McCarthy at Fitzroy Crossing.



Above: Russell Smith, a Gooniyandi ranger working on the cemetery project. Photo by B. Llamas.



Above: Bastien Llamas (L) and Azure Hermes (R) extracting DNA and documenting the process. Photo by A. McCarthy.

Strategic goal 3: partnerships

Cultivate partnerships with Indigenous communities, government, and national and international research organisations, to advance Indigenous genomics.

Research organisations

NCIG is gaining recognition for the high standard of its ethical processes, and is being sought out by Indigenous organisations and by research groups working in Indigenous health and genomics. The recurring theme in many discussions is ethical and sustainable approaches to data governance and sovereignty. NCIG's Governance Framework and consultation and consent protocols are nation-leading initiatives that can contribute to the development of national data standards for Indigenous genomic research.

Community Engagement

Tiwi Islands

NCIG hosted Richard Tungatulum, Stanley Tipiloura and Leslie Tungatulum (28 January to 3 February), representing the Tiwi Land Council and the Tiwi Research Committee. The three spent time in detailed discussion with NCIG and also with AIATSIS, exploring the Tiwi-related collections held at both centres. We agreed to pursue research partnerships with them in the future, subject to funding and appropriate approvals. There are 329 Tiwi samples in the NCIG collection.



Above: Richard Tungatulum, Stanley Tipiloura, Mick Dodson and Leslie Tungatulum at JCSMR. Photo by S. Easteal



(Left to right) Leslie Tungatulum, Maxim Nekrasov (Assistant Manager of Biomolecular Resource Facility), Richard Tungatulum, Stanley Tipiloura, Devashi Paliwal (NCIG undergraduate student), touring the JCSMR's genome sequencing facility. Photo by S. Easteal.

Annual Update to Communities (Yarrabah and Titjikala)

An annual roadshow is conducted to inform community members of NCIG's research progress. The 2018 roadshow visited Yarrabah in Queensland and Titjikala in the Northern Territory. Led by Azure Hermes from NCIG and accompanied by Dr Ashley Farlow (University of Melbourne, co-investigator on NCIG's NHMRC Genome Assembly project), plain English preliminary findings were given to the Yarrabah Shire Council, Yarrabah community members and at a Titjikala community meeting. Enduring relationships, epitomised by the annual visit to report to our partner communities, are key to NCIG's highly successful community engagement outcomes.

Galiwin'ku (Elcho Island)

The NCIG Collection holds over 700 biospecimens collected from Galiwin'ku. NCIG was heavily engaged with this community in 2018, working with Indigenous community development organisation Yalu Marnggithinyaraw. Rosemary Gundjarranbuy and Raylene Ralmirri from Yalu visited NCIG from 7 to 14 April to prepare matters for NCIG's community engagement program. Yalu provided community research assistants for NCIG's subsequent consultation visits throughout the year.



Above:
 Rosemary Gundjarranbuy, community leader from Galiwin'ku, taught NCIG scientists about Galiwin'ku marriage law during her visit to NCIG. Genetics has been well-understood by Indigenous Australians for a very long time. Photos by A. Hermes.

Western Australian Aboriginal Health Ethics Committee (WAAHEC) & Kimberley Aboriginal Medical Service (KAMS)

A delegation from the WAAHEC and KAMS visited NCIG in August for two days of discussion about developing a partnership for the ethical oversight of research and clinical use of Indigenous genomic data. The committee is photographed (below) after their tour of the National Computational Infrastructure (NCI).



Left to right: Cyril Archer, Adam Huttner-Koros (NCI), Simon Easteal, Rob McPhee, Dennis Simmons, Francine Eades, Tara Rowe and Chris Bin Kali.

Northern Land Council (NLC)

The NLC issued a Research Permit to NCIG on 16 April, enabling research activity to commence on Galiwin'ku.

Kimberley Aboriginal Law and Culture Centre (KALACC)

Azure Hermes attended the Kimberley Land Council's 40th Anniversary event and the KALACC Annual General Meetings at Ngumpan community, Fitzroy Valley, September 2018, by invitation.

Indigenous representation on Genomics Health Future Mission

NCIG's Board Chair made representations to the Commonwealth Minister for Health to request Indigenous representation on the steering committee of the Genomics Health Futures Mission. He was supported in this by Ms Pat Turner of NACCHO and Ms Pat Anderson of Lowitja Institute. This resulted in the inclusion of an Indigenous representative on the steering committee, and establishment of an Indigenous Advisory Committee.

Telethon Kids Institute, Perth

Simon Easteal and Azure Hermes visited the Telethon Kids Institute in Perth where they gave a presentation and held discussions about shared approaches to data governance and sovereignty.

Montreal Conference

Simon Easteal and Azure Hermes were invited to attend the *Closing the Genomics Research Gap Symposium* at McGill University in Montreal, Canada. This important meeting brought together genome science researchers, policy experts and clinicians from around the world to discuss the effects of disparity in genome research and ways to address it.



Above: a view of the Montreal skyline from the Saint Lawrence River. Photo by J. Stenhouse.

Unexpectedly, Simon and Azure gave the opening public lecture in place of Joanna Mountain, Senior Director of Research at 23andMe who had to cancel at short notice. Needless to say, these were big shoes to fill in front of an expectant audience. Simon and Azure quickly developed content and presented in an interactive question-and-answer format, which was well received.

This successful presentation opened useful and interesting conversations with genomic science colleagues and Canadian First Nations people at the conference.



Above: Azure Hermes (second from left) talks to Inuit throat singers performing in a street festival in Montreal during her attendance at the conference. Photo by S. Eastal.

Genetics Society of AustralAsia Annual Conference

Dr Hardip Patel, Mr Renzo Balbo and Mr Tim McInerney attended the Annual Conference of the Genetics Society of AustralAsia at the University of Canberra. All three presented their research to genetics researchers with varied interests.

Dr Patel's abstract was selected for seminar presentation at the Annual Australasian Genomic Technologies Association (AGTA) held in Adelaide in October. Many researchers in the field of human disease and genetic research participated in this conference. The researchers present expressed interest and enthusiasm for NCIG's work, and there was widespread understanding amongst the researchers at the seminar that Indigenous genomics is essential if equitable clinical care is to be achieved via 'precision medicine'.

Strategic goal 4: a sustainable future

Secure the future of the Centre.

Core output

The significant seed funding provided by ANU has enabled NCIG to reach and sustain its current operational status. The ANU supports core functions encompassing board and governance, management and administration, Indigenous community consultation, bioinformatic analysis and laboratory facilities. ANU's current funding commitment to NCIG extends until 2021.

Sequencing, data analysis and other direct research costs, are supported by funding of approximately \$0.75 million per annum from the National Health and Medical Research Council (NHMRC) and Bioplatforms Australia.

The future of national biomolecular data capability

Data capability remains a pressing issue for the nation, the university and NCIG. Nationally, investment and policy decisions are being made now that will have long-term, substantial impacts on medicine and health care in Australia. NCIG has a role to play in ensuring that Indigenous Australians are not by-passed in this process.

Importantly, without national capability in data processing, data storage and data management, the promise of genomic medicine will be difficult to realise. Thus, NCIG's future is closely affected by the national genome research strategy currently being developed.

There are three related activities, which are seminal for NCIG:

1. **The Australian Bioinformatics Commons** developed by the National Collaborative Research Infrastructure Strategy agencies, commonly known as NCRIS.
2. **The Health Genomics Policy Framework** developed by the Commonwealth Department of Health.
3. **The Genomics Health Futures Mission** funded from the Medical Research Future Fund through the Department of Health.

The Australian Bioinformatics Commons (data infrastructure).

The intention of this multi-year, staged initiative is to establish national capability and national resources in bioinformatics infrastructure and bioscience data infrastructure.

The NCRIS agencies have provided \$2.5m in 2018-19 for the initial Pathfinder Phase of the project and NCIG's Director, Professor Simon Easteal is a member of the Project Steering Committee.

The National Health Genomics Policy Framework

Following the publication of the Policy Framework early in 2018, the Australian Health Minister's Advisory Council provided funding for consultation about establishing a national approach to optimise the clinical usefulness of a reference genome for Indigenous Australians. NCIG provided advice to the relevant policy group in the Department of Health.

Genomics Health Futures Mission

NCIG's Chair, Mr Mick Gooda, wrote to the Health Minister, the Hon Greg Hunt MP, drawing attention to the absence of Indigenous representation on the Genomics Health Futures Mission Steering Committee which is establishing the operational plan for the expenditure of \$500 million over 10 years. Consequently, an Indigenous forum was established to provide input to the Steering Committee's report before it is submitted to the Government.

STATUTORY INFORMATION

Governance Board

The Board met four times in 2018 and key outputs included the NCIG Governance Framework, the variation to the Ethics Protocol, a protocol for samples of deceased people without living representatives, a protocol for board member rotation and recruitment, and the 2019 Operational Plan.

Meetings held

Board Member	Meeting 5 5 Mar 2018	Meeting 6 8 Jun 2018	Meeting 7 3 Sept 2018	Meeting 8 12 Dec 2018
Mr Mick Gooda (Chair)	●	●	●	●
Dr Misty Jenkins (Deputy Chair)	●	●	●	●
Professor Mick Dodson AM	●			
Professor Ngiare Brown	●	●		
Dr Simone Reynolds	●	●	●	●
Dr Mark Wenitong		—	—	—
Mr Glenn Pearson	—	—	●	●
Professor Don Chalmers	●	●		●
Professor Margaret Harding	●	●	●	—
Professor John Bekkers		●	●	
Professor Simon Easteal (Director)	●	●	●	●
Ms Jackie Stenhouse (Secretariat)	●	●	●	●
Professor Mick Cardew-Hall (in attendance)	—	—	—	●

Retirements and appointments

Dr Mark Wenitong retired from the Board in June and Mr Glenn Pearson accepted the vacant Board seat. Mr Mick Gooda and Professor Ngiare Brown retired effective 31 December 2018 and Associate Professor Gareth Baynam and Dr Lyndon Ormond-Parker accepted seats on the Board effective 1 January 2019. Professor Margaret Harding departed the ANU and therefore also left the Board of NCIG effective 30 September 2018. Professor Keith Nugent will take up the vacated Board seat upon his commencement in the role of DVC–Research and Innovation in January 2019.

NCIG Team

Staff

Director – Professor Simon Easteal (0.8 FTE)
Manager, Strategic Relationships – Dr Michael Dobbie (0.2 FTE)
Indigenous Community Engagement Coordinator – Ms Azure Hermes (1 FTE)
Bioinformatic Lead – Dr Hardip Patel (1 FTE)
Administrator | Board Secretariat – Ms Jackie Stenhouse (0.8 FTE)

Research Assistants – Ms Alice McCarthy, Mr Mark Hermes, Mr Div Randev, Ms Claire Hubbard, Ms Anusree Sivadas (Casuals)

Students

Mr Shaun Lehmann – PhD candidate
Mr Tim McNerney – PhD candidate
Mr Renzo Balboa – PhD candidate
Ms Devashi Paliwal – Undergraduate PhB candidate

Academic Visitors

Associate Professor Stephen Leslie – Visiting Fellow
Dr Ashley Farlow – Visiting Fellow

Financials

ANU awarded NCIG base funding for five years from 2017 to 2021. In 2018 this funding supported salaries, community engagement and other operating costs.

The John Curtin School of Medical Research continued to host NCIG, providing salary for three staff, office and lab space, and school support services (such as finance and HR).

In 2014 Bioplatforms Australia committed \$500,000 to NCIG for sequencing costs. Of this \$420,000 was expended by the end of 2018. The remainder will be drawn down over 2019. Bioplatforms Australia has committed a further \$500,000 for the continuation of sequencing and analysis.

Funding from an NHMRC project grant commenced in 2018 (\$1.4m over three years, 2018-2020).

The financial report attached shows that NCIG operated within its means in 2018.

NCIG Financial Report - 2018

	Tied Funding				Untied Funding	
	Salaries supported by JCSMR (Director, Strat Reln Mgr,	Governance Board Costs	BPA funds (held by the Garvan) Sequencing	NHMRC Ref Genome Grant \$1.4m over 3 yrs (2018-2020) Yr 1: \$564,650	NCIG General Operating Funds	Donation (Canberra Medical Society)
Carried Fwd (from 31/12/17)	\$0.00	\$16,060.12	\$335,350.00	\$0.00	\$85,512.47	\$47,639.91
Income						
Student Fees						
Other Income				\$572,555.30	\$1,080.00	
Internal Sales				(\$300.00)		
Internal Allocations						
Operating Grant	\$338,651.58	\$30,000.00			\$290,262.00	
Investment Income					\$735.62	\$735.62
Total Income	\$338,651.58	\$46,060.12	\$335,350.00	\$572,255.30	\$377,590.09	\$48,375.53
Expenditure						
Salaries & Related Costs	\$338,651.58				\$283,294.48	
Equipment - Capital						
Equipment - Non-Capital					\$13,485.18	
Scholars Expenses					\$700.00	
Utilities & Maintenance		(\$500.00)				
Travel Field & Survey Expenses		\$13,066.02		\$90,406.47	\$23,029.71	
Expendable Research Materials			\$254,562.00	\$64,928.85	\$10,520.00	
Contributions						
Consultancies				\$7,892.81		
Consumables		\$7,761.60			\$298.34	
Depn & Amort						
Internal Purchases						
Other Expenses		\$5,793.40		\$4,851.14	\$3,693.68	
Contingency						
Total Expenditure	\$338,651.58	\$26,121.02	\$254,562.00	\$168,079.27	\$335,021.39	\$0.00
End of year result	\$0.00	\$19,939.10	\$80,788.00	\$404,176.03	\$42,568.70	\$48,375.53

Source: P12 FMR at 31/12/18

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Indigenous communities and organisations

Galiwin'ku (Elcho Island) community, Northern Territory
Kimberley Aboriginal Medical Service (KAMS)
Kimberley Law and Culture Centre (KALACC), Fitzroy Crossing, Western Australia
Northern Land Council
Titjikala community, Northern Territory
Tiwi Land Council, Northern Territory
WA Aboriginal Health Ethics Committee (WAAHEC)
Yarrabah community, Queensland