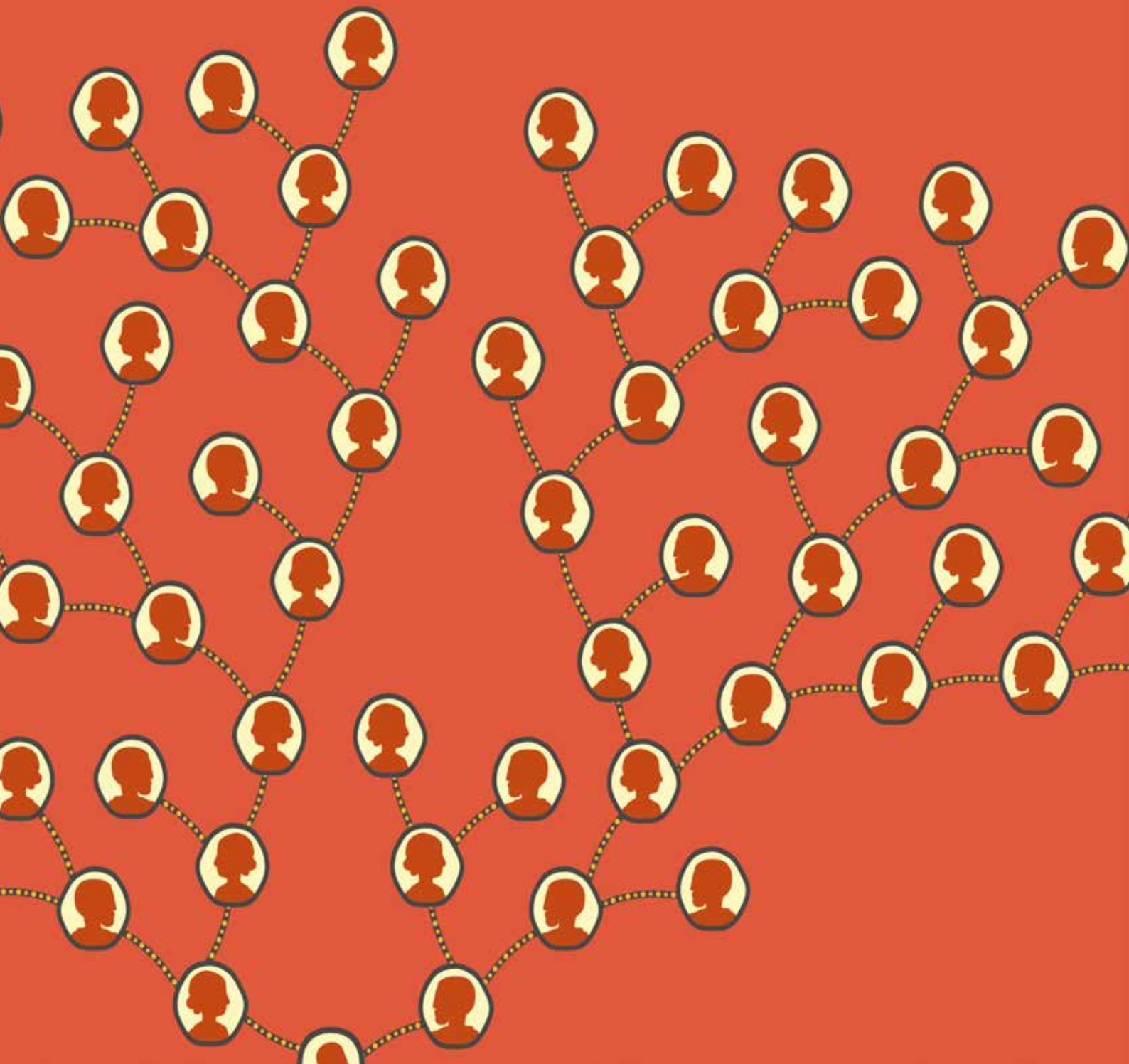


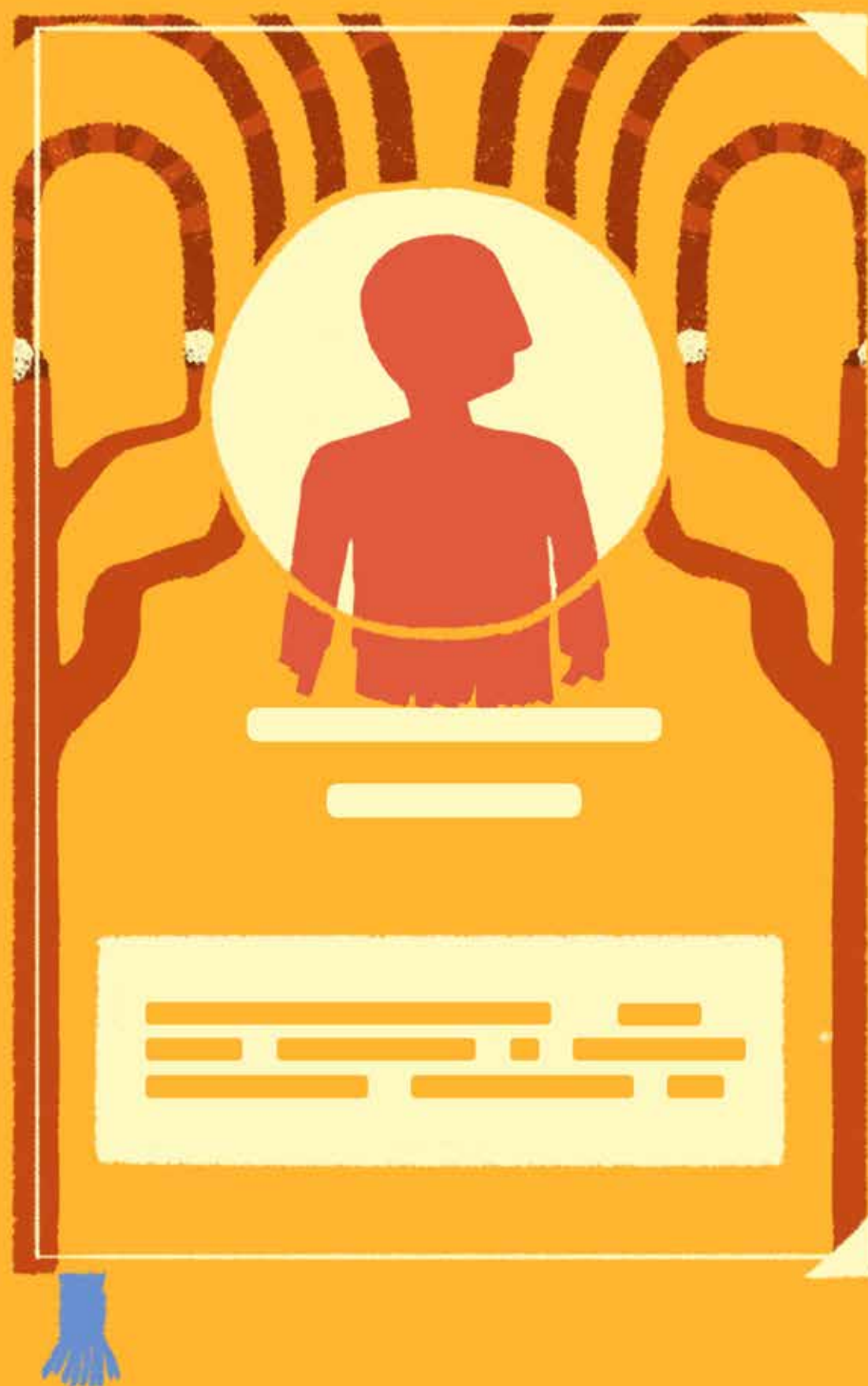


**NCIG**

NATIONAL CENTRE  
FOR INDIGENOUS  
GENOMICS

## 2017 ANNUAL REPORT





# Contents

<b>Chairman's Report</b>	<b>3</b>	<b>Growing through sharing</b>	<b>14</b>
		Education	14
<b>Creating a world-class research resource</b>	<b>4</b>	Training	15
Mission	4	Continuous learning	15
Vision	4	Seminars & workshops	15
Strategic Plan	4	Academic & research relationships	15
Operational Plan	4	Advisory networks	16
		Indigenous organisations	16
<b>2017 Highlights</b>	<b>5</b>	Philanthropic support	16
<b>Placing Indigenous Australians at the forefront of genomics</b>	<b>7</b>	<b>A world of opportunity</b>	<b>17</b>
The impact of genomics	7	Director's study tour	17
		Bioinformatic Lead visits EBI	19
<b>Gaining knowledge and understanding</b>	<b>8</b>	<b>Statutory information</b>	<b>20</b>
The NCIG Project	8	Governance Board	20
NHMRC Project Grant: Biobank Networks, Medical Research and the Challenge of Globalisation (2015-2017)	8	NCIG team	21
NHMRC Project Grant: An Indigenous Reference Genome – Indigenous inclusion in the benefits of genomic medicine (2018-2020)	8	Financials	21
		NCIG 2017 Finance Report	22
<b>On the road to building relationships</b>	<b>9</b>	<b>Acknowledgements</b>	<b>24</b>
		Funding	24
		Advisors	24
		Research collaborators	24
		Indigenous communities and organisations	24







## Chairman's Report

I write this introduction for the first Annual Report of the National Centre for Indigenous Genomics seven years after the concept for the Centre was proposed. In 2011 ANU asked me and other Indigenous Australians to consider the future of a long-dormant collection of Indigenous blood samples held in the freezers at the John Curtin School of Medical Research – the samples which are now known as the NCIG Collection.

Immediately, we saw the Collection had immense cultural, historical and scientific importance. We recommended the Collection be brought into research use again, but we were not prepared to endorse the well-worn path in which Indigenous Australians were *researched upon* without their involvement, and, as often as not, for purposes that would deliver little benefit to them.

NCIG grew from our vision for a proper partnership between the original donors, their families, descendants and communities, and the University.

To its great credit, ANU established the Centre on terms that embedded the Indigenous voice into the very core of NCIG: its goals, its policies and its practices respect Indigenous culture and values, and Indigenous models of decision-making.

As this Annual Report will show, the result has been a success. Indigenous Australians are engaging with NCIG with a degree of confidence and enthusiasm that raises hope for the future.

Indigenous Australians have the poorest health of any group in Australian society.

NCIG's work with Indigenous communities has the potential to put Indigenous Australians at the leading edge of genomic medical discovery, and to change the trajectory of health outcomes for Australia's first peoples.

2017 was a watershed year for NCIG – the *National Centre for Indigenous Genomics Statute 2016* came into effect. This signalled the University's long-term commitment to the Centre, its Collection and the principle of Indigenous leadership. The Indigenous-majority Board was enlarged and the Centre's Strategic Plan was developed along with supporting measures in the form of an Operational Plan and a Policy Framework.

The Centre's staff travelled thousands of kilometres around the country to consult with donors and communities, gathering consents for participation and producing the first 84 genome sequences. There is much more to come.

NCIG can lead the world in Indigenous genome research. It truly is bringing together the world's oldest living culture with its newest science.

**Mick Gooda**  
Chair  
NCIG Governance Board  
February 2018

# Creating a world-class research resource

For the first time, Australia has a platform to engage Indigenous Australians in genomics. The NCIG model puts Indigenous Australians in charge of their samples, their data and the research purposes for which the samples and data are used. NCIG is creating Australia's first Database of Indigenous Genomes.

Why do we need a Database of Indigenous Genomes?

We are entering the age of personalised medicine and increasingly our medical care will be guided by our individual genome sequence data. Analysis of human DNA helps us understand how diseases affect some groups more than others, or affects them differently. We know a great deal about the genomes of people of European ancestry but much less about the genomes of people from other parts of the world, and almost nothing about the genomes of Indigenous Australians.

To address this knowledge deficit, NCIG is creating a new resource of great importance.

## Mission

NCIG's mission is to convert its unique collection into a world-class research resource.

## Vision

NCIG's vision is to be a trusted, enduring resource for genomic research leading to better health and wellbeing for Indigenous Australians.

## Strategic Plan

The Board developed a five-year Strategic Plan that sets out the guideposts for the NCIG journey.

Between 2017 and 2021, NCIG will:

1. establish and maintain excellence in governance and management
2. maximise the value of the Collection by applying technical and scientific excellence
3. build a network of relationships and partnerships with communities, government, and national and international research organisations
4. secure the funding base and build the profile of the Centre.

## Operational Plan

2017 was Year 1 of the Strategic Plan and, accordingly, the operational focus was on foundational activities aligned with the four key elements of the Strategic Plan.

1. Policies and procedures were reviewed and revised to ensure alignment with the new Statute. The revised policies and procedures – collectively called the *Governance Framework* – will be operational in 2018. The staff structure and role descriptions were reviewed and modified to ensure the Centre is better positioned to deliver its objectives.

2. Genome sequencing commenced, following a careful assessment to identify the best technical and scientific processes and service providers to meet NCIG needs.
3. Relationships were established with Kimberley Aboriginal Medical Service (KAMS), the WA Aboriginal Health Ethics Committee, Tiwi Land Council, Department of Education (Research Infrastructure Branch), Ernst & Young Consulting and the Australian Genomics Health Alliance. These relationships will be developed in 2018 and beyond. Existing relationships with the Kimberley Aboriginal Law and Culture Centre (KALACC), Yarrabah community and Tiijikala community were deepened.
4. NCIG led a successful NHMRC Project Grant application in collaboration with the University of Melbourne, Walter and Eliza Hall Institute (WEHI) and the Western Australia Department of Health (\$1.4 million over three years, commencing in 2018).

## 2017 Highlights

**11**

trips  
to remote  
communities

**217,714**

kilometres travelled  
by NCIG staff to  
conduct community  
consultation

**508**

consents  
obtained

**144**

genome sequences  
completed or in  
progress

**\$1.4M**

awarded  
to NCIG  
by NHMRC

**12.3**

terabytes of  
genome data  
generated

**23**

students and  
interns spent time  
at NCIG

**1**

statute

**6 of 9**

board members are  
Indigenous

**5**

five-year strategic  
plan in place for  
2017-2021

**8**

collaborations and  
partnerships

**24**

visits and meetings  
with related national  
and international  
organisations







# Placing Indigenous Australians at the forefront of genomics

Indigenous people around the world are under-represented in the key genome reference databases that underpin quality genomic research, and Indigenous Australians have almost no presence in these important research assets. NCIG is an Indigenous-led initiative to ensure personalised medicine and other genomic advances alleviate, rather than widen, the gap for Indigenous Australians.

## The impact of genomics

- Genomics, particularly 'genomic medicine' or 'precision medicine', has the capacity to improve detection and treatment of cancer, chronic conditions such as kidney disease and cardiovascular disease, and rare diseases (which tend to be genetic).
- Genome sequence data is widely used in genealogical research and may offer many Indigenous Australians whose family connections have been lost a better understanding of their ancestry.
- Genomic sequence data will provide a comprehensive map of genetic variation across much of Australia. The data could be used to understand ancient human migrations to and across Australia. A body of knowledge of this type may also help identify the geographical origin of human remains, allowing repatriation from museums and other institutions all over the world back to Country.

NCIG does not propose to enter all these fields directly. NCIG's role is to:

- establish a governance and ethics model that encourages Indigenous Australians to engage in genomic research with confidence in the integrity and usefulness of the research, and with full control over their participation
- create and manage a comprehensive Indigenous genome reference database.

NCIG's impact will be:

- helping to **improve Indigenous health and wellbeing** by facilitating health and medical research
- establishing **better engagement and research models** that recognise, respect and respond to Indigenous culture
- contributing to the broader **national and international development of ethics** and project protocols for biomedical research.

The NCIG model of direct involvement by Indigenous people is having a profound impact on the way research is conducted. It is establishing new levels of best practice in, and in some cases entirely new approaches to:

- research governance
- informing participants about research and communicating research outcomes
- developing strong lasting relationships with participants that extend across generations
- incorporating family and collective interest into decision-making about research
- managing large, complex and sensitive datasets.

## Gaining knowledge and understanding

Ongoing research lies at the heart of NCIG's ability to manage its Collection in a way that not only provides a world-class resource but gives Indigenous Australians a leading role in establishing a framework for genomics.

### The NCIG Project

The establishment and ongoing curation of the NCIG Collection is a research project and is central to achieving the Centre's vision of being a trusted, enduring resource for Indigenous genomic research.

The Collection comprises three distinct bodies of material – biological samples, documents and data. Ongoing work aims to enhance understanding of the contents of the Collection, identify appropriate physical and digital management tools, and understand cultural attitudes to the Collection and their effect on how it is managed and used.

In 2017 the following work was undertaken on all three parts of the Collection.

1. Biological samples: the **Freezerworks** software, which is used to maintain the Participant Register and the Sample Register, was upgraded. By the end of the year, 184 genomes were sequenced in full or were in the process of being sequenced.
2. Documents: a pilot project was completed to improve the annotation of documents in the **Online Heritage Resource Manager** and a User Guide was completed. This work will continue on more of the Collection in 2018.

3. Data: NCIG was awarded 1.25 million hours of **computation** through the National Computational Infrastructure (NCI) from two competitive allocation processes: the National Computational Merit Allocation Scheme 2018; and the ANU Allocation Scheme 2018. NCI donated 100 Tb of **data storage** to NCIG. Data from the first sequences was received and analysis commenced.

Underpinning NCIG's Collection management decisions is the expanding base of feedback gathered by the Indigenous Community Engagement Coordinator (ICEC). The ICEC consults with individuals who have samples in the Collection, or their surviving family, and their local communities to understand their preferences for their samples and their view of the Collection being used for research in general.

### NHMRC Project Grant: Biobank Networks, Medical Research and the Challenge of Globalisation (2015-2017)

Led by the University of Sydney, this project aimed to provide evidence to inform the development of ethically-rigorous and culturally-informed strategies to ensure that Australians contribute to, and benefit from, international biobank networks. NCIG's role was to investigate Indigenous Australians' knowledge of and attitudes towards biobanks.

### NHMRC Project Grant: An Indigenous Reference Genome – Indigenous inclusion in the benefits of genomic medicine (2018-2020)

Working with statistical geneticist Associate Professor Stephen Leslie, and computational biologist Dr Ashley Farlow, both from the University of Melbourne. Through this project NCIG will establish an Indigenous Australian reference genome using advanced genome sequencing technologies and data analytics.

The reference genome will be the cornerstone of future genomic research and its clinical application in Indigenous communities. Without it, the benefits of genome science are likely to miss Indigenous Australians.



# On the road to building relationships

The NCIG Indigenous Community Engagement Coordinator (ICEC) travelled extensively in 2017, establishing and strengthening ties with the people who are most affected by, and who will most affect, the work of the NCIG. Reassured by NCIG's respectful approach and Indigenous oversight, Indigenous Australians are giving thoughtful feedback, and their support, to the Centre.

The groundwork laid down in recent years began to yield benefits, and in 2017 the resources allocated to the community consultation program were boosted. On most trips, the ICEC was accompanied by one or more support staff. This assisted the consultation work, and enhanced the skills and knowledge of NCIG's staff, students and

collaborators about our engagement process and the conduct of the NCIG project.

The ICEC built on the relationships with Yarrabah<sup>1</sup> and Titjikala<sup>2</sup> communities in 2017. With more than 300 Tiwi samples in the NCIG Collection, the Tiwi Islands were a focus during the year and a

productive relationship has developed with the Tiwi Land Council, Tiwi Ethics Committee and the community.

NCIG ran an information stall at the biennial Laura Dance Festival in Cape York. This was an opportunity to lightly announce NCIG's existence to Cape York communities and allowed the ICEC to meet community leaders. The contacts made at Laura will be nurtured in the coming 12-24 months.

By the year's end, NCIG had established the wishes of donors (or those who speak for them) for 508 samples in the Collection. Consistently across communities, 90 per cent of donors are consenting to their sample being included in the Collection and used in research. Two themes that emerged from engagement and consultation were a strong desire to contribute to:

- medical research for the sake of better health for children, grandchildren and the generations to come; and
- a knowledge base that may help members of the Stolen Generation reconnect with their origins.



<sup>1</sup> Yarrabah is located in the Cairns region, Queensland

<sup>2</sup> Titjikala is located in the Alice Springs region, Northern Territory



FEBRUARY – Titjikala, NT



JULY – Laura Festival, Qld





JULY – Laura Festival, Qld





Professor Eastale with the samples







MAY – Tiwi Islands



JULY – Laura Festival, Qld



## Growing through sharing

Sharing knowledge, resources and expertise with a network of partners and organisations is a key part of the NCIG's strategic plan. To that end, staff and representatives took every opportunity to participate, educate, listen and learn during 2017.



Left to right: Seth Seden, Izayah Davis and Max Chesini at the NCIG session of the ANU Indigenous STEM Summer School. (Image Credit: Stuart Hay, ANU)

### Education

- NCIG has developed a body of educational material for use in undergraduate education, ensuring Indigenous content in human genetics and genomics course, and providing the basis of community-based educational programs.
- NCIG hosted a session about Indigenous genomics for the ANU Indigenous STEM Summer School for high school students, on 12 December. The session was designed and led by Dr Michael Dobbie, Ms Azure Hermes, the NCIG Intern Ms Alice McCarthy and NCIG PhD students, Mr Tim McInerney and Mr Renzo Balboa. The photograph

above was the feature image on an ANU Newsroom website story<sup>1</sup>, and was taken at NCIG's session in the labs at The John Curtin School of Medical Research. The students applied genetic concepts to test synthetic blood to solve a hypothetical challenge.

<sup>1</sup> <http://www.anu.edu.au/news/all-news/brian-schmidt-inspires-high-school-student-to-follow-his-dreams>



## Training

NCIG was accepted as a host in the internship program of the Aurora Project, which aims to build capacity in Indigenous sector organisations and their support staff. The project's internship program offers career-building experiences in Indigenous sector organisations to graduates and post-graduates from a range of disciplines. NCIG's first intern was Ms Alice McCarthy, an ANU anthropology graduate, who completed a project centred on the NCIG document collection and its digital platform. After her voluntary internship, Ms McCarthy was employed on a part-time basis to continue this work.

## Continuous learning

- Ms Jackie Stenhouse attended the Our Community *Board Builder Conference*, Melbourne, 6 March.
- Ms Azure Hermes attended the AIATSIS and University of Melbourne *Data Sovereignty Conference*, Melbourne, 10-13 July.
- Professor Easteal attended the Wellcome Genome Campus *Genomics of Common Disease Conference*, Cambridge UK, 6-9 September.
- Ms Hermes attended the Arabena *First 1000 Days Symposium*, Brisbane, 16-20 October.
- Professor Easteal attended the Institute of Public Administration Australia ACT Division *Public Section Data Integration Conference*, Canberra, 3 November.

## Seminars & workshops

- Dr Michael Dobbie gave an invited presentation at the workshop *Publicly-funded data – emerging national and international trends*, Australian Commonwealth Department of Education and Training, 22 March.
- Professor Easteal gave an invited presentation at the *Gene Mappers 2017 Conference*, Adelaide, 26-28 April.
- Professor Easteal gave an invited presentation at the Theodosius Dobzhansky Centre for Genome Bioinformatics, St Petersburg State University, 19 June.
- Professor Easteal gave an invited presentation at the Finnish Institute of Molecular Medicine, Helsinki, 25 June.
- Professor Easteal gave an invited presentation at the Centre of Genomics and Policy, McGill University, Montreal, 19 September.
- Dr Patel attended the Wellcome Genome Campus *Big Data in Biology and Health Conference*, Cambridge UK, 25-27 September.
- Professor Easteal attended and presented at the *Related Histories: Studying the Family Conference*, National Library of Australia, Canberra, 28 November.
- Professor Easteal hosted Professor John Christodoulou (Murdoch Children's Research Institute) at JCSMR on 27 October. Professor Christodoulou spoke for the JCSMR Seminar series, and participated in a genomics and data roundtable at NCIG including academics from NCIG, The John Curtin School of Medical Research and the National Computation Infrastructure.

## Academic & research relationships

- Research project collaborators Associate Professor Stephen Leslie and Dr Ashley Farlow visited NCIG on 10-13 February. Dr Farlow accompanied the NCIG ICEC on the first community consultation visit to the Tiwi Islands, conducted in February 2017. Dr Farlow visited NCIG on 23-25 October to collaborate on initial data results for the Indigenous Reference Genome project.
- Professor Jane Kaye, University of Oxford, visited NCIG on 25 October. Professor Kaye, a legal academic, has research interests and expertise in genomics from the perspective of biobanks, privacy, data-sharing frameworks and governance.
- Professor Easteal visited Professor John Mattick (Garvan Institute, Sydney) on 5 December. Professor Mattick is a leading player in national efforts to establish research data infrastructure to harness the potential of 'precision medicine'.
- NCIG collaborated with the Australian Genomics Health Alliance (AGHA) on the development of a platform for dynamic consent. AGHA also co-invested in the salary of NCIG Bioinformatic Lead Dr Hardip Patel for his contribution to the development of a framework for ethical long-term governance, management and storage of clinical genomic data. Dr Patel had a particular remit, on behalf of NCIG, to ensure Indigenous interests and values are accommodated in AGHA's core activities.

## Advisory networks

- Professor Easteal accepted an invitation from the Deputy Secretary of the Commonwealth Department of Health to sit as an expert advisor on the National Genomics Health Policy Framework Expert Working Group and participated in the Project Reference Group Roundtable on 7 December in Canberra.
- Mr Ken Wedgwood and Mr Joe Hedger, advisors from Ernst & Young Consulting, visited throughout the year, providing pro-bono strategic advice about funding. Mr Wedgwood and Mr Hedger met the NCIG Board informally on 20 November.
- Professor Easteal was appointed as an Associated Staff member of the Theodosius Dobzhansky Centre for Genome Bioinformatics at the St Petersburg State University, St Petersburg, Russia.



Left to right: Professor Simon Easteal, Dr Peter Gibson.

## Indigenous organisations

- NCIG Board Chair Mr Mick Gooda, and NCIG Indigenous Community Engagement Coordinator Ms Hermes, met with the Western Australia Aboriginal Health Ethics Committee in Broome on 7 December to discuss an approval process for NCIG consultation and engagement in WA Indigenous communities.
- Ms Hermes made formal presentations and held meetings with the Tiwi Land Council throughout 2017.

- Ms Hermes met with Anindilyakwa Land Council (representing Groote Eylandt), sponsored by Ms Libby Massey, CEO of the MJD Foundation, in May.

## Philanthropic support

Professor Easteal hosted the Treasurer of the Canberra Medical Society, Dr Peter Gibson, at the JCSMR Director's Morning Tea on 13 December, and received a donation of \$37,409.



## A world of opportunity

International visits in 2017 highlighted how much the NCIG has to learn from leading initiatives and organisations around the world. It was also clear the world has much to learn from us.

### Director's study tour

Professor Simon Eastal, Director of NCIG, undertook a global study tour from June to September. The purposes of visiting internationally important centres of excellence in human genetics were to:

- promote NCIG internationally
- acquire first-hand experience of world's best practice
- identify opportunities for future partnerships and collaboration.

The study tour was a valuable opportunity to understand the magnitude of the NCIG undertaking and also its profound importance.

Professor Eastal was deeply impressed with developments in the UK, Finland, Canada and elsewhere. Health and medical research has been transformed by genomics over the past decade, particularly in the UK. The central importance of large datasets is now taken for granted. The requisite systems – legislation, policies, funding, expertise, infrastructure, standards and a cooperative research culture – are in place and they continue to be developed at an extraordinary pace.

It was clear NCIG cannot depend on Australian initiatives and organisations alone for scientific infrastructure. To implement world-best practice, and

to deliver real benefits to Indigenous Australians, coordination, cooperation and integration with broader initiatives will be required. Yet it was equally clear that NCIG stands above most similar initiatives around the world. Our consultation and engagement processes are highly culturally attuned, based on respectful relationships and Indigenous models of decision-making, and they work. In this aspect, NCIG is a world leader.



Professor Simon Eastal visiting Genome British Columbia at the Michael Smith Genome Sciences Centre in Vancouver, September 2017.

## SCIENTIFIC OUTREACH

### Meetings and visits conducted during the study tour

Organisation	Meeting/contact with	Position	Date	Venue	Background/Purpose
<b>European Bioinformatics Institute / Sanger Institute</b>	Paul Flicek	Lead Scientist Ensembl	25–27 Sept	Wellcome Genome Campus, UK	Current working arrangements and potential future collaboration
	Dylan Spalding	EGA			
	Simon Bent	Decipher			
	Ernesto Lowy Gallego	IGSR			
<b>Michael Smith Genome Sciences Centre</b>	Prof Steve Jones	Head of Bioinformatics and Associate Director, Michael Smith Genome Sciences Centre, BC Cancer Agency;	24 Sept–4 Oct	Vancouver	Potential future collaboration, consultation on genome centre management and operations
<b>Department of Medical Genetics, University of British Columbia</b>	Prof Laura Arbour	Professor	24 Sept–4 Oct	Vancouver	Potential future collaboration
<b>Centre for Molecular Medicine and Therapeutics, University of British Columbia</b>	Dr Wyeth Wasserman	Professor	24 Sept–4 Oct		Potential future collaboration
<b>Centre of Genomics and Policy, McGill University</b>	Prof Bartha Knoppers (+other researchers at McGill University)	Director	17–24 Sept	Montreal	Potential future collaboration
<b>Genomics Quebec</b>	Francis Ouellette	VP Scientific Affairs	17–24 Sept	Montreal	Potential future collaboration
<b>amazon.com Inc.</b>	Vickie Schneider	Scientific Program Manager, Amazon Research, Cambridge, UK	Various	Cambridge	Consultation on genome centre management and operations
<b>CyVerse</b>	Jason Williams	Lead – Education, Outreach, Training	6 Sept	Video-link	Potential future collaboration
<b>The Wellcome Trust</b>	Dr Michael Dunn	Head, Genetics and Molecular Sciences	14 Sept	London	Potential for funding
<b>Sanger Institute</b>	Prof Richard Durbin	Head, Department of Genetics, University of Cambridge	8 Sept	Wellcome Genome Campus	Potential future collaboration





A view of the Wellcome Genome Campus, Hinxton, UK

## Bioinformatic Lead visits EBI

In September, Dr Hardip Patel, the NCIG Bioinformatic Lead, visited the European Bioinformatics Institute (EBI) at the Wellcome Genome Campus in Hinxton, UK. His purpose was to investigate the use of Ensembl resources for the NCIG project. Ensembl is a publicly-funded non-profit scientific organisation located

in six sites across Europe, including Hinxton. The Ensembl project, now in its 19th year, creates, integrates and distributes reference datasets and analysis tools that enable genomics. Ensembl software and data are freely available, making it instrumental to genomic research worldwide.

Dr Patel learned about the computer system architecture, software and principles for data storage, access and

analyses as applied to genomics data at the Ensembl and European Genome-Phenome Archive (EGA) within EBI. This knowledge and contacts with EBI personnel will assist the development of data infrastructure at NCIG. Dr Patel gave a seminar and presented a poster about NCIG during his visit, which was received with interest. NCIG was perceived as an essential project for the 21st century.

# Statutory information

## Governance Board

Effective from 1 January 2017, the NCIG Board was increased by two members to nine members, six of whom are Indigenous. The Board met four times in 2017 and its main focus was to review and develop the policy framework to align it with the new Statute, and to write a five-year Strategic Plan and an annual Operational Plan for NCIG.

Name	Meeting 1 13 Mar '17	Meeting 2 6 Jun '17	Meeting 3 5 Sep '17	Meeting 4 12 Nov '17
Mr Mick Gooda (Chair)	●	●	●	●
Dr Misty Jenkins (Deputy Chair)	●	●	●	●
Professor Mick Dodson AM	●	●	●	●
Professor Ngiare Brown	●	●	●	●
Dr Simone Reynolds	●	●	●	●
Dr Mark Wenitong	●	●		●
Professor Don Chalmers	●	●	●	●
Professor John Bekkers	●	●	●	●
Professor Margaret Harding	●	●	●	●
Professor Simon Eastale (Director)	●	●	●	●
Ms Jackie Stenhouse (Secretariat)	●	●	●	●



### Board Meeting #1, March 2017

Back Row (left to right): Dr Mark Wenitong, Prof Ngiare Brown, Dr Simone Reynolds, Prof Margaret Harding, Prof Don Chalmers, Prof John Bekkers.

Front Row (left to right): Dr Misty Jenkins, Mr Mick Gooda, Prof Simon Eastale, Ms Jackie Stenhouse



## NCIG team

In 2017 the staff on NCIG were:

- Director – Professor Simon Eastale
- Manager – Dr Michael Dobbie
- Indigenous Community Engagement Coordinator – Ms Azure Hermes
- Bioinformatic Lead – Dr Hardip Patel
- Biorepository Lead – Ms Susan Tan
- Administrator | Board Secretariat – Ms Jackie Stenhouse

Photograph below.



### NCIG Staff and Students

Back Row L-R: Ms Susan Tan, Mr Shaun Lehmann, Mr Renzo Balboa, Mr Tim McInerney, Ms Jackie Stenhouse

Front Row L-R: Dr Hardip Patel, Ms Azure Hermes, Prof Simon Eastale.

## Students

- Mr Shaun Lehmann – PhD candidate
- Mr Tim McInerney – PhD candidate
- Mr Renzo Balbo – PhD candidate
- Mr Ian Brettell – Honours candidate

## Intern

- Ms Alice McCarthy (six-week placement via Aurora Project)

## Financials

In conjunction with the passage of the *NCIG Statute*, ANU awarded NCIG base funding for five years from 2017 to 2021. The first year's funding supported salaries, community engagement and other operating costs.

JCSMR continued to host NCIG, providing office and lab space, school services support (such as finance and HR), and salary support for three staff.

An NHMRC Project Grant supported the NCIG community engagement program until August 2017.

In 2014 Bioplatforms Australia committed \$500,000 to NCIG for sequencing costs. Of this, \$164,650 was expended in 2017. The remainder will be drawn down over 2018.

In December, the Canberra Medical Society (CMS) donated \$37,409, the proceeds from its *Sunday Dreaming* fundraiser, to NCIG. This is the second donation to NCIG by CMS. This important funding has supported the design and production of communication assets, including the NCIG introductory animation and the NCIG logo.

The financial report attached shows that NCIG operated within its means in 2017. Confirmation was received at the end of 2017 of a new NHMRC Project Grant commencing in 2018 (\$1.4m over three years).

## STATUTORY INFORMATION

## NCIG 2017 Finance Report

	Salaries supported by JCSMR (Director, Mgr, Administrator)	Governance Board Costs	Carry Forward from 2016 (Lead Bioinformatician Salary)	NCIG General Operating Fund
	R42300	R42300-01	R42300-02	R42300-OP
<b>Total Income</b>				
Student Fees	\$0.00	\$0.00	\$0.00	\$0.00
Other Income	\$0.00	\$0.00	\$0.00	\$0.00
Internal Sales	\$0.00	\$0.00	\$0.00	\$0.00
Internal Allocations	\$0.00	\$0.00	\$0.00	\$250,000.00
Operating Grant	\$286,383.97	\$30,000.00	\$0.00	\$0.00
Investment Income	\$0.00	\$0.00	\$0.00	\$0.00
<b>Total Income</b>	<b>\$286,383.97</b>	<b>\$30,000.00</b>	<b>\$0.00</b>	<b>\$250,000.00</b>
<b>Total Expenditure</b>				
Salaries & Related Costs	\$287,753.20	\$0.00	\$94,847.37	\$98,000.12
Equipment - Capital	\$0.00	\$0.00	\$0.00	\$0.00
Equipment - Non-Capital	\$0.00	\$0.00	\$454.39	\$9,838.65
Scholars Expenses	\$0.00	\$0.00	\$0.00	\$2,200.00
Utilities & Maintenance	\$0.00	\$0.00	\$586.36	\$3,340.00
Travel Field & Survey Expenses	\$0.00	\$9,973.09	\$4,948.24	\$46,208.68
Expendable Research Materials	\$0.00	\$0.00	\$9.09	\$59,500.07
Contributions	\$0.00	\$0.00	\$0.00	\$8,353.00
Consultancies	\$0.00	\$777.00	\$0.00	\$13,994.82
Consumables	\$0.00	\$0.00	\$237.13	\$28,035.70
Depn & Amort	\$0.00	\$0.00	\$0.00	\$0.00
Internal Purchases	\$0.00	\$0.00	\$0.00	\$0.00
Other Expenses	\$0.00	\$3,189.79	\$895.77	\$7,470.15
Contingency	\$0.00	\$0.00	\$0.00	\$0.00
<b>Total Expenditure</b>	<b>\$287,753.20</b>	<b>\$13,939.88</b>	<b>\$101,978.35</b>	<b>\$276,941.19</b>
<b>Current Year Operating Result</b>	<b>(\$1,369.23)</b>	<b>\$16,060.12</b>	<b>(\$101,978.35)</b>	<b>(\$26,941.19)</b>
<b>Transfers Inflow/(Outflow)</b>				
Transfer from other (CMBE + JCSMR)	\$0.00	\$0.00	\$0.00	\$38,333.00
Transfers to other	\$0.00	\$0.00	\$0.00	(\$2,000.00)
<b>Transfers Inflow/(Outflow)</b>	<b>\$0.00</b>	<b>\$0.00</b>	<b>\$0.00</b>	<b>\$36,333.00</b>
<b>Net Current Year Operating Result</b>	<b>(\$1,369.23)</b>	<b>\$16,060.12</b>	<b>(\$101,978.35)</b>	<b>\$9,391.81</b>
Prior Year Cash Result	\$4,961.30	\$0.00	\$101,978.35	\$0.00
<b>Balance at 31 December 2017</b>	<b>\$3,592.07</b>	<b>\$16,060.12</b>	<b>\$0.00</b>	<b>\$9,391.81</b>



Former NCIG General Operating Fund	NHMRC Biobank Grant (Community Consultation + Salary)	Donation (Canberra Medical Society)	Total	BPA funds (held by the Garvan).  Sequencing
R42850-0011	S42300-03	E42974-04		
	\$0.00	\$0.00	\$0.00	
	\$262,359.51	\$70,619.18	\$332,978.69	
	\$0.00	\$0.00	\$0.00	
	\$0.00	\$0.00	\$250,000.00	
	\$0.00	\$0.00	\$316,383.97	
	\$0.00	\$1,037.78	\$1,037.78	
<b>\$0.00</b>	<b>\$262,359.51</b>	<b>\$71,656.96</b>	<b>\$900,400.44</b>	
	\$198,393.95	\$0.00	\$678,994.64	
	\$0.00	\$0.00	\$0.00	
	\$989.09	\$0.00	\$11,282.13	
	\$0.00	\$0.00	\$2,200.00	
	\$0.00	\$0.00	\$3,926.36	
	\$51,369.43	\$0.00	\$112,499.44	
\$9,775.00	\$317.41	\$0.00	\$69,601.57	\$164,650.00
	\$4,997.00	\$0.00	\$13,350.00	
	\$1,862.00	\$0.00	\$16,633.82	
	\$3,208.65	\$24,017.05	\$55,498.53	
	\$0.00	\$0.00	\$0.00	
	\$0.00	\$0.00	\$0.00	
	\$1,221.98	\$0.00	\$12,777.69	
	\$0.00	\$0.00	\$0.00	
<b>\$9,775.00</b>	<b>\$262,359.51</b>	<b>\$24,017.05</b>	<b>\$976,764.18</b>	<b>\$164,650.00</b>
<b>(\$9,775.00)</b>	<b>\$0.00</b>	<b>\$47,639.91</b>	<b>(\$76,363.74)</b>	<b>(\$164,650.00)</b>
	\$0.00	\$0.00	\$38,333.00	
	\$0.00	\$0.00	(\$2,000.00)	
<b>\$0.00</b>	<b>\$0.00</b>	<b>\$0.00</b>	<b>\$36,333.00</b>	
<b>(\$9,775.00)</b>	<b>\$0.00</b>	<b>\$47,639.91</b>	<b>(\$40,030.74)</b>	<b>(\$164,650.00)</b>
	\$0.00	\$0.00	\$106,939.65	\$500,000.00
<b>(\$9,775.00)</b>	<b>\$0.00</b>	<b>\$47,639.91</b>	<b>\$66,908.91</b>	<b>\$335,350.00</b>

# Acknowledgements

## Funding

The Australian National University

Bioplatforms Australia

NHMRC

Australian Genomics Health Alliance

National Computational Infrastructure

Canberra Medical Society

## Advisors

Ernst & Young

## Research collaborators

University of Sydney

University of Melbourne

Dr Gareth Baynam, University of Western Australia

## Indigenous communities and organisations

Yarrabah Community, Queensland

Titjikala Community, Northern Territory

Tiwi Land Council, Northern Territory







## National Centre for Indigenous Genomics

The John Curtin School of Medical Research  
The Australian National University  
Building 131, Garran Road  
Acton, ACT 2600, Australia

### Postal address

The John Curtin School of Medical Research  
The Australian National University  
GPO 334, Canberra, ACT 2601, Australia

T +61(0)2 6125 1811

F +61(0)2 6125 2499

**Freecall: 1800 100 912**

E [jcsmr.ncig@anu.edu.au](mailto:jcsmr.ncig@anu.edu.au)

