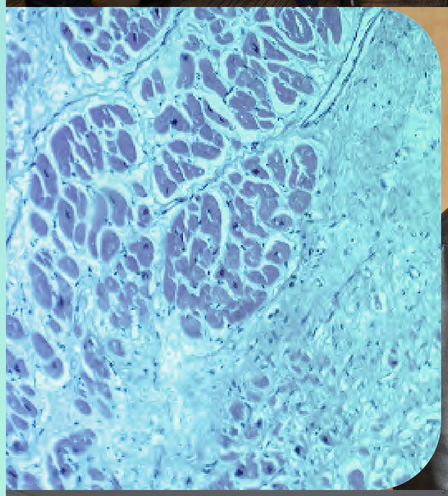
BioGrid

20TH ANNIVERSARY

BioGrid Annual Report 2023–24



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2023-24 Snapshot

5.4 million
unique records available

42 Members and Collaborators
representing 82 institutions

21 current institution ethics approvals
covering 39 sites

127 active research projects during 2023-24, represented across all states and the ACT

377 journal publications reported to date that have utilised BioGrid for their research

20 years of BioGrid timeline:

2003

Peter Gibbs (then at Royal Melbourne Hospital and Ludwig Institute for Cancer Research), Peter Colman (Royal Melbourne Hospital) and Terry O'Brien (then at Royal Melbourne Hospital and University of Melbourne), saw the potential benefits of creating a way to safely and securely access distributed clinical data sets for research, which resulted in BioGrid's unique federated model.

2004

IBM wins tender to establish a federated data technology model for MMIM project.

Members and Collaborators

BioGrid Australia Ltd is a not for profit company limited by guarantee. Its members are health services, universities and research institutes. At the time of this report, BioGrid's overarching evergreen collaboration agreement has been executed with 42 institutions (representing 82 sites across Australia) covering the management of governance, intellectual property, data access, undertaking projects, commercialisation and publications.

ACT Health
Canberra Hospital

Alfred Health
The Alfred
Caulfield Hospital
Sandringham Hospital

Austin Health
Austin Hospital
Heidelberg Repatriation Hospital

Baker Heart & Diabetes Institute

Barwon Health
University Hospital Geelong

Bendigo Health
Bendigo Hospital

Central Adelaide Local Health Network
Royal Adelaide Hospital
The Queen Elizabeth Hospital

Eastern Health
Angliss Hospital
Box Hill Hospital
Healesville Hospital
Maroondah Hospital

Gold Coast Hospital and Health Service*
Gold Coast University Hospital
Robina Hospital

Genesis Care

Goulburn Valley Health

Grampians Health Ballarat
Ballarat Base Hospital
Queen Elizabeth Centre

Hudson Institute of Medical Research

Latrobe Regional Hospital

La Trobe University*

Mater Health Services Brisbane
Queensland Diabetes and Endocrine Service
Mater Hospital Brisbane

Melbourne Health
The Royal Melbourne Hospital

Metro North Hospital and Health Service
Royal Brisbane and Women's Hospital
Prince Charles Hospital

*Non-Member Collaborator of BioGrid Australia

2005

MMIM pilot project expands to include additional disease areas and hospitals, with funding from the Federal Government for 2 years.

BioGrid 20TH ANNIVERSARY

BioGrid Annual Report 2023-24

Metro South Hospital and Health Service*
Princess Alexandra Hospital

Monash Health
Monash Medical Centre, Clayton
Monash Medical Centre, Moorabbin
Casey Hospital
Dandenong Hospital

Monash University*

Murdoch Children's Research Institute

Northern Adelaide Local Health Network
Lyell McEwin Hospital
Modbury Hospital

Northern Health
The Northern Hospital

Peninsula Health
Frankston Hospital
Rosebud Hospital

Peter MacCallum Cancer Centre

South Metropolitan Health Service*
Fiona Stanley Hospital

South Western Sydney Local District
Bankstown, Bowral, Camden, Campbelltown, Fairfield and Liverpool Hospitals

St John of God Health Care
Ballarat, Bendigo, Berwick, Bunbury, Burwood, Geelong, Geraldton, Midland, Murdoch, Mt Lawley, Richmond, Subiaco and Warrnambool Hospitals

St Vincent's Hospital, Melbourne

St Vincent's Hospital, Sydney*

Sydney Local Health District
Royal Prince Alfred, Concord Repatriation General, Balmain, Canterbury and Sydney Dental Hospitals

Tasmanian Government Department of Health and Human Services
Royal Hobart Hospital
Launceston General Hospital

The Royal Children's Hospital

The Royal Women's Hospital

The University of Melbourne

The University of New South Wales

The University of Western Australia

The Walter & Eliza Hall Institute of Medical Research

Victorian Comprehensive Cancer Centre Alliance

Western Health
Footscray Hospital
Sunshine Hospital
Williamstown Hospital

West Moreton Hospital and Health Service*
Ipswich Hospital

*Non-Member Collaborator of BioGrid Australia

Chair's Report

2023-24 was a year of further consolidation for BioGrid, as we continued to deliver to our corporate strategy. 2024 also represents a significant milestone for BioGrid, as we celebrate our 20th year of operation.

Dr Rob Grenfell

BioGrid Australia was originally established as the Molecular Medicines Informatics Model in a visionary move by a collaboration of researchers who could foresee the value in being able to easily share research data without compromising the privacy of research participants, and while taking into account the special governance and ethics requirements for multi-site research. This was in an environment where electronic medical records did not even exist so the potential power of digital clinical data collection was still just an idea.

Fortunately, Peter Gibbs (then at Royal Melbourne Hospital and Ludwig Institute for Cancer Research), Peter Colman (Royal Melbourne Hospital) and Terry O'Brien (then at the Royal Melbourne Hospital and University of Melbourne), saw the huge potential benefits of creating a way to safely and securely access distributed clinical data sets for research, which resulted in BioGrid's unique federated model.

The deep understanding these researchers had of the challenges of using clinical data for research informed what is now Australia's only collaboration network with the legal and ethical framework to enable the sharing of near real-time health and medical data for research. To further streamline access, they enabled the development of BioGrid's unique governance framework, which ensures that medical research is accelerated through the provision of enduring, curated clinical data linkages.

I also acknowledge the work done by our inaugural directors: Bryan Williams, BioGrid's first Board Chair, Rob Merriel and Julian Clark. This team worked hard to establish BioGrid as a going concern, as it evolved from being a scientific project into a company limited by guarantee with 18 founding members.

In terms of the current reporting year, 2023-24's environment was one where we saw the health sector continuing to recover from the COVID-19 pandemic effects, and there is no doubt that the effects will still be felt for some time.

This has the potential to position BioGrid positively, as research institutions look for innovative ways to meet their research needs, and hospitals seek more efficient ways to meet their requirements for tracking and measuring continuous improvement.

This is reflected in a segment of BioGrid's activities that is steadily growing – the creation of bespoke registries for clinical data collection. A number of projects in 2023-24 involved the use of registries for a

Continued on next page

2006

Australian Cancer Grid project is funded under Victorian Government's Healthy Futures Initiative.

2007

MMIM project is renamed and branded BioGrid Australia. SAS upgraded to Business Enterprise for querying and reporting data.

variety of uses, including tracking the effectiveness of surgical treatments for particular cancers. The BioGrid Board is certain that this is an area that will continue to grow in coming years for prospective data collection, and it is now established in the minds of our partners as an area where BioGrid can offer significant value.

We are also seeing an increasing appreciation in the research community of the utility and cost-effectiveness of ingesting, linking and curating existing clinical data, particularly from electronic medical records, for new research programs. The flexibility and power of BioGrid's data sharing platform is opening up new ways of doing research, and providing the ability to think innovatively about projects that in the past would have presented significant challenges, like the study of rare diseases. BioGrid is a partner in several MRFF Research Data Infrastructure grants awarded in 2023. These grants are facilitating complex data harmonisation and sharing by leveraging BioGrid's unique data governance framework and infrastructure platform.

The Board remains confident that BioGrid's strategic direction is still relevant and achievable, however in early 2024 the Board and Executive team conducted a 'mini review' of the strategy to ensure it continues to reflect our business plan requirements for the next 12 months. Through this process we strengthened the links between our strategic objectives and the way we measure our operational activity, ensuring that BioGrid continues to be firmly focused on our growth focus.

Our financial results for the 2023-24 year were not as strong as expected due to a number of factors outside of our control, however this is the environment we operate within, with our members and collaborators dependent on research funding processes that can cause unexpected delays.

The BioGrid team's ability to respond to these types of issues is, as always, commendable and always focused on doing what works best for our members and collaborators. I am very proud of their unwavering commitment to improve processes to ensure continued service delivery to our clients.

The Board is looking ahead to the next financial year with great optimism, as a number of projects that were delayed in 2023-24 will be realised in 2024-25.

It's important to note a significant milestone for BioGrid – 2024 is our 20th year of operation, and the sustainability of this organisation and the belief in the vision of its founders is due to the passion and leadership of BioGrid's CEO Maureen Turner and her team, as well as our members who have steadfastly worked to realise the potential of BioGrid's unique and indeed ground-breaking services.

BioGrid's highly positive reputation in the research community is a testament to the vision that has been maintained over the past 20 years.

BioGrid's highly positive reputation in the research community is a testament to the vision that has been maintained over the past 20 years, and the excellent work done to build the technological capacity and professional capability in the BioGrid organisation to deliver this vision.

Congratulations to all at BioGrid for another commendable year and the positive growth that is driving the organisation forward to an exciting future.

Dr Rob Grenfell

Chair, BioGrid

BioGrid Australian Cancer Grid project under Melbourne Health is named a Computerworld Honors Laureate.

2008

CEO's Report

Happy 20th Anniversary to BioGrid!

It has been my great privilege to lead BioGrid as CEO for 12 years, and to work with our executive team since I joined the organisation 15 years ago. I have watched our organisation go from strength to strength as the unique services we offer to the medical research community have been increasingly recognised. This has gone hand-in-hand with the evolution of technology that enables us to fully realise the vision that originally created our organisation.

Working over the years with our valued members and collaborators has been very rewarding. Not only are they great advocates for BioGrid, they are generous in their support for sharing the BioGrid story. I enjoyed seeing many of them at our 20th Anniversary Event on Tuesday 26 November 2024, talking about their projects and sharing their successes.

BioGrid's increasing financial sustainability over the past few years has been a gratifying vote of confidence in our services, thanks in part to our Board and members' support for changes to the way we price our services.

While member organisations pay an annual membership fee for access to our platform for their entire organisation, we have had to implement a number of changes so that we can continue to service the costs of doing business. These included introduction of the **research user access fee** (per project) and updating our daily charge out rates for fee-for-service work. However we are still competitive in the market while providing a superior level of customer service.

These changes ensure that we are able to service the increasing overhead costs associated with our business, and attract and retain the best and the brightest people to provide our specialised services.

Maureen Turner

In 2023-24 we are reporting a small loss due to a number of factors outside of our control. These include the ARC Portal's 5-year funding ending in January 2024 and delays in project agreements being executed.

On a positive note, the delayed project agreements will now occur in the following financial year, assisting us to achieve a healthy 2024-25 financial year.

With an eye on the future, BioGrid will be embarking on a partnership with Aridhia, an organisation that specialises in secure ISO27001 certified and GDPR compliant Digital Research Environments.

Continued on next page

BioGrid Australia becomes a company limited by guarantee with 18 founding members.

2009

BioGrid partners with Roche on a prospective study into clinical outcomes of Bevacizumab use in metastatic colorectal cancer (TRACC).

2009

BioGrid Annual Report 2023-24

CEO's Report

The Aridhia Digital Research Environment or DRE, is a health and biomedical informatics platform that addresses many of the principal data challenges involved in scaling innovative health research and health delivery services. We are pleased to be partnering with this global company to deliver a secure DRE that will provide greater scope for future services for BioGrid's members and collaborators.

We already have a number of projects currently being negotiated that will be dependent on the Aridhia cloud-based DRE, and we anticipate that this will in the future be a significant driver of BioGrid's growth.

In summary, 2023-24 has been a year of continued growth and consolidation for BioGrid, and I look forward to the next 12 months with great anticipation, as I foresee the work done over the past few years coming to fruition with exciting work ahead. Thank you to my wonderful team at BioGrid, without whose commitment and hard work none of our success, or that of our partners, would be possible.

I'd also like to thank the Board and the Member Management Committee, who continue to provide invaluable guidance and support. Their faith in the value of BioGrid has been very much appreciated, and I look forward to working with them again in the coming year.

Finally, I'd like to thank our research partners and their continued belief in what we do. Their recognition of the uniqueness of BioGrid and appreciation for what we do confirms our own confidence in the value of our work, and drives us forward for the next 20 years.

Maureen Turner

CEO, BioGrid

In summary, 2023-24 has been a year of continued growth and consolidation for BioGrid, and I look forward to the next 12 months with great anticipation.

2010

Sir Gustav Nossal launches CART-WHEEL.org, world's first ethically approved website questionnaire for consumer driven research into rare tumours and molecular sub-types of common tumours. CART-WHEEL was developed by and is hosted and managed by BioGrid.

2011

BioGrid membership expands to

25

members and collaborators.

About BioGrid

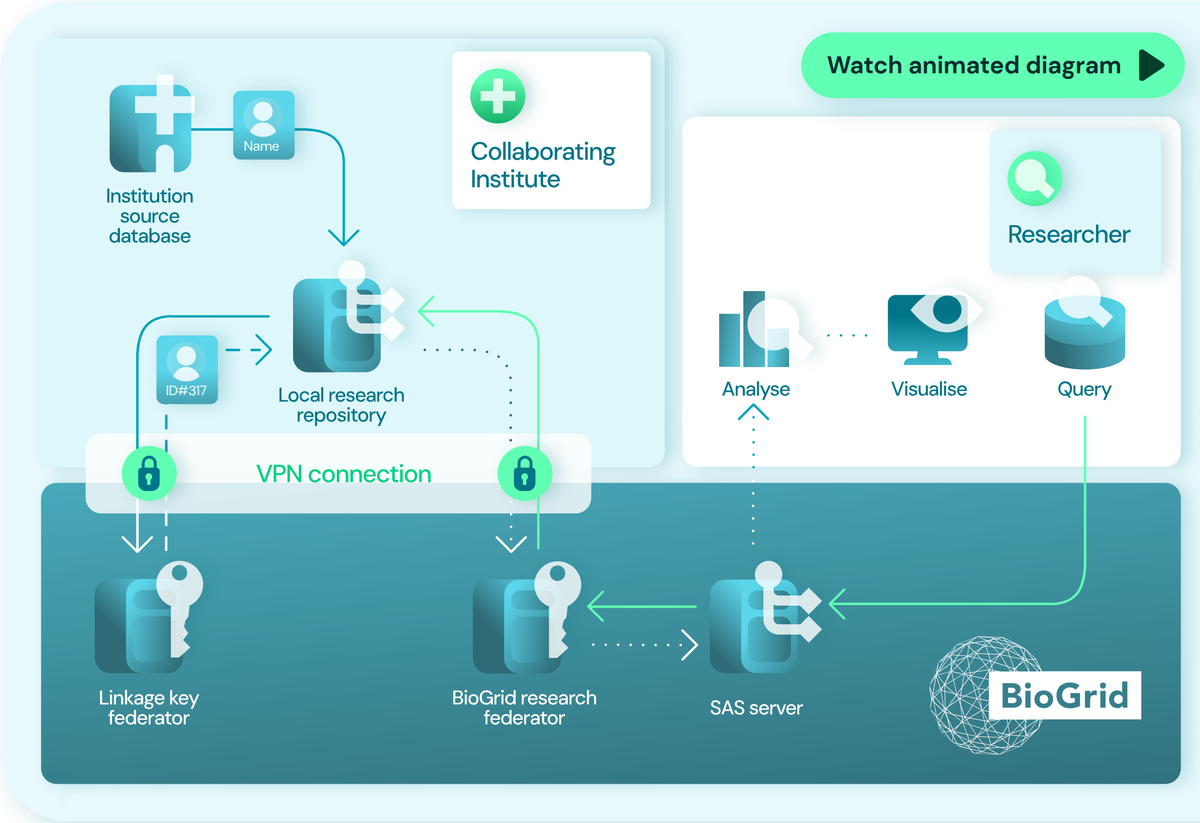
BioGrid Australia Ltd is a not-for-profit service provider established and owned by the health and medical research community, for the health and medical research community, to provide a vitally important national data sharing platform that supports local and international health and biomedical research.

BioGrid specialises in near real-time linkage and curation of hospital-based and managed clinical treatment outcomes, genomic, biospecimen, imaging and patient administration system data.

BioGrid's members are health services, universities and research institutes that utilise this trusted virtual real-time data-sharing platform to conduct collaborative multi-site research.

One of the key benefits of BioGrid's service is the secure coding of patient data, ensuring that no identifying information is supplied to researchers using the data. BioGrid is the only collaboration network in Australia with the legal and ethical framework to enable the sharing of near real-time health and medical data for research.

In addition, BioGrid's unique governance framework ensures medical research is accelerated through the provision of enduring, curated clinical data linkages. For more information on how BioGrid works, what data is linked to BioGrid and how to access data, go to **www.biogrid.org.au**.



2012

BioGrid wins People's Choice Excellence in Business Intelligence Award.

Using patient registries to expand understanding of urological cancers

Principal Investigator – A/Prof Ben Tran, WEHI

The treatment landscape for genitourinary cancers is rapidly evolving. There are multiple new treatments demonstrating survival benefits across all cancers.

Clinicians need to better understand how these treatments will be used in a real-world setting, and whether the improved outcomes translate from trials into the real world. In addition, real world data is required to identify the evolving areas of need for our patients.

Registries, containing treatment data prospectively supplied by clinicians, are a valuable tool for collecting data, especially when the clinical locations or patient populations are dispersed or small in number.

The Walter and Eliza Hall Institute has created four registries: ePAD, KRAB, BLADDA and iTestis, to support a greater understanding of genitourinary cancers and the outcomes of various treatments.

ePAD

ePAD (Electronic Prostate cancer Australian Database) was developed in 2016 to support clinicians by collecting real world information about patients with advanced prostate cancer.

The program evaluates the impact of age, cardiovascular co-morbidity and performance status on treatment recommendations, as well as interactions with other treatments where co-morbidities exist. It maps survival outcomes and investigates the role of novel hormonal therapies in changing tumour biology.

KRAB

Until now, there has been little local data regarding the treatment landscape for Metastatic Renal Cell Carcinoma (mRCC) in Australia.

Kidney canceR Australian registry and Biobank (KRAB) is Australia's first prospective mRCC Registry, bringing together genitourinary clinicians from around Australia and facilitating collaboration in the RCC space, beginning with data, but with potential for translational research too.

Continued on next page

2013

One million individuals linked through BioGrid's platform and 99 publications produced from studies utilising data linked to BioGrid. AIHW NDI data becomes available through BioGrid on a project-specific basis.

2014

BioGrid's 10th anniversary celebration combined with launch of Health and Biomedical Informatics Centre (HaBIC) at University of Melbourne.

Projects

Using patient registries to expand understanding of urological cancers

BLADDA

The BLADDA project is a multi-centre, noninterventional study that aims to collect data and biospecimens in patients with muscle invasive and advanced bladder cancer in Australia.

This data will be used to determine patterns of treatment, facilitate translational research and be used as a platform from which registry based trials can be conducted.

iTestis

Germ cell tumours (GCTs) are rare compared to other cancers, but are still the most common type of cancer in young men.

These cancers are highly treatable, but determining the most appropriate treatment for each patient relies on a good foundation of clinical data. iTestis was developed to fill the gap in detailed national clinical data to help clinicians to assess treatment options and resulting outcomes for their GCT patients.

BioGrid's role

BioGrid provides the software development services required to create these registries, working closely with clinicians to ensure data collection applications match the clinic workflow for ease of use.

Once created, the registries are connected to BioGrid's data linkage platform. BioGrid's secure infrastructure, data linkage and curation is underpinned by BioGrid's ethical and governance framework, enabling data to be used for approved collaborative clinical audit and research projects.

Read more about the genitourinary cancer registries that BioGrid is working on

Bupa Health Foundation funds a collaboration between VCCC Alliance, University of Melbourne and BioGrid to link primary care and hospital data for the first time in Australia.

2015

ePAD prostate cancer registry sponsored and developed by BioGrid is initially funded by Astellas, AstraZeneca and Janssen.

CART-WHEEL questionnaire is expanded for global WhiMSICAL study.

2016

iTestis – helping clinicians improve outcomes for germ cell tumour patients

Principal Investigator – A/Prof Ben Tran, WEHI

Germ cell tumours (GCTs) are rare compared to other cancers, but are still the most common type of cancer in young men, formed from reproductive cells and mostly occurring in the testicles. These cancers are highly treatable, but determining the most appropriate treatment for each patient relies on a good foundation of clinical data.

At its core, the treatment of GCT has remained the same over many years. However, there are many nuances associated with its treatment that may not be known to clinicians who don't see these cancers regularly or frequently. These include simple things such as chemotherapy dosing, dose intensity, use of imaging, and surgical techniques, and understanding the impacts of these variables can make a difference to treatment outcomes.

In addition to the difficulty accessing information about treatments and subsequent outcomes, the rarity of GCTs makes it difficult to enrol sufficient numbers of patients onto clinical trials that address important clinical questions.

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2017

BioGrid submits and links adult Type 1 diabetes data to Australian Diabetes Data Network funded by JDRF.

2017

PURPLE pancreatic cancer registry is developed and linked by BioGrid for WEHI.

iTestis created to collect high quality national clinical data

A team at the Walter and Eliza Hall Institute of Medical Research (WEHI) has developed iTestis to fill the gap in detailed national clinical data to help clinicians to assess treatment options and resulting outcomes for their GCT patients.

iTestis is a detailed database with a user-friendly web-based interface that facilitates prospective collection of high quality clinical data and record tissue location data from GCT patients treated in Australia.

BioGrid's role

BioGrid's secure platform underpins the iTestis database, and BioGrid's experience over 15 years with building and managing registries provides the ideal skill-set for supporting iTestis' future objectives.

An important recent feature of the iTestis registry is the ability for patients to complete online questionnaires that assist treating clinicians to better manage patient care and quality of life due to feedback received. This capability was developed by BioGrid as an improvement upgrade to the iTestis software.

Dynamic reporting of iTestis registry data provided by BioGrid enables A/Prof Tran and his colleagues to review data they have each collected which can assist with cohort identification and analyses.

BioGrid's solution means that a significant data set can be provided for participation in global initiatives like G3 projects, and enables iTestis to be expanded to include international sites.

Read the full iTestis case study >

iTestis is a detailed database with a user-friendly web-based interface that facilitates prospective collection of high quality clinical data and record tissue location data from GCT patients treated in Australia.

BioGrid links and curates data for first *Closing the Gap on Indigenous cardiovascular health* project led by Luke Burchill.

2018

VCCC Data Connect: Understanding cancer patients' journey of care

Principal Investigator: Dr Alex Lee, Research Fellow

Work done in collaboration with the Data Connect team: Damien McCarthy, Rebecca J Bergin, Dr Javiera Martinez Gutierrez, Chris Kearney, Dr Shaoke Lei, Sally Philip, Dr Meena Rafiq, Dr Brent Venning, Olivia Wawryk, Dr Jianrong Zhang and Prof Jon Emery

In an Australian first, the linking of primary care and hospital data has been made possible through Data Connect, a major collaboration between the VCCC Alliance, the University of Melbourne, hospitals and BioGrid Australia.

Leveraging the power of data

The overall objective of this work is to improve outcomes for cancer patients and to inform policy decisions by bringing a data-driven lens to the entire patient journey of care.

Connecting healthcare data from general practice and hospitals is essential for understanding the factors that contribute to delayed cancer diagnosis and treatment.

When cancer patients are diagnosed and move from primary to hospital care, and back for post-treatment care, this can impact how their health issues are identified and solved. Bringing together data sources will help to better understand where patients access care, how they're being diagnosed and their quality of life after treatment.

Partnering with BioGrid to resolve linkage and governance challenges

VCCC Data Connect uses BioGrid's federated data infrastructure to address these challenges by providing data through a single service. This removes the need for researchers to apply for data access through multiple different organisations, while also meeting the ethics, governance, and privacy requirements of data custodians, clinicians and patients.

BioGrid's infrastructure and unified governance processes enable the connection of primary care data from two primary care databases, hospital data from hospital admissions, emergency department presentations and outpatient care.

Read the full VCCC Alliance Data Connect case study

ANZTHOR – supporting improved thoracic surgery outcomes

Principal Investigator(s): A/Prof Phillip Antippa OAM, Head of Thoracic Surgery, The Royal Melbourne Hospital, and A/Prof Gavin Wright, Director of Surgical Oncology, St Vincent's Hospital Melbourne

Improving the quality of care was the objective driving the establishment of the Australian and Aotearoa New Zealand Thoracic clinical quality registry (ANZTHOR) by the Australian & New Zealand Society of Cardiac & Thoracic Surgeons (ANZSCTS).

Despite major improvements over the years in thoracic surgery and the way it's done, prior to ANZTHOR there was no tracking of the results of thoracic surgery, and no mechanism for reviewing the work volumes. This meant it was impossible to get a clear view of whether there was a variation of care across Australian providers.

"It's very hard to put your finger on what thoracic surgery is in this country. We want that picture and we also want to ensure there's at least a minimum quality of surgery across the board," says A/Prof Gavin Wright, Director of Surgical Oncology at St Vincent's Hospital in Melbourne. "That's the number one priority for ANZTHOR – getting a view of how the field is performing across the board."

The way ANZTHOR does this is by focusing on data relating to the marquee operation for thoracic surgeons, which is lung resection to cure lung cancer.

> "That's the number one priority for ANZTHOR – getting a view of how the field is performing across the board."
>
> **A/Prof Gavin Wright**

Continued on next page >

Projects

ANZTHOR - supporting improved thoracic surgery outcomes

Analysis of data in ANZTHOR will drive improvements in hospitals

One of the benefits of collecting thoracic surgery data is that helps identify outlier cases, enabling an investigation of why these outliers are happening.

"All of our key quality indicators are within the control of the surgeon, and when we can use the data to identify issues we can then fix those issues," says A/Prof Wright.

Use of the registry is already shedding light on the results of procedures, highlighting subtle differences in outcomes that might not have been obvious if comparative data had not been collected over time.

ANZTHOR rollout timed to support national health initiatives

The rollout of ANZTHOR has been timed to support the National Lung Cancer Screening Program starting in July 2025.

"We're encouraging hospitals to come on board before the screening program starts, because we believe ANZTHOR will be very helpful in ensuring transparency in terms of best practice," says A/Prof Wright. "We really want to make sure these patients, who are asymptomatic with a curable cancer, experience minimum harms and maximum cure rates."

"We're encouraging hospitals to come on board before the screening program starts, because we believe ANZTHOR will be very helpful in ensuring transparency in terms of best practice."

A/Prof Gavin Wright

2018

VCCC Alliance strategic research plan funds a Data Linkage Capability program, focussing on linkage of primary care and VCCC hospital data.

2018

BLADDA registry is developed by BioGrid for WEHI, collecting data and biospecimens in patients with muscle invasive and advanced bladder cancer.

Projects

ANZTHOR - supporting improved thoracic surgery outcomes

How ANZTHOR works, supported by BioGrid

ANZTHOR captures clinical, procedural, and pathological data at the point of care, and will include patient demographics, prognostic variables, quality of care indicators, operation details and outcome data collected at various points of the patient's hospital journey, including at the time of the operation, at hospital discharge, and retrospectively, via data linkage, in order to enable good quality follow-up.

The initial phase of the ANZTHOR database uses the Research Electronic Data Capture (REDCap) platform which is hosted by BioGrid Australia. The plan is to minimise the work required by clinicians by developing an online data entry platform such as a mobile app.

ANZTHOR will also allow all individual clinicians and sites to have access to their own data as well as facilitating dynamic reporting.

One of the key benefits of BioGrid's service is the secure coding of patient data, ensuring that no identifying information is supplied to researchers using the data. BioGrid is the only collaboration network in Australia with the legal and ethical framework to enable the sharing of real-time hospital-based health and medical data for research.

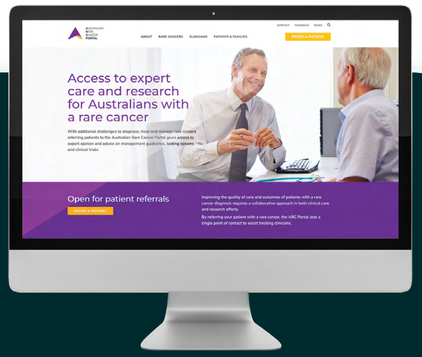
In addition, BioGrid's unique governance framework ensures medical research is accelerated through the provision of enduring, curated clinical data linkages.

"We approached BioGrid because of their track record in registries across all sorts of specialties, says A/Prof Wright. "And because we found them absolutely responsive in the design of the registry - the ongoing support we've had has been fantastic. Their training of our staff and people like myself who want to use the analytical software like SAS Enterprise Guide.

"They've been writing modules for us so that we can have tailor made dashboards and the ability to interact almost at a personalised level for each hospital. And we just love that federated database system - to be able to send a central query in and ask the question of the entire network. Very simple once you have the approval from the data custodian at each site."

> "We approached BioGrid because of their track record in registries across all sorts of specialties"
>
> A/Prof Wright

Read the full ANZTHOR case study >



ARC Portal, a referral program for doctors with rare cancer patients, launches with a five year funding program under Australian Genomic Cancer Medicine Centre (now known as Omico). ARC Portal is developed, hosted and managed by BioGrid.

2019

National Cancer Cohort Platform (NCCP) launched in 2024

NCCP
The National Cancer Cohort Platform

The National Cancer Cohort Platform (NCCP) project, which is supported by BioGrid Australia, was launched on Monday 29 May.

The NCCP project involves the KConFab, Lifepool, Melanoma Research Victoria, Australian Ovarian Cancer Study, and Variants in Practice (ViP) Study partner cohorts.

These large databases of patient information, biospecimens, prior research, and other data will be brought together to a common location to enable more expansive research projects.

The launch event provided an overview of the project including the aims, outcomes and approach to the build of this new digital asset. Representatives from the five partner cohorts explained the work they do and discussed the opportunities the NCCP project will bring.

Maureen Turner, CEO of BioGrid Australia, gave an overview of how BioGrid's platform will facilitate the NCCP's digital asset, and Sophy Athan, VCCC Alliance Consumer Advocate & Leader provided a consumer perspective. A/Prof Ashley Ng shared his insights into the value of a centralised data platform and the opportunities that it creates.

Through this project BioGrid Australia, the Department of Health Services Research at Peter MacCallum Cancer Centre and the VCCC Alliance will establish a new research infrastructure that will set a standard in collaborative, large-scale health research.

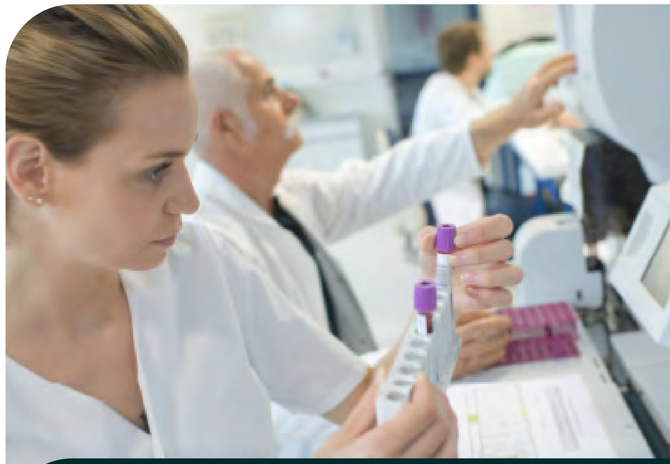
The NCCP project is funded by the Medical Research Future Fund, and is part of the National Critical Research Infrastructure initiative designed to identify and fund world-class health and medical research.

Read more about the NCCP Project on the Peter MacCallum Cancer Centre website

2020

BioGrid achieves its first success working with a project team to secure an MRFF grant, awarded to Prof Karin Thursky of Peter MacCallum Cancer Centre for Invasive Fungal Infections Surveillance project.

BioGrid Australia to develop Australia and New Zealand's first Dermatology Registry



In 2023 BioGrid Australia was announced as the developer and host for Australia and New Zealand's first Dermatology Registry, a significant new initiative led by the Skin Health Institute, in collaboration with dermatologists across Australia.

The registry, which has been live since September 2023, is designed to improve the quality of care for people living with skin conditions by informing dermatologists of the efficacy and risks of current and emerging treatment, the risk factors for developing a skin condition, and the impact these conditions have on the quality of life of the patients.

BioGrid is providing a suite of support services for the registry, including the development of the registry, hosting and maintenance, data ingestion and reporting.

One of the key benefits of BioGrid's service is the secure coding of patient data, ensuring that no identifying information is supplied to researchers using the data. BioGrid is the only collaboration network in Australia with the legal and ethical framework to enable the sharing of real-time health and medical data for research.

Read more online >

BioGrid is the only collaboration network in Australia with the legal and ethical framework to enable the sharing of near real-time health and medical data for research.

Technology

Upgrade of BioGrid's linkage technology to LinXmart

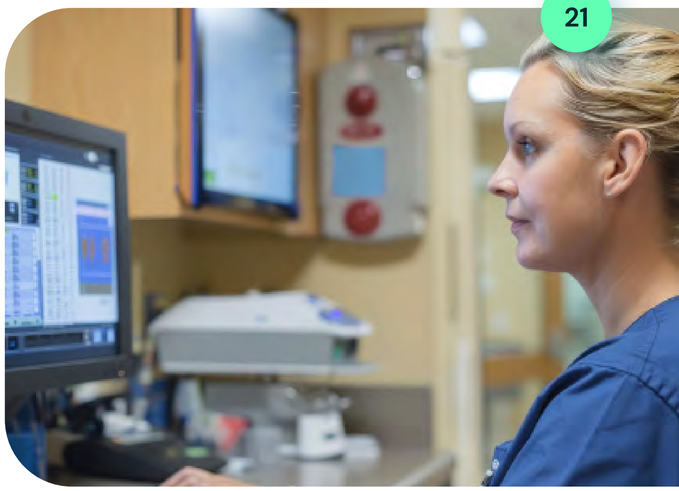
In 2023-24, BioGrid implemented an upgrade to its record matching technology to ensure that BioGrid's partners and collaborators continue to have access to world-class data linkage services.

Data linking is central to BioGrid's services, so security is of the utmost concern. The new software implemented is LinXmart, developed by Curtin University's Centre for Data Linkage, which provides secure and sophisticated ISO27001 certified encrypted data linkage.

LinXmart is secure, fast and scalable, with sophisticated data management features that handle growing datasets and dynamic linkages over time. This will ensure BioGrid's service can grow as the number of our collaborators and projects grows. It is also compatible with BioGrid's future move to a cloud-based digital research environment.

LinXmart is currently used by the Victorian Agency for Health Information, NSW Health's Centre for Health Record Linkage, and Swansea University (UK).

The first phase of this upgrade went live in May 2024. Over time, all data linked to the BioGrid platform will transition to being processed for record matching through LinXmart.



Websites upgrade

BioGrid, ARC Portal and CART-Wheel websites were refreshed this year, providing a cleaner interface for visitors to the sites as well as making them easier to manage.

BioGrid's digital partner, PIXO, works with non-profit organisations across Australia and internationally, and manages BioGrid's digital communication platforms. Over the final quarter of 2023, the PIXO team worked with BioGrid, ARC Portal and CART-Wheel teams to design the new websites and migrate the content to the new platform.

Key upgrades to the websites include improved graphics, a refreshed colour palette, and a clearer modular layout. The new platform also makes it easier to manage the website content, with a sophisticated template structure that simplifies website page design.

BioGrid membership expands to

42

members and collaborators.

LA TROBE UNIVERSITY

2020

Our People

BioGrid organisational realignment

Following the growth that BioGrid has seen over the past twelve to eighteen months, we reviewed our operations and realigned our executive team to position us for future growth.

A new position was created, Head, Business Development and Programs, which will be recruited during 2025. This role will be responsible for procuring and managing the development of major programs of work.

Senior managers Wisam Abdelaziz and Javier Haurat, have had their position titles updated to better reflect the seniority of their roles and the scope of their responsibility. Wisam is now Head, Infrastructure and Data Engineering, and Javier is now Head, Data Science and Registries.

Allison Bourne's Ethics and Governance role was expanded to include the role of Privacy Officer. Allison is now Ethics, Governance and Privacy Manager, and is now part of the executive Management Team.

2021

BioGrid develops for Peter Doherty Institute for Infection and Immunity Australia's first virtual biobank under APPRISE program.

APPRISE
AUSTRALIAN PARTNERSHIP FOR PREPAREDNESS RESEARCH ON INFECTIOUS DISEASE EMERGENCIES

2021

BioGrid develops and hosts Australia's first thoracic surgery registry, ANZTHOR for Australian & New Zealand Society of Cardiac & Thoracic Surgeons.

ANZTHOR
ANZSCTS Thoracic Surgical Registry

BioGrid Annual Report 2023-24

Governance

BioGrid Australia Ltd is a company limited by guarantee which means the not-for-profit company is owned by its members. The company is governed by a Board of Directors on behalf of the members. Each member institution has one full voting representative on the Member Management Committee.

Dr Rob Grenfell

MBBS, MPH, FAFPHM, MAICD

Director since October 2017;
Chairman since September 2018

Chief Strategy & Regions Officer, Grampians Health, 2022 – present

Dr Rob Grenfell, a Public Health Physician, has broad-ranging public health experience including;

- National Medical Director at BUPA Australia New Zealand,
- National Director Cardiovascular Health at the Heart Foundation,
- Strategic Health Advisor to Parks Victoria,
- Senior Medical Advisor at the Department of Health Victoria,
- Physician in charge of travel health BHP, and
- General Practice.

He was a member of the Safety and Quality Outcomes Committee of the Hospital Innovation Reform Council, a member of the Victorian Quality Council and Member of the Health Advisory Committee of the National Health and Medical Research Council.

- Director, Western Victoria Primary Health Network (2024 – present)
- Director, Grenfell Health Consulting (1997 - present)
- Special Health Advisor, CSIRO, (2020 - 2023)
- Director - Health and Biosecurity, CSIRO (2015 – 2020)
- Director, Maree Stopes Health (2011 - 2016)
- Chair, General Practice Victoria (2007 - 2010)
- Director, General Practice Victoria (1998 - 2007)

Affiliate Associate Professor Paul Cooper

BSc, PhD, GradDip Bus, FAIDH, CHIA, AFHEA, GAICD

Director since August 2018 and Deputy Chair since September 2018

Director, Longboardfella Consulting Pty Ltd, 2016 – present

A/Prof Paul Cooper obtained his PhD at Melbourne University, and a Graduate Diploma Business (Organisational Development) at RMIT University. He is a Fellow of the Australasian Society of Health Informaticians and a Certified Health Informatician (Australia). He is Deputy Chair BioGrid Australia and Associate Professor Health Informatics at Deakin University. He is an Editor for Pomegranate podcast of the Royal Australasian College of Physicians.

Paul specialises in independent strategic advisory services aimed at helping organisations make the most effective use of information and digital capabilities. Paul believes strongly in the benefits of diversity and has been a diversity champion throughout his career.

- Non-Executive Director, healthAbility (2024 – present)
- Member, Human Research Ethics Committee, St Vincent's Healthcare (2019 - present)
- Member, WEHI Advocacy and Support Committee (2017 - present)
- Affiliate Associate Professor, Health Informatics Management, Faculty Health, School of Medicine, Deakin University (2016 - present)
- Digital Content Curator, Australasian Institute of Digital Health, Victorian Branch (2021 – 2022)
- Director, Victorian Continence Resource Centre (2015 - 2020)
- Secretary, Australasian Institute of Digital Health, Victorian Branch (2017 - 2019)
- Director, Digital Health, Department of Health and Human Services, Victorian Government (2017 - 2018)

BioGrid develops and hosts the National Antibiotic Allergy Network's database for inpatient antibiotic allergy testing led by Prof Jason Trubiano.

2022

Mr Christopher Arnold AM

B Comm, MBA, FCPA, FAICD

Director since March 2014

Principal, Hodgson Associates, 2010 – present

Mr Chris Arnold has held six executive CEO roles across hospitals/health services, legal firms and accounting & financial services firms. His most recent executive role was as part-time Executive Director of the Skin & Cancer Foundation Inc. This role was was complemented by 10 years consulting as a principal of Hodgson Associates. His consulting work covers primarily mid-sized professional services organisations in governance, strategy and business development governance.

With a long history in contributing to the Community, Chris has held directorships with Philanthropy Australia, Australian Communities Foundation, Arts Access Victoria, and currently the Melba Opera Trust (in addition to BioGrid Australia), refer to directorship listing below.

In 2019 Australia Day honours, Chris was awarded an AM (Member, Order of Australia) for his significant services to community through medical research organisations including BioGrid Australia. The award specifically refers to his leadership of the global Human Variome Project, where he led the organisation for three years as Chair.

- Director, IPC Health Ltd (2022 – present)
- Deputy Chair, Melbourne Anglican Foundation (2021-present)
- Director, Australian World Orchestra (2019 - present)
- Director, Melba Opera Trust (2017 - 2020)
- Director, Skin & Cancer Foundation Inc (2009 - 2019)
- Chair, Human Variome Project International Ltd (2014 - 2017)
- Director, Human Variome Project International Ltd (2008 - 2017)
- Chair, Telediagnostics Pty Ltd (2010 - 2016)
- Director, Philanthropy Australia (2003 - 2009)
- Director, Australian Communities Foundation (1999 - 2007)

BioGrid develops KRAB, Australia's first kidney cancer registry and biobank, and iTestis, Australia's first germ cell tumour cancer registry and biobank.

2022

Mr David Polonsky

B Bus, CA, TIA, MAICD

Director from January 2015 to November 2024

Director, DRP Consulting Pty Ltd, 1996 – present

Chair, Finance, Audit and Risk Committee since October 2017

David has over 35 years' experience in accounting and business. David's career spans running his own private practice to working with mid to top-tier firms.

After merging his successful private practice with Nexia Australia in 2011 (which rebranded to Moore Stephens in 2015), he was appointed as a Director in the Business Advisory division, refer to directorship listing below.

Currently, David is the Managing Director of DRP Consulting Pty Ltd, which provides accounting, taxation, superannuation and consulting services to businesses, professionals and high net worth families. David provides these services across private, commercial and not-for-profit industry sectors, including professional services, health and medical, architecture and construction, IT and biotech.

David's community leadership contribution includes current non-executive directorship with a Spirit of Australia Foundation.

- Director, Moore Stephens (Vic) Pty Ltd (formerly Nexia Melbourne Pty Ltd), (2011-2017)
- Director, Private Ancillary Funds various to 2022
- Director Spirit of Australia Foundation (2018 – present)

2023

ePAD project expands into Asia (Singapore and South Korea), funded by MSD.

Australasian Dermatology Registry developed and hosted for Skin Health Institute.

2023

Three successful MRFF grant partnerships: national cancer cohorts platform, AI infection surveillance and federated learning infrastructure.

2024

Six million individuals linked through BioGrid's platform and 377 publications produced to date from studies utilising data linked to BioGrid.

Professor Karin Verspoor

BA, MSc, PhD, GCUT

Director since August 2016

Executive Dean, School of Computing Technologies, RMIT University, 2021 – present

Karin has extensive experience in text and data analytics in biomedicine. Trained as a computational linguist, her contributions range from formal representation of biomedical data to machine learning over biological databases and analysis of social media for public health purposes.

She has published in journals including Nature Methods, Bioinformatics, and BMC Bioinformatics. Her group's 2014 article in BMC Bioinformatics was selected as a Best Paper in the 2015 Yearbook of Medical Informatics. She held previous posts as the Scientific Director of Health and Life Sciences at NICTA Victoria Research Laboratory, at the University of Colorado School of Medicine, at Los Alamos National Laboratory, and in AI start-ups, refer to directorship listing below.

- Fellow, Australian Academy of Technological Sciences and Engineering (2024 – present)
- Honorary Professor, School of Computing and Information Systems, University of Melbourne (2021 - present)
- Fellow, Australasian Institute for Digital Health (2020 - present)
- Co-Founder and Victoria Note Lead, Australian Alliance for Artificial Intelligence in Healthcare (2019 – present)
- Deputy Director, ARC Industrial Transformation Training Centre in Cognitive Computing for Medical Technologies (2018 - present)
- Professor, School of Computing and Information Systems, University of Melbourne (2017 - 2021)
- Director of Health Technologies, Melbourne School of Engineering, University of Melbourne (2020 - 2021)
- Deputy Director, Centre for Digital Transformation of Health, University of Melbourne (2019 - 2021)
- Fellow, Centre for Business Analytics, Melbourne Business School (2015 - 2020)
- Deputy Head of School (Research), School of Computing and Information Systems, University of Melbourne (2019 - 2020)
- Deputy Head of Department (Operations), Department of Computing and Information Systems, University of Melbourne (2015 - 2019)
- Deputy Director, Health and Biomedical Informatics Centre, University of Melbourne (2014 - 2019)
- Associate Professor, School of Computing and Information Systems, University of Melbourne (2014 - 2016)
- President, Australasian Language Technology Association (ALTA) (2013 - 2014)
- Scientific Director, Health and Life Sciences, National ICT Australia (NICTA) (2012 - 2014)

Professor Clare Scott AM

MBBS, PhD, FRACP, FAHMS

Director since March 2020

Joint Division Head, Clinical Discovery Translation, Walter and Eliza Hall Institute of Medical Research, 2019 - present

Head, Ovarian and Rare Cancers Laboratory, Walter and Eliza Hall Institute of Medical Research, 2010 - present

Consultant Medical Oncologist, Peter MacCallum Cancer Centre (2016 - present), Royal Women's Hospital (2010 - present), Royal Melbourne Hospital (2006 - present)

Clare heads the Ovarian and Rare Cancers Laboratory at the Walter and Eliza Hall Institute of Medical Research. She has 20 years' experience in treating breast and ovarian cancer and in clinical cancer genetics in Familial Cancer Clinics. Clare has been Principal Investigator for more than ten cancer clinical trials of targeted therapy. In the laboratory, Clare has developed ovarian and other rare cancer pre-clinical models and is using genomics to study targeted drug combinations to combat drug resistance.

Clare has established a rare cancer research program to improve access to targeted treatments for patients diagnosed with a rare cancer. Clare was awarded the Sir Edward Dunlop Cancer Research Fellowship from Cancer Council Victoria (2012) and a Clinical Research Fellowship from the Victorian Cancer Agency (2011, 2017). In 2018, Clare was recognized for her work in gynaecological cancers with the Jeannie Ferris Recognition Award from Cancer Australia.

Clare's contribution to the community is reflected by her instigation of and participation in the WEHI's Consumer Advisory Panel, now a leading example of involvement of the public in a Medical Research Institute. Clare also leads CART-Wheel.org, a BioGrid Australia platform for consumer data entry for people with a rare cancer who would like to participate in data collection for research.

- Chair, Australia New Zealand Gynaecology Oncology Group (ANZGOG) (2022 - present)
- Member, Executive Board of Directors, Gynaecologic Cancer Inter-Group (GCIG) (2022 - present)
- Director, Cancer Trials Australia (2021 - present)
- Chair, International Rare Cancer Initiative (IRCI) Board (2020 - present)
- Chair, Gynaecological Cancer, University of Melbourne (2018 - present)
- Member, International Rare Cancer Initiative (IRCI) Board (2015 - present)
- Chair, Rare Cancers Group, Clinical Oncology Society of Australia (COSA) (2015 - present)
- Director, Australia New Zealand Gynaecology Oncology Group (ANZGOG) (2014 - present)
- Member, Scientific Advisory Board Oncology One (2021 – 2023)

BioGrid's 20th anniversary celebration event highlighting BioGrid's journey as a leader in Australian health informatics.

Read more about BioGrid's 20th anniversary celebration

2024

BioGrid 20TH ANNIVERSARY

BioGrid Annual Report 2023-24

Financial Summary

BioGrid's financial results reflect over $155,000 of investment over the last three years in developing and modernising the Company's infrastructure to a nationally accredited secure digital research environment and curated data service platform.

This investment provides the foundation for ongoing service improvements to satisfy customer requirements and expectations as well as increase the profitability and success of the Company in the future.

While the company recorded a loss of $17,709 for the year ended 30 June 2024 (2023: $91,906 surplus) and Net Equity of $13,497 at 30 June 2024 (2023: $31,206), the directors believe stability of activity during the year with the commencement of contracts relating to MRFF grants and new customers is providing opportunities for growth. This year's results reflect delays in finalising contractual arrangements, together with the completion of a major project earlier in the year, which resulted in the reduction in turnover compared to the previous year.

Looking forward, we anticipate an increase in turnover and profitability being budgeted for the year ending 30 June 2025 based on work that was committed in this financial year. This will provide a more solid financial position to enable BioGrid to grow and invest in the business so that members and customers will benefit from the unique and comprehensive services being provided.

To ensure BioGrid's ongoing operation with a positive new cash flow position, we continue to carry out governance and business development initiatives which are in line with our middle and long term strategic objectives. These activities are focused on creating a pipeline of commercial activity and increasing awareness of BioGrid's services in our market, domestically and internationally.

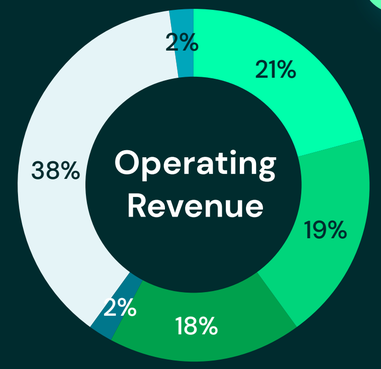
BioGrid remains the only collaboration network in Australia with the legal and ethical framework to enable the sharing of near real-time health and medical data for research. Accordingly, it is well positioned to take advantage of opportunities as they arise nationally and internationally.

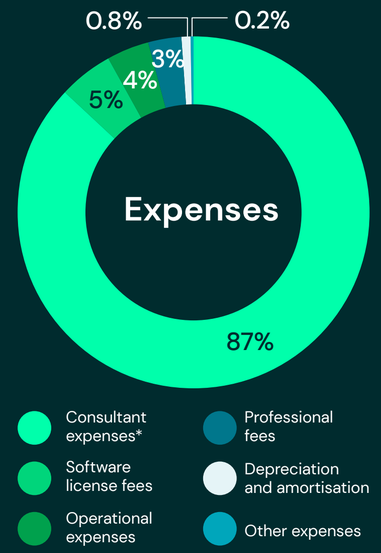
To assist with the realisation of our strategic objectives, BioGrid's Directors and management continued to work closely with our key stakeholders. These institutions and individuals continue to show their support for the Company and its strategic direction, which is driven by the increasing data and security needs of the research community.

Read full Financial Report here >

$155,000

of investment over the last three years in developing and modernising the Company's infrastructure





* Consultant expenses include payments to Melbourne Health who provide staff contract and payroll services to BioGrid.

BioGrid Annual Report 2023-24

Financial Summary

Revenue and Expenditure for the year ended 30 June 2024

	2024 $	2023 $
Operating revenue		
Commercial-led project income	**556,150**	828,550
Member subscriptions	**498,152**	487,705
Investigator-led project income	**474,751**	600,014
Researcher user access fees	**56,890**	-
Grant income	**975,938**	1,072,622
Other income	**57,339**	54,993
Total Revenue	**2,619,220**	3,043,884
Expenses		
Consultant expenses *	**(2,290,967)**	(2,553,540)
Software license fees	**(130,681)**	(148,963)
Operational expenses	**(116,475)**	(147,285)
Professional fees	**(73,930)**	(61,071)
Depreciation and amortisation	**(20,691)**	(32,419)
Other expenses	**(4,185)**	(8,700)
Surplus/(Deficit) for the year	**(17,709)**	91,906

* Consultant expenses include payments to Melbourne Health who provide staff contract and payroll services to BioGrid.

Read BioGrid Australia's full Financial Statement for 2023-24 here

Statement of Financial Position as at 30 June 2024

	2024 $	2023 $
ASSETS		
CURRENT ASSETS		
Cash and cash equivalents	**39,548**	127,065
Trade and other receivables	**789,029**	472,100
Other assets	**72,291**	9,290
TOTAL CURRENT ASSETS	**900,868**	608,455
NON-CURRENT ASSETS		
Property, plant and equipment	**11,018**	14,967
Intangible assets	**264,649**	146,482
TOTAL NON-CURRENT ASSETS	**275,667**	161,449
TOTAL ASSETS	**1,176,535**	769,904
LIABILITIES		
CURRENT LIABILITIES		
Trade and other payables	**651,288**	505,858
Other liabilities	**511,750**	232,840
TOTAL CURRENT LIABILITIES	**1,163,03**	
TOTAL LIABILITIES	**1,163,038**	
NET ASSETS	**13,497**	
EQUITY		
Accumulated surpluses	**13,497**	31,206
TOTAL EQUITY	**13,497**	31,206