



Industry Genomics Network Alliance

**Industry Genomics Network Alliance  
(InGeNA)**

**Annual Report 2021-22**

**AICH**

## Acknowledgments

We gratefully acknowledge the advice, input and support of the many organisations and individuals who through user research, engagement and consultation processes contributed to developing this document.

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InGeNA recognises Aboriginal and Torres Strait Islander peoples as the First Peoples of this nation. We recognise the ongoing traditional and modern cultural practices and connection to Country held by Aboriginal and Torres Strait Islander peoples. We acknowledge Elders past, present and emerging as the Traditional Custodians and Lore Keepers of the world's oldest living culture.

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## Introduction

Genomics holds great potential to improve the lives of individual Australians. The healthcare system is transitioning from one that is reactive, illness focused and uniform to one that is predictive, preventive and focused on the individual. Genomics plays a large part in enabling this shift. As well as being used diagnostically to identify serious genetic conditions, genomic screening can be used to identify individual risk factors for a variety of health concerns.

Industry is a key player in the development and implementation of genomics in healthcare. InGeNA gives industry an avenue to join the conversation and build a more connected genomics landscape, helping to identify the major roadblocks to implementation and doing our part to contribute to solutions, encouraging innovation and driving implementation of genomics.

## Chair's Message

InGeNA emerged as a new and united industry voice in the healthcare landscape at a time when the battle with COVID-19 brought the world of genomics into the lives of almost all Australians.

As we progressed our first-year agenda, we saw precision health, underpinned by genomics, benefiting individuals, families, carers, and the health system more broadly. The community's understanding of genomics was essential to allowing the swift development of vaccines, diagnostics, tests and as a tool for epidemiologists.

This sharp focus on public health helped to crystallise the work of InGeNA, embedding consumer advocacy into our organisational DNA.

From health data to DNA, privacy and telehealth, Australians have grown their digital health maturity during the pandemic. It makes the possibilities of our future precision health system more tantalising. Genomics is already engaged across many facets of healthcare as it already enables access to treatment in areas like cancer and rare diseases. Testing, diagnosis, care and treatment could soon be tailored for patients and consumers based on their unique profile as a human being.

The challenges we identified in our first year will continue to form the basis of our collaborative work. As health and social care is provided in a digital world, the need for a workforce enabled with digital health and specifically knowledge of genomics is clear. And, while genomics will one day be omnipresent, Australia - like most nations - has a long way to go to translate the opportunities it presents society.

I would like to thank all the members of InGeNA, its staff and our valued partners as together we pursue our vision of realising the full potential of genomics to personalise healthcare.

**David Bunker**

InGeNA Chair



## Our members

InGeNA is a united voice for Australian industry partners contributing our skills and expertise to the rapidly developing field of genomics. As an independent, trusted, and credible voice for industry, InGeNA is able to advocate for genomics in healthcare, and for the industry more broadly, without the perception of lobbying for the benefit of just one individual organisation. This voice is valuable to smaller companies, which may not otherwise have a platform to have their views and needs heard, and also to larger companies which can present a united voice when speaking alone to government, partners, and/or collaborators.

InGeNA was formed by a group of industry organisations, hosted by the Australasian Institute of Digital Health (AIDH), to bring a shared perspective on critically important areas underpinning the future of genomics.

- A patient-centred approach
- Digital infrastructure & principles
- Workforce planning & skills
- Government policy making

Our **vision** is to realise the full potential of genomics to personalise healthcare.

Our **mission** is to harness the collective skills and expertise of industry to integrate genomics into healthcare.

At the end of February 2022 InGeNA closed its first full financial year with 21 member organisations, eight more than the 13 founding members.



## Our partners

The formation of InGeNA has given other members of the genomics landscape a convenient method to engage with the genomics industry. Any organisation or individual needing to consult with industry can come to InGeNA to access an audience of a variety of passionate industry players, all in one place.

Alliance members share a vision for Australia’s leadership in the adoption of genomics in healthcare

- Better health outcomes
- Healthcare value and affordability
- A trusted, equitable and ethical genomics ecosystem

Collaboration across the key sectors of diagnostics/pathology, tech and pharma will ensure long and far-reaching benefits for Australian health consumers.

At the end of February 2022, we had a network of 16 partner organisations.



## Promoting patient advocacy

An initiative like InGeNA can work with patient groups to address concerns about ‘big business’ in health and build trust in the health environment. Trust that is earned allows efficiency gains in the system, as patients and industry can better work together with government and research in a cohesive environment. Monica Ferrie, CEO of the Genetic Support Network of Victoria and part of the Genetic Undiagnosed And Rare Disease (GUARD) collective, sits on our steering and management committees as our dedicated consumer representative, and we include patient representatives on our project working groups



## The InGeNA Secretariat

InGeNA is hosted by the Australasian Institute of Digital Health (AIDH), Australia's leading organisation in health informatics and digital health. AIDH provides the operational support to allow InGeNA to focus on the task of realising the full potential of genomics to personalise healthcare.

Our team brings together a diverse set of skills.



### **David O'Driscoll**

InGeNA Program Director

David has a background in digital health and information architecture and governance, and was the lead author for the Blueprint for National Approach to Genomic Information Management. He is a Fellow of the AIDH and holds his CHIA certification.



### **Carla Carroll**

InGeNA Program Manager

With an M. Phil in Microbiology, Carla's fascination with pure science has evolved into a passion for the application of novel discoveries and innovative technologies into healthcare to drive better outcomes through precision health.



## Reflections on InGeNA's first 18 months

Hosted by the AIDH and with the support of MTPConnect, InGeNA was officially launched on stage at the Brisbane Digital Health Institute Summit in November 2020. At that time, 13 companies had signed on as the founding members of InGeNA. By the end of 2020, the group had agreed on a set of guiding principles, vision and mission statements to articulate our common purpose and unite us as an alliance.

The first six months saw us generate a flurry of activity. We very quickly grew to 19, then 20, then 21 members. Members of our Steering Committee were learning to work with other members from organisations of vastly different sizes, structures, and from different sub-sectors relevant to genomics.

InGeNA gained a large number of partners quickly, too, including Australian Genomics who were integral to helping us build our network and gain credibility with major landscape players.

With generous matched funding from MTPConnect, we were able to take on four publication-based projects in our first year, one under each of our strategic pillars:

- Quantifying the benefits of genomics
- Access and equity
- Workforce
- Data and technology innovation.

These ambitious projects were initiated in 2021, between producing webinars, convening a strategy day, a virtual conference, publishing regular newsletters, and building connections between industry and the broader genomics landscape.

Vital to finding our direction was our patient advocacy representative Monica Ferrie, CEO of the Genetic Support Network of Victoria (GSNV). Ms Ferrie, along with additional consumer representatives embedded in our working groups, keeps us grounded and focused on the ultimate purpose of InGeNA: to improve healthcare outcomes for patients.

At the close of February 2022, we had launched two of the four reports and were in the final phases of readying the remainder for online publication. David O'Driscoll had joined us as the Program Director. We retained 20 members moving into our second year, and this momentum was enough for InGeNA to become self-sufficient as a member-funded organisation. We have settled into a regular cadence of activity and are in a prime position to leverage the efforts of our first 18 months.

## Providing value to our stakeholders

Understanding and providing value to sector stakeholders is critical to a member-based organisation. Here we present some of the ways that InGeNA is focused on providing such value.

### Our members and beyond

InGeNA provides a platform for networking for companies and individuals within the genomics ecosystem. InGeNA Steering Committee meetings and quarterly member forums have connected InGeNA members and their staff not only to each other, but to a wide range of organisations and individuals including:

- AusBiotech
- The Australian Digital Health Agency
- Australian Genomics
- The Commonwealth Department of Health
  - Genomics and Emerging Technologies branch
  - National Digital Health Strategy
  - Office of Health Technology Assessment
- The Garvan Institute
- The Genomic Institute Queensland
- Omico
- Medicines Australia
- The National Computational Infrastructure (NCI)
- Professor Ainsley Newson, Professor of Bioethics at the University of Sydney
- Professor Alex Brown, Professor of Aboriginal Health Research at the South Australian Health and Medical Research Institute (SAHMRI)

Members are also provided with weekly bulletins covering updates in the world of genomics, the work of our members and partners, and relevant news from Canberra.

Most importantly, InGeNA provides members and industry more broadly with the opportunity to work cooperatively to contribute to our mission of harnessing the skills and expertise of industry to integrate genomics into healthcare in Australia. Members drive the direction of our projects and of our messaging as we work towards a common goal of improving health outcomes and building a robust and productive genomics industry for Australia.

### Our Partners

InGeNA Steering Committee meetings have hosted presentations from Australian Genomics, NCI, Omico, STARDIT, SAHMRI, and The Garvan Institute. These Partners are given the opportunity to engage with the genomics industry to receive advice and feedback on their plans and proposals, or simply to build lines of communication and hear our perspective. As ongoing relationships develop between InGeNA and our Partners, the quality of discourse and the input from industry improves. In multiple cases this has led to InGeNA members having ongoing engagement with a Partner on an individual basis; this may be in the form of providing funding, in-kind support, or in-depth advice. The outcome is that even though InGeNA rarely funds external projects directly, access to our members through the network can become a source of funding for our Partners.

Our Partners also have access to the events hosted by InGeNA and AIDH. InGeNA is a network alliance, and our network of partners helps facilitate collaboration across the field. InGeNA events are an opportunity for disparate

members of the genomics landscape in Australia to come together and hear each-others' challenges and opportunities. Building community is essential if we are to recognise and address the challenges that we face in translating genomics research into clinical practice in Australia.

Putting this community into action, InGeNA and our Partners undertake mutual signal-boosting. The InGeNA newsletter mailing list consists of over 550 highly engaged contacts, and we have access to the broader digital health community through AIDH. InGeNA releases a monthly newsletter to this mailing list, and our Partners are invited to submit content. We have promoted events for Australian Genomics, ARCS, SING, AusBiotech, the many patient organisations that we work with, and others. Partners and are featured prominently on our website and new partnerships are highlighted in the monthly newsletter.

### Australians (consumers and patients)

Genomics holds great potential to improve the lives of individual Australians. The healthcare system is transitioning from one that is reactive, illness focused and uniform to one that is predictive, preventive and focused on the individual. Genomics plays a large part in enabling this shift. As well as being used diagnostically to identify serious genetic conditions, genomic screening can be used to identify individual risk factors for a variety of health concerns.

Industry is a key player in the development and implementation of genomics in healthcare. InGeNA gives industry an avenue to join the conversation and build a more connected genomics landscape, helping to identify the major roadblocks to implementation and doing our part to contribute to solutions, encouraging innovation and driving implementation of genomics.

In August 2021, InGeNA held a round table event inviting representatives from Genetic Alliance, Rare Cancers Australia, the Leukaemia foundation, Rare Voices Australia, SCN 2 Australia, SMA Australia, SWAN Australia, and the Victorian Clinical Genetics Services (VCGS) to provide feedback on InGeNA's work program for 2022.

InGeNA's advocacy efforts towards integrating genomics into healthcare in Australia are guided by an ambition to act for the good of patients/consumers. We hope that our efforts will lead to improved, equitable access to genomics technologies for all Australians.

### Healthcare funders and policy makers

InGeNA aims to assist healthcare funders and policy makers by providing an avenue for industry engagement that is independent, trusted, and credible. Our members cover the entire value chain for genomics, making us a valuable source of expert input that cuts across diagnostics/pathology, technology/data, and pharmaceuticals. The value InGeNA brings is reflected in the depth of engagement sought by policy makers.

Representatives from the Commonwealth Department of Health regularly meet with the InGeNA secretariat to allow mutual information sharing and the development of a strong working relationship. Our quarterly forums are a valuable opportunity for government to engage industry members. MSAC have reached out to InGeNA for comment on applications concerning genomics. In our 2021/2022 year, InGeNA submitted responses to the following consultations and proposals:

- Genomic Health Futures Mission Roadmap
- National Medicines Policy Review
- NSW Cancer Plan
- Primary Health Care 10-year Plan

## Researchers

InGeNA gives researchers an audience to help evaluate proposals for commercialisation and implementation of genomics technologies. In our 2021/2022, we provided letters of support for the following grant funding applications:

- MRFF 2016124 - Pathways to benefit for Indigenous Australians in genomic medicine, Professor Alex Brown, Australian National University (ANU) and Telethon Kids Institute (TKI)
- MRFF 2015531 - Ethical governance for clinical and genomic data, Professor Ainsley Newson, The University of Sydney
- DISER - The Precision Oncology Screening Platform enabling Clinical Trials Australia (PROSPECT), Omico

Omico was ultimately successful in their application, with the outcome of the MRFF grants yet to be announced at time of writing.

Each of these researchers has also presented to the InGeNA Steering Committee at one of our monthly meetings, providing a separate opportunity for support from individual InGeNA members and to improve visibility and awareness of their work. Just like we do for our Partners, InGeNA represents a potential source of additional funding or in-kind support for research collaborators.

## Achievements

### Major Publications

InGeNA has published five major documents and reports in its first full year of operations.



**[InGeNA Strategic Plan April 2021](#)**: The InGeNA Strategic Plan highlights the breadth and range of industry groups committed to working together to bring a shared perspective on critically important areas underpinning the future of genomics.



**[Genomic Data in Australia](#)**: The collection, management and exchange of genomic data into healthcare delivery is critical to supporting better person-centred care, driving value to the health system and to building a thriving research ecosystem. The delivery of mature genomics information management which supports the integration of genomics into mainstream health care requires a comprehensive and collaborative approach. The genomics industry has an important role in delivering this maturity and ensuring that value is derived for all stakeholders.

As a united voice for the genomics industry, InGeNA has undertaken a review of the Australian genomic data landscape to identify the challenges and opportunities evidence regarding the management, governance, sharing and use of genomic data to support better outcomes for all Australians.

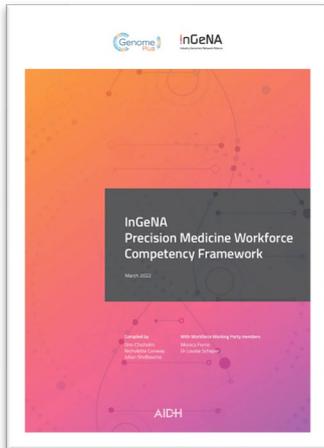
Engagement with stakeholders from industry, healthcare, research and consumers indicated three consistent themes, being a need for clarity in how the sector communicates, certainty about regulatory and compliance matters, and the importance of standards adoption to support the application of genomics to realise the value for people, the healthcare sector and the research community.



**[Valuing the Impact of Genomics on Healthcare in Australia](#)**: InGeNA commissioned Deloitte Access Economics to conduct research which will provide a snapshot of the potential value of genomics on healthcare in Australia by profiling a suite of case study applications across the screening, diagnosis, and treatment stages of the care continuum.

Within each case study, a cost-effectiveness analysis is performed to quantify the extent to which the additional upfront costs of genomic testing (compared to current practice) are offset by longer-term benefits such as improved health outcomes, cost-savings to the health system, and productivity gains to society.

Providing evidence on the impact of genomic testing relative to current practice is important given that access to these potentially lifesaving technologies in Australia varies, with some already being embedded into national, publicly funded health systems while others are offered only in some jurisdictions, only in the private sector or directly to consumers.



[Precision Medicine Workforce Competency Framework](#) (published Apr 2022): As our healthcare system transitions from a specialist and disease-centred system to a learning healthcare system driven by precision medicine, the competencies and capabilities of the various workforces servicing this sector also need to change.

The InGeNA Workforce Precision Medicine Competency Framework is needed because since the sequencing of the human genome, there has been a steady rise in the impact of genomics in the practice of medicine. It is difficult for individuals, their managers, and employers to keep abreast of the rapidly changing requirements for keeping up to date with this evolving ecosystem.

The Precision Medicine Competency Framework includes analysis of the needs for a future precision medicine-based workforce that is fit for purpose and aids individuals and employers to identify and address competency gaps in precision medicine.



[Future Directions for Health Technology Assessment in Australia](#) (published Jun 2022): Future directions for health technology assessment in Australia provides a unified industry viewpoint on how the reform of the HTA system could substantially improve and enhance access to genomic technology for health consumers. InGeNA's view is there would be more equitable access to genomic testing if health technology assessment (HTA) processes were improved.

Genomics is complex and evolving rapidly. Therefore, successful integration into clinical practice will require effective collaboration across the genomics value chain, including Government, pathologists, healthcare professionals, consumers and suppliers of genomic technologies.

This whitepaper was produced by HTANALYSTS, with broad stakeholder input to identify current HTA challenges and potential solutions for genomic technologies such as large panel tests.

The whitepaper outlines how the HTA review could address many challenges such as the length and efficiency of the Medical Services Advisory Committee (MSAC) HTA process, and improve transparency around evidentiary requirements, value definition and transparency. It says the reform process could also address larger issues such as funding models and broader legislation.

## Events

InGeNA has been actively promoting industry’s contribution to genomics in 2021. Four webinars with a total of 521 registrations and 261 attendees have been held. In addition, two quarterly forums have been held, open to both InGeNA Member Representatives and the staff of their organisations.



Perhaps our most significant event in 2021 was the three-day event held in conjunction with AIDH’s Health Data 21 conference. While a virtual event due to the constraints of COVID, we achieved a total of 188 session views.

On November 16, we held a webinar for Commonwealth parliamentarians and their staff, hosted by the Honourable Dr Katie Allen MP, member for Higgins. The webinar allowed attendees to understand the importance of genomics to the people of Australia, not only for the clinical opportunities, but also for the economic benefits that can accrue from a strong genomics sector.



## Patient Engagement

We are endlessly thankful to Monica Ferrie for ensuring InGeNA remains focused on what really matters: patient outcomes. Monica volunteers her time to InGeNA and is our gateway to the patient advocacy world. To augment Monica's presence as consumer representative on the InGeNA steering committee, we strive for patient representation on our working groups as well.

In the 2021/2022 year these roles were filled by Heather Renton, CEO of SWAN Australia on our Access and Equity working group and Jan Mumford on our Quantifying the Benefits of Genomics working group. Monica Ferrie led the patient voice on the Data and Technology Innovations and Workforce working groups. Heather and Jan have been very generous with their time and input to help InGeNA be the best we can be, and we are grateful. Thank you.

To achieve a broader diversity of input from patient advocacy groups for our 2022/2023 work plan direction, we held a virtual round table discussion in August of 2022 with representatives from Genetic Alliance, Rare Cancers Australia, the Leukaemia foundation, Rare Voices Australia, SCN 2 Australia, SMA Australia, SWAN Australia, and the Victorian Clinical Genetics Services (VCGS) invited to talk to the InGeNA Program Manager and talk about what value InGeNA can bring to the space.

## Future Goals

Based on our successes to date, InGeNA has identified projects and activities across our focus areas.

### Quantifying the benefits of genomics

InGeNA is working towards an annual benchmarking activity to assess Australia's progress through planned genomics initiatives and provide visibility on projects with broader ecosystem significance. This will begin with a review of current initiatives and strategic frameworks in place in Australia, looking at case studies of similar projects on the international stage, and finally producing a report that follows how Australia is tracking against these plans.

### Access and equity

In the access and equity stream of work, InGeNA will focus on promoting the white paper produced in 2021, and advocating for its recommendations. This will include working closely with Medicines Australia on their HTA review, and engagement with Commonwealth and jurisdictional governments. The goal is to produce publications which succinctly and clearly articulate individual points of relevance from the white paper.

### Workforce

There are opportunities for an internship initiative to support workforce development throughout the genomics sector. This will begin with scoping work to determine the current state of internships and relationships with universities amongst InGeNA members. There will be a focus on promoting InGeNA at events and building our network.

### Data and technology innovation

InGeNA aims to be involved in the Department of Health's proposal to set up a national registry for genomics tests. We also seek involvement in Standards Australia establishment of genomics informatics standards in Australia. Four case studies will be developed, each highlighting an important aspect of genomic data management.

### Advocacy

InGeNA plans to engage with State and Territory Departments responsible for Health and for Industry and Innovation. Advocate for integration of genomics into healthcare at multiple levels of decision-making.

## Financial report for 2021-22

InGeNA gratefully acknowledges the support provided by MTPConnect during our first year of operations.

### Revenue

Member contributions	\$491,908
Other contributions	\$300,000

**TOTAL Revenue** **\$791,908**

### Operational costs for Secretariat

Staffing	\$223,589
Management fee	\$22,667
Other operational expenses	\$14,297

**TOTAL operational costs** **\$260,283**

### Project expenses

Staffing	\$23,994
Project consultant fees	\$264,654
Other consultant fees	\$48,238
Marketing costs	\$27,068

**TOTAL project costs** **\$363,954**

**TOTAL Expenses** **\$624,237**

