



Queensland  
Genomics  
**Health Alliance**

# *Personalised Medicine and You*



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# *Personalised Medicine and You*

## **Welcome and session overview**

**Katrina Cutler**

Communications and Engagement Manager, QGHA  
Ex-Officio Member of the QGHA Community Group



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# *Personalised Medicine and You*

## Session overview - 1

### 1. An introduction to genomics and personalised medicine

**Dr Aideen McInerney Leo**, Genetic Counsellor and Researcher, Queensland University of Technology; Member of QGHA Community Group

### 2. Introducing Queensland Genomics Health Alliance

**Katrina Cutler**, Communications and Engagement Manager, QGHA; ex officio Member of QGHA Community Group

### 3. Genomics in healthcare, the ethics, legal and social implications

**Dr Nic Waddell**, Co-lead, QGHA Ethics, Legal and Social Implications Project; Group leader, Medical Genomics, QIMR Berghofer; ex officio Member of QGHA Community Group



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# *Personalised Medicine and You*

## Session overview - 2

### 4. Beyond the science: A personal genomics story

**Gary Hondow**, Health Consumer and Carer; Member of the QGHA Community Group

### 5. Genomics and personalised medicine – why community engagement is essential

**David Bunker**, Executive Director QGHA; ex officio Member of QGHA Community Group

### 6. The QGHA Community Group: our vision, mission, objectives and areas of action

**Dr Erin Evans**, Board Member, Health Consumers Queensland; Chair, QGHA Community Group



# An Introduction to Genomics and Personalised Medicine

*The benefits for you*

**Dr Aideen McInerney Leo**

Genetic Counsellor and Researcher, Queensland University of Technology

Member of the QGHA Community Group

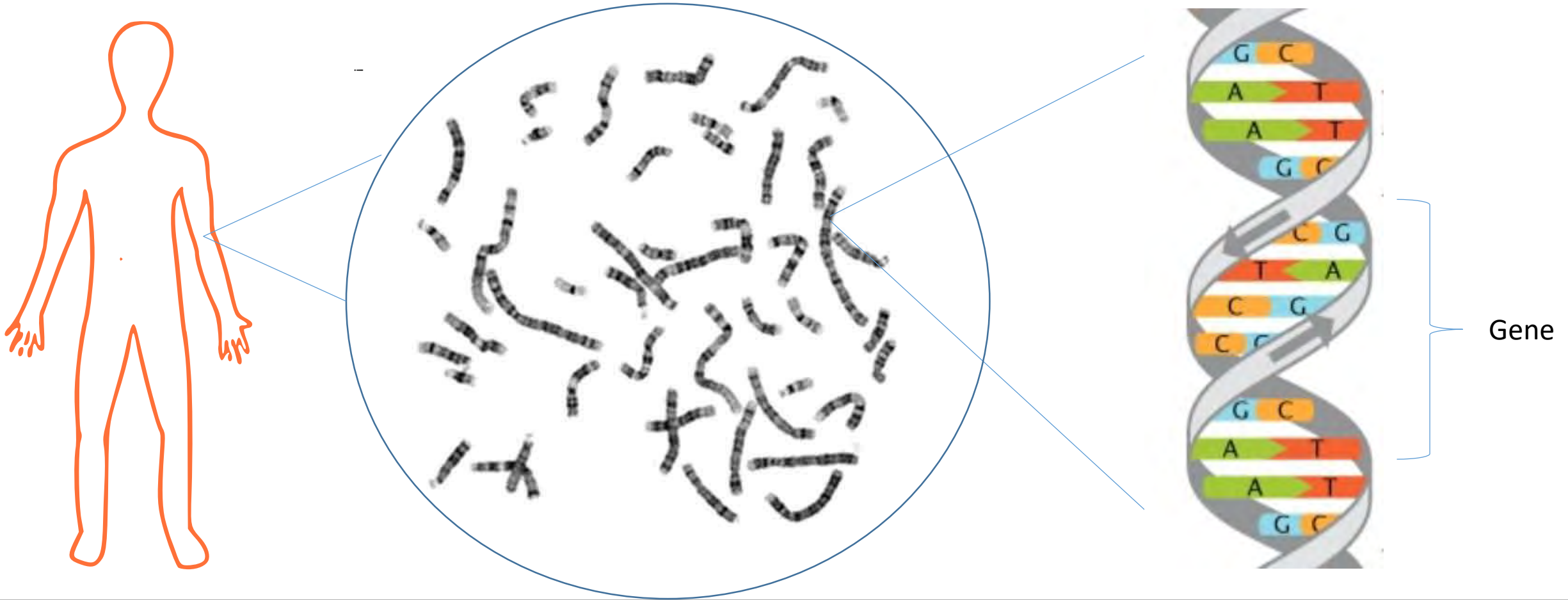


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# Overview

- Traditional Clinical Genetics
- Advances in Genetic Testing
- Pros and Cons of New Genetic Tests
- Clinical Implications of Genetic Testing
- Personalised Medicine

# Genetics



# Traditional Genetic Testing





# Traditional Genetic Testing

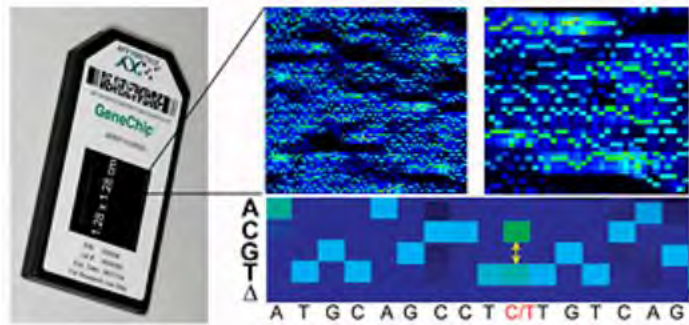
- Looking at the genetic code (sequence) of one gene at a time



- Sequential testing

# Advances in Genetic Testing

- Array Genotyping – check for specific variant at specific location – add two baits

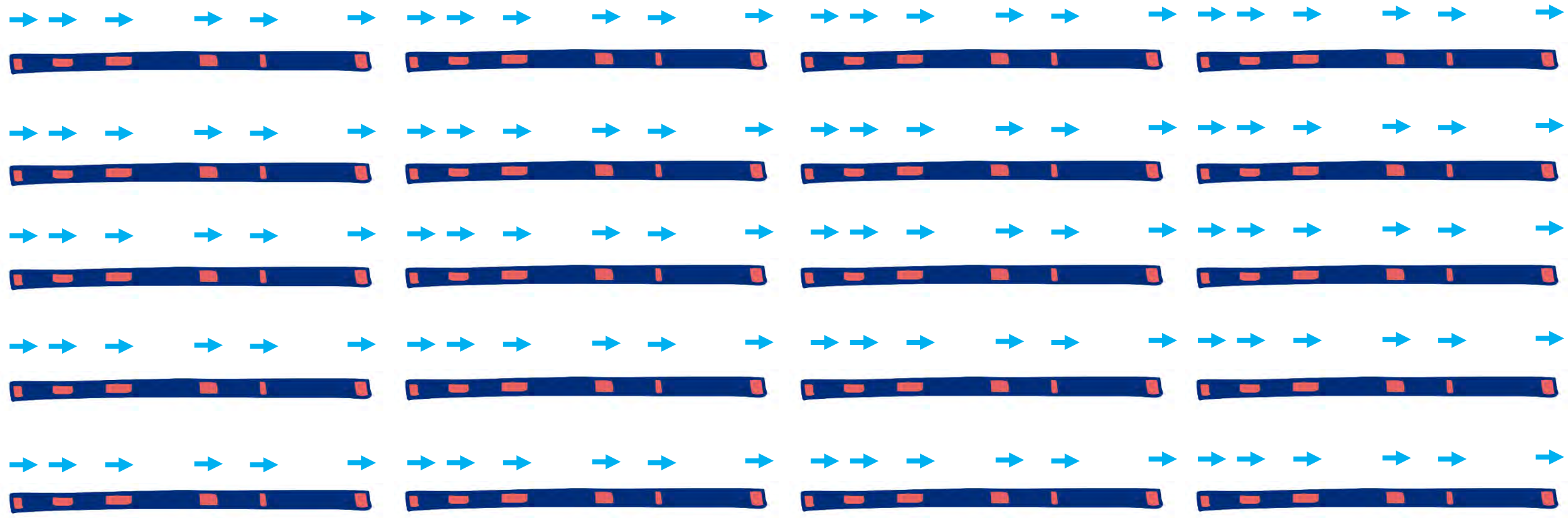


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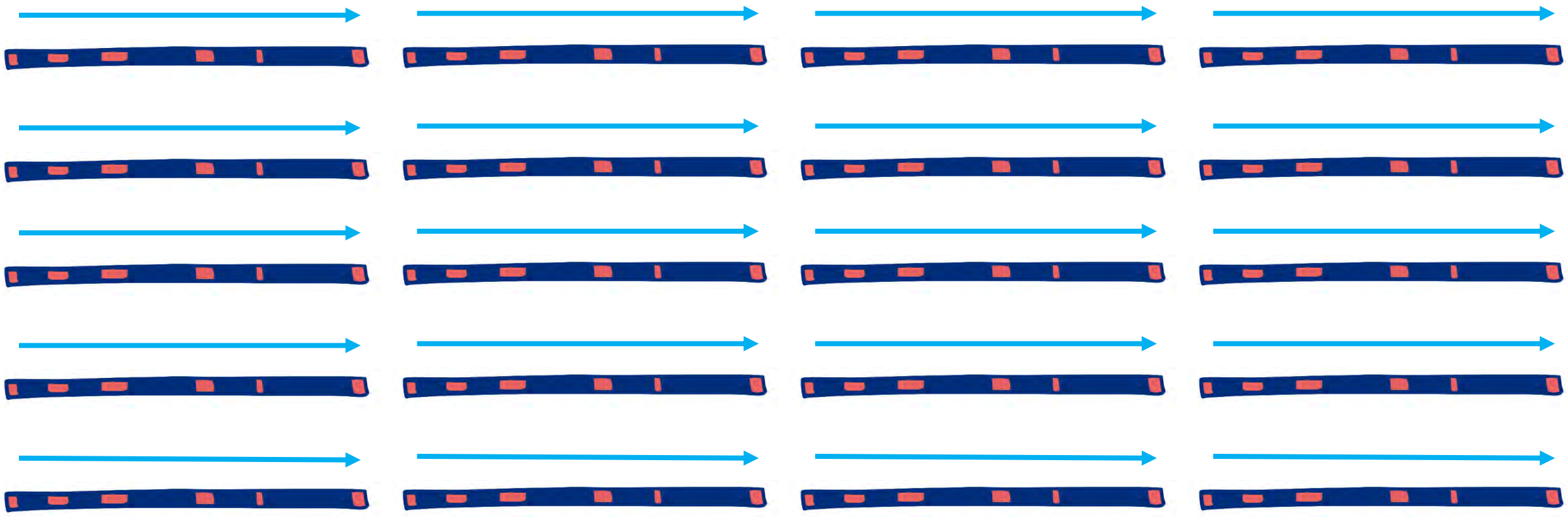
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- Massively parallel sequencing
  - 10's to 100's of genes specific to disorder in question = **Panels**

Figure from [http://ur.umich.edu/0506/Oct17\\_05/02.shtml](http://ur.umich.edu/0506/Oct17_05/02.shtml)



# WHOLE EXOME SEQUENCING



# WHOLE GENOME SEQUENCING

# Clinical impact of New Genetic Tests

- Faster
- More affordable
- Higher diagnostic rate
  - Infants with suspected genetic disorders
    - 13% diagnosed with traditional evaluation
    - 56% diagnosed with WES
- Positive health economics
  - Use of WES early in the diagnostic pathway - one-third the cost per diagnosis

# Clinical impact of New Genetic Tests - Challenges

- Variants of uncertain significance
  - Unexpected Findings
  - Incidental Findings
    - Accidental Finding
    - Intentional Screening
  - Insurance and/or work Discrimination
- 
- Consenting and results disclosure require time and training



# Personalised Medicine

# Cancer sequencing

- Identify mutations which have implications to
  - Diagnosis
  - Prognosis
  - Treatment
- How is it done?
  - DNA extracted from tumour
  - Sequenced for specific mutations known to inform management
  - Now WES/panel sequencing done and data filtered to look for mutations in known cancer genes.



# Pharmacogenomics

- Safety (Adverse Drug Reactions)
  - 2-3% (230k) hospital admissions per year in Australia (AU\$1.2 billion)<sup>1</sup>
  - Can have severe or fatal outcomes, particularly in paedics and geriatrics<sup>2,3</sup>
  - Genetic factors estimated to be responsible for ~25% ADRs<sup>4</sup>
- Efficacy
  - Responsiveness
  - Resistance
- Performed by microarray - <\$100 per patient

1. Roughead et al 2016

2. Impicciatore et al 2001

3. Budnitz et al 2007

4. Sim, Kacevska et al 2013

# Conclusion

- Genomic Testing transitioning from rare disorders to common conditions
  - Cancer genomic sequencing already part of clinical care
  - Pharmacogenomic
- Interpreting and managing data presents significant challenges
- Clinical Implications of testing means consenting and results disclosure requires time and training

# An Introduction to Genomics and Personalised Medicine: *The benefits for you*

## Wrap up and questions...



# Introducing QGHA

*How we're addressing the challenges of implementing genomics into clinical care*

**Katrina Cutler**

Communications and Engagement Manager, QGHA

Ex-Officio Member of the QGHA Community Group



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With the aim of *demonstrating the value* of genomics in everyday healthcare, and to *improve the health* of Queenslanders, the Queensland Genomics Health Alliance drives collaboration across the state's health system and research and academic communities.



Photo by rawpixel.com on Unsplash

The Queensland Genomics Health Alliance is a \$25m Advance Queensland Initiative over 5 years.

Funded by Queensland Health, administered by the University of Queensland

Queensland Genomics will systematically address the key healthcare implementation challenges through a series of:

- Clinical Projects and
- Capability-building Workstreams.



**Workforce able to incorporate genomics into health care**

**Develop an evidence base for clinical genomics**

**Establish timely and cost-effective diagnostic workflows**

**Genomic sequence results are used for the benefit of patients**

**Build public awareness and understanding**

**Develop a system for managing clinical genomic data**

**Accelerate translation of research**

**Make a positive contribution, nationally and internationally**

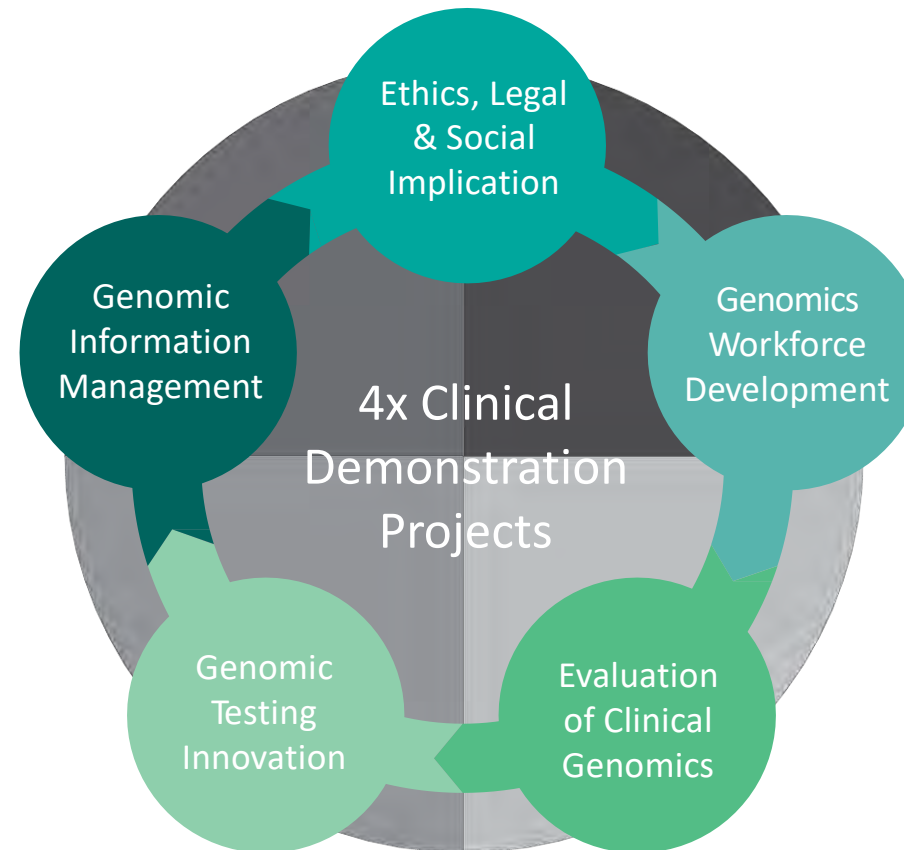


The **Capability Building Workstreams** are:

- Ethics, Legal and Social Implications of Genomics
- Genomic Workforce Development
- Evaluation of Clinical Genomics
- Genomic Testing Innovation
- Genomic Information Management

The four disease areas selected as **Clinical Demonstration Projects** in Round 1 are:

- Melanoma
- Lung Cancer
- Hospital-acquired Infections
- Maturity-Onset Diabetes of the Young (MODY)





**Queensland Government**

**Queensland's Health and Hospital  
Services  
Genetic Health Queensland  
Forensic & Scientific Services**



**THE UNIVERSITY  
OF QUEENSLAND**  
AUSTRALIA



**QIMR Berghofer**  
Medical Research Institute



THE AUSTRALIAN  
**E•HEALTH**  
RESEARCH CENTRE



*Exceptional People. Exceptional Care.*





## Genomics collaborations in Australia

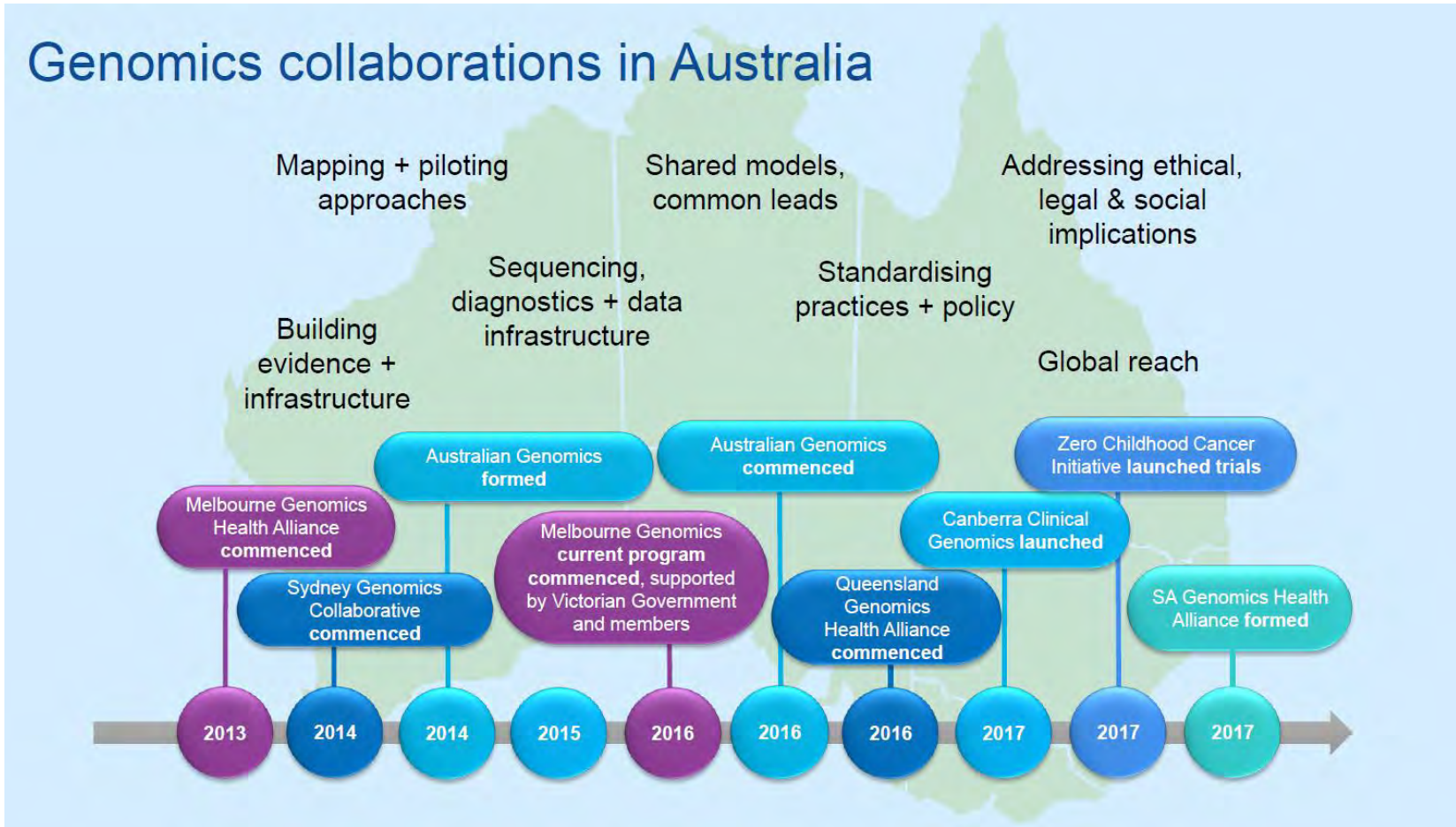
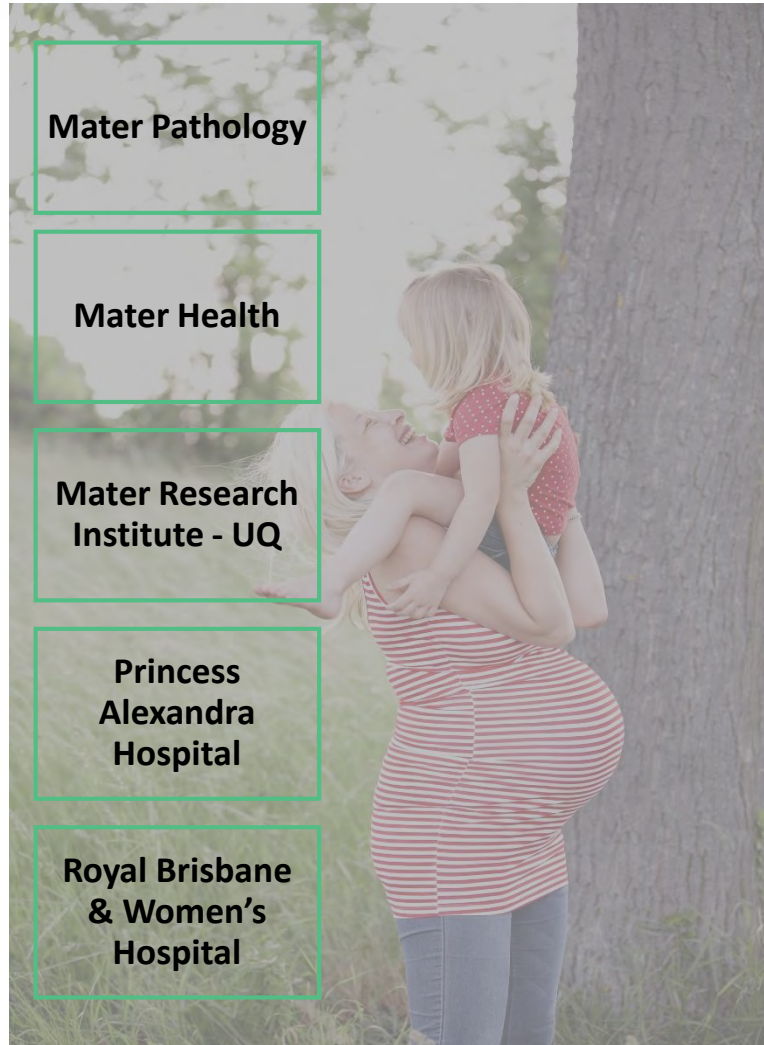


Image courtesy of Melbourne Genomics Health Alliance





## Clinical Demonstration Project

**Project Lead:** Prof. John Prins (Mater Research Institute – UQ)

**Summary:** NATA-accredited 13 gene Illumina panel screening will be applied to 490 women (Mater Mothers) detected with gestational diabetes to build a phenotypical reference for MODY for guided diagnosis and treatment options.

### Objectives:

- To understand the impacts of MODY testing on detection rates in women with gestational diabetes
- To provide optimal management of mother and fetus through results received by 31 weeks gestation
- To advise family members of a MODY mutation and advise further testing
- To evaluate the cost of MODY testing
- To draft protocols for MODY testing in women with gestational diabetes to guide the clinical workforce in genetic testing.



Forensic and  
Scientific  
Services, QH

Children's  
Health  
Queensland  
(CHQ)

Pathology  
Queensland

Princess  
Alexandra  
Hospital

Royal Brisbane  
& Women's  
Hospital

The University  
of Queensland

## Clinical Demonstration Project

**Project Lead:** Prof. David Paterson (Royal Brisbane & Women's Hospital – UQ)

**Summary:** By using WGS and SNP technologies, this project will focus on building a reference library to allow a detailed characterisation of antibiotic resistant microbial pathogens to understand the transmission of nosocomial infectious between patients in order to help optimise clinical management and enhance infection control interventions.

**Objectives:**

- To provide clinically-actionable, validated and timely genomic analysis of bacterial pathogens isolated from hospital-admitted patients
- To develop and enhance existing bioinformatic pipelines within Pathology Queensland to facilitate routine genomic analysis of bacterial pathogens
- To provide a detailed analysis of patient-to-patient transmission of bacterial pathogens in order to inform infection prevention and control responses
- To reduce the overall burden of nosocomial infections and prevent outbreaks before they become established
- To provide an example of 'best-practice' for future integration of microbial genomics into routine clinical microbiology
- To establish a genome-sequence based catalogue of bacterial isolates that will allow subsequent isolates from new outbreaks to be put into context with historical isolates.





### Clinical Demonstration Project

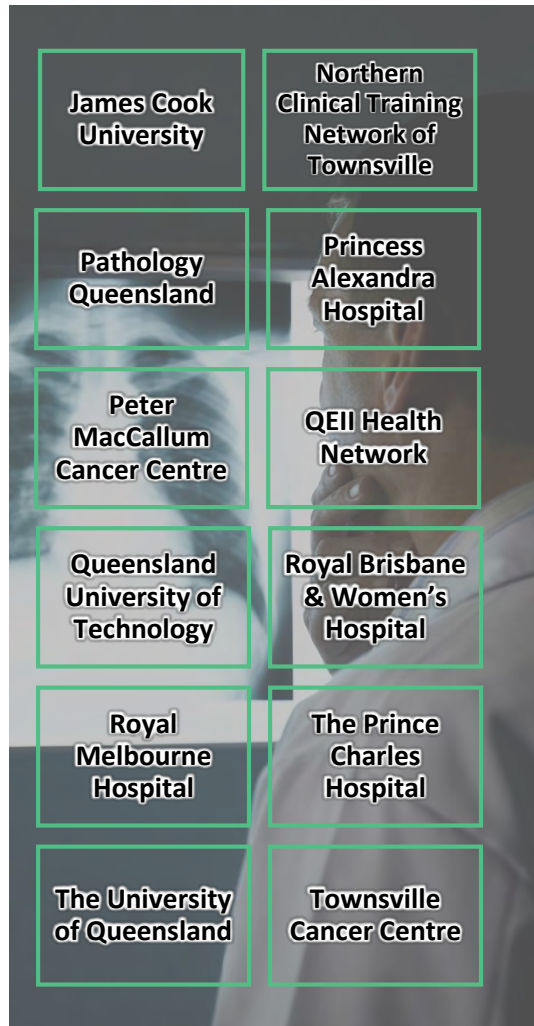
**Project Lead:** Prof. Matt Brown (Princess Alexandra Hospital – QUT)

**Summary:** A new model of genomic testing for lung cancer will be tested in comparison to current diagnosis (by PQ, 40% accuracy) and tested within both metropolitan and indigenous communities in Qld.

Also developing an app-based consenting procedure.

#### Objectives:

- To lay the framework for introducing comprehensive genomic profiling into lung cancer management in Queensland
- To assess the impact of genomic profiling on clinical care and patient outcomes
- To assess the acceptability of genomic profiling with patients
- To develop and optimise models for the provision of comprehensive genomic profiling of lung cancers to urban, regional city and remote Queensland
- To compare models with standard care and assess costs, outcomes, engagement in trials and acceptability to patients and lung cancer teams
- To address the provision of genomic medicine services to indigenous communities in urban, regional city and remote areas in Queensland
- To establish a system of review and feedback to ensure service optimisation.



James Cook University	Northern Clinical Training Network of Townsville
Pathology Queensland	Princess Alexandra Hospital
Peter MacCallum Cancer Centre	QEI Health Network
Queensland University of Technology	Royal Brisbane & Women's Hospital
Royal Melbourne Hospital	The Prince Charles Hospital
The University of Queensland	Townsville Cancer Centre



### Clinical Demonstration Project

**Project Lead:** Prof. Peter Soyer (Princess Alexandra Hospital – UQ)

**Summary:** As Queensland has the highest melanoma incidence and associated mortality rates in Australia (and the world), this project focuses on the prevention and early detection of melanoma using WES (NATA accredited facility, currently no standard protocol) and 3D body photography of moles on 1261 volunteers, in order to determine genetic risk along with validated phenotypic risk scores (i.e. family history, number of moles, environmental, physical).

#### Objectives

- Prevent melanoma and facilitate early detection and treatment
- Progress knowledge of genetic changes associated with naevi morphology and melanoma to a point where recommendations can be made to the workforce
- Conduct germline analysis of patients at high risk of melanoma
- Develop protocols for targeted melanoma screening in high risk individuals and families
- Build clinically focused research into the education of current and next generation health professionals ensuring that our recommendations for change in practice are implemented.

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Alexandra  
Hospital

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Technology

The  
University  
of Queensland

QIMR Berghofer  
Medical Research  
Institute



Australian  
National  
University

Genetic Health  
Queensland

QIMR Berghofer  
Medical Research  
Institute

James Cook  
University

Queensland  
University of  
Technology

The University of  
Oxford

The University of  
Queensland

University of  
Tasmania

The University of  
Sydney

## Ethics, Legal & Social Implications of Genomics - *Capability Building Workstream*

**Project Co-Leads:** Dr Nic Waddell (QIMR Berghofer), Prof. Belinda Bennett (QUT), Prof. John Devereux (UQ)

**Summary:** This application brings together a world-class team of scientists, legal experts, ethicists and physicians who will work together to develop protocols and policies within 6 themes:

- Community Engagement
- Clinical Use of Genomics
- Consent
- Justice
- Genomic Research
- Health Systems

The overall aim of the project is to ensure the safe delivery of genomic medicine for the people of Queensland. The project will also assist the successful demonstration projects in obtaining ethics approvals (Priority – address the CDP project needs).

### Objectives:

- Actively support the implementation of ethics, legal and socially related processes and practices within each QGHA Clinical Demonstration Project
- Actively leverage the experience of QGHA Clinical Demonstration Projects
- Contribute to the formal evaluation of each QGHA Clinical Demonstration Project
- Establish a strong foundation for further QGHA ethics, legal and social policy research, translation and implementation
- Build upon existing Queensland and emerging best practice.





## Establishment of MSc in Diagnostic Genomics at Queensland University of Technology and development of continuing education material for workforce development

Australian e-Health Research Centre, CSIRO	Australian Genomics Health Alliance	Brisbane Genetics	Children's Cancer Institute
Genetic Health Queensland	Genome One	Human Genetics Society of Australasia	Innovative Genetics Diagnosis
Macquarie University	Mater Health Services	Melbourne Genomics Health Alliance	Murdoch Children's Research Institute
Pathology Queensland	PathWest	Princess Alexandra Hospital	QIMR Berghofer
Qld Cyber Infrastructure Foundation Ltd	Qld Fertility Group	Queensland University of Technology	Royal Brisbane & Women's Hospital
SA Pathology	SEALS Pathology Laboratory (Vic)	Sullivan Nicolaides Pathology	The University of Sydney
	The University of Queensland	Vic Clinical Genetics Services	

### Genetic Workforce Development Capability Building Workstream

**Project Lead:** Prof. Lyn Griffiths (QUT)

**Summary:** In conjunction with the Human Genetics Society of Australasia Board of Censors, this project team aims to develop a MSc in Diagnostic Genomics curriculum (first in Australia) and course materials to upskill scientists and clinicians in genomics.

**Objectives:**

- Partner with collaborators to utilise course materials for CEPD for clinicians and scientists in genomics, bioinformatics, and ethics, legal and social implications of clinical genomics
- Develop online program materials for MSc Diagnostic Genomics
- Enrol approximately 20 students per annum beginning 2018
- Facilitate student placements through Queensland and Australia
- Provide a pathway for the certification of molecular biologists, cytogeneticists, and biochemical geneticists in Australia.



### Evaluation of Clinical Genomics - *Capability Building Workstream*

**Project Lead:** A/Prof. Louisa Gordon (QIMR Berghofer)

**Summary:** This project aims to identify what health resources are required for everyday genomic testing to bring about the most benefit to patients. The framework will have a health economics focus in this first phase but will draw in a broader range of outcomes, where feasible, for a societal view of the potential value of genomic medicine.

**Objectives:**

- To determine the economic costs of genomic testing
- To evaluate the cost effectiveness of genomic testing in specific disease and testing contexts, compared with standard care
- To provide a budget impact analysis from Queensland Health's viewpoint
- To examine patient and clinician satisfaction, knowledge and acceptance of genomic testing.



**Murdoch  
Children's  
Research  
Institute**

**Pathology  
Queensland**

**QIMR Berghofer  
Medical  
Research  
Institute**

**Queensland  
University of  
Technology**

**The University of  
Queensland**

**The University of  
Sydney**





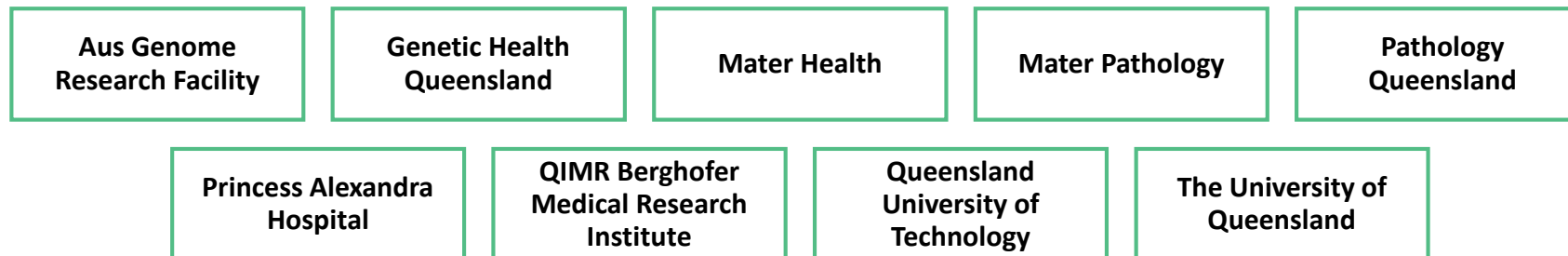
## Genomic Testing Innovation - *Capability Building Workstream*

**Project Lead:** Prof. Sunil Lakhani (Pathology Queensland – UQ)

**Summary:** Building on the state-wide network of PQ, this project will focus on the development and implementation of Quality Management Systems for genomic sample collection, processing, tracking and timely delivery of reports to the clinic (ISO13485), and work with other Capability Building Workstreams and Clinical Demonstration Projects to develop other innovative tools.

### Objectives:

- To develop and implement a quality management system for sample collection, processing and tracking, and timely delivery of reports
- To establish accreditation for all providers of genomic data
- To utilise Queensland's statewide pathology network to deliver genomic services
- To establish systems for prospective comparison of the performance of new genomic approaches for implementation
- To develop new tools such as point of care testing and analysis pipelines.



**Genomic Information Management - *Capability Building Workstream***

Aus e-Health Research Centre, CSIRO	<p><b>Project Co-Leads:</b> Dr David Hansen (Australian e-Health Research Centre, CSIRO), John Pearson (QIMR Berghofer)</p> <p><b>Summary:</b> Establish, implement, and evaluate the Queensland Genomics Information Management Architecture (QGIMA) which will support the use of genomic information by patients, clinicians and researchers in Queensland. In particular:</p> <ul style="list-style-type: none"><li>• Data Repository</li><li>• Data Share</li><li>• Analysis Pipeline</li><li>• Clinical Systems</li><li>• Genomic Test Ordering/Analysis/Report</li></ul> <p><b>Objectives:</b></p> <ul style="list-style-type: none"><li>• To define a Queensland genomics information management architecture which will support the definition, processing, management and exchange of genomic information in clinical settings and with researchers</li><li>• To test the Queensland genomic information management architecture through proof of concept implementations with QGHA's Clinical Demonstration Projects</li><li>• To evaluate and provide feedback on the existing information pipelines for QGHA's Clinical Demonstration Projects</li><li>• To contribute to test ordering and reporting of genomic analysis</li><li>• To define how Queensland can access, use and contribute to pathogenic variant &amp; gene information</li><li>• To collaborate with existing implementations in the Australian Genomics Health Alliance and the Global Alliance for Genomics and Health.</li></ul>
Pathology Queensland	
QIMR Berghofer Medical Research Institute	
Qld Cyber Infrastructure Foundation Ltd	
Queensland University of Technology	
The University of Queensland	



## Introducing QGHA

*How we're addressing the challenges of implementing genomics into clinical care*

**Wrap up and questions...**



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# Genomics in healthcare

*The ethics, legal, and social implications*

**Dr Nic Waddell**

Co-lead, QGHA Ethics, Legal and Social Implications Project

Ex-Officio Member of the QGHA Community Group

Group leader, Medical Genomics, QIMR Berghofer



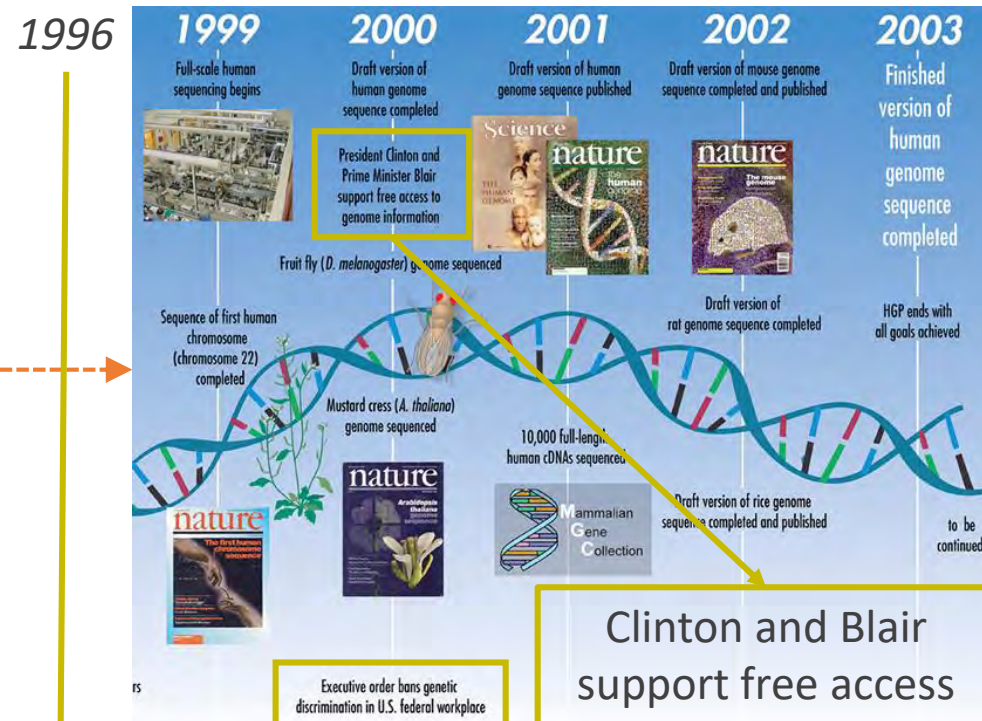
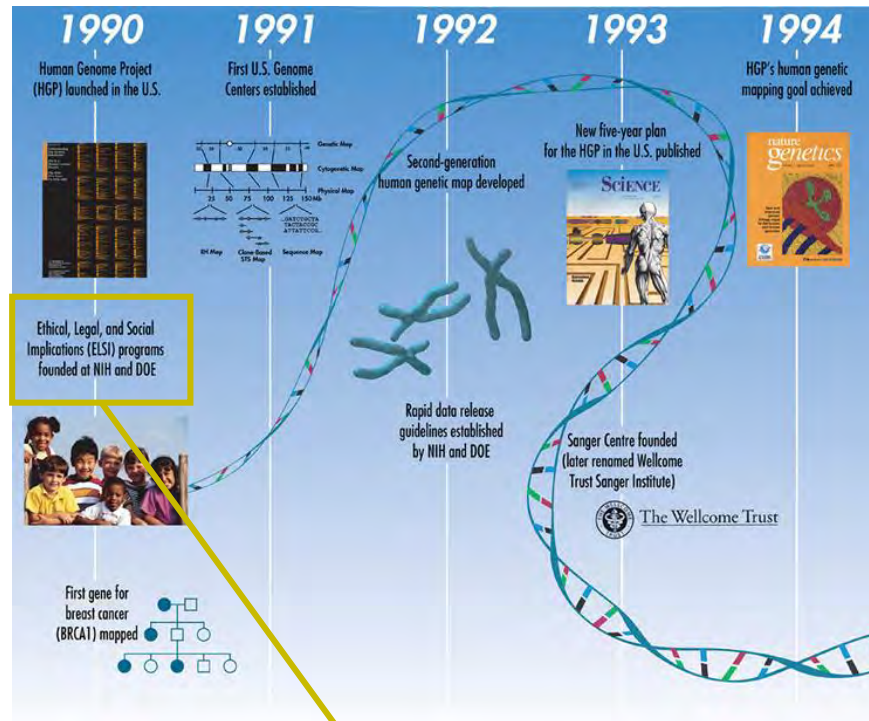
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# The human genome project: 13 years and \$2.7 billion

Lander et al *Nature* 409, 860-921 (2001)

Venter et al *Science* 291, 1304 (2001)



Ethical, legal and social program founded by NIH and DOE

Clinton and Blair support free access of genomic information

Executive order bans genetic discrimination in US federal workplace

Bermuda principles  
 Aim to make the entire sequence freely available in the public domain for both research and development in order to maximise benefits to society

# Genomics in the health care

100,000 whole genomes from NHS patients

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## Data Access and Use

An individual's data will not be released

De-identified data is analysed within a secure, monitored environment

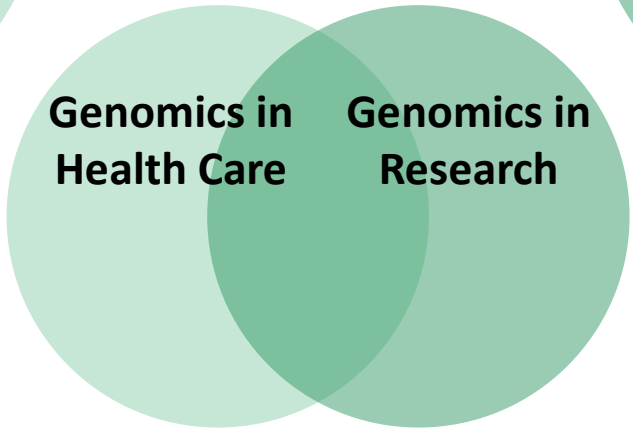
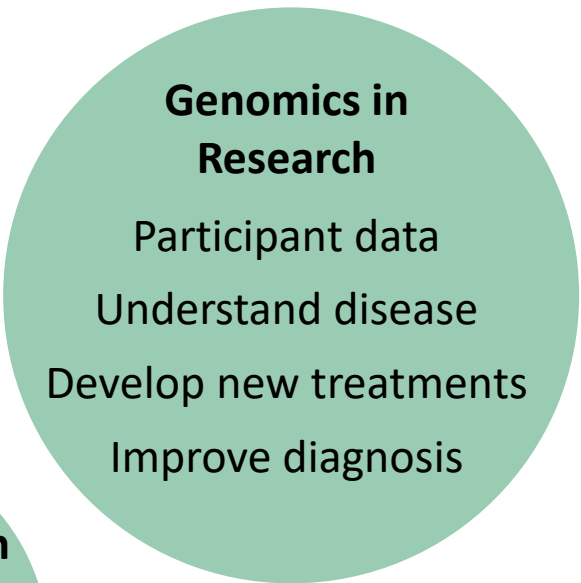
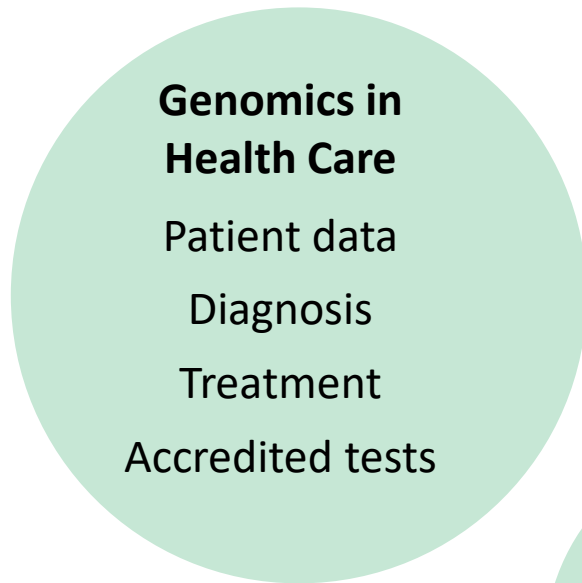
## Who has access?

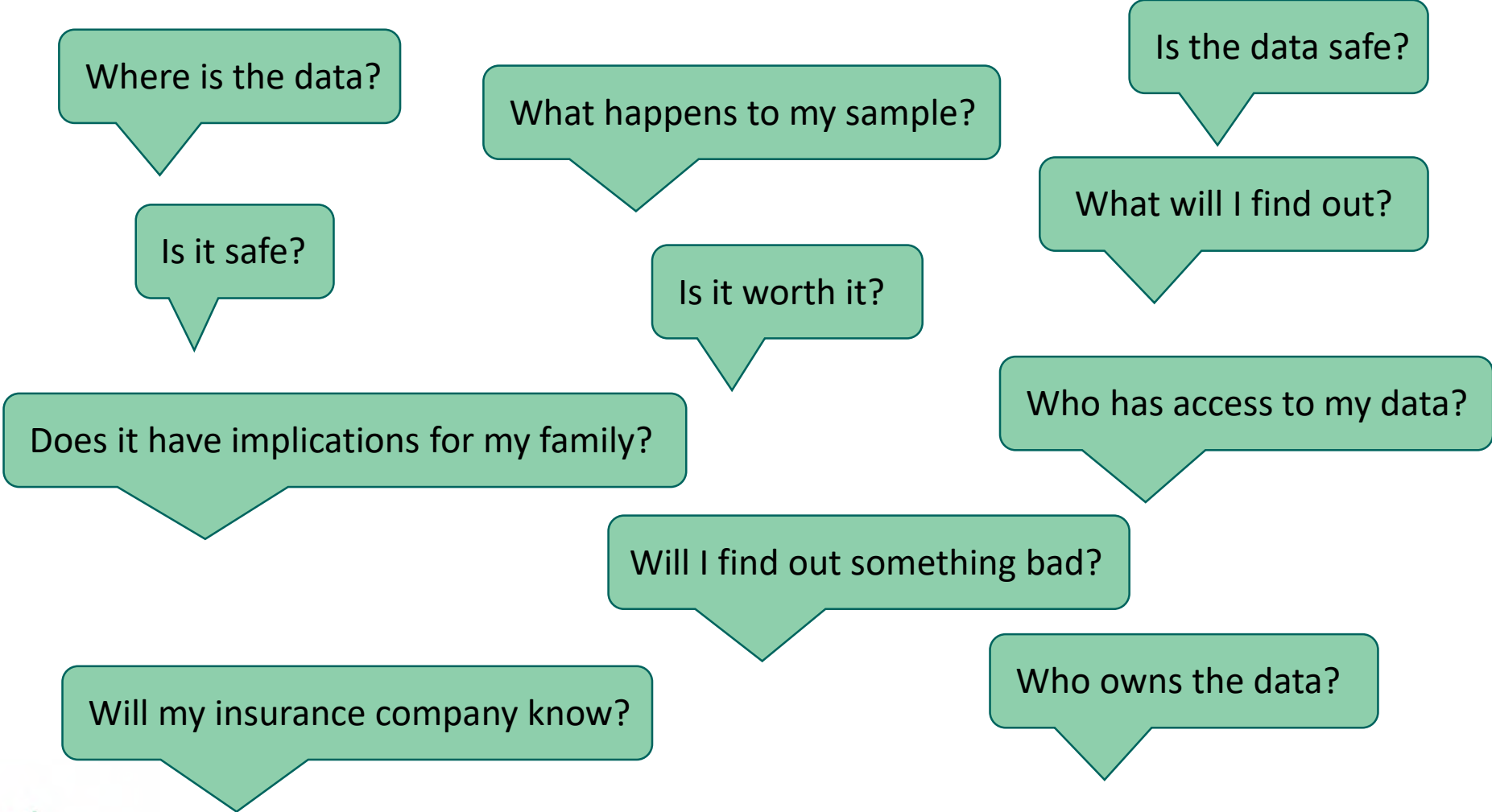
Doctors, nurses and healthcare professionals in NHS Genomic Medicine Centres have access to information about the patients they are caring for

Researchers must apply to access the de-identified genomic and health data

Scientists and clinicians will access the data for a variety of research









# 'Informed' consent

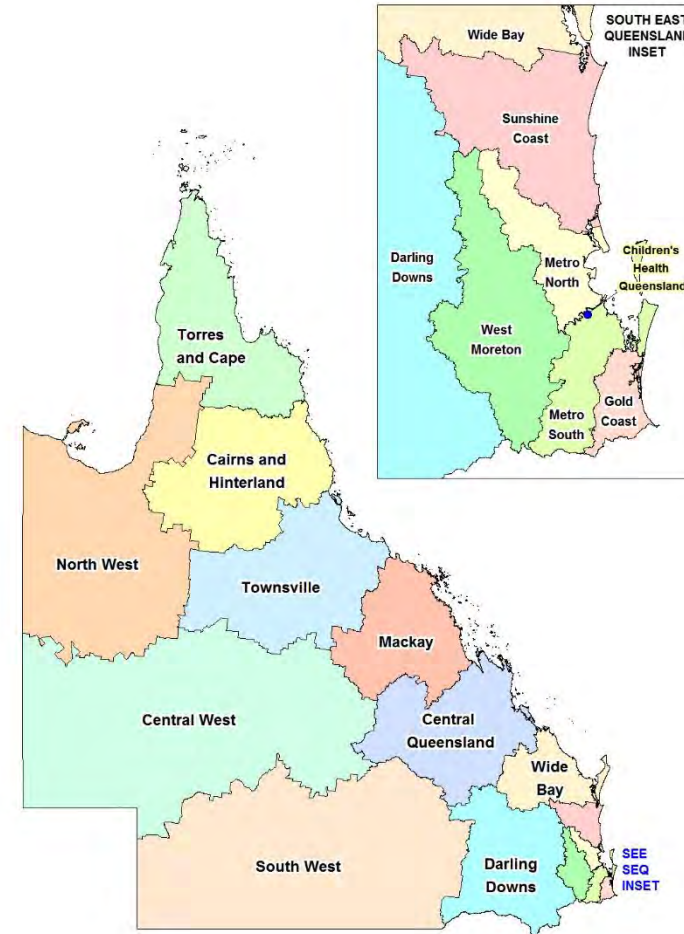
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- Purpose of test
- Medical implications
- Possible risks and benefits
- Possible implications to family members
- Made aware of privacy rights
- Where their DNA will be stored
- Who will have access to their personal information



# Equity of access

- Location
- Cost of tests
- Reimbursement of tests
- Availability of tests



# Incidental or secondary findings

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- A whole genome test will identify all variants in the genome
- On Average a person will have 3-7 pathogenic variants
- These variants may be associated with other conditions
- The findings may have implications to family members and future children

# Genetic discrimination

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- Third party use of genetic information
  - Employer
  - Insurance companies
- Deter people from participating in genomic research
- Australian Genetic Non-Discrimination Working Group (AGNDWG)

## **Parliamentary Committee releases recommendations from Inquiry into Australia's life insurance industry**

**9.1** - .....assess the consumer impact of imposing a moratorium on life insurers using predictive genetic information, unless the consumer provides genetic information to a life insurer to demonstrate that they are not at risk of developing a disease

# Patient expectations

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- Test may yield 'uncertain' results
- Data may be reanalyzed periodically with an update to diagnosis
- Test may find a result but there is no treatment available



# Some questions to consider

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- Should consent for research be “opt out”?
- Should patients and participants be made aware of incidental findings?
- How would you feel about your genome data being shared?
- Should we sequence all newborns?

# Genomics in healthcare

*The ethics, legal, and social implications*

**Wrap up and questions...**



# **Beyond the science**

## *A personal genomics story*

**Gary Hondow**

Health Consumer and Carer

Member of the QGHA Community Group



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# Genomics & Personalised Medicine

*Why community engagement is essential*

**David Bunker**

Executive Director, QGHA

Ex-Officio Member of the QGHA Community Group



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# Program Approach

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As an *investment and collaboration vehicle*, the Alliance will develop clinical utility evidence for genomics in everyday healthcare, by:

- Investing in clinical projects with an implementation and/or innovation focus;
- Commission activities to develop core genomics capability and infrastructure in partnership with relevant health system functions and state-wide services;
- **Engage and activate community representation in the program through our Advisory Group and their community networks**

# Quadruple Bottom Line

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The QGHA is focused on its eight Core Objectives within four outcome themes:

- Patients and Community
- Clinicians and Clinical Practice
- Health System
- Research

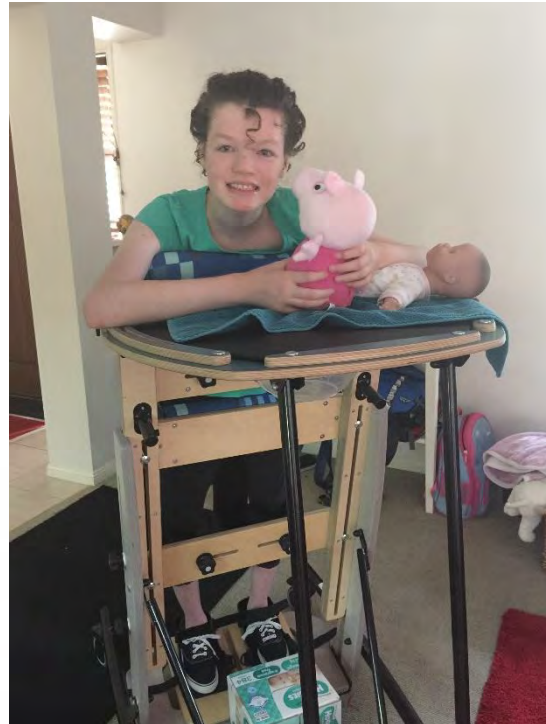




Daelle testing out her new wheelchair adapted car.



Recovering after bi-femoral and pelvic osteotomies



# Genomics & Personalised Medicine

*Why community engagement is essential*

**Wrap up and questions...**





# The QGHA Community Group

*Our vision, mission, objectives and areas of action*

**Dr Erin Evans**

Chair of the QGHA Community Group



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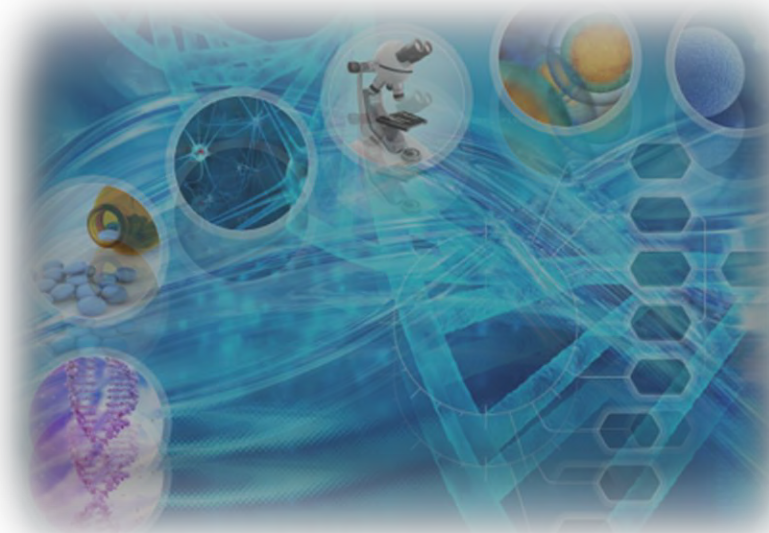
# Foundations of the QGHA CG

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QGHA Community Advisory Group was established in late 2017

HCQ contacted to provide representation of consumers

Focus on legitimate partnering with consumers to co-design, ensure system improvements in research translation, community equity and access to services.



Report to QHGA ED and supported by the Business Team

Support the 5 year program of QGHA

Meet quarterly

# Queensland Genomics Health Alliance Community Group



## Our Vision

The Queensland Genomics Health Alliance Community Group is an active collaborator within the health system working with researchers, clinicians and communities to facilitate equitable and accessible person-centred care for all Queenslanders.

## Our Objectives

- To collaborate with Queensland Genomics Health Alliance and support its vision and mission
- To serve as an active conduit to consult, promote, and engage the people of Queensland in the work of Queensland Genomics Health Alliance and its partners
- To support the development of a health system that delivers the earliest possible diagnosis, appropriate intervention and follow up, and responds to patient needs in a flexible and nuanced person-centered way
- To advise Queensland Genomics Health Alliance projects on better ways to link and communicate with patients and their families, helping to ensure a patient and delivery focus



(L to R) Back row: Gary Hondow, Louise Healy, Satrio Nindy Istiko, Greg Pratt Front row: Aideen McInerney-Leo, Jessica Bean, Katrina Kutler, Nic Waddell, Erin Evans, Lindsay Fowles, David Bunker Missing: Andrew Hallahan



### Collaboration

We support and drive collaboration and communication locally, nationally and internationally between community, consumers, advocacy groups, clinicians, health systems, researchers and others, with the aim of informing the implementation of genomics into healthcare.

### Equity and Access

We support equity of access to genomic medicine regardless of location, education, language, socio economic status, or health literacy. We work to improve clarity of treatment pathways, diagnostic tools and genomic medicine.

### Education

We build education on different perspectives of genomic medicine within communities of health consumers, carers, clinicians, researchers, health administrators and advocates.

### Advocacy

We advocate for the community with government, NGOs and the private sector to enable patient-centred personalised medicine now and into the future.

### Foundation and prioritisation

Our role is to lay down the tracks and set the direction to build long term changes in the health system for the introduction of genomics. We work to help prioritise activities, balancing the desire to make a difference not only today, but also in the longer term.

### Real world context

We help to frame actions and decisions within the real-world context experienced by consumers and community. We work to improve the understanding of researchers, clinicians, and decision makers in the health system about the real-world impacts of decisions, and the current experiences and challenges of consumers, families and communities.

## Areas of Action: our work with key stakeholders

### QGHA

- Collaborate with QGHA and support its vision and objectives
- Serve as a conduit to consult and promote, and to engage the people of Queensland in the work of QGHA and its partners
- Focus on consumer issues – in QGHA projects and the broader program
- Ensure activities of QGHA are relevant and beneficial to patients and communities across Queensland

### Community

- To be a voice for all Queenslanders
- Engage with the community – educate so that utility and limitations of genomics is understood, and community concerns addressed. Use positive stories regarding genomics to build awareness and understanding
- Increase awareness about the lives of people with genetic conditions. Help to bridge knowledge gaps
- Ensure the views of different sectors of the QGHA community are considered in implementing genomics

### Clinicians

- Enable clinical understanding in 'real world' context
- Support better education of clinicians in medical training, and ongoing professional development

### Health System

- Lay the foundations for health system to implement genomic medicine, ensuring diverse community voices, needs and issues are understood and responded to
- Support development of patient-centred policy, design and implementation
- Provide community input into patient-facing resources
- Provide a patient/community voice to enrich the application of genomics for patient benefit
- Create change and make genomics more accessible
- Help to identify future important areas in genomics where Queensland can have the greatest impact
- Help prioritise activities and balance what makes a difference today with what makes a difference in the longer term
- Provide a reality check about the consumer experience and the challenges of getting on, or being on a treatment pathway and the impacts that this has on the consumer and their family, friends and community

### Research

- Advise research projects on better ways to link and communicate with patients
- Support a community voice in development of genomics research and policy
- Ensure research focus remains on improved healthcare and patient needs

# Principles of Engagement

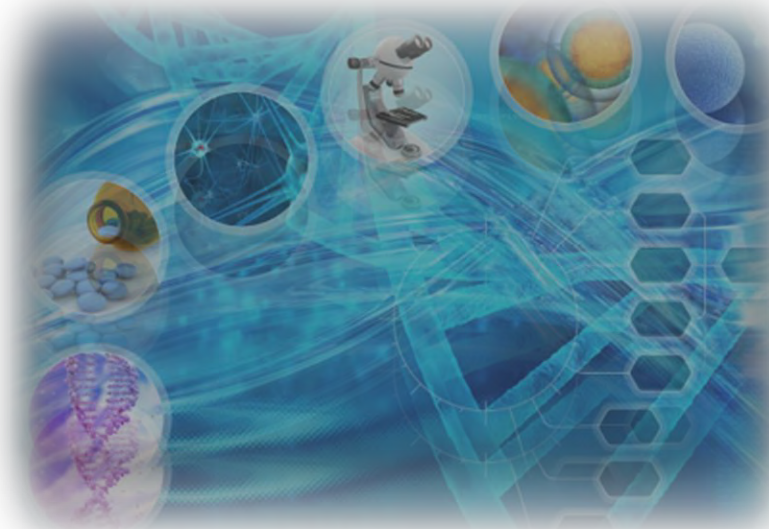
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Inclusive: representative of views of diverse stakeholders

Informed: provide information for participants to make informed recommendations

Transparent: open and honest engagement

Respectful: of differing perspectives and viewpoints



- Challenges: representing diversity in a “specialised” area that is relevant to all however impacts a smaller %
- Patient registry to enable access and speed of access to services that provide clarity and pathway
- Much of what we do now will have long term impacts. Feedback about our impacts are often delayed and indirect.



# The QGHA Community Group

*Our vision, mission, objectives and areas of action*

**Wrap up and questions...**







Queensland  
Genomics  
**Health Alliance**

# *Thank you*

*Please join us in the Concourse for the networking, drinks and close*



@QLDgenomics

#QLDgenomics



### **Document Purpose**

This document provides an executive-level briefing on the Queensland Genomics Health Alliance, including the program’s objectives and purpose, its governance, structure and operation, and the focus of the Round 1 Clinical Demonstration and Capability-building Projects.

### **Document Control**

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