Melbourne Genomics
Health Alliance

Benefits of a statewide approach to genomic healthcare

White paper from Genomics in Hospitals Workshop

April 2023

Alliance members

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The University of Melbourne
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Executive summary

This white paper outlines key opportunities for a statewide, strategic approach to genomics.

Senior leaders from Victorian hospitals identified these opportunities at a workshop organised by Melbourne Genomics in March 2023, which was opened by the Victorian Department of Health Secretary, Professor Euan Wallace AM.

Appropriate implementation of genomics across Victoria represents one of the biggest changes in healthcare in the last 50 years. It is vital to get it right: available to all who need it, used appropriately and efficiently, and guided by value-based principles.

The right pieces are in place.

The Victorian Government has invested in the Melbourne Genomics Health Alliance since 2016. Because of this investment, there is evidence of when genomics offers most utility for Victorian patients. There is a Victorian-built data platform that makes genomic testing efficient and scalable. There will soon be evidence of which models of care best enable health services to offer genomics, and what guidance is needed to do it safely and effectively.

Workshop participants saw immense value in a statewide approach to genomics, including:

- Supporting equity of care through referral pathways across health services
- Ensuring a sustainable and genomics-competent workforce
- Demonstrating value-based care through statewide approaches to data capture
- Building community trust and confidence in genomic medicine

The time is right, too.

The Victorian Government is in the process of developing its 2033 vision of change in health and care, aiming for 'Victorians to be the healthiest people in the world'.[1] Genomics is not only key to this vision, but can be a perfect test case for a joined-up, accessible and consumer-centred system.

Genomics bridges specialties. It can predict and avert health risks. It can diagnose many conditions and cancers quickly, and treat them precisely. It's instrumental in stopping the spread of viruses and superbugs.

Statewide leadership at this critical time can make genomics part of routine healthcare, for all Victorians who need it.

[1] Department of Health. *Our Operational Plan 2022-23* [Internet]. Victoria: Victorian Government; 2022. Available from https://www.health.vic.gov.au/department-of-health-operational-plan-2022-23

Introduction

Melbourne Genomics Health Alliance is a collaboration of leading hospitals, research and academic institutions, funded by the Victorian Government to expand the use of genomic medicine.

In March 2023, Melbourne Genomics convened a workshop to develop a capability assessment tool that could support hospitals in implementing genomic medicine safely and effectively. The Genomics in Hospitals workshop was attended by 29 healthcare leaders: including Board members, chief medical officers and clinical directors as well as health economists, genomics experts and consumer advocates. (See appendix for a list of participants.)

The workshop was introduced by Professor Euan Wallace AM, the Victorian Department of Health Secretary. Professor Wallace invited participants to consider equity, value-based care, a learning workforce, and community involvement in the implementation of genomics.

The genomics capability assessment tool for Victorian health services will be published in a separate paper; however group discussion on safe and effective implementation raised issues and opportunities that cannot be addressed by hospitals alone.

Healthcare leaders at the workshop overwhelmingly saw value in a statewide approach to genomics, guided by the Department of Health. The key benefits are summarised on the following pages.

What is genomics?

Genomics is an area of medical science that examines the genomes of humans and other organisms. It can be used to predict, prevent, diagnose and treat illnesses, or to track the spread of bacteria and viruses such as COVID-19.

Opportunities for statewide leadership in genomics

This paper summarises issues relevant to a statewide approach to genomics, which were raised in the Genomics in Hospitals workshop held on 8 March 2023.

Equity of care

All Victorians who need a genomic test should be able to get one, along with appropriate follow-up care. Melbourne Genomics is road-testing various models of care with regional and metropolitan hospitals, but statewide leadership is needed for effective adoption across the health system.

While some genomic medicine is routine, much is complex and emerging: requiring highly-specialised staff across a range of disciplines to deliver safely and effectively. As such, not every hospital will be able to offer the full range of genomic medicine, nor can genomics be provided equitably without the involvement of primary and community health services.

A statewide approach could help establish referral pathways between services, and ensure appropriate support for individuals and families across all the services they require.

Some workshop participants pointed to the way NHS England's genomics strategy embeds genomics across the care continuum in the health system.[2]

Cross-hospital, cross-speciality and cross-disciplinary models of care will be also needed. These do not yet exist in genomics and limit its wider use. Current Melbourne Genomics projects are providing real-world evidence to inform statewide approaches.[3]

Partnerships with Aboriginal health services are necessary for culturally safe provision of genomic medicine. Projects underway with the Australian Indigenous Genomics Network ('ALIGN') offer a valuable starting point.

[2] NHS England. Accelerating genomic medicine in the NHS [Internet]. London: NHS England; 2022 Available from https://www.england.nhs.uk/publication/accelerating-genomic-medicine-in-the-nhs/

[3] Melbourne Genomics Health Alliance. *Bringing genomics into Victorian healthcare: Barriers, insights and solutions* [Internet]. Victoria: Melbourne Genomics; 2022

A learning workforce

Genomics is expanding beyond genetic services, and now touches almost every specialty. Its broader implementation cannot be led solely by existing genetic medicine services.

Genomic capabilities are required across the broader health workforce: to ensure genomic medicine is integrated into existing models of care, and to support expansion into a range of medical specialties at a time when services specialising in genetics are overstretched and struggle to keep up with existing demand.

Workshop participants saw education and training as one component of a holistic workforce strategy. Promising education opportunities currently exist through the Melbourne Genomics program, including introductory and specialist modules on applying genomics within a range of specialties. There is high take-up of these modules around Victoria. However, genomics education opportunities may decline after the program ends in 2025, unless a sustainable model of delivery is established, with reach across the state.[4]

Some genomic medicine workforce challenges cannot be addressed solely through education and training. For example, given the cross-disciplinary and cross-specialty nature of genomic medicine, new models for credentialling and scope of practice will be needed. This is wider than the role of the colleges: an integrated approach to credentialling will strengthen safety and clinical governance.

Finally, primary and community health workforces also have a vital role to play, and would benefit from tailored genomic education, clear role delineation and effective referral pathways.

[4] See for example NSW Health's approach to genetics and genomics education. NSW Health. *NSW Health Genomics Strategy: Implementation Plan 2021-25* p.7 [Internet]. New South Wales: NSW Government; 2021. Available from https://www.health.nsw.gov.au/services/Publications/genomics-implement-plan.pdf

Value-based care

Statewide approaches to data capture will be vital to demonstrate the costs, benefits, value and impact of genomic medicine. This data would inform robust decision-making to achieve value-based care.

Melbourne Genomics clinical projects have already shown that genomics can deliver value for Victorians: by improving health outcomes, reducing hospital stays, avoiding invasive tests, and identifying genetic risks within families. These studies, however, focussed only on participating hospitals.

Hospital leaders at the workshop expressed strong support for collective ways to capture data. Data capture systems could be designed proactively for use across the state – rather an ad hoc approach by individual hospitals – with health services then collecting data prospectively and consistently across the health system. This would enable the Victorian Government to demonstrate value-based care, using measures like improved health outcomes arising from early diagnosis and intervention; cost savings from hospital avoidance and fewer invasive tests; reduced prescription costs; and reduced adverse events.

Capturing quality assurance and quality improvement data at a statewide level would also enable cross-hospital comparisons and aggregate analyses.

Workshop participants also felt that genomic data itself had lifetime value. Its use should be controlled by patients, and it should be integrated with other health records.

One way to realise this value is to make genomic test reports accessible through My Health Record or hospital electronic medical records (EMRs). Melbourne Genomics is currently trialling an integration between its clinical genomic data platform and one hospital's EPIC EMR.

"Genomics isn't like any other test. The urine or blood test you did last week won't matter soon, but you own your genomic test data for life."

Prof Jo Douglass,

Director of Research and James Stewart Professor of Medicine,
The Royal Melbourne Hospital and University of Melbourne

Community involvement

Healthcare leaders wanted to see broader community involvement in genomics, with many raising the risks of inadequate engagement.

Valuable lessons can be learned from the COVID-19 vaccine rollout, as well as the Department of Health's current research on awareness of options for care outside hospitals. These examples point to the need for targeted strategies to engage healthcare providers, community groups and the general public.

Applying these lessons to genomics would help Victorians understand the value of genomic medicine, build trust in the healthcare system's management of genomic data, and reduce the negative impact of misperceptions, misinformation and disinformation.

"I'm looking at genomics through a rural, regional and multicultural lens. We need to think about entire families as patients, as they've all got a shared interest in those same genes. We need to engage communities rather than just consumers. We need to reach communities where people have poor health literacy, or a history of suspicion at what they perceive as government initiatives with hidden agendas, particularly when those communities already have lower health outcomes."

Dr John Elcock,

Chief Medical Officer, Goulburn Valley Health

Summary:

Opportunities for statewide leadership

- Coordination across hospital, primary, community and specialist health networks, to give all Victorians equitable access to genomic medicine
- Ensuring a sustainable and genomics-competent workforce, across a wide range of specialties and workplaces
- Capturing data system-wide to demonstrate value-based care, using measures such as improved health outcomes, hospital avoidance, reduced prescription costs and reduced adverse events
- Protecting Victorians' genomic data while ensuring its meaningful use in their healthcare
- Building community trust in genomic medicine and mitigating the damaging impacts of misperceptions and misinformation

Conclusion

While health systems continually need to adopt new practices and technologies, genomics presents a particular challenge, and one of healthcare's biggest changes in the last 50 years.

It bridges multiple specialties. It spans predictive health, diagnosis and treatment. It can significantly change how we manage cancer and tackle global health threats like superbugs. And it has lifetime implications for the care of individuals and families.

Now is the time to think about system-wide implementation, in clear alignment with Victoria's 2033 vision for connected healthcare. The evidence to inform real-world implementation is already being generated through the Melbourne Genomics program.

Genomics is a key pillar of a modern, safe and sustainable healthcare system that meets the needs of Victorians now and into the future.

Appendix

Participants at the Genomics in Hospitals workshop: 8 March 2023

Prof Alex Boussioutas, Alfred Health

Prof Kirsty Buising, The Royal Melbourne Hospital

A/Prof Tom Connell, The Royal Children's Hospital

Prof Jo Douglass, The Royal Melbourne Hospital and University of Melbourne

Dr John Elcock, Goulburn Valley Health

Dr Tim Fazio, The Royal Melbourne Hospital and University of Melbourne

Monica Ferrie, Genetic Support Network of Victoria

Dr Lucy Fox, Austin Health

Michael Gorton AM, Alfred Health

Dr Jason Goh, Monash Health

Dr Kushani Jayasinghe, Monash Health

Dr Dishan Herath, Peter MacCallum Cancer Centre

Prof Ben Howden, The University of Melbourne

Dr Aamira Huq, Royal Melbourne Hospital

A/Prof Kerryn Ireland-Jenkin, Austin Health

A/Prof Cate Kelly, Melbourne Genomics Health Alliance

Dr Fergus Kerr, The Royal Melbourne Hospital

Prof Peter Kerr, Monash Health

Prof Richard Leventer, The Royal Children's Hospital

Senthil Lingaratnam, Peter MacCallum Cancer Centre

Charlotte McArthur, Austin Health

A/Prof Cathy Quinlan, The Royal Children's Hospital

Prof Gary Richardson, Cabrini Research

Dr David Speakman, Peter MacCallum Cancer Centre

Dr Michelle Tew, The University of Melbourne

Dr Bryony Thompson, The Royal Melbourne Hospital

Tim Tran, Austin Health

Dr Janney Wale, consumer advocate

Professor Sue White, Murdoch Children's Research Institute

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