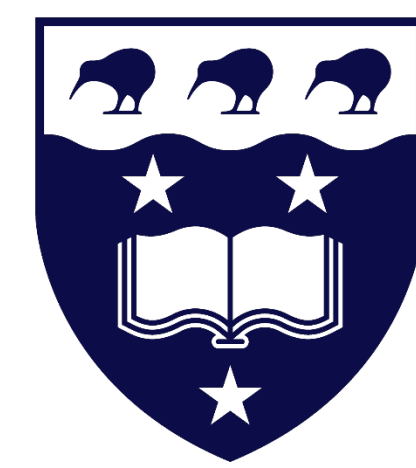


Justifying Investment in Genomics Research Infrastructure: International Expert Perspectives and Lessons for Aotearoa New Zealand



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Abstract

Governments are increasingly investing in genomics research infrastructure, yet the policy and economic reasoning behind these investments remains unclear. This study explored how international experts understand the justification, governance, evaluation, and sustainability of large-scale genomics infrastructure.

Nine semi-structured interviews were conducted across seven countries. Findings suggest that investment decisions were shaped not only by economic evidence, but also by political timing, public trust, legal frameworks, patient advocacy, institutional champions, data infrastructure, and expectations of future public value.

Introduction

Genomics research infrastructure includes the platforms, policies, data systems, sequencing capacity, governance arrangements, workforce capability, and research programmes that enable genomic data to be generated, stored, analysed, reused, and translated into health-system decision-making.

Unlike a single medicine or diagnostic test, genomics infrastructure is difficult to evaluate using conventional cost-effectiveness approaches. Benefits may be long-term, uncertain, distributed across multiple sectors, and dependent on future data reuse, public trust, workforce development, legal governance, and clinical translation.

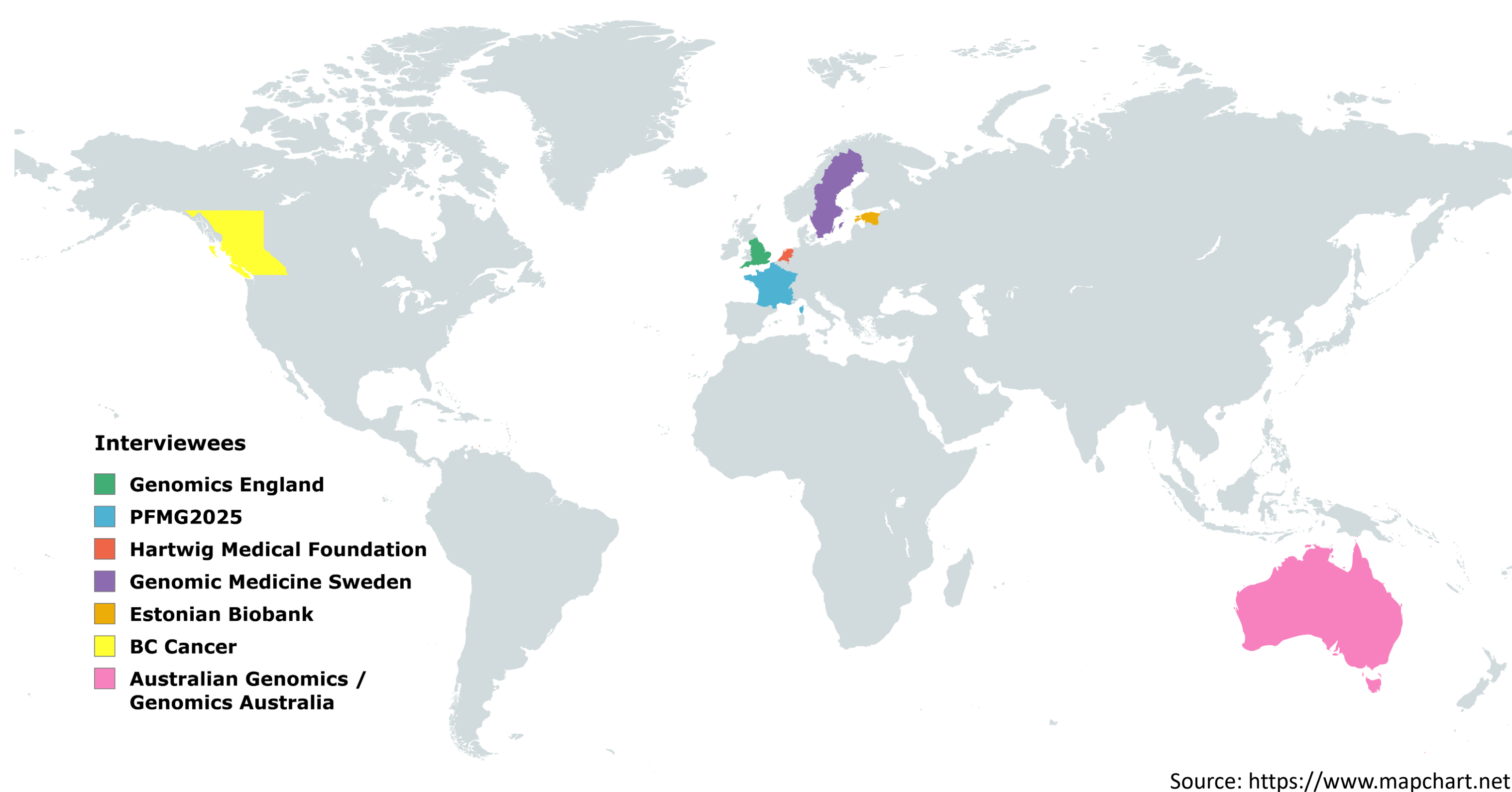
For Aotearoa New Zealand, the investment question is not simply whether genomics can produce value, but how that value should be defined, measured, governed, and sustained in ways that reflect health-system priorities, equity, Māori data sovereignty, and Te Tiriti o Waitangi.

Methodology

Semi-structured interviews were conducted with international experts in genomics research infrastructure, health economics, policy, clinical implementation, data systems, and governance. Nine interviews across seven countries: Canada, England, France, the Netherlands, Australia, Sweden, and Estonia.

Interviews explored how initiatives began, how investment was justified, what evidence was used, how governance was structured, and what lessons may be relevant for Aotearoa New Zealand.

Transcripts were analysed using Framework Analysis with deductive and inductive coding. Initial codes were informed by the interview guide, literature review, and conceptual framework; additional codes captured emerging themes, including public trust, legal infrastructure, patient advocacy, fragmented funding, and the evidence-to-policy gap.



Results

Economics was not enough: Investment decisions were shaped by political timing, clinical need, public trust, patient advocacy, institutional champions, and international comparison.

Value was broader than cost-effectiveness: Participants described value in terms of diagnosis, prevention, treatment selection, data reuse, workforce capability, research outputs, and public-good knowledge.

Governance made value durable: Sustained value depended on legal frameworks, clear accountability, data governance, stakeholder coordination, and long-term funding.

Evidence did not guarantee uptake: Strong clinical or economic evidence did not always translate into reimbursement, routine care, or sustained policy support.

Small-country lessons matter: Estonia and Sweden show that smaller countries can build strong infrastructure through coordination, public legitimacy, and strategic investment.

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Country	Model type	Key lesson
England	Centralised delivery vehicle	Political ambition can mobilise investment
France	National health-system plan	Innovation funding can enable early implementation
Netherlands	Philanthropic cancer data asset	Sustainability needs system integration
Canada (BC)	Embedded evaluation	Learning health systems can generate evidence
Australia	Research collaboration	Evidence alone does not ensure uptake
Sweden	Distributed coordination	Decentralised infrastructure can work
Estonia	Law-backed biobank	Legal foundations and trust sustain value

Conclusion

International experience suggests that genomics research infrastructure should be evaluated as a long-term investment in health, research, data, legal, and equity, rather than as a single technology or diagnostic test.

Across the nine interviews, investment decisions were shaped by more than formal economic evidence. Participants described the importance of political commitment, public trust, patient advocacy, legal frameworks, institutional champions, stakeholder alignment, and clear governance arrangements. A key finding was that evidence generation alone was not enough. Several countries generated clinical, scientific, or economic evidence, but still faced barriers translating that evidence into reimbursement, routine care, or sustained policy support.

For Aotearoa New Zealand, this means that any future investment framework must consider not only whether genomics can produce value, but also how that value can be defined, governed, measured, implemented, and sustained over time.

Overall, genomics research infrastructure should be treated as a system-wide investment in future health capability, not simply as a sequencing platform.

Recommendation

A New Zealand investment framework should consider:

- Health-system benefits: diagnosis, prevention, treatment, and service planning
- Research benefits: data reuse, knowledge generation, and clinical trial readiness
- Long-term genomic data infrastructure and governance
- Māori data sovereignty and Te Tiriti obligations
- Public trust, transparency, and community engagement
- Patient and whānau involvement from the design stage
- Workforce and capability development
- Sustainability beyond short-term project funding
- Clear pathways from evidence generation to policy uptake

Take home message: Genomics research infrastructure is not just a sequencing platform. It is a long-term investment in health, data, trust, governance, and future capability.

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