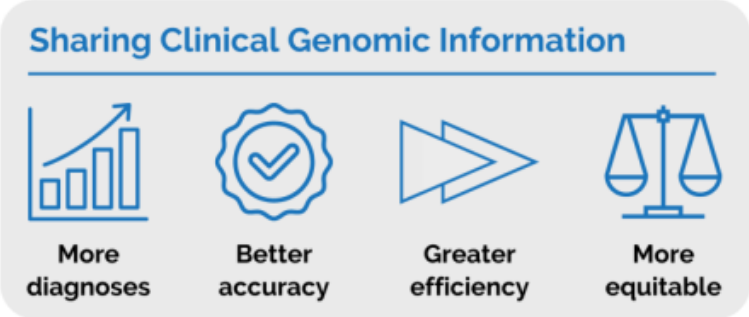
Executive Summary

The National Approach to Genomics Information Management (NAGIM) outlines a vision for coordinated national genomic data and infrastructure in Australia.

In the clinical setting, national data access is needed to maximise public health benefits and improve diagnostic yield, accuracy, efficiency, and equity.



However, due to Australia's federated healthcare system, pathology providers face significant challenges accessing genomic data generated by other services—hindering timely and accurate diagnosis.

The Clinical NAGIM project, led by pathology services, identified two priorities:
1) Aggregated genomic data access, to improve efficiency for prioritising variants; and
2) Patient-level genomic data and clinical phenotype access for increasing diagnoses.

Services across four jurisdictions participated in developing and piloting a technical platform for sharing aggregated genomic data. Three services successfully shared baseline aggregated data. The project highlights opportunities to **build on the aggregrated model** and, critically, **the need to move towards patient-level data access to fully realise clinical benefits**

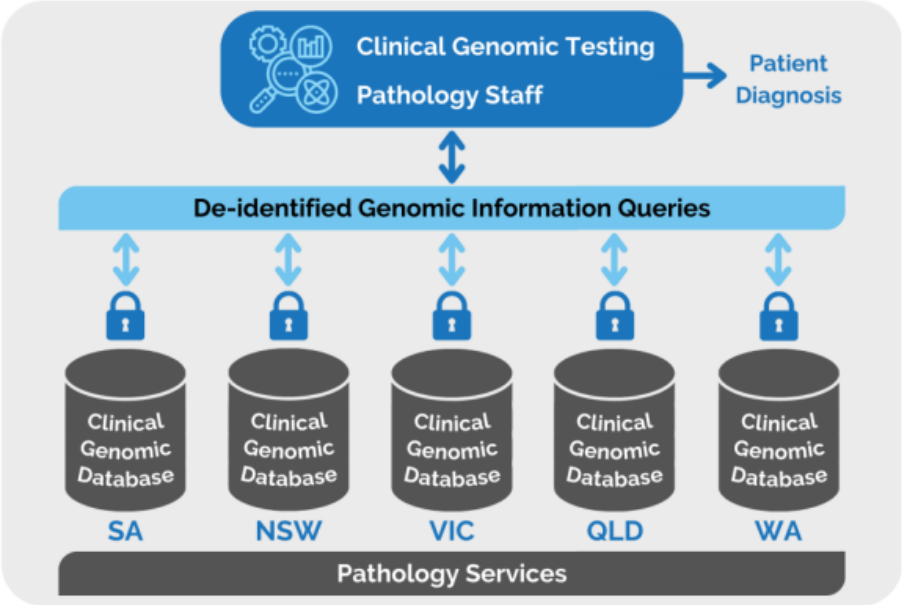
Scaling nationally co-ordinated clinical data access requires addressing both technical and non-technical considerations. These include legal and governance frameworks, patient consent processes, Indigenous data sovereignty, and public trust in platform infrastructure and data use.

Strong public support was identified for using genomics data in diagnostic care and a clear need for cross-jurisdictional access across pathology services.

Recommendations are provided around data and infrastructure, legal and governance, consent, Indigenous data, public acceptability and diagnostic research.

Several infrastructures may be progressed from here, including:

- Centralised or federated platforms for aggregated data (as piloted)
- Extending existing centralised knowledgebases (such as Shariant)
- A centralised trusted data environment for patient-level data, or
- Federated systems for patient-level data



Exemplar model for federated access to healthcare genomic information in Australia

Patient-level data offers the greatest clinical utility, though with greater governance barriers. While a centralised model is technically simpler and easier to govern, a federated approach may be necessary where data cannot leave a jurisdiction due to legal or policy constraints.

To progress nationally, the suggested next steps are:

- **Advance to patient-level diagnostic data access**, building on the foundations established by the Clinical NAGIM project
- **Commit funding or incentives** to support data sharing infrastructure, clarify patient consent for clinical versus research use, and strengthen data access policies and mandates
- **Establish Executive Agreements** across jurisdictions and services to formally endorse clinical data sharing for diagnostics (as recommended by Genome Canada)
- **Prioritise implementation** of this report's recommendations, through the National Health Genomics Policy Framework (NHGPF) and Genomics Australia

After more than a decade of stakeholder engagement with limited national investment or progress, urgent coordinated action is required to avoid further fragmentation across jurisdictions and to preserve stakeholder support and momentum**.**

National approaches to clinical data access will ensure genomic data within diagnostic services can be used to maximise public health benefit - for patients and health services.