

Viewpoint

A Review of Genomic Data Holdings in the Atlantic Provinces

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The review by McDonald and colleagues¹ asks a simple question: What genomic data has been collected in Atlantic Canada, and can anyone actually use it? The data exist. Researchers and clinicians have been generating it for decades. But almost none of it meets FAIR standards.

This is not unique to the Atlantic provinces. Across Canada, genomic datasets sit with individual researchers, on institutional servers. Some sit with third-party sequencing companies abroad. Consent forms were written for clinical care, not secondary research. Linking genomic results to health administrative records is technically feasible in most jurisdictions but practically difficult in nearly all of them. For the health technology assessment community, this means the genomic evidence needed to evaluate new therapies often does not exist in a form that anyone can access.

Genome Canada is working on this. The Canadian Precision Health Initiative (CPHI) is building a federated data platform with a target of 100,000 participants with linked genomic and health data. The Pan-Canadian Genome Library (PCGL) provides the infrastructure for standardized storage and access.

Both of these are also designed with the equity gap this review documents in mind. Nearly every Atlantic dataset draws from populations of European descent. CPHI is recruiting from underrepresented communities, including Black Nova Scotians, so the national picture reflects who Canadians actually are.

The review also makes clear that researchers and clinical labs in the region are already moving. The Atlantic Cancer Consortium and Atlantic PATH have built federated models with formal access processes. National infrastructure does not only get built from the top down. It connects what is already growing on the ground.

Reference

1. McDonald T, Entz R, Lambert-Côté L, et al. A review of genomic data holdings in the Atlantic provinces. *Can J Health Technol.* 2026;6(7). <https://canjhealthtechnol.ca/index.php/cjht/article/view/JA0006>.