

# Leveraging Human Rights to Clarify the Risk of Genetic Discrimination in Pediatric Oncology

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## 4. RESEARCH QUESTION

- How can human rights be leveraged to promote greater inclusion in pediatric cancer research?



## 6. OUTCOMES & IMPACT

- This project will generate legal, ethical, and policy-relevant tools, including consent clauses, to improve inclusion in pediatric oncology research while ensuring meaningful protection against GD.



## 5. TIMELINE & RESULTS



Project Launch

2024

## 1. BACKGROUND & AIM

Genetic discrimination (GD) is defined as unfair treatment based on actual or presumed genetic traits<sup>1</sup>. Despite the passage of the Genetic Non-Discrimination Act (GNDA), concerns about GD among parents and researchers persist and are frequently cited in pediatric genomics research, potentially contributing to hesitation around children's participation<sup>2</sup>.

This study aims to leverage human rights principles to establish an appropriate balance between the right to participate in health research of children and ethical safeguards that respond to real risks of GD in pediatric genomic research.

## 2. RESEARCH OBJECTIVES

- Develop a human rights-based framework to inform research ethics and policy reforms in pediatric genomics
- Gather perspectives from parents of pediatric patients and researchers on GD risks and research participation
- A model consent clause for GD

## 3. STUDY METHODS

- Systematic literature and international human rights instruments review
- Qualitative analysis of research consent forms across Canada and France
- Survey parents/guardians and researchers to better understand their views and preferences on GD.

2025

### Human Rights Instruments Review

A "Points to Consider" entitled *Rethinking Risk: Genetic Discrimination and Children's Right to Participate in Research* was submitted to the peer-reviewed journal *FACETS*.

### Layered Human Rights Protections in Research



Extensive protections exist but rarely reach parents clearly.

548 Articles Reviewed (2015–2025)

### Major Findings:

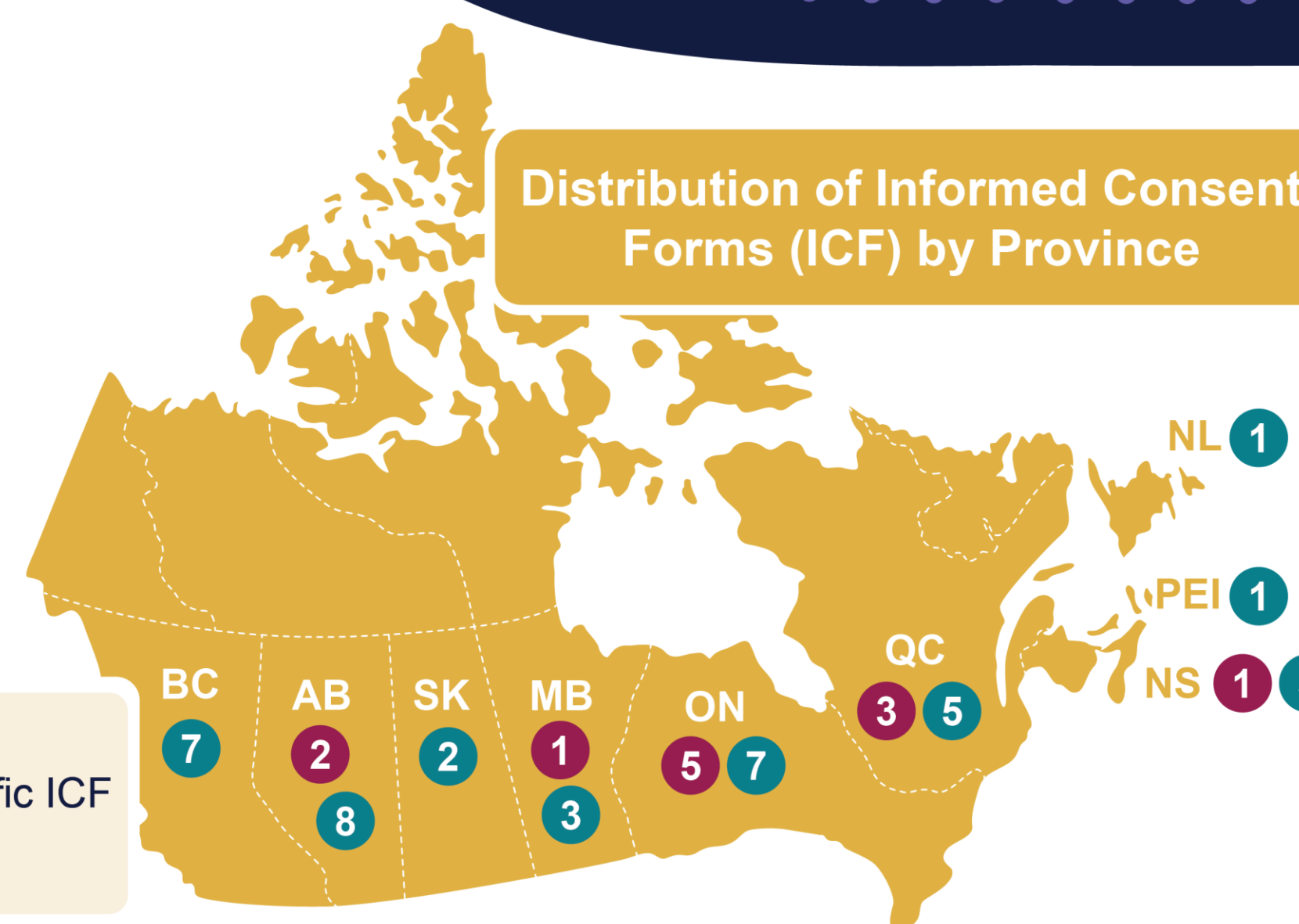
- Widespread Fears of GD
- Concerns about Misuse of Genetic Information
- Concerns about Genetic Privacy:
  - Health Insurance
  - Employment
  - Life Insurance

### Systematic Literature Review on the occurrence of GD

A review of 548 articles (PubMed, Medline, Scopus; 2015–2025) identified limited documented evidence of genetic discrimination.

### References

- Kaiser, B., Uberoi, D., Raven-Adams, M.C. et al. A proposal for an inclusive working definition of genetic discrimination to promote a more coherent debate. *Nat Genet* 56, 1339–1345 (2024). <https://doi.org/10.1038/s41588-024-01786-8>
- Prince, A. E. R., Roche, M. I., & Ladd, J. M. (2019). Attitudes toward genetic discrimination in the United States: Perspectives of patients and family members. *Journal of Genetic Counseling*, 28(2), 341–352. <https://doi.org/10.1002/jgc4.1096>



### Consent Forms Analysis & Survey Study (ongoing)

A preliminary analysis indicates that GD is rarely framed as a distinct risk and is folded into privacy discourse in pediatric research.

2026

2027

Project Completion



Poster Design by Kacey Miranda San Diego

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