Journal of Rural and Community Development

How to Best Implement Shared Benefits From Human Genetic Research: Harnessing and Applying Lessons from Canada's Mining Sector and Resource Regions

Author: Janelle Skeard

Citation:
Skeard, J. (2026). How to best implement shared benefits from human genetic research: Harnessing and applying lessons from Canada's mining sector and resource regions. *The Journal of Rural and Community Development*, *21*(1), 139–165.

Publisher:
Rural Development Institute, Brandon University.

Editor:
Dr. Doug Ramsey

ISSN: 1712-8277 © Authors
www.jrcd.ca

How to Best Implement Shared Benefits From Human Genetic Research: Harnessing and Applying Lessons from Canada's Mining Sector and Resource Regions

Janelle Skeard
Memorial University of Newfoundland
St. John's, Newfoundland and Labrador, Canada
janelle.skeard@mun.ca

Abstract

Questions of benefit-sharing have long been asked in relation to natural resources. Newfoundland and Labrador (NL), with its rich history of resource development in sectors like mining and offshore oil and gas, provides a unique opportunity to learn from and apply valuable lessons from these industries to maximize the shared benefits of human genetic research (HGR) within the province and ultimately elsewhere. As the field of human genetics rapidly advances, offering insights into health and disease and creating new related industries and development strategies that view genetic material as a "resource", it becomes essential to consider how such knowledge can be harnessed for the betterment of the local population. Drawing parallels from successful models in other sectors, particularly mining, this manuscript explores innovative approaches to best ensure shared benefits from HGR in NL. By examining the strategies and mechanisms that have led to successful resource development and more equitable distribution of benefits in the mining sector, I investigate how to apply these strategies in HGR, ultimately enhancing healthcare outcomes for the people of NL, particularly in rural regions which have historically been more affected by genetic conditions. This manuscript utilizes insights gained from key informant interviews and focus groups with citizens to analyze the possible applications from the mining sector for developing genetic resources. Finally, it provides recommendations for an appropriate benefit-sharing mechanism drawing from the core concepts of governance and distributive justice.

Keywords: Benefit-sharing; resource development; genetic research; founder populations; core-periphery dynamics

Comment maximiser le partage des retombées de la recherche en génétique humaine: tirer parti et appliquer les leçons du secteur minier et des régions riches en ressources naturelles du Canada

Janelle Skeard
Memorial University of Newfoundland
St. John's, Newfoundland and Labrador, Canada
janelle.skeard@mun.ca

Résumé

La question du partage des retombées de la recherche en génétique humaine se pose depuis longtemps. Terre-Neuve-et-Labrador (T.-N.-L), riche d'une longue histoire d'exploitation des ressources dans des secteurs comme l'exploitation minière et l'industrie pétrolière et gazière extracôtière, offre une occasion unique de tirer des leçons précieuses de ces industries et de les appliquer afin de maximiser les retombées partagées de la recherche en génétique humaine (RGH) dans la province et, à terme, ailleurs. Alors que le domaine de la génétique humaine progresse rapidement, offrant des perspectives sur la santé et les maladies et créant de nouvelles industries connexes et stratégies de développement qui considèrent le matériel génétique comme une « ressource », il devient essentiel de réfléchir à la façon dont ces connaissances peuvent être mises à profit pour le bien-être de la population locale. En établissant des parallèles avec des modèles fructueux d'autres secteurs, notamment l'exploitation minière, ce document explore des approches novatrices pour assurer au mieux le partage des retombées de la RGH à T.-N.-L. En examinant les stratégies et les mécanismes qui ont permis un développement réussi des ressources et une répartition plus équitable des bénéfices dans le secteur minier, j'étudie comment appliquer ces stratégies à la recherche génétique humaine, afin d'améliorer les résultats en matière de santé pour la population de T.-N.-L, en particulier dans les régions rurales historiquement plus touchées par les maladies génétiques. Ce manuscrit s'appuie sur les informations tirées d'entrevues avec des informateurs clés et de groupes de discussion avec des citoyens pour analyser les applications possibles du secteur minier en matière de développement des ressources génétiques. Finalement, il formule des recommandations pour un mécanisme de partage approprié des bénéfices, basé sur les concepts fondamentaux de gouvernance et de justice distributive.

Mots-clés : partage des bénéfices ; développement des ressources ; recherche génétique ; populations fondatrices ; dynamique centre-périphérie

1.0 Introduction

In the late 1990s, a group of researchers from Baylor College of Medicine, Texas, visited Grand Falls-Windsor, a rural community in the central region of the island of Newfoundland, where they drew blood samples, collected family and medical histories, and then vanished. They were subsequently dubbed the "Texas Vampires." In the wake of their visit, families were left wondering whether they carried the gene related to arrhythmogenic right ventricular cardiomyopathy (ARVC), a condition that at the time was undetectable, untreatable, and, if afflicted, almost certainly meant death. Suspecting their relatives had the gene but unable to confirm if they had it themselves, created a high anxiety waiting game for many. Further, the lack of information (or benefits) for families meant that patients were unable to make informed decisions about their healthcare and their families' best interests.

This incident gave rise to a broad discussion in the province about medical ethics and how to ensure that the best interests of residents were considered when medical research took place in NL. This ultimately led to the establishment of the provincial Health Research Ethics Board (HREB), which currently oversees all health and genetics-related research in the province, as well as the commission of a policy document (Pullman & Latus, 2003) addressing the policy implications of commercial HGR in NL. Despite these efforts, most recommendations from the 2003 report remain unimplemented. Beyond the financial costs of such research, there are also social and emotional costs, such as stress, anxiety, and frustration stemming from a lack of information. The story of the Texas Vampires further prompts questions about who benefits from medical and genetic research, and how those benefits should be shared with the communities whose data made the research possible. It should be noted, however, that benefits do not necessarily mean financial compensation for participation. In the case of the Texas Vampires, simply having received results or updates from the research would have been a valuable benefit to patients.

Questions of benefit-sharing have long been asked in relation to natural resources. NL's history of resource development in sectors like mining and offshore oil provides an opportunity to apply lessons from these industries to the governance and practice of HGR. As human genetics advances, offering insights into health and disease, it is essential to harness this knowledge for local benefit. This manuscript explores how successful strategies from mining can ensure shared benefits from genetic research in NL. By examining equitable benefit distribution in mining, I aim to enhance healthcare outcomes, particularly in rural regions historically affected by genetic conditions.

This manuscript rests on two assumptions: (1) the genetic material and data of Newfoundlanders and Labradorians is a resource that can be leveraged for research purposes, and (2) lessons from other resource sectors can apply to managing the NL Genome. The first assumption is supported by decades of medical and genetic research in NL. The second forms the basis of examining how benefits from NL's genetic resources can be shared with the province.

2.0 Literature Review and Background

The literature review and background for this paper are subdivided thematically into two realms: a background and history of genetic research and resource management in NL, and some necessary context pertaining to benefit-sharing and ensuring that in practice it is just and equitable. The literature surrounding benefit-sharing is substantial, given that the notion spans several industries and is applied in a myriad

of ways. To best incorporate benefit-sharing in the scope of this paper, I have selected key concepts from that literature (social license to operate, impact benefit agreements, regulation as a broad mechanism, and governance).

2.1 The Newfoundland Genome, Its Value, and Implications

To understand the potential of developing and sharing benefits from NL's genetic architecture, it is essential to recognize the unique value of NL's population for genetic research. As a founder population, NL demonstrates the founder effect—a reduction in genetic diversity when a new population is established by a small group from a larger population (Rahman et al., 2003). Most NL European ancestry traces back to Ireland and England, resulting in a higher likelihood of common genetic profiles among individuals, facilitating the identification of specific alleles associated with disorders. Close-knit family structures, well-documented genealogical and medical records, and a general willingness of residents to participate in scientific research further enhance NL's suitability for genetic studies (Pullman & Latus, 2003). Consequently, NL has a higher prevalence of certain diseases, such as familial colorectal cancer, compared with the national average (Green et al., 2007). NL's genetic research potential has long attracted interest, notably during the Texas Vampires scandal in the late 1990s as outlined above (see also Skeard, 2024).

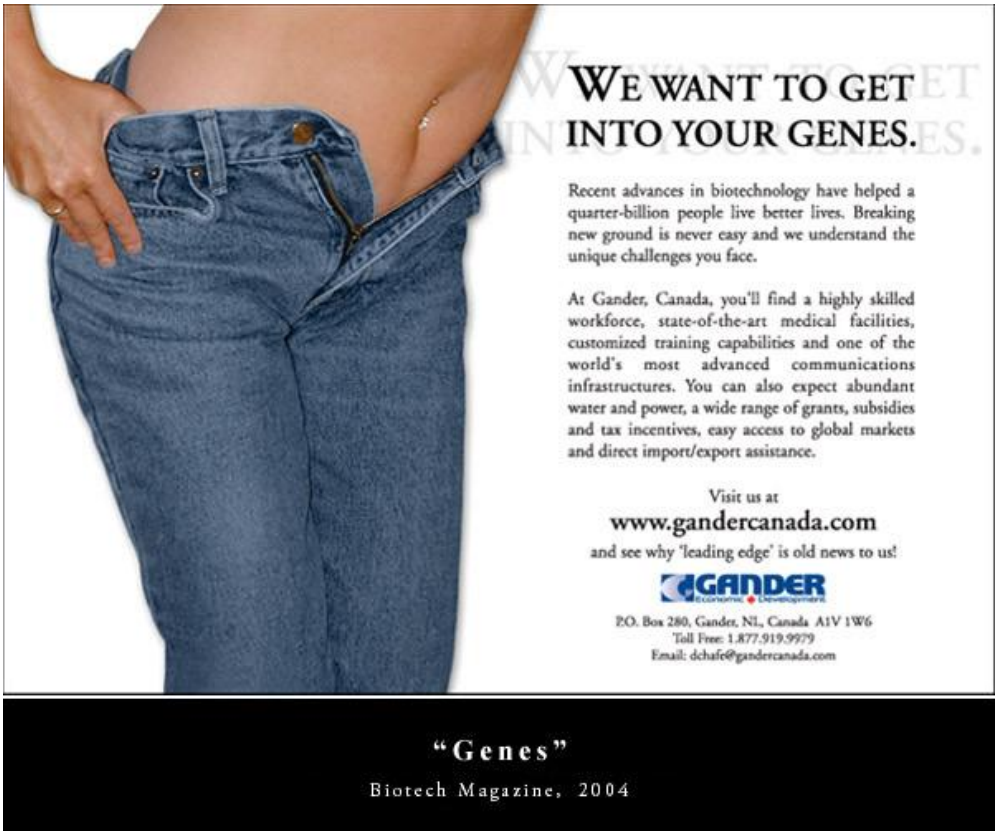
2.2 Rural and Regional Nuances of the NL Genome

There is a geographic component to the way in which genetic illnesses and burdens are distributed across NL. This is in large part due to the ways in which the island was inhabited throughout the 1700s and 1800s (Gilbert et al., 2023). Early European colonial settlers primarily established outport communities oriented around the fishery, leading to regions that today remain far less densely populated than the Avalon Peninsula, which contains NL's capital and only Census Metropolitan Area (Statistics Canada, 2019). Because of this, several regions and communities (mostly rural and remote) have their own particular genetic ailments that afflict residents in disproportionate numbers.

There are some key examples of the regional and geographic nuance of the founder effect in NL. ARVC, the condition at the heart of the Texas Vampires scandal, is a genetic condition affecting the heart muscle, primarily the right ventricle. In ARVC, healthy myocardial tissue is progressively replaced by fibrous and fatty tissue, leading to disruptions in the heart's electrical activity and increasing the risk of arrhythmias and sudden cardiac death (Corrado, 2017). For many with the condition, the first symptom is often sudden cardiac death, making diagnosis and pre-emptive treatment crucial for survival. In another instance, a family on the northern peninsula of NL suffers from Congenital Indifference to Pain (CIP), a rare mutation in which those afflicted cannot feel pain (Abraham, 2007). Allderdice Syndrome primarily afflicts residents from a rural community on the west coast of the province and is characterized by congenital abnormalities, low birth weight, hand and facial abnormalities and psychomotor dysfunction (Allderdice et al., 1975). This specific condition, within the parameters of health service provision on the island of Newfoundland, not only disproportionately affects residents from a single region, but because it presents itself in newborns and given that the province's only children's hospital is nearly an eight-hour drive from the town, those affected bear additional burdens of trying to access specialist care.

While the existence of genetic disorders in rural areas is a burden for local communities and the provincial government, it should also be noted that within the past two decades, some areas have made attempts to harness the NL Genome in their economic development efforts with moderate success. For example, the Town of Gander in central NL, ran a rather provocative ad campaign in the early 2000s inviting biotechnology researchers to utilize data from local residents (see Figure 1). This "geno-hype"—the assumption that genetic research will inevitably translate into commercial gains—reflects the eagerness with which some communities sought to leverage perceived biotechnology and research potential. In the context of rural Newfoundland, in an area that is largely socially conservative, such an attempt was particularly charged. It is worth noting that this campaign was largely unsuccessful, with no notable research projects undertaken in the area as a result. Today, the town's economy remains largely centred around the aviation industry (together with its role as a regional service centre), although recent gold exploration projects in the area have shown considerable promise for future mineral development (Town of Gander, n.d.).

Figure 1: Genetic Research Ad Campaign from the Town of Gander, 2004.



Source: Biotech Magazine (2004).

The other, more successful example is an initiative from the Town of Grand Falls-Windsor, the same community at the heart of the Texas Vampires scandal. The Excite Corporation was established by the town in 1999 to increase investment and facilitate research and industry partnerships in the healthcare and technology sectors in the region (Excite Corporation, 2023). Notably, genomics is listed as an initiative and the Genomics Based R&D Centre for Health plays a key role in patient

recruitment, assessment, and data collection across multiple projects. Leveraging genetic conditions in the region, two studies on the genetics of hearing loss and the genetics of mental health have been undertaken and utilized local data (Excite Corporation, 2023).

2.3 Resource management in NL

NL's history with natural resources reflects a cycle of mismanagement and economic instability, notably seen in the aftermath of the cod moratorium in the early 1990s. Scholars like Marland (2010) underscore a desire for increased provincial control over resources, driven by economic nationalism and a quest for self-determination. This sentiment arises from a need to shield against enduring economic hardships caused by external mismanagement or exploitation, advocating for sustainable resource governance strategies to secure long-term prosperity. Management decisions pertaining to economic and development activities often take place in the urban areas of the province, while peripheral regions often experience economic challenges and dependencies.

Natural resource management in NL is intricately tied to the province's historical, economic, and social dynamics, with many regional economies driven by the extraction and utilization of various resources. Scholars like Bavington (2010) emphasize the need for sustainable resource management strategies that consider the well-being of both core and peripheral communities, addressing historical imbalances inherent in natural resource management. The principle of adjacency, which reinforces the notion that individuals should have the first right to benefit from resources near their communities, aligns closely with the efforts of communities to claim rights to resources like shrimp in NL (Foley et al., 2015). Traditional resource sectors offer valuable insights into resource development and benefit distribution, advocating for local communities to receive the greatest share of benefits.

2.4 Regulating and Managing Genetic Resources in NL

Oversight of genetic and health research in NL is centralized under HREB, which operates under the authority of the Health Research Ethics Authority (HREA) and was formally established in 2011 (Badaiki et al., 2022). This governance model exists within a broader Canadian context in which health research oversight is decentralized and informed by multiple regulatory and ethical frameworks, including the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) and Health Canada's recognition of the International Council for Harmonisation–Good Clinical Practice (ICH-GCP) standard (Alas et al., 2017).

How to best regulate, access, and identify ownership of human genetic material is a complicated topic. Bodily autonomy is widely recognized as a foundational individual right (Nielsen et al., 2019), yet questions of ownership become considerably more complicated when attention shifts from the body itself to information derived from it. Classical theories of property link ownership to the application of individual labour to resources that are unowned or held in common (Locke, 2003 but originally published 1689; Nielsen et al., 2019). This framework has long underpinned market-based systems in which individuals may claim, transfer, or sell the products of their labour. Genetic data, however, challenges the assumptions embedded in these traditional property models. Unlike many other forms of personal data, genetic information is inherently relational; it conveys information not only about the individual contributor, but also about biologically

related family members and, in some cases, broader communities. Arguments that frame genetic samples as the exclusive property of the individual, such as proposals advocating direct financial compensation for biological materials, risk obscuring this shared dimension of DNA (Bear, 2004; Spinello, 2004).

The concept of "community" is used broadly in both the academic literature and everyday discourse, with meanings that vary by context. In this work, and particularly in relation to benefit-sharing, community generally refers to the broader population of NL. This framing reflects an inclusive understanding of community that extends beyond narrowly defined groups based on genetic relatedness or research participation and is discussed throughout the paper in relation to the broader social and institutional context of genetic research in NL.

Because genetic information extends beyond the individual (proband) and provides information about others, many argue that genetic information is unique and thus necessitates a unique set of rules to govern its use. This concept, "genetic exceptionalism," argues that genetic data is too different from other forms of information to be able to rely on the mechanisms that govern them (Pugh, 2022). Similarly, there have been international efforts to categorize and provide guidance on benefit-sharing from non-human resources (e.g., Nagoya Protocol, Convention on Biological Diversity). However, the human dimension (including the concept of community) complicates questions surrounding ownership when it comes to genetic data. While international bodies such as the Human Genome Organization (HUGO) have made broad statements about benefit-sharing and genetic data, there is no formal requirement for acknowledging and benefiting populations that contribute to genetic research.

2.5 Social License to Operate

One resource-related concept applicable to genetic resource development in NL is the social license to operate (SLO). Originating from traditional extractive industries, SLO denotes mutually beneficial terms for resource development, including a company's efforts to collaborate with local communities (Gehman et al., 2017). Emerging in the 1980s-1990s, SLO aimed to enhance legitimacy and transparency in mining. Ideally, companies engaging in mineral resource exploitation would foster trust and community buy-in through resident engagement to gain SLO (Gehman et al., 2017). SLO is an ongoing process of fostering sustainable, trust-based relationships between industry, stakeholders, and communities, which aims to prioritize fairness, governance, and trust (Moffat et al., 2016). It incorporates governance mechanisms for accountability and transparency, involving various stakeholders, especially local communities, in resource development and its benefits. Stakeholders' diverse needs and values must shape discussions on resource governance. This is particularly important in medical and genetic research due to the communal nature of genetic resources. Engaging with the community, providing genetic resources offers insights into communal values, aligning with community engagement principles (CDC, 1997). Community engagement mirrors aspects of SLO, as the latter often involves community input. SLO serves as a broader framework where community engagement is a tool for attaining and sustaining a social license.

2.6 Impact Benefit Agreements/Industrial Benefit Agreements (IBAs)

The term *IBAs* refers to Impact Benefit Agreements, Industrial Benefit Agreements, or Community Benefit Agreements, which, in the Canadian context, emerged post-amendment of the Constitution Act in 1982 to recognize Indigenous rights, significantly affecting resource development, primarily mining (Panagos & Grant, 2013). These bilateral agreements ensure that Indigenous communities benefit from resource development on their land, typically including provisions for profit sharing, employment opportunities, environmental monitoring, and socio-cultural guidelines (Panagos & Grant, 2013; Mille & Sweeney, 2013). While IBAs have been criticized for potentially curbing legal avenues for Indigenous groups, they have increasingly become vital tools in ensuring equitable benefit-sharing and sustainable development in both Indigenous and non-Indigenous contexts, fostering community resilience and self-determination while addressing socio-economic and environmental impacts (Cascadden et al., 2021; Söderholm & Svahn, 2015; Gunton & Markey, 2021; Browne & Robertson, 2009). Additionally, outside of academic articles, some guides to negotiating IBAs can prove useful in the context of genetic resource development. Gibson & O'Faircheallaigh (2015) emphasize that for communities, the process of negotiating IBAs with industry stakeholders is perhaps equally as important as the outcome (i.e., benefits), in large part because the process of identifying clear values can reinforce the community's ability to plan collectively.

2.7 Regulation as a Mechanism

Resource development in NL involves obtaining permits, coordinating with government divisions, and conducting environmental impact assessments (EIAs) to inform decision-making and ensure mitigation of significant impacts (Government of NL, 2019; Government of Canada, 2020). These assessments also consider effects on local residents and provide opportunities for public engagement, which is crucial for guiding the development of projects like the NL Genome to benefit the province's residents effectively.

NL has formal regulatory structures for genetic and health research overseen by HREB, complying with the Tri-Council Policy Statement (TCPS) for human research (HREA, 2019). While TCPS2 offers minimal guidance on benefit-sharing, scholars like Pullman & Latus (2003) emphasize the need for separate discussions to avoid conflicts of interest. Rahman et al. (2003) and Moulton (2000) highlight NL's suitability for genetic research, echoing Pullman & Latus's (2003) call for local regulatory oversight given the province's unique genetic architecture.

2.8 Governance

Governance refers to the decision-making process involving multiple stakeholders at local, provincial, national, and international levels, aiming to steer a group or society (Rhodes, 1997). It is generally inclusive and bottom-up, contrasting with the top-down nature of government while intentionally incorporating representation from various actors (Jentoft & Chuenpagdee, 2009). Governance structures often mix top-down and bottom-up elements, emphasizing stakeholder participation. Stoker (1998) views governance as network-based and self-governing, though some hierarchy usually persists (Whitehead, 2003; Diefenbach & Sillince, 2011). Modern resource governance is multi-level, involving private sector roles in social responsibility. Collaborative governance, which engages diverse stakeholders, is

crucial, relying on face-to-face dialogue, trust building, and shared understanding (Ansell & Gash, 2008; Emerson et al., 2012).

Collaborative governance in health care is widely regarded as good practice for supporting integrated care that responds to the needs of patients and stakeholders, and as a stabilizing framework in the context of evolving policy environments (Frankowski, 2019; Gordon et al., 2020). Given that human genetic research inherently involves groups rather than isolated individuals, the presence of effective governance structures is essential to the development of benefit-sharing models that adequately address concerns such as privacy, consent, and ownership, and that support equitable distribution of benefits. As Jones et al. (2014) observe, research involving groups has long been recognized as presenting distinct ethical and governance challenges.

Community engagement has been proposed as a means of bridging the divide between researchers and participants, fostering trust and shared understanding throughout the research process. In the context of genetic research, community engagement is particularly important, as genetic information is shared within families and, in some cases, broader communities rather than belonging solely to individuals. In this sense, genetic resources can be understood as communal in nature. Consequently, there is a strong argument that communities should have a role in decisions regarding data use and, where benefit-sharing is involved, in determining how benefits are returned. However, the literature continues to raise concerns about how community should be defined, a question that has direct implications for engagement strategies and governance approaches (Clinical and Translational Science Awards Consortium [CTSAC], 2011). Understanding the nuances of what constitutes a community, including shared values and concerns, is therefore a critical component of effective and ethical governance.

Both natural resource and healthcare governance in Canada are multi-level and multi-faceted, involving local communities, Indigenous governments, industry, and federal and provincial policymakers (Lockwood et al., 2010; Bradshaw et al., 2020; CTSAC, 2011; Institute for Public Administration of Canada [IPAC], 2013). In NL, healthcare governance is primarily a provincial responsibility, integrating federal funding and determining budget allocations and health authority structures. Genetic data necessitates robust governance and community engagement because it is inherently communal, providing information about donors, their families and communities. This ensures equitable benefit-sharing and addresses concerns like privacy, consent, and ownership (Jones et al., 2014).

2.9 Distributive Justice

Distributive justice concerns the fair allocation of advantages and disadvantages within a society, profoundly shaping people's lives (Lamont & Favor, 2017; Deutsch, 1975). It requires determining what constitutes the 'goods' and 'burdens' and how to distribute them fairly. In industries such as mining, resource development benefits like job creation and community investment are discussed with stakeholders to ensure adequate compensation (Heffron, 2020). In HGR, achieving distributive justice is complex due to historical disparities in benefit distribution (Pullman & Latus, 2003). Daniels (1981; 2001) argues that healthcare as a fundamental right, should be viewed through the lens of distributive justice. In Canada, basic health services are provided under the Canada Health Act, with healthcare costs shared collectively through government-regulated means This framework opposes direct payments to research participants and promotes mechanisms that serve the greater public good.

2.10 Benefit-Sharing

Benefit-sharing is where governance and distributive justice converge, involving the equitable distribution of benefits from resource development to the broader population, particularly those in regions where resources are extracted (Gehman et al., 2017). This concept spans various industries and is rooted in the idea that genetic resources belong to humankind and their benefits and burdens should be universally shared (HUGO Ethics Committee, 2000; Sheremeta & Knoppers, 2003). In NL, benefit-sharing is pivotal in natural resource sectors like mining and oil and gas, leveraging mechanisms to distribute economic and other benefits to the wider community.

The concepts outlined above—particularly the social license to operate, impact benefit agreements, governance, distributive justice, and capacity building—also informed the empirical design of this study. These frameworks shaped the development of the interview and focus group guides, which were structured to elicit participants' perspectives on how benefits from genetic research should be defined, governed, and distributed, and who should be involved in decision-making processes. Rather than testing a single model of benefit-sharing, the study used these concepts as sensitizing lenses to explore whether, how, and to what extent participants drew on analogies from natural resource development when discussing genetic research in Newfoundland and Labrador.

3.0 Methods

3.1 Key Informant Interviews

Key informant interviews involve interviewing individuals with a high level of expertise or experience to gain insight into a topic (Bernard, 2011). In this research, key informant interviews were utilized to provide insight into the current capacity for building and maintaining a benefit-sharing model in genetics, best practices for doing so, as well as past experiences in benefit-sharing in the NL context. The interviews were semi-structured and, depending on the interviewee's background, focused on either the policy and legislative aspects of benefit-sharing or how to best proceed in establishing a framework for equitable benefit-sharing in the province.

Snowball sampling was employed to identify participants, and policy makers, legislative officials, and researchers familiar with the subject were interviewed. Given the relatively limited discussion of the research topic within provincial policy circles (e.g., government representatives), most participants with relevant expertise were identified using the Government of Newfoundland and Labrador directory. Snowball sampling was then employed for policy and legislative participants, as well as researchers, given their familiarity with other experts in the field. Snowball sampling was used as a secondary recruitment strategy to help mitigate potential sampling bias that can arise when participants recommend others with similar perspectives or beliefs (Kirchherr & Charles, 2018). In cases where chain referral was utilized, recommendations were systematically tracked, and attention was paid to who suggested whom, acknowledging that personal or professional relationships may influence referrals. This approach—monitoring the recruitment chain, as described by Kirchherr and Charles (2018)—helps reduce the risk of overrepresentation of closely connected individuals who may hold similar viewpoints. While acknowledging potential sampling bias, efforts were made to diversify sources by cross-referencing with the government directory. Eleven interviews were conducted between January and November 2023, encompassing

stakeholders from genetic research, government, privacy, and resource development. Despite challenges in securing interviews, insights proved invaluable, achieving theoretical saturation early on. Although only 11 interviews were completed due to participant reluctance, data collection was augmented by focus groups targeting citizens, ensuring comprehensive data coverage.

Table 1: Summary of Interview Participants

Subject category	Number of participants/interviews
Policy makers	2
Academic	3
Private industry	2
Subject matter experts (IBAs, Privacy)	2
Economic/regional development	2

3.2 Focus Groups

Focus groups provide an interactive setting for exploring diverse perspectives. Their strength lies in generating nuanced insights through group dynamics, fostering open discussion and elaboration on participants' views (Morgan, 1996). However, focus groups can be prone to groupthink and may struggle to recruit participants with contrasting viewpoints. To address these limitations, the facilitator encouraged active participation from all members, and used varied recruitment strategies, including online sessions to increase accessibility.

Three focus groups were conducted in July 2023 via Microsoft Teams, enabling province-wide participation. These sessions involved 12 participants in total, recruited through social media, local media, and word of mouth, with half residing in rural/remote areas and half in urban centers. Focus groups provided insights from citizens not captured in key informant interviews. Understanding residents' views on genetic data and its potential use for the province was essential. Questions gauged participants' familiarity with genetic research and natural resources, explored potential benefits from research, and identified regional nuances in distributing those benefits.

3.3 Analysis

Both interviews and focus groups were analyzed using thematic analysis, a method for identifying, analyzing, and reporting patterns (themes) within data (Braun & Clarke, 2006). This systematic approach can be inductive or deductive. Inductive thematic analysis involves letting themes emerge naturally from the data, with researchers immersing themselves in the content to generate themes that capture its essence (Braun & Clarke, 2006). Conversely, deductive thematic analysis applies pre-established codes or theories from existing literature to the data, offering a structured framework for interpretation (Fereday & Muir-Cochrane, 2006). While inductive analysis fosters discovery and exploration, deductive analysis ensures alignment with existing theories, providing a structured interpretation (Braun & Clarke, 2012). Data from focus groups were analyzed using thematic analysis to identify recurring themes and patterns, enabling meaningful conclusions from participants' perspectives (Guest et al., 2012).

This project employed both inductive and deductive thematic analysis. Some themes were anticipated based on literature reviews and guided the study's scope and questions, while it was also necessary to allow new themes to emerge from the data. This hybrid approach provided a comprehensive understanding, allowing emergent themes to be identified while considering established theories or concepts. As noted by Fereday & Muir-Cochrane (2006), a hybrid approach requires systematic rigor in identifying themes and determining which data components fall within these themes. The interdisciplinary nature of this project necessitated that broad themes from the literature guide data collection and analysis while confirming existing themes and deducing new ones from the data.

3.4 Theoretical Saturation

Theoretical saturation in qualitative research marks the point where no new information or data emerges, providing a comprehensive understanding of the phenomenon under study (Guest et al., 2006). At this stage, additional data collection fails to yield novel insights or add new dimensions to the emerging themes (Saunders et al., 2018). Researchers achieve a sufficient breadth and depth of information to ensure the identified themes or categories are exhaustive and adequately represent diverse perspectives (Francis et al., 2010). Further data collection or analysis at this point is unlikely to significantly alter or enhance the understanding of the phenomenon (Saunders et al., 2018). In this project, themes and concepts repeated as early as the second interview and consistently appeared in subsequent interviews and focus groups. Notably, the idea of a centralized genetics institute/infrastructure was raised consistently by interview participants from various backgrounds, such as genetics researchers, IBA experts, and economic experts, highlighting its importance across different fields.

4.0 Findings and Discussion

The central tenet of this manuscript focuses on the benefit-sharing aspect of resource development and genetic research in NL. All participants strongly supported benefit-sharing for genetic research, believing that the province's citizens should be the primary beneficiaries. There was significant discussion about considering the NL Genome similarly to traditional natural resources. While genetic data is not a traditional resource, principles of resource development can provide valuable insights into managing it and ensuring equitable benefit distribution. This section outlines several themes and concepts consistently discussed by participants, highlighting how resource development principles can guide genetic research benefit-sharing in NL.

The themes presented below are interpreted in dialogue with the literature on benefit-sharing in natural resource development and governance, as well as scholarship on the ethical and social dimensions of human genetic research. While participants did not explicitly reference academic frameworks, their language and concerns closely aligned with established concepts such as social license to operate, collaborative governance, distributive justice, and capacity building. In several cases, participant perspectives reinforced existing findings from the natural resources literature; in others, they extended these ideas into the distinct context of genetic research, where the communal and relational nature of genetic data introduces additional ethical and governance considerations.

4.1 Conceptualizations of the NL Genome as Paralleled with Natural Resources

Parallels to other traditional resource sectors and concepts emerged through several interviews and focus groups. The language and ideas that were discussed by participants integrated several concepts from the more traditional natural resource literature. The language of natural resource development resonates particularly well with residents of NL given the province's historical economic reliance on developing several key resources. As one focus group participant articulated, "Natural resources is one of the things politicians talk about all the time. It's how we measure where we are economically."

Current resource development policy requires that the province evaluate the potential benefits from resource development and ensure that resource management decisions result in the provision of benefits for the province. When speaking with a mineral policy and development expert, it was noted that "We have a certain series of priorities that we're looking to manage on behalf of the province. One, of course, is prudent resource management and development so that the province realizes the benefit from its natural resources." Thus, the notion of benefit-sharing inherently underscores resource development efforts in NL. Many participants felt that the first step towards governing the province's genetic resources and leveraging them for benefits was ensuring that there was a thorough understanding of the NL Genome's market value and ability to be utilized by stakeholders. As one economic development expert put it,

> Someone needs to be aware of what is the market for the genome specificity of NL. And if that market is giant like oil in terms of potential economic benefit, then it's worth a lot more investment and effort getting the regulations straight… And then it's a provincial resource, just like maps of rocks (personal communication, March 30, 2023).

Many interview and focus group participants compared genetic resource development to traditional natural resources, noting the current application of this concept to wind energy in NL. Given the province's history of resource development without reaping significant economic benefits, participants expressed concerns about policymakers not fully understanding the potential value of genetic research and resources before attempting to develop or regulate them. As an economic development expert pointed out:

> There's a lot of talk now on the wind power on hydrogen. And there are many examples in history of in Newfoundland and elsewhere of resource promise and resource disappointment. I think it's like any other potential economic opportunity, it must be subject to rigorous critique, evidence gathering, analysis. And then put through the policy lens of opportunity and priorities (personal communication, March 30, 2023).

While the NL Genome is compared to traditional natural resources, it is unique and unlike any other type of data or material. This concept, known as *genetic exceptionalism*, underscores the unique ethical, social, and legal considerations associated with genetic research. Genetic exceptionalism posits that genetic information requires special treatment distinct from other forms of medical or personal data due to its unique characteristics. Genetic data reveals not only an individual's disease predispositions but also familial, ancestral, and potentially stigmatizing information. Scholars emphasize the need for stringent safeguards to protect privacy, prevent discrimination, and ensure informed consent in genetic research. This concept profoundly impacts policy development in genetic studies, challenging researchers and policymakers to balance scientific knowledge with individual rights (McGuire & Burke, 2008; Juengst, 1998). Thus, utilizing lessons from the mining sector to adapt and apply to developing genetic resources will require additional consideration.

4.2 Strong Support for Benefit-Sharing

Since healthcare expenses are primarily covered by tax contributions, it has been argued that benefits should be distributed equitably among the populace rather than favoring a select few. This notion contrasts with suggestions for direct benefit and payment to research participants, such as the calculation put forward by John Bear (2004). As discussed in section 4.9 targeting benefits to local communities both recognizes the contributions that make genetic research possible, while also treating that genetic data is inherently communal. This notion was reiterated throughout the data collection process for this project. Participants agreed that benefit-sharing for genetic research should be a priority for the NL government, recognizing that genetic information belongs communally to the residents of the province, and its use should benefit NL. NL Information and Privacy Commissioner:

> We ourselves are currently suffering from the burden of this incredibly valuable resource… It's almost like if we found out that we were sitting on an immense pool of asbestos which everybody really wanted, but it was poisoning us at the same time. And so I think therefore there's a logical connection there to flowing the benefits back into that, which will save us (personal communication, March 8, 2023).

It was clear that participants felt strongly about the need for citizens to be the primary beneficiaries of genetic research in the province. However, for a benefit-sharing framework to be operationalized, there are some key components that participants felt were necessary, including: a collaborative governance structure, thinking about benefits innovatively, building capacity, and establishing a centralized genetics institute.

4.3 The Need for Collaborative Governance and Meaningful Engagement

Ownership of genetic material and data remains a contentious issue. Unlike other medical history or body parts, genetic data has a familial component, providing information not only about the donor but also their families and sometimes communities. Therefore, a collaborative approach to managing genetic resources is

essential. Governance of genetic data and material in NL must be distinguished from government control, as many individuals mistrust the provincial government's ability to manage this potential resource on its own.

Collaborative governance that emphasizes partnerships, shared responsibility, and inclusivity, suits complex challenges like developing the NL Genome and genetic resources. Participants highlighted the need for a multi-stakeholder approach, involving various stakeholders to ensure benefits are appropriately shared. Several emphasized that governing genetic data requires input from citizens and community representatives, reflecting the participatory nature of collaborative governance over traditional top-down methods. As one Geneticist/Genetic Researcher put it:

> I think one of the things that we're missing is a steering committee that would have people from the innovation group of the provincial government, the Department of Health and Community Services, the university, NLCHI, all those players around the table to formulate a central vision. And then come up with a strategy of how we achieve that vision. And I think that's been lacking a lot (personal communication, January 31, 2023).

A focus group participant pointed out, "Community leaders are always important, especially when they're well-respected… what's the word, transparency. The whole process needs to be transparent."

The need of diverse insights and stakeholders was also echoed by commercial genetics representatives. As one participant noted:

> The biosciences sector, including researchers and sponsors, can seek to work with the provincial government and other institutional stakeholders, like NL Health Services and MUN, to identify opportunities and implement coordinated strategies to sustainably increase the amount and impact of genetic research in the province (personal communication, November 3, 2023).

Further emphasizing the need for a collaborative approach to governance, many participants viewed genetic data as incredibly intimate information about a person's health and the health of their family members. It was also discussed that in the event of a data breach, one's genetic data cannot be replaced or changed (like a driver's license number or SIN card), and because of this it must be handled with the utmost care.

4.4 Meaningful Engagement of Citizens (SLO)

The concept of the social license to operate is an integral one in the natural resource development sphere. The SLO indicates community buy-in to support and allow resource development projects to occur near communities. To obtain SLO for genetic resources it is essential to meaningfully engage citizens.

There is an important differentiation to be made between the engagement of citizens and the *meaningful* engagement of citizens. What became clear across data collection was that not all efforts to consult with residents are understood as

meaningful efforts. Many recognized that prior attempts at community engagement by the provincial government felt shallow and were only undertaken as part of an obligatory consultation process. Several participants criticized the provincial government's public consultation process, which relies on a government website and virtual advertisements. As one focus group participant noted, "To engage the public there has to be a group in Newfoundland, not just 20 people, but hundreds. We need to ask them how we can meaningfully engage the public because we're not asked that any longer" (personal communication, July 7, 2023).

Obtaining the social license is a necessary component of successfully governing genetic resources in NL. Given that genetic data is unique (as discussed above), there is a necessary recognition to work with citizens to understand, develop, and manage this as a potential resource. The SLO is central to collaborative governance and as the NL Information and Privacy Commissioner points out:

> In my view, social license is not something that exists and you go out and find it. It's also not something that you can build from the top down, but socialize and change and evolve over time and interaction. And so it can be built, but not unilaterally. It has to be built collectively from the bottom up and the top down at the same time. And, and this is something that I think should not be taken for granted, but it should be assessed. And, I think that the province needs to go on a journey of it (personal communication, March 8, 2023).

Participants' emphasis on trust, transparency, and ongoing engagement closely mirrors the natural resource literature on social license to operate, which frames SLO as a dynamic, relational process rather than a one-time approval (Dare et al., 2014; Moffat et al., 2015; Gehman et al., 2017). However, applying SLO to genetic research introduces additional complexity. Unlike mining or energy projects, genetic data cannot be geographically bounded or temporally contained, reinforcing participants' concerns that social license for genetic research must be continuously renegotiated and embedded within long-term governance structures rather than project-specific consultations.

4.5 Mistrust/Weariness of Government Control

One key aspect of collaborative governance is that it is not driven by government. As opposed to top-down government regulation and oversight, the central tenet of governance is that it is built from the ground up with multiple stakeholders. This is especially important when you consider the fact that many residents of NL express concern with government's management of the province's natural resources. Resource management is not a new concept to Newfoundlanders and Labradorians. As outlined earlier in this paper, NL has a prolific history with resource management (and mismanagement) alike. Because of this, it is not surprising that many participants advocate for input from several stakeholders, including citizens. As one focus group participant remarked, "Newfoundland has so often gotten into developing resources and messed things up. We've gotten things wrong and allowed ourselves to be taken for a ride by a lot of these big companies" (personal communication, July 7, 2023).

The distinction between governance and government was also discussed by an economic development expert when the topic of resource development came up:

> The vicious circle, the linkages, the benefits being captured by companies and workers and governments outside the community, the region, the province, the country… you become resource dependent. And it's why there are many jurisdictions on earth that are resource rich, but desperately poor, and there are many jurisdictions that are resource poor and quite rich. And the bottom line on that final point… is governance. Good governance, not just government (personal communication, March 30, 2023).

Resource development and management, inclusive of stakeholder and resident engagement, requires that multiple voices are present. The importance of collaborative governance is underscored by the recognition that government alone is not sufficient to manage a resource as complex as that of genetic data. Any effort to manage genetic resources in NL and establish a framework for benefit-sharing requires intrinsic collaboration.

4.6 Innovation and Benefits

The idea of thinking innovatively about what constitutes a *benefit* consistently emerged. It was emphasized that benefits should not only be defined in economic terms. For instance, an expert in IBAs recounted negotiating the development of an aluminum smelter in Iceland. Instead of building worker accommodations outside the community, they constructed the camp within it. Once vacated, the camp, was converted into a community center for residents. This approach exemplified long-term, non-economic benefits. As the IBA expert recounted defining benefits, "… involves imaginative in-depth consultation, thinking about how else the project could benefit the local community, the region, or indeed the nation." (personal communication, March 9, 2023).

Innovative thinking is essential for determining benefits from HGR in NL, as this work often doesn't yield direct economic profits for commercial entities. Genetic research typically takes 15–20 years to develop potential marketable products, making royalties or other economic benefits hard to anticipate. As one genetic researcher observed:

> It's hard to quantify the economic benefits. It's easier to qualify it by saying that the whole premise of us doing this type of research is to hopefully identify things that can improve the delivery of healthcare through genetics or genomics for our population (personal communication, January 26, 2023).

4.7 Capacity Building

Benefit-sharing in natural resource sectors, including mining, has shifted over the past 15–20 years towards investing in capacity building with recognition that this results in longer-term benefits. Investments that were once made in infrastructure

(such as community centers) are now more often directed toward developing expertise and resources. Capacity building is crucial for fostering sustainable development, effective resource management, and equitable benefit-sharing. The dynamic nature of natural resource industries requires stakeholders, including governments, communities, and industry players, to possess the necessary skills, knowledge, and organizational capacities. Capacity building initiatives empower individuals and institutions to navigate challenges associated with resource extraction, environmental conservation, and community engagement through improved governance and decision-making processes.

In HGR in NL, capacity building involves training highly qualified personnel, establishing roles for genetic counselors and researchers, and securing funding for external grants. Several participants emphasized that developing local expertise is essential to address genetic-related ailments and sustain research in the province. As one IBA expert noted, "let's not train people for jobs, let's train them for careers" (personal communication, March 9, 2023).When considering capacity building as an investment towards genetic research one economist bluntly stated, "you can't go wrong by increasing the ability to educate and do research in areas that are important to your population" (personal communication, March 7, 2023). When asked about how the province could go about building capacity in HGR, most participants from interviews and focus groups alike had the same idea: a centralized genetics institute.

4.8 Bringing it all Together—A Centralized Genetics Institute

The idea of a centralized genetics research institute emerged in the first key informant interview and was reiterated in subsequent interviews and focus groups. Such an institute would ensure researchers have consistent access to equipment and personnel, preventing funding gaps from disrupting their research. As a genetic researcher pointed out, "even if you are successful there's always peaks and drops in terms of funding" (personal communication, January 31, 2023).

As discussed earlier in this paper, direct benefits such as drug development from genetic research are decades away from sample collection and lab work. To operationalize benefits from this research the focus should be on building capacity. As one geneticist/genetic researcher stated:

> I'd like to see a concerted understanding of the power of genetics in Newfoundland and Labrador, such that we create an Institute of Genetics Research… based in Newfoundland and Labrador… and can have satellites anywhere, have projects going anywhere. I would like to see that as benefit-sharing for genetics research (personal communication, January 26, 2023).

It was also recognized that an institute for genetics could take many shapes, whether in a building of its own, or have its objectives realized through governance mechanisms. One suggestion came from another genetic researcher who remarked "Whether it's a formalized institution or done informally through steering committees… It's just a matter of who is leading it, and how much drive they have to move it forward" (personal communication, January 31, 2023).

There would be several benefits of establishing a centralized genetics institute, namely: a formal avenue for training and building expertise and capacity; the ability

to bring together researchers with clinical geneticists who can work with patients directly; and the possibility of establishing a biobank and data repository that could be accessed by external researchers. As one researcher pointed out, the NL government does not have any policy that requires commercial genetics companies to provide funding to the healthcare system, should their research result in additional healthcare resources to take care of a patient.

I think they need to get it written in policies that if the companies are going to get involved, if they increase the burden on the healthcare system by identifying people with genetic diseases that now need preventative or curative treatments, that's a burden. It's an advantage for the population, but it's an immediate burden to the health system.

Thus, having funded positions for genetic counsellors through a centralized genetics institute could help manage additional investigations or treatments required through identifying patients who either have, or are at higher predisposition for, certain conditions. Additionally, a biobank could potentially stand to benefit both NL researchers as well as national and international researchers and companies. This could enable the provincial government to not only generate revenue from accessing the province's genetic architecture but provide a repository that can be used by researchers with potential health improvement outcomes.

4.9 Rurality and Core-Periphery Dynamics

It is well-known that natural resources are commonly located in rural and remote regions, while the management decisions pertaining to them are often delegated to the more urban centres. The equitable distribution of benefits was a topic that came up several times throughout data collection. Not only is it an ethical consideration, it is also a pragmatic one when considering the nature of human genetics. In NL for instance, there are certain regions of the province that experience higher instances of genetic conditions. Any attempt at benefit-sharing must take these nuances into account and as one genetic researcher pointed out:

> I think in terms of healthcare, it's important. Especially for our communities that are affected with different conditions, that they have the support given what's in their community. So Port de Grave would have, you know a clinic up there for cardiac conditions… at least one expert out there because, you know, they have huge families that have a high risk (personal communication, January 26, 2023).

Another option that was discussed was ensuring that there is a practitioner in an afflicted community that has knowledge and expertise in any prevalent genetic conditions, given that intervention could help save a patient's life.

A centralized genetics institute in NL, with satellite clinics throughout the province, would ensure access to genetic testing and healthcare for residents outside urban centers. This province-wide network would account for regional and community nuances, including specific conditions. This approach aligns with distributive justice, ensuring benefits are equitably and accessibly provided to all residents.

4.10 To Genetics and Beyond

The fact that benefit-sharing lessons from natural resource development can be applied to genetic research provides a strong argument for the applicability of key lessons learned within this project to other novel and upcoming developments. Of particular interest, wind development and hydrogen manufacturing are currently being discussed in NL. At the same time, the NL government has ongoing projects to undertake consultations with residents regarding various topics (e.g., critical minerals). There were several lessons and themes discussed throughout this research project that could also be considered within the scope of other industries.

1. The necessity of resident and citizen input:

   Engaging with citizens is crucial for resource development projects, but it must be meaningful, not just perfunctory. Current engagement methods relying solely on websites exclude older demographics and those without stable internet access. Effective citizen engagement requires a multi-pronged approach, integrating online and in-person consultations, advertised through mail-outs, online ads, and news station programming. The engagement timespan must reflect the topic's complexity, with adequate time and resources devoted to gathering and integrating resident input meaningfully. This ensures inclusivity and thorough representation of community perspectives in decision-making processes.

2. The value of building capacity:

   Investing in people, education, and resources was considered the ideal way to optimize benefits. Educating and training individuals for careers as opposed to singular jobs enables a highly skilled workforce that can further train HQPs. Additionally, building capacity requires a government to consider long-term investments and opportunities, such as the ability to earmark funding envelopes to be used as leveraged funds in national and international granting competitions. Increasing the overall return on investment is a long-term strategy that requires government support.

3. The importance of considering regional dynamics:

   NL is not the only area (province, territory, or otherwise) that is home to various regional dynamics within its borders. Any attempt to develop resources, implement new policies, or gauge economic potential requires a thorough understanding of the dynamics at play within and amongst communities and regions. This is particularly important in areas in which resource development (or other activity) has had historical contentions. Ensuring that regional nuances are incorporated into any type of policy or planning can make efforts more effective, efficient, and equitable.

5.0 Conclusion

The province of NL is no stranger to the development of natural resources. At the same time, the province also faces significant challenges regarding the provision of healthcare services and doing so within budgetary constraints. NL's founder population provides a unique opportunity for genetic research within the province while at the same time adding costs to an already strained healthcare system. However, we can look to other industries to learn key lessons about managing NL's genetic resource and offsetting some of its costs. In particular, the mining sector in

the province offers insights into ensuring that residents and the provincial coffers benefit from current and future studies. There are unique parallels to other natural resource sectors that have been echoed by participants throughout this project, namely the need to think innovatively when considering what constitutes a *benefit* to be leveraged from genetic research, as the sector is much different than more traditional resource-related industries. Several opportunities to expand the existing benefits from this resource while recognizing local and regional differences have been identified in this research and warrant future research and consideration.

References

Abraham, C. (2007). Surviving the perils of a life without pain. *The Globe and Mail*. https://www.theglobeandmail.com/life/surviving-the-perils-of-a-life-without-pain/article17993508/

Alas, J., Godlovitch, G., Mohan, C., Jelinski, S., & Khan, A. (2017). Regulatory framework for 139 conducting clinical research in Canada. *Canadian Journal of Neurological Sciences, 44*(5), 469–474. https://doi.org/10.1017/cjn.2016.458

Allderdice, P. W., Browne, N., Murphy, D. P. (1975). Chromosome 3 duplication q21 leads to qter deletion p25 leads to pter syndrome in children of carriers of a pericentric inversion inv(3) (p25q21). *American Journal of Human Genetics, 27*(6), 699–718. https://pmc.ncbi.nlm.nih.gov/articles/PMC1762887/

Ansell, C., & Gash, A. (2008). Collaborative governance in theory and practice. *Journal of Public Administration Research and Theory, 18*(4), 543–571. https://doi.org/10.1093/jopart/mum032

Badaiki, W., Pyper, E., Lester, K., Skeard, J., Penney, M., Shin, J., Fisher, B., Hew, H., Gulliver, S., Gulliver, W., & Rahman, P. (2022). Laying the foundation for real-world evidence studies of psoriatic disease in Newfoundland and Labrador. *International Journal of Population Data Science, 1*(7), https://doi.org/10.23889/ijpds.v7i1.1690

Bavington, D. (2010). From hunting fish to managing populations: Fisheries science and the destruction of Newfoundland cod fisheries. *Science as Culture, 19*(4), 509–528. https://doi.org/10.1080/09505431.2010.519615

Bear, J. (2004). "What's my DNA worth anyway?" A response to the commercialization of individuals' DNA information. *Perspectives in Biology and Medicine, 47*(2), 273–289. https://doi.org/10.1353/pbm.2004.0017

Bernard, H. R. (2011). *Research methods in anthropology: Qualitative and quantitative approaches*. AltaMira Press.

Bradshaw, K., Christmas, B., & Lueck, D. (2020). An introduction to "overlapping resources and mismatched property rights." *International Journal of the Commons, 14*(1), 553–556. https://doi.org/10.5334/ijc.1070

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2012). Thematic analysis. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. L. Sher (Eds.), *APA handbook of research methods in psychology: Vol. 2. Research designs*: *Qualitative, qantitiative, neuropsychological, and biological* (pp. 57–71). American Psychological Association. https://psycnet.apa.org/doi/10.1037/13620-004

Browne, M. W., & Robertson, K. (2009). *Benefit sharing agreements in British Columbia: A guide for First Nations, businesses, and governments*. Woodward & Company. https://fnbda.com/wp-content/uploads/2024/01/hw03b_benefit_sharing_final_report.pdf

Cascadden, M., Gunton, T., & Rutherford, M. (2021). Best practices for impact benefit agreements. *Resources Policy, 70*, 101921 https://doi.org/10.1016/j.resourpol.2020.101921

Centers for Disease Control and Prevention (CDC). (1997). *Principles of community engagement*. Agency for Toxic Substances and Disease Registry.

Clinical and Translational Science Awards Consortium, Community Engagement Key Function, Committee Task Force on the Principles of Community Engagement. (2011). *Principles of community engagement* (Second Edition).

Corrado, D., Link, M. S., & Calkins, H. (2017). Arrhythmogenic right ventricular cardiomyopathy. *The New England Journal of Medicine*, *376*(1), 61–72. https://doi.org/10.1056/NEJMra1509267

Daniels, N. (1981). Health-care needs and distributive justice. *Philosophy and Public Affairs, 10*(2), 146–179.

Daniels, N. (2001). Justice, health, and healthcare. *American Journal of Bioethics, 1*(2), 2–16. https://doi.org/10.1162/152651601300168834

Dare, M. L., Schirmer, J., & Vanclay, F. (2014). *Community engagement and social licence to operate*. *Impact Assessment and Project Appraisal*, *32*(3), 188–197. https://doi.org/10.1080/14615517.2014.927108

Deutsch, M. (1975). Equity, equality, and need: What determines which value will be used as the basis of distributive justice? *Journal of Social Issues, 31*(3), 137–149. https://doi.org/10.1111/j.1540-4560.1975.tb01000.x

Diefenbach, T. & Sillince, J. (2011). Formal and informal hierarchy in different types of organization. *Organization Studies, 32*(11), 1515–1537. https://doi.org/10.1177/0170840611421254

Emerson, K., Nabatchi, T., & Balogh, S. (2012). An integrative framework for collaborative governance. *Journal of Public Administration Research and Theory, 22*(1), 1–29. https://doi.org/10.1093/jopart/mur011

Excite Corporation. (2023). Initiatives. *Excite!* https://www.excitecorp.nf.ca/

Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods, 5*(1), 80–92. https://doi.org/10.1177/160940690600500107

Foley, P., Mather, C., & Neis, B. (2015). Governing enclosure for coastal communities: Social embeddedness in a Canadian shrimp fishery. *Marine Policy, 61*, 390–400. https://doi.org/10.1016/j.marpol.2014.11.009

Francis, J. J., Johnston, M., Robertson, C., Glidewell, L., Entwistle, V., Eccles, M. P., & Grimshaw, J. M. (2010). What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychology & Health, 25*(10), 1229–1245. https://doi.org/10.1080/08870440903194015

Frankowski, A. (2019). Collaborative governance as a policy strategy in healthcare. *Journal of Health Organization and Management, 33*(7), 791–808. https://doi.org/10.1108/JHOM-10-2018-0313

Gehman, J., Lefsrud, & L., Fast, S. (2017). Social license to operate: Legitimacy by another name? *Canadian Public Administration, 60*, 293–317. https://doi.org/10.1111/capa.12218

Gibson, G., & O'Faircheallaigh, C. (2015). *IBA community toolkit: Negotiation and implementation of impact and benefit agreements*. Walter and Duncan Gordon Foundation. https://gordonfoundation.ca/wp-content/uploads/2017/02/toolkit-english.pdf

Gilbert, E., Zurel, H., MacMillan, M., Demiriz, S., Mirhendi, S., Merrigan, M., O'Reilly, S., Molloy, A., Brody, L., Bodmer, W., Leach, R., Scott, R. E. M., Mugford, G., Randhawa, R., Stephens, J., Symington, A., Cavalleri, G., & Phillips, M. S. (2023). The Newfoundland and Labrador mosaic founder population of an Irish and British diaspora from 300 years ago. *Communications Biology, 6*(469). https://doi.org/10.1038/s42003-023-04844-9

Gordon, D., McKay, S., Marchildon, G., Bhatia, R., & Shaw, J. (2020). Collaborative governance for integrated care: Insights from a policy stakeholder dialogue. *International Journal of Integrated Care, 20*(1), 3, 1–11. https://doi.org/10.5334/ijic.4684

Government of Canada. (2020). *Basics of environmental assessment under CEAA 2012.* Retrieved from the Impact Assessment Agency of Canada https://www.canada.ca/en/impact-assessment-agency/services/policy-guidance/basics-environmental-assessment.html

Government of Newfoundland and Labrador. (2019). *Guide to the environmental assessment process*. Retrieved from the Department of Municipal Affairs and Environment, Environmental Assessment Division, St. John's, NL.

Green, R. C., Green, J. S., Buehler, S. K., Robb, J. D., Daftary, D., Gallinger, S., McLaughlin, J. R., Parfrey, P. S., Younghusband, H. B. (2007). Very high incidence of familial colorectal cancer in Newfoundland: A comparison with Ontario and 13 other population-based studies. *Familial Cancer, 6*(1), 53–62. https://doi.org/10.1007/s10689-006-9104-x

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*(1), 59–82. https://psycnet.apa.org/doi/10.1177/1525822X05279903

Guest, G., MacQueen, K. M., & Namey, E. E. (2012). *Applied thematic analysis*. SAGE Publications.

Gunton, C., & Markey, S. (2021). The role of community benefit agreements in natural resource governance and community development: Issues and prospects. *Resources Policy, 73*, 102152. https://doi.org/10.1016/j.resourpol.2021.102152

Health Research Ethics Authority. (2019). *Health Research Ethics Authority Act*. SNL 2006, c H-1.2 (consolidated version current to 2019). https://canlii.ca/t/55zb6

Heffron, R. J. (2020). The role of justice in developing critical minerals. *The extractive industries and society*, *7*(3), 855–863. https://doi.org/10.1016/j.exis.2020.06.018

Hugo Ethics Committee. (2000). Statement on benefit sharing. *Clinical Genetics, 58*(5), 364–366. https://doi.org/10.1034/j.1399-0004.2000.580505.x

Institute for Public Administration of Canada (IPAC). (2013, March). Healthcare governance models in Canada: A provincial perspective. https://neltoolkit.rnao.ca/sites/default/files/Healthcare%20Governance%20Models%20in%20Canada_A%20Provincial%20Perspective_Pre-Summit%20Disscussion%20Paper%20March%202013.pdf

Jentoft, S., & Chuenpagdee, R. (2009). Fisheries and coastal governance as a wicked problem. *Marine Policy, 33*(4), 553–560. https://doi.org/10.1016/j.marpol.2008.12.002

Jones, D., Bush, P., & Macaulay, A. (2014). Beyond consent: Respect for community in genetic research. https://doi.org/10.1002/9780470015902.a0005179.pub2

Juengst, E. T. (1998). Group identity and human diversity: Keeping biology straight from culture. *American Journal of Human Genetics, 63*(3), 673–677. https://doi.org/10.1086/302032

Kirchherr, J., & Charles, K. (2018). Enhancing the sample diversity of snowball samples: Recommendations from a research project on anti-dam movements in Southeast Asia. *PloS One, 13*(8), e0201710. https://doi.org/10.1371/journal.pone.0201710

Lamont, J., & Favor, C. (2017). Distributive justice. *The Stanford Encyclopedia of Philosophy*. https://plato.stanford.edu/entries/justice-distributive/

Locke, J. (2003). *Two treatises of government and a letter concerning toleration.* (I. Shapiro, Ed.). Yale University Press. (Original work published 1689)

Lockwood, M., Davidson, J., Curtis, A., Stratford, E., & Griffith, R. (2010). Governance principles for natural resource management. *Society and Natural Resources, 23*(10), 986–1001. https://doi.org/10.1080/08941920802178214

Marland, A. (2010). Masters of our own destiny: The nationalist evolution of Newfoundland Premier Danny Williams. *International Journal of Canadian Studies, 42*, 155–181. https://doi.org/10.7202/1002176ar

McGuire, A. L., & Burke, W. (2008). An unwelcome side effect of direct-to-consumer personal genome testing: raiding the medical commons. *JAMA, 300*(22), 2669–2671. https://doi.org/10.1001/jama.2008.803

Mills, S., & Sweeney, B. (2013). Employment relations in the neostaples resource economy: Impact benefit agreements and Aboriginal governance in Canada's nickel mining industry. *Studies in Political Economy, 91*(1), 7–34. https://doi.org/10.1080/19187033.2013.11674980

Moffat, K., Lacey, J., Zhang, A., & Leipold, S. (2016). The social licence to operate: A critical review. *Forestry: An International Journal of Forest Research, 89*(5), 477–488.

Morgan, D. L. (1996). Focus groups. *Annual Review of Sociology, 22*, 129–152. https://doi.org/10.1146/annurev.soc.22.1.129

Moulton, D. (2000). Newfoundland and Labrador: It's all In the Genes. *Canadian Medical Association Journal, 163*(3), 321–321-b.

Nielsen, M, Kongsholm, N, & Schovsbo, J. (2019). Property and human genetic information. *Journal of Community Genetics, 10*, 95–107. https://doi.org/10.1007/s12687018-0366-4

Panagos, D., & G. Grant. (2013). Constitutional change, Aboriginal rights, and mining policy in Canada. *Commonwealth & Comparative Politics*, *51*(4), 405–423. https://doi.org/10.1080/14662043.2013.838373

Pugh, J. (2022). Genetic exceptionalism, revisionism, pluralism and convergence in the ethics of insurance: response to commentators. *Journal of Medical Ethics, 48,* 879–880. http://dx.doi.org/10.1136/medethics-2022-108153

Pullman, D., & Latus, A. (2003). *Policy implications of commercial human genetic research in Newfoundland and Labrador*. A report for the Newfoundland and Labrador Department of Health and Community Services. https://hdl.handle.net/10161/8126

Rahman, P., Jones, A., Curtis, J., Bartlett, S., Peddle, L., Fernandez, B., & Freimer, N. (2003). The Newfoundland population: A unique resource for genetic investigation of complex diseases. *Human Molecular Genetics, 12*(2), R167–R172. https://doi.org/10.1093/hmg/ddg257

Rhodes, R. A. W. (1997). *Understanding governance: Policy networks, governance, reflexivity and accountability*. Open University Press.

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & Quantity, 52*(4), 1893–1907. https://doi.org/10.1007/s11135-017-0574-8

Sheremeta, L., & Knoppers, B. M. (2003). Beyond the rhetoric: Population genetics and benefit-sharing. In W. Pter, & C. B. Onuwueke (Eds.), *Accessing and sharing the benefits of the genomics revolution. The International Library of Environmental, Agricultural and Food Ethics, vol 11* (pp. 157–182). Springer. https://doi.org/10.1007/978-1-4020-5822-6_8

Skeard, J. (2024). "Unnatural resources?": Parallels and distinctions between the Newfoundland Genome and traditional resource sectors. *Journal of Community Genetics, 15*(4), 449–459. https://doi.org/10.1007/s12687-024-00715-w

Söderholm, P., & Svahn, N. (2015). Mining, regional development and benefit-sharing in developed countries. *Resources Policy, 45*, 78–91. https://doi.org/10.1016/j.resourpol.2015.03.003

Spinello, R. A. (2004). Property rights in genetic information. *Ethics and Information Technology, 6*(1), 29–42. https://doi.org/10.1023/b:etin.0000036157.14807.b0

Statistics Canada. (2019). *Focus on Geography Series, 2011 Census*. Retrieved from https://www12.statcan.gc.ca/census-recensement/2011/as-sa/fogs-spg/Facts-cma-eng.cfm?LANG=Eng&GK=CMA&GC=001

Stoker, G. (1998). Governance as theory: Five propositions. *International Social Science Journal, 50*(155), 17–28. https://doi.org/10.1111/issj.12189

Town of Gander. (n.d.). *Business sectors in Gander.* Retrieved from https://www.gandercanada.com/business-and-development/sector-profiles/

Whitehead, M. (2003). 'In the shadow of hierarchy': Meta-governance, policy reform and urban regeneration in the West Midlands. *Area, 35*(1), 6–14. https://doi.org/10.1111/1475-4762.00105