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First Nations Information Governance Centre
Le Centre de gouvernance de l'information des Premières Nations

RECOGNIZING RELATIONS:
CONNECTING TO THE CREATOR'S GIFTS
A First Nations Discussion Guide on Biobanking and Genomic Research

ABOUT THE ARTIST

The cover and interior art for this publication is by Tsista Kennedy, an Anishinaabe Onyota'a:aka artist from Southern Ontario. Born in 2001, Kennedy is a self-taught artist who works primarily in digital, but also creates work with ink on watercolour and sketchbook paper.

Kennedy's love of art began in his early childhood when his teachers would often find more doodles on his classwork than answers and equations. At 14, he created his first Woodland Art piece, a style which his art had followed ever since. Kennedy's unique variation of the Woodland style is marked by semi-bold black lines, intricate patterns, and vibrant colors, all of which combine to make the artwork flow elegantly across the canvas. Because of his ability to convey stories and messages through his artwork, Kennedy has been commissioned by many organizations, universities, and businesses.

Kennedy's artwork isn't solely rooted in Indigenous traditionalism or Indigenous modernism. Rather he sees it as a merging of the two. With his personal experiences and stories thrown into the mix, combining these two perspectives provides the inspiration behind some of his artwork today. However, as a frequent daydreamer many of his best art pieces simply begin as images that pop into his head. For more information on Tsista's art, please visit Hotdogwaterart.com

ABOUT THE ART

Kennedy's cover art for this discussion guide illustrates what he sees as a collaborative approach between Indigenous Peoples and those overseeing the research and management of biological specimens.

The illustrations found within the guide speak to the idea that within conversations surrounding biobanking and genomic research, individuals can reflect on their own creation stories and how they pertain to these elements of life on our earth and how they should be treated and respected. The images emphasize how all life is connected, and how all come from a place of sacredness and divinity, thus requiring the utmost respect when being worked with and researched. The images are meant to emphasize the feeling of partnership, mutual respect, and knowledge sharing.

ABOUT FNIGC

The First Nations Information Governance Centre (FNIGC) is an incorporated, non-profit organization committed to producing evidence based research and information that will contribute to First Nations in Canada achieving data sovereignty in alignment with their distinct world views. FNIGC is strictly technical, apolitical, is not a rightsholding organization, and does not speak directly for First Nations.

Mandated by the Assembly of First Nations' Chiefs-in-Assembly (AFN Resolution #48, December 2009), FNIGC's Mission is to assert data sovereignty and support the development of information governance and management at the community level through regional and national partnerships. We adhere to free, prior, and informed consent, respect Nation-to-Nation relationships, and recognize the distinct customs of First Nations, to achieve transformative change. Our work includes research and analysis of the technical elements of First Nations data sovereignty.

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INTRODUCTION

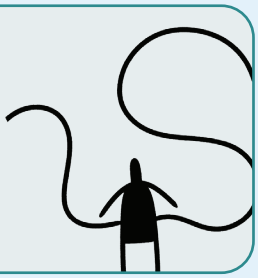
This conversation guide aims to increase First Nations' knowledge about biobanking and genomic research. Throughout the guide, there are reflection questions that are meant to foster conversations about the cultural relevance and priority of biobanking and genomic research. These priorities include the proper use, collection, storage and governance of First Nations' biospecimens.

CULTURE IS OUR FOUNDATION

Traditional Knowledge is the foundation for how to live a good life. Understanding your tradition and culture will help guide decisions in life.

Each First Nation is unique and has their own Creation Story. All are true and valid.

REFLECTION QUESTION #1: From your Creation story and world view, think about the essence of "life." What name do you have for it, what is its significance, and how should these elements be regarded and treated?



As you progress through this guide, keep this knowledge at the forefront of your considerations and discussions.

DNA AND GENOMES

What is DNA?

DNA (or, deoxyribonucleic acid) is a molecule that holds our unique genetic codes. Think of it as a recipe book containing the recipes to make all the proteins in our bodies.

DNA is made of four chemical building blocks (or "bases") and the order of these blocks forms genes (the instructions to make proteins). A person's DNA is present in nearly every cell in their body.

Some common places where DNA is found in people and animals include blood, hair, and saliva. DNA of the land is also found in plants and microorganisms living in soil and water.

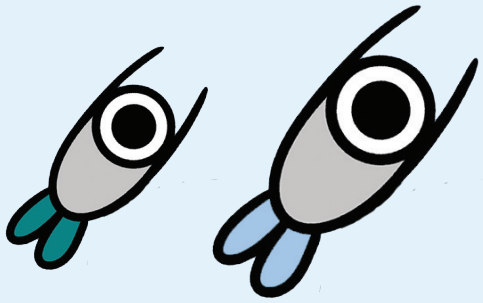
What is the genome?

The genome is made up of genes and contains all the DNA instructions found in our body that are responsible for the development and functioning of our body. The human genome has about 3billion base pairs of DNA.

What makes genomes diverse?

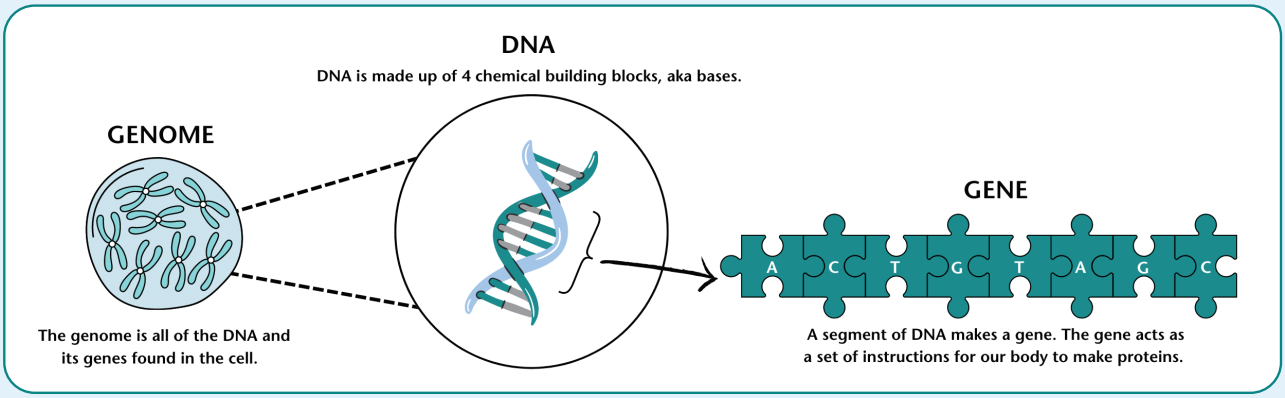
The DNA from any two people is 99.9% identical. This means that we share a common "recipe" that directs our development and functioning. The differing 0.1% results from **variants**.

Variants in our DNA in combination with our environment and life experiences—including trauma in a parent or grandparent — determine our uniqueness in terms of abilities, health, behaviour and even physical appearance.



What is epigenetics?

Epigenetics is the study of the changes in the expression of DNA due to conditions in the external environment. While one's environment and life experience can temporarily change the expression of the inherent gifts The Creator carried in our DNA, these changes in DNA expression are not permanent. There is potential to reverse or shift these changes in expression and return to a state of wellness through Indigenous culture.[1]



[1] Mary Deleary (2019). Indigenous Knowledge and Epigenetics. Thunderbird Partnership Foundation. https://www.afn.ca/wp-content/uploads/2019/04/Indigenous-Knowledge-Epigenetics.pdf

What is genomic research?

Genomics is the study of an individual's genes (aka, the genome), including the interactions of these genes with each other and with the environment.

Examples of environmental influences that can impact our DNA expression include: *sources of food and water, exposure to contaminants, climate, social and economic conditions, etc.*

REFLECTION QUESTION #2: What would you want to know about yourself and your relations if you could read your genome like a book?

WHAT IS BIOBANKING?

Biobanks are entities that collect, store, and/or preserve, test, and analyze collections of biological samples and their attached data. This information can then be used for research or decision-making by a doctor around treatment. (Note: the potential applications of biobanking will be discussed in later sections of this guide.)

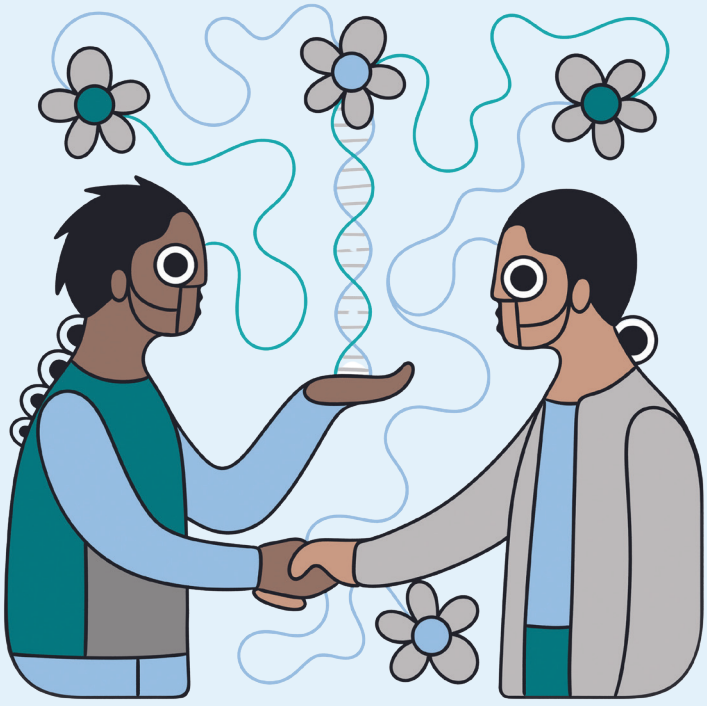
Biological samples collected for biobanking include blood, DNA, urine, hair, saliva and other bodily fluids and tissues. Once collected, the biological samples are stored in refrigerators, freezers or other devices that will preserve the samples. The "expiration date" of a biological sample is flexible and depends on its intended application and how it is stored. There are also biobanks that have been created for animals and plants.

Where are biobanks held?

Biobanks are usually created by and located within hospitals, research centres, universities and other research organizations.

What happens at a biobank and where are these activities performed?

Biobanks collect, store, distribute and transport biological samples. The data associated with the samples may also be collected, stored and shared with researchers who have successfully applied to use the samples for research purposes.



HISTORY OF BIOBANKING AND GENOMIC RESEARCH IN INDIGENOUS COMMUNITIES

The history of biobanking and genomic research in Indigenous communities is marred by a number of high-profile ethical breaches by researchers.

In the 1980s, the Nuu-chah-nulth Nation in British Columbia provided DNA samples to Dr. Richard (Ryk) Ward, a non-Indigenous researcher, who promised that they would be used to study the then-high rates of rheumatoid arthritis in their communities. However, the researcher also used their DNA samples for studies on human migration and retroviruses. The researcher also transported the Nuu-chah-nulth DNA samples across the world, where they were used for purposes that they were never intended for.

A retrovirus is a virus that uses RNA as its genomic material rather than DNA. When a retrovirus infects someone, it uses the infected person's genetic machinery to reproduce and spread across their body.

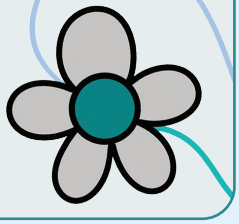
In the United States, the Havasupai tribe faced a similar situation in the 1990s, when they provided DNA samples to researchers from Arizona State University who said they intended to use them to study diabetes in the tribe. Instead, the samples were used for studies on migration, inbreeding, and schizophrenia.

In the 1990s, the Human Diversity Genome Project oversaw the collection of DNA samples from Indigenous populations from ten countries, excluding Canada, without considering the populations' interest in the project. The researchers would visit communities, collect samples, and never return or report back to the community with the results of their research.

In 2005, the National Geographic's Genographic Project reached out to Indigenous Peoples from around the world with the intention of mapping human migration routes. Indigenous Peoples saw no benefit from this project and, in fact, felt threatened by the ulterior motive to deny Indigenous Peoples' rights to their resource-rich territories.

These and other unethical research practices by genomic researchers have contributed to a general lack of trust in biobanking and genomic research in general, with many communities justifiably reluctant to take part in their studies.

REFLECTION QUESTION #3: Given the history above, what would help instill trust in a biobanking or genomic research project in your community? Would there be any pre-conditions or agreements that you would insist on?



BENEFITS OF BIOBANKING AND GENOMIC RESEARCH FOR FIRST NATIONS

One of the negative side effects of the distrust of researchers in First Nations communities is an unequal distribution of the positive benefits that can result from participating in biological research.

Taking part in biobanking and genomic research can help to shrink what's known as the "genomic divide," which, according to the World Health Organization, is "the disparity between genomic information available for people with European and Asian backgrounds, and that for Indigenous and other populations in genomic studies."

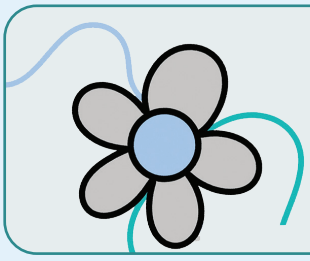
This genomic divide has resulted in a lack of representation of First Nations in healthcare research for rare diseases that often affect First Nations people. Closing this gap can increase the potential for different or more effective medical treatments.

A good example is "precision medicine," which looks at a person's genes, environment, and lifestyle to select a treatment that works best for them. Biobanks can also reduce the potential for increased physical harm by minimizing the number of repeated samples taken from an individual for different research or clinical purposes.

Not only can genomic research benefit First Nations health and well-being, but it can also help conservation efforts by monitoring the health and diversity of plant and animal species on the land and in the waters. Further, biobanking can be applied to help with the identification of loved ones and the reunion of families, including reuniting Survivors of the Sixties Scoop with their families.

Biological samples hold essential knowledge about the genetic makeup of the individual self, meaning that genomic research gives individuals the opportunity to learn more about themselves.

Given that our genes are a record of all our ancestors and links to our current relations, genomic research can provide insights into our connections to the community, potentially spanning generations. Therefore, biobanking and genomic research have the potential to be a tool for First Nations community members to learn about themselves, individually and collectively.



REFLECTION QUESTION #4: What possibilities might be imagined for individual, collective and relational healing through biobanking and genomic research?

RISKS, MISUSES, AND LIMITATIONS OF BIOBANKING AND GENOMIC RESEARCH FOR FIRST NATIONS

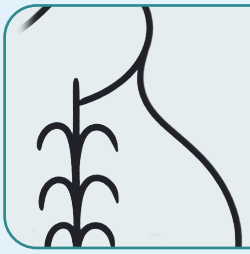
Although there may be some benefits of biobanking and genomic research, there are also potential risks that cannot be ignored, some of which have been covered in the previous section on the history of genomic research in Indigenous communities.

If proper governance and data-sharing agreements are not put in place, biological samples may be used for purposes that are different from First Nations' priorities. The information derived from the biological samples may be used against First Nations, specifically by government agencies or the insurance industry.

Information from biological samples can also be used for profit-making industries like ancestry testing kits (which undermines First Nations' self-determination of kinship) and pharmaceutical companies. In these situations, First Nations people are in a position of harm rather than benefit. There are also some opportunities for potential stigmatization due to a loss of privacy and re-identification. For example, in a 2006 research study, the Māori in New Zealand were wrongfully and insensitively misrepresented as an aggressive population as a result of having a "warrior" gene.

If anonymity and deidentification are maintained, there are still potential mental or spiritual harms that must be considered in the process of biobanking and genomic research. Any biological sample is embedded in a relational context in its natural environment. The sample should be viewed as part of an individual who is surrounded by a set of relations that are external to themselves. The relational context of a biological sample is full of psychological, spiritual and cultural significance. If a biological sample is separated from its context without the proper cultural protocols, there is always a risk of spiritual, psychological and cultural alienation.

By alienation we mean a harmful separation of individuals from themselves and from others; an emptiness caused by loss of and isolation from one's sense of self, society and environment.



REFLECTION QUESTION #5: How should biological samples be handled to provide the necessary care to prevent misuse and alienation?

CONSIDERATIONS WHEN ENGAGING WITH RESEARCHERS ON GENOMIC RESEARCH AND BIOBANKING

When deciding to undertake genomic research and biobanking, it is important that First Nations communities establish a clear set of expectations and requirements for the researchers involved. For example, it is essential to consider whether the initiatives reflect the needs of their community. Additionally, it is important to assess whether the researchers prioritize strong, trusting partnerships with the community.

This can be accomplished through participatory research, where the community participates in all aspects of the research project, including design, data collection, and interpretation. First Nations communities have the right to exercise the First Nations principles of OCAP® during all phases of the research and should ensure that researchers are up to date on their OCAP® training prior to conducting any research.

Throughout the partnership, the researcher should also learn and respect the community's cultural protocols and world views. The researcher should engage in culturally safe and ethical practices.

First Nations communities may want to develop protocols that outline how biological samples and data are to be respected, collected, transported, stored, used and shared in alignment with the First Nations principles of OCAP®. Data-sharing agreements would clearly describe First Nations' ownership and control over their information. First Nations should also consider who is profiting from their genomic information since, historically, First Nations have not obtained the benefits from previous projects.

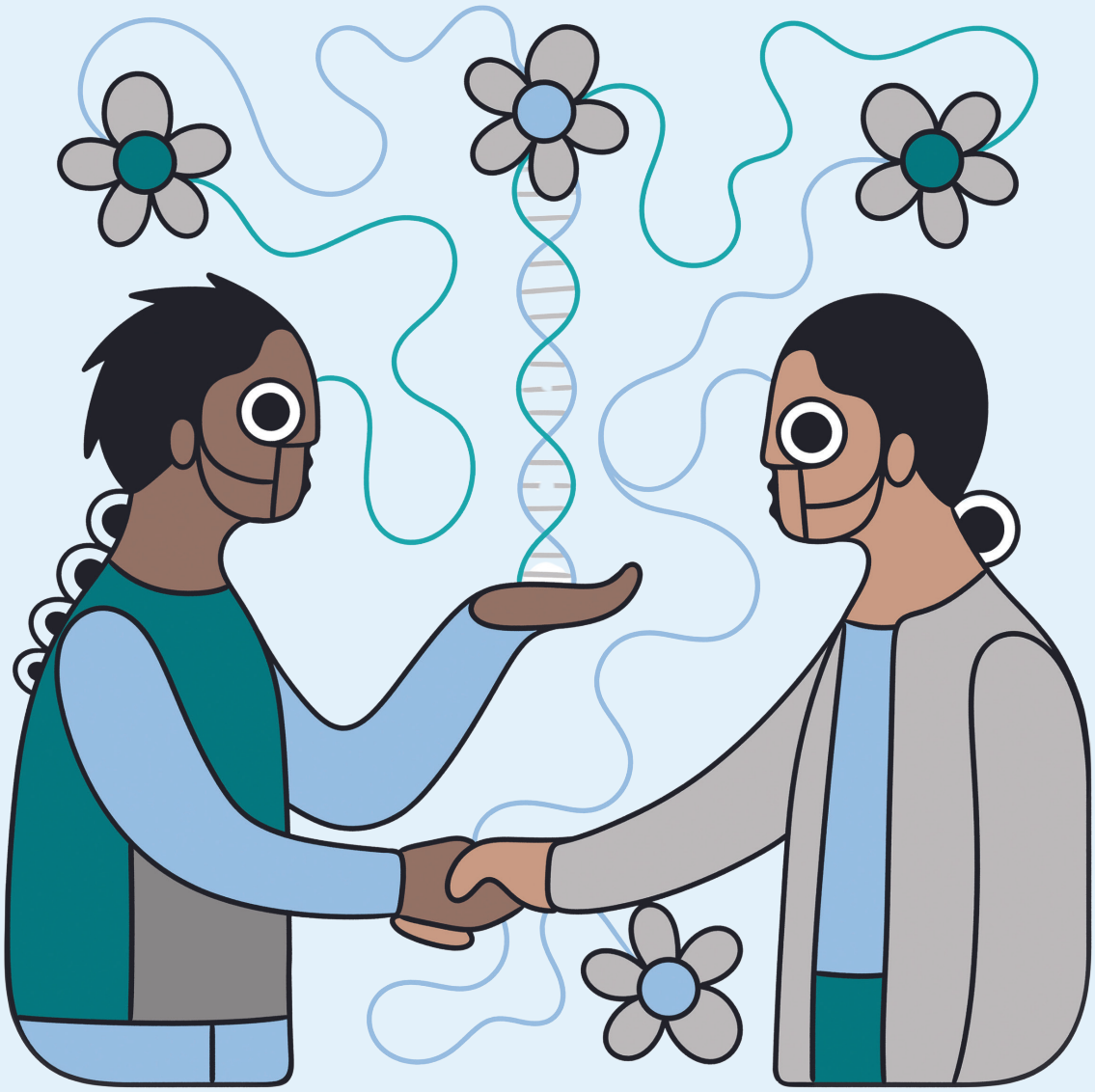
The First Nations principles of OCAP® refer to First Nations' rights to own, control, access, and possess their data and information. These principles should be the foundation for how First Nations research is conducted and how their data and information should be handled.

First Nations may want to consider gender when undertaking genomic research and biobanking initiatives. Historically, most biological research endeavours have solely been tested with men.[2] The biological reasoning given for this was women's menstruation cycles. Over the course of a month, women's bodies change, which may not allow for reliable research outcomes compared to men who don't have the same changes. Although studies have begun to see the benefits of including more women in biological research, most studies define sex on a binary (i.e., male or female) and fail to address the impact of gender [3], which may include Two-Spirit and other gender diverse individuals. It is also important to consider that there may be cultural and spiritual contexts that are gender-specific, giving the biological samples' distinct significance.

[2] Bohannon, Cat. (2023). Eve: How the Female Body Drove 200 million Years of Human Evolution. Random House Canada.

[3] Subramaniapillai, S., Galea, L. A. M., Einstein, G., & de Lange, A.-M. G. (2024). Sex and gender in health research: Intersectionality matters. *Frontiers in Neuroendocrinology*, *72*, 101104. https://doi.org/10.1016/j.yfrne.2023.101104

It is important to consider research relationships that may be rooted in systemic racism. This includes considering power differences between the researcher and the community. Building a trusting, long-lasting relationship can support a healthy environment for good research to take place. Creating these relationships takes time and involves ensuring First Nations participate in all aspects of the research and have strong governance over the processes. Additionally, the researcher must maintain regular communication with communities throughout the entire project.



GOVERNANCE

Good governance over biobanking and genomic research is essential for First Nations communities. Genomics research should be First Nations-led with the OCAP® principles asserted throughout the research process.

This includes upholding First Nations protocols for:

- collection,
- storage,
- analysis and interpretation,
- primary and secondary (using biological specimens or information for a purpose not initially intended) use,
- sharing of biological material or data,
- rematriation (returning the sacred to Mother Earth), or
- repatriation (returning the biological samples to the individual who provided them).

This affirms First Nations data sovereignty at broader individual and collective levels.

Participation in genomic research can involve "DNA on loan." This means that a donated biospecimen does not belong to the biobank or researchers but belongs to the individual from whom it was obtained. In New Zealand, Māori people have explained this concept as *Tākoha.*

"DNA on Loan" emphasizes that a donated biospecimen belongs not to the biobank or researchers, but to the individual from whom it was obtained.

"*Tākoha*" sees the donation of a biologic sample—a part of a person—as a sacred gifting of the responsibility for stewardship vested in the team for the donated sample. This is a concept described by Hudson et al. Hudson is a Māori scholar who consulted with Māori communities in New Zealand to describe participation in a biobank.

First Nations' participation in genomic research should also involve transparent, informed, free, prior and ongoing consent. Importantly, genomic research should also involve Elders, youth and community leaders in making decisions about genomic research with First Nations. It is essential to note that these considerations are dependent on each community's cultural protocols.

BIOBANKING AND GENOMIC RESEARCH IN INDIGENOUS COMMUNITIES

Below are some examples of biobanking and genomic research initiatives in Canada that partnered with, or were led by, Indigenous populations.

The **Northern Biobank Initiative** engaged with many First Nations communities in northern British Columbia to understand their views and perspectives around biobanking to guide and inform the potential establishment and governance of the **Northern British Columbia First Nations Biobank**.

The goal of the **Silent Genomes Project** is to reduce disparities in healthcare and improve diagnoses for Indigenous children with genetic diseases. Activities focus on:

- engagement, governance and capacity building;
- precision diagnosis for children with genetic conditions;
- developing an Indigenous Background Variant Library to allow for precision diagnosis; and
- studying the economic impact of precision diagnosis.

Critical Indigenous Genomics and Governance (aka **the Summer Internship for Indigenous Peoples in Genomics Canada**) is an intensive annual workshop for Indigenous Peoples to build Indigenous governance capacity and scientific knowledge in genomics, bioinformatics, critical Indigenous studies, and anticolonial approaches to bioethics.

Led by the Thunderbird Partnership Foundation and allies, **Creating Ethical Spaces for First Nations Research and Wellness** is an education curriculum that has a Two-Eyed Seeing framework and can be used as a tool for co-learning and participatory research processes that support First Nations-led research projects.

An Indigenous Background Variant Library (IBVL) is a database that shows how frequent a DNA variant occurs in Indigenous Peoples with no severe genetic conditions. BVLs need to represent diverse populations since variants may be common in one group of people but not another. To date, Indigenous Peoples are not well-represented in the BVLs that are available. Current BVLs primarily represent populations of European or Asian descent.

The **Canadian Alliance for Healthy Heart & Minds First Nations** (CAHHM-FN) Cohort examines how a person's environment is associated with health behaviours and the presence or progression of chronic disease risk factors and chronic diseases. In the CAHHM-FN cohort, each community owns its data and controls its dissemination and use. The data is held centrally under the stewardship of McMaster University.

The **Canadian Biobank and Data Alliance** enables rapid sharing of biological samples, data pertaining to the collected samples, and resources for biobanking among researchers across Canada. CIEDAR **(CoVarr-Net's Indigenous Engagement, Development and Research)** is supporting this initiative through the development of community engagement plans that would facilitate and address the needs and wants of a given First Nation as it relates to biobanking and genomic research.

The **DNA to RNA (D2R) Program** at McGill University is working towards developing an inclusive RNA therapeutics program (using genomic data) to advance health outcomes for diverse populations globally, including Indigenous populations.

With the increasing number of people needing stem cell transplants, **Héma-Québec** launched a study to raise awareness in First Nations communities to increase the number of registered potential donors in a stem cell registry. These registries need to represent the diversity of populations since both the donor and recipient need to have a similar genetic background. This way, First Nations patients waiting for a stem cell transplant can hopefully have a cure and recover from their disease.

Examples of these efforts have occurred internationally as well, including:

- **Te Mata Ira** in New Zealand (Guidelines for Genomic Research with Maori), **National Centre for Indigenous Genomics** in Australia,
- **Alaska Area Specimen Bank**,
- **Native BioData Consortium**, and
- **Papa Ola Lokahi** (United States).

THE PATH FORWARD

There is a need to build capacity for First Nations communities to meaningfully engage in these initiatives and other genomic research. It is important that training and capacity building are grounded in support for nation-specific understandings of genomic research.

Nation-specific understandings of genomic research include identifying what it is, how it should be done, and for what purposes. This will ensure that the biomedical and technical training and capacity building are not done in a way that reinforces dominant colonial practices of processing, storing, and using biosamples.

Further, biobanks and genomic research about First Nations must be First Nations-led and/or First Nations-owned. It is important that future biobanking and genomic research projects are grounded in principles of First Nations self-determination and sovereignty. For biobanking and genomics initiatives that involve partnerships with external institutions and researchers, biological samples and their associated data must be accessible to First Nations.

This means that First Nations must not just have physical access to the data but also the ability to work with the information in a way that contributes to their collective benefit as they see it. Through these processes, the OCAP® principles will be respected and asserted.

REFLECTION QUESTION #6: How can your First Nation ground future research projects in biobanking and genomic research in First Nations self-determination and sovereignty?

ADDITIONAL RESOURCES

Videos

GenomeTalk. (2018, July 3). *Indigenous Peoples & Genomics: Starting a Conversation*. https://www.youtube.com/watch?v=-wivIBDjoi8

UBC Learning Circle. (2021, February 11). *The Northern First Nations Biobank: Partnering to Reduce Inequity in Access to Genomic Research*. https://www.youtube.com/watch?v=dwUBqVgd9J0

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