

## Head Office

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## INFORMATION IN A GOOD WAY DATA SOVEREIGNTY

### How it will inform a health data system for the southern 34

On September 24, 2021, the SCO Chiefs in Summit passed a resolution called Information in a Good Way that looks at the way the southern 34 manage their individual community's data. It is a commitment to Data Sovereignty, which means putting the control over information use, sharing and storage into the hands of the people that created it - YOU! Data Sovereignty is a very important part of the work of Health Transformation.

At the heart of the Chiefs in Summit resolution is OCAP™ - short for Ownership, Control, Access, and Possession. OCAP™ was created by the First Nations Information Governance Centre and ever since, has served as a guiding principle that informs First Nations data and strengthens the idea that Indigenous communities and organizations should have more say in how their information is used. Ownership, Control, Access, and Possession need to be in place for us to realize Data Sovereignty.

Health Transformation means better, more accessible health for First Nations people. Moving forward, the health data First Nations generate, whether they see a medical professional, fill a prescription, or visit a hospital, won't just go off to be stored in a government data centre. Instead, your data will live forever in your community where it can be used, how and when communities see fit.

When we take control of our data, it can be used to improve existing programs or create new ones. It can be protected and not sold or given to outside researchers without written, prior and informed consent. It can be passed down to be used in an unlimited number of ways. It can provide good, community-based jobs for our youth, who will learn how to protect it, give it a good home and keep it safe. Once that good home is built, it will be time for all of the community's health data to return. This is what we call Data Repatriation or the returning of historical information to those who created it and can most benefit from it.

Having older data in community will make it easier to see trends and successes, as well as missteps or programs that caused harm. Most importantly, once it is home, our health data will never leave again without our full understanding of what it is being used for and our permission.

**The Data and Evaluation sub-committee of Health Transformation is made up of Health Directors, Community Leaders, SCO Staff, Knowledge Keepers, and health/social services professionals. We are working with good people to design a health data system with Information in a Good Way at its heart.**