

# THE POWER OF DATA

**KAHNAWAKE, QUEBEC** – On the south shore of the St. Lawrence River about 15 minutes outside the metropolitan island of Montreal sits one of the biggest, and arguably best-known, First Nations territories in Canada: the Mohawk Nation of Kahnawake.

Stretching over nearly 50 square kilometres this bustling First Nations community (the largest in Quebec) is home to nearly 10,000 people, including the award-winning textile artists Babe and Carla Hemlock, conductor John Kim Bell (the first indigenous person to conduct a symphony orchestra), Pan-Am Gold Medalist Waneek Horn Miller, and Olympic Gold Medalist Alwyn Morris — not to mention generations of steelworkers who during the 20th century helped shape the New York City skyline, including the World Trade Centre, Brooklyn Bridge and the Empire State Building.

But flip through a history book and you'll learn that this community's reputation reaches well beyond the last century. Kahnawake has played key roles in landmark moments throughout history, including the Two-Row Wampum Treaty of 1613, the formation of the Six Nations Iroquois Confederacy in 1722, and the armed resistance against American troops during the War of 1812.

Given this track record of trailblazers and visionaries it should come as no surprise to learn that Kahnawake is also on the forefront when it comes to harnessing the power of data.

Last year, following months of discussions, Kahnawake became the first community in the history of the First Nations Regional Health Survey (FNRHS, or RHS) to assume full responsibility for the landmark survey within their community.

Since April 2015 Kahnawake has been in charge of every detail of the RHS Phase 3 (the latest cycle of the survey) from administration, sampling and recruitment to community engagement, deployment, and data collection — a massive undertaking that is typically led by the First Nations Information Governance Centre (FNIGC) and its Regional Partners, the First Nations of Quebec and Labrador Health and Social Services Commission

## Kahnawake

How one Mohawk community is embracing the power of data in a unique and inspiring new way



Aerial view of Kahnawake, Quebec

(FNQLHSSC). The innovative approach was a first for everyone involved, but the community proved uniquely suited for the task.

“I think everyone knows that Kahnawake is very advanced in many areas” says Chief Rhonda Kirby who sits on the Mohawk Council of Kahnawake. “We’ve always tried to have a very proactive approach, and we see the importance of having our own community members get involved in the RHS. So we’re happy to be a part of this.”

For 20 years the RHS has been a key source of data for First Nations communities and federal departments who want to inform their policy and planning with quality, relevant information.

Established in 1997 the RHS is the only national First Nations-governed health survey in Canada. Overseen by the FNIGC, a First Nations run non-profit, and its Regional Partners the RHS gathers vital information in more than 250 on reserve and northern First Nations communities using Western and traditional understandings of health and well-being.

Discussions between the FNQLHSSC and Onkwata’karitáhtshera (Kahnawake’s health and social service agency), began in July 2014, with an agreement being finalized six months later. The mutually beneficial deal allows the two organizations to share RHS data with each other, meaning Kahnawake will get access to their

community level data which they will use for programming and planning — such as their upcoming Community Health Plan.

“It’s very important to us that we make sure that we’re going in the right direction and that we understand what the needs of the community are.” Chief Kirby says. “The data that we receive from the RHS will help us to either change that direction, or improve on what we currently have.”

Thanks to its rapidly expanding population, Kahnawake is faced with a range of issues including housing, elder care, mental health, substance abuse, Mohawk language-use, and high school non-completion — not to mention the high prevalence of diabetes, cancer, obesity and cardiovascular disease.

Some of these issues are being addressed by a \$21-million renovation of the Kateri Memorial Hospital, the only on-reserve facility of its kind in Quebec. Built in 1986, it is in the midst of a long-overdue facelift that will boost its capacity from 43 beds to 73, see 100 new employees hired and include an X-Ray department and a Traditional Medicine unit – the only one of its kind in the province. But without quality data gathered by First Nations for First Nations it’s difficult to know if projects like these are targeting community health needs.

“Up until now a lot of our information has been anecdotal. An individual would tell somebody that they had a condition, like scleroderma, and we’d hear about it from other people. But it was hearsay” says Valerie Diabo Director of Nursing at Kateri Memorial. “We’re hoping that the RHS will give us strong data to support some of the information that we’re getting. For example, it will let us know how many of our kids are smoking. Do we need to put new programs in place to help with that? This data is going to give us a look at trends; things to look out for that maybe we haven’t included in our Health Plan.”

This enthusiasm for the Power of Data extends to all aspects of Khanawake’s RHS efforts. Blair Armstrong, the RHS Community Coordinator for Onkwata’karitáhtshera, says they have mobilized all of their resources in an “all-hands-on-deck” effort to get the word out.

This includes RHS radio ads, live interviews, posters, flyers, brochures, survey progression thermometers, social media outreach, YouTube ads, spots on community television stations, and outreach booths at community events like harvest fairs, craft fairs, and even blood donor clinics.



“We definitely have a lot of promotions out there.” says Armstrong. “You can even see RHS ads up on our big electronic billboards.” He says the feedback from the community so far has been “fantastic.”

Their passion for the RHS is undeniable and even infectious. After spending a day in town you get the real sense that everyone in this community understands that quality data can be the key to real substantive change. You might even call them Power of Data disciples.

“Everyone at FNIGC is impressed with the kind of efforts and initiatives that Khanawake is putting forward with the RHS,” says Addie Pryce, FNIGC’s RHS & Capacity Development Coordinator. “They really are a model to others who are looking for innovative ways to both gather and use First Nations data.”

It’s an effort that couldn’t have happened without the cooperation and initiative of FNIGC’s Regional Partners in Quebec, who were the first to identify this new way forward.

“Our number one priority is to get the data back to the communities so they can put it to work and make something concrete with it” says Jonathan Leclerc, the FNQLHSSC’s Regional RHS Coordinator. “One of the reasons I like working with Khanawake is that they’re not doing the survey just to do the survey. They have a vision, and they know what they want to do with the data. It’s quite inspiring for us.”

“Sometimes when you’re doing this work, you feel like not everyone understands the importance of what you’re doing. But here, we feel like Yeah, it is important.”

**For more information about the RHS and FNIGC, please visit [FNIGC.ca](http://FNIGC.ca)**