Question 1

I understand that we are in phase 1 of the work, however, could you please share what would be the expectations from the regional health authorities' data users?

Answer (1/2)

The network of regional centers will serve the data and statistical needs of communities and their organizations such as First Nations health authorities in that territory, as they see fit. Health authorities are a key part of the First Nations growing ecosystem of institutions, working in all sectors (health, housing, education, employment, etc.). These institutions will require expert-driven reliable data and statistical services from regional centers. Today, we estimate that the ecosystem consists of over 1800 organizations ranging from First Nations governments to service delivery, policy, and advocacy entities).

As part of this ecosystem of First Nations institutions, First Nations health authorities are responsible for collecting and administering the health data pertaining to the services or programs they are responsible to delivery. Accordingly, each health authority will determine how to leverage their regional data and statistical center.

Answer (2/2)

The kinds of services these authorities may want to obtain from their regional center could include things like conducting special health surveys to address data gaps, aggregating health data to build statistical portraits and conduct research and analysis at the regional and national levels as well as implementing health data literacy programs or training.

At this stage of the implementation of the FNDGS, regional data champion teams are engaging communities and leadership to identify the priority capacity building needs and expectations. Ultimately, it's the communities and their organizations who will determine the form and function of these Centers. Accordingly, it is anticipated that regional First Nations' health authorities will also be engaged in the same way(s) to determine how their regional center could support them. These needs are expected to vary from one region to the next and inform which capacities each center will need to serve in the health sector.

Question 2

What are some of the outcomes/achievements of the funding received from the federal government funding? And what more can be done to support data linkages between First Nations communities and provincial and federal data systems?

Answer (1/2)

Phase 1 implementation extends for 3-years, ending in FY 2025-26. It will result in the development of 10+1 regional blueprints describing A) the governance body and/or structure their regional Centre will build, and B) the data capacity building priorities their Centre will focus on first (i.e., the capacities needed to deliver priority services needed/as determined by rights holders).

It is expected that priority capacity building needs will cover the core statistical functions that are typically found in statistical institutions (from data collection/repatriation to data development, analysis, research and dissemination). Centers could also include other services such as data stewardship services as well as the development of data capacities within communities, including data literacy and training services.

Answer (2/2)

Altogether, there is a lot to be done. It will be for each region to determine the priority capacities (or functions) they will want to advance first for their center, including with respect to data linkages.

Regions may also want to build up capacities to advance data sharing agreements with F/P/T partners prior to getting into data linkages for the purpose of assessing their quality and usefulness. Determining data quality is a labor-intensive process that requires unique skillsets including data analysis and IT/IM expertise.

Today, in many cases, First Nations do not have the capacity to undertake this kind of work yet. Overall, it is expected that the scope and pace of capacities (or new functions) to be built in each regional center will vary across regions. This will be a multiyear undertaking, which ultimately will provide First Nations with the human and technical infrastructures they need to protect and leverage their data, including for data linkages.

Question 3

Do you have any sense of a timeline for when the data hubs could take over responsibility for disease surveillance data?

Answer

No. As explained in question #2, it will be for each region to determine which capacities and services they will want to build up first.

It should be noted that health surveillance functions typically fall under the responsibilities of health authorities. In such cases, it will be for those entities to determine how they will leverage the data infrastructure (human and technical) of their regional center.

These new "data service relationships" between First Nations health mandated organizations and their regional data hubs are expected to emerge and solidify as implementation of the centers progresses.
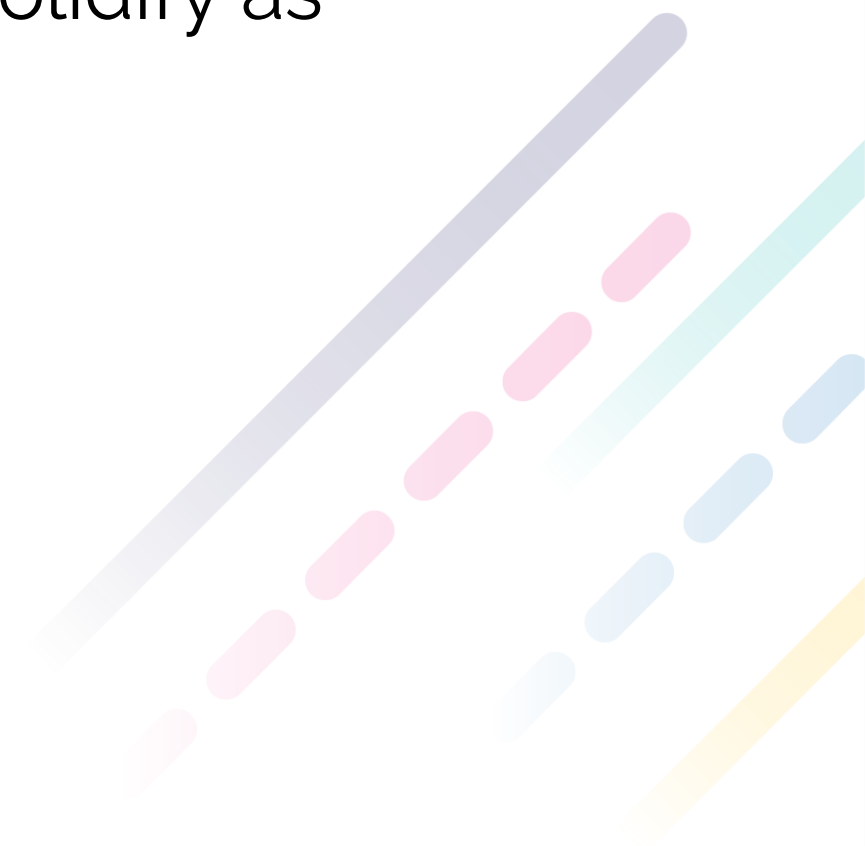
Question 4

We are searching for strategies to implement OCAP in national surveillance where data collection identifies Indigenous identity but not specific Nation or community - knowing that national Indigenous groups are overwhelmed with collaboration requests, what are your advices?

Answer

First Nations-led organizations are indeed overloaded with engagement requests that create significant pressures on their already scarce resources. To break this vicious cycle, it is critical for First Nations organizations to build up the core capacities they need to be equal partners and, therefore, meaningfully participate and benefit from such collaboration in a manner that is sustainable.

This is why the network of fully functional regional data centers as envisioned by the FNDGS is critical. Simply put, we do not have yet the data capacity to partner effectively, which prevents us from participating, contributing to and benefiting from collaboration in various sectors, including with respect to implementing OCAP and/or ensuring the protection of Indigenous information. We need to build that up, over time. And that's what we are in the process of doing.

Our advice is that you engage your regional data champion team to identify with them the priority areas where capacities should be built. This is about taking ownership for shaping and forming your regional center.
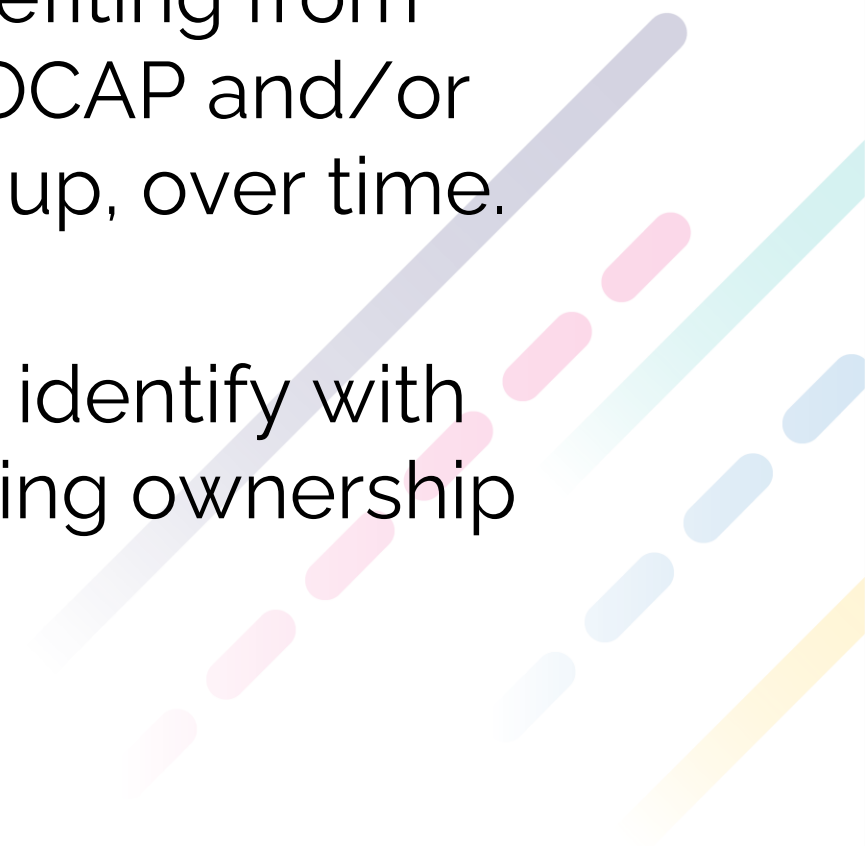
Question 5

Work context: Inuit Population of Nunavik. I am interested in data sovereignty and how we could support implementation of change in vision, especially for Surveillance data of pop Health, including determinants of health and not only infectious diseases.

Answer

The Inuit are developing their own unique strategy for data governance. The data champion team at FNIGC met with the Inuit team working on it at ITK a few times (2022-23 timeframe), explaining our process and how we developed the First Nations Data Governance Strategy (the FNDGS). Capacity building is something we all need to do; the Inuit are no different than First Nations, from that perspective. It's how we will go about doing so, and what we'll do first, that will be unique.

You may want to reach out to ITK and explore with them how their distinct data strategy will/can address your specific priority needs in a meaningful and sustainable manner.

You may also be interested in looking at measure #30 in the United Nations Declaration Act Action Plan which was released (tabled to) Parliament on June 2023. It refers to the recognition of data sovereignty and distinction-based data strategies for Inuit, Metis and First Nations.

Question 6

How non-Indigenous organizations can appropriately manage Indigenous data that they may hold? (As is often the case with the structures in the provincial public health system)

Answer

As envisioned by the FNDGS, a key objective is to build the capacities First Nations need to sit and actively participate at core F/P/T data governance tables led by departments or agencies which collect, hold and/or use Indigenous data, such as ISC and Statistics Canada. As part of the implementation of FNDGS, this is one of key priority areas where capacities must be built at the regional and national levels.

A key objective is to shift the relationships on the governance of Indigenous data. This process has been initiated but it will take time.

Another key undertaking is to develop and disseminate OCAP policies as well as training programs targeted to non-Indigenous organizations. The FNIGC's OCAP training program is an example of such critical efforts.

Finally, if a non-Indigenous entity does in fact hold First Nations data it's recommended that they connect with the community in question to inform them and inquire as to what they want you to do with the data. As per the OCAP principles it's the community who legitimately own their data and it should be up to them as to what happens to the data.

Question 7

Is there a recommendation for PHAC Surveillance Systems to either use CIHI or Statistics Canada Indigenous data standards for collection?

Answer

    This would have to be confirmed by the PHAC/CIHI. However, we understand that organizations such as Statistics Canada, ISC's FNIHB, CIHI as well as Canada Health Infoway are working with HC, PHAC and P/Ts to advance data standards. This is why it is essential for First Nations to build the capacities they need to equally participate, contribute to and benefit from such standards, and ensure they reflect their own realities and needs.

    As part of the Phase 1 of the FNDGS, we have been establishing a First Nations-led health data clearing house table involving those federal departments and agencies to better understand health data modernization efforts and ensure First Nations can identify the capacity building needs for sustainable collaboration on this front.

Question 8

I'm curious what decisions are surrounding historical data - as well as what's been discussed about sharing / owning data going forward?

Answer

If you're referring to archives and data/information that may be held by First Nations themselves (in band offices for example) – we can confirm that more than one region plans to focus on this in Phase 2, as a demonstration project with select / interested communities, for ultimate roll-out to all communities in the region. Many communities have prioritized the protection and preservation of historical data and information including blueprints, maps, audio and video, admin data, etc. – as data.

With respect to sharing/owning data going forward, the FNDGS envisions that capacities will be built or expanded across centers to accelerate the implementation of data sharing (access) agreements, including for data transfers back under the control of First Nations so that they can possess and control them as they see fit as not all data held by F/P/T governments are of quality, relevant or usable.

Question 9

If possible, could you please share examples of how data was collected, analyzed and used in decision making?
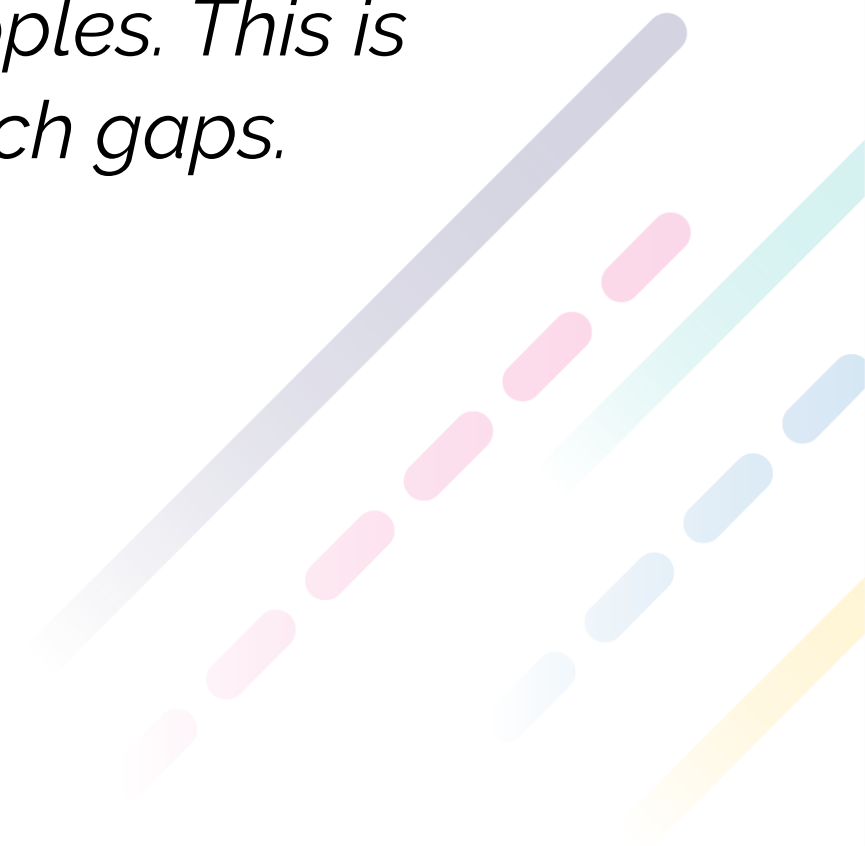
Answer (1/2)

Ultimately, data collected and managed is useless if it does not support decision-making whether it is for strategic and operational planning purposes, continuous policy or program improvements and/or the measurement of, and reporting on progress against specific objectives. In other words, data is only valuable if it creates new information to support decision-making.

Every day, such decisions are made at all levels by First Nations communities and organizations, leveraging the information available. However, significant data gaps exist in almost every sector which negatively impact services to First Nations peoples. This is why the FNDGS is also about building capacities in centers to help close such gaps.

Answer (2/2)

The FNIGC's regional health and socio-economic survey program provide essential data that provide portraits of the well-being of First Nations peoples across the country, identifying progress and/or gaps that will ultimately help inform policy and program changes. For instance, as a result of the COVID pandemic, the collection of data has demonstrated that First Nations peoples were more negatively impacted compared to non-Indigenous people which subsequently informed policy and program change requirements, notably with respect to Early vaccine rollout

Another example is the transfer of First Nations children in care under the control of First Nations. Data (or lack of data) have been instrumental in supporting the advocacy for such transfers, notably the failures of F/P/T governments in protecting First Nations children and the inherent rights of First Nations to take care of their own children.

There are many other examples where data plays a critical role in decision-making including in land claims, resource revenue sharing, housing, environment protection, and emergency management where data is instrumental in decision-making. A literature review would provide many more examples.