

General Public Views on Uses and Users of Administrative Health Data



P. ALISON PAPRICA, DIRECTOR, STRATEGIC PARTNERSHIPS, ICES
MICHAEL SCHULL, CEO & PRESIDENT, ICES

MAY 12, 2016



Acknowledgements

- Jacqueline Forrester, Susan Shiller
- Funding for this study was provided by the Ontario SPOR SUPPORT Unit (OSSU)
CIHR, the Ontario Ministry of Health and Long-Term Care and the Ontario Ministry of Research and Innovation have partnered to fund the OSSU as part of Canada's Strategy for Patient-Oriented Research (SPOR)

Conflicts of Interest

- None to declare

Objective

- High profile initiatives and reports highlight the potential benefits that could be realized by increasing access to health data
 - Strategy for Patient-Oriented Research data platform core function
 - Accessing Health and Health-Related Data in Canada – Canadian Council of the Academies
 - Unleashing Innovation: Excellent Healthcare for Canada – Report of the Advisory Panel on Healthcare Innovation
 - Government of Ontario’s Open Data Directive
- But do members of the general public share this view?
- The objective was to gain insight into the general public’s attitudes toward users and uses of administrative health data
 - In particular, information was sought to inform ICES decisions related to potential expansion of Data & Analytics Services (DAS) to the include services for the private sector

Method

GENERAL PUBLIC

- 2 x focus groups in Toronto
- 2 x focus groups in Thunder Bay
- Good mix of gender, age, household income and education level
- Good mix of different levels of trust towards researchers to follow rules and levels of support towards data linkage for health research
- Fieldwork: Sept. 23rd & 24th, 2015
- Professional moderator (Ipsos Reid)
- Q&A with ICES staff after formal session concluded



For the most part, the public are not losing sleep over the collection and use of data

- Generally acknowledged that both private and public sector collect data on individuals
- Most take this as a given and few expressed a strong opinion on the merits or concerns around this topic area
- The main **concerns** raised were:
 - security of personal data** (CRA and Scotiabank hacking incidents were referenced)
 - selling of private data** for marketing / profit

I'm a little apathetic about it, to be honest. Everybody just wants to know as much as they can about you for their own reasons. So they're going to do something with it at some point.

(Thunder Bay)

My main concern is all the club cards you get for stores. Data information is sold to insurance companies and it puts you at a high risk and then your premiums are changed.

(Thunder Bay)

Personal data, like banking and stuff, I want that to be secured.

(Toronto)

The concept of linked health data for research was difficult for the public to understand

- In several instances, participants **misunderstood** and provided their views about **how personal data should be combined to improve services for individuals** interoperable EMRs)
- Despite being given information and clarification from moderator, this **confusion** re-emerged several times

It's like one-stop shopping. Once you get into the system, all your information is in one place, for your services or programs or health care, whatever that you may need to link up to, to help you in your health.

(Thunder Bay)

I had my parents both in long-term health care and I did have a problem at one point where certain information was not shared between the pharmacy and the doctor and home care. And so I was constantly calling to make sure things were done properly. Oh, we don't have a record the doctor said. It became a very big problem.

(Toronto)

Using linked health data for research was seen to “make sense” and not be a “big deal”

- There was no outright opposition to the concept of using linking health data for research purposes
- There was appreciation that this type of analysis is needed to **monitor what is happening in the system and to aid planning**; indeed, this was common sense to some
- The case study was positively received and helped participants understand the tangible benefits (ICES research on how the antibiotic trimethoprim-sulfamethoxazole was associated with increased cardiac mortality [Antoniou et al, CMAJ])

I think it's fine! If they need statistics it's fine. I don't think it's a big deal. They need to know what's happening
(Toronto)

I can see the benefit to use it so they can follow trends and everything. Its kind of something I assumed they did already.
(Thunder Bay)

The case studies shows how research can be beneficial. I mean even though the deaths were relatively small, several hundred and more than ten thousand people, it really served them well to figure out that that a certain drug had double the risk as opposed to other antibiotics.
(Toronto)

I think it's helpful in some ways. They find out more things that and more information about things that are useful in healthcare.
(Thunder Bay)

However, public support was conditional on several factors...

- **Reassurances that data does not contain identifying information**
 - The fact that the ICES datasets used for research do not include identifying information was a key factor in support
 - There is scope for more assurances to be provided around how identifiers are used to link data, and when/how identifying information is removed
 - This stemmed from the assumption that personal information is not “lost” forever; it must be somewhere in the system

The anonymity of those individuals, the privacy of those people should be maintained. I think that's what's critical here.

(Toronto)

If nobody's personal information is being compromised in any way, it's just data, then I'm not really too worried about whose hands it's going into, because it's not going to affect anybody negatively. It's just data for research.

(Thunder Bay)

When they're removing people's information and they're linking all of this information. I mean. That information is not lost. It's got to be somewhere.

(Toronto)

I take issue with the concept of deletion of personal data. Simply because as an individual who's worked with computers, the use of the delete is not total and final.

(Thunder Bay)

However, public support was conditional on several factors...

- **Who has access to data and for what purpose matters**

- Unprompted, participants noted distrust in private sector research driven by perception that profit would be the main motive; this issue was compounded by belief that figures can be manipulated to show any result
- There was more trust that research conducted by government and academics would benefit the public; this was not universal
 - a minority wondered whether private sector ultimately funds academic research

It would be important to me to know who is viewing this data. I trust the government to act in our best interest. At the same time, you don't know about lobbyists and all these other pharmaceutical companies.

(Toronto)

Because government should have our backs and if they're doing a study it's probably a good thing which is to benefit individuals and better health care. But I have an issue if it is gathering information to sell a drug to make an extra dollar.

(Thunder Bay)

Not much credibility if it's from a drug company, and if it's from a university, not as bad, but who's behind them? Even universities, you have corporations which donate to universities, they have endowments, they fund different programs within universities, they fund studies.

(Toronto)

Public had a generally negative gut reaction to expansion to allow private sector uses/users

- When specifically asked about private sector uses/users, many of the objections echoed concerns expressed (unprompted) earlier in the session:
 - **distrust of private sector's** inherent motive to make money and thus incentive to **manipulate the data**
 - sense that it is **not right for a public body to sell public data** to the private sector
 - more people accessing the data increases **danger of misuse or data loss**

It's really unclear what the intentions of the private sector are. There's no guarantee that's what they're doing.

(Thunder Bay)

You can make anything look good by changing the scale of something, or a graph. You have integrity because you're an academic. You're not looking for the data to match and prove your hypothesis. Which I don't think is the case in the private sector

(Toronto)

They are essentially selling your information. Where does it stop? I mean, are they going start selling our tax information to other financial institutions?

(Toronto)

Less security. Information can somehow slip out. Especially when there's more people involved.

(Toronto)

A few were neutral or saw potential benefits to private sector uses/users

- The general public appreciated that private sector work with ICES data would result in **more research and therefore more knowledge**
 - “Fresh eyes” may generate new insights
 - Public perception that private sector tends to attract the smartest individuals
- Also made reference to the fact that information used by researchers is de-identified and / or the overwhelming amount of data collected on individuals nowadays when describing why they didn't have strong feelings

People who are really good at this kind of work always tend to work for the private sector because the money's better. And even though ICES is there and they have scientists, someone with a fresh idea can come in and see something that's totally different.

(Toronto)

I like the idea, the increased availability of data, may increase the availability of research, which would then increase the availability of health care options, or improved health care options for everyone.

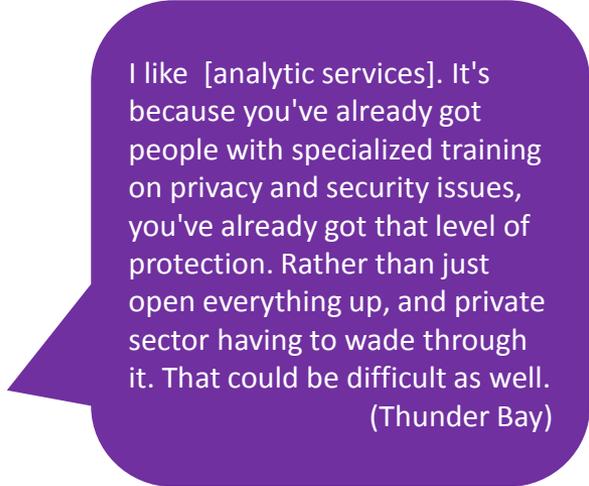
(Thunder Bay)

Personally I'm not really surprised, and I don't really care. I mean, who has a social media account? Our information is always circulating. We are always giving out information. It's always being passed.

(Toronto)

Analytical services for the private sector was preferred over access to data

- This view was particularly strong in the subset of general public participants that were most concerned about private sector uses/users
- The perceived benefits of analytic services over access to data included:
 - **more trust in ICES analysts/scientists** who have been trained to work with data
 - **ICES analysts/scientists are more familiar with the databases** hence easier for them to do the analysis than private sector researchers



I like [analytic services]. It's because you've already got people with specialized training on privacy and security issues, you've already got that level of protection. Rather than just open everything up, and private sector having to wade through it. That could be difficult as well.
(Thunder Bay)

How the findings from the focus groups are being used at ICES

Findings reinforced the principles that underpin this work

1. Projects undertaken must align with ICES mission and be in the public interest
2. ICES must be transparent about the projects undertaken
3. Work undertaken with the private sector must strengthen our ability to deliver on our mission & vision and not distract from it

DAS FAQs include examples of private sector studies that would be supported/not supported

FAQ 20. What is an example of a private sector study that DAS analytic services might support?

- Several private sector organizations have expressed interest in using DAS analytic services for studies that determine the overall health service utilization and costs for a group of people that have a certain condition compared to the overall health service utilization and costs for a group of people who are as similar as possible except that they do not have the condition. Companies use those kinds of statistics in submissions that they make to governments and government-funded agencies. Previously, the submissions that these companies have made to the Ontario government and its agencies have been based mostly on data from other provinces or countries. Private sector organizations have also expressed interest in studies that would provide statistics about the real-world effectiveness of a drug or medical device after the product has been launched. These examples, and all research studies performed through DAS analytic services, would require Research Ethics Board approval (see DAS FAQ 19).

FAQ 21. What is an example of a private sector study that DAS would NOT support?

- DAS would NOT provide analytic services for a study performed primarily or solely for commercial purposes. For example, DAS staff would NOT perform a market research study designed to identify the sites in Ontario that have the lowest rates of usage of a specific pharmaceutical product or medical device.

Transparency

- [Short ICES video for the general public \(under development\)](#)
 - Not sufficient (or wise) to simply state that population-wide administrative data are used in research studies, video will:
 - Include examples of studies that are likely to be relevant to the general public illustrating the public benefit
 - Emphasize that identifying information is removed from datasets before they are released for research
 - Refer to privacy and security safeguards
- [Transparency in private sector work](#)
 - When project begins ICES will make public: project names, research question(s) and companies involved when projects begin
 - Results are available to MOHLTC/CADTH/OHTAC at the same time that companies receive them
 - All results and dataset creation plans publicly available no later than one year after report provided to the company (see [DAS FAQ #22](#))

Limited DAS analytic services for the private sector

FAQ 23. Why aren't private sector researchers offered the full range of DAS services including access to data? Will this change in the future?

- In 2015, ICES undertook a pilot project which included studies that involved both access to data and analytic services for private sector researchers. Based on an evaluation of that pilot, and input obtained from stakeholders including focus groups with members of the general public, ICES has decided to begin providing analytic services for private sector researchers, but not access to data. The experience that is gained delivering DAS analytic services for the private sector beginning in June 2016, combined with findings from additional sessions with the public and information about service delivery options, will be used to determine ICES' long-term approach to work with private sector researchers.

FAQ 15. Does this mean that private sector organizations will now be working with ICES data?

- No. Private sector organizations will only see results reports that include statistics such as the total number of people that are identified as having a condition in Ontario in a specific time period, the number of hospitalizations associated with that condition, etc. DAS staff and scientists will perform the analyses that generate results reports for private sector researchers.

Next Steps

- Additional focus groups with members of the general public
- Consideration of the findings of the Wellcome Trust report: *The One Way Mirror: Public attitudes to commercial access to health data, e.g.,*
“In general, participants used four key tests in order to judge the acceptability of a company accessing data. The company had to pass all the tests to be acceptable to them:
 - *WHY - Is it for a particular public benefit and not just private profit?*
 - *WHO - Can the people using my data be trusted to produce a public benefit?*
 - *WHAT - Am I giving sensitive data? Could it be linked back to me?*
 - *HOW - Are there safeguards in place to keep my data private and secure?”*
- Additional focus groups including assessment of:
 - How important users/uses of linked health administrative data is vs. other topics (e.g., interest in interoperable EMRs)
 - Trade offs (private sector use vs. submissions to Ontario decision making bodies based on data from other jurisdictions)
- Additional ICES engagement with members of the public (e.g., on public-oriented research findings)

Conclusions

- Members of general public were generally supportive of research based on linked administrative health data but with conditions
 - particularly when the possibility of private sector research was discussed
- Notably, and citing security concerns, focus group participants preferred models that had a limited number of individuals or organizations accessing data
- Findings from the focus groups are informing ICES' work
 - with the private sector
 - in ICES' communications broadly
- Additional focus groups and other engagement with the public is planned