

## Appendix 2 (as supplied by the authors): Representative verbatim statements illustrating major and minor themes

### Appendix 2 – Box 1: Major theme 1 – the need for assurance about privacy and security

#### Subtheme – generic skepticism about the ability of any organization (in any sector) to ensure privacy

- Everybody likes to keep their information quiet. It depends. I don't trust the banks and how they keep their information, they're always getting hacked, people are getting hacked. Thunder Bay 2015-Group 1
- What was the last one [hacking incident], with the government. Anybody recall that? ... CRA, Oh Canada Revenue [Agency], yeah, that's what it was. It was huge one, yeah. Thunder Bay 2015-Group 2
- I'm not really a Facebook person. I know the internet and your stuff can be stolen. Thunder Bay 2015-Group 2
- Because it's the digital age, now, too, and anything can be hacked. Look at the guy who just hacked Yahoo from here in Ontario. Sudbury 2017-Group 2

#### Subtheme – importance of de-identification and other privacy and security measures for health data

- Well I think because it's health data, it's really important to keep it safeguarded. It's not just some random information. It's personal information. Really personal information. Toronto 2015-Group 2
- I mentioned at the start that if this was a guarantee that my privacy would be secure then I would be for it [research based on linked administrative health data] – Toronto 2015-Group 1
- The anonymity of those individuals, the privacy of those people should be maintained. I think that's what's critical here – Toronto 2015-Group 1
- It sounds good. I'm curious what they [ICES] are doing to actually ensure the security of data. Since it's very personal, it's like you're putting it all in one spot. There have to be huge firewalls to protect that information. Toronto 2017-Group 1

#### Subtheme – external oversight of health data was valued

- It stands out that it's an outside party that's doing the oversight, it's not internal to the institute, it's external - the IPC [Information and Privacy Commissioner of Ontario]. So that's a good thing – Thunder Bay 2015-Group 2
- PHIPA [the Personal Health Information and Protection Act]. It just reassures me that somebody's got some form of control on how the information is gathered and how the information is distributed. Thunder Bay 2015-Group 1
- I found it encouraging that the information and privacy commissioner has an oversight over it and it renews every three years. I found that encouraging. Someone's keeping an eye on it. Sudbury 2017-Group 1.

#### Subtheme – incomplete confidence in processes intended to ensure privacy and security of personal health information

- You can build a profile of individual without necessarily ever knowing their name, simply by picking up one piece of data here and one piece of data there. They're not necessarily been identified, but they still serve to build a notion of who that person is. Thunder Bay 2015-Group 1
- I liked that the personal information is removed, but I have the same thought – like really? [disbelief] It's great on paper, but someone's going to make a connection somewhere or something's going to happen – Toronto 2015-Group 1
- I believe that if someone ...if a hacker or there's some computer problem, right? Which has happened before, many, many times – personal information can get out there. Toronto 2015-Group 1

#### Subtheme – increased risk if more individuals and organizations are provided with access to health data

- I don't like the idea that it's branching out and then branching out, and then who knows where it's going to branch out to. Toronto 2015-Group 1

- Information can somehow slip out. Especially when there's more people involved. Thunder Bay 2015-Group 2
- You've already got people [at ICES] 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. Thunder Bay 2015-Group 2

Appendix 2 – Box 2: Major theme 2 – general support for research based on linked administrative health data with some conditions

Subtheme –linked administrative health data are an asset that should be used for research

- For me, I think this is a really great use of the information that's already being collected. It's sitting there, it's waiting to be used. Sudbury 2017-Group 1
- You can't go forward unless you have information. And the way to get information on a broad scale is through data collection. Thunder Bay 2015-Group 2
- I don't have a problem with any data being collected or used, I think that's the way of it, I think that's what we have to do. Data is collected to make changes, that's what it's for. Thunder Bay 2015-Group 2
- It's already been collected... it's there and it can be used. So why shouldn't they, if they can get access? It would be so helpful. Toronto 2015-Group 2

Subtheme – importance of public benefit

- If they're collecting 25 years of data they're going to discover that certain medications are unhealthy or not fit for people, so that's-- there's a big benefit in this for sure. Toronto 2017-Group 2
- I can see the benefit to use it so they can follow trends and everything. It's kind of something I assumed they did already. Thunder Bay 2015-Group 1
- It just shows how research can be beneficial. I mean even though the deaths were relatively small, several hundred in more than ten thousand people, it really served them well to figure out that that certain drug had double the risk as opposed to other antibiotics. It was beneficial in the long run. Toronto 2015-Group 1
- I do know people who don't take their illnesses as seriously as they should and then don't take their medication. So in that aspect, yeah, I can see a good benefit. Sudbury 2017-Group 2

Subtheme: concerns about how the study findings could be used or misused

- That's broad and scary ....this is Big Brother watching you, asking me if I'm taking my medication? I see insurance companies loving this. Sudbury 2017-Group 1
- And then they combine all that together, and they say, okay, well, this person has got this and this and this. Wasting medication or treatment or whatever on this person, beyond this age is useless. Let's just let this person die. Thunder Bay 2015-Group 1

Appendix 2 – Box 3: Major theme 3 – mixed and more negative reaction when there is private sector involvement

Subtheme: concerns about private sector motives, particularly pharmaceutical companies' motives

- I do like the idea of collecting data for the greater good, but that data, if it's for the profit of somebody, I have a problem with that. Sudbury 2017-Group 1
- What is the information used for? Again, what are they using it for? To try to help people...Or are they just looking at it at a way- okay, we can sell more cancer drugs. Thunder Bay 2015-Group 1
- I've taken some statistics courses before and one of the things I remember from the course is that you can take data, and you can interpret it any way you want depending on what you're looking for. And companies do that all the time. Toronto 2015-Group 1

- I'd rather not have a private company because I feel like they're just out to make money and it's not really about doing the research of helping diabetics [or] helping asthma patients. Sudbury 2017-Group 2
- If it's a pharmaceutical company, they have a vested interest in selling that drug and making money, so inevitably there's a bit of cynicism. Toronto 2017-Group 2

Subtheme – benefits of involving the private sector

- People who are really good at this kind of work always tend to work for the private sector because the money's better.... someone with a fresh idea can come in and see something that's totally different. Toronto 2015-Group 2
- An aspect I liked was the collaboration [private sector using government-generated data]. We need society to collaborate more for the common good... to improve the life of Ontarians. Toronto 2017-Group 2
- I find that there's going to be multiple uses for that kind of information... this is a collaborative way that they can help companies and encourage them to come up with products we all need. Sudbury 2017-Group 1

Subtheme: expect public benefit in exchange for ability to use public data in private sector studies

- If they're going to use the public data, then they really have to give a good price on the medication. Toronto 2017-Group 1
- A pharmaceutical company is taking data that's funded by our tax dollars and being used to basically turn a dollar at the end of the day, I feel that's a misuse of that data. I do believe, though, that if that data came at a premium to a private institution with a fund that went into our healthcare system, I might not be so adverse to it. So if they paid into the Ministry of Health, I would have no issue with them utilizing the data that was funded by our tax dollars. Sudbury 2017-Group 1
- I guess I just think maybe they [the private sector] could fund their own research. I'm not sure the taxpayers should pay for it. But I guess, as you said, if they're giving us an appropriate price or a better drug being released, then I guess it's okay. Toronto 2017-Group 1
- I think there's a negative connotation with private sector, and so I mean, who are we to say the private sector is not wanting to find a way to better equip the Northern Ontarians with this type of medication at a lower price, that they can reach a large group? We're automatically associating that with negativity, and I'm not looking at it that way. Thunder Bay 2015 Group 1

Appendix 2 – Box 4: Minor theme 1 – low knowledge and understanding of research based on linked administrative health data

- Is this actually happening today, where they're collecting a lot of data? Toronto 2017-Group 2
- We don't know them (ICES) so how can we trust them. We've never heard of them until today, so we can't possibly trust them. Thunder Bay 2015-Group 1
- [Indicating that the participant has confused research based on linked administrative health data with integration of data to inform individual patient care] I had my parents both in long-term healthcare 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 2015-Group 1
- [Indicating that the participant has confused research based on linked administrative health data with integration of data to inform individual patient care] 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 healthcare, whatever that you may need to link up to, to help you in your health. Thunder Bay 2015-Group 2

Appendix 2 – Box 5: Minor theme 2 – variation in opinions about the need for people to provide consent for use of data when datasets do not contain identifying information

- Either way it doesn't matter to me. Because the people that didn't give consent are being anonymous anyway. Toronto 2017-Group 1
- I don't think consent is needed as much to gather data when it's nameless and faceless. Toronto 2017-Group 2
- How come we didn't get permission that our data is in a study? I can understand where that discomfort is coming from. Sudbury 2017-Group 1
- It comes back to the consent. I think it would be strange, let's say I had an infection and go to the doctor, and my information isn't just being used in healthcare, but it's being moved external to a drug company. And I get the purpose is to get funding to have more adequate treatment, but I hate not knowing. Like you don't go into a doctor's office thinking this information of mine is going to be used. Toronto 2017-Group 2
- And I think if it's something the company's doing because they want stats on how their drugs are being used, then I think people should be consenting to it. I don't need to make them even more profitable than they are without my consent. Sudbury 2017-Group 2
- So the first thing is no one really tells you when you go to the doctor that your data will be shared, right? That's number one. We don't know. They haven't gotten anyone's consent. Toronto 2015-Group 2
- Because you always have to have consent of the person. Thunder Bay 2015-Group 1