Appendix 1 (as supplied by the authors)

DISCUSSION GUIDE #1 FOR 2015 FOCUS GROUPS

Stakeholder Perceptions: Focus groups and Ideation sessions regarding access and use of health and health-related data

INTRODUCTION (10 MINS)

- Thank participants
- No right or wrong answers, everything is confidential (not identified with you individually), explain recording

& client viewing, opportunity at the end to ask an ex

- Around the table introductions…what you do, family, hobbies, etc.

1. CONTEXT: TOP OF MIND VIEWS OF WHO / WHY DATA IS COLLECTED (5 MINS)

- What kind of people or organizations work with data? PROBE: government, private companies, not for profit sector
- How is this data used by the different organizations? How do you feel about the way data is used?

PROBE: government, private companies, not for profit sector

2. REACTIONS TO WHAT DATA LINKAGE IS (25 MINS)

GIVE PARTICIPANTS HANDOUT WITH HIGH LEVEL EXPLANATION OF HEALTH RESEARCH & DATA LINKAGE.

I'll give you 3-5 mins to read the handout on your own and once everyone has read through it, we will have a discussion on your thoughts.

The purpose of today's session is to get your feedback on uses of linked health data.

What do we mean by health data?

- Health data are generated when government departments and other organisations deliver a service.
- For example, imagine an Ontario senior who goes to see their family doctor with a concern. The doctor fills out a report about the visit and submits it to the government to get paid. The report includes basic information such as the name and OHIP number of the patient, the date of the visit, and a description of the service provided. The government maintains a database of these physician claims.
- If the patient is given a prescription for a drug that is funded by the government, this is not included in what the physician submits to the government. Instead the pharmacist who fills the prescription sends a report to the Ontario government's Drug Benefit program. The pharmacist's report includes basic information such as the patient name and OHIP number, what drug was prescribed and the dosage. The Ontario Drug Benefit program has a database of reports submitted by pharmacies from across the province.
- Even though the data from the doctors' reports and the pharmacies' reports are both collected by the Ontario government, the physician claims databases and the Ontario Drug Benefit database are stored indifferent parts of the system. They are not automatically linked.

Appendix to: Paprica PA, Nunes de Melo M, Schull MJ, et al. Social licence and the general public's attitudes about research based on linked administrative health data: a qualitative study. *CMAJ Open* 2019. doi: 10.9778/cmajo.20180099. Copyright © 2019 Joule Inc. or its licensors

What is 'data linkage' and how is it done?

- Data linkage is when we connect 2 or more databases, for example, using the examples above, using the OHIP number or patient name to link the records from doctors' reports and pharmacies' reports
- Once data are linked, all personally identifiable information is removed (e.g., names, addresses, OHIP numbers, specific dates of service).
- This creates a larger dataset of de-identified linked data.
- Hospital data, long-term care homes data, demographic data, social services data and information from patients' electronic medical records held by family doctors can all be linked, so linked datasets can be large and cover many service providers and sectors.

Why link data for research purposes?

- By linking more 2 or more databases, researchers and health system planners have access to more information about what is happening in and across the healthcare system.
- It is important to note that researchers who use linked health data do not look at individuals, they study what is happening for specific patient groups or for the healthcare system overall.
- What are your immediate reactions to this information? What stood out for you personally?
- How do you feel about linked data? Are you reassured or concerned by this? What makes you say that?
- How do you feel about the reason given for why researchers may study linked data? What do you feel are the benefits for this type research? Can think of any drawbacks?
- What else would you like to know about the process or the reasons for linking data? What is your reason for wanting this information? What impact would this information have on your view?
- MODERATOR RECAP ON CONCERNS MENTIONED AND PROBE: What needs to happen to address your concerns? What do you need to know or what safeguards need to be in place to make you feel reassured?

3. REACTIONS TO CASE STUDY ON HOW DATA LINKAGE HAS BEEN USED IN PAST (5 MINS)
I have another handout I'd like you to read which provides an example of research using linked data.

Case study

- Researchers wanted to study how different antibiotics combined with cardiac medication affect the risk of sudden cardiac death in older patients.
- Even though the number of deaths associated with the antibiotic and cardiac medication was small (hundreds of deaths in more than 10,000 people over 17 years), by performing a population-level study with administrative data, the researchers were able to determine that one particular antibiotic (trimethoprimsulfamethoxazole) had more than double the risk of sudden cardiac death compared to other antibiotics.
- The researchers published this result in the Canadian Medical Association Journal and recommended that doctors consider antibiotics with lower risk, particularly for patients who are most at risk of sudden cardiac death.
- Now that I have given you a bit more information, what impact, if any, does it have your views on research based on linked data?

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- Do you think this type of research should be done? Why / Why not? Can you see any more benefits to research using health data? Can you see any more drawbacks?
- To what extent does the case study address some of the issues or questions we discussed earlier?
- Does it raise any new questions or concerns? What else do you need to know about this topic? Why is this important for you to know?
- MODERATOR RECAP ON CONCERNS MENTIONED AND PROBE: What else needs to happen to address your concerns? What else do you need to know or what other safeguards need to be in place to make you feel reassured?

4. REACTIONS TO ICES (10 MINS)

GIVE PARTICIPANTS HANDOUT TO READ

- The Institute for Clinical Evaluative Sciences (ICES) is a not-for-profit independent research institute that houses a linked data repository with de-identified records for more than 13 million Ontarians.
- The ICES Data Repository is based primarily on data for services funded by the Ontario Ministry of Health and Long-term Care since 1986. It also includes data from registries, surveys, electronic medical records and research studies. These data are collected mostly by Ontario's Ministry of Health and Long-term Care, health care providers, and other ministries, agencies and research organizations.
- For more than twenty years, ICES data have been used in research studies that evaluate health care delivery and outcomes. For example, ICES data have been used to examine the role that neighbourhoods play in the diabetes epidemic and quantify how poor diet and physical inactivity affect life expectancy in Ontario.
- ICES is permitted to receive and use personal health information because it has a special designation under Ontario's Personal Health Information Protection Act. It is a designation granted by the Information and Privacy Commissioner (IPC) of Ontario, based on a review of an organization's privacy practices. ICES is one of a handful of organizations with this designation, which is subject to ongoing IPC oversight and renewal every three years.
- ICES uses a variety of measures to protect the information entrusted to it. Physical security measures, technological safeguards like encryption and policies all work together to protect information.
- Having heard about ICES, what are you immediate reactions to it? Does it make you feel more reassured about research based on linked data? Why is that?
- What else do you need to know about ICES that would ease concerns?

5. REACTIONS TO WHO HAS ACCESS TO ICES DATABASES (45 MINS)

The handout I am giving out now outlines who has access to ICES databases.

Who has access to ICES databases?

- Before March 2014, only ICES scientists and analysts were able to access ICES data and it had to be accessed at physical ICES centres. ICES scientists must hold university appointments. All ICES scientists and analysts receive specialized training on privacy and security and enter into agreements with ICES that require them adhere to policies related to privacy and security that have been reviewed and approved by the Information and Privacy Commissioner of Ontario.

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- In March 2014, ICES established a new function that provides academic researchers who are not ICES scientists with access to de-identified ICES data. The datasets that these non-ICES scientists access are less detailed than those used by ICES scientists at ICES centres, and can be accessed through a secure virtual environment that ICES controls, the data never leave ICES' secure environment.

- ICES is now considering establishing processes that would allow private sector researchers to make use of ICES data. For example, ICES data could be used by private sector researchers to estimate how common certain conditions are in the Ontario population, and to provide information about how patients with those conditions are using the healthcare system.

- There are two broad options:

1. **Provide access to de-identified data**: Private sector researchers would be given access to deidentified dataset and would perform their own analyses. The datasets would be less detailed than what is available to ICES scientists at ICES centres. Access would be controlled by ICES, the data never leave ICES' secure environment.

2. **Proving analytic services**: ICES analysts would perform the analyses for the private sector researchers. The private sector researchers would only see the results of the analyses.

- Any thoughts on who has access to ICES database at the moment? Does it make sense or not? Why is that?

- What are your reactions to the idea of allowing private sector researchers to work with ICES data in the future? Good idea? Bad idea? Why?

- There are two options for moving forward with this proposal. Do you have a preference between the two options? Why one and why?

- What other safeguards would be important to you regarding private sector researchers working with ICES data? Why is this important?

- What if I told you that in other provinces and countries with similar health data linking programs already provide private sector researchers with access to data or analytic services? Does that have any impact on your views? Why / Why not?

GIVE OUT HANDOUT ON REB.
I have a final handout I'd like you to take a look at.

Research Ethics Boards

- When any researcher wants to perform a study using ICES data, they must first obtain approval from a

Research Ethics Boards (REB).

- ICES scientists and academic researchers submit applications to the REBs at the universities and/or teaching hospitals where they work. For example, ICES scientists who work at ICES Central submit an application to the Sunnybrook Research Institute's REB.

- Private sector researchers would also need to obtain approval from a REB before initiating any study based on ICES data. REB approval would be required for both access to data and analytic services.

- REBs at universities and teaching hospitals are set up to provide a service to their own researchers, so private sector researchers would generally make submissions to private accredited organizations that perform independent REB reviews for a fee. Most of the work these private REBs do is for private

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sector research studies. Some universities and hospitals also use these private REBs in cases where they have more submissions than their internal REBs can review.

- What stood out in this handout? Why is that?
- Does this information change your views at all when it comes to giving access to private sector researchers? How so?
- Does the fact that private sector researchers would use private Research Ethics Boards impact your views?

Why/ Why not?

6. Q&A WITH ICES EXPERT (15 MINS)

OPPORTUNITY FOR ICES EXPERT TO ADDRESS KEY QUESTIONS RAISED IN DISCUSSION SO FAR & FOR PARTICIPANTS TO ASK ANY ADDITIONAL QUESTIONS

- What impact, if any, does this information have on your views? Why is that?

7. FINAL COMMENTS (5 MINS)

- Based on everything we discussed what was the most important takeaway for you personally? Why is that?
- What is your final advice to ICES as they continue to consider giving private sector researchers access to data and/or providing analytic services?
- What is your final advice to ICES in terms of how they should communicate with the public about research conducted using linked data? What are the most important points they should put across? Why is that?

Thank participants & end

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DISCUSSION GUIDE #2 FOR 2017 FOCUS GROUPS

Public attitudes about private sector involvement in research studies based on administrative data

1. INTRODUCTION (10 MINS)

- Thank participants
- No right or wrong answers, everything is confidential (no comments are identified with you individually), explain recording & client viewing, opportunity at the end to ask questions of a representative from the Institute for Clinical Evaluative Sciences at the end
- Around the table introductions…what you do, family, hobbies, etc.

2. CONTEXT: PROVIDING PARTICIPANTS WITH AN UNDERSTANDING OF DATA LINKAGE & ICES (15 MINS)

SHOW VIDEO TWICE & PROBE:

- What stood out for your most and why? Do you have any questions? How do you feel about data linkage?
- Having heard about the Institute for Clinical Evaluative Sciences, what are your immediate reactions to it? How, if at all, does it impact how you feel about research based on linked administrative health data? (Listen for reassured / skeptical) Why is that?
- Do you have any questions?
- FOLLOWING WILL BE PROVIDED IN A POWERPOINT DECK. MODERATOR WILL FOCUS ON SLIDES WHERE THERE SEEMS TO BE CONFUSION / FURTHER QUESTIONS

What do we mean by administrative health data?

- Administrative data is generated when government departments and other organizations deliver a service.
- For example, imagine an Ontario senior goes to see their family doctor with a concern. The doctor fills out a report about the visit and submits it to the government to get paid. The report includes basic information such as the name and OHIP number of the patient, the date of the visit, and a description of the service provided. The government maintains a database of these physician claims.
- If the patient is given a prescription for a drug that is funded by the government, this is not included in what the physician submits to the government. Instead the pharmacist who fills the prescription sends a report to the Ontario government's Drug Benefit program. The pharmacist's report includes basic information such as the patient name and OHIP number, what drug was prescribed and the dosage. The Ontario Drug Benefit program has a database of reports submitted by pharmacists from across the province.
- Even though the data from the doctors' reports and the pharmacists' reports are both collected by the Ontario government, the physician claims databases and the Ontario Drug Benefit database are stored in different parts of the system. They are not automatically linked.

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What is 'data linkage' and how is it done?

- Data linkage is when we connect two or more databases, for example, in the scenario above, using the OHIP number or patient name to link the records from doctors' reports and pharmacists' reports.
- Once data are linked, all personal identifying information is removed or replaced with a confidential code (e.g., names, addresses, OHIP numbers, specific dates of service).
- This creates de-identified linked data.
- Hospital data, long-term care homes data, demographic data, social services data and information from patients' electronic medical records held by family doctors can all be linked, so linked datasets can be large and cover many service providers and sectors.

Why link data for research purposes?

- By linking two or more databases, researchers and health system planners have access to more information about what is happening in and across the healthcare system.
- It is important to note that researchers who use linked health data do not look at single individuals, they combine data from many people to look at what is happening for specific patient groups, entire regions, or for the healthcare system overall.
- In Canada, all research studies based on linked administrative health data require the approval of an independent external research ethics board.

The Institute for Clinical Evaluative Sciences

- The Institute for Clinical Evaluative Sciences is a not-for-profit independent research institute that houses a linked data repository with de-identified records for more than 13 million Ontarians.
- The Data Repository at the Institute for Clinical Evaluative Sciences is based primarily on data for services funded by the Ontario Ministry of Health and Long-term Care since 1986. It also includes data from registries, surveys, electronic medical records and research studies. These data are collected mostly by Ontario's Ministry of Health and Long-term Care, health care providers, and other ministries, agencies and research organizations.
- For twenty-five years, data at the Institute for Clinical Evaluative Sciences has been used in research studies that evaluate health care delivery and outcomes. For example, data at the Institute has been used to examine the role that neighbourhoods play in the diabetes epidemic and quantify how poor diet and physical inactivity affect life expectancy in Ontario.
- The Institute for Clinical Evaluative Sciences is permitted to receive and use personal health information because it has a special designation under Ontario's Personal Health Information Protection Act. It is a designation granted by the Information and Privacy Commissioner (IPC) of Ontario, based on a review of an organization's privacy practices. The Institute for Clinical Evaluative Sciences is one of a handful of organizations with this designation, which is subject to ongoing IPC oversight and renewal every three years.
- The Institute for Clinical Evaluative Sciences uses a variety of measures to protect the information entrusted to it. Physical security measures, technological safeguards like encryption and policies all work together to protect the information.

3. REACTIONS TO THE CASE STUDIES (60 MINS / 20 MINS PER CASE STUDY PLUS OVERACHING QS)

PROVIDE HANDOUTS ONE AT A TIME AND ASK PARTICIPANTS TO GO THROUGH IT ON THEIR OWN AND INVITE THEM TO UNDERLINE ITEMS THAT THEY LIKE OR DISLIKE. EACH CASE STUDY WILL BE DISCUSSED IN TURN

THE ORDER OF THE CASE STUDIES WILL BE ROTATED BETWEEN GROUPS.

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1. Using administrative data to study the long term effect of a new drug

A drug company wants to fund a study that uses linked administrative health data held at the Institute for Clinical Evaluative Sciences to monitor what happens, over many years, to a group of people who are taking a prescription drug to treat diabetes that has recently been approved for use in Canada.

The company has completed a clinical trial in Ontario which included people with diabetes that received the new drug, and people with diabetes that did not get the new drug. All the patients in the trial have provided consent for their administrative to be linked and used for research. The follow up study would use hospital and physician billing data to determine whether the people who got the new drug during the study are, collectively, more or less likely to be hospitalized or develop certain conditions (e.g., kidney failure) compared to the group of people who did not get the new drug. Personal details such as name, addresses and the exact dates of treatment would be removed or converted to coded information before the data were used by the research team.

The study would be performed by an independent academic researcher with a university appointment. The company would be an "arm's length" funder – they would not have any involvement in the design of the study, analyses or interpretation of the findings. The study would be required to have all of the usual approvals for research based on linked administration data, including the approval of an external research ethics board. In this case the company would only see the results of the study and summary data and statistics, not the de-identified individual-level data. The results of the study would be made public on the website of the Institute for Clinical Evaluative Sciences no later than one year after the study had been completed.

There are several ways that the drug company might use the findings of the study. In some cases, government funders require companies to monitor the effects of their products after they have been launched, so the results could be sent to a ministry or government agency. Most, but not all, drug companies encourage or require that the results of the studies they fund be published in peer-reviewed academic journals and presented at conferences. If the study showed that the new drug has long-term benefits, it is likely that the company would refer to the findings in marketing materials.

Both companies and governments are increasingly interested in long-term "real-world" evidence about the effectiveness of drugs. Governments usually do not fund studies like this one because they expect companies to fund their own research.

- To what extent do you feel that the study would be an appropriate use of administrative health data? What makes you say that?
- Are there any specific details that were 'deal breakers' for you? What are they and why?
- How do you feel about the reasons given for why the company might be interested in a study like this one? Do these reasons justify the use of administrative health data or not? What makes you say that?
- [If not the first study presented] How do you feel about this study compared to the other examples? Do you see it as more or less acceptable? About the same? What are the main reasons that you say that?
- If you had to choose between the study happening with private sector funding or not happening at all, which would you choose and why? Could I get everyone to record their own answer on the handout? ONCE EVERYONE IS DONE RECORDING THEIR ANSWER: With a show of hands, who felt that it is better that the study did not happen at all? What were your main reasons?

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2. Use of administrative data to study the impact of an infection on the healthcare system

A drug company wants to conduct a study related to the infectious diarrhea caused by the Clostridium difficile (C. diff) bacteria. The company sells products to treat this type of infection. The drug company wants to know how many new cases of C. diff infection there are in Ontario each year, what types of health services people with C. diff infections receive and the cost of those health services to the Ontario government. The company wants to study the impact of C. diff infection in general, and not the effect of any particular product used to treat C. diff infections.

The drug company would like to use linked administrative health data related to C. diff infections held by the Institute for Clinical Evaluative Sciences. The records of Ontario residents who had a C. diff infection in the last five years would be part of this study, but the individuals wouldn't be identified or know that they are part of the study. If someone you know had a C. diff infection in the last five years in Ontario, there is a good chance that the records from their health care experience would be part of the study. Personal details such as name, addresses and the exact date of treatment for C. diff infection would be removed or converted to coded information before the data were used by the research team.

The study would be required to have all of the usual approvals for research based on linked administration data, including the approval of an external research ethics board. In this case, the drug company would design the study and would be required to have the design approved by an external research ethics board. If the study design was approved, the staff at the Institute for Clinical Evaluative Sciences would perform the analysis based on the company's study design and provide the company with a report with the findings. The company would only see the results of the study and summary data and statistics, not the de-identified individual-level data. The results of the study would be made public on the website of the Institute for Clinical Evaluative Sciences no later than one year after the study had been completed.

There are several ways that the drug company might use the findings of the study. It is likely that they will use the information in submissions to governments or government agencies when they are trying to make the case for government funding of their products. Most, but not all, drug companies encourage or require that the results of the studies they fund be published in peer-reviewed academic journals and presented at conferences. Companies often use the findings from studies that support the use of their products in marketing materials.

Companies are interested in studies like this one because they use the findings in economic models that estimate the costs and benefits of their products. Governments and government agencies are less likely to provide the funds for a study like this one because they expect companies to fund their own research. In cases where companies use previously published data, or data from other jurisdictions, in their submissions to governments, there can be disagreement between the company and the government about whether the costs and benefits estimated based on old data or data from other places would apply for Ontario.

- To what extent do you feel that the study would be an appropriate use of administrative health data? What makes you say that?
- Are there any specific details that were 'deal breakers' for you? What are they and why?
- How do you feel about the reasons given for why the company might be interested in a study like this one? Do these reasons justify the use of administrative health data or not? What makes you say that?
- [If not the first study presented] How do you feel about this study compared to the other examples? Do you see it as more or less acceptable? About the same? What are the main reasons that you say that?
- If you had to choose between the study happening with private sector funding or not happening at all which would you choose and why? Could I get everyone to record their own answer on the

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handout? ONCE EVERYONE IS DONE RECORDING THEIR ANSWERS: With a show of hands, who felt that it is better that the study did not happen at all? What were your main reasons?

3. Use of administrative data to study what happens when people with chronic diseases don't take their medication as recommended

A large drug store company wants to perform a study that would provide information about people who DO NOT take their prescription medicines according to their doctor's instructions. Other published studies have shown that many people with chronic diseases do not take their medication as directed and that complications due to this "non-adherence" to prescription medications results in hospitalizations and billions in health care costs every year. For example, because people with high blood pressure (also known as hypertension) often do not have obvious symptoms, there is relatively high non- adherence to hypertension medications – the result being strokes, heart attacks and other complications that could have been avoided. The new study would look at the impact of non-adherence in Ontario and what patient factors (e.g., age, geography, type of chronic condition) are associated with non-adherence to prescription medications.

The study would make use of linked administrative data held at the Institute for Clinical Evaluative Sciences and data from the drug store company. If someone that you know has a chronic disease and gets their prescription filled at this drug store chain, there is a good chance that the records from their health care experience would be part of the study, but the individuals wouldn't be identified or know that they are part of the study. Their name, address and exact dates of service and prescription filling would all be removed or converted to coded information before the data were used by the research team. Data from drug store would be used to determine whether records belonged in the adherent or non-adherent category. For example, if there were records for someone who had a prescription for hypertension medication that was supposed to be filled every three months, and it was only filled every 6 months, the records would go into the non-adherent group. Data from the Institute for Clinical Evaluative Sciences would be used to measure hospitalizations and other health system use for the non-adherent and the adherent groups, and analyses would be performed to determine the impact of non-adherence and which patient factors are associated with non-adherence.

The study would have all of the usual approvals required for research based on linked administration data including the approval of an external research ethics board. The drug store company would design the study and would be required to have the design approved by an external research ethics board. If the study design was approved by the research ethics board, staff at the Institute for Clinical Evaluative Sciences would perform the analysis based on the company's study design and provide the company with a report with the findings. The company would only see the results of the study and summary data and statistics, not the detailed individual-level data. The results of the study would be made public on the website of the Institute for Clinical Evaluative Sciences no later than one year after the study had been completed.

There are different ways the company might use the findings of the study. If the study finds that certain populations are less like to be adherent to their prescriptions, the company may develop educational materials and/or targeted incentives that are designed to persuade or influence those groups to take their medications (e.g., if they found that young men with hypertension are less likely to take their medication as prescribed, they might offer a reward designed to appeal to young men). They may also publish the findings in a peer-reviewed academic journal or present it at conferences.

Companies would be interested in studies like this one because they allow them to improve their practices and sales and help patients. Governments would also likely be interested in the results of studies like this one, but they may have higher priority activities to invest their dollars in (e.g., they might focus research dollars on topics that they can address through government policy and/or focus dollars more on services than research.)

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- To what extent do you feel that the study would be an appropriate use of administrative health data? What makes you say that?
- Are there any specific details that were 'deal breakers' for you? What are they and why?
- How do you feel about the reasons given for why the company might be interested in a study like this one? Do these reasons justify the use of administrative health data or not? What makes you say that?
- [If not the first study presented] How do you feel about this study compared to the other examples? Do you see it as more or less acceptable? About the same? What are the main reasons that you say that?
- If you had to choose between the study happening with private sector funding or not happening at all, which would you choose and why? Could I get everyone to record their own answer on the handout? ONCE EVERYONE IS DONE RECORDING THEIR ANSWERS: With a show of hands, who felt that it is better that the study did not happen at all? What were your main reasons?

4. Overarching Question to Probe

- In all the examples, researchers that were completely independent of the company performed the analyses and worked with the data. Would you feel differently if the plan was changed and the analysis was conducted by a PhD trained researcher who is paid or employed by the company? This could be a scientist who is an employee of the company, or a scientist working at a university who works as a consultant for the company. What if I told you that this trained researcher would be identified by name and credentials in the submission to the research ethics board? Does this have any impact? Does it change your opinion in any way? How so?

5. Q&A WITH A REPRESENTATIVE FROM THE INSTITUTE FOR CLINICAL EVALUATIVE SCIENCES (15 MINS)

OPPORTUNITY FOR ICES REPRESENTATIVE TO ADDRESS KEY QUESTIONS RAISED IN DISCUSSION SO FAR & FOR PARTICIPANTS TO ASK ANY ADDITIONAL QUESTIONS

- What impact, if any, does this information have on your views? Why is that?

Thank participants & end

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