



Data Services at NB-IRDT – What can we do for you?

Lunch and Learn Session
October 19, 2022

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Video

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Slides

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My name is Lindsey Gilbert. I'm the manager of Data Services here at NB-IRDT and I'm really glad everybody has been able to join today, for me to share a little bit about NB-IRDT Data Services and what we can do to support your data needs. So, I will figure out how to move my slides - there we go. Everybody can see that? Good, yes, looks great. Okay thank you.

So a little bit about the plan for today: we'll talk a little bit about what NB-IRDT Data Services are, we'll get right into the meat of the presentation and talk about what we can do for you in terms of supporting access to NB-IRDT platform data for your research, for providing secure data storage so you can do your data management and our secure research environment and also to facilitate the linkage of new data that you might have, or be interested in having, to NB-IRDT platform data that we already hold. We'll move on from that and talk just a little bit about an HDRN partnership that Data Services has, to support multi-jurisdictional research. We'll meet the data services team and talk a little bit more about some of the services that we provide and then we'll end at the end with summary and questions. And I do want to say in advance I got very excited with the PowerPoint animations, so just be prepared for that.

So what is NB-IRDT Data Services? Or, I guess I should say, what are data services? NB-IRDT is a Research Data Center, so we offer access to large administrative data sets that are linked and placed in customized project folders to fit your specific research needs. So, what that means is, you don't come in and access the data sets just as they are - each research question is reviewed through a data access process and then there are custom project folders set up with the specific data needed to answer that research question. There's a Research Data Center in almost every Canadian province, in case anybody doesn't know, and we'll talk a little bit more about that later when we talk about our HDRN partnership.

As you'll see here, I mentioned that the linked data is "pseudonymous", so I want to define that for anybody who might be unfamiliar with the term.

Pseudonymous means that any direct identifiers in those administrative data sets that we hold are taken away or transformed into a different identifier and then we keep the things that are indirect identifiers, such as a date that a service was accessed, a medical diagnosis, a length of hospital stay, those types of examples. We keep that in the data set so it can inform the research that you're doing.

We offer those things in our secure research environment. We have this environment available at three physical facilities. These are located at UNB Fredericton, UNB Saint John and UDM in Moncton. So, we have three sites where you can come and access your data and we offer support.

Oh, my animations might not be working, hold on. It's all part of this, right okay, let's try this again... Here we go.

We offer support throughout the data life cycle. So, if anybody's familiar with the data life cycle, if once you're looking at your collection, access, use, dissemination and disposition NB-IRDT Data Services touches all of those components, but for today what I'd like to do mostly is to focus on the access and collection piece, because those are your entry points to NB-IRDT. So, we'll start there and then, at the end when you meet the staff, I'll mention a little bit more about what we do.

So, you got a sneak preview of this slide but we're back. We're going to focus on three scenarios in terms of access and collection and entering NB-IRDT Services via the Data Services team. So, if you have a researcher policy question that could be potentially answered by our data, we can certainly help you there. For

example, maybe you want to study cancer incidents in a particular population and you know that NB-IRDT carries cancer data - then you would come to see Data Services to see how you would get access to our data to do that work.

The second scenario that we'll cover is if you have data to store. So, if you're working on a research project and maybe you've requested access to a sensitive data set from another organization and they want to make sure that you have the means to securely store and access that data, we have the ability to help you with that. Or maybe you've collected some data yourself and you need that secure storage and management mechanism. We can help you with that too.

And finally, the third scenario that we'll look at is a combination of those two items. So maybe you don't just have a research question, or you don't just have data. Maybe you'd like to bring in some data and link it to what we already have on the platform to answer a specific research or policy question.

So, for example, if you're a healthcare provider with data on an intervention that you've done, and you'd like to link to administrative data to evaluate the effectiveness of that intervention, that's something that we do. Or if you want to conduct survey research and want to link that survey data to our administrative data to answer a research question that you have related to that, those would be places where you would pursue this scenario.

And a little cheesy note for you - just that we're your 'one-stop shop' for data.

So, for scenario one, we'll walk through this. I really wanted to frame this in sort of a 'Choose Your Own Adventure' kind of way. So, if you're initiating research at NB-IRDT, I really want to stress that everything starts at Data Services. So, you know you want to do research and there are a few levels of support that you

can choose regardless of what that is. Come see us at Data Services and we can help you along the road to getting where you need to go.

Specifically, in terms of choosing a level of research support, I like to think of it as a 'full-service' ranging to 'self-service' types of options. So, there are a lot of different combinations that are possible, but I broke it down into three kinds of common scenarios that you might be able to relate to.

So, the first scenario is a research contract. This is really your full-service option where NB-IRDT will consult with you to design the research, to submit the data access paperwork, conduct the analysis and deliver the results at the end. So, you can speak with us, arrange a contract, arrange payment and that is a service that is possible at NB-IRDT.

We also offer analytical services. As a package, that's really kind of a 'partial-service' kind of option if you want to think of it that way. So maybe you want to design a study, you can submit the data access paperwork on your own and maybe even you want to conduct some of the analysis, but you would really just like some assistance from our analytical team to help you carry out the research - that is a possibility as well.

And then your 'self-service' option would be if you have your own team. You have everything under control, all you need to do is get access to the data to do what you need. That is possible as well. So how do you initiate all three of these options? You start the conversation with a feasibility request. So, we're happy to say that there isn't a lot of guesswork on your side, regardless of what you want to do with research. Fill out our feasibility application and we'll be able to direct you according to what you want to do. We are redesigning our feasibility request to become a little more general because, as NB-IRDT evolves, there are a lot of different situations that maybe haven't occurred in the past.

But what I would suggest there is just to fill out what you can in the form - it's meant to be a communication mechanism that lets us connect you with the service that you need. So, there's a link there to the request, and I should say, at the end of the presentation I will share a PDF and all of these links will be available.

Okay, the second scenario if you recall, thanks to this little thumb drive. If you have data to manage, we can help you do that too and I broke that down into three scenarios for another 'Choose Your Own Adventure'. So, you can sense a theme here...

When you're choosing your data sharing approach you can add data to the MBRU team platform and that would mean that you're becoming an NB-IRDT data partner. So that means that you'd like to share the data set that you have with other researchers so that they can conduct their work as well. We'll add it to our platform and make it available for researchers to request through our data access request process.

We also recognize though, that some data is only appropriate to link for one specific project. So that's possible as well. For example, maybe you have a very specific project that you're running in a very specific data set and it's not appropriate to be on the platform or used by anyone else. We can make sure that we bring it in and it's just available for the one use.

And then, of course, there's that third scenario where you need to store data, but you don't want to link anything to it at all. You don't want to store it on the platform, you just need it to be in our secure research environment for you to go in and access and do whatever you need to do. Or maybe you don't need anything, maybe you just need somewhere for it to securely live. We can provide that service for you as well.

So, to initiate the conversation on these items, I would suggest at the moment ... current state, just emailing us at NB-IRDTData@unb.ca , let us know what you'd like to do and our staff can help you. I am excited though to announce that future state, and by future state I mean probably within the next month, and this is for... also if anybody watches this recording... there will be a data transfer initiation form available. That's something that we've just developed. That's something that you can find on the NB-IRDT website. There's a link to the data section on the last slide and you'll be able to fill that out, send it in to us and then it answers some preliminary questions that just helps us route your request a little bit faster. So, we're really excited to have that service improvement.

The third scenario - that's really the combination of scenario one and two. So, if you want to put data on the... or if you want to link data, sorry, to the NB-IRDT platform to answer a research or policy question, you might wonder: "Where do I start?" So, there are a couple of options. It depends basically on whether the data has been collected already or not. So if you have data that's already collected - it's already available, maybe it's with you, maybe it's with another source, the best thing to do would be to reach out to us on the data team and our Data Transfer Coordinator will work with you to determine what agreements are needed, if consent needs to be addressed or, you know, what needs to happen before this data can be transferred and linked.

Alternatively, if you haven't collected the data quite yet, there's a really good opportunity to get in touch with us first and what that will do is we can ensure that we can help with anything regarding... if you have questions about consent. Just making sure that everything's in order to make sure that we'll have the authority to link the data to administrative data later. And we can also initiate a multi-phase data access request, which means that we would be able

to help you secure an REB approval to collect that data and that would start with a feasibility request.

So, it feels like we went through that a little bit quick, but we will have lots of time for questions. I do want to touch on our HDRN partnership for multi-jurisdictional research. So, if you're wondering, if you haven't heard of the Health Data Research Network (HDRN) before, basically it's a collaboration between data centers and other data organizations across Canada, and that includes organizations like Statistics Canada the Canadian Institute for Health Information and other partners... and the goal is to advance research data access and opportunities across the country. So that's a really exciting partnership because, by data services being so heavily involved in this network, we are working to expand opportunities for multi-jurisdictional research which we're really happy about.

The Data Access Support Hub (DASH), I want to mention that as well. That is a sub-project of the Health Data Research Network (HDRN). We also, at Data Services, have been heavily involved with that initiative. And what DASH is, is a one-stop data access service portal for researchers requiring multi-regional data in Canada. Definition lifted from website, but hopefully you get the idea. By coordinating multi-jurisdictional research requests through DASH, we were really able to reduce a lot of the administrative burden for researchers. If anybody's tried to do multi-jurisdictional research before, I'm sure you have a lot of messy stories to tell. So, we want to work to make that experience easier. One of the things that we did recently was we worked with the team to create what's called the DASH DAR form and this allows a person to submit one Data Access Request (DAR), which gets submitted to all selected data centers that they want to work with, simultaneously. I do want to clarify that, that doesn't mean that the data is pulled together. That's something that we're limited and unable to do at the moment due to legislation, but we do want to at least make sure that we

can do our coordinated data request and reduce the amount of duplication of work as much as possible. So, it's a really big development and if you want to learn more, I've included the link there that you can access in the PDF.

So now we'll go through and meet the Data Services team. We have six core members of the team right now, but we also work with a lot of amazing students that are currently with us doing privacy work, data work, all kinds of different things... but these are our main members of the group: our Data Transfer Coordinators, our Data Access Coordinator, Database Administrator, our Privacy Officer, they are all working to provide service throughout the data life cycle.

The animation's back, so I just wanted to go through quickly and kind of give a sense of each person and where they might touch on the life cycle, to give you a more fulsome sense of all the activities that go on in Data Services. So, for example, our Data Transfer Coordinator Megan Pike - she facilitates really the everything-to-do with data transfer; all of those things in scenario two that we were talking about: about sharing your data via data sharing agreement, adding it to the platform, maybe just doing an agreement for a single use or just storing it just to have that management platform. Megan helps with all of those components. She also communicates heavily with the Data Access Coordinator to make sure that, in situations like scenario three where data access and data transfer are happening together, to physically facilitate that linkage so that that can happen and she also coordinates data destruction and return which goes into the disposition part of the life cycle because, of course, once we bring data in, eventually the data needs to be destroyed or returned or however it's agreed in the data sharing agreement, so Megan makes sure that happens.

Meanwhile, our Data Access Coordinator, Afton Levine, she's more about coordinating everything "access". So that can be anything from making sure

that feasibility requests go to the right people... she coordinates the entire data access request from beginning to end, so once you indicate that you'd like to submit a data access request, Afton's your guide. So, you don't have to worry about not knowing what the next step is or how to proceed. Afton will support with that. She also works with the dissemination piece of the data life cycle, so once data is accessed, you've done the use component of analysis and the data is ready to disseminate and your research product is ready ... you've created your report or your presentation or whatever's going to happen, she oversees the embargo process, which is something that's required before ... your research products, sorry, can be shared with the public.

And our Data Service Coordinator, Carla Hubby, she works on some interesting projects related to data collection, which is coordinating data acquisition projects across multiple organizations. So that is heavily connected to the Health Data Research Network. There are some projects happening right now with organizations such as CANpath, where we're hoping to get those data sets into multiple data centers and to provide access to those where it doesn't currently exist. And Carla also supports policy and procedure documentation for all data services team activity, which touches all pieces of the life cycle.

Then we have our Database Administrator, he advises on variables during the access process, he prepares the custom project folders for applicants to use, he facilitates the data release for dissemination and he deletes and destroys data as appropriate during the disposition phase of the life cycle. So he deals with a lot of pieces of this process and our privacy officer and research associate, Donna Curtis Maya, is really heavily involved in pretty much all of these processes as we operate on a principle called Privacy by Design, so everything that we do is based on the privacy principles, so Donna advises on privacy best practices for the collection of data, she reviews data requests for access, she

oversees the privacy training for use and she oversees auditing for all stages of this process to make sure that everything is being done correctly.

And for me, I guess I support the team in carrying out their work in all of these stages, so I'm more of a supporting player and everybody else here I would say are really the stars of the show.

Okay, so an overview of what we talked about today. Data services can help you access data to answer a research question and, regardless of your service level whether you want to go research contract and get your full service or if you really just need to go in and access the data and want to do all of the research and analysis on your own, you want to start with the feasibility request. We also talked about transferring data to NB-IRDT, whether that's becoming a data partner and adding data to the research data platform, whether that's linking to platform data just for one project or securely managing data in our secure research environment without adding it to a platform or linking to anything. And you can initiate that by reaching out to NB-IRDTdata@unb.ca or, as we mentioned, in a future state you'll be able to fill out a data transfer initiation form.

And in the scenario that we talked about where you're collecting data that will eventually be transferred to NB-IRDT and linked, the first step, of course, is to fill out a feasibility request so we can help you through that process and if you've forgotten everything that we've talked about in this presentation and you don't know where to start, reach out to NB-IRDTdata@unb.ca . The contact information is also on the last slide and our friendly and professional team is honestly just more than happy to guide you with every step.



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If you have questions, or would like to know more about NB-IRDT visit us online or contact us:
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