The Perspectives of Social Service Participants on Consent, Privacy of Information and Data Governance

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Overview

The objective of this report is to provide new insight about the perspectives of social service recipients, an often-underrepresented group, about consent, the privacy of information and data governance. The report begins with a brief overview of the information sharing landscape in Alberta, followed by a summary of existing research examining different attitudes and perspectives on data usage, and concludes with the findings of our study.

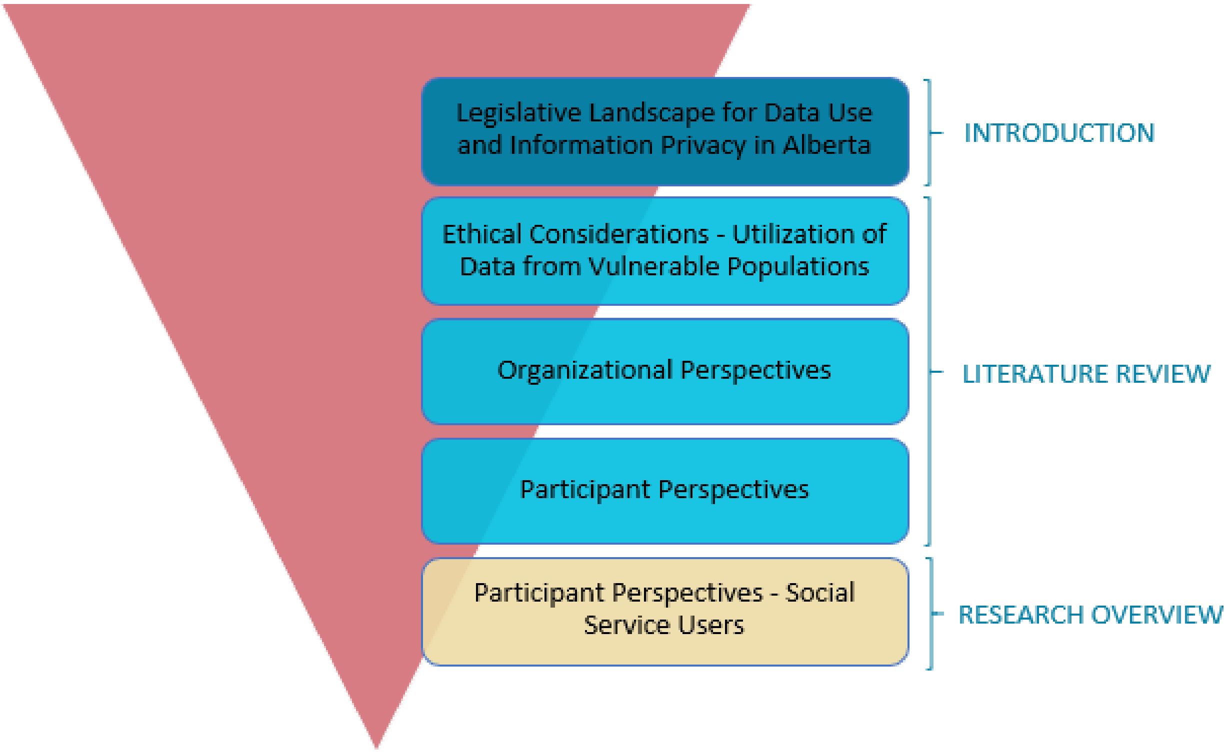

Figure 1. Report overview

Introduction

In the Alberta not-for-profit sector, discrepancy exists in the areas covered by legislation governing the utilization of personal information (Manhas, 2017). The development of information privacy policy is an ambiguous and hard-to-navigate field. There are three main pieces of provincial legislation that govern information privacy in Alberta: (1) the Freedom of Information and Protection of Privacy Act (FOIP), which deals, almost exclusively, with information that is not health -related that is held by public entities; (2) the Health Information Act (HIA), which governs the use of health information by designated custodians; and (3) the Personal Information Protection Act (PIPA), which concerns personal information held by private-sector organizations. Because PIPA only applies to organizations involved in commercial (profit-seeking) activities, it rarely applies to non-profit service agencies. Furthermore, non-profits are not subject to scrutiny under Research Ethics Boards (unless handling health information or working in affiliation with an academic institution). This leaves not-for-profits largely unregulated, and unclear on how best to when it comes to establishing privacy policies (Manhas, 2017).

This ambiguity is of concern for agencies that provide social services to vulnerable populations, where the collection of identifying information is a necessary operational procedure. The use of this data beyond the originally-intended operational use becomes increasingly challenging. Manhas (2017) notes that, although not-for-profits have the jurisdiction to do what they wish with their collected data if it meets the limited existing legal imperatives, defining and adhering to best practices is still very important.

"NFP (not-for-profit) clientele place great trust in their organizations when seeking services and supports. That trust could be severely damaged or lost, if there were privacy breaches or risks of harms because NFPs did not consider client preferences and protections in their use and disclosure of the data." (Manhas, 2017)

The specific mention of "client preferences" in the above quote enforces the need to include participants in decision-making about data governance. This report seeks to serve as an example of such client perspectives could be considered by not-for-profits when developing data and information privacy policies.

Despite the challenges surrounding data utilization, "secondary data use when aimed at improving service delivery or outcomes within the NFP sector and its client population, respectively, can be realized without sacrificing individual privacy and organizational trust" (Manhas, 2017). It is essential to include participant perspectives in the process of developing organizational policy: it is their information that is being collected and utilized. It is important for vulnerable populations, where personal information is often subject to fraud or misuse (Hartman, 2015) and where the circumstances described in their information may be sensitive, for example including information on housing status, or a history of addictions and substance use.

Literature Review

Introduction

A literature review was conducted to provide an overview of existing research about perspectives on data collection, organizational data use and data sharing for secondary data use. It includes three categories of perspectives: ethical, organization-level and participant-level – all of which are covered in separate sections below. Across these three categories, three sectors are represented: institutional (i.e., Government or healthcare-related), private, and not-for-profit. The not-for-profit sector is noticeably under-represented, which is indicative of the research gap this report is attempting to fill.

The *University of Alberta Libraries* and *Google Scholar* were the two primary databases used to conduct this review. Searches were performed with combinations of keywords and phrases such as: ‘perspectives on data use’, ‘researching vulnerable populations’, ‘secondary data use’, ‘non-profit data’, and ‘privacy of information’. Sources cited include peer-reviewed scholarly works, grey-matter research and government-produced reports. A chart summarizing the findings is presented in Table 1 (page 8) in addition to the findings depicted in the following written sections.

Ethical Considerations

We define Ethical Considerations as … *areas that have been identified by arms-length researchers or groups who have studied the underlying sociological, psychological or legal principles and their implications related to data utilization*

In this section, rather than focusing on the ethics of data use in general, a particular focus is taken on ethical perspectives on research and the use of data from members of vulnerable populations. Non-profit agencies typically provide services aimed at supporting vulnerable persons. The American Journal of Managed Care defines ‘vulnerable populations’ (a term often used in healthcare) as a group which includes, “the economically disadvantaged, racial and ethnic minorities, the uninsured, low-income children, the elderly, the homeless, those with human immunodeficiency virus (HIV), and those with other chronic health conditions, including severe mental illness” (AMJC, 2006). There is significant research investigating the ethical principles that should be followed when collecting and using data from different subsets of this group, both in academic research settings, and in community-based research.

One of the central underlying themes in this pool of research is an emphasis on participant-centred research strategies and the co-directed use of data for research or advocacy as activities that contribute to research being done in a more ethical fashion. Munro et al. states that researchers “need to ensure that the well-being of children [study participants] takes centre stage throughout the research process” (2005). Munro et al. go on to emphasize the importance of informed consent when collecting and using their information, including informing participants of “the extent to which the data may be used in other research projects” (2005). It is not only necessary for the needs of participants to be front-of-mind when collecting and using their data, but it is also necessary to include those participants in decision-making about that data use. In an article for the New York University Review of Law and Social Change, Gius (2018) argues that advocacy cannot be effective unless the people being advocated for are participating in that advocacy. To deny them that role would be to exclude them, in other words, to deprive them of dignity – which defined as “shared, equal social status”(2018). The capacity-related constraints such as staff juggling multiple responsibilities may inhibit community-based organizations from regularly consulting their participants on matters related to their data. Any data derived advocacy on participants’ behalf is recognized, but it does not supersede individual rights for self-determination and control (Gius, 2018). Neglecting to include marginalized groups in decision-making about their own lives by "participating in typical top-down decision-making processes may affirm existing power structures, thus risking affront to dignity" (Gius, 2018). Instead, consultations and consensus-building are more likely to meet the ethical goal of enabling participants to have significant control over the project (Gius, 2018).

Another theme is the contentious role that legislation continues to play when it comes to governing how to ethically handle data from vulnerable populations. Both Munro et al. (2005) and Menih (2013) suggest that legislation has become an overly cumbersome barrier to research, stopping the very research that governments require to create evidence-based policies, especially for vulnerable populations. In the non-profit sector, social service providers host large amounts of data that could be used secondarily to help the people from which it was collected, so finding a balance between restriction and investigative freedom is certainly a challenging but, important part of data governance. This is precisely where participants should be included to help define the boundaries surrounding appropriate use of their data. The following two sections seek to identify both organizational and individual responses to the nature of where this balance should lie, as well as to shed light on other perceived benefits and drawbacks pertaining to data use.

Organizational Perspectives

We Understand Organizations as … *bodies collecting data from subjects*

We looked to the literature to see how organisations perceive data risks, how they value data utilization and how they deal with ethical concerns around data privacy.

Key themes include the perceived benefits of collaboration between service providers, an emphasis on obtaining informed consent and concerns related to capacity.

In a report produced by a team from The George Washington University about the state of homelessness in the Metropolitan Washington Region, recommendations were made on data integration and coordinated care for recipients of social services between jurisdictions of the metropolitan area (Buckley et al., 2009). The report involved surveys and interviews of both representatives of service providing agencies, as well as individuals who self-identified as homeless. Results demonstrated that the primary issue that service providers face is the sharing of data both between agencies in neighbouring jurisdictions, and also between agencies that operate in the same jurisdiction (Buckley et al., 2009). With the problem clearly identified, the benefits of a proposed solution (a Web-Based Homeless Management Information System) also became clear: reduced or eliminated duplication of both services and data collection; coordinated care and case management; accuracy in counting numbers of homeless people; reduced costs; and as a result of these direct benefits, improved service provision, on the whole (2009). Alongside potential benefits, the perspectives of local service providers highlighted areas of challenge. Protecting privacy and confidentiality was a top concern: service providers acknowledged that "data sharing is a sensitive matter". Other concerns included double data entry, lack of funding and issues related to standardization versus customization of data entry software. Ultimately, the report recommended that the Metropolitan Region move forward with the web-based HMIS, with accompanying recommendations emphasizing the importance of consent and urging the government to allocate sufficient funding toward this initiative (2009).

Similar perspectives were found to be held by Albertan not-for-profit agencies. In a survey of 116 Albertan not-for-profits, the majority (76%) held the view that their data was an asset that could be leveraged (Zhang & Barbosa, 2018). The most commonly mentioned perceived benefits included collaborating with other not-for-profits, leveraging data for funding purposes, utilizing data for research, and improving service provision (Zhang & Barbosa, 2018). Just as in the case of Washington Metropolitan, certain challenges were identified that must be faced to achieve the previously mentioned benefits. 'Privacy concerns' was the number one selected reason for not sharing data, followed by the belief that data sharing was not legally permissible, and then thirdly, that capacity for such work was not available (Zhang & Barbosa, 2018). This indicates a clear need for improved knowledge around what is legally permissible in terms of data usage and what can be done to mitigate privacy concerns. Once greater understanding of these two areas is established, advocating for resources to be allocated to data work could become not only a higher priority for non-profits, but also significantly easier as noted in a report from the Interagency Council on Homelessness Calgary – Community Conversations (ICHC, 2012).

Despite this lack of clarity surrounding privacy of information and data governance for non-profits, many organizations still see data utilization and integration as a necessary step to move forward in efforts to support vulnerable populations. In a report investigating the perspectives of Calgary social service providers, participating agencies "stressed the need to have good information to assist with designing programs and determining priorities" (ICHC, 2012). They also indicated that being able to share (more than just some) client information would not only be helpful, but that it would be "critical", and that a "formal process [should] be developed for centralized data collection" (ICHC, 2012). In conjunction with collaboration between not-for-profits, collaboration between the work of provincial ministries should also be occurring to help aid vulnerable populations more effectively (ICHC, 2012). Not-for-profits recognize how maximizing data usage will have tremendous effects in their work, and that taking steps to mitigate challenges regarding data sharing would be worth the effort.

Indigenous communities, too, recognize how efforts to better their communities "should be strengthened by the research" that comes from their own members' data. The Assembly of First Nations' Chiefs Committee on Health's perspective on data governance stems from the OCAP model, wherein they operate under the principles that an Indigenous community holds the right to ownership, control, access and possession of their members' data (First Nations Information Governance Centre, 2007). Ensuring that self-determination and control over data are rights that are reserved for members is of highest priority. The report states that the goal of research should be to make discoveries which could support the well-being of their communities, and that it should allow individuals the ability to "[take] control [of] and [manage] their health information" (First Nations Information Governance Centre, 2007).

Participant Perspectives

We Understand Participants as … *the people from whom data is collected*

When narrowing in on participant perspectives, the main focus of our own research, certain motivating factors can be seen to influence individuals' views on the utilization of their data. The largest segment of literature regarding participant perspectives on data governance and information privacy occurs in the healthcare sector, particularly genomics. One such example is a study analyzing the perspectives of research participants' views on the governance and sharing of their de-identified genomic data

(Goodman et al., 2017). Goodman et al., (2017) note that most participants were in support of their data being deposited in a repository and were motivated by the idea of it being utilized in as many research studies as possible, both with the intent of helping others, and with the hope of finding solutions for their own medical issues. Similar results were found by Zarate et al (2016), and Manhas et al., (2015). The desire to help others and to help themselves appear to be core values behind participants' motivations to support the utilization of their data.

Participants are concerned about the privacy of their information (Goodman et al., 2017) and hold this principle in tension with the aforementioned desire to contribute to societal benefit. Kim et al. reported that "respondents value individual control over societal benefit, but societal benefit over privacy", which they interpreted as meaning participants simply want to have control over who and for what purpose their data is being used, even if it still being used widely (2015). In order for participants to act on their motivations to help others by allowing their data to be used for research, they need to be convinced of the privacy, security and transparency of the process involved (Kim et al., 2015).

Willingness to share data varies depending on the type of organization that will be using it, with participants being more willing to share with hospitals and universities, and less willing to share with private sector organizations like insurance and pharmaceutical companies (Kim et al., 2015). The sector itself may be a large influencing factor; in one review, it was found that "while individuals were generally willing for data or biospecimens to be shared with other academic researchers, individuals were less willing for their data to be shared in federal databases or with commercial enterprises" (Garrison et al., 2016). This reinforces the idea that a participant's decision to share their data is dependent both on the purpose aligning with their values, as well as the existence of appropriate measures to mitigate risk.

Consent, as a recognized means of addressing the previously mentioned issues, seems to be a necessity for participants. This is acknowledged across differing aspects of data governance, where participants require permission for differing data types including de-identified data (Manhas, 2016) and for differing data uses such as for healthcare provision and for research (Kim et al., 2015). In terms of defining the type of consent participants feel is most appropriate, it was found in a review of 48 studies that broad consent is preferred by participants over "tiered or study-specific consent" (Garrison et al., 2016). The reasons behind this perspective were attributed to the desire for a balance between convenience and security. As previously mentioned, the requirements for appropriate consent processes in the social service arena are ill-defined and highly dependent on the context. For social service agencies, there is an absence of information about what social service recipients expect from consent processes when dealing with their data.

Although great value is provided by these studies, and the ones presented in Table 1, the perspectives of individuals in the non-profit sector, especially those who are recipients of social services, are largely unheard. People in this group may have different values, motivations, and cautions to bring forward: ideas that our research seeks to shed light on.

Table 1. Literature Review Chart

Sector	Article	Perspective Type	Key Perspective Factors
Institutional	Castaneda-Guarderas et al., (2016)	Emergency department staff and patients	Shared decision making to mitigate patient mistrust; Re-structuring power imbalances; careful collection of group-specific data to inform decision making
	Fält, Sarkadi, and Fabian, (2017)	Participant (Nurses, teachers, parents)	General support for data sharing, perceived that it will identify and help resolve issues for children with difficulties; Identified need for structures and practice to ensure responsible sharing
	Goodman, et al., (2018)	Participant (Patient) Genetic Researchers Institutional Review Board (IRB)	Both researchers were less likely than participants or IRB's to believe that participants would be at risk from de-identified data sharing; there should be collaboration between stakeholders when determining data governance policy
	Manhas et al., (2015)	Participant (Parents)	Repositories from which data can be stored and accessed for secondary use allow the maximization of data use for participants, researchers and funders; Participants need privacy relationship building and data governance to be addressed
	Robinson et al., (2015)	Participant (Patients with HIV)	Trust; Fear of discrimination; Stigma
	Roffee and Waling (2017)	Participant (LGBTIQ victims of violence and harassment)	Concerns about the utilization of data for purposes outside those which were consented to; Inaccurate representation
	Tenopir et al., (2011)	Scientists	Effective and responsible data sharing inhibited by outdated culture and practices in research sector; data sharing important for maximizing data use
	Wilson et al., (2015)	Mental health professionals	Confidentiality vs. sharing with caregivers and other healthcare professionals; consent from patient required
Commercial	Culnan, et al., (1999)	Participant (Customer)	Reassurance of information privacy procedures
	Kumar et al., (2018)	Participant (Social media users)	Perceived trust, which was influenced by the nature of previous experience with a site, is vital for user to disclose information; intent to share information with others helps mitigate trust concerns
Ethical	Gómez-Barrosoa, Feijóo, and Martínez-Martínez, (2018)	Ethical	Ethical concerns related to ease of data collection and exploitation due to rise of digitalization

Conclusion

The results of the literature review reveal a limited body of knowledge surrounding participant perspectives on information privacy and data governance: in particular, the perspectives of social service recipients.

Research Questions

The study objective was to gather the perspectives of social service participants. We sought to answer the following questions:

What are the views of people who access social services that are aimed at eliminating poverty, including housing, family and employment services on:

a) the collection of their data?
b) the use of their data for operational purposes?
c) the use of their data for evaluation and research purposes?
d) the types of consent processes they would prefer?

Methods

Overview

This project included 5 community focus groups (or workshops) to discuss the research question. An animated video vignette and example reports served to ensure all participants were familiar with the topic to participate meaningfully. The project incorporated follow-up communication for participants to provide feedback on the findings, including emails and an opportunity to attend lunch.

Recruitment

People who were accessing Bissell Centre services and who were over 18 were eligible to participate.

Recruitment for the workshops occurred in four ways: (1) the display of posters in each of the two Bissell Centre buildings; (2) requests for staff to directly inform the participants with which they work, (3) prior to Workshop 5, phone call invitations were made from a caller list, which was composed of participants who had been active in Bissell Centre's database anytime two months prior to the focus group and (4) anyone who was currently at Bissell Centre accessing services was invited to join. Participants were reimbursed for their time with ten-dollar gift cards and either a snack or lunch provided in the workshops. The workshops took place either after a women's lunch program at Bissell Centre (Workshops 1 and 4) or in the Bissell Centre Community Space (Workshops 2, 3 and 5).

Ethics

Prior to the initiation of the research project, the A pRoject Ethics Community Consent Initiative (ARECCI) Ethics Screening Tool and the ARECCI Guideline Tool were both used to evaluate the potential ethical risks posed by the proposed project and whether those risks were appropriately mitigated. The project received a score of 88 points, which is categorized as 'minimal risk'. Insight gained from these tools were incorporated in the project protocols.

Participants filled out a consent form to participate and were given an information sheet to keep that included contact information for the project lead. This was explained and read out verbally at the beginning of the workshops.

Focus Groups

Materials

Several materials were used to facilitate the focus groups. The first of these materials was a semi-structured focus group guide (Appendix 2) which was created with the intent of directing the conversation without being overly restrictive. The structure of the guide was inspired by the instrument used by Manhas (2016). Stephanie Breakey attended all workshops, acting as moderator (1-3) and as co-facilitator (4-5). Maria Savidov (1) and Rayann Fleming (2-3) both acted co-facilitators. Genna DiPinto was the moderator for workshops 4-5.

The other materials were intended to provide enough context of the topic to ensure the workshop participants could engage in the conversation in an informed manner. We created a video vignette[1] which illustrated the journey of a participant's data when accessing services at Bissell Centre, which was accompanied by a flowchart handout. Other handouts were also provided, such as an explanation of how the focus group would operate and a visual report as an example of how aggregate data is used currently.

Consent Poll

A poll was administered at the end of each workshop to survey participants for their views on consent. The presented options for consent were created based on the options outlined in a similar Alberta-based study (Manhas, 2017). The language describing the differing types of consent frameworks was changed to a simplified English, and participants were asked to indicate when they would want to be asked for consent in three different situations. Participants were asked to respond individually on a sheet of paper that indicated the options.

Consent Poll		
	• When Should John Be Asked Permission to <u>Collect</u> His Information? ____ • When Should John Be Asked Permission to <u>Share</u> His Personal Information for a referral? ___ • When Should John Be Asked Permission to <u>Share</u> His Anonymous Information? ____ *(fill in blank at end of sentence with the corresponding number)*	
1	Ask Every Time	Sarah asks John if she can take notes when she meets him, and the next time she meets him. Maya also asks John if she can take notes when she meets him.
2	Ask at the Start Only	Sarah asks John if she can take notes when she meets him. She doesn't need to ask him again. John can tell Sarah he changes his mind at any time.
3	Ask at the Start, and Every Two Years	Sarah asks John if she can take notes when she meets him. If John is still connected to Bissell in two years, his worker will need to ask again then.
4	Ask at the Start, and Ask if Something Changes	Sarah asks John if she can take notes when she meets him.
5	Tell, Don't Ask	Sarah tells John she will be taking notes, and if John preferred she didn't he needs to tell her and then she won't store them in the database.

Table 2. Consent Poll and Response Options

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[1] URL for animated vignette https://www.youtube.com/watch?v=tU7K2GZL600

Mid-Study Evaluation

An informal mid-study evaluation took place after the third workshop. Analysis occurred to measure consistency to ensure the same questions were touched upon in each workshop and to assess whether or not it appeared participants held an informed understanding of the subject matter being discussed. The review found that there was a high level of consistency between workshops in terms of adherence to the interview guide, without unnecessary restriction. It also resulted in the creation of a flowchart (see Appendix 3) to accompany the video vignette, and a small modification to how the poll questions were presented.

Analysis

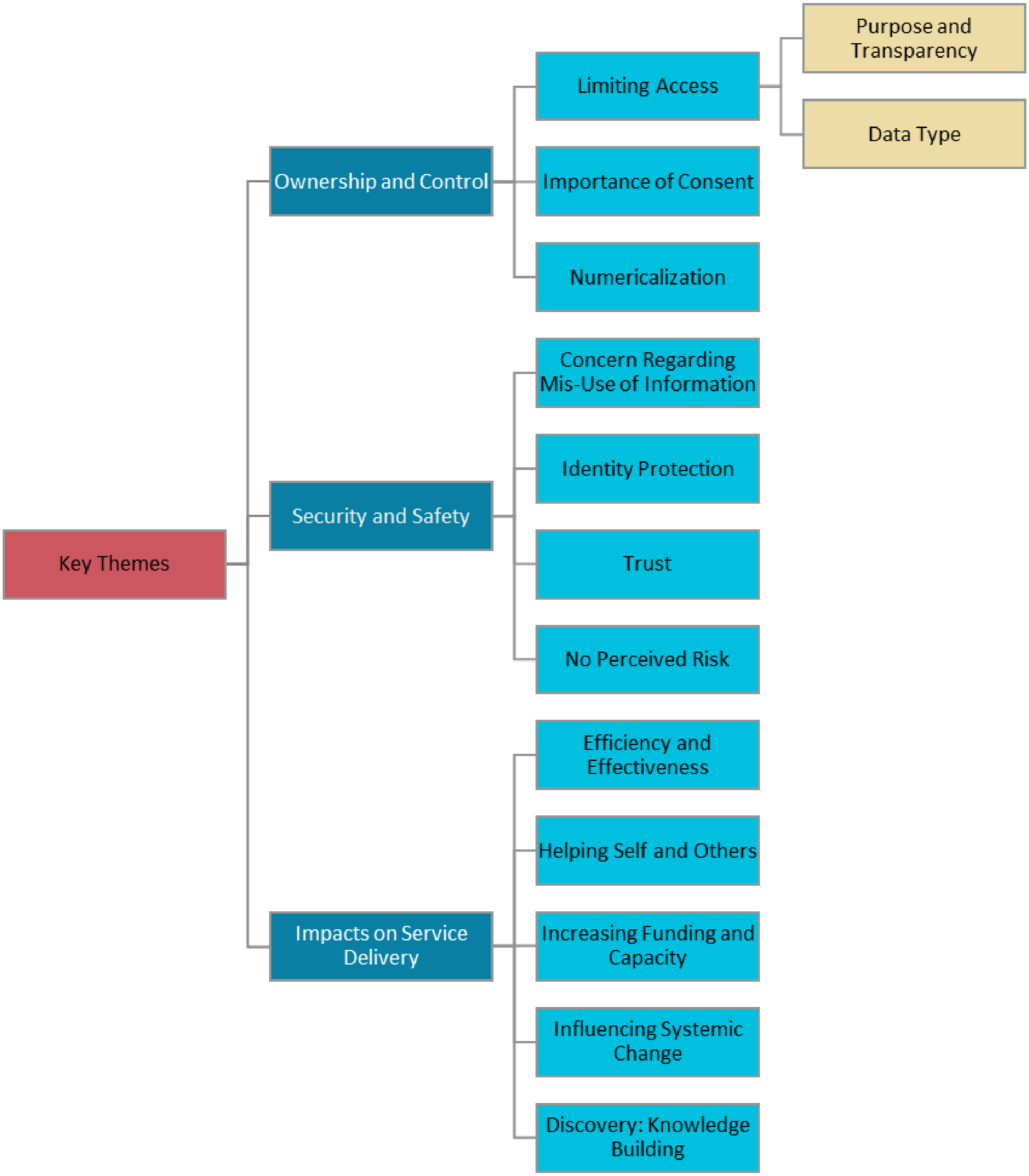
The focus groups were audio recorded and transcribed. All identifying information was omitted from the transcriptions. RQDA (Huang, 2016), an extension of the data analysis software, R, was used to code the transcriptions. Coding was executed inductively, with the objective of allowing themes to arise naturally from the transcriptions. Themes were grouped together or parsed apart after several iterations of analysis. Genna DiPinto coded all the transcripts, and Stephanie Breakey reviewed a sample of these codes (3/5 of the transcripts).

Follow-Up

Participants were asked if they wanted to "stay in the loop" and hear about the outcomes of this project and learn about future Bissell data projects. They were asked to indicate their preference on the consent form and provide contact information. Drafts of the findings were circulated to those who wished to be informed, and an invitation to discuss the findings over lunch was extended. Those who couldn't make lunch were given the opportunity to discuss the findings over the phone.

Results

Summary of Themes



Participants

Five focus groups with a range of 6-9 participants each took place between the months of May and June of 2018, resulting in a total sample size of 36 individuals. The sample contained 20 men and 16 women. Two of the 36 individuals participated in two workshops.

Themes

[2]Three overarching themes, which include twelve sub-themes, were used to categorize the results of our qualitative analysis.

1. Ownership and Control

This theme speaks to the notion that data which has been collected and stored retains significance for the person who shared it. Moreover, that the person who shared it desires to be able to exercise some type of control over what will happen to their information.

Limiting Access

The prevention of over-access and over-sharing of information were key themes that arose in workshop discussions. Participants were clear that collecting unjustifiably large amounts of information or sharing information with unjustifiably wide networks is not an acceptable practice. Participants want to be informed of who is accessing their information, and they want to be assured that any plans to share their information will first receive consent from participants. This includes sharing data within an agency, to other agencies, or to other external groups.

> *I know Calgary and all the companies get to look at it and then another worker at another place can say ah we know what you're up to cause they read the file and then one of the workers can see everything and read everything and she knows what you're up to and so I don't agree with that, I think it should stay where it is, with the worker, and if you* [participant] *want to expand it, then you have the right to do that, you could say well I want it to go to here to go to there, so that I got better opportunities and chances…because once people get to view that it can become a sphynx* [Workshop 3]

Although government access to data was a subject area not prompted by questions, some participants expressed their views about sharing data with government bodies. Some felt that doing so would give government an opportunity to over step their bounds, "Don't tell the government any of it." [Workshop 2] meanwhile others felt the government already had all their information.

Another issue that participants felt needed to be addressed is the length of time that data can be stored and used. Participants desired clarity on how they can change their minds, revoke consent, or how they could have their information deleted if they so desired.

> *I can make my file ripped up or whatever, I can tell them to forget about my opinion* [Workshop 5]

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[2] Note: where a quote is preceded by 'P' or 'F' it is to differentiate between speakers where P stands for participant, and F stands for facilitator. Likewise, 'P1', and 'P2' differentiate between two different participants in conversation.

Purpose and Transparency

Being informed about the intent of the research for which data would be used is a necessity, participants felt. Informed consent needs to include details about the focus area, intent and context of the initiatives for which data would be used.

> *When you're agreeing to something and you're saying hey I agree to it, but you've not got all the aspects yet, and so what are they doing, what are they using it for, without that information, to agree on something like that, not sure it's really in the best interest of the individual…* [Workshop 3]

Without this surrounding knowledge, participants feel that they are not able to consent to the use of their data.

Data Type

The format and nature of data content influence how people feel about data use and data sharing. Participants view personal information with high levels of importance and expect to be able to exercise control over who has access to personal information and when they have that access. This attitude shifts when the conversation is focused on anonymous information, with participants less focused on maintaining control of their information once it had been anonymized or aggregated. However, this does not mean they do not care about anonymized information, as discussed in the review of the poll on consent later.

> *That's the best way to share information is anonymously. If it's personal personal information, sometimes I'd draw the line there.* [Workshop 1]

Data linking was mostly perceived as a good thing, with one participant describing his understanding of the process: "This is John, this is the same person, we're helping him and if he goes to other agencies, he's still the same person. It helps." [Workshop 4]

Importance of Consent

It was emphasized repeatedly that data utilization was not a concern, it just needed to be conducted responsibly. Appropriate, ongoing, and informed consent was the solution proposed most often when it came to defining responsible use. Participants made it clear that they just wanted to be included in the decisions about how their data is used so that they can remain in control of it. They also demonstrated awareness of legal boundaries and consent requirements:

> *They cannot have access without asking that person for information, or they signed a paper, saying they're ok with sharing information with other people, but if they did not sign a paper, there's no need.* [Workshop 1]

If an agency decided it was interested in using data beyond its original purpose, participants indicated that an agency would "have to contact everyone and say hey, are you agreeable to sharing this and people using it, you know and saying ok" [Workshop 3].

Consent was seen as an efficient solution to a complicated problem: "A written [consent form] only takes a second to print a piece of paper, it only takes less than a second for us to sign a paper." [Workshop 5]. It is also perceived as an opportunity for the agency requesting information to show participants that it values their trust and takes their input seriously. If participants feel that an agency is making a deliberate effort to protect their interests, then the sentiment is mutual.

> *You put your trust into an organization, you trust them so you have to bend a little bit for them too, so you agree to sign that paper, you agree to give your information, so now you come back and say, ok I'm going to, ok I'll print this paper for you and yes please sign it and I'll be happy to get the information.* [Workshop 5]

Instead of dismissing the need for consent when it comes to what agencies perceive as small uses of data, or uses that are warranted because participants will benefit, informed consent should still be required as participants view this as a decision they should make, not the agency. Participants expressed a need to find a solution that allows them to retain control, and to be assured that their information will not be open to misuse. However, they acknowledged that this requirement needs to be met with a solution that is not too onerous for either the agency or the participant.

> *Every two years, once should be good enough if he knows what kind of information and where it's going right, every two years for Bissell Centre seems appropriate* [Workshop 1]

Numericalization vs Personhood

Benefits and drawbacks of anonymization via numericalization were identified by participants. Some viewed de-identification as a way of protecting their identity and security of information. Others were concerned that despite the privacy and security benefits of de-identification, becoming "labeled as numbers" [Workshop 4] posed a risk for loss of personhood. This loss was interpreted as a loss of human uniqueness and a diminishment of the person's complex life and experiences. It was seen as a way of eliminating the typical channels of person-to-person communication to get fast and easy access to information. Converting identifying information to numbers to circumvent more difficult privacy issues is more efficient, yes, but it does not serve as a substitute for direct communication and consent.

> *I have this anonymous person, yes, but this anonymous person is a real human being and you know like, it'd be proper if you'd just go through our hoops - like let's communicate together, instead of saying ok (participant name), like we're going to use you to put you as a different name, why? Why should I - my name is (participant name), or my name is Helen, like what the hell? My name is on that piece of paper.* [Workshop 5]

2. Security and Safety

Concern Regarding Mis-Use of Information

Participants feared that if sensitive information was put in the wrong hands it could be used against them through discrimination or judgement. Multiple participants stated that intentional efforts to ensure data is not used in a derogatory manner would be a condition for data sharing.

> *I would love to help somebody else, take my info, as long as you're not using it to slander me, put me down* [Workshop 2]

Participants shared reasons that they would worry about sharing information, which included the concern of their residential address being shared with a family member who is not welcome or feeling that someone was invasively asking for information due to prejudice. Participants shared stories about how personal data was used with negative intent by others in the past, some citing family members, former partners, or landlords. These accounts included cases of perceived discrimination and being the victim of financial fraud. Others shared negative experiences involving the misuse of information in an agency setting, or the trepidation that a case worker may pry in their file. Each of these concerns causes reduced trust.

> *I don't find it appropriate sometimes where you know they'll pull out your file and all of the sudden, there's like three or four people … and they go 'oh yeah, we can use this person as an example today' … If you're going to do that, bring that person in and say here, we need your signature.* [Workshop 5]

Identity Protection

Given these concerns, the prevention of identity fraud and other misuse of personal information was a high priority for participants. Ensuring that only required information is requested of them by agencies was another important point, as mentioned previously. Collecting or sharing unneeded personal information puts more at risk than is required. This leads participants to be stringent when deciding to share their personal information.

> *Its good to share some information but not too much information, just enough so that it can help and is not collected for the wrong reasons, [be]cause you never know these days, there's a lot of fraudulent stuff going on.* [Workshop 1]

Trust

Some participants viewed their data as a form of currency, as though a transaction was occurring when they received services in exchange for information about them. This exchange seems to justify the risk of sharing. With this exchange comes a need for trust in the agency with which data is being shared:

> *You're doing yourself your own favour because you're homeless and you have to find a house, so you put your trust into these people*. [Workshop 5]

The maintenance of this trust, on the part of the agency, is required for participants to feel safe when sharing their data and when accessing services.

No Perceived Risk

Conversely, a minority of participants felt apathetic towards efforts to maintain confidentiality and control over information flow, as one participant put it, "it's not like it was a big secret in the first place"

[Workshop 2]. Others believed they had already consented to any use of their information, and that this did not warrant any further consultation: "Well, I signed a paper giving permission to do anything that they need to do." [Workshop 2].

As illustrated earlier, the format the information is held and shared in is important. No perceived risk to anonymous data sharing was another sentiment that was noted: "I can't see anything where it would go wrong its all based on studies right" [Workshop 3] or, as another participant stated, "It's just numbers it's not personal." [Workshop 4].

3. Impacts on Service Delivery

Participants perceive data usage as a way of increasing efficiency and streamlining service delivery, resulting in not only more effective service delivery, but greater capacity to serve more people. For some, these anticipated outcomes justify the risk of sharing their information.

Efficiency and Effectiveness

Data sharing between service-providing agencies was seen as a benefit that could prevent errors and speed-up service delivery and enhance communication. Many participants expressed the belief that data sharing could make navigating the system faster by reducing repetition, "You don't have to repeat the same story a million times" [Workshop 2], reducing the number of physical locations a participant would need to visit because all of their information would be "… in one spot instead of going to two different places" [Workshop 2] and it would result in everyone – meaning participant and service providers – being "on the same page" [Workshop 2]. Some participants openly expressed frustration about the current state of the system, citing the lack of efficiency caused by an absence of communication and information sharing between overnight shelters, or even within branches of the same agency:

> *That's just like example for shelters right, ok, I was at [Branch 1] and then I went down to [Branch 2] … and they didn't even have any information on me about my being at [Branch 1] … you know, it's ridiculous. They should have that information, then they'll speed up the process more.* [Workshop 3]

When asked about data linkage, a process where an individual's name and date of birth would be hashed into an unidentifiable numerical code, and then tracked within and between agencies, participants acknowledged the potential for further improvements in efficiency. Linking may allow for more accurate homeless counts, "Because [otherwise] they would have misinformation as to how many people were homeless" [Workshop 4], the ability to record whether or not the same person was accessing services at different agencies, and if referrals were completed. Participants felt that if linking were to reduce the number of repeat names on waitlists for services such as housing, it would be a "good idea, because your waiting period wouldn't be as long" [Workshop 5]. Similarly, participants thought the ability to limit "double-dipping" [Workshop 2] would be a good thing for managing the supply of long-term resources such as housing, but on the contrary, some participants feared that the ability to inhibit double dipping for short-term basic resources, like food, would negatively impact them as it would limit the number of times and places they may be able to access resources.

Helping Self and Others

Participants felt that if their data could help better serve themselves, as well as other members of the community, that it would be worthwhile to collect and share. They were aware that the social workers they interact with are better equipped to help them when they knew more of their story.

> *The more information you give, the more help you get. They can assess what you need* [Workshop 2]

> *Like he's saying like being handicapped, if that info is in there, more people will be able to figure out ok this guy needs special help* [Workshop 2]

Altruistic motivations were repeatedly stated (at least once in almost every workshop) as a factor that participants consider in the authorization for the utilization of their data for learning:

> *Sure, if it helps better the community, yup* [Workshop 1];
>
> *If it helps somebody else, then I don't see why they'd have a problem with it."* [Workshop 2];
>
> *F: So what kinds of things do you think are the most important for us to study?*
> *P: Whoever needs it the most.* [Workshop 3];
>
> *Oh, if it's for kids, why not?* [Workshop 4];

Although altruism was mentioned as a consideration for data utilization, other considerations were also stated, indicating that altruistic motives are important, but not the only thing that participants need assurance of in order to consent to the use of their data.

Increasing Funding and Capacity

There was a clear understanding among participants that certain data could be used to leverage funding and attract diverse donors for the service agency. Participants viewed this as a beneficial purpose for the utilization of data, which would result in improved service provision due to greater capacity. One participant stated that "If you need it for stats to get funding to build a better building, go ahead." [Workshop 2]. Another acknowledged that "the data they're taking kind of toward the needs of funders and stuff like that, so they are a necessity." [Workshop 3]. It was also mentioned that data may reveal the success of certain programs, which may motivate funders to contribute to the cause: "Maybe people want to donate to certain different parts of this, cause they don't know which is the best, what's working, what's not…" [Workshop 2].

Influencing Systemic Change

Participants acknowledge that data can be leveraged to catalyze positive change. Using data to influence decision-making within Bissell Centre and other service agencies was seen to be a beneficial outcome.

> *Participant 1: To improve whatever system, whether it's childcare or…*
> *Participant 2: Statistics speak volumes* [Workshop 3]

The potential to share data with government was seen as a mechanism for political change. One participant felt that only aggregate information should be shared with government: "like Rachel Notley for instance, she's coming over to take data, give her a number, don't give her you know [personal information], just give her the numbers of how many people are homeless, or how many people are in the hospital, or whatever just give her just that number." [Workshop 5] Aggregate data such as this, could be used to influence public policy.

One participant seemed to note that the people who are not housed may not yet even be in the system, and as such may be invisible in the reporting:

> *I don't think there's any point in these places in even doing any of this stuff like looking into it …should almost be done like computer style you know [but] if you don't have housing then you're not on there, that's just how it goes you know, you're not part of it.* [Workshop 2]

They feel that this means that information used to depict the current state of homelessness may not be an accurate representation, and this may impact how government or agencies supply services.

Participants even highlighted how the qualifications of the analyst could affect how information is interpreted, which in turn influences the use of that information for advocacy.

> *They have to be qualified … They know what they're doing, they know how to do statistics … I think they have to know what they're doing, to be able to fight for people right?* [Workshop 2]

Discovery: Knowledge Building

Data is viewed as something that can be used for discovery: to identify issues, service gaps and find answers that participants have. In the 'Priority Issues to Study' section, specific areas that participants perceive as top research priorities are listed. Trying to figure out "How many structures sit empty?" [Workshop 5] compared to how many people require housing is one such question that arose. Other questions such as wait times and the number of parents requiring holiday gifts for their children also came up. Participants recognized that data could be used to find answers to their questions, that those answers could help improve service delivery, which would then lead to positive impacts on the lives of community members.

Priority Issues to Study

Participants were asked to identify any issues that they perceived as a top study priority. The objective of this question was to determine if participants had preferences about the research purpose for which their data would be used, not just whether or not they approved of their data being used for research, in general.

Housing was the most frequent response, with participants indicating that they would like answers about wait times, the amount of available housing and whether or not certain resident types are more likely to get housed before others, such as families with children versus individuals without children. One participant asked a question that could be answered by research on housing:

> *How long does it take like if we were to apply for housing program? Say I need to get more stabilized housing for my children, my children just got taken away – apprehended – like two weeks ago and one of the barriers was the housing situation, I need more space for my kids. I have 7 children and applying for a housing, like housing through you guys, how long would that take?* [Workshop 4]

Family services and mental health were also top priorities.

Table 3. Participant-identified priority areas for research and the number of times each area was identified in focus group discussions

Priority Issue to Study	Frequency of Response
Housing	5
Family Support and Daycare	4
Mental Health	3
Supporting Newcomers/Immigrant Populations	2
Substance Use and Addictions	1
Supporting Indigenous Populations	1
Employment	1
Physical Health	1
Transportation	1

Consent Poll

We asked participants to individually identify both the frequency and the type of consent that should be asked of them for the sharing of different types of data. Following filling in the poll, group discussion about why they responded as they did illuminated their choices. We did not note whether anyone changed their poll response in line with the group discussion.

The majority (67%) of participants shared the opinion that they should be asked less frequently than every time for their data to be collected. 'Ask at the Start and Every 2 Years' was the preferred option among that group. Rationale behind this fell mostly to preserving efficiency.

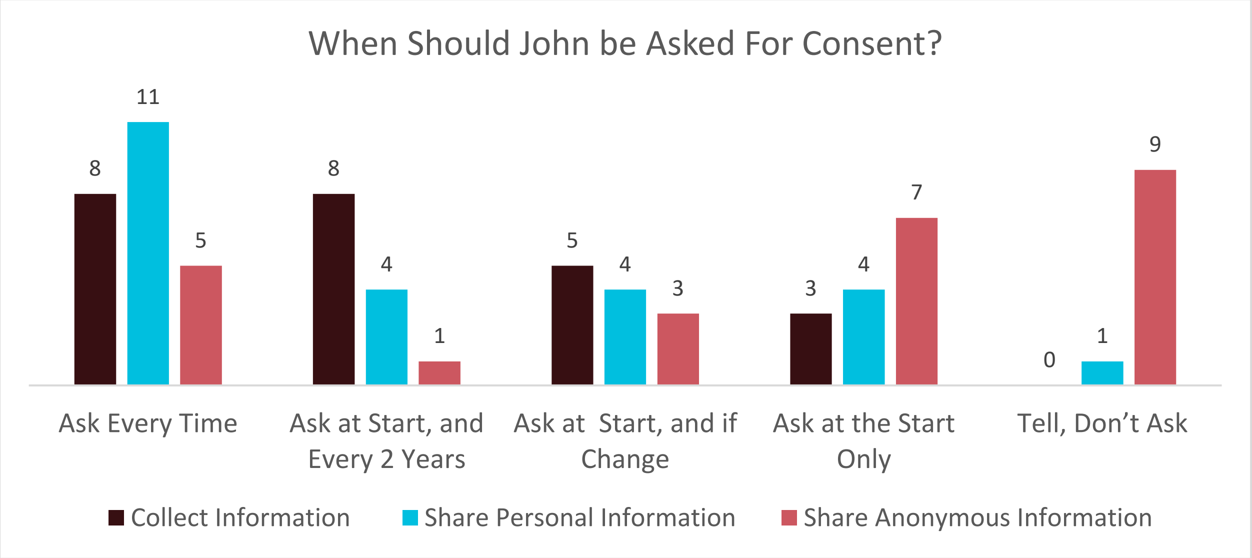
> *But every time would be like what if they go there everyday and pull out the same information and they just get to know this information once they see that… That would be too much* [Workshop 4]

Still, 33% felt that they should be asked every time.

36% of participants shared the opinion that they should be told, not asked, for consent when sharing their anonymous data.

46% of participants shared the opinion that they should be asked every time for their personal data to be shared. Some expressed motivations tied to mistrust. "Every time for personal, cause you're going to a different agency right and you're referring, I don't trust a lot of agencies." [Workshop 2] Others felt that they didn't need to be asked for consent if they had already been referred to a particular agency in the past: "I don't know, I don't want to be signing every time you know if it's the same agency, but if it's a different agency I want to yeah." [Workshop 2].

There is a general trend observed in the graph, where responses cluster toward the left, or more restrictive end of the spectrum, when they are asked about sharing personal information. Whereas the trend clusters towards the right, or more permissive end when sharing anonymous information. These trends are useful guides for creating consent procedures.



Discussion

Our findings support the overarching conclusion that participants are proponents of data sharing and utilization, as long as they are enabled to give informed consent, through the provision of appropriate information about how and why their data will be used. This conclusion runs parallel with other research indicating similar participant perspectives (Goodman et al., 2017). Despite these similarities, different motivations, areas of concern and special considerations were identified in our study that were not identified in other work; these factors may be distinct to people who access social services, including housing, family and basic needs.

What makes this situation distinct from that of other related literature, is the nature of the service agency sector and the nature of the challenges faced by the groups served by it. In an academic setting, for example, participant data is being collected and utilized for the primary, and typically only, purpose of supporting research. In health systems and in the social service sector, however, participant data is used primarily for operational purposes. Unlike the health sector, social service organisations vary in their capacities and resources for data utilization and oversight. The fact that the type of data discussed in this study is collected for operational purposes does not limit its inherent potential to be leveraged for other purposes. It does open a complex conversation about how agencies can use data for research-centric purposes, like agency-level evaluation, data linkage between agencies and external advocacy, whilst typically operating with limited resources.

Higher-level purposes such as these are difficult to conceptualize at the front lines of service – the place where data is being collected. Many of those who access services at Bissell Centre, and agencies like it, face adversity in many forms. Mani et al., found that people experiencing scarcity of finances show a decline in cognitive function of about ten IQ points (2013). They note that people experiencing poverty can spend all of their mental capacity on juggling resources, which can leave them with little or no "cognitive bandwidth" to consider less immediate or tangible issues (Sleek, 2015). These circumstances could explain the fact that the focus group conversations frequently returned to the question of how to access services, rather than the question of how data serves to address systemic-level issues. This implies that it could be valuable to revisit and review conversations about consent and data periodically as social service recipients' circumstances change.

Despite these barriers, participants expressed valuable perspectives about how, when and why their data could be leveraged. Consistent with existing literature, participants are keen for their data to contribute to increased knowledge of the sector and to support the greater good, a concept Manhas et al. coined as 'Altruism with Limits' (2015). There was a clear sentiment that participants are interested not just in seeing their information used in a responsible way, but in ensuring that insights are leveraged to support others in need. This could be interpreted as moral impetus to maximize data use, providing the criteria of informed consent and appropriate securities have been met.

Expectations held about consent processes were also made clear. Participants in this project emphatically expressed the importance of informed consent. This is in line with research regarding data stored in research data repositories (Manhas et al., 2016), healthcare record management (Kim et al., 2015) and biobank storage (Garrison et al., 2016). Informed consent functions as an important tool for the maintenance of control over data utilization, and as such, it facilitates trust in the agency or institution. There is tension between this emphasis on consent and the desire to reduce inefficiencies.

Transparency regarding the extent of the potential uses of data is essential to reducing this tension, as well as gaining and maintaining participants' trust.

The analysis also revealed disparate understandings of ownership of information and a divergence between ethical and legislative standards. Although not-for-profits may not be legally required to obtain permission prior to using and sharing anonymous information (Manhas, 2017), participants may still want to be asked, or at least informed, about this practice. Our results indicated that 36% of participants wished to be 'told not asked' about sharing de-identified information, but 33% indicated that they would like to be either 'asked every time' or 'asked at the start only' for permission to share anonymous data. Kim et al. found that 86.7% of study participants preferred to be asked for permission first (2015). Models allowing for the withdrawal of consent may provide a compromise. Adding to the confusion is the fact that participants may vary in knowledge and understanding of their legal rights in terms of privacy of information. To mitigate the effects of this disparity and divergence, service agencies should acknowledge their role as stewards of data and explore avenues to ensure participants maintain ownership and control of their information wherever possible.

Leveraging social services operational data for research purposes is a relatively new endeavour and is fueled by technological advances of the past ten years. There is increased work to create strategies to achieve this aim, for example the Ontario Non-profit Network has published a primer document which seeks to lay the foundations to create a data strategy to equip Ontario's non-profit sector (Ontario Nonprofit Network, 2015). Almost half of our focus group participants (47%) expressed interest in informing these strategies and in engaging in the conversations that address the tensions between maintaining control of how data are used and creating efficiency and governance strategies. Their desire to contribute to this conversation syncs with the call for co-creation apparent in Gius' (2018) work.

This project includes some limitations. One of which is inherent to the context of people who are experiencing poverty. We hold reservations regarding the neutrality of the materials shared in the workshops to inform all the participants about the conversation topic. The idea of sharing data to create learnings for the purposes of advocacy to make the system better is particularly enticing for people who see the system as broken, and who possibly are living in extraordinarily difficult circumstances. Given this, it may be difficult to say, no I don't want my information shared for that purpose. Further work could be undertaken with people who have lived experience of poverty but are no longer facing its daily realities to corroborate the finding that participants are not only permissive, but enthusiastic about sharing their information for learning. One mitigating factor is the fact that there were a small number of people who expressed reservations and concerns. This setting also provides the strength for the project, as to our knowledge it is unique in eliciting perspectives of social service participants.

Moving forward, service agencies should:

- take intentional action to address strategies for potential mis-use of data;
- ensure that the organization's role is that of a steward, not an owner; and
- establish a mechanism for hearing stakeholder voices.

Recommendations

The following are recommendations for Bissell Centre and other social service agencies:

1. **Review consent protocols with participants** and create a plan for updates if necessary
2. **Review policies with participants** regarding data governance and update where necessary
3. **Create training for staff** regarding the importance of consent – not just to fulfill the necessary paperwork, but from the perspective of participants
4. **Create a stakeholder group** that includes participants to guide decisions regarding ongoing data collection, analysis and sharing

Appendix

Appendix 1: Workshop Schedule and Questions

DETAILS

- When participants arrive, the co-facilitator will go through the following with them:

*this is a checklist – can do simultaneously with welcome section.

- *Signed copy of the informed consent form*
- *Introduce project contact information*
- *Ensure knowledge of refreshments/washroom facilities' location*
- *Answer any questions or concerns*

Moderator will facilitate mingling and informal introductions among participants

WELCOME

Welcome everyone. We want to thank you for agreeing to spend this time with us.

Before we delve into our questions and main discussion, let's start with some brief introductions.

- *We can stop at any time. We will be recording this workshop to make sure we note everyone's opinion accurately*
- *We ask that all will respect each others confidentiality, and not share things discussed here outside this group, and we ask that we are respectful of one another and not speak over one another*
- *This is a discussion-based workshop, we'll be trying to find areas that we agree on, and areas that we have different opinions on*
- *I have a list of questions that we'll work through, and you can ask me to repeat, and reword them anytime*
- *Bissell Centre wants to hear your opinions on how we store information like case notes We also want your opinions on how we should or shouldn't use that information*
- *Your opinions will impact our policies on privacy and consent, and we will be sharing some of the results of this workshop and three other workshops at conferences, or in reports*
- *If you want to see the results/reports, put your contact information on the consent form*
- *Does anyone have any questions before we start?*

Opening Question

We'd like to start off with introductions.

I would like us to go around the room. I would like you to say your name and tell us about your favourite place to visit in Edmonton.

Video

We'll watch a 2-minute video about the journey that information takes when you get to Bissell Centre.

- First, do you have any clarifying questions about the content of the video?
- Okay, then let's start with what you thought about different scenes in the video

    - *Which scene stuck with you? Why?*
        - *What did you think of Sarah saving John's case notes?*
    - *Which scene did you not like? Why?*
        - *What did you think of Maya checking the file?*
        - *What did you think of Carter getting anonymous information?*

Data governance (30 mins)

Personal Information for Service Provision at Bissell Centre

- Let's talk about sharing information when someone comes for services, for example housing services like John did.
    - *What do you know about participant files?*
    - *Is there anything that you'd like to know that you don't know?*
    - *What questions might John have about his information?*
- Sometimes information collected in participant files is called data.
    - *Who do you think should have access to John's information?*
        - *His case worker?*
        - *His housing workers?*
        - *Other Bissell workers?*
    - *Who do you think should NOT have access to John's information?*

- *What comes to mind when you think of a worker accessing a John's information so that they can work with John?*
    - *Why do you think that?*

[Flowchart and matrix are distributed]

There are multiple reasons why we would want to share data. Let's walk through the flowchart: first, on the left side, you'll see how information with a person's name attached could be used. John's data is collected at starting point when he first arrives at Bissell looking for services. That personal information is stored in his file. That information could be shared within Bissell, to his caseworker, other caseworkers, or other staff within Bissell. That information could also be used to refer him to other agencies like Mustard Seed to get services Bissell doesn't offer. The information has his name attached, and it is used to help get him services.

Then, if you look at the right side of the flowchart, you'll see his information is being anonymized, so his name and other personal information is being removed, and that data is studied. It could be studied by an employee within Bissell, or a researcher or student who is trying to learn about how things can be improved in the whole system. The studying of anonymous information doesn't directly impact John's access to services, but it might help identify areas for improvement at Bissell or all across the city.
Lead into questions about thoughts on sharing for referrals…

Sharing Personal Information for a Referral

- We want to think about data sharing between agencies when someone gets a referral for services at the new agency. This is a pretty normal situation.
  - Imagine Sarah gave John a referral to the Mustard Seed. She would need to share his name, his contact information, and why he's going with the Mustard Seed worker.
    - *What do you think of this?*

Sharing Information for Research or Quality Improvement

- Sometimes we look at all the information that we collect to see how many people are coming to different programs, and if that program is helping. For example, Community Bridge is an eviction prevention program, we'll look to see how many people didn't get evicted, and which people those most likely were (families). This tells us that we need to work harder to make sure single people don't get evicted.
    - *What do you think of this?*
    - *Do you think this is okay? Why? Why not?*
    - *Do you think this should happen? Why? Why not?*
- Sometimes learning or research with the grouped information is done in Bissell Centre, like the example for Community Bridge above. But we've been asked to share information with others, so that they can study it and learn about what's working and what's not working. One example would be a university student who would want to use it for a project they need to do, maybe to find out if time spent with an employment worker means someone is more likely to get a job. They could then share what they learned with Bissell Centre.
    - *What do you think of the idea of others outside of Bissell Centre using the grouped information?*
    - *Why do you feel this way?*
    - *Are there certain times it would be a good idea, or times it would be a bad idea?*
      - *When would you feel comfortable with other researchers using data collected by the Bissell Centre during everyday activities/services?*
      - *What or when would you feel uncomfortable with this type of sharing?*
      - *Is there anything you would never want shared?*
      - *Is there anything that you would not mind if it was usually shared?*
    - *How would we tell when it's a good idea?*
    - *Does it make a difference if it's anonymous or not anonymous?*

Data linkage

- Imagine someone wanted to know how many people total were looking for affordable housing in the whole city, but it didn't matter who those people were.
- So, if John also went to the Mustard Seed as well as Bissell Centre, he's just one person looking for affordable housing, not two people.
- Imagine that Bissell Centre and Mustard Seed could both share information with a researcher. Imagine the researcher was able to match the information. After the matching was done, then the researcher made it anonymous, so anyone else who studied information about the whole of Edmonton would not know that John went to both, but that whoever then studied it might know that a male who's 55 went to both.

        - *What comes to mind when you think about the idea of matching the information, but keeping identifying information secure?*
            - *Anything else?*
        - *What thoughts do you have, if any, for the participants? For the researchers? For the agencies?*
            - *Why do you think that?*
        - *Hypothetically, would you be okay if John's information was matched, and then made anonymous before the researcher shared it with anyone else, so no one knew it was him?*
            - *Why would this be okay?*
            - *Why would this not be okay?*
            - *How would you feel about this situation?*

Who gets to see and use the information?

- If Bissell Centre were to share information, who would it be okay for Bissell to share with?
    - *What type of work could it be shared for?*
    - *What would the person have to do for it to be okay for information to be shared with them?*
    - *Are there certain types of work or people it should never be used for?*
    - *Does security matter if the data is being shared? If so, what should the security do/be?*

Break – 10 minutes

Types of consent processes (30 mins)

- Getting permission from people is a very important step before information can be collected and shared with people who've been screened.

- Generally called consent, permission gathering can take a few different forms.

- There are mainly five different ways to ask for permission to collect, and share information (hand out of the list, facilitator to read all out).

- For each type, we're going to imagine what John would have wanted to happen. When John first came to Bissell, he shared information about his income, his housing situation, other areas in his life where there are strengths and where there are barriers or problems for him, for example how he has lots of family support that he can rely on, but also struggles with keeping his job.

- When Should John Be Asked Permission to **Collect** His Information?
- When Should John Be Asked Permission to **Share** His **Personal** Information for a referral?
- When Should John Be Asked Permission to **Share** His **Anonymous** Information?

To fill out the poll, write the number of the consent process you prefer by each question. So, for question one, if you think John should be asked to collect his information at the start of his time at Bissell and again every 2 years, write a number 3 beside question 1.

What would you like to see happen with your data when it is studied?

- When someone either at Bissell Centre, or someone else who's qualified, studies the information, what would you want them to achieve with their studies?
    - Why is this an important area for you?
    - How do you think the topic should be chosen?
    - Why do you think this?
    - What types of opportunities do you think participants should have to suggest topics to be studied?
    - What do you think would qualify someone to study the data? Volunteers? University students?
- When those studies are turned into reports, what do you think should happen to those reports?
    - Would you care about whether you had an opportunity to read them?
    - What opportunities might people be interested in regarding future data initiatives?

Closing Up

All things considered, hypothetically would you be willing to share your information, so it can be studied? And remember, your response is in no way binding.

- *Did the discussion today influence your willingness?*
- W*hat was most influential in this decision?*

Moderator summarizes top 3-5 key points in the discussion. Emphasis on perceived risks, benefits, and any preferences amongst governance and protective strategies.

- *OR MODERATOR notes some of the points of greatest discussion by the group as a recognition that we heard them.*
- *Did I correctly describe what was said?*

As you recall, the purpose of this conversation is to understand your perspective as a Bissell Centre participant about collecting and sharing participant information. With that in mind, is there anything else you want to add to the discussion?

- *Have we missed anything?*
- *Is there anything else that we should have talked about but didn't?*
- *Is there a key point that was not emphasized as much as you would like?*
- *Would you be interested in future discussions of this type?*

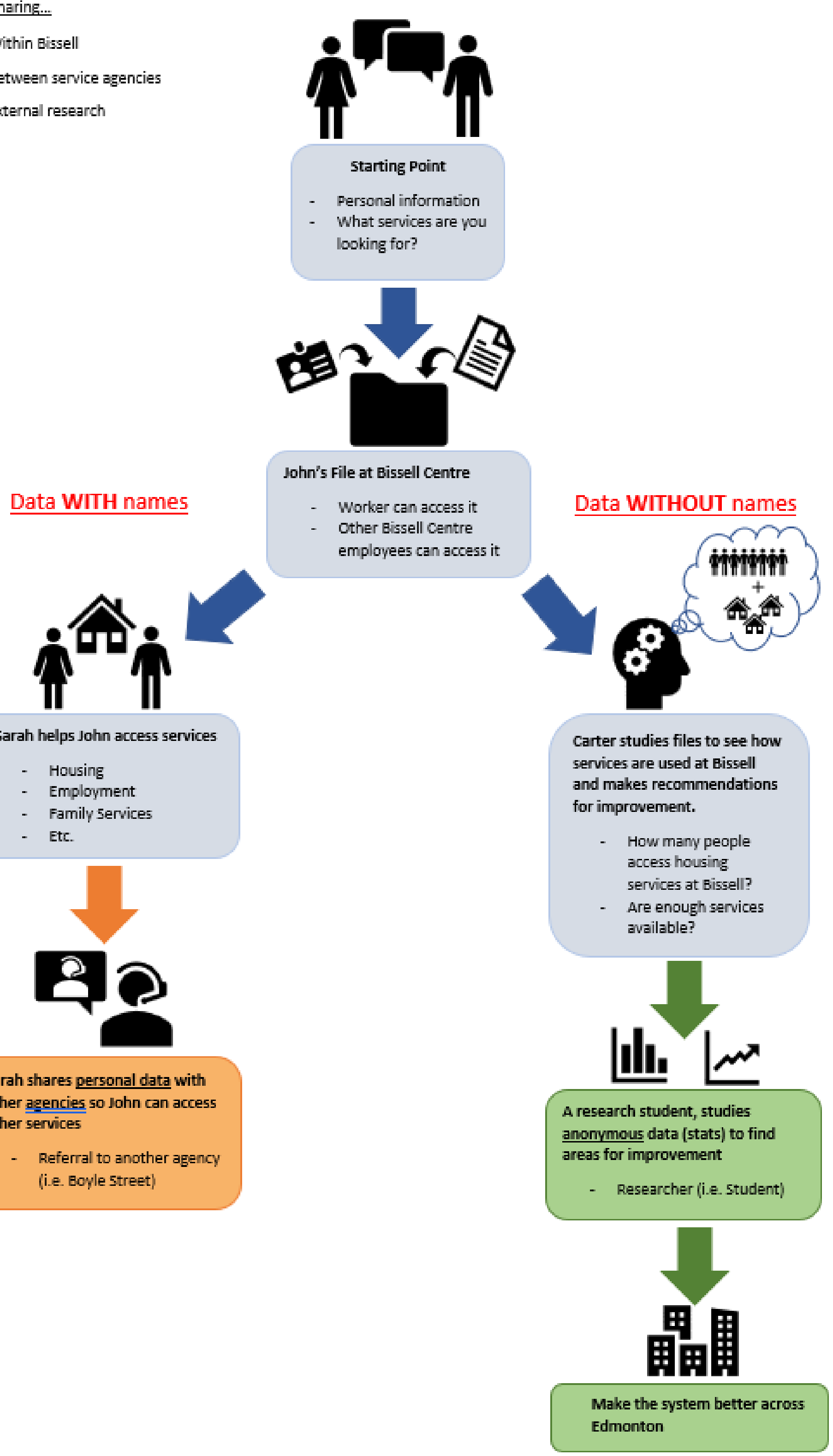
Here is a hand-out containing some information on the work that Bissell Centre does in the background that spurred this conversation. The sheet also contains contact information for our team if you have any questions or concerns.

Thank you for your time and thoughtful contribution.

Appendix 2: Flowchart

Data sharing…

🟦 Within Bissell
🟧 Between service agencies
🟩 External research



Starting Point

- Personal information
- What services are you looking for?

John's File at Bissell Centre

- Worker can access it
- Other Bissell Centre employees can access it

Data WITH names

Sarah helps John access services

- Housing
- Employment
- Family Services
- Etc.

Sarah shares personal data with other agencies so John can access other services

- Referral to another agency (i.e. Boyle Street)

Data WITHOUT names

Carter studies files to see how services are used at Bissell and makes recommendations for improvement.

- How many people access housing services at Bissell?
- Are enough services available?

A research student, studies anonymous data (stats) to find areas for improvement

- Researcher (i.e. Student)

Make the system better across Edmonton

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