



A REVIEW OF THE ETHICAL
CONSIDERATIONS SURROUNDING
INFORMATION SHARING AND INFORMED
CONSENT IN THE HOMELESS-SERVING
SECTOR

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Executive Summary

Intro

Agencies in the homeless-serving sector collect a variety of information from some of Calgary's most vulnerable citizens. This information is critical to providing care and supports to individuals experiencing structural vulnerabilities. Ensuring that best practices for data collection and information sharing are used across and within agencies is of utmost importance to maintaining ethical integrity.

This environmental scan is the first stage of a multi-phased project focused on addressing a gap in knowledge surrounding information sharing and consent practices in the homeless-serving sector. The findings and standards identified in this report aim to support recommendations for future action in potentially drafting an ethical framework to govern information sharing between agencies in Calgary.

Methods

This environmental scan encompassed searching academic journals, grey literature, professional organizations and conference programs. Two academic databases were searched, which yielded 256 articles that were then scanned based on abstract content. Special attention was given to information that was related to operations and programming. Solely theoretical work was excluded from the results; however, exceptions were made for publications that were referenced in meetings or were relevant to ethically framing the objectives of this project.

Parallel to the literature scan, staff from organizations and individuals were interviewed. The purpose of these interviews was to provide a more in-depth understanding of the ethical factors that shaped their existing policies and practices surrounding the protection of client or patient information.

Findings

No existing ethical frameworks were found that strictly identify and evaluate the considerations of sharing information across agencies in the homeless-serving sector. As a result, this report lays out standards and factors that impact information sharing more generally. This included ethical standards defined by relevant local professional organizations.

The following themes emerged from interviews and the literature:

- Non-Maleficence
- Autonomy
- Beneficence
- Justice

Framework Guidance

In addition to further details on the above, this report shall provide guidance on the following areas to assist in the development of a local ethics framework that will guide decision-making around sharing information between agencies:

- Proposed definitions to be used in future work
- Documentation procedures
- Training for staff

Recommendations

Based on the information gathered in the environmental scan, it is recommended that an interdisciplinary committee should be brought together to draft the following:

- Shared values, facts and goals that will inform the work. As part of this a common language and definitions should be agreed upon
- Scenarios for staff to understand potential risks and biases that impact ethical information sharing
- A decision-making tool to assist staff in determining whether it is appropriate to share a client's information
- Determine suggested training strategies for organizations

Introduction

Background

Since the successful implantation of HMIS, agencies in Calgary's homeless-serving sector have been able to better serve clients. Being able to share information more broadly within this system has the potential to further enhance these benefits. It is hoped that sharing information between homeless-servicing services would eliminate service duplication, provide coordinated case management and lead to the provision of better services to people experiencing homelessness.

The purpose of this report is to identify relevant work related to information sharing and informed consent practices in homeless-serving sectors globally. The findings and standards identified can be used as a tool to help develop an ethical framework and policies surrounding sharing information between agencies in Calgary.

Methods

The ethical considerations surrounding information sharing were explored through two lenses. First, informal interviews were conducted with people both in Canada and globally who work in the homeless-serving sector, bioethics and/or information management. The purpose of these interviews was to provide a more in-depth understanding of the ethical factors that shape policies and practices surrounding protecting client or patient information.

Parallel to this, a scan of the grey literature was completed to find reports and other relevant information that speaks specifically to the programing implications of ethical information sharing considerations. The academic literature was also searched in hopes of finding research where collaboration has occurred with organizations in the homeless-serving sector. Second, using the same search methodology, an environmental scan was completed to identify best practices for gathering informed consent from individuals who are experiencing structural vulnerabilities and may be intoxicated.

The search encompassed scanning academic journals, grey literature, conference programs, professional organizations as well as searching specific agencies, organizations and initiatives related to homelessness and information sharing. Special attention was paid to information that was related to operations and programing. Solely theoretical work was excluded from the results. Exceptions were made for publications that were referenced in meetings or were relevant to ethically framing the objectives of this project.

Academic Literature

PubMed and JSTOR were the databases used to search the academic literature. The following search terms were used:

Data sharing search	Consent search
Data OR information	Informed OR expressed OR direct
Share OR Disclos* OR release OR use	Implied
Client OR Patient	Consent OR Assent
Homeless* OR social services OR shelter	Capacity OR intoxicat* OR understanding
Policy OR framework OR decision making	
Ethic** OR Moral*	

This search yielded 256 articles, which were scanned based on abstract content. Based on the scope of the environmental scan, 48 were read in full. The references of all 48 articles were mined, producing an additional 9 papers.

Globally, the homeless-servicing sector is incredibly diverse, therefore it is critical throughout this project to carefully evaluate how generalizable the findings are. Through scanning both academic and grey literature, the key authors were identified and asked to have conversations surrounding their work. The aim of these interviews was to provide a more in-depth understanding of the risk-analysis that was part of their work. Additionally, these conversations indicated the transferability of ethical considerations.

Grey Literature

The search of the grey literature was conducted in Google. The first 10 pages of results were scanned. In comparison to the academic scan, this search focused on identifying relevant authorities, organizations or stakeholders, such as government bodies, homeless-serving organizations and data collectives.

The following news outlets were searched for articles that covered issues related to information sharing: *The Washington Post*, *The New York Times*, *CBC*, *The Guardian* and *BBC*.

The following professional conference programs were searched between the years of 2014-2019: The National Health Care for the Homeless Conference and Policy Symposium, The Canadian Alliance to End Homelessness, The National Alliance to end Homelessness, The European Conference on Homelessness, The Canadian Bioethics Association, The American Association of bioethics and Humanities, The American Public Health association, The Canadian Public Health Association, the Swiss Conference on Data Science.

Professional Networks

Interviews with the following professional organizations occurred: The Alberta College of Social Workers, The Alberta Medical Association, The Canadian Association of Psychologists, The Canadian Counselling and Psychotherapy Association, The Canadian Medical Association, The Canadian Association of Social Workers, The College and Association of Registered Nurses of Alberta, The College of Alberta Psychologists.

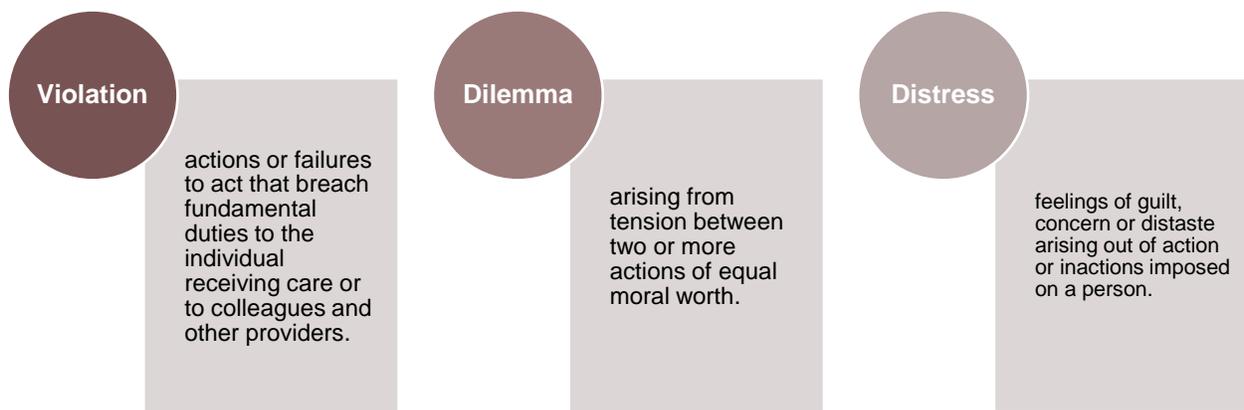
Questions were centered around the considerations that impacted how documents surrounding professional conduct and ethical guidelines were drafted. Additionally, questions were asked related to the scope of practice within their regulated body, specifically what type of consent was required to share client information.

An introduction to ethics

Every day, people encounter ethical issues, whether it be at work, or at home. Ethics not only encompasses what *ought* to be done, but also what *must* be done in a compassionate and just society. Ethics can be referred to as a systematic study of standards of conduct and moral judgments, as well as a system or code of morals of a particular group or profession.

Common ethical problems can often be categorized as: (1) threats to health and basic well-being; (2) threats to liberty, freedom and privacy; and/or (3) threats to acquired goods, such as education, health care, transportation or other assets.

Types of ethical problems



* Adapted from the College and Association of Registered Nurses of Alberta's *guidelines on Ethical Decision-making for registered nurses in Alberta* (2010)

The process of ethical decision making is concerned with arriving at the best course of action, in order to best serve the interests of all involved stakeholders. At times, there may be situations where there are conflicts between principles and uncertainty about what course of action to take. At times, there are equally compelling reasons for or against two or more possible courses of action.

Below is a standardized method that outlines a common approach to ethical-decision making that can be applied in a variety of different scenarios.

A Standardized ethical decision-making process



* Adapted from: Alberta Health Services ethics framework, McDonald's Framework for ethical decision making (2001) and Gibson et al.'s Organizational ethics" chapter in *The Cambridge Textbook on Bioethics* (2009)

Often, ethics is presented as a set of values, theories or principles. One prominent approach to ethics is Beauchamp and Childress's *Principles of Biomedical Ethics*. Beauchamp and Childress propose that ideally, the following four principles should be respected for practice to be considered ethical:

Autonomy: capable and competent individuals have the basic right to self-determination, independence and freedom, enabling them to make informed choices.

Nonmaleficence: to do no harm. This principle obliges us to act in such a way that we prevent or remove harm from our clients and ourselves.

Beneficence: to do good. This principle requires that we perform acts that will benefit clients.

Justice: the obligation to be fair to all people, treating people according to their need. The principle of justice can be further expanded to include distributive justice such as fair access to, and allocation of, resources and procedural justice or shared decision making. It involves including people in the decisions that affect them.

What is an ethics framework?

Ethical decision making is a complex process. At times, staff may be confronted with situations where they do not know what is the "right" or "wrong" course of action; in ethics this is commonly referred to as a "grey area". An ethics framework can act as a tool to facilitate conversations on how to navigate complex situations between colleagues. Built on agreed upon values, an ethics framework aims to highlight key issues and frame appropriate actions. When confronted with a morally complex situation, having a framework can help guide support staff and inform policy.

The purpose of an ethical framework is to:

- outline values, principles and standards to guide decision making
- be a resource to identify, examine and resolve ethical issues
- promote ethical reflection
- facilitate accountability
- support the provision of services to the highest ethical standard in order to create an ethical environment.

A clear ethical framework is:

- consistent

- recognizes potential bias and disagreement
- evaluated and discussed regularly

Ethical Themes

In their book “Principles of biomedical ethics” Beauchamp and Childress define four principles of equal moral value: non-maleficence, beneficence, autonomy and justice¹. These principles are accepted within bioethics as the standard theoretical framework to guide ethical situations. The four principles of bioethics were developed to analyze moral conflicts in medicine; however, they are widely applied to a diversity of scenarios in ethics.

This section of the report defines Beauchamp and Childress’s principles of bioethics and applies them to information sharing in the context of the homeless-serving sector. These ethical themes can be applied to the findings of this report to encourage critical ethical reflection.

Non-Maleficence¹

The principle of non-maleficence is the duty to do no harm and to protect others from harm. Non-maleficence includes minimizing harms that may be, anticipating harms which might occur and avoiding harm. Such harms are not restricted to physical harms, but include feelings of helplessness, isolation and powerlessness, to name just a few of many important considerations.

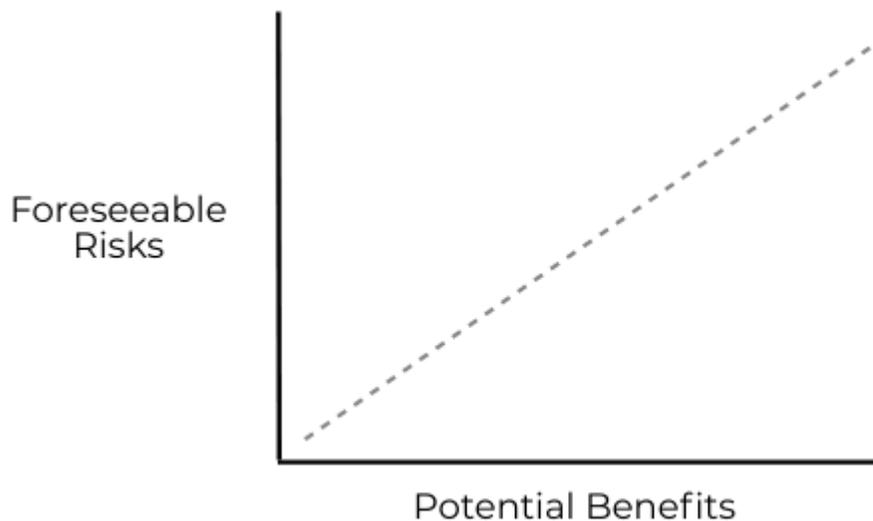
Risk

In order for policy and procedures to promote nonmaleficence, it is critical to evaluate the associated foreseeable and preventable risks. When evaluating ethically appropriate risks, the principle of proportionality is used, which states that the benefits of sharing information must be greater or equal to the burden of harm. Therefore, a higher degree of justification is required proportionally to the risk or sensitivity of information being shared.

It is important to note that if the risk associated with a certain decision is unknown, that in and of itself is considered a risk due to the potential for unintended consequences. Mistakes cannot be reversed, therefore policies and procedures should err on the side of caution if there is a potential to intrude on an individual’s rights and freedoms.

The graph below visually demonstrates the principle of proportionality- generally speaking, if a decision falls on or under the dotted line, it can be considered ethically justifiable. This graph can be used as a tool in phase two of the project to plot various scenarios related to future information sharing policies.

Principle of Proportionality



The type of information that is shared between agencies will have varying levels of potential associated harm; for example, sharing a client's name would be considered lower risk than sharing their case notes.

When evaluating the risk of a specific decision it is important to have individuals from a variety of backgrounds and experiences present to identify a diverse perspective on possible associated harms. For example, on the surface, sharing only a client's name with other agencies appears to have little or no associated potential harms. However, if a client has checked into a wet shelter, even though only the client's name is being shared, this may reveal other potentially stigmatizing information, such as substance use.

Autonomy¹

The term “autonomy” is derived from two Greek words: "auto" which means "self" and "nomos" which means rule or regulation. To live autonomously is to lead one's own life, *not* to rule over others.

The principle of autonomy is the right to choose for oneself what one believes to be in one's best interests. From the principle of autonomy comes the commitment to respect clients' choices and promoting an individual's ability to make informed choices. The rights to refuse treatment, to privacy, to truth-telling and to confidentiality are also duties which evolve from this principle

Privacy and Confidentiality²

Privacy is a fundamental right that is rooted in autonomy. When sensitive or personal information is collected, professionals have an obligation to protect the privacy, safety and dignity of the individuals whose information was collected.

The terms privacy and confidentiality are often used interchangeably, however, there is a key distinction. Confidentiality concerns the information itself (whether it is disclosed or not). In comparison, privacy deals with the impact a disclosure has on the individual whose information was shared. Confidentiality is a duty, whereas privacy is intimately linked to the individual and focuses on the circumstances under which the information was used.

It is important to strike a delicate balance between enabling access to a client's information, while still respecting their right to privacy and control over the confidentiality of their personal information. This is especially true when discussing the information of someone experiencing homelessness, as they may not be aware of their rights and may have a history of having their privacy exploited.

Consent³⁻⁵

Consent is a mechanism that is used to respect an individual's autonomy. This section will distinguish between the different types of consent and outline unique factors that should be considered when obtaining consent to share the information of someone experiencing homelessness.

Informed Consent is a process of communication that enables individuals to make decisions in an informed and voluntary manner. There are ethical and legal reasons to obtain

explicit consent from a client before sharing their personal and sensitive information. It is important that informed consent is explained to the client both theoretically and in practical terms and that they have an understanding and appreciation of all the facts, implications and future consequences of what they are giving consent to.

In a research context, Institutional Research Boards often require that informed consent be written, as this promotes accountability and clear documentation processes. There are circumstances in medicine and research, where verbal consent is accepted, such as in emergency situations or very low risk research. Benefits to verbal consent include expediting intake and reducing burden on clients. It is recommended that for information sharing in Calgary's homeless-Sector that written consent is obtained to prevent the unintended ethical and logistical challenges that can be associated with verbal consent.

Implied Consent is much more informal than informed consent and as a result is often discouraged in ethically complex situations. Instead of explicitly asking for an individual's consent, their actions or the circumstance are used to imply their consent.

Capacity vs. Competence⁶

Often the terms capacity and competence are used to discuss an individual's ability to have decisions. However, there is an important distinction between the terms. Competency is much broader in scope as it evaluates whether an individual can make any decisions at all. In comparison, capacity is case specific and is determined by the context of the situation.

In Applebaum's article *Assessment of Patients' Competence to Consent to Treatment*⁷ he outlines the legally relevant criteria for decision-making capacity (Refer to Appendix ii). Applebaum outlines a table of relevant criterion, tasks, and questions to determine the decision-making capacity of a patient. While this was developed to inform medical decision making, it acts as a clear example that competency is a sliding scale that can be applied in the homeless-serving sector.

When determining whether an individual has the capacity to make a decision, the following questions should be considered:

- Can the individual understand the available options?
- Can the individual appreciate the significance of their decision?
- Can the individual weigh the risks and benefits associated with the situation?
- Can the individual express a choice?

If an individual is unable to understand all four of these elements, they cannot provide consent. If the situation is not an emergency and an individual is temporally incapacitated, due to factors such as substance use, it is recommended that consent is obtained at a later time.

Assent

If an individual does not have capacity, assent to participate may be obtained. Assent is given when an individual expresses willingness to participate, but is unable to consent. Often assent is discussed in the context of pediatrics, as we value a child's input into their care decisions, but legally they do not have the authority to consent (in most circumstances). In order to assent, an individual still must understand the proposed decision in general, its expected risks and possible benefits, and the activities expected of them.

Assent in isolation is not sufficient as it is not a replacement for consent. If assent is given, informed consent must still be obtained from the individual's parents or guardian or must be obtained by the individual at a later time.

Beneficence¹

The principle of beneficence is the *duty* to benefit others. A central belief reflected in this principle is the duty or obligation to assist others, to contribute to their welfare, and in doing so, to always act in the best interests of the client.

Best interest

The standard of best interest is widely used in ethics, law and as a basis for social policy and decision-making involving minors or individual's with varying degrees of competence. Best interest is based in general on what is considered to promote the best outcomes for an individual or group.

The obligation to do good towards others and to act with best interests in mind, without an appropriate balance of attention to the principle of autonomy, can lead to *paternalism* in health care. Paternalism can be a well-intended action as it intends to promote the best outcomes for the client, however, it does not balance with the patient's right to choose and be in charge of their own decisions.

The best interest standard has come under scrutiny lately as an individual's or systems values inherently colour what is considered in someone's best interest. The homeless-serving sector is comprised of a large spectrum of approaches, that at times may not work in harmony. When drafting an ethical framework it is critical to be aware of where tension exists between philosophies, in order to address bias and reduce conflict which may lead to moral distress.

Justice¹

At the core of the principle of justice is the value that there is fairness based on the equal worth of individuals. While there are several criteria that may be applied to determine fairness, such as “to each according to worth, to each according to need, to each according to contribution”. A value commonly held in Canada is that of equity- fairness according to need.

Distributive justice is at the core of all the work agencies do in the homeless-serving sector. As a result, considerations of fairness are embedded in the principles outlined in this report. As discussed in the professional guidance section, there are unique ethical sensitivities when policies impact individuals experiencing homelessness. It is important to be aware of how factors such as power dynamics and trauma can influence an individual's perception of their rights and the voluntariness of their consent.

Upholding high ethical standards is of the utmost importance when drafting policy and frameworks that impact individuals who have or are experiencing structural vulnerabilities. These decisions can exacerbate a person's already marginal position in the political, social and economic structures of society.

Findings

No existing ethical frameworks were found that strictly identify and evaluate the considerations of sharing information across agencies in the homeless-serving sector. As a result, this report is focused more broadly on ethical and information sharing principles or policies that can be interpreted to guide future best practices in the homeless-serving sector.

For the search related to consent practices, professional guidelines provided a foundation to guide potential ethical information sharing practices. Professional guidelines provide a rigorous definition of the minimum ethical requirements for consent. As a result, they are highly applicable to the future outcomes of this project.

This section will provide the following:

1. Examples of various information sharing practices in the homeless-serving sector globally. This section does not provide analysis or recommendations based these cases. Rather, its intent is to provide examples of different approaches to information sharing in the homeless sector;
2. Important considerations related to informed consent practices, as set out by key organizations.

Information sharing practice examples

20,000 Homes^{a,8,9} outlines clear terms and conditions for agencies surrounding information sharing in their “20,000 Homes Campaign Data Sharing agreement”. In order to share a client’s information, written (if possible) informed consent, must be obtained before information is shared. The consent process must clearly outline the potential uses of information. If a client does not consent to their information being shared, they will not be denied services or benefits. 20,000 Homes states that all staff who work with client information should receive training that is refreshed regularly surrounding the protections of personal information.

Dufferin County^{b,10-13} uses HFIS to share information between a set group of agencies in the homeless-serving sector and has a clear interagency information sharing agreement. Clients can opt-in to sharing their information by providing their informed consent. No information is shared until informed consent is obtained. Personal information is only shared for: (1) The

^a 20,000 Homes is a campaign led by the Canadian Alliance to End Homelessness. The goal of the national movement is to work collaboratively to permanently house 20,000 of Canada’s most vulnerable people.

^b Dufferin County is in Central Ontario

purposes of supporting a person's access to services related to homelessness prevention and/or obtaining and maintaining housing; and (2) Coordinating care, services, and benefits for persons and families served by one or more Partner Agencies. Separate consent is required to disclose personally identifying housing and case information.

All partnered agencies and their staff have to sign the collective's confidentiality and user agreement. Additionally, all staff must receive training on the collective agreement and more general privacy policies.

The Region of Waterloo^{c,14,15} uses HFIS to share information within their Housing Stability System (HSS). During intake, clients are asked to opt-in to sharing their information with HSS. If a client refuses to consent to sharing their information, they will only be able to access essential/emergency services, such as shelter and outreach. In order to access additional services, such as housing case management consent to share information with HSS must be provided.

Humboldt County^{d,16} embraces a broad definition of a circle of care and uses HMIS to link information from education, health, human services, housing and justice. This integrated system is used to help coordinate housing referrals and identify clients for outreach.

When a client enters the system, informed consent is obtained and they are presented with the option to opt-out of sharing their information with the various partners that are part of this collective. Between health care providers implied consent is sufficient, as this is a defined system of care. Only the client's name and where appropriate, general condition is shared between agencies and providers; any additional information that may be required has to be requested.

St. Mungo's^{e,17} uses an opt-in system and requires informed consent to be obtained from individuals before any of their information is shared. Their forms clearly list which organizations and professionals the individual is consenting to share their information with as well as what information will be disclosed. A client's consent can be withdrawn at any time and is revised at regular intervals. If there is a request for an organization or use is not explicitly consented to by the client, further consent will be sought from the client.

^c The region of Waterloo is a municipality in Southern Ontario.

^d Humboldt County is on the northern coast of California

^e St. Mungo's is a homeless-serving agency in London.

Alberta First Nations Information Governance Center¹⁸⁻²²

The Alberta First Nations Information and Governance Centre (AFNIGC) aims to empower Indigenous control and capacity to promote ethical and relevant processes in research as well as the collection, utilization and storage of data. In 2002, AFNIGC put forth the principles of “Ownership, Control Access and Possession” (OCAP) to become the standard for conducting ethical research with Indigenous communities.

The OCAP principles recognize the history of grievances and violations that have occurred in research in Indigenous Communities. By creating an ethical space of understanding and transparency, it is hoped that these principles will help produce more relevant results, which in turn will lead to positive, and lasting change for Indigenous communities.

As the OCAP principles focus on ethical data practices in a research setting, it is important to recognize that they cannot directly be applied to information use in the context of providing care to a client or patient. However, the value and philosophy of OCAP is still incredibly important. At the core of the OCAP principles is an individual’s and community’s inherent right to self-determination. AFNIGC defines the OCAP principles as follows:

Ownership- Refers to the relationship of a First Nations community to its cultural knowledge/data/information. The principle states that a community or group owns information collectively in the same way that an individual owns their personal information.

Control- The Aspiration and rights to maintain and regain control of all areas of their lives. The principle of ‘control’ asserts that First Nations people, their communities and representative bodies must control how information about them is collected, used and disclosed. The element of control extends to all aspects of information management, from collection of data to the use, disclosure and ultimate destruction of data

Access- To information about themselves and their community. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding who can access their collective information.

Possession- or stewardship, a mechanism to assert and protect ownership or control.

Tri-Council²³

The Tri-Council is comprised of The Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council (NSERC), and the Social

Sciences and Humanities Research Council (SSHRC). Collectively they serve as the primary mechanism to support and promote ethical conduct in research.

The “Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans” (TCPS2) is an essential authority for conducting research in Canada. As this report does not evaluate the ethical considerations of sharing information in the context of research, TCPS2 is not directly relevant. However, the following considerations are highly relevant to this report:

General Principles of Consent

- Shall be given voluntarily (Article 3.1)
- Consent can be withdrawn at any time; this includes the withdrawal of existing data (Article 3.1)
- Consent is an ongoing process (Article 3.1)

Respect for persons: “Some people may be incapable of exercising autonomy because of youth, cognitive impairment, other mental health issues or illness. While autonomy may be considered a necessary condition for participation in research, involving those who lack capacity to make their own decisions to participate can be valuable, just and even necessary. For those prospective participants, additional measures are needed to protect their interests and to ensure that their wishes (to the extent that these are known) are respected... Even when the requirements of free, informed and ongoing consent cannot be met, Respect for Persons requires involving individuals in circumstances of vulnerability in decision making where possible. This may include asking about their feelings regarding participation and/or for their assent.”

Factors that can impact the voluntariness of consent:

- Undue influence
 - Incentive
 - Manipulation
 - Coercion
- Power dynamics
- Relationships of dependency
- Potential to suffer disadvantage if consent is not provided

Vulnerable populations

Article 4.7: “The core principles of Respect for Persons, Concern for Welfare, and Justice entail special ethical obligations toward individuals or groups whose circumstances may lead to their vulnerability in the context of a specific research project and limit their ability to fully safeguard their own interests. Those who are owed special ethical obligations may include individuals who are institutionalized, those in dependent situations, or those whose circumstances (e.g., poverty or poor health status) may render even modest participation

incentives so attractive as to constitute an inducement to take risks they would otherwise not take. Their situation may also compromise the voluntariness of consent in other ways. However, individuals should not automatically be considered vulnerable simply because of assumptions made about the vulnerability of the group to which they belong. Their particular circumstances shall be considered in the context of the proposed research project.”

Office of the Information and Privacy Commissioner of Alberta²⁴

The Office of Information and Privacy Commissioner of Alberta (OPICA) conducts independent reviews on public bodies, health custodians and organizations in response to requests for information under the three access and privacy laws in Alberta: (1) The Freedom of Information and Protection of Privacy Act (FOIP Act); (2) Health Information Act (HIA); and the Personal Information Protection Act (PIPA).

Under privacy laws, organizations are generally required to obtain meaningful consent for the collection, use and disclosure of personal information. In order to obtain consent, an individual needs to understand the nature, purpose and consequences of what they are consenting to.

OPICA outlines the following principles for meaningful consent:

1. Emphasize key elements;
2. Avoid information overload; and
3. Facilitate understanding by individuals, certain elements warrant greater emphasis or attention in order to obtain meaningful consent.

In general, organizations must emphasize the following key elements when requesting information:

- What personal information is being collected?
- What personal information is being, or may be, collected about them? This must be done with sufficient precision for individuals to meaningfully understand what they are consenting to.
- Who is information being shared with?
- What is the purpose of sharing personal information?
- What are the potential risks of harm or other consequences?

The consent process should:

- consider the client’s perspective and be accessible, user friendly and understandable. This may require creativity and innovation;
- be an ongoing process. Organizations should also consider periodically reminding individuals about their privacy options and inviting them to review these.

Professional organization’s codes of ethics

College and Association of Registered Nurses of Alberta²⁵⁻²⁸

The College and Association of Registered Nurses of Alberta (CARNA) states that to obtain valid informed consent from an individual to disclose information, it must:

- Explicitly state what health information will be disclosed
- State the purpose(s) for disclosure
- Identify the person(s) to whom the health information will be disclosed to
- Include patient acknowledgement
- Have an effective and expiry date
- Include a statement indicating the patient can revoke their consent at any time
- Be in writing or electronic

Health information may only be disclosed without consent in limited circumstances (in accordance with HIA Section 35), including to:

- another custodian, or its affiliate, for any of the Authorized Uses and in some situations to the government of Canada or of another province or territory for the government's use for health system planning/management and health policy development;
- a person who is responsible for providing continuing care and treatment to the individual; and/or
- family members of the individual, or a close personal friend, if the information is provided in general terms and concerns the presence, location, condition, diagnosis, progress and prognosis of the individual on the day on which the information is disclosed, unless contrary to the express request of the individual.

Canadian Association of Social Workers and the Alberta College of Social Workers²⁸⁻³⁰

The Canadian Association of Social Workers (CASW) and the Alberta College of Social Workers (ACSW) state the following values that are highly relevant to this report:

Promotion of Client Self-Determination and Informed Consent

- Social workers promote the self-determination and autonomy of clients, actively encouraging them to make informed decisions on their own behalf.
- Social workers evaluate a client's capacity to give informed consent as early in the relationship as possible.

- Social workers recognize that in some cases their ability to promote self-determination is limited because clients may not be capable of making their own decisions, are involuntary or because clients' actions pose a serious threat to themselves or others.

CASW and ACSW's code of ethics states that written consent *must* be obtained from clients in order to disclose any of their information (Section D.7). The only exemptions to this are:

- If a client is at risk of harming themselves or others OR
- There is a legal requirement to share information, such as a court order

Under the ethical standards of CASW and ACSW, a client must understand the nature of the services they're accessing and any potential consequences in order to obtain valid consent. CASW and ACSW consider it out of scope to obtain implied consent to disclose information to other agencies. In order for registered social workers to comply with their code of ethics, informed consent must be obtained.

CASW and ACSW require the informed consent process to include clear information regarding:

- with whom the information will be shared;
- what information will be shared;
- the intended purpose for sharing the information;
- whether the client has a right to request that identifying information be excluded; and
- any other information particular to the specific request that a reasonable person would want to know.

In all circumstances where information about a client is being released, the following principles apply:

- information will only be released to those who "need to know;"
- only the minimum amount of information required to address the need will be released;
 - Where legislation or agency policy permits sharing information without client consent, a social worker will still seek consent unless there is an urgent need to release the information without consent.
 - When information about a client is required from other sources, a social worker will make a reasonable effort to explain this to the client, decide with the client what other sources are to be used and seek agreement on the method of obtaining the needed information.

Canadian Psychologist Association and the College of Alberta Psychologists^{31,33}

Consent to disclose personal/confidential information

Unless required by law, psychologists shall disclose personal and confidential information only with a client's consent. If reasonable, the consent should be written, signed, and dated by the client, preferably in the presence of the psychologist. The consent should be of an informed nature (confirming that the client appreciates the consequence of the disclosure) and should specify the information to be disclosed, the intended recipient of the disclosure, and the (reasonable) period of time for which consent is granted.

Clients should usually be presumed competent to make decisions about the disclosure of their personal and confidential information unless a formal order is in place appointing a guardian or an agent for them. Where a formal order is in place, the consent of the guardian or agent is required for disclosure of information about the client.

Circumstances in which consent is not required

Psychologists may disclose personal or confidential information without a client's consent when there is likelihood of imminent and grave harm to the client and/or a third-party, or when required to do so by law. In these circumstances, psychologists will limit disclosure to persons who reasonably need to know and to the extent necessary in the circumstances.

Special Considerations: Clients presenting with reduced capacity

Decision-making capacity refers to the client's ability to understand a situation, identify decisions required, and ability to identify possible courses of action (along with the possible consequences). Clients who do not appear to understand the information provided or who do not appear to appreciate the reasonably foreseeable consequences of the decision to participate in treatment may be unable to provide consent.

Generally, psychologists assume an adult client is capable of providing their own consent to services unless there is evidence that the client is experiencing reduced capacity. Reduced capacity may arise for a variety of reasons: a) impairment, b) cognitive decline (e.g., due to aging, head injury, psychosis), and c) intellectual disability.

In these situations, psychologists are to follow the general principles of informed consent/assent, recognizing it may be helpful to use different formats, communication aids, interpreters, assistive devices, and/or longer time frames for making decisions. As well, psychologists are to obtain informed consent from a legal guardian when possible.

Canadian Medical Association³⁴⁻³⁷

The Canadian Medical Association's code of ethics, states "While informed consent is required as a general rule, physicians may infer that they have the patient's *implied* consent to collect, use, disclose and access personal health information (1) for the purpose of providing or assisting in providing care (i.e., share only the necessary information with those involved within

the patient's circle of care); and (2) to store personal health information in a medical record (i.e., paper, electronic, or hospital-based). Physicians will want to consider if it is appropriate in the circumstances to advise the patient when a disclosure has been made.”

Core virtues: Compassion, honesty, humility, integrity and prudence.

Core commitments: well-being, respect for persons, commitment to justice, professional integrity and competence, professional excellence, self-care and peer support, inquiry and reflection.

Core responsibilities: patient-physician relationship, decision-making (empower the patient to make informed decisions, respect their decision making, accommodate a patient with cognitive impairments to participate as much as possible)

Framework Guidance

Based on the guidelines defined by various professional organizations, it is strongly recommended that written informed consent is obtained by individuals before their information is shared. In order to promote the client's autonomy, individuals should have the opportunity to opt-in to sharing information with the organizations of their choosing. If an individual is deemed not to have the capacity to make this type of decision upon intake, the consent process should occur at a later time, such as during a meeting with a case manager.

Clear documentation of disclosure requirements should be developed that outline: what information is being shared, the requestor as well as the provider and the reason for accessing information. This is critical to creating a transparent process and building or maintaining trust with a client. Strong policies and procedures that go beyond the legal requirements need to be accessible and effectively communicated to staff and clients. This is essential to promoting ethical actions in the grey areas of the law.

Strict reporting should monitor access and can support further refining policies and procedures in the future. If a breach occurs, concise policies and procedures need to be in place to address the violation and potential adjustments should be made (if relevant) to prevent similar situations from occurring in the future.

If an ethical violation occurs, it is recommended that this is used as a learning tool for staff to better identify ethical courses of action in the future. When using mistakes as a learning opportunity for staff, it is important that confidentiality is upheld and that it is done in a safe environment.

To maintain strict ethical standards surrounding information sharing, it is recommended that each agency trains a specific group of staff that will be able to request and provide client information. Training a specific group of staff will heighten their awareness to the sensitivities surrounding information sharing and will decrease potential ethical violations. Ideally, these staff would be members of a professional organization, as members of a regulated body already have a standardized code of ethics that they are required to adhere to.

It is critical that the procedures that are developed surrounding information sharing do not create unjust barriers to clients or agencies. Creating a clear decision-making tool based on shared values aims to support frontline staff to act with confidence when making decisions in morally challenging situations and help facilitate a more integrated approach to care.

The above processes should be guided and supported by a clear ethics framework. The first step in drafting an ethical framework is determining relevant moral standards. While each individual agency has established values and objectives, these standards likely vary between agencies. Therefore, it is recommended that the prospective collective of agencies who want to share client information with each other need to draft a unique set of values of principles. This set of mutual ideals will act as a foundation of future frameworks and will help guide decision

making in morally challenging situations. These principles will act as a compass for staff when they are confronted with an ethically challenging situation.

What is considered an ethical decision is framed by contextual features. Working through case studies helps staff understand the potential consequences of various decisions and identify morally significant factors. Additionally, these case studies can help identify personal biases and conflict between how different agencies or individuals approach certain situations.

Next Steps

Based on the information gathered in the environmental scan, it is recommended that an interdisciplinary committee should be brought together to draft the following:

1. Develop a community code of ethics though defining shared values, facts and goals, which should be prioritized individually and as a group. The results from this deliberation will determine a clear framework for sharing client information between agencies.
2. Develop a decision-making tool to assist staff in determining whether it is appropriate to share a client's information. Regardless of the specific concern, this framework should facilitate collaboration in delivering client-centered care at the highest ethical standard. A clear ethics framework on ethical information sharing should inspire confidence in staff to make decisions in "grey areas", however, in the instances where staff are morally unsure, supports and resources need to be available to staff who encounter moral uncertainty.
3. Define the levels of risk associated with sharing particular types of client information.
4. Scenarios for staff to understand potential risks and biases that impact ethical information sharing.
5. Determine suggested training strategies for organizations
6. Identify an ethics committee to develop the above and following implementation, to monitor when it is appropriate to share information, refine policies and address breaches when they occur.

Forming an ethics committee

The committee that is assembled to accomplish the above activities should have a diversity of experiences to ensure that a holistic understanding of the situation is created and potential risks are appropriately identified. This list should be reviewed to ensure that critical stakeholders were not overlooked. Suggestions include representatives from:

- **The immigrant and refugee community** - There are unique risks and concerns^f associated with sharing an individual's information who is from an immigrant or refugee community. In order to mitigate these risks for individuals who are experiencing homelessness and belong to an immigrant or refugee community, it is recommended that this perspective is represented. Recommended organization: Mosaic Refugee Health.
- **Indigenous communities** - Recommended Organization: The Alberta First Nations Information Governance Centre.
- **Lived experience** – Recommended organization: The Client Action Committee and/or Grateful or Dead.
- **Law** - To address the complexity of ethical and legal requirements surrounding consent procedures. Recommended organization: The University of Calgary, A professor of law and/or ethics (with an understanding of law).
- **Healthcare**- Recommended Organization: CUPS or one of the Alberta College of Social Workers.
- **Ethics** - Recommended organization: Alberta Health Services, Clinical Ethics Service or an individual with clinical ethics experience.
- **The homeless-serving sector** - at front line, program management, director and systems planner levels. These individuals should all be from different organizations that practice diverse philosophies of care.

^f This logic may need to be extended to other groups that have unique risks associated with information sharing, such as HIV status or LGBTQ+, where additional representation may be important.

Conclusion

Agencies in the homeless-serving sector collect a variety of information from some of Calgary's most vulnerable citizens. This information is critical to providing care and supports to individuals experiencing structural vulnerabilities. Ensuring that best practices for information collection and information sharing are used across and within agencies is of utmost importance to maintaining ethical integrity.

This environmental scan is the first stage of a multi-phased project focused on addressing a gap in knowledge surrounding information sharing and consent practices in the homeless-serving sector. No explicit or consensus framework for assessing the ethical factors related to information sharing in the homeless-serving sector was found. As a result, this project could make Calgary a leader in developing best practices of sharing information in the homeless-serving sector that are evidence based and ethically sound.

Sharing client information between agencies has the potential to enable positive and sustained transitions for individual's accessing these services. While drafting the policies and procedures surrounding information sharing, it is of the utmost importance to uphold high ethical standards. This will protect the rights of the client as well as promote enhanced ethical decision making among staff.

Appendix i

Report Author Bio

Emma Buzath has a background in population health with a focus on vulnerable populations and ethics. She has published work on prison health ethics, force feeding, and the opioid crisis and has travelled globally to present this work. Her work has focused on fostering community capacity in a variety of settings and building communities of practice. Specifically, this has included working for rural hospice societies, HIV Community Link, the Cumming School of Medicine, CAMPP (the Calgary Allied Mobile Palliative Program) and Street CCRED (Community Capacity in Research Education and Community Development). Emma has received training in ethics at Johns Hopkins University and has trained and taught at Yale's Interdisciplinary Centre for Bioethics. Currently she is enrolled in a masters of bioethics at Columbia University and is a teaching associate for Columbia's master's course on research ethics. She is committed to addressing the social determinants of health as an advocate. Emma is incredibly passionate about addressing inequities through policy and clinical practice in the hope of providing more compassionate and dignified care to people, regardless of their postal code.

Appendix ii

Glossary of Terms

Assent- An expression of approval or agreement by demonstrating a willingness to proceed. Typically, assent is sought when working with a minor, someone who has diminished capacity or in emergency situations.

Autonomy- Capable and competent individuals have the basic right to self-determination, independence and freedom, enabling them to make informed choices.

Beneficence- to do good. This principle requires that we perform acts that will benefit clients.

Best interest- interests that support the dignity and well-being of individuals and groups; morally justifiable.

Capacity- An individual's ability to understand a situation, identify decisions required, and ability to identify possible courses of action (along with the possible consequences). This is case specific.

Code of ethics- A way to articulate common values identified by a collective group. These principles serve as a foundation to an ethics framework and reflect the community's unique considerations.

Competence- An individual's ability to make decisions. This is broader in scope than capacity.

Ethics- A field that systematically evaluates the ethical, legal and social implications of standards of conduct and moral judgements. The process of ethical decision making is concerned with arriving at the best course of action, in order to best serve the interests of all involved stakeholders.

Ethics Framework- A tool to facilitate conversations on how to navigate ethically complex and at times ambiguous situations. An ethics framework is built on agreed upon values, and aims to highlight key issues and frame appropriate actions.

Informed Consent- A process of communication where explicit and voluntary consent is provided by an individual deemed to have capacity. Informed consent can be written or verbal, however written consent promotes accountability and transparency through clear documentation processes.

Implied Consent- The assumption of an individual's consent based on their actions or the circumstances.

Nonmaleficence- to do no harm. This principle obliges us to act in such a way that we prevent or remove all foreseeable and avoidable harm from our clients and ourselves.

Opt-in- Express consent is provided before an individual is included.

Opt-out- An individual is automatically included, until they actively dissent.

Appendix iii

Applebaum's legally relevant criteria for decision-making capacity

Table 1. Legally Relevant Criteria for Decision-Making Capacity and Approaches to Assessment of the Patient.

Criterion	Patient's Task	Physician's Assessment Approach	Questions for Clinical Assessment*	Comments
Communicate a choice	Clearly indicate preferred treatment option	Ask patient to indicate a treatment choice	Have you decided whether to follow your doctor's [or my] recommendation for treatment? Can you tell me what that decision is? [If no decision] What is making it hard for you to decide?	Frequent reversals of choice because of psychiatric or neurologic conditions may indicate lack of capacity
Understand the relevant information	Grasp the fundamental meaning of information communicated by physician	Encourage patient to paraphrase disclosed information regarding medical condition and treatment	Please tell me in your own words what your doctor [or I] told you about: The problem with your health now The recommended treatment The possible benefits and risks (or discomforts) of the treatment Any alternative treatments and their risks and benefits The risks and benefits of no treatment	Information to be understood includes nature of patient's condition, nature and purpose of proposed treatment, possible benefits and risks of that treatment, and alternative approaches (including no treatment) and their benefits and risks
Appreciate the situation and its consequences	Acknowledge medical condition and likely consequences of treatment options	Ask patient to describe views of medical condition, proposed treatment, and likely outcomes	What do you believe is wrong with your health now? Do you believe that you need some kind of treatment? What is treatment likely to do for you? What makes you believe it will have that effect? What do you believe will happen if you are not treated? Why do you think your doctor has [or I have] recommended this treatment?	Courts have recognized that patients who do not acknowledge their illnesses (often referred to as "lack of insight") cannot make valid decisions about treatment Delusions or pathologic levels of distortion or denial are the most common causes of impairment
Reason about treatment options	Engage in a rational process of manipulating the relevant information	Ask patient to compare treatment options and consequences and to offer reasons for selection of option	How did you decide to accept or reject the recommended treatment? What makes [chosen option] better than [alternative option]?	This criterion focuses on the process by which a decision is reached, not the outcome of the patient's choice, since patients have the right to make "unreasonable" choices

Applebaum, P. (2007). Assessment of patient's competence to consent treatment. *New England Journal of Medicine*, 375:1834-1840.

Appendix iv

Key Guiding Questions

1. What are the shared goals and values between different agencies?
2. If there is conflict between agreed upon values in a particular situation, how will this be resolved?
3. What information is essential to have access to in order to better meet the needs of people experiencing homelessness?
4. How can a client's autonomy be enhanced?
5. How can we respect a client's decision-making ability or potential?
6. What expectations does the client have for their care/when accessing the service?
7. What is the nature, purpose and utility of sharing a specific piece of information? What are the Risks and Benefits?
8. What is the process for if a client wants to withdraw their consent?
9. What is the process if a new agency is considered part of the information sharing collective? Are clients re-consented?
10. How long will a client's consent to share information be valid for?
11. How does the process that is developed for information sharing impact agencies who do not use HMIS?

Appendix v

Consulted bodies and professionals

A. Professional bodies, organizations and Agencies

ACSW
Alberta Health Services, Ethics Service
The Alberta First Nations Information Governance Centre
The Alberta Medical Association
The American Association of Bioethics and Humanities
The American Association of Public Health
Auckland Plan 2050
BC Housing
Boston Health Care for the Homeless Program
Built for Zero
The Calgary Board of Education
The Calgary Homeless Foundation
The Canadian Association of Bioethics
The Canadian Association of Public Health
The Canadian Association of Psychologists
The Canadian Counselling and Psychotherapy Association
The Canadian Medical Association
The Canadian Association of Social Workers
Centre for Homeless Impact (Scotland)
The Chicago Alliance to End Homelessness
City Ambition Network (Scotland)
The College and Association of Registered Nurses of Alberta
The College of Alberta Psychologists
The Community Ethics Network (Toronto)
Corporation for Supportive Housing
DataKind
The Engine Room, Responsible Data
The European Observatory on Homelessness
The Health Quality Council of Alberta
HIV Community Link
Health and Social Care, North Lanarkshire (Scotland)
The Homeless Hub
Homeless Link (England)
King County's Health Care for the Homeless Network
Michigan Coalition Against Homelessness

National Health Care for the Homeless Council
National Human Services Data Consortium
NSW Government, Family and Community Services (Whales)
Office of the Information and Privacy Commissioner of Alberta
Partnership for Strong Communities
Simon Community (Scotland)
St. Mungo's (England)
Tri-Council Panel on Research Ethics
20,000 Homes

B. Individuals

The United States

Cornell University, Decision of Medical Ethics, Professor
Columbia University, Professor of Clinical Ethics
Columbia University, Professor of Law and Bioethics
Eccovia Solutions, Director of Health and Human Services and Public Sector
The Hastings Centre, Fellow
Ohio State University, Professor of Social Work
Oregon Health and Science University, Assistant Professor of Social Work
The University of North Carolina at Charlotte, Institute for Social Capital, Data and
Research Associate
The University of Pennsylvania, Professor of Social Policy
The International Association of Privacy Professionals, Privacy and information privacy
consultant
Rhode Island College, Professor of Social Work
Yale University, Assistant Professor of Emergency Medicine
Yale University, Professor of Law and Director of Bioethics

Canada

The University of British Columbia, The W. Maurice Young Centre for Applied Ethics,
Professor of ethics
The University of British Columbia, Associate Professor of Nursing
The University of Calgary, Assistant Professor of Social Work
The University of Calgary, Professor of Computer Engineering, interest in data networks
The University of Calgary, Clinical Lecturer in Psychiatry
The University of Calgary, Clinical Lecturer in Ethics
McGill University, Integrated Studies in Education, Assistant Professor
The University of Ottawa, Professor of Law
St. Michael's, Centre for Urban Health Solutions, Associate Scientist
The University of Toronto, Department of Information, Professor

The University of Toronto, Professor of Nursing
The University of Victoria, Professor of Nursing

Europe

Aachen University, Postdoctoral Ethics Fellow (Germany)
The Danish Center for Social Science Research, Senior Researcher (Denmark)
The Geneva University Hospital, Assistant Professor of Psychiatry (Switzerland)
Lund University, Professor of Social Work (Sweden)
Radboud University Nijmegen, Professor of Political Science (Netherlands)
The University of Amsterdam, Professor of Social and Behavioral Sciences (Netherlands)
The University of Twente, Postdoctoral Researcher in Ethics and Data Science

The United Kingdom

Oxford University, Postdoctoral Research Fellow in Psychiatry
Heriot-Watt University, Institute for Social Policy, Housing & Equalities Research,
Professor

Australia

Deakin University, Associate Professor of Bioethics and Health Humanities
Monash University, Professor of Social and Political Philosophy

Appendix vi

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Other Important Resources

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