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# OPEN COMMUNICATIONS SUMMARY REPORT

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2018-2019

# CHH Open Communications Working Group 2018-2019 Summary Report

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## Background

The Collaborative for Health and Home (CHH), formerly known as the Calgary Recovery Services Task Force (CRSTF) is a committee of homeless-serving agencies, government, and interested stakeholders who have come together to consider ways of collaboratively responding to the complex health, housing, and supports needed for individuals experiencing chronic homelessness in Calgary.

The CRSTF Final Report and Recommendations (Link to full report in Appendix) listed out 7 recommended actions to support its purpose. Each recommendation formed working groups, including recommendation #5, “Ensure open communication through appropriate and timely access to information amongst organizations and agencies serving homeless Calgarians.”. The Open Communications Working Group (OCWG) was formed based on the notion that “sharing information between organizations serving the same individual can help increase the continuity of care that individuals receive, reducing the number of times they have to reiterate their needs and decreasing the possibility that they will experience negative outcomes because of lack of coordination.”

The OCWG composed itself of representatives from several homeless serving agencies, SORCe, a professor from the University of Calgary and a representative from the Government of Alberta.

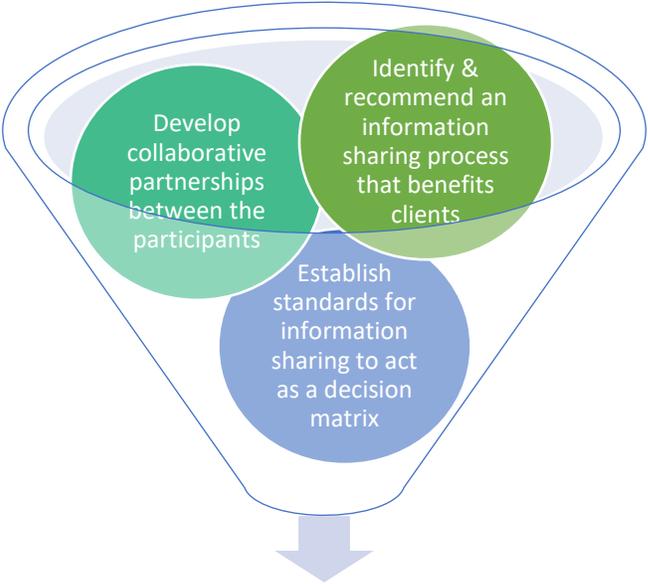
The below statements were created by the group to allow all members to align interests and to ensure this work relates to their organization’s business plans. OCWG has a vision where:

- A set list of Homelessness Serving agencies, their volunteers and staff, have access to valid and reliable information on homeless Calgarians.
- Continuity of care is increased:
  - The number of times people must reiterate their needs is reduced
  - The number of negative outcomes is reduced or removed
  - Improved Coordination between systems, staff and participants
  - Reduction in number of people becoming homeless
  - Reduction in the length of time being homeless
  - Reduction in the number of people becoming homeless again

The group then reviewed its vision and set out the below specific goals. This was used to provide the group scope for their time committed.

1. Recommend an information sharing process that benefits the clients
2. Recommend tactics to increase collaborative partnerships between participants in the homeless serving system-of-care
3. Recommend standards for information sharing to act as a decision matrix to guide the system-of-care
4. Identify relevant initiatives and draw from learnings in other sectors, to guide and support open communication within the system-of-care

Having these ambitious goals in mind, the group used multiple work planning exercises to develop tactics. These would serve as the starting point of work. The group sub-divided the work into smaller sub-groups, based on subject matter experts and interests, to maximize the capacity of the team. The identified 3 tactics were supported by 5 actions:



This report will hopefully allow the readers the opportunity to review the work completed by the OCWG in hopes of highlighting the group’s accomplishments, learnings, continued gaps and recommended steps forward.

## Top accomplishments

1. Engaged Community members, individuals with lived experience, around information sharing
2. Environmental scan about legislations governing information sharing practice. Gained a foundational knowledge of the legislations which control information sharing and how they apply to our sector
3. Environmental scan of all unique identifiers used to link client level information across North America
4. Developed a Unique Identifier Grid to determine accuracy rates, pros and cons of the options available
5. Participated in the Social Impact Lab innovation process, tested and built a prototype information sharing kiosk
6. Created a list of potential participating agencies for information sharing
7. Developed an information sharing hierarchy that could be adopted
8. Engaged agencies on a current state analysis of information sharing to understand existing barriers
  - a. Service Provider Information Survey
  - b. Scanned venues and agencies to understand methods and mediums of communicating consent
9. Developed an educational video which can be used to discuss information sharing with clients
10. All members undertook training and completed Government of Alberta - ISS e-course - <http://www.humanservices.alberta.ca/department/iss-courses-and-training.html>

## How do we share information?

Sharing client information is a fundamental step in providing meaningful, holistic services because it is the main way to gather together all the resources the client has accessed or needs to access. Because this step is so crucial to the Homeless Serving System of Care (HSSC), it begs the question: how do we share information? Receiving client consent is the foundation to ensuring access to client information amongst agencies serving homeless Calgarians. Understanding what is currently happening within the HSSC in Calgary assists the community in determining the definition of “Informed Consent”, and in guiding recommendations on information sharing processes.

To answer this question, three research projects were completed:

1. A Scan was completed to determine which primary guiding privacy legislation are used. If organizations used multiple legislations, then legislations were ranked as primary, secondary or tertiary.
2. Service Provider Information Sharing (SPIS) survey was conducted with staff at various agencies. Staff were asked to self-report their comfort level regarding sharing client information and their knowledge of various legislations.
3. Members of the client action committee were interviewed about what their expectations were around consent and information sharing.

## Primary Guiding Privacy Legislation

### Current Landscape - Calgary Homeless Serving System of Care (HSSC)

Each agency has their own intake<sup>1</sup> process which includes a release of information consent component. Upon review it was discovered that there are many similarities, but nothing has been standardized across the sector. The only exception are agencies who utilize HMIS or accredited through a CHF funded program Where agencies are mandated by a HMIS-participating agency agreement to read a verbal notification which is in accordance with Alberta’s Freedom of Information and Protection of Privacy Act (FOIP Act) to each client, however the notification provides very limited consent to agencies to be able to share client information to each other.

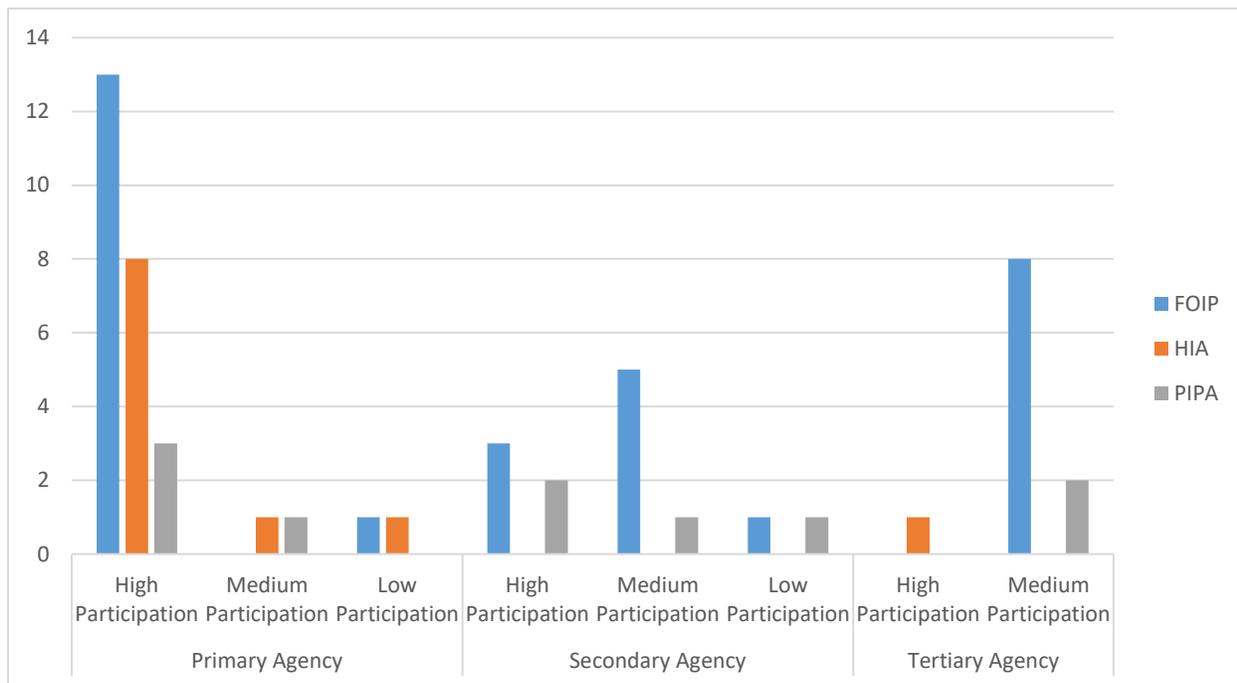
To provide clarity on this, organizations were asked which privacy legislation acted as their primary guide for setting their consent policies. Agencies were toured by members of the OCWG in downtown Calgary to see first-hand how consent was provided and understand the different methods that are used to obtain consent and inform clients.

[Appendix A](#) provides a comprehensive list of all the organizations interviewed and which legislation(s) they follow. In the cases where multiple legislations were applied, the legislations were ranked as primary, secondary, and tertiary. The below graph shows which legislations are followed most frequently.

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<sup>1</sup> Intake is the process through which a client is registered with an organization in order to gain access to resources

**Graph 1: Agency Participation of Primary Guiding Privacy Legislations**



What was soon understood is that there are many legislative components to this sector and not all organizations are held to the same set of standards. Just under half of the organizations that were reviewed fell into a minimum of two legislative bodies, primarily FOIP and HIA.

In working with the Information Sharing Strategy of the Government of Alberta we explored the function of service delivery groups. Groups that could be formed among multiple stakeholders, that meet the legislative frameworks and encourage information sharing. Examples of where this is used, Health sector, Education sector and Coordinated Access and Assessment.

## Service Provider Information Sharing

Research on how various government agencies and other service agencies defined informed consent was also completed through the Service Provider Information Sharing (SPIS) survey (Available by request). This survey asked staff to self report their level of knowledge and comfort regarding sharing client information.

### Research Questions

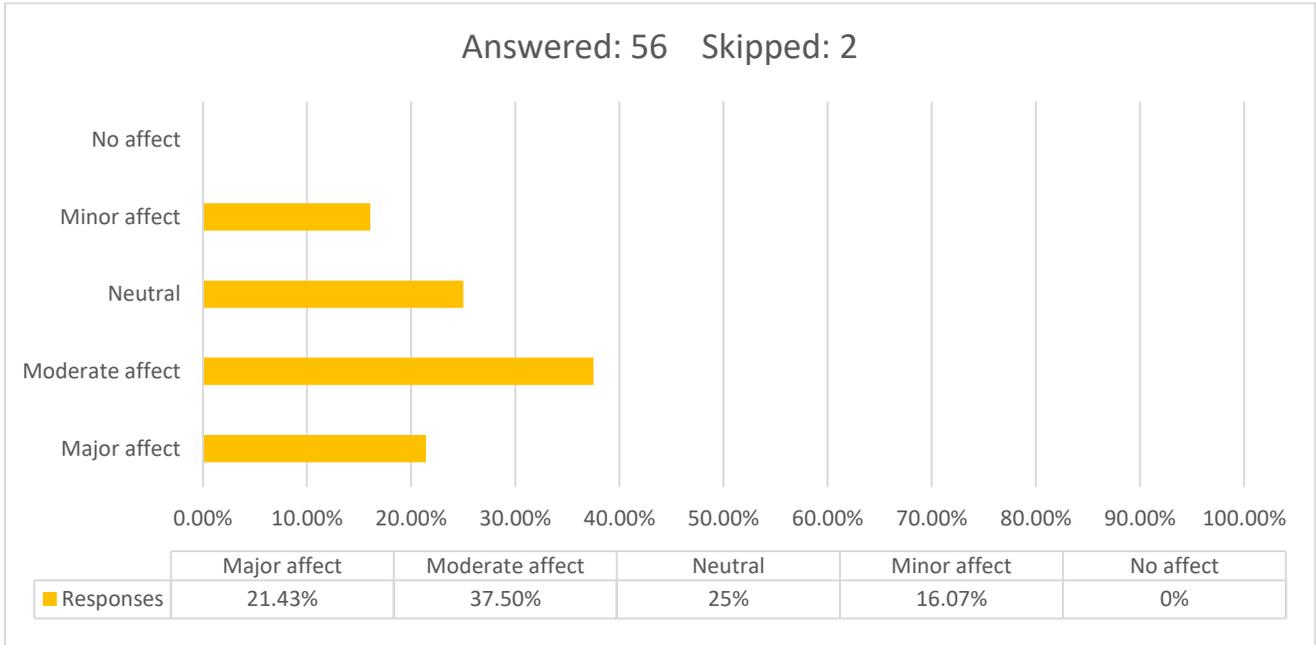
#### Methods

There were two events in which the survey was provided to be completed by agencies; The HMIS user group meeting which is primarily attended by HMIS agency admins, and the CHH Anniversary event.

#### Results

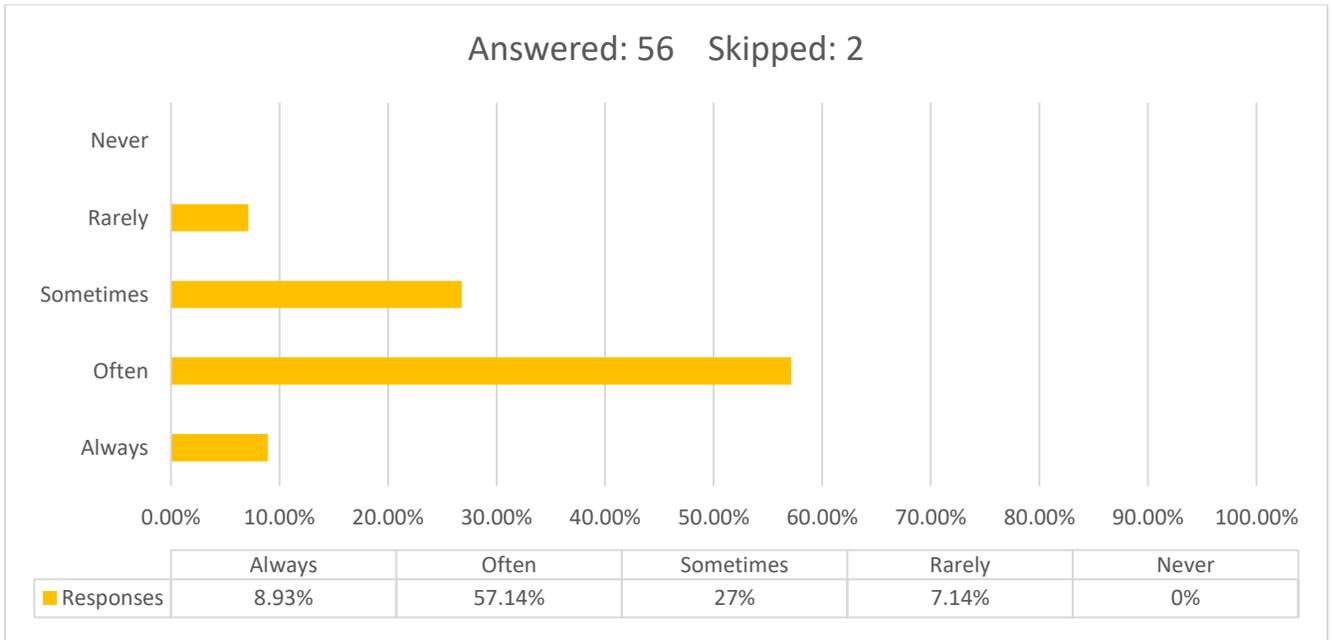
The SPIS survey we received 57 respondents, primarily from the Homelessness sector. Overall, a majority of SPIS survey respondents felt that current client consent processes created a barrier to information sharing and contributed to a negative effect for client outcomes (Q8).

**Q8 Do you think that there is a negative effect to client outcomes due to current information sharing barriers?**



With regards to whether or not clients were truly informed when giving consent, 65% of respondents stated that, in their opinion the client always or often understands informed consent (Q7).

**Q7 In your opinion, does a client understand what informed consent is when you explain it to them?**



**To Share or Not to Share**

Once we receive Consent from a client it is time to Share! Right?! Our research shows that sharing information within this sector can be quite complex. Agencies are confused by legislations, processes,

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which lead them to question their authority to share. Based on the SPIS survey (Q15), more than half the respondents highlighted the below five as the top current barriers to sharing client information. These are ordered by the most selected first.

- Client consent
- Fear of Liability and consequence
- Agency Process
- Lack of knowledge
- Interpretation of legislation

Most non-profits identified do not have an in-house privacy expert or a specialized privacy officer and without those experts readily available to guide decision making staff lose confidence, increase fear of liability and play it safe by not sharing information.

Training and education are pieces of the solution to help build confidence and clarity of information sharing protocols. This was tested with two local agencies. There are Information Sharing training videos available from the Government of Alberta. These agencies provided a pre-training and post-training survey to their staff. Notably, items such as; level of confidence of info sharing dramatically increased their confidence and understanding post training.

### Personal Information Video

One of the items we discussed was educational tools for agencies and clients on what happens with personal information. An information video was created to potentially be used by agencies to share with clients. This is still in draft mode and not finalized but has been tested with Client Action Committees. We felt this was a way of taking legal jargon and providing the information in a consumable way. This would also allow agencies to have a standard tool to use. The most current version of the video may be found here: <https://www.youtube.com/watch?v=G-DPaRyQcVg&feature=youtu.be>.

The Client engagement was completed in November 2018 with an adult and youth lived experience groups as well as with clients at the DI. Constructive feedback was provided by the members of the groups. Overall people felt that this information was helpful but would rather a person explain it to them than watch a video. Some clients raised concerns regarding language and tone which require further investigation. A second attempt of the video has not yet been completed or presented back to the lived experience groups.

### Informed Consent Approach

After completing a thorough environmental scan of the definition of informed consent (Q6 & Q9 of Appendix B), we have summarized the commonalities between them. There are two steps:

1. **INFORM** - Provide the information to the client:
  - What information is being collected or disclosed
  - For what purpose
  - To whom; and
  - For how long
2. **CONSENT** - Receive valid consent from the client
  - Client is aware and understands what you are explaining them
  - In most cases verbal notification and consent is acceptable

While it is impractical to complete a one-size fits all verbal or written notification as these elements do change from agency to agency, a template with the same language is possible to create. The main goal and advantage would be that with the same underlying elements present in consent notification, clients would become accustomed to seeing the same language and practice across organizations making it easier for them to be informed on what it means to give consent.

### Client Action Committee Interview

We engaged the Calgary Homeless Foundation (CHF) Client Action Committee (CAC) and those with lived experience at the Calgary Drop-In & Rehab Centre Society ([Appendix B](#)). A preliminary consultation with CAC was conducted on July 13<sup>th</sup>, 2017. The goal of the consultation: Educate clients on where their data goes and educate agency staff on what their practice can be to be aligned with standards and they can feel confident when sharing information.

Further to this, Calgary Reads was contacted via email regarding plain language and literacy. A scan of web-based resources such as consent form examples, training resources and existing methods of communication was undertaken also. The CHF Homeless Management Information System (HMIS) team completes annual reviews of HMIS usage at participating agencies and the information which has been obtained in previous years regarding agency barriers to information sharing and operational consent processes were scanned as well.

The conversation with CAC showed that CAC members' beliefs around informed consent fit this definition: "Consent is informed when there is an awareness or understanding by both parties of what specific information is being shared with a specific group or agency for a specific purpose".

### Unique Identifiers (UIDs)

To share information across agencies and systems one needs to ensure that partners have a data matching or authentication process. This is to ensure that clients are not incorrectly identified when receiving services. How does one match client information from database to database? A few examples are; in the health sector they use the provincial health number, some places use provincial ID, driver's license number or social insurance number. In the United States many homeless serving agencies will utilize these methods to ensure that client's information is matched and tracked appropriately. In Canada the legislation prevents agencies from tracking those government issued ID numbers in their system. The OCWG wanted to identify the UIDs that have been used in our sector and understand the pro's and cons of each.

Currently the most commonly used method in Calgary is an algorithm which creates a UID for each client. This method uses a mix of first name, last name, date of birth and gender.

Locally there is an agency who utilizes agency issued ID badges which the agency has determined to be quite successful for effectiveness of tracking of their services. However, there is a cost for re-issuing lost badges.

Another local agency uses fingerprint technology as clients enter their organization. This has also been proven to be successful in diminishing the duplication of clients being entered into the database.

The OCWG made a list of all known UID's that have been used and challenged them against a list of reliability questions (Contact CHH staff to see the full work completed).

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What this quickly identified is that the current practice of algorithm based UID is the most common solution for leveraging existing infrastructure. However, in theory if all agencies were using facial recognition as their UID, data matching would be the most accurate in this case.

Several concerns were identified and discussed regarding the challenges with using facial recognition as the UID, and the OCWG explored strategies for how a facial recognition UID system could be put in place across the HSSC.

One strategy that was deployed included a team within the OCWG joining the Social Impact Lab for a 10-week intensive exploration to answering the question: How might we effectively provide self-serve support that enables the client to meet their own wellness and housing needs? A video of their efforts were catalogued here: <https://youtu.be/G-DPaRyQcVg>.

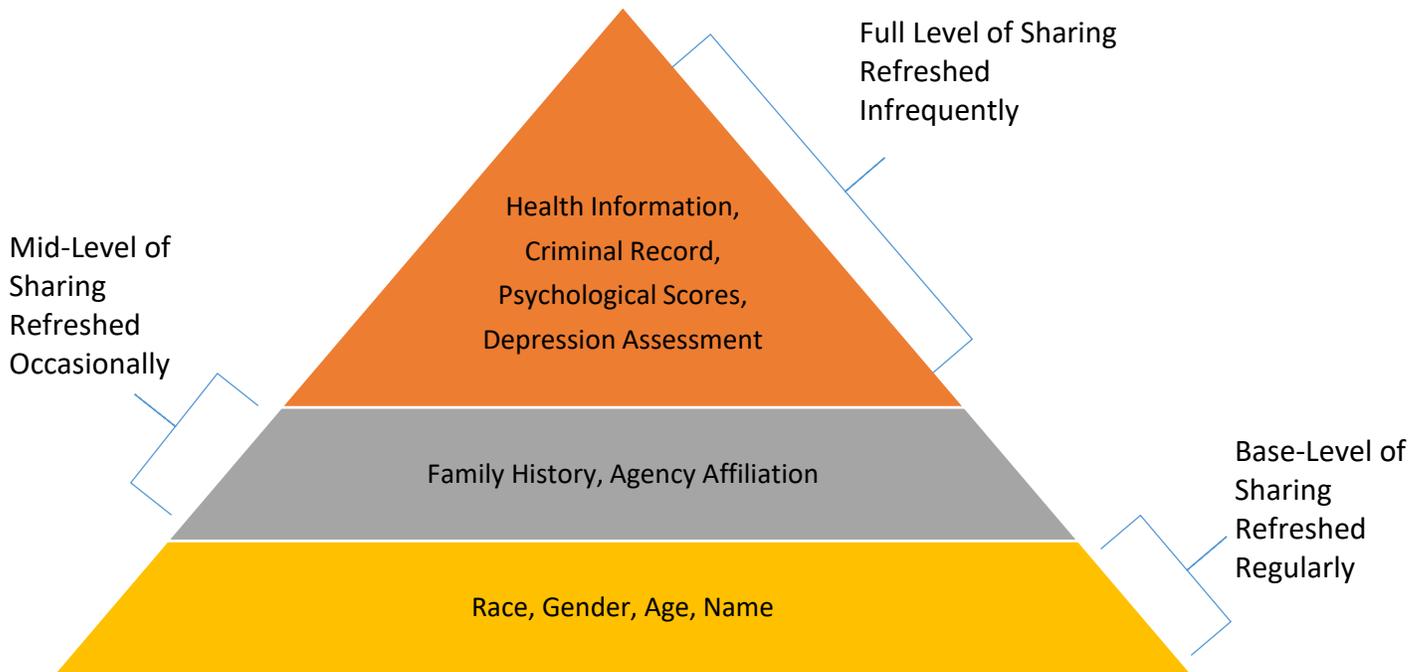
The next step identified was for CHH to invest in a Privacy Impact Assessment (PIA) to understand the legal considerations for setting up self-serve kiosks with facial recognition and a cloud-based connectivity system that would share information between kiosks at various agencies.

There has been no further investigation to what margin of error is acceptable for the sector. Do we require 100% accuracy and if yes, at what risk. While the group concluded that there were risks involved with not having 100% accuracy there was no thorough assessment of the severity and likelihood of such risks occurring beyond anecdotal evidence available.

### When We Share What Do We Share?

The OCWG created a suggested outline of various levels of client information and recommendations on frequency of sharing. This will be vetted with the stakeholders who would be completing information sharing as part of the next phase of the project. An environmental scan of other homeless serving systems across North America could be of value to understand what information levels they have agreed could be shared.

**Graph 2: Levels of Information Sharing**



## Moving Forward

In no particular order, below are the recommended areas of interest to move this work forward.

- Develop a legal and ethically sound framework that agencies can adopt across sectors which would create a way for information sharing to easily occur. The CHH Steering Committee is considering a proposal on this in Q1 FY20.
- All agencies adopt a standard of client notification which enables the information sharing framework. Leverage the collaborative services delivery group model. The CHH Steering Committee is developing a project plan to move this forward in FY20.
- All client-facing documentation is to be at the 5<sup>th</sup> grade reading level.
- All levels of the Agency should be held accountable to ensure all levels of staff receive training on the rights and responsibilities of collecting and sharing information. The intent is to install confidence in sharing information.
- Leveraging existing infrastructure to pilot information sharing practices; ie HMIS
- Assess and mitigate where possible, risks to increasing data linkage match rate by enhancing data collection processes of base level information - name, DOB, gender - to be able to reduce the margin of error in data linkage.
- Continue to monitor the evolution of unique identifiers and client data matching processes in society to identify new and improved ways of data linkage.
- Review and consider revisions to the developed video on informed consent for clients and present back to CHH Steering Committee for endorsement if desired.
- Following a discussion on April 5<sup>th</sup> with the CHH Steering Committee, an ethics review is to be completed prior to proceeding with further investigations into using biometrics as a UID under the CHH banner.

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## Appendix A: Agency

### Participation of Primary Guiding Privacy Legislations

#### **FOIP**

##### **Primary Agency**

Alberta Community & Social Services - Housing & Homeless Supports

High Participation

Alpha House Society

High Participation

Calgary Homeless Foundation

High Participation

Calgary John Howard Society

High Participation

Calgary Police Service

High Participation

City of Calgary

High Participation

CUPS (Calgary Urban Project Society)

High Participation

Hindsight Group

Low Participation

Inn From The Cold

High Participation

Mustard Seed

High Participation

SORCe

High Participation

Street CCRED

High Participation

The Alex Community Health Centre

High Participation

YW Calgary

High Participation

##### **Secondary Agency**

Aboriginal Friendship Centre of Calgary

High Participation

Alberta Children's Services

Medium Participation

Alberta Indigenous Relations

Medium Participation

Alberta Justice & Solicitor General

Medium Participation  
Alberta Supports/Alberta Works/AISH

High Participation

Aspen

Medium Participation

CASS (Calgary Alternative Support Services)

High Participation

Children's Cottage/Brenda's House

Medium Participation

Distress Centre

Low Participation

##### **Tertiary Agency**

Awo Taan Women's Emergency Shelter

Medium Participation

Boys & Girls Club of Calgary

Medium Participation

Calgary Dream Centre

Medium Participation

Calgary Transit

Medium Participation

Discovery House

Medium Participation

Keys To Recovery

Medium Participation

Woods Homes

Medium Participation

YW Calgary - Sheriff King Home

Medium Participation

#### **HIA**

##### **Primary Agency**

Alberta Health Services - Community, Rural, & Mental Health

High Participation

Alberta Health Services - Indigenous Health Program

High Participation

Alberta Health Services - Provincial Planning & Capacity Management

Medium Participation

Canadian Mental Health Association

High Participation

Cumming School of Medicine

Low Participation

Emergency Medical Services

High Participation

Foothills Medical Centre - ER

High Participation

Fresh Start Recovery Centre

High Participation

HIV Community Link

High Participation

SHARP Foundation

High Participation

##### **Tertiary Agency**

Calgary Sexual Health

High Participation

#### **PIPA**

##### **Primary Agency**

Calgary Drop-In & Rehab Centre

High Participation

Canadian Centre for Male Survivors of Child Sexual Abuse

Medium Participation

Elizabeth Fry Society

High Participation

United Way of Calgary & Area

High Participation

##### **Secondary Agency**

Aboriginal Standing Committee on Housing & Homelessness

High Participation

Horizon Housing Society

Medium Participation

Salvation Army - Centre of Hope

Low Participation

Sunrise Native Addictions

High Participation

##### **Tertiary Agency**

Calgary Women's Emergency Shelter

Medium Participation

Community Resource Centres

Medium Participation

## **Appendix B: Client Action Committee Initial Interview About Informed Consent**

### **What is your understanding of "informed consent"?**

- being fully aware: sharing specific information with specific group(s) for a specific reason.
- Appropriate information is being requested
- Purposeful

### **What information would be included in the informed consent?**

- topic specific
- audit trail can be done by a third party
- everything related to the topic, including length of time and how it will be used.
  - e.g. the CAA form
- what is being collected, for what purpose, for how long
- an individual should not be punished for not sharing information
- What is being shared in aggregate versus what is being shared that is identifiable

### **What assumptions do you have around informed consent?**

- someone has all the information about a service
- the client understands
- offers information to a similar service
- public service information sharing is the same or similar as private services
- Difference between "information on you" and "*your* information"
  - Agencies are collecting different things
- "Assumption that everyone has access to everything" (referring specifically to CHF ServicePoint)
- "Police can access my records at some places"
- Privacy is a legal right
- Privacy is not a legal right

### **What barriers have you experienced with informed consent?**

- consent is not done with every client (implied or verbal consent)
- issues / questions / confusion around guardians, power of attorney, etc.
- when the client doesn't understand for a variety of reasons
- Frontline staff not having adequate training/understanding of why information is being collected (eg. Frontline staff conducting SPDAT weren't qualified)
- "the circumstances I am in as a homeless person are the barriers"
- "consent form or freeze to death"
- Forms – too many, tired of filling them out
- Trust of frontline worker
- Sharing personal information is traumatic and can also be traumatic for the frontline staff

### **What would make informed consent easier?**

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- plain language
- uniformity / consistency of the form > AISH, AB Works, ASHB, homeless serving agencies
- standard practices > length of time, etc.
- disclosure
- capacity
- voluntary consent
- trust of frontline worker
- Clearer forms
- The ability to opt-in to what you're comfortable with
- Reconsider what is necessary at point of entry into a program vs. can be asked later on when rapport stronger
- No questions on gender identity, sexual expression or police involvement
- Levels of consent
- Meet the client where they are at (regarding what is comfortable to share) versus what you need