

Provincial Human Services and Justice Coordinating Committee

Guidelines for Enhancing the Engagement of People With Lived Experience Across the HSJCC Network

November 2021



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INTRODUCTION

The HSJCC Network recognizes the essential and ongoing value of engaging individuals who have lived experience in the human services and justice sectors. As a cross-sectoral, collaborative network, the expertise and dedication of people who have lived experience has enhanced the impact of our work in countless ways. People with lived experience bring to the table a deep understanding of the systemic issues HSJCCs seek to address. First-hand experiences can illustrate the realities of navigating complex systems, illuminating barriers and inequities. Beyond their personal experiences, many individuals with lived experience contribute an in-depth knowledge of sectoral issues gained through years of advocacy work and organizing.

For HSJCCs to engage people with lived experience in a meaningful manner, it is important that members with lived experience are recognized as experts alongside all other committee members. This requires moving beyond a focus on representation to addressing power imbalances and removing barriers to participation. In turn, committees will need to reflect deeply on their existing practices and commit to creating a culture of inclusion.

This resource was developed to provide guidance to local and regional committees in the HSJCC Network for the purpose of engaging people with lived experience in a meaningful and effective manner. It provides strategies and resources to help direct committees in their engagement work.



LEARN MORE ABOUT THE HSJCC NETWORK

Visit our website to learn more about the HSJCC Network. Join the mailing list to get updates on projects, webinars and events.

Learn more: hsjcc.on.ca



HISTORY

People With Lived Experience (PWLE)ⁱ have been working, writing, and organizing to achieve change in numerous systems related to mental health, substance use, and within the anti-psychiatric and prison reform movements for many years. When adopting practices that support having people with direct experience at the table, it is essential for the HSJCC Network to acknowledge the history and context within which this participation has arisen. While there have been legislative changes and a rise in engagement discourse in recent years, the underpinning efforts and labours of people with lived experience have been longstanding. This is particularly true of Black, Indigenous, and racialized communities.

Psychiatric Consumer/Survivor Movements

Advocacy by people with lived experience in the mental health system has evolved over many decades, with different approaches and terminology adopted over the years. In the 1960s and 1970s, the psychiatric consumer/survivor movement emerged as writers and activists began applying a critical lens to the experiences of patients in the traditional mental health system.¹ This movement created a sense of community around shared experiences that were previously seen as individual. Activists applied a human rights perspective to their issues, concentrating on injustices and deficiencies within the system, with a focus on institutionalization.

Although grassroots in nature, this movement has continued to evolve, encompassing many divergent perspectives and ideologies. Over time, people with lived experience have begun to advocate for greater involvement in policy, research and service provision. Today, consumer/survivor organizations and programs operate under different models and frameworks, providing supportive services to people with lived experience in addition to their ongoing advocacy.

Prisoners' Rights Movements

The 1960s and 1970s were also a time of significant organizing for individuals who were involved in the criminal justice system in Canada. In line with the growing human rights movements, prisoners were organizing at a larger scale to improve conditions and treatment in Canadian institutions. These activities led to greater recognition of the rights of offenders, structural changes within institutions and more focus on rehabilitation and reintegration.

A notable demonstration of activism from this movement was the establishment of Prisoners' Justice Day. On August 10, 1975, prisoners refused to work and conducted a hunger strike in the memory of Eddie Nalon, a prisoner who died in segregation in an Ontario prison the previous year. Nalon's death led to a recommendation by the Coroner's Jury for a reduction of punishment by segregation.² The Nalon inquest was one of numerous official inquiries from that time around the use of segregation/solitary confinement, an issue advocates continue to be critical of today. Overtime, many grassroots groups, community organizations and service providers have evolved to advocate for the rights of individuals in correctional institutions and the provision of services and supports for those who have been released.

ⁱ While this guidebook uses the terminology People with Lived Experiences (PWLE), there are a variety of terms and labels used by different individuals and groups to identify this population. Many of these terms carry different significance and meaning to people with lived experience, and someone's preferred terminology will likely depend on their individual experiences.

THE HSJCC NETWORK

Human Services and Justice Coordinating Committees (HSJCCs) were established in response to a recognized need to coordinate resources and services, and to plan more effectively for people with complex human service needs who are in conflict with the law. HSJCCs' advocacy and support for people who experience conflict with the law is congruent with the mandate of Ontario's *Patients First Act* (2016). There are currently 38 Local committees, 14 regional committees and one Provincial table.

About this project

The HSJCC Network draws frequently upon the expertise and resources of people who have lived experience in the human services and justice sectors in its work at the local, regional and provincial level. In response to requests from committee members for additional guidance and support in improving the engagement of people with lived experience, the Provincial HSJCC approved the establishment of an Advisory Committee to oversee this work in November 2019. The PWLE Advisory Committee was first convened in April 2020.

Survey overview

This guidebook was informed by two surveys that were conducted in the Fall of 2020. The first survey was completed by the Chairs/Co-Chairs of Local and Regional HSJCCs. The purpose of this survey was to gain a better understanding of how people with lived experience are currently engaged within the HSJCC Network. This survey was completed by 26 respondents.

The second survey was completed by current HSJCC members who identify as people with lived experience. The purpose of this survey was to understand how the experiences of these members in the HSJCC Network can be improved. This survey was completed by 8 respondents.

Terminology used in this guidebook

For the purposes of this work, the PWLE Advisory Committee has defined a person with lived experience as *“an individual who has direct experience with mental health and/or substance use disorders and has used the resources of the mental health system and/or has come into contact with the criminal justice system.”*⁷

Many of the strategies in this guidebook are intended to support HSJCC members who are serving openly in a role as a person with lived experience. We acknowledge that there may be members with lived experience who are serving on HSJCCs in other capacities and who may or may not have disclosed this information to the rest of the committee. Each member has different needs and comfort levels around disclosure, and their individual preferences must be respected and supported.

UNDERSTANDING MEANINGFUL ENGAGEMENT – BEYOND TOKENISM

Engagement is not just about having a person with lived experience on a committee. Truly meaningful engagement is about creating ways to collaborate and communicate, and it is a valuable, productive experience on projects or initiatives. Attention must be paid to unequal power in the room, and action must be implemented to ensure members can fully participate in discussions, decision-making and committee activities. Meaningful engagement requires that committees are mindful of their motivations for including people with lived experience and ensures that those voices are genuinely heard and honored. It requires working in a manner that supports the goals of each person with lived experience so that they can properly perform their role.

Rooted in intersectionality and anti-oppression frameworks, meaningful engagement reduces harms and barriers, offering opportunities for collaboration.

Refers to genuine, equitable, and affirming processes to integrate the perspectives and expertise of people with lived experience within the mental health and addictions system, from policy development to point-of-care (15). Ensuring that engagement is “meaningful” for everyone involved, especially for persons with lived experience, is important.³

In *Ontario’s Patient Engagement Framework*, Health Quality Ontario outlines six guiding principles for building successful engagement which can be applied to many different approaches, regardless of the goals and desired outcomes. The six principles are: 1) Partnership; 2) Learning; 3) Empowerment; 4) Transparency; 5) Responsiveness; and 6) Respect. Health Quality Ontario recommends that a comprehensive patient engagement strategy should include a strategic goal and embed the above guiding principles into its framework.⁴

To elaborate where the principle of “empowerment” is concerned, it is the process through which people gain more control over the things that affect their lives. Through empowerment, people are able to express their needs, voice their concerns, and become involved in decision-making that will impact them.⁵

Capacity-building is an additional strategy for facilitating engagement that involves the development of skills, knowledge and resources that will enhance someone’s ability to take action.⁶ In other words, a meaningful approach to engaging people with lived experience will ensure that people can openly express their views on the issues being discussed without fear, and actively participate in committee activities and decision-making.

STRATEGIES FOR IMPROVING ENGAGEMENT

LAYING THE GROUNDWORK FOR MEANINGFUL ENGAGEMENT

The survey conducted of the Chairs/Co-Chairs of Local and Regional HSJCCs demonstrated that each committee has a different level of engagement with people with lived experience. Of the 26 respondents, eight committees have members who identify as having lived experience. Some committees have made attempts to improve the representation of people with lived experience in their membership, while others have not yet addressed this issue.

Clarify your goals for engaging people with lived experience

In order to identify appropriate strategies for improving engagement, it is important for committees to assess their current status of engagement and articulate how they would like to improve. These goals should be developed in collaboration with the full membership, including current members with lived experience.

Some examples of goals for improving the engagement of people with lived experience are attracting new members, improving the experience of existing members, providing better supports, training and education opportunities for people with lived experience, and building relationships with networks and organizations that represent people with lived experience.

Considerations that may affect goal setting:

- What level of engagement does the committee currently have with people with lived experience?
- Are there any hesitations or concerns within the membership that need to be addressed?
- What does this committee hope to achieve by engaging people with lived experience?
- How will the committee know when they have achieved their goals?

Building in flexibility for meaningful engagement of people with lived experience

It is important for each committee to reflect on how their committee functions and to identify whether there are any changes necessary to create an environment that is comfortable, accessible, and safe for people with lived experience to participate in. In addition, committees should work together to assess whether there are barriers preventing potential members from joining or actively participating in committee work.

Considerations for building in flexibility include:

- What may have prevented the committee from engaging people with lived experience in the past?
- Should changes be made to the way the committee functions to create an inclusive environment?
- Would the committee benefit from any type of training or education that would help improve their capacity for this type of engagement (e.g., diversity and inclusion)?

Creating a plan for improving engagement of people with lived experience

The committee's agreed-upon goals and current levels of engagement will inform the strategies best suited for improving engagement. Once the appropriate strategies have been identified, the committee can develop an "action plan" to outline the activities and timelines necessary to achieve their goals.

Considerations for developing an action plan include:

- Can any of the activities be included in the committee's workplan and reporting process?
- Do changes need to be made to the Terms of Reference to reflect the inclusion of people with lived experience?
- How will the committee measure success when it comes to achieving its goals?
- Is there a process to demonstrate how a person with lived experience's feedback is being incorporated?

The sections below outline strategies and recommendations related to accessibility and confidentiality. Please refer to these sections when identifying barriers and developing your goals and action plan.

RECRUITMENT AND ORIENTATION

Attracting new members

Although the HSJCC Network has long recognized the value of engaging with people with lived experience in its work, many committees have struggled to attract members who identify as having lived experience. In the survey conducted of Chairs/Co-Chairs of Local and Regional HSJCCs, 53% of Chairs/Co-Chairs reported their committee has made attempts to attract new members with lived experience.

There are a variety of strategies a committee can use to engage new members, and the most appropriate strategy will depend on the committee's priorities.

Some of the strategies that Local and Regional Committees have implemented to attract people with lived experience include:

- Reaching out to community agencies to identify and connect with potential members (e.g., past clients, community advocates, partners)
- Reaching out to networks, groups or organizations that represent the interests of people with lived experience (e.g., consumer/survivor groups or peer support networks)
- Inviting potential members to join working groups or subcommittees relevant to their interests
- Asking committee members to identify potential members through their networks
- Approaching someone in the community directly

Connecting with groups that represent the perspectives of people with lived experience

Connecting with groups that represent the perspectives of people with lived experience directly is a highly effective way to identify potential members and create opportunities for partnerships and collaboration. According to the survey, 72% of committees engage with organizations that represent people with lived experience. The examples provided included community agencies that work with individuals with lived experience as well as groups that represent those perspectives directly. To provide a more diverse range of lived experience perspectives, it's helpful to identify members who are connected with these networks and can speak to views and experiences beyond their own.⁸

Groups that represent the perspectives of people with lived experience operate in a number of forms both independently as well as in association with a variety of larger organizations and institutions. There are a number of ways committees can identify these groups in their own communities.

The **Ontario Peer Development Initiative (OPDI)** is a network of Consumer/Survivor Initiatives and Peer Support Organizations across Ontario. OPDI maintains a comprehensive list of these groups across the province, which can be found online: <https://www.opdi.org/members/member-list>

In addition, many peer support programs are housed at **Canadian Mental Health Association** branches across Ontario. You can learn more about programs offered at your local CMHA at: <https://cmha.ca/find-your-cmha>

Examples of groups representing the perspectives of people with lived experience directly

Sound Times (Toronto): <https://soundtimes.com/>

PASAN: <http://www.pasan.org/>

Empowerment Council (Toronto):
<https://empowermentcouncil.ca/>

Toronto Prisoners' Rights Project (Toronto):
<https://www.torontoprisonersrightsproject.org/>

Consumer Survivor Initiative of Niagara (CSI Niagara):
<http://www.initiativeniagara.ca/>

Consumer Survivor Initiatives Network (Durham Mental Health Services):
<https://dmhs.ca/consumer-survivor-initiatives-network/>

Friends and Advocates Peel Dufferin: <https://fapeel.org/>

HANDS The Family Help Network:
<https://thefamilyhelpnetwork.ca/>

Krasman Centre (York/South Simcoe):
<https://krasmancentre.com/>

H.O.P.E. (Brant): <https://hopebrant.ca/>

Mental Health Rights Coalition (Hamilton):
<http://mentalhealthrights.ca/>

NISA/Northern Initiative for Social Action (Sudbury):
<http://nisa.on.ca/>

PARC - The Parkdale Activity-Recreation Centre (Toronto):
<https://parc.on.ca/>

Peer Support South East Ontario: <https://psseo.ca/>

Psychiatric Survivors of Ottawa: <https://www.pso-ottawa.ca/>

CAN-VOICE, Consumer Survivor Community Support Services (London): canvoice@gtn.net

Oxford Self Help Network (Oxford):
<http://hosted.ocl.net/projects/selfhelp/index.html>

Mental Health Support Network (London):
<https://mentalhealthsupportnetwork.org/>

Timmins Consumer Survivors Network INC. (Timmins):
tcncoordinator@gmail.com

North Western Ontario Peer Council (Thunder Bay):
ptcouncil@tbaytel.net

People Advocate For Change Through Empowerment (P.A.C.E.): <https://pace-tbay.net/>

John Howard Society of Toronto Mental Health and Addictions Peer Supports (MAPS) Program:
<https://johnhoward.on.ca/toronto/services/addiction-harm-reduction-services/>

Creating a diverse membership

HSJCC membership should reflect the diversity of the communities they serve. Diverse perspectives create a deeper understanding of the issues being discussed and the approaches required to address them. As such, it is critically important that committees make the effort to identify a broad range of perspectives they want represented and reach out to different demographics in their work to engage people with lived experience.

Consideration should be given to the following when devising a strategy for attracting new members:

- What perspectives are currently missing from the discussion table?
- What networks, partnerships and individual connections could be used to help engage new members?
- How do the committee's values, goals and objectives align with those of potential members?
- Are there additional ways that the perspectives of people with lived experience could be incorporated in HSJCC work (e.g., partnerships, consultations, working groups)?

Additional recruitment strategies:

- Developing a recruitment package that can be sent to potential members
- Inviting potential members to sit in on meetings and attend events as a guest
- Meeting with potential members one-on-one to determine if the committee is a good fit

Orientation for people with lived experience

To ensure a relationship that is respectful, transparent, and mutually beneficial for all parties, it is important that new members are provided with as much information about the committee as possible when they join. Providing an orientation to new members who have lived experience will help ensure they have a clear idea of the committee's goals and membership responsibilities.

One-on-one orientation

It is recommended that the Chair/Co-Chairs connect with new members before their first meeting to provide an overview of necessary information, answer questions and identify whether the new members have any concerns. This orientation should include:

- An overview of the committee's vision, goals and objectives and a sense of the values and perspectives that inform the work
- An overview of membership responsibilities, including time commitments and meeting schedule, as well as structure and group discussion style
- An opportunity to hear about the new member's individual goals and expectations and discuss opportunities for personal development

- An opportunity to identify any supports or accommodations, including training and education, that would help the member fully participate
- An overview of policies and procedures around honoraria and expenses
- An opportunity to identify potential concerns the member may have around comfort and safety. This might include negative experiences with some current members (i.e., police, judges, corrections), or sensitive and triggering topics

Establishing a point-of-contact for people with lived experience

Someone's experience as a person with lived experience on a committee can be impacted negatively in a variety of ways. Power dynamics and stigma can play a role in whether a member is comfortable participating or whether the person feels heard. It is important for people with lived experience to have a way to express concerns, request support, and provide honest feedback about the experience.

Each committee should identify a point-of-contact for the person with lived experience to reach out to between meetings to ask questions or address concerns. The point-of-contact should check in regularly with the member and look for opportunities, or supports, that will allow the member to become more engaged. If a person with lived experience decides to leave the committee, the point-of-contact may consider following up, with the member's permission, to hear about the member's experiences and suggestions for improvement in the future.

Developing an orientation package:

An additional strategy involves developing an orientation package for new members that includes the Terms of Reference, Workplan, commonly used terms and acronyms and other relevant documents.

ACCESS AND EQUITY

Addressing accessibility concerns for HSJCCs

In the surveys, meeting accessibility was identified as the top challenge in engaging people with lived experience in committee work. Current HSJCC members who identify as having lived experience reported that the following issues prevented them from fully participating in the work of their HSJCC committee:

- Meeting accessibility and transportation issues
- Meeting times conflicting with work schedules
- Feeling as though they don't belong on the committee
- Feeling like diverse perspectives are not being heard or taken into consideration

Members with lived experience also ranked the following supports they thought would improve the experience of people with lived experience on HSJCCs:

1. Training and education opportunities
2. Honoraria
3. One-on-one support
4. Other: Access to Wi-Fi at meetings; transportation; and parking expenses

Addressing equity issues

It is important that when committees approach topics of meeting accessibility and barriers to participation, they consider things through the lens of equity and intersectionality. In this approach, we recognize that social identities such as race, class, gender, etc. may overlap and intersect with lived experience in the mental health system or criminal justice system which further impacts experiences of oppression and marginalization.

Inequities occur as a result of differences in opportunities and resources.⁹ In order for people with lived experience to participate fully, committees need to ensure there are no barriers that might prevent their engagement. Applying an equity lens to this engagement work will ensure that the individual's needs guide the accommodations and supports provided.

Creating a culture of inclusion

Before beginning the engagement process, it is recommended that committees take the time to critically reflect on how they operate in terms of structure, processes, and culture. Committees should assess their understanding of best practices in diversity, equity and inclusion and whether there are changes that need to be implemented to create a culture of inclusion that expands beyond tokenism.

Committees should reflect on power dynamics and the decision-making process from a lens of intersectionality. Invisible power imbalances can exist within a committee environment both on an interpersonal level and

between organizations. To address those imbalances, it is recommended that committees consider participating in training that provides members with deeper knowledge about diversity, equity, and inclusion. Training focused on topics like anti-oppression and stigma can help enhance the understanding of power dynamics that might exist within a committee.

Engaging with Indigenous communities

As the HSJCC Network engages with Indigenous populations in various ways, it is strongly recommended that committees assess whether there is a need to build cultural competencies for engaging with Indigenous communities. Training to promote cultural competencies can provide opportunities to learn how to hear and understand different perspectives and engage with Indigenous peoples in a respectful, culturally safe way.

Examples of cultural competency training opportunities:

Indigenous Relationship and Cultural Safety Courses offered by Cancer Care Ontario:

<https://www.-cancercareontario.ca/en/resources-first-nations-inuit-metis/first-nations-inuit-metis-courses>

San'yas: Indigenous Cultural Safety Training Program delivered by the Provincial Health Services Authority of British Columbia: <https://www.sanyas.ca/>

Ontario Indigenous Cultural Safety (ICS) Program offered by Indigenous Primary Health Care Council:

<https://www.iphcc.ca/ontario-ics-program/>

Removing barriers to participation - identifying necessary accommodations or supports

The survey responses made it clear that there were a variety of reasons that may prevent people with lived experience from fully participating in their committee work. The supports necessary to help improve their experiences will depend on the needs of the individual. When assessing necessary accommodations or supports it is recommended to follow the direction of the individual member. Making assumptions about what someone might need should be avoided. Instead, ask about their preferences and work with the person to find a solution tailored to their needs.

Some methods for addressing barriers to participation include:

Meeting format

- Consider whether standard meeting times work for the member's schedule, especially those not available during typical workday hours.
- Schedule meetings and provide meeting materials in advance. Consider whether the meeting materials are easy to access digitally and written in clear, plain language.
- Consider whether the meeting location is fully accessible to all members or whether it may create discomfort for persons with lived experience (e.g., courthouses, police services, treatment facilities, hospitals, etc.). Work with the individual to find ways to alleviate discomfort (e.g., meet the person outside and walk in together).

Atmosphere

- Create a friendly and welcoming atmosphere in meetings. Provide introductions, nametags, and the option to share preferred pronouns for new members.
- Include a land acknowledgement at the beginning of each meeting.

Discussions and decision-making

- Ensure diverse perspectives are heard and acknowledged. Give every voice equal weight and equal time. Be open to hearing negative opinions or unconventional suggestions, as they may be rooted in that person's lived experience.
- Listen to and acknowledge comments and feedback. Be transparent about the decision-making process and explain why input was or was not used.
- Develop meeting agendas and discussion topics in collaboration with the group. Ensure that people with lived experience have an opportunity to contribute to agenda development.
- Assess the committee's decision-making process to ensure it is transparent, accessible, and inclusive. Accommodate members who may need more time to understand an issue, come to a decision and provide feedback.
- Be mindful of invisible power imbalances that may alienate members from the decision-making process. This may include members who hold positions of authority (i.e., judges, police officers, CEOs, etc.) or members from larger organizations.

Language

- Ensure all communication, both in-meeting and online, is clear and easy to understand. Consider whether additional supports, such as translation or note-taking, may be required.
- Avoid use of jargon and acronyms in discussions and have members define terms they use in meetings. Commonly used acronyms should be provided to new members in their orientation.
- Ensure the language in the group is inclusive and non-stigmatizing.

Transportation/travel

- Cover travel expenses for people with lived experience to attend meetings, including transit fare, parking and gas. Be clear about how expenses are reimbursed.
- Consider additional transportation concerns, especially in areas where public transportation is less accessible.

Technology and digital access

- Consider whether there are resources members with lived experience need to fully participate in meetings or review materials, for example: a phone, data plan, laptop or internet access.
- Work with partners to identify ways to provide access to needed resources, such as using computers at a partner agency or local library, mailing printed documents to members in advance of meetings, or providing tablets or phones on loan.

Additional strategies:

- Ensure there is room in the budget to provide an honorarium or cover additional expenses.
- Work with partner organizations to provide necessary resources and cover any expenses.
- Use group agreements to ensure all members have the same understanding about how meetings are conducted.

COMPENSATION AND SUPPORT

Guidance for providing honoraria

One barrier that may prevent people with lived experience from participating in HSJCC work is a lack of compensation. Many members with lived experience are participating in HSJCC work as volunteers and may not be supported by other organizations for their time. Providing an honorarium ensures that no one incurs a cost for participating in HSJCC work. It also demonstrates that everyone's time and expertise is valued equally.

It is recommended that committees provide people with lived experience with an honorarium for their participation in meetings. Compensation should be provided in a manner that works for the transfer payment agency as well as the recipient.

The Provincial HSJCC has developed an **Honoraria Policy** outlining the provision of honoraria for participation in Provincial HSJCC work. This policy can be adapted to Local and Regional HSJCCs with considerations made for specific budgets and transfer payment agencies (see **APPENDIX C** for sample Honoraria Policy).

Considerations for providing honoraria:

- Anticipating and including honoraria and additional expenses in the HSJCC's yearly budget
- Working with partner organizations to help cover honoraria and additional expenses

Committees should ensure the process used to provide honoraria meets legal requirements and tax considerations for the recipient. Committees should ensure that individuals receiving income assistance are not impacted by the method of compensation. For individuals who are receiving income support from the **Ontario Disability Support Program**, exemptions are available for certain types of voluntary payments and gifts up to stated maximum amounts including honoraria. Please refer to [Policy Directive 5.8 of the Ontario Disability Support Program](#) for more information.

Education and training opportunities

In the survey, training and education opportunities were identified as one of the best supports that committees could provide to improve the experience of people with lived experience. Training and education opportunities can help members with lived experience to develop skills, enhance their knowledge and participate in a more active and meaningful manner. They can also help members achieve their personal goals.

The availability of training and education opportunities may also create a greater incentive for people with lived experience to become involved in the HSJCC. When engaging with new members, it is recommended that committees take the time to learn about training and education opportunities that might be of interest or benefit to each individual.

Educational opportunities

As a member of the HSJCC Network, people with lived experience may have the opportunity to participate in many educational offerings that can deepen their knowledge of specific issues and allow them to share their expertise. Examples of educational opportunities include webinars, training workshops, educational courses, forums, Think Tank Days, consultations and conferences.

The Provincial HSJCC frequently supports the participation of people with lived experience in a variety of knowledge exchange events, including their Biennial Conference, forums, and consultations. Committees should look for such opportunities either through the HSJCC Network or through their local connections.

Training opportunities

Capacity building opportunities, such as training and skill development, can enhance members' abilities to actively participate and engage with HSJCC work. They can also help people with lived experience move toward their personal goals. Some examples of training opportunities that may be useful include leadership, facilitation, communication/media training, public speaking, and advocacy.

Examples of training and education opportunities for people with lived experience:

CAMH Recovery College courses: nonclinical-based education and training programs offered to people who have experienced mental health and/or addiction challenges: <https://recovery-college.camh.ca/>

Working for Change Programs: offers leadership, pre-employment training programs and runs a speaker's bureau: <https://workingforchange.ca/upcoming-programs/>

Ontario Peer Development Initiative: ODPU Peer Support Core Essentials Program:
<https://www.opdi.org/training/opdi-core-training-essentials-program>

Support House Centre for Innovation in Peer Support: Virtual Learning Centre: offers Peer Professional Development Webinar Series, Trainings and Workshops:
<https://supporthouse.ca/peer-services/virtual-learning-centre-resource-hub/learning-centre/>

PRIVACY AND CONFIDENTIALITY

Information-sharing and sensitive topics

For HSJCC members who are serving openly in a role as a person with lived experience, there may be an expectation that they will share their personal experiences with the committee. It is of fundamental importance that people with lived experience are enabled to choose when, and about what types of information, they share with the group.

People with lived experience may have had negative experiences in past interactions with people working in the human services and justice sectors. It is vitally important that the comfort level of members with lived experience is respected in terms of information sharing within the group. Some individuals may take more time, and require more support, to feel comfortable participating.

It is possible that some subjects being discussed in committee meetings may be sensitive or triggering for people with lived experience. For example, it may be difficult to hear people discussing sensitive topics in a frank or impersonal manner. Committees should be mindful about the types of topics being discussed and use care to manage the tone with which such issues are being addressed.

Suggested strategies for dealing with sensitive subject matter include:

- Have the point-of-contact follow up with the member if discussions appear to be distressing or upsetting, or if the member becomes suddenly disengaged.
- Be open to feedback from a person with lived experience about how to address sensitive topics, appropriateness of language, and other related considerations.
- Create group agreements where necessary to ensure all committee members are clear on the best way to approach sensitive topics.

It is important to remember that the comfort level of each person with lived experience is different. Some members may have no issues discussing sensitive topics. Relatedly, the types of issues that may be sensitive will depend on the individual.

Addressing confidentiality concerns

During HSJCC meetings, sensitive or personal information may be shared, either about a member or regarding clients and community members. It is of the utmost importance that committees ensure all members agree about the way confidential information is shared and take care to avoid disclosing personal information to any third party.

For people with lived experience, disclosure of their personal information to anyone outside the committee may have particularly negative or harmful impacts. Establishing a policy of absolute confidentiality is the optimal way to address concerns and build trust with new members.

Concerns around confidentiality and information-sharing should not be a barrier to engaging people with lived experience. It is the responsibility of the committee to adapt its operations to ensure confidentiality is maintained for all members.

A **Confidentiality Agreement** is the most effective way to ensure absolute confidentiality for all committee members. This document should outline what constitutes “confidential information” and responsibilities required of committee members. The Provincial HSJCC PWLE Advisory Committee developed a Confidentiality Agreement to protect the information of their own committee members. This template can be adapted to meet the needs of Local and Regional Committees (see **APPENDIX D** for sample Confidentiality Agreement).

Issues to consider when developing a Confidentiality Agreement include:

- What types of personal and sensitive information might be shared in this committee?
- In what ways could personal or sensitive information be disclosed to third parties (word of mouth, meeting documents shared or uploaded online)?
- What committee practices need to be changed to ensure confidentiality is maintained?
- Who should be included in this agreement (members, co-chairs, administrative staff)?

APPENDIX A: GLOSSARY OF TERMS

Accessibility for Ontarians with Disabilities Act (AODA): A piece of provincial legislation that ensures goods, services, facilities, employment, accommodation and buildings are accessible to individuals.

Cultural Competency: the ability to understand and interact with people from other cultures in a safe and effective manner.

Cultural Safety: creating an environment where the history of Indigenous peoples is acknowledged and respected in order to improve the provision of care and services in a safe and equitable manner.

Diversity: the existence of differences in characteristics and lived experience in a group that may relate to race, gender identity, sexual orientation, age, class, religion, mental or physical disability, among others.

Equity: fairness in opportunity achieved by reducing unnecessary and avoidable differences created by systematic disparities.

Inclusion: the intentional process of addressing inequities and embracing diversity in a given space.

Intersectionality: a framework for understanding how different aspects on someone's identity, such as race, class and gender, intersect and combine to create different experiences of privilege and oppression.

Marginalization: a social process which excludes individuals or groups from access to power and resources in a society.

Ontario Disability Support Program: a social assistance program in Ontario that provides income and employment support to eligible residents who have disabilities.

Personal Health Information Protection Act (PHIPA): PHIPA provides a set of rules for the collection, use and disclosure of personal health information.

Stigma: negative associations or stereotypes associated with certain characteristics.

Tokenism: actions that are the result of pretending to give advantage to people with lived experience who are often treated unfairly, in order to give the appearance of fairness.

APPENDIX B: ADDITIONAL RESOURCES

Aronstein’s Ladder of Engagement

The Citizen’s Handbook

https://www.citizenshandbook.org/arnsteins_ladder.pdf

Ontario Patient Engagement Framework

Health Quality Ontario

<https://www.hqontario.ca/Portals/0/documents/pe/ontario-patient-engagement-framework-en.pdf>

Take your patient partnership to the next level

Health Quality Ontario

<https://hqontario.ca/Portals/0/documents/pe/patient-partnering-next-level-en.pdf>

Six ideas on designing advisory councils for the participation of experts with lived experience

Maytree

<https://maytree.com/stories/six-ideas-on-designing-advisory-councils-for-the-participation-of-experts-with-lived-living-experience/>

More than Paint Colours

Empowerment Council

<https://www.empowermentcouncil.ca/wp-content/uploads/2021/02/More-Than-Paint-Colours-Dialogue-Power-Process-1.pdf>

Build Equity and Diversity Into Your Engagement Activities

Health Quality Ontario

<https://www.hqontario.ca/Patient-Partnering/Patient-Partnering-Tools-and-Resources/Resources-for-Health-Care-Providers/Build-Equity-and-Diversity-Into-Your-Engagement-Activities>

Engaging People With Lived/Living Experience: A Guide for Including People in Poverty Reduction

Tamarack Institute

<https://www.tamarackcommunity.ca/hubfs/Resources/Publications/10-Engaging%20People%20With%20LivedLiving%20Experience%20of%20Poverty.pdf>

APPENDIX C: SAMPLE HONORARIA POLICY

Provincial Human Services and Justice Coordinating Committee (P-HSJCC) Honoraria Policy

1.0 PURPOSE

The purpose of this policy is to set out the P-HSJCC's commitment to providing honoraria to persons with lived experience engaged in its ongoing work.

2.0 BACKGROUND AND OVERVIEW

The P-HSJCC recognizes the importance and value of the full participation of persons with lived experience and family members in its work. In keeping with this philosophy, the P-HSJCC draws frequently upon the expertise and resources of persons who have lived experience in the human services and justice sectors and their family members in HSJCC work at the Provincial, Regional, and Local levels.

In 2019, the P-HSJCC approved the establishment of a Standing Advisory Committee in response to a recognized need from HSJCC committee members for additional guidance and support in improving the engagement of persons with lived experience.

Advisory Committee members prioritize, promote, and draw from the experiential knowledge, history, writing and research driven by people who are service users and/or current and former prisoners of carceral institutions. Their work is further grounded via key tenets of intersectionality theory which acknowledges the complexity of discrimination for individuals who are diversely situated and impacted by structural barriers, oppression and violence.

It is important for the P-HSJCC to recognize the barriers to engagement, and the contributions and commitments of persons with lived experience. The provision of an honorarium and reimbursement of relevant expenses can provide the necessary support to allow persons with lived experience to participate on an equal basis and encourages a diversity of involvement. Furthermore, providing honoraria is an important way of recognizing the expertise and significant time commitments to the work of the P-HSJCC.

3.0 DEFINITIONS

Person or people with lived experience:

As outlined in the P-HSJCC's Advisory Committee on Engaging Persons with Lived Experience across the HSJCC Network Terms of Reference, a person with lived experience is defined as an individual who has direct experience with mental health and/or substance use disorders and has used the resources of the mental health system and/or has come into contact with the criminal justice system.

Family members: Family members of persons with lived experience can include a broad range of support persons such

as relatives, partners and friends who come forward in times of need.

Expense(s): Incurred costs that are directly related to a person with lived experience's involvement in P-HSJCC related activities for which compensation is paid (i.e., travel and accommodation costs).

Honoraria: A payment in recognition of an act or service provided by person of lived experience who contribute their time under specific circumstances for the P-HSJCC.

4.0 POLICY STATEMENT

Honoraria are to be provided to persons with lived experience whereby the P-HSJCC has requested their participation in a pre-approved activity that assists in the delivery, development, or evaluation of P-HSJCC related functions including Network Support, Communications and Knowledge Exchange and Provincial Project Work.

The Provincial HSJCC is committed to ensuring projects are developed with a budget to support honoraria and engaging people with lived experience at the outset of a project.

5.0 ELIGIBILITY

Payment of honoraria **will be made** when individuals are:

- Invited by the HSJCC Secretariat to make a pre-approved contribution to the work of the P-HSJCC. These activities may include, but are not limited to:
 - o Participating as a member of an advisory committee outlined in the P-HSJCC Terms of Reference
 - o Participating in a virtual or face-to-face meeting related to P-HSJCC work
 - o Presenting or co-presenting at a P-HSJCC webinar, forum or conference
 - o Advising on P-HSJCC project activities
 - o Reviewing and providing input into P-HSJCC related materials or resources
 - o Not funded by another organization to represent it in engagements with the P-HSJCC

The payment of honoraria **will not be made** under the following circumstances:

- Where the individual is funded by another organization or group to represent it in engagements with the P-HSJCC
- For open invitations to attend P-HSJCC related events or functions
- For ad hoc communication and discussions with the HSJCC Secretariat or P-HSJCC via email
- Where an individual is a professional consultant, contracted to advise on P-HSJCC related work
- For preparation, travel or reading time (unless formally agreed on by the HSJCC Secretariat in advance)
- Hired staff of the HSJCC Secretariat who identify as people with lived experience

6.0 PAYMENT RATESⁱ

An honorarium will be discussed with the individual in advance of any P-HSJCC related activity that may be considered eligible for compensation.

Honoraria rates are as follows:

Full day rate (up to 7 hours)	\$150.00
Hourly rate	\$30.00
Flat rate for presenters and speakers at a webinar, forum, or conference	\$100.00

The applicable honorarium rate will be communicated with the individual in advance of the activity. The maximum time that one may be compensated in one day is 7 hours.

7.0 TRAVEL AND ACCOMMODATION EXPENSES

Should travel and accommodation arrangements be required to participate in P-HSJCC activities, arrangements must be approved by the HSJCC Secretariat in advance.

ⁱ For individuals who are receiving income support from the Ontario Disability Support Program, exemptions are available for certain types of voluntary payments and gifts up to stated maximum amounts which includes honoraria. Please refer to [Policy Directive 5.8 of the Ontario Disability Support Program](#) for more information.

APPENDIX D: SAMPLE CONFIDENTIALITY AGREEMENT

P-HSJCC PWLE Advisory Committee Confidentiality Agreement

I. INTRODUCTION

The Human Services and Justice Coordinating Committee Network (HSJCC) aims to meaningfully and respectfully engage with persons who have lived experience in the human services and justice sectors. The HSJCC considers the contributions of persons with lived experience to be fundamentally important to the mandate of the HSJCC network which concerns coordinating resources and services, and effectively planning for people with clinical needs who are in conflict with the law. The knowledge, experience and vantage points of persons with lived experience, however, are grounded in information that is personal, sensitive, and confidential and may, if disclosed to third parties, cause harm to the persons.

II. PURPOSE

This Confidentiality Agreement is intended to protect the privacy of persons with lived experience in their interactions with the HSJCC Advisory Committee Engaging Persons With Lived Experience (Advisory Committee) and Secretariat Staff. These interactions may result in persons with lived experience disclosing information of a personal and sensitive nature, which, if disclosed to third parties, may cause harm to the persons with lived experience. Therefore, it is of the utmost importance to take action preventing the disclosure of any information to third parties about persons with lived experience, to avoid causing them harm.

III. CONFIDENTIAL INFORMATION

For this Confidentiality Agreement, “confidential information” includes, but is not limited to:

1. Information that identifies the person with lived experience, including name, address, or phone number.
2. Information that relates to the family of the person with lived experience.
3. Information regarding abuse, trauma, criminal or other justice-related involvements experienced by the person with lived experience or that may relate to her/his health, immigration, employment, or housing status.
4. Any information that may identify the person with lived experience or potentially place the person or a member of her or his family, at risk.
5. Information contained in any file or document, whether in digital or written format, including handwritten notes and audiofiles.

IV. TERMS

By signing this Confidentiality Agreement, you are agreeing:

1. That all communications between persons with lived experience, the HSJCC Advisory Committee Members and Secretariat Staff, whether in writing or verbally expressed, are confidential information and protected by this Confidentiality Agreement.
2. HSJCC Advisory Committee Members and Secretariat Staff shall not disclose confidential information to a third party without the express written consent of the person with lived experience.
3. HSJCC Advisory Committee Members and Secretariat Staff shall not disclose confidential information to a third party without the knowledge and written consent of the HSJCC.
4. As a means of ensuring confidentiality to the greatest extent possible, no recording, audio-file, transcript, or interview notes will contain the name or other identifying features of a person with lived experience, subject to Paragraph 5.
5. That the HSJCC Advisory Committee and Secretariat Staff may disclose your name as a Member of the HSJCC Advisory Committee in furtherance of HSJCC business.
6. That you, as a HSJCC Advisory Committee Member or Secretariat Staff member, have a duty to keep the confidential information of a person with lived experience confidential for the duration of your term as a HSJCC Advisory Committee Member or Secretariat Staff member, including after your employment or volunteer status ends.
7. You understand that should you fail to comply with the terms of this Confidentiality Agreement, your participation as a HSJCC Advisory Committee Member or Secretariat Staff may be terminated.

V. DECLARATION

I, _____ (print name), have read the HSJCC Confidentiality Agreement above and understand and agree with its Terms, including my responsibilities as a HSJCC Advisory Committee Member or Secretariat Staff Member (circle the appropriate choice).

Signature of Committee Member/Staff

Date

REFERENCES

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- 8 Soh, B.L. (2019). Six ideas on designing advisory councils for the participation of experts with lived/living experience. Maytree. Retrieved from: <https://maytree.com/stories/six-ideas-on-designing-advisory-councils-for-the-participation-of-experts-with-lived-living-experience/>
- 9 Public Health Agency of Canada. (2007) Glossary of Terms. Retrieved from: <https://www.canada.ca/en/public-health/services/public-health-practice/skills-online/glossary-terms.html#e>