

Peterborough Drug Strategy Lived Experience Advisory Panel

Panel toolkit/How to start a panel

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Panel snapshot

Name: Lived Experience Advisory Panel (Shortened to ‘the PDS panel’ or ‘the panel’)

Panel members: 12 local people who have diverse experiences with substance use and/or supporting people who use substances.

Panel established: 2018

Goal: The panel presents a platform where people with lived experience (PWLE) with substance use, are paid to leverage their experiences to contribute insights that inform local programs, policies, and initiatives. Simultaneously, it offers organizations an invaluable opportunity to receive feedback on their activities and make necessary adaptations to more effectively cater to the needs of individuals who have navigated experiences with substance use.

Process: Local organizations present their specific policies, programs, or initiatives to a panel, seeking valuable feedback from the panelists on how to enhance their effectiveness in meeting the needs of people who use drugs (PWUD). Organizations are expected to report to the panel on how what they learned in the consultation will impact their work.

“You could not replicate the feedback shared by the panel. Being able to interact with the panel firsthand was extremely beneficial to my learning... the feedback shared by the group heavily influenced [our work]” (Presenter, 2023)

Key takeaways:

1. Panelists are paid an hourly wage that is reflective of their lived expertise.
2. PDS provides expansive training opportunities for panelists’ capacity building.
3. The panel is evaluated consistently to look for ways to better processes.

“Being seen, being heard, being valued. It is and has been life changing, lifesaving, and life affirming. The opposite of addiction is not sobriety - it is connection, respect, friendship, creativity, self-worth.” (Panelist, 2022)

Background and rationale

Community-based methods are emerging as best practice in program delivery, policy making, and research in many different fields. This means using a bottom-up (rather than top-down) approach to solving complex problems. As the drug poisoning epidemic continues to worsen, “evidence supporting the engagement of people with lived experience or ‘peers’ at different stages of policy, program, and research development shows positive health outcomes” (Ti, Tzemis, & Buxton, 2012 p. 1). People who use drugs (PWUD) and/or people with lived experience (PWLE) are repeatedly calling on individuals in power to include them in decision-making. Many borrow the phrase from the disability rights movement, stating “nothing about us without us”.

The Centre for Innovation in Peer Support (2021) states that meaningful change emerges when lived experts are involved, and that this “... change is well beyond the healthcare parameters and more about social change”. It is thinking about a person beyond a pathology. Despite its importance, “gaps in the current evidence highlight the need for additional research to explore and document the engagement of PWUD in the areas of policy and program development” (Ti, Tzemis, & Buxton, 2012 p. 1). This toolkit aims to provide an example of an advisory panel of PWLE and PWUD.

In 2017-2018, Peterborough Drug Strategy (PDS) piloted a one-year advisory panel for people who have lived experience. The purpose of the panel was for community members who have experience with substance use to help inform local programs, policies, and initiatives. The panel offered a paid consulting services for PDS member organizations (partners of the organization). While the panel saw huge success in informing local policy and programs, the one-time funding ended, so the panel had to reduce its operations in 2018. However, periodically, the panel was brought back together at the cost of agencies being consulted. During the pilot project, PDS learned:

1. There is an incredibly knowledgeable community of people who have used substances who are an integral resource for shaping services and programs in the community.
2. Relationship building is important for trust, confidence, and continuity through the project.
3. Demand for the panel’s services increased over time.
4. The panel is an avenue to help move forward the conversation about involving people with lived experience in the planning and development of local programs.

In late 2021, PDS received funding that allowed the organization to reinstate the Lived Experience Advisory Panel ('the PDS panel' or 'the panel') consistently until at least March 31, 2023 (which has now been extended to March 31, 2024). The new panel, made up of some people from the 2017-2018 panel and some new members, has served a similar paid consultant role for community agencies. The Panel is now a service offered to any organization that is interested in hearing the perspectives of PWLE and PWUD. In addition, the panel integrated a new co-chair structure, which will be elaborated on later.

This toolkit is focused on the panel's evolution, current practices, philosophy, and sustainability. It will explore recruitment and onboarding, compensation, the consultation process, staff responsibilities, co-chair responsibilities, and the evaluation process.

Starting a Lived Experience Advisory Panel

Recruitment and pre-hire information

To recruit panel members, PDS used several avenues. This was to ensure that the call for panel members was widely distributed and reached the most people. Of note, advertising was done through social media avenues and email (figure 1), and through a series of posters that were distributed through the community.

Do you want to help make a difference in your community? We want to hear from you!

The Peterborough Drug Strategy is looking for people to help shape programs and services in our community based on their experience with drugs and alcohol

We are looking for people who either:

- Have struggled with substance use, including alcohol, prescription medications, legal or illegal drugs; or
- Are a family member of someone who has struggled with substance use

Details: We are looking for people of different ages, races, genders, socio-economic status, types of substance use, etc. No work experience is necessary. We will help you with training and education in a friendly environment. Must be 18 years or older and have use of a computer and email. You will be paid for your time.

Learn more by contacting Jessica Penner: jpenner@peterboroughdrugstrategy.com

Figure 1. Example of advertising for the panel. This format was adapted to other distribution materials, including posters.

Interested individuals emailed the contact information provided and were prompted to complete an application form. This included:

- A demographic questionnaire
- Several short questions about interest in the work, lived experience, and time commitment/availability.

Following an active recruitment stage, interviews were done to learn more about the prospective panelists (appendix A). **The purpose of this process was to understand individual experiences, to ensure that potential panelists demonstrated a readiness and understanding of the panel, and to ensure that diversity was being represented on the panel.** Questions in the interview included, for example:

- 1) Why do you think you would be a good addition to the panel?
- 2) What are your experiences with the substance use treatment system and what did you like or what would you like to see changed?
- 3) How do you deal with stressful situations and how do you practice self-care?

All panel members from the pilot project were invited to re-join the panel, and approximately half of the members of the pilot project were interested and/or available. An original panel member was hired to participate in the interviews along with PDS staff to have diverse perspectives represented in the decision-making process.

As needed, there have been additional recruitment periods to fill panelist turnover or to add panelists to the roster. The additional recruitment periods have followed similar processes. PDS' goal is to have 12 consultants on the panel at any given time.

Onboarding and training

Following the hiring of panel members, it is important to organize an orientation for the group. The initial meetings are intended to focus on member introductions, for new members to learn about the panel, and for logistics. Logistics include meeting dates, communication, and contact information, organizing a meeting schedule, trainings, direct deposit forms, and how to invoice the organization.

In the following months, it is important to begin more intensive training with the panel. In the case of PDS, the panel participated in a variety of training and development sessions, including:

- 1) **Team building:** a consultant was hired to work with the panel on to help establish each of their strengths, communication, and conflict resolution styles. The consultant used this information to as a map to create strength-based team charter which included ground rules centered around professionalism, confidentiality, curiosity, effort, self-care, balanced perspective, managing team toxins, and establishing best practice in communication.
- 2) **Accounting:** an accountant was hired to present to the panel and to answer questions. The accountant had expertise in Ontario Works (OW) and Ontario Disability Support Program (ODSP) and presented on how the income related to the panel might affect the panelist's taxes if they are supported by these programs. The accountant was also available to answer any questions related to taxes and consultancy income.
- 3) **Democracy and social change:** the panelists were invited to participate in a 5-part workshop to learn about a) the levels of government, b) the electoral system, c) how to respectfully disagree, and d) how to respectfully disagree. The goal of this training was to help panelists understand how social change happens

Throughout their time on the panel, panelists are continually offered professional development and training opportunities, that might help them understand the intersectionality of issues

better, or that will help improve their interpersonal, communication, and leadership skills. All trainings attended by panelists are free, and each panelist is paid their hourly wage for attending. In addition, in 2023 during a recruitment for 3 panel members to replace individuals who had left, the group participated in another round of teambuilding training.

As will be discussed in the panel evaluation, members of the PDS panel have found the training opportunities incredibly valuable to strengthen their systems awareness and in using their lived experience to contribute to discussions that they might not have direct experience with (for example, homelessness). The trainings have also been important in capacity building of panelists for their professional lives outside of the panel (for example, gaining fulltime employment).

Team Charter

During the orientation of the panel, the group works with a facilitator to construct a 'team charter'. The charter acts as a way for the group to discern the shared purpose and ground rules (communication, confidentiality, etc.). Each time members are added to the panel, the charter is reviewed and revised.

Compensation

Background

The compensation philosophy for people who have lived experience is described in detail in the attached document titled, *Compensating People who have Lived Experience at PDS*. While historically, organizations have expected people to volunteer their time or to accept gift cards as adequate compensation, a host of research has indicated the array of problems with this approach. The [BC Centre for Disease Control](#) states, "best practice... is compensating peer research assistants for the work they are expecting to do rather than expecting them to volunteer their time". The panel is touted as a group of individuals who are lived *experts* and are paid accordingly.

PDS follows the leadership of organizations like the [BC Centre for Disease Control](#). They provide resources like a checklist of payment considerations before and during peer engagement, which includes:

Before Committing to an Engagement:

- Ensure there is a leadership commitment to pay peers.
- Ensure there are financial resources available to support equitable peer payment.
- Decide on the number of peers to engage and confirm payment amounts so that budgets can be allocated appropriately.
- Ensure there is administrative support available so peer payment processes can be coordinate.

- Ensure financial processes are in place so that peers can be paid in a way that best suits them.

Before Engaging Peers:

- Review Peer Engagement Principles and Best Practice Guidelines.
- Develop a process or solution to mitigate delays in payment.
- Ensure there is a discreet place to pay peers.

Engagement:

- Discuss the role expectations and payment amount with the individual.
- Discuss the maximum number of hours expected for the engagement with the individual.
- Discuss with the individual how they would like to be paid and when.
- Discuss any other costs that will be covered and offer options for when and how they will be paid.
- Ask the individual if there are any barriers to participation.
- Ask the individual about income or disability assistance and discuss the implications of receiving an income.
- Discuss tax implications and income reporting requirements.¹

PDS compensation model

Currently, members of the PDS panel are paid between \$30 and \$40 based on experience/years on the panel (current as of July 2023). This compensation is based upon PDS' compensation policy for PWLE. It is important to note that [the United Way of Peterborough & District](#) calculated that the living wage in Peterborough was \$19.05 per hour in 2022.

The stated hourly wage is used for:

- One-hour preparation for each meeting (which includes reading the material provided by the agency being consulted)
- Two-hours for each consulting session.

In addition, if the session is in-person, transportation costs and refreshments are paid for by PDS. To ensure that barriers to participation are considered, the panel is given the opportunity to send written consultant notes for a session, if they are unable to attend.

Currently, all members of the panel are paid through direct deposit to a bank account. Although several [Best Practice Guidelines](#) state that cash is the preferable option and PDS recognizes that direct deposit can be a barrier, it has not been an issue for the current panel members. If a panel member were to identify direct deposit as a barrier, PDS would work to accommodate that individual.

¹ As discussed in the Onboarding and Training section, PDS has hired an accounting consultant to work with the panel. This accountant meets with the panel yearly to answer tax questions.

Following each consultation session, panel members are to send the panel coordinator an invoice (Appendix B) and any receipts they would like reimbursed. PDS works to have each panel member compensated as quickly as possible (within one week), and sometimes quicker (for example, around the holidays).

Consultation Service

Recruitment

When the PDS panel began, it proved to be initially difficult to find presenters from agencies that were interested in consulting PWLD. However, calls for consulting PWLD and PWUD in policy and programs increased, and agencies began hearing about the panel through word-of-mouth and through the coordinator of PDS advocating to agencies. Now, the panel is sought out by PDS partners and other community agencies. The coordinator, at times, does need to send a prompting email to organizations if they are experiencing a period of lower uptake.

While the interest in consultation has increased, it is integral that there is an intentionality to the consultation. This means that the PDS panel is not intended to be used as a ‘check-box’ for an organization, and resists the tokenism that has been the critique of other processes. The panel emphasizes engagement as a guiding principle. It is not just a ‘working group’ and expects its feedback to be incorporated into practice.

Organizations consulted

The following list is a sample of the organizations and topics that the panel has consulted on. While some topics might not be in the direct expertise of panel members, they are given the time and compensation to prepare.

| Agency | Topic |
|---|--|
| City of Peterborough | Community Safety and Wellbeing Plan. |
| FourCAST | Early Stabilization Team (EST). |
| Peterborough Drug Strategy/Peterborough Public Health | Presentation to the city re: homelessness, housing, and substance use. |
| Rapid Access Addiction Medicine (RAAM) clinic | Changes and structure of the clinic. |
| Peterborough Public Health | Cold weather homelessness planning. |
| FourCAST | Strategic planning. |
| United Way Peterborough | Housing and homelessness report. |
| Peterborough Public Health | Overdose alerts/toxic drug alerts. |
| FourCAST | Detox beds planning in the region planning. |
| Bridges out of Poverty | Program structure and changes. |

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|----------------------------|-----------------------------|
| Peterborough Drug Strategy | Planning for engaging PWLE. |
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Consultation process

The typical consultation process for a given organization follows these steps:

1. Consultation proposal: The organization proposes a consultation to the PDS panel coordinator, who decides if it fits within the group's capacity (see recruitment).
2. Administration: A meeting is booked with the panel.
3. Preparation: If the organization has any contextual material for the presentation, the material will be sent at minimum one week before the consultation (panel members are compensated for preparation – see compensation section). This material might be a document, policy, video, presentation, news article, etc. The intention is to ensure panel members have enough background information and context to discuss at the meeting.
4. Presentation: The organization will begin with a 30-minute presentation, outlining the project or program that they are requiring consultation on. This might be a PowerPoint presentation or a general discussion.
5. Feedback: The panelists then begin their consultation. Often, the organization will ask specific questions and the panelists will respond. As consultations are currently occurring over Zoom, panelists use the 'raise hand' function to take their turns speaking. In addition, some will also use the 'chat' function. The PDS panel encourages flexibility and dynamism, to allow to conversation to naturally explore the topic.
6. Evaluation: 1-2 months after each consultation session, the organization is sent a survey that asks them to comment on how the consultation shaped their program design.

Staff responsibilities

Two staff members support the panel as part of their role at PDS. One staff member coordinates the panel, and the other provides administrative support.

1. Panel coordination: the panel coordinator supports the panel, supports the co-chairs, recruits the presenters, organizes panel payment, disseminates material pertinent to meetings, sets the schedule, recruits members, etc.
2. Panel administrative support: this PDS staff person takes and distributes minutes at the meetings, develops and analyzes panel evaluation, creates dissemination material or the panel, and supports the coordinator and the panel generally, as needed.

Co-chair pilot program

Selection process

In 2022 PDS and the panel established that the next step in the panel's development is for **nominated panel members to take on an official leadership role on the panel**. The co-chair model could be established at the outset of a new panel, instead of as a second step. The selection process (Appendix C) followed a collaborative nomination structure where individuals were nominated by their peers or were self-nominated. Through a closed ballot system, two individuals (co-chairs) were selected.

Co-chair duties

The responsibilities of the chair (or co-chair) are:

1. To serve as a spokesperson for the panel.
2. Attend relevant community meetings on behalf of the panel, as required.
3. Help set agendas, call meetings, and solicit input from all members (with support from the panel coordinator).
4. Helps to open the meetings by welcoming committee members, land acknowledgements, presenting the meeting agenda, introducing the guest presenter(s), and leading member introductions.
5. Facilitates all members contributing to the discussion (with support from the panel coordinator).
6. De-brief with PDS staff to determine successes and challenges, and how to improve panel structure.

As the pilot program develops, additional roles may be added to the position. The co-chairs are paid at the same rate as consulting but are subject to more hours (~3 hours) of additional paid work per month.

Evaluation process

Methods for evaluation

Periodically, the panel participates in an evaluation process. Evaluation is integral in the refining the design of the PDS panel, as well as an opportunity for panelists to reflect on their experiences as a lived experience consultant.

Evaluation results

The full evaluation process and results are outlined in the document titled Peterborough Drug Strategy Lived Experience Advisory Panel Evaluation.

Interested in learning more?

Please get in touch with our panel if you have any additional questions and if you need support in starting a Lived Experience Advisory Panel in your community. Please email info@peterboroughdrugstrategy.com to inquire.