

Guidance on developing a Lived and Living Experience Recovery Community Panel in Edinburgh

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EXECUTIVE SUMMARY

This report presents insights from ‘lived and living experience’ (LLE) work delivered by Edinburgh Voluntary Organisations’ Council (EVOC) on behalf of the Edinburgh Alcohol and Drug Partnership (EADP). The objective of this work was to explore the way in which a Lived and Living Experience (LLE) Community Panel (CP) could be developed and integrated into EADP activities. A trial LLE initiative was implemented in the form of collaborative group sessions. The discussions centered on LLE CP mechanisms, their overall rationale, potential formats, and methods in the context of care access and navigation.

Four recurring key themes emerged as contributing towards continued integration and development of LLE:

Theme 1: “An emphasis on LLE Voice and sense of community”

- a) LLE involvement held enthusiastic resonance in the community.
- b) Strong sentiments of ‘wanting to give back’ and ‘wanting to help others in need’ were frequently expressed. A sense of ‘contributing to positive change for the community’ carried overall importance and purpose.
- c) Empowering the independent LLE voice is essential. Transparency on how LLE voices can affect change in Edinburgh’s Drug and Alcohol treatment and recovery landscape should help contribute to meaningful engagement.

Theme 2: “A need for safe, secure, and welcoming spaces”

- a) Creating a safe and welcoming environment that inspires confident expression of LLE voices is necessary. This is especially important considering the adverse effects of stigma.
- b) Barriers to participation are common and may differ from person to person. The participation pathway needs to be open and agile.
- c) Commitment to ensuring diverse representation of LLE Voices: who among us is not being heard?

Theme 3: “Structure and consistency is important but also flexibility”

- a) Structured and consistent engagement pathways can help create a space that feels safe and secure and encourage committed participation and further LLE uptake.
- b) Too much structure can also be a barrier to participation so there needs to be some flexibility and less formal time built in.
- c) Different voices need different spaces. Collectively decide which formats will work, why, when and how.

Theme 4: “Visions and Values We Want”

- a) Each independent LLE group to self-determine core values for the sessions and spaces involving their members.
- b) Respect for all LLE Expressions in the rich complexity as a core, grounding belief.
- c) Commitment to ensure LLE autonomy and independence.
- d) Confidentiality and informed consent on what information is shared, how, why, when and for how long.

Building on gathered collaborative community insights, this report issues **two key recommendations** towards future LLE-related work within the EADP system and its ecology:

1. Resourcing the structures of LLE Integration within the host organisation through a designated Coordinator/Facilitator Role.
2. Implementing a flexible LLE Engagement-Participation Pathway which can foster autonomous collaboration.

INTRODUCTION

LLE Integration in Wider Scottish Policy and Practice

The rationale for commissioning LLE involvement stems from a longstanding and well-established emphasis on it being identified as ‘the missing piece in the puzzle’ for achieving better health or recovery outcomes within the Drug and Alcohol landscape. The Scottish Government’s 2018 Alcohol and Drug treatment strategy [‘Rights, Respect, and Recovery’](#) defines ‘people with LLE’ as integral to the ‘partnerships’ aimed at the reduction of alcohol use, harm, and deaths. The 2020 [SHAAP Report](#) encourages the adoption of LLE as a “core modus operandi embedded throughout the [ADP] systems” with annual reports reflecting and providing evidence on LLE-led learning outcomes and modifications. Locally, the 2012 Pan-Lothian [‘Hear our Voice’](#) report outlines a three-tier approach for the involvement of community involvement with clear goals and outcomes.

Creating an integration pathway for LLE within the EADP

The emerging national policy and practice imperative, alongside the EADP’s commitment to ensure the involvement of lived experience in the co-production and delivery of services and quality improvement processes as outlined in the [EADP 2021-2024 strategic plan](#) provided the rationale for the creation of a new ‘Development Worker’ role for creating an integration pathway for LLE within the Edinburgh ADP system and landscape. Funded by the Edinburgh Alcohol and Drug Partnership (EADP) and placed with the Edinburgh Volunteer Organisations’ Council (EVOC), the newly appointed Development Worker (DW) explored the development of a ‘community panel’ (CP) mechanism to embed LLE voices in the EADP decision-making processes.

Process Narrative and Scope

The EVOC Development Worker was inducted through a process of structured meetings with key LLE stakeholders. The induction process provided an exchange of information, skills and knowledge needed to develop and implement an explorative CP mechanism. Expressions of interest were distributed through networked connections in the EADP network. In-person efforts were also made to actively seek participation.

The work activity culminated in a series of LLE-informed in-group sessions and workshops delivered in October and November 2023. The exploratory initial phase of the work was necessarily open-ended and experimental. A hybrid format of in-person and online participation was offered to widen the catchment and improve participation. The DW also participated in other LLE-informed group activities in Edinburgh.

METHOD

Initial stages involved identifying and modelling practice methodologies to encourage and integrate LLE voices.

The work was divided into two parallel streams informing each other:

Stream A Landscape Analysis: Fostering community connections and building momentum towards the new LLE initiative with a focus on participant recruitment.

- ⇒ developing an understanding of LLE within partner and community organisations within Edinburgh
- ⇒ Learning from similar LLE initiatives.
- ⇒ Utilising established networks to disseminate LLE information and encourage participation.

Stream B Service Design: Developing and running the initial set of independent LLE sessions.

- ⇒ Block 1 October 2023: South East and the North East locality.
- ⇒ Block 2 November 2023: North West and South West localities.

Both work strands involved an embedded process of data-gathering which prioritised LLE voices.

Consulting the Network

To inform the design, development, and delivery of an LLE panel, the DW invited LLE lead workers in different regions to share insights and expertise on developing and running LLE initiatives.

The list of 1-1 meetings held between the DW and the respective LLE Facilitation Leads or Development Workers are as follows:

Region/Organisation	2023 Meetings
Glasgow	August
Fife	May & September
Dumfries and Galloway	September
Corra Foundation	November

Participatory Learning

In October and November, the development worker attended several on-going groups and activities delivered by different organisations in the community.

The aims of participation were to:

- ⇒ gain insight on how the groups were run
- ⇒ discuss LLE and how the participants would envision a panel while promoting the independent sessions
- ⇒ explore experiences of drug and alcohol service provision as well as recovery activities in Edinburgh

The discussions highlighted themes around **access to information, mental health, stigma, social isolation and waiting list time.**

List of Groups attended:

Group	Date attended	No. of Participants
Turning Point Scotland	05/10/2023	4
The Sorted Project	09/10/2023	7
The Bothy	11/10/2023	7
CGL Women's Recovery Group	11/10/2023	7
ERA Community Cafe	18/10/2023	10+
Rowan Alba CARDS Group	01/11/2023	8
Ritson Smoothie Club	13/11/2023	3

Though several other groups were contacted, the short timeline and some structural changes in their organisations' management did not allow for visits to be arranged during the duration of this project.

'Your Voice Matters' Sessions

Aiming to incorporate of a wider range of LLE Voices in the development of the LLE panel, 'Your Voice Matters' sessions were arranged independently by EVOC ([See appendix 2](#)). The sessions sought input from LLE persons on, **1) LLE vision for the proposed LLE community Panel** and **2) A rehearsal of how the LLE community panel function** with an open question of – How has the LLE experience of the Edinburgh treatment and recovery services been – highlighting good and bad practices.

A total of six sessions (five in-person and one online) were run in two separate blocks each targeting a different locality in Edinburgh.

Your Voice Matters Sessions			
Block A South East and North East		Block B North West and South West	
13/10/2023	Bethany Christian Trust	01/11/2023	The Health Agency
16/10/2023	The Grassmarket Community project	21/11/2023	Online (Zoom)
19/10/2023	Bethany Christian Trust	30/11/2023	Muirhouse Millenium Centre

Participation in these sessions fluctuated between 1 to 8 participants. Some of the participants attended multiple sessions and expressed their interest in getting involved with the panel when established. The independent sessions were promoted for the participation of adults (18+ years) who had lived or living experiences of drug or alcohol use, including families, friends, and carers, who lived within the four localities of Edinburgh.

Equality Monitoring information was not asked for at this stage. There was an equally significant presence of people who were in long-term and early recovery as well as those who are currently receiving treatment from a drug and alcohol service. Some participants identified as family members and carers. Some of the participants attended in both capacities as a person in a long recovery and as peer-worker.

During the promotion and recruitment, some peer workers expressed that they would not be able to attend a public programme as they could potentially meet someone they are supporting, and the matters discussed in the sessions might affect their therapeutic relationship.

FINDINGS

This section consolidates key learnings and insights from the all converging strands of development work activity.

A: Learning to Design Pathways for LLE Engagement

The early stage of the project required open-ended experimentation and exploration. While LLE engagement has some years of history through 'service user' or 'peer' involvement, a CP mechanism is a relatively new emerging concept.

Overwhelming support for LLE CP was evidenced in early discussions. However, it did not readily translate into easy implementation of a panel mechanism.

Key Learnings	Suggestions/ Potential Future Directions
<p>There was a tangible momentum and enthusiasm around LLE engagement among service providers and the community.</p> <p>There does however remain profound uncertainties over what a new model of LLE integration is attempting to do differently from what has been done before:</p> <ul style="list-style-type: none"> • The logistical specifics of LLE CP integration is still largely undefined. • Insufficiently distinguished from previous methods of collating LLE voices. • Persistent ambiguity regarding the terms of engagement and an unclear LLE CP member journey pathway remained a significant challenge for meaningful involvement. <p>For example, the term 'panel' caused several concerns to be raised. For many in the LLE community, the term carried negative associations owing to bad experiences in panels convened by the statutory bodies. People said they have repeatedly experienced unequal power dynamics in 'panels' organised by the Local authority, the social services or the criminal justice services.</p>	<p>At the outset, a clear explanation of the host organisation's LLE CP expectations and aspirations would help establish goodwill.</p> <ul style="list-style-type: none"> • There is a need to explain how new initiatives seek to differ from previous attempts to gather LLE voices to feedback and influence change. • Transparency from the host organisations on the proposed LLE embedding mechanism EADP and other decision-making. • Consider creating easy-to-understand materials for the LLE Community: <ul style="list-style-type: none"> • "Journey of Your LLE Voice: What Do We Do with What You Share with Us" • "You Said, We Did" • Caution should be paid to the use and application of 'official' and difficult to interpret documents and information. • Involve participants in naming the initiative and in setting up role names and initiatives. <p>Clear joint consensus on previously agreed upon scope, role and timeframe expectations.</p>
<p>The limited time in organising the first set of independent sessions needs to be recognised as a barrier, negatively impacting promotion and recruitment and resulting in low engagement.</p>	<ul style="list-style-type: none"> • Some time should be spent mapping and networking with potential LLE stakeholders in the EADP catchment. • Engagement and involvement strategies should be developed with long-term collaboration and co-production in mind. • Longer timeframe necessary to carry out meaningful promotion allowing potential participants to make travel or other arrangements.

B: Lessons from Elsewhere: Overview of Similar LLE Initiatives

A: Lived and living experience initiatives in Edinburgh:

Alongside looking at the LLE groups in other regions, we came in contact with similar lived and living experience initiatives currently underway in Edinburgh, albeit both being at an early stage of delivery.

Scottish Drug Forum living experience engagement group

Scottish Drug Forum (SDF) is an organisation which provides expert and resource support on drugs and related issues. Functioning independently, they seek to:

- improve the quality, range and effectiveness of service and policy responses to problematic drug use in Scotland
- reduce future and recurring problematic drug use
- promote and sustain recovery from drug problems through informing, supporting, leading and representing.

One of the ways SDF tries to achieve these aims is through supporting groups of people with current living experiences of drugs and alcohol use and/or in support treatment services through empowering them to influence the policies that affect service provision - may that be local, regional or national.

Currently, SDF is supporting groups in eight places across Scotland including Glasgow city, Fife, Borders, East Ayrshire and more meeting almost weekly. Supported by an SDF facilitator and facilitators from the local partners, the members raise issues that affect them and decide of what issues to focus on, and the decisions and discussions are brought to the ADP management meetings where most key partners will be in attendance to work towards resolving these issues.

Some of the recurring topics of discussion in these groups:

- Medication Assisted treatment standards
- Addiction services
- Residential rehabilitation
- Housing or homelessness
- Mental Health treatment
- Lack of opportunities in the local areas

The membership in these groups varies. The group in east Ayrshire has 25 members out of 40-50 interested people. However, the membership is open to anyone who has current living experience of drugs use and or treatment services. The members are remunerated at living wage rate, usually through paypoint vouchers, optional career progression opportunities and trainings are available.

In addition, the members are provided with training in the key areas including Naloxone, Harm reduction, Mental health, Medication Assisted treatment as well as Facilitator training. SDF aims to empower and support the group members to independently facilitate the groups and enable the groups to be constituted as independent groups in their own right. Thus, they plan to gradually hand over more responsibilities to the group members as it progresses.

Alongside the training and development opportunities, the group members would also have access to drug testing, and other harm reduction mechanisms. Members who are in need of support are also connected with the local drugs and alcohol service partners.

Currently, SDF is looking to start a Living experience group in Edinburgh as well.

'Substance' - Patient's council drug and Alcohol collective advocacy (Royal Edinburgh Hospital as well as in the community)

Royal Edinburgh Hospital Patient's council provide collective advocacy for people with experience of drug and alcohol use who are in the hospital and in the community. While upholding one of the key provisions of the MAT standards, the collective advocacy group "creates spaces for people to get together, support each other to explore shared issues and find common ground". It helps reduce a person's feeling of isolation in their experiences and find commonalities with others who may have had similar experiences. It provides a platform for people to support and amplify each other's voices.

Working closely with patients at the REH and the Ritson clinic, the group is now taking steps to expand in the community. The participation in the group is voluntary. The group will seek to bring attention to matters that affect the people most, and is self-directed group, with full autonomy on what pieces of work to undertake and how to act on them.

Commonalities and differences

Both these groups share a lot in common with the proposing LLE panel, in that they aim to embed and empower lived and living experience at the core of any decision-making processes. However, they also present differences that are nuanced.

SDF living experience engagement panel seeks to only include 'living' experience. The rationale being that the term 'lived experience' is widely used to describe and associated by people who are in long term recovery, thus might not accurately represent the realities of those who are currently using drugs and/or receiving support from alcohol and drug treatment services.

Both the drug trends and patterns and treatment services and methods (including the substitute medications) will have changed significantly since those in long-term recovery were using. Unless the person has ongoing links to the drugs and alcohol support landscape or kept their knowledge up to date, it would be difficult for them to comment on the contemporary drugs and alcohol related issues.

Furthermore, in hindsight, people's understanding of and discourse surrounding their own drugs and alcohol use changes due to several factors including society and socio-economic conditions, which recovery model that they follow (psychological, faith based, etc.).

The collective advocacy group, abiding by the principles of independent advocacy, are self-directional and autonomous. It shall set its own agenda and priorities which at times could align with EADP priorities, however, will remain out of EADP oversight to maintain its independence. A collective advocacy group's scope also goes beyond EADP engagement - in that the group is able to flexibly work across disciplines and sector boundaries.

Having mentioned these nuances, conversations with SDF lived experience engagement team and the Patient's council collective advocacy worker, there was an enthusiasm to work in conjunction with each other. The SDF living engagement group, by having a representative in the regional lived

and living experience groups (e.g. Glasgow) already has demonstrated how each group could work together.

B: Beyond Edinburgh: Other LLE groups in Scotland

Glasgow Reference Groups

Glasgow reference group was established in 2019. Due to the Covid-19 outbreak, they resorted to meetings online and then decided to meet face to face when the restrictions were lifted. Initially a mixed group (e.g., women, men, carers, etc.), subsequently evolving into multiple groups to address issues and concerns faced specifically by different groups of people

Different reference groups:

- a) Mixed group
- b) Women
- c) Family and Carers
- d) Peer workers

The membership is open to both lived and living experience with a low threshold. The group membership is usually between 10 and 15. typically meet once a month for 1 – 1.5 Hours, but in times when hosting special events or working on specific ADP agenda or projects, working groups will be formed and these working groups will meet as frequently as needed. The group also invites partnership board members, other Exec, Managers, professionals, etc. or whoever is trying to implement new projects or improve services or any other community related activities, to bring forward their proposals, ideas, etc. to receive the group's input. The group is also consulted on ADP's planning activities and are involved in all stages such as implementation, monitoring and evaluation. The agenda and the direction of each meeting is set by the members.

Fife Lived Experience Group

Fife Lived Experience Panel is going through a refresh. The previously tenured panel of about 15 people initially met online monthly, moving on to some face-to-face meeting. The panel consisted of a Coordinator; a Chair - rotating every 3 months; Secretary - selected by and within the panel and members. The coordinator was employed with SRC and was responsible for facilitating the panel and bringing action points discussed at the panel to the Fife ADP meetings.

From mid-2023 the Fife Lived Experience Group has been adjusting to a range of factors, including, panel members, who were mostly in their late recovery stage, moving on into employment and other priorities.

The following were put forward as key issues faced by the panel:

- Not having formal agenda
- No clear purpose
- Not having a reliable structure
- Communication and logistical issues
- Not having a premise
- Not having sustainability measures put in place when members started moving on

Recently a development lead was put in post (who was also a panel member previously) for the refresh working alongside Scottish recovery consortium.

In its tenure, the panel successfully influenced Fife ADP in some key projects such as a recovery café in Levenmouth (two more recovery cafes to be started), recruitment of two independent advocates, and training on a human rights-based approach.

Dumfries and Galloway

The LLE Panel in Dumfries and Galloway is currently in the planning stage. They are following a model developed by the lived experience panel in the Borders. The LLE panel is envisioned to discuss the ADP meeting agenda and papers prior to the ADP meetings. A selected lived experience rep from the group would subsequently represent the decisions and action points agreed in the panel at the ADP meetings.

Due to issues specific to rural areas with concerns of travel distances limiting the frequency of meetings and the capacity of participants to commit time to the panel, they are currently contemplating online meetings (rather than in person).

The Dumfries and Galloway development lead mentioned having relaxed discussions followed by tangible decision making through what they called a 'development day' – essentially a café style event with food and opportunities to communicate and connect. Creation of a paid peer naloxone programme in the area has'.

Borders

Using the forum's Terms of Reference as well as discussions with others involved in the forum we were able to learn the following about the Borders Forum. The Borders Lived Experience forum was set up to input into the Borders ADP in their overall strategy – design, implementation and evaluation of the local services.

The group provides a mechanism to:

- Contribute to the evaluation of the local ADP Strategy and Delivery Plan
- Influence the development of future service planning
- Influence the understanding of the needs of people with lived experience from alcohol and drugs and wider services
- Contribute to national and local consultations and engagement processes
- Exchange relevant information

The group is supported by a sub 'secretariat' group, composed of officers including, 'We are with you', 'serendipity recovery community network', and the ADP support team. The group was considered as a subgroup of the ADP and the findings and work of the group was presented to the ADP and the papers were held by the secretariat group.

The group convenes monthly for 2 hours though the duration of these meetings are extended when particular focus is needed on specific pieces of work, for example, development sessions or strategy consultation.

Corra Foundation Lived Experience group

Corra Foundation is a Scottish grant- making charity that is about strengthening and amplifying people's voices and their power to make change. Working alongside other funding partners, including the Scottish Government, they seek to make available funding for organisations with three aims in consideration, as outlined in their 10 year mission and strategy statement for 2020-2030.

- ⇒ The power to create change rests with people themselves.
- ⇒ People with ideas for radical change are supported, skilled, confident, and connected.
- ⇒ People are working together to respond to the big challenges facing Scotland.

As part of the grant making process all the grant applications are consulted with a lived and living experience group, who are tasked with reviewing the applications and informing whether to approve, not to approve or approve with changes. As such Corra's LLE panel is focused towards a single objective, in contrast to the regional ADP panels who are expected to respond to ever changing and sometimes multiple pieces of works as needed by the community and the particular ADPs.

The panel is comprised of 20 members in total of which only 10 members are invited to take part in a particular meeting. The members are recruited through organisations and services that work with people with experiences of drug and alcohol use, whether active or history of, including the major Alcohol and drug treatment providers as well as other organisations including Scottish Drug Forum, Scottish Recovery Consortium, Edinburgh Recovery Activities, Simon Community. The primary reason for this recruitment method seems to be the availability of support for the members through these organisations should a need arise for it.

The roles and the responsibilities are well defined in a 'briefing document'. The members are remunerated for their time and are also offered:

- Briefing and debriefing calls before and after LEP meetings as requested by the panel member.
- Training relevant to the panel member's role or directing to training offered by other organisations.
- Opportunities for panel members to attend Learning Network meetings where topics relevant to the National Drugs Mission are explored.
- Visits to National Drugs Mission funded projects.
- Employment references for LEP members who have attended at least 3 meetings.

Learnings

The overview of these different LLE initiatives highlight that each group had particular needs and objectives which dictated how the group is organised. However, the following were identified as key features for a successful LLE group or forum:

- Autonomy/independence - the groups are self-directed and have control over the agenda and discussions of the meetings
- Having a clear purpose and aims
- Having clearly defined communication pathway with Local ADP - Established communication pathway with the Local ADP that is bi-directional thus everyone involved is clear in how their activity is processed and affects change.
- Needing Support and Facilitation - facilitation and 'secretarial' support for the groups in its proceedings, including logistics and promotion
- Having a premise for the meetings

C: Learning from LLE Voices	
<u>Community</u>	
Key Learnings	Suggestions
<p>The participants repeatedly emphasised community as a positive and necessary force in their lives.</p> <ul style="list-style-type: none"> • Belonging to a community can be integral to successful recovery. • It can help mitigate social isolation and depression. • It enables members to connect and seek/offer support. • People feel the ‘need to be part of something’. • ‘Shared experiences’ as providing a good base for connection. 	<p>The proposed LLE CP should aim to foster a sense of community across LLE spaces and sessions.</p> <p>The Proposed LLE CP should have a social dimension to it.</p> <p>Draw on ‘shared experiences’ to build community.</p>
<u>LLE Voice</u>	
Key Learnings	Suggestions
<p>“It is only through having lived experience can one have true empathy.” – Participant.</p> <ul style="list-style-type: none"> a) Meaningful and NOT tokenistic inclusion. b) Confidentiality and consent. 	<p>How do we collate the expression and articulation of LLE without interfering with autonomy and independence?</p> <p>Use a mix of creative, non-verbal consensus-building exercises to foster safe spaces driven by shared values.</p> <p>Clear frameworks on confidentiality and consent.</p>
<u>Structured (but also informal)</u>	
Key Learnings	Suggestions
<ul style="list-style-type: none"> • The panel needs to be structured and focused. • Having a purpose and working towards an aim was important for the participants. • “People need to feel productive”. • An informal panel would run the risk of not focusing on the issues and arriving at any solutions. However, a completely formal panel would end up distancing members 	<p>Striking a balance between formal and informal is necessary. Building on previous experiences, group members expressed alternating focused LLE sessions (formal) with a drop-in social cafe with loosely-structured and open-ended facilitation (informal).</p>

Safe, Secure and Welcoming Spaces

Key Learnings	Suggestions
<ul style="list-style-type: none"> • The panel should be a safe space for people to voice their opinions free from judgement and penalty • This is especially important for people with experiences of stigma and discrimination. • Participants did not always feel comfortable sharing that they have substance use (including alcohol) issues with their loved ones, friends or colleagues. • Confidentiality breaches and consent violations are unfortunately a common experience when sharing openly with family, friends and colleagues. 	<p>The panel needs to be open and welcoming. It was realised that many people may feel hesitant and anxious when first joining or attending a group. Having a person responsible for a buddy system to receive and support the newly joined members was suggested.</p> <p>The naming of the Initiative/Panel/group should itself be open to collaborative decision-making with the LLE community. Refer to ambiguous sentiments about the term 'Panel' in earlier sections of this report.</p>

Barriers to Participation

Key Learnings	Suggestions
<p>The clash of time availability invited commentary on the optimal structuring of group engagement.</p> <p>It was suggested that the panel should also accommodate those who are unable to commit time during the usual business hours (9 am-5 pm) as it is recognised that many people in the recovery community will have life commitments (E.g.: employment, social and care responsibilities) which would be a barrier to their participation.</p> <p>While most people were willing to volunteer their time, travel costs and potential loss of income were raised as factors that could negatively affect participation.</p>	<p>It was proposed that some panel meetings could be held either in the evenings or on the weekends.</p> <p>2 hours every four weeks was recognised as a reasonable expectation of commitment. However, people expressed willingness to commit time as needed if the panel is working on a specific piece of work.</p> <p>While promoting and soliciting LLE engagement membership, be clear on recompense.</p>

Membership

Key Learnings	Suggestions
<p>Unanimous agreement that the panel membership should be open to all those who have lived and living experience of alcohol or drug use.</p> <p>It was recognised that there is a need to include more people with living experience of alcohol or drug use.</p> <p>“It’s one’s group to go and feel comfortable sharing opinions. If mixed (family and service users) either of them may not be able to fully say what they need to” - Participant.</p> <p>It was discussed that the group should be more than 5 for the panel to not feel like a small group of individuals. However, the participants also felt that the group need not to be large as that may impede members from forging a belonging to the group</p> <p>Furthermore, there was enthusiasm among participants, as well as professionals, for the panel to reach out to the people who aren’t engaging with any services. Some participants mentioned that they had not even heard about Drug and Alcohol support services prior to reaching a crisis point. If they had, they reflected, their recovery could have started much earlier.</p> <p>However, some people felt that it was important to meet as a wider group occasionally. And there was an understanding that the subgroups may not start together.</p> <p>It was discussed that the group should be more than 5 in order for the panel to not feel like a small group of individuals. However, the participants also felt that the group needed not to be large as that may impede members forging a belonging to the group. A membership of 8-12 was considered acceptable for most participants.</p>	<p>It was suggested that the membership can be fluid, i.e.: people could have the option to engage when the topics that interest them are being discussed and to be able to “feel comfortable in re-engaging” even if one was not in attendance “for a long time”.</p> <p>Most participants also were in favour of establishing different subgroups: Family; Unpaid Carers; Women; Peer workers; and Localities (SE, SW, NE, NW). It was discussed that people belonging to these subgroups would have different needs and priorities.</p> <ul style="list-style-type: none"> ● Establishing different LLE groups can help prevent potential clashes of interest. For example, many pointed out the ‘veterans’ could be a potentially differing category as some participants pointed out that being in the forces fosters a certain culture and discipline. Drinking alcohol, it was mentioned, is one of the significant ways through which they forge camaraderie and bonding. This makes it harder for some to adjust to community life after forces. <p>Most participants deemed a membership ranging from 8 to 12 as acceptable.</p>

<u>Independence</u>	
Key Learnings	Suggestions
<p>People felt that it was important for LLE panel members to have control over the proceedings of the panel.</p> <ul style="list-style-type: none"> Being able to set and direct agendas and priorities was put forward as an important aspect to ensure that they can voice their opinions without hesitation and make meaningful changes. 	<p>While it was recognised that the panel would be in regular contact with EADP, people wanted autonomy to engage freely with other services and groups in the community including the other LLE engagement initiatives across the city.</p>
<u>Engagement with EADP</u>	
Key Learnings	Suggestions
<p>Participants stated that they wanted to avoid having a constant presence of the EADP staff/representative at the panel meetings. The reason for this is that the staff presence could either unintentionally or intentionally influence decision-making within the panel. Some people thought that could lead to panel members self-censoring.</p> <p>There is an expressed need to counter patterns of tokenistic inclusion of LLE expressions. Participants described previous experiences of LLE engagement that rendered participation meaningless.</p> <p>Some participants experience office premises as hostile to free or meaningful LLE expression. They reported the likelihood of feeling intimidated when participating in discussions. It was suggested that spaces are not value-neutral, and certain spaces that carry treatment or care navigation authority might hinder and disempower LLE engagement.</p>	<ul style="list-style-type: none"> Panel to retain autonomy over their agenda which could include EADP items. Pull-in EADP representatives when required. Recognising EADP as a partner and a resourcing body for panel activities and reportage, members wish to maintain a relationship whereby EADP could be invited along to the meetings as required. EADP to be invited to some 'panel' meetings as well as having 'panel' reps at EADP meetings. It was agreed that there needs to be a bilateral communication between the panel and EADP. EADP needs to keep communicating with the 'panel' and feedback back. EADP's communication is expected to be constant and consistent. <ul style="list-style-type: none"> The communication, people highlighted, should be clear, of simple language and direct. For its work to feel meaningful, the people expect EADP and other partners to act upon the issues raised at the panel and communicate transparently about the actions taken to address those issues. (Eg: you said/we did)

	<ul style="list-style-type: none"> ● Participants wondered whether EADP meetings be held in community settings so less intimidating for 'panel' reps to attend. Making non-LLE informed spaces welcoming to LLE expression and participation. <ul style="list-style-type: none"> ○ It might be more empowering for people to be heard from where they are rather than being expected to fit into already existing structures of obtaining feedback. ○ Experimenting with social spaces within the scope participant's daily activity is to be encouraged.
<u>Facilitation And Support</u>	
Key Learning	Suggestions
<p>People found it necessary for the panel to be supported by a dedicated facilitator, whose role would be to support the panel with its logistics and administrative tasks. The facilitator would also be expected to take note of any discussions and action points occurring in the panel.</p> <p>Furthermore, the facilitator would be responsible for identifying needs of the panel and its members and make the necessary arrangements to address those. This would include venue hire, food and refreshments as well as identifying training and development opportunities that may allow panel members to perform their roles.</p> <p>Qualities and specifications of the Facilitator as outlined by the participants:</p> <ol style="list-style-type: none"> 1. Friendly personality 2. Approachable 3. Non-judgemental 4. Compassionate 5. Respectful 6. Preferably someone who has lived experience <p>For the panel to function as intended, it needs to be able to have access to material resources.</p>	<p>Many agreed that the facilitator, representing the panel, should be present in various recovery community events and programmes, to develop membership and to promote the aims of the panel.</p> <p>Given that there is much interest in fluid membership and engagement according to a theme, it was also suggested the facilitator would be tasked with keeping the panel members and the interested parties in the know (e.g., newsletter)</p> <p>In terms of logistics, many people said they prefer a central location that might be more suitable for a collective panel (that's not locality-based). It was also stressed that the panel should meet at the same venue for meetings consistently and that the venue should be a comfortable space and accessible.</p>

Reciprocity and Incentives

Key Learnings	Suggestions
<p>'Reciprocity' is key to working with people. ensuring that people get something back for their input of time, energy and expertise. 'Incentives' were found helpful for the meaningful engagement and contribution of LLE individuals in decision-making processes that affect them.</p> <p>National-Collaborative's recent 'Experiences of Human Rights in Relation to Substance Use' analysis report highlights the importance of incentives in enlisting the contribution of the LLE individuals into decision-making processes that affect them.</p> <p>LLE Initiatives would benefit from a good review process and monitoring and evaluation frameworks.</p>	<ul style="list-style-type: none">• Our discussions brought to light the expectations of receiving suitable training and support.• People expressed that they would need preparatory support for them to engage with the panel processes and the EADP papers.• Participants were also enthusiastic about accessing leadership training as to take on more proactive roles within the panel as well as in the community.• While most people were willing to volunteer their time, travel costs and potential loss of income were raised as factors that could negatively affect participation. <p>While autonomy is to be respected, monitoring and evaluation processes should be in place to strengthen the initiative's overall sustainability and accountability.</p>

RECOMMENDATIONS:

Following the discussions, the DW had with the professionals, other regional ADP LLE groups, and adopting the recommendations from other reports produced, the following recommendations put forward for the Edinburgh Lived and Living experience panel

Panel format and membership -

- Forming a panel with 8-12 regular members within whom a chairperson and a secretary will be selected rotating every three months is recommended.
- The minimum membership should be 5
- The membership is recommended to be open for anyone who is 18+, and either has historical or current experience of using alcohol or drugs.
- Initially establishing two groups - people with direct experience and people who are family or unpaid carers, with the view to developing other subgroups in the future. Subgroups suggested: Women, Peer workers, LGBTQ+ and Veterans.
- The panel membership needs to be diverse to include participation from groups of varied backgrounds, including BME and LGBTQ+ communities - steps need to be taken to promote participation.

Commitments and Expectations -

- It is recommended that it is reasonable to ask for a commitment of 2 hours every 4 weeks.
- It is suggested that in addition to the formal panel meeting, a cafe style drop-in is also arranged every 4 weeks

Training and Support -

- The panel should be assisted by one or more facilitators (a full time equivalent), who would support the panel with the organising, promoting, administration as well as with keeping people and members connected.
- Training should be offered to panel members that would allow them to engage well in their roles.
- The panel members should be offered career development, leadership development and up-skilling opportunities should they wish.

- It is recognised that the panel might discuss matters that could potentially impact its members' mental health or (re-)trigger cravings or urges. A debriefing session should be held, and the facilitator should be available to provide extra support if needed.
- It is recommended that the panel has access to a budget to facilitate its own functioning and any activities it may undertake to promote lived and living experience engagement or recovery focused systems of care.
- It is recommended that the facilitator(s) will, as part of their role, be responsible for recruiting and replenishing membership - by way of constant promotion and engagement.

Should this work sit independent of the ADP?

- The work should sit independent to the EADP, with an organisation, applying the principles of independent advocacy. The organisation should not provide any other service but lived experience engagement to avoid potential conflicts of interest.
- If that is not possible, it is recommended for it to function under the EADP, with its independence ensured (following the examples of other ADPs discussed above)
- The panel should form their own agenda in addition to EADP items
- The LLE reps should attend EADP meetings, and EADP representative should also be invited to panel meetings.
- EADP meetings need to be inclusive and would benefit from being held in community spaces
- **EADP papers need to be circulated enough in advance so that the panel has ample time to read the papers and meet to discuss papers before EADP meetings.**

Engagement with EADP

- The LLE panel reps should be invited to participate in various EADP meetings and forums.
- The following EADP groups and forums (however, not limited to) are where LLE would be most impactful
 - EADP Executive Group meeting
 - The Adult treatment and recovery Collaborative
 - The Whole family Collaborative

Reciprocity and Recompense -

- While participation in the panel is voluntary, any travel or other expenses acquired by a member to attend the meetings needs to be reimbursed, within reason, to mitigate barriers to participation as much as possible.
- Participation of members in any special work beyond the regular activities of the panel (that is codesign, consultation or evaluation exercises) need to be remunerated.
- The above should be available for training opportunities also.

NEXT STEPS FLOW CHART

Speaking to commissioning and managing boards, the report outlines how a lived and living experience panel should be brought together. It calls for greater attention to developmental resourcing and committed ongoing support that is needed to ensure active and meaningful community engagement. The report aims to provide a snapshot of common understanding and the conceptual infrastructure that underpins LLE community panels. The report should inform and improve their roles and responsibilities both with the LLE community panel and within the commissioning organisational entity (EADP).



Facilitator recruitment:

The next steps to follow this report will be the recruitment of the facilitator(s). Facilitator(s) will be responsible at the initial stage to bring a panel together and develop resources.

An ideal facilitator will have the following characteristics:

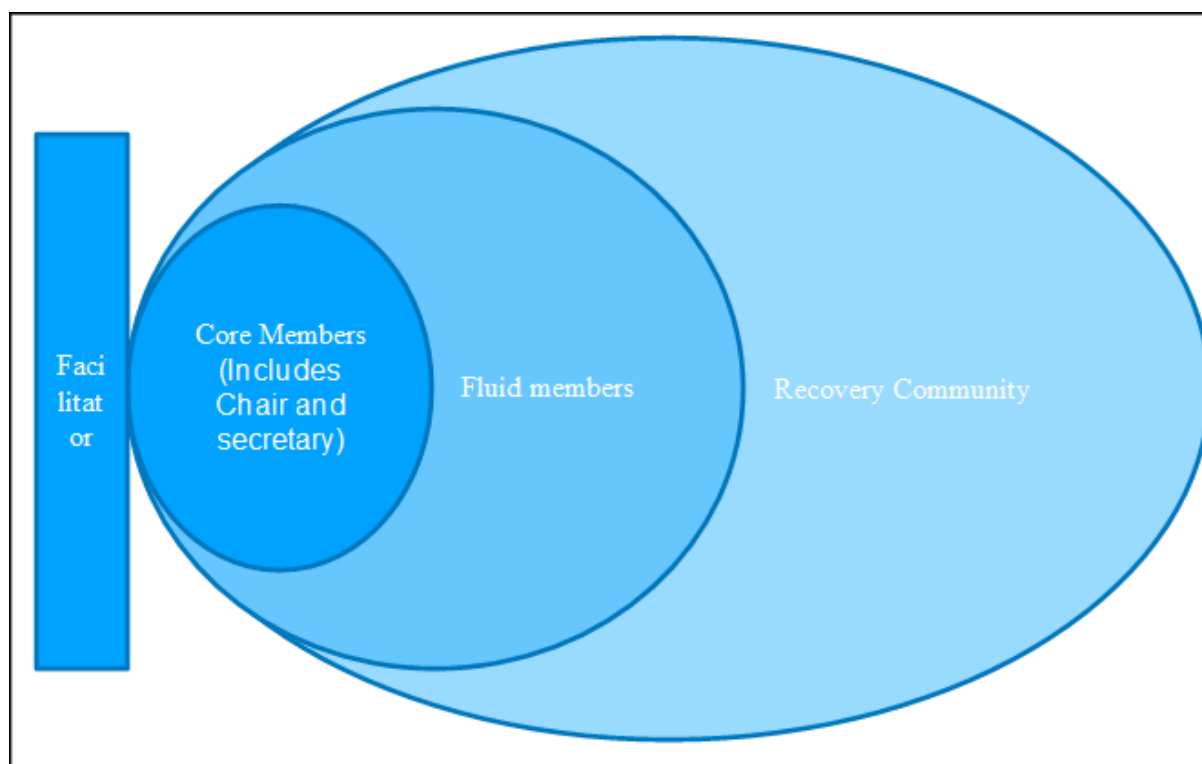
- Friendly
- Approachable
- Non-judgemental
- Compassionate
- Respectful
- Preferably someone who has lived experience

Facilitator will be responsible for fostering and maintaining community and inter-organisational connections and networks. They are recommended to take part in different drug and Alcohol recovery forums – Craigmillar recovery forum, Substance Use Network Edinburgh (SUNE) etc.

Recruitment of members and establishing a working group:

During our exploration, the effort to establish a LLE panel was met with great support and enthusiasm. It is imperative that the recruitment of members commences at the soonest to benefit from this momentum.

The panel is suggested to focus on developing a terms of reference document and increase its membership. For that purpose, the facilitator will work towards forming an initial working group.



Securing training and resources:

Organisations such as Scottish Drugs Forum (SDF) and Scottish Recovery Consortium (SRC) are a good source to meet the training needs as they provide LLE focused training across Scotland. Organisations such as Volunteer Edinburgh and Media Education had developed courses with local colleges which would provide their participants qualifications in Community or volunteer leadership.

Suggested topics that the panel could discuss:

On different occasions, it came up that the panel should have a well-defined purpose and it needs to be able to meaningfully make change. During the independent sessions participants were able to share some areas of concern within the Edinburgh recovery landscape that the panel could undertake in its inception.

- Mental Health Support
 - Better access to mental health support **alongside** substance and alcohol support
 - *“they don’t want us to talk about our mental health in recovery groups”*
 - *“Once you’ve stopped with the drugs or alcohol you’ve then got your mental health left to deal with”*
 - *“You have to stop using before you can get mental health support”*
 - *“How do I cope with what comes up in therapy without the drugs”*
- Waiting lists
 - *“You can’t help an addict next week, you’ve got to help them today”*
- Better signposting to services (signposting to other groups and activities was reported as not always happening at the recovery hubs)
- Reducing stigma
- How to better educate people around drugs and alcohol
- Impact of poverty on addiction
- Drug consumption rooms
- Recovery – people mentioned wanting there to be more focus/emphasis on recovery alongside harm reduction.

APPENDIX

A1: Lived and Living Experience Commentary on Care/Recovery Navigation

Here presented are some of the questions and statements that were prominent in the group sessions. Showing both the good practices as well as some of the needs as identified by the participants.

What's Working?

- Linkage between recovery activities and the services.
- Generally good reception of the Hubs, Turning Point/CGL and the Access Practice.

"Turning Point was life changing"

"CGL was very helpful"

"ERA saved my life."

- SMART – CBT adapted support (though the SMART groups are not as widely available as the AA groups.
- Holistic support at the Access Place. Enthusiasm for one stop shop model.

"More like the Access Place"

Why was it working?

- Good relationship with staff.
- Open, friendly and non-judgmental space
- Availability of choice and person-centred support.
- Sense of community
- Ease of access (One-stop shop model)

What isn't working?

- Long waiting lists for detox and rehab
- Waiting list for mental health support following abstinence. "felt let-down"
- Visibility: Several people mentioned, not having heard of services like Turning point/CGL prior to their referral from GP. Not even seen leaflets
- Mentioned that they might have sought support well before reaching harmful levels.
- Information not being easily available. Information to be available easily in public and not for people to have to search for (usually online) – "public safety adverts" "information hubs"
- Several recovery activities are available, but the information has not been dispersed well.
- It was also mentioned that there needs to be a worker to support people access these activities (perhaps take them to these events or perhaps help them identify and make connections for them)
- Same focus needed for alcohol as the focus on Drugs

- After-hours/weekend support or recovery cafe (not crisis support)
- Short term project funding (not making people feel secure as to whether certain activities will be available. – need for continuous funding)
- Not many service users know of MAT standards and what underpins their treatment, thus their rights.

Additional Remarks

1. **Signposting** – people saying they felt it isn't happening within the recovery hubs and would like their workers there to be able to signpost to other groups and activities so people can fill up their days with different things. Someone mentioned travelling to Glasgow to access recovery activities as they felt there wasn't enough happening in Edinburgh or they weren't aware of what was happening.
2. **Recovery** – some people said they would like more emphasis to be on recovery rather than only focussing on harm reduction. People mentioned that recovery was never mentioned when they attended the hubs for support.
3. **Easy Access to information** - people mentioned that they rarely knew about the alcohol and drug support services prior to being referred to the services themselves. It was suggested that a hub in a visible area that caters to everyone with specialised information would be very helpful.
4. **Advocacy and information about MAT standards** - Many of those in attendance at the sessions mentioned that they did not hear about MAT standards prior to that day. They also mentioned that they did not know what their rights were in relation to their treatment. This makes it harder for people to access standard quality of care. One family member highlighted that "knowing how to speak the lingo of the drug and alcohol field helps with effective navigation of the treatment". We were also informed of some delays in accessing advocacy.
5. **After-hours/weekend support** - people raised not having a recovery cafe to go to in the evenings or at the weekends as a great gap in Edinburgh. ERA has received praises from several people who attended the sessions, however, the community cafe only being available on Wednesdays was flagged as doing very little to bridge the gap. Several people reported that their drug and alcohol use has been a product of isolation and loneliness. Having a social space available for people to go to at any time they want to, received much favour from participants as a great idea.

A2: Exhibits

Exhibit: Flyers promoting for “Your Voice Matters” Sessions



Your voice matters

Join us to share your views on what alcohol and drug support should look like in Edinburgh.

Your voice is key to shaping better support.


Open to adults who have lived or living experience of drug or alcohol use.

Join us for food and a chat on any of the following dates:

Fri 13 Oct 2023	Mon 16 Oct 2023	Thu 19 Oct 2023
1pm – 3pm, Learning Centre, 65 Bonnington Rd, Edinburgh, EH6 5JQ	6pm – 8pm, Grassmarket Community Project, 86 Candlemaker Row, Edinburgh, EH1 2QA	1pm – 3pm, Learning Centre, 65 Bonnington Rd, Edinburgh, EH6 5JQ

Text or call Elii to register: 0751-382-6652

The work and findings from these sessions will be reported to the Edinburgh Alcohol & Drug Partnership.



Your voice matters

Join us to share your views on what alcohol and drug support should look like in Edinburgh.

Your voice is key to shaping better support.

Open to adults who have lived or living experience of drug or alcohol use. **Free Bus/Tram DAYticket** available at sessions for those attending.

Free food and entry at the in-person sessions

Fri 3 Nov 2023	Tue 21 Nov 2023	Thu 30 Nov 2023
1pm - 3pm The Health Agency, Wester Hailes Healthy Living Centre, EH14 3JF	2pm - 3.15pm Online - Zoom Please register for the Zoom link	1pm - 3pm Muirhouse Millenium Centre, 7 Muirhouse Medway, EH4 4RW

Text or call Elii to register: 0751-382-6652

The work and findings from these sessions will be reported to the Edinburgh Alcohol & Drug Partnership.



Exhibit: Flyers promoting for Sessions held with some on-going groups and activities

Join us to share your views on what alcohol and drug support should look like in Edinburgh.


Your voice...

- can help develop a better understanding of the needs of people with lived and living experience
- can help improve services
- can help improve the outcomes for people

Open to adults who have lived or living experience of drug or alcohol use.

Join us for food and a chat:

Wednesday 11 October
Women's Recovery Group



You must register with CGL first to attend. **Funded by:**

EVOC INFORMATION DEVELOPMENT RECOVERY **Edinburgh Alcohol & Drug Partnership**

The work and findings from these sessions will be reported to the Edinburgh Alcohol & Drug Partnership.

Join us to share your views on what alcohol and drug support should look like in Edinburgh.


Your voice...

- can help develop a better understanding of the needs of people with lived and living experience
- can help improve services
- can help improve the outcomes for people

Open to adults who have lived or living experience of drug or alcohol use.

Join us for food and a chat:

Monday 9 October, Panacea



You must register with the Sorted Project to attend. **Funded by:**

EVOC INFORMATION DEVELOPMENT RECOVERY **Edinburgh Alcohol & Drug Partnership**

The work and findings from these sessions will be reported to the Edinburgh Alcohol & Drug Partnership.

Join us to share your views on what alcohol and drug support should look like in Edinburgh.

Your voice...

- can help develop a better understanding of the needs of people with lived and living experience
- can help improve services
- can help improve the outcomes for people

Open to adults who have lived or living experience of drug or alcohol use.

Join us for a cuppa and chat:

Wed 18 Oct, 11.30am – 3pm,
Recovery Community Café,
Walpole Hall St Mary's Cathedral, accessed via
Manor Place or Palmerston Place, Edinburgh



The work and findings from these sessions will be reported to the Edinburgh Alcohol & Drug Partnership.

EVOC INFORMATION DEVELOPMENT RECOVERY **Edinburgh Alcohol & Drug Partnership**

GLOSSARY:

EADP	EADP is a partnership of statutory, third and volunteer sector organisations overseeing the strategic direction to reduce alcohol and drug related harm in Edinburgh. This is generally done through designing, developing and implementing strategies and services to address Alcohol and drug related issues in Edinburgh and by maintaining a coordinated service provision through all its partner agencies
MAT Standards:	<u>Medication assisted treatment (MAT) standards</u> refer to 10 evidence-based standards published by the Scottish government for the delivery of safe, accessible, high-quality drug treatment across Scotland.
Lived Experience	Experience(s) of people for whom a social issue, or a combination of issues has had a direct personal impact.
Living Experience	Current and active experience(s) of a social issue, or a combination of issues having a direct personal impact
Indirect lived and living Experience	Indirect lived experience can be defined as proximate, second-hand lived experience. It generally related to: <ol style="list-style-type: none"> 1. Drug and Alcohol use and it's adverse impact on a family member, carer, close friend or another person 2. Use of drug and alcohol support services by a family member, carer, close friend or another person
CGL	Change Live Grow is a charity providing drug and alcohol psycho-social support in Northwest, Southeast and Southwest localities of Edinburgh

TPS	Turning Point Scotland is a charity providing drug and alcohol psycho-social support in the Northeast locality of Edinburgh
SUNE	Substance Use Network Edinburgh is a forum of third sector organisations providing support for the recovery community in Edinburgh. It aims to improve the effectiveness and maximise the contribution of Edinburgh's voluntary sector to the planning and delivery of services and activities for tackling issues around drug and alcohol use.
SRC	Scottish Recovery Consortium is a national organisation working to promote recovery across Scotland
SDF	Scottish Drug Forum is a national organisation who provide resource and expertise around drug related issues across Scotland.
REH	Royal Edinburgh Hospital
Ritson Clinic	Inpatient Drug and Alcohol detox unit for all the Edinburgh localities.

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