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Introduction

The National Collaborative is a project that not only aims to empower people affected by substance use but will also set out how the rights to be included in the forthcoming Human Rights Bill can be effectively implemented. It will do this by applying a human-rights based approach to co-design a Charter of Rights.

As part of this process, a Call for Evidence was launched to gather views from around Scotland about people's experiences of substance use and human rights. This brought together people affected by substance use, their families and people working across a wide range of services and ran between May and August 2023.

We would like to thank each and every person who took part and contributed their views as well as the groups and organisations who ran sessions and made it all possible.

In total, more than 650 people took part in 8 national sessions, 37 community conversations and surveys conducted in-person and on-line.

Five of the national sessions were in-depth with a focus on a particular right. The rights included the right to health, the right to the social determinants of health, the right to participation, the right to private and family life and criminal justice related rights. Communities chose whether to focus on these particular rights or have a more general conversation around human rights and substance use. See 'Acknowledgements' on p.28.

A wide range of experiences and perspectives were gathered. Whilst some issues may have been specific to a locality there were also common themes that run throughout Scotland. [See our summary version here.](#)

Although it must be recognised that people felt there were many barriers to accessing their rights and being treated with dignity and respect, in many of the conversations there was also a recognition that things have been starting to change for the better and there was often a real sense of hope that further improvements are on their way.



Methodology

The National Collaborative are employing the FAIR model of a human rights based approach. The first stage of this is Facts – to develop an evidence base of experience of substance use. This involved issuing a Call for Evidence around the barriers faced by people affected by substance use in realising their human rights and what change should look like to better meet people’s needs.

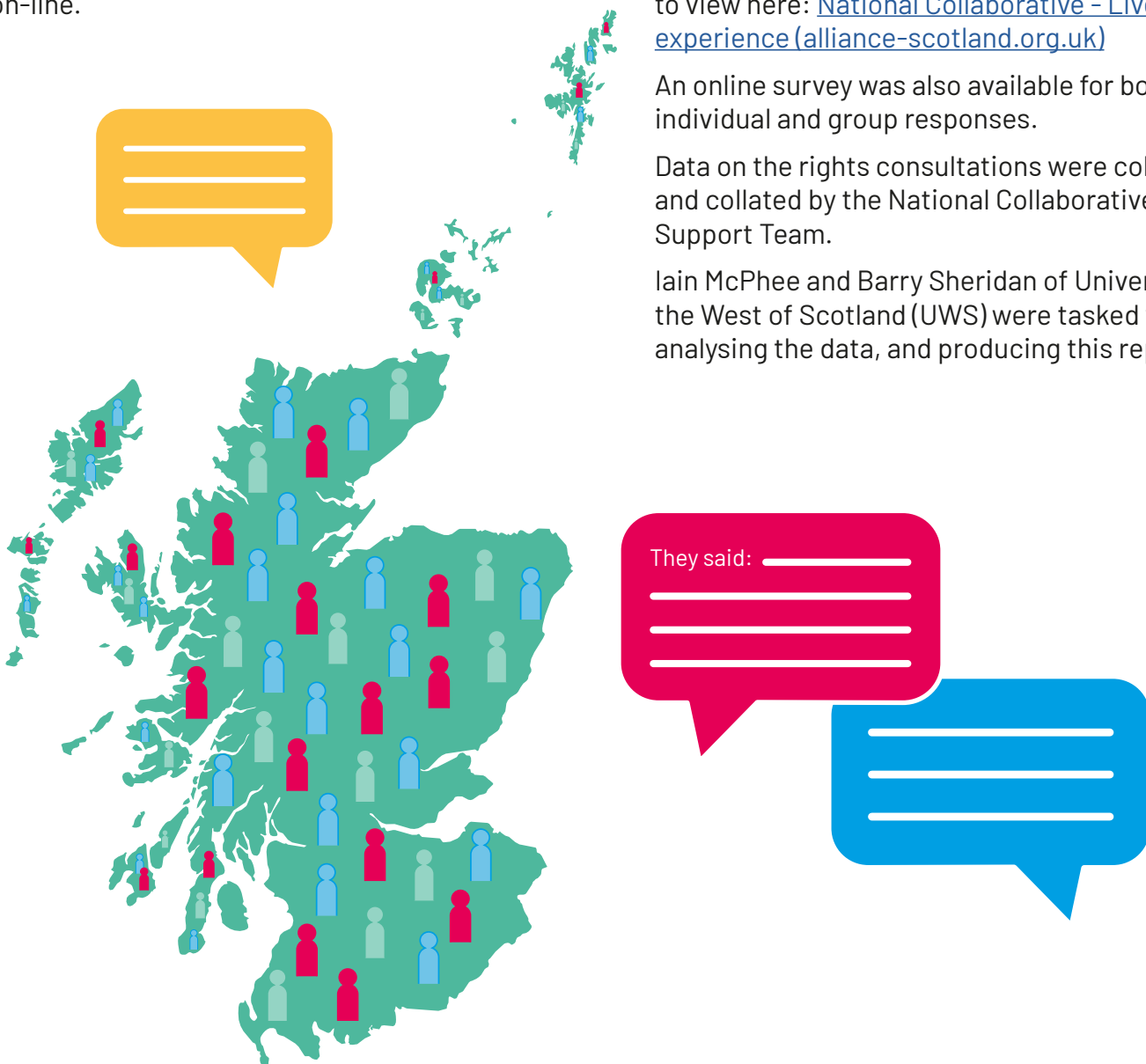
The Change Team identified what they considered as the most important rights for people affected by substance use and a series of questions were produced around each of these rights (see Appendix 1). The National Collaborative hosted deep-dive sessions on each of these rights in Glasgow, Edinburgh, Dundee, Kilmarnock and Lanarkshire. Further, general sessions were held in Aberdeen, Inverness and on-line.

Community conversations were undertaken by reference groups affiliated with the National Collaborative and numerous other organisations and groups. Drop-in support sessions were held for potential hosts and a facilitation pack was provided. Facilitation and small grants were available upon request. The community conversation activity packs, themed around general rights and specific rights, are available to view here: [National Collaborative - Lived experience \(alliance-scotland.org.uk\)](http://alliance-scotland.org.uk)

An online survey was also available for both individual and group responses.

Data on the rights consultations were collected and collated by the National Collaborative Support Team.

Iain McPhee and Barry Sheridan of University of the West of Scotland (UWS) were tasked with analysing the data, and producing this report.



The report presents information gathered from across Scotland and is presented using the 'PANEL' principles:

PANEL Principles



Participation:

people have a right to be involved in decisions that affect their rights. Participation must be active, accessible and meaningful.



Accountability:

there should be monitoring of how people's rights are being affected, as well as remedies when things go wrong.



Non-discrimination:

all forms of discrimination must be prohibited, prevented and eliminated. People who face the biggest barriers to realising their rights should be prioritised.



Empowerment:

everyone should understand their rights, and be fully supported to take part in developing policy and practices which affect their lives.



Legality:

approaches should be grounded in the legal rights that are set out in domestic and international laws.

Ethics

Secondary data analysis did not require that UWS seek ethical approval.



Data analysis

Data was analysed using Iterative Categorisation (IC), a rigorous and transparent technique for analysing textual data (Neale, 2016). Consistent with this approach, documents were read and re-read to ensure familiarisation. A descriptive analysis emerged on reading the documents, and a coding structure emerged from these processes:

1. Broad themes emerged informed by the National Collaborative question format for each domain.
2. An interpretative analysis identified sub themes informed by pragmatic reasoning to reveal the simplest and most likely conclusions from the analysis (Neale, 2016).
3. Identifying themes consistent with the PANEL principles.

Limitations

It was not feasible to gather detailed demographic information about the people who took part in conversations. However, we do know that there was participation from some of the individuals and communities we wanted to reach – those who are seldom-heard and who are at particular risk of being denied their rights.

Common Themes

The common themes identified in the analysis of data are presented using the PANEL principles.



Participation

People accessing services do not know their existing rights and are unable to exercise them.

People are often not empowered to engage in making recommendations about their care.

Involvement of family members in care, treatment and support has seen some improvement but is inconsistent, creating barriers to meaningful participation.

A power imbalance exists between duty bearers and rights holders. This power imbalance exists between statutory and voluntary sectors in relation to joint working.



Accountability

Allocation of public monies are generally not prioritised for areas of deprivation which exacerbate long-term health issues and life expectancy.

Support services lack visibility and people often don't know where to go for help, with restricted opening hours being a further concern.

A lack of access to transport is a significant barrier to access support that promotes good health. This is more challenging in rural and island locations.

Organisations are moving towards a rights based approach, particularly in relation to the implementation of the MAT Standards.

Professional work boundaries prevent services working together effectively (described as silo based), in particular mental health and addiction services.

While things are improving, challenges remain in accessing mental health services by people affected by substance use.

Complaints processes are often perceived as adversarial and punitive.

High staff turnover leads to many challenges, in particular lacking time or knowledge to respond to rights holders affected by substance use.

Whilst duty bearers refer to being trauma informed, participants do not consider this the same as trauma responsive.

There are difficulties in evaluating services and holding poor practice accountable.



Non Discrimination

Discrimination in relation to social class is reported, and while change is evident, stigmatising stereotypes discriminate against people who are affected by substance use.

Witnessing an overdose and calling an ambulance is difficult if the individual is known to services with experience of substance use.

Access to pain medication is difficult for people who have used opiates, and are known to services.

A lack of privacy and experiences of stigma and discrimination, particularly in pharmacies and justice settings.

Women with children report that duty bearers across all sectors lack awareness of rights resulting in breaches of rights to privacy and family life.

A lack of equivalence of care and support in justice settings compared to community based treatment and support.

While there are significant challenges in relation to socio economic differences in terms of quality of life, community approaches to tackling these challenges are making a difference.



Empowerment

The development of Lived/Living Experience Panels are a positive step, however there is a perception that they are sometimes selected to meet the needs of duty bearers.

While many rights holders and duty bearers do not know about human rights - what they are and when they are breached - there are signs that things are improving.

The importance of advocacy for individuals and their families was widely recognised.

Challenges exist in how to reward and recognise the contributions of people with lived and living experience when acting as experts.

Training and education are essential to increase career opportunities.



Legality

Whilst people welcomed the forthcoming Human Rights Bill they also recognised that this needs to be properly implemented and resourced to be effective.

Results

The analysis of the feedback is presented via the PANEL principles, specifically: **participation, accountability, non-discrimination, empowerment and legality.**

Participation

Within the PANEL principles, participation is described as: (being) involved in decisions that affect rights, that are active, accessible and meaningful.

This section presents the following themes: (i) knowledge of rights (ii) family participation, and (iii) power imbalances.

i. Knowledge of rights

There is a sense that people do not know what rights they have, or what service options are available to them.

“ If people knew more about their rights and entitlements it would make a big difference ”¹

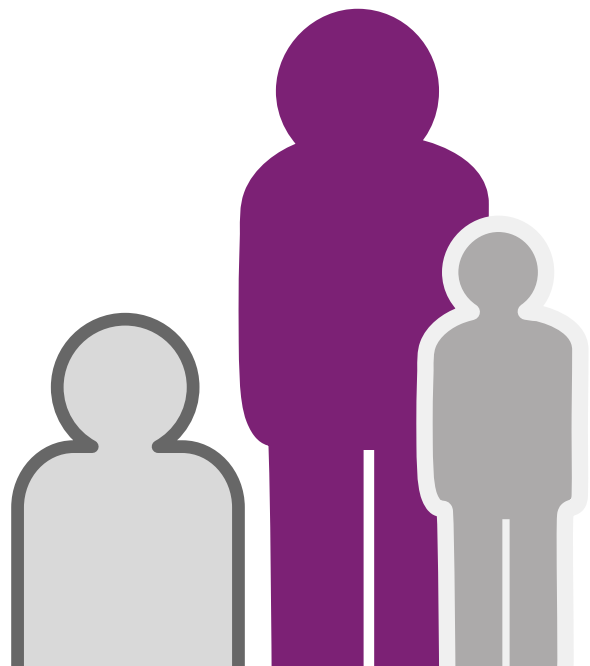
People affected by substance use encounter challenges to meaningfully participate in decision making in care planning. This was reported by individuals, group representatives and family members.

“ Services happen to people unless you’re able to speak for yourself ”²

“ Nobody tells you about carers’ rights. ”³

Advocacy is often provided across many services. However, it was noted that advocacy provided in some settings could be improved.

“ More lived experience (LE) within advocacy services employed as peer advocates, this happens already but more opportunities should be made available for peer advocates within independent advocacy ”⁴



ii. Family participation

Participants report that the rights of families are increasingly recognised across services, although report that family support offered is patchy and inconsistent throughout Scotland.

“ I have felt included with my son’s support within recovery services. ”⁵

“ There’s a lot of mistrust between families and services – ‘us versus them’ dynamic. ”⁶

The third sector, often as the first point of contact, create opportunities for joint working and breaking down barriers between professionals, people affected by substance use, and families:



“ In Fife family support teams sit alongside treatment services and link in with the treatment recovery workers and psychologists (and are) good examples of how families are in the body of that ”⁷

However, a lack of ways for families to be involved in care planning was also mentioned in some conversations. This occurs despite a belief that there is legislation to support involvement.

“ If families are educated and aware of rights, then this can empower them to understand when rights are breached ”⁷

Participants indicate that confidentiality in relation to data protection (GDPR) can be used as a barrier to meaningful participation even when there are legitimate reasons, and in making a complaint or making suggestions about their own or a loved one’s care.

“ Family members need to have the ability to talk to care and treatment services. ”⁸

“ using GDPR: to prevent sharing of information with families. Recognition of families as key allies, using their expertise, transparent services, and not using GDPR to create barriers and prevent families’ involvement. ”⁹

This occurs despite the belief that existing legislation provides families with a legal right to be involved in the care of a loved one.

“ There are existing rights-participation request under community empowerment act ”¹⁰

Equally, it was reported that people accessing support may not wish for their family members to be involved in decisions that affect them.

Emergency services that care for individuals in crisis do not always communicate with families. NHS Scotland hospitals are described as inconsistent in providing information about discharge of loved ones.

“ gulf between services as they are and rights to be ascribed ”¹¹

Many kinship carers and family members report feeling excluded in meaningful ways in caring for loved ones affected by substance use.

“ In crisis families are left isolated and responsible for care but not with tools (to cope) ”¹¹

Family members feel that social class is a barrier to engaging with services, describing negative stereotypes associated with certain families, geographical locations, and the use of non-prescribed substances.

“ Services are not interested in what a family member has to say. What does the family member know? The staff have studied for 3 years so believe this makes them far more qualified than listening to any ideas from "a druggies maw ”⁷

The following quote captures what individuals and families affected by substance use want:

“ a safe place to live, to access food, gain employment, help with chronic conditions, kinship issues, helping people with their mental health and wellbeing or just taking the time listen. People don't want to have to tell their story multiple times or visit multiple places. ”¹²

In relation to services for young people there were concerns around continuity of care once the individual turns sixteen:

“ (one) is considered an adult at 16...how are they expected to cope with adult services staff? This is why there are so few (who) access services ”⁷

iii. Power imbalances

Participants describe a negative experience when engaging with certain professions including GPs and hospital staff, Local Authority Social Work Services staff and Police Scotland officers. These reported negative experiences limit meaningful participation in decision making in care planning when interacting with these duty bearers.

“ Doctors and hospitals cause people a lot of anxiety to even attend clinical environments where there can be judgement from other people or staff ”¹³

“ three strikes and your out ”³

Participants viewed community and voluntary (sometimes referred to as third sector) services positively.

“ They show you flexibility and kindness whereas statutory services are bound by risk and procedure ”⁶

However, it was also reported that the important role that these services play is often not recognised by statutory services.

“ Statutory services aren't signposting on to third sector services ”³

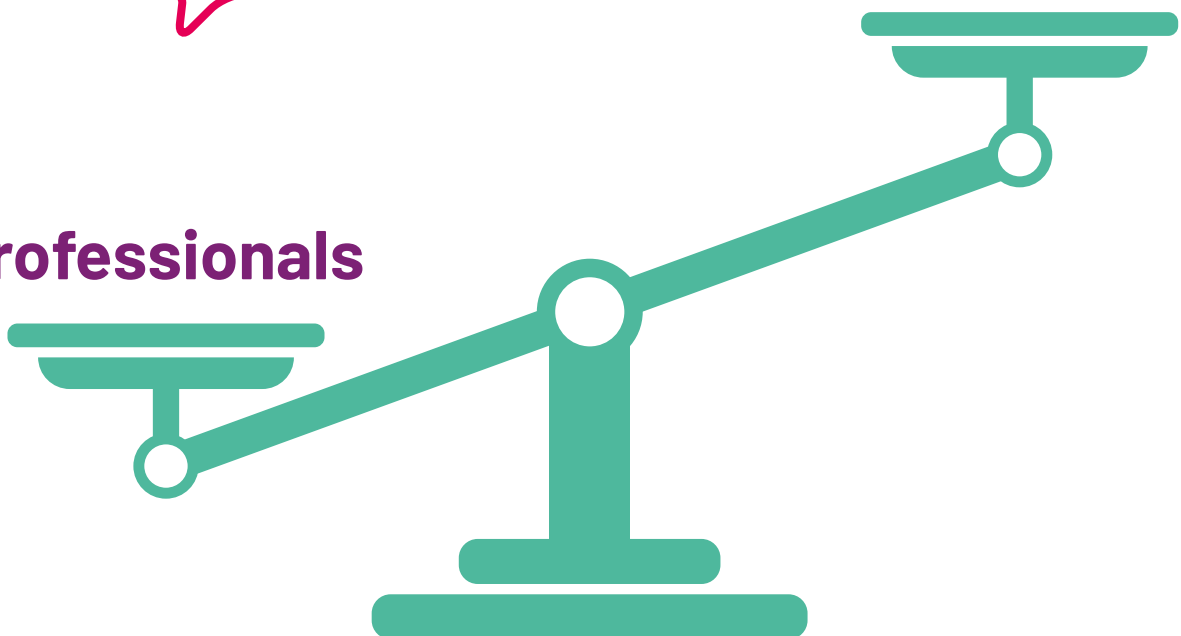


Participant examples of good practice

- Collaborative working, recovery walks, SMART recovery and community events.
- Family Support services were reported as good examples of meaningful participation.

Professionals

People



The PANEL principles note that in relation to accountability, there should be monitoring of how people's rights are being affected, as well as remedies when things go wrong.

This section presents the following themes: (i) funding (ii) service provision (including MAT Standards, Mental Health services and Criminal Justice services), (iii) workforce (iv) complaints and making suggestions for improvement and (v) monitoring and evaluation.

i. Funding

Allocation of public monies are commonly not prioritised for areas of deprivation which exacerbate long-term health issues and low life expectancy.

In deep dive discussions it was noted that at a national level the Scottish Government have progressive legislation in relation to tackling inequalities (e.g. Fairer Scotland Duty). However, it remains unclear if funding is targeted to areas disproportionately affected by inequalities.

“ ...proper funding means proper service, and staff that are well cared for and supported so that they can be compassionate ”¹⁴

The short term project funding approach to service commissioning was described as limiting availability of services that promote good health within community and justice settings.

“ We need to be brave and disinvest in what is not working. We need to really listen to what communities want to be able to build this ”¹⁵

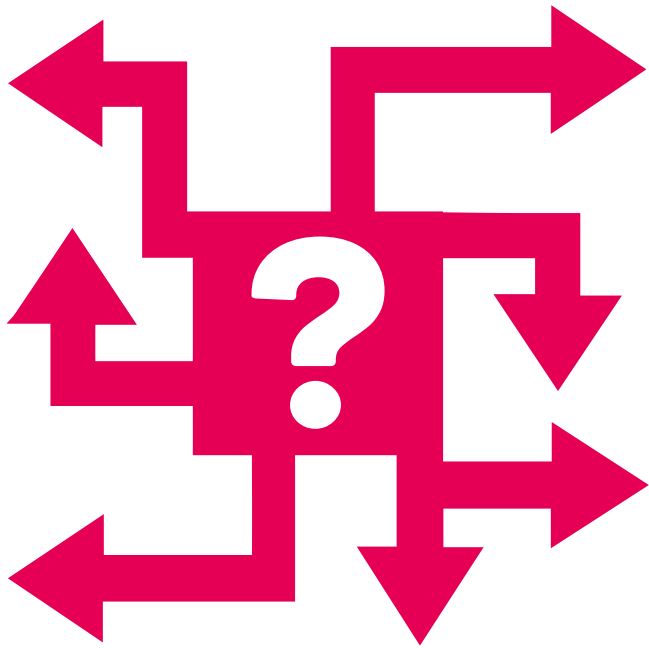
Participants note that 'justice' service funding and commissioning concentrates on 'crisis' and addressing drug related offending rather than prevention, and participants consider this as setting people up to fail:

“ We are constantly setting people up to fail rather than providing support in early adulthood, increasing diversion schemes and community resources ”¹⁶

Other funding issues reported include Local Authority budgets being separated, for example in Edinburgh there is a separation between North, South, East, West making tackling city-wide issues difficult. Treatment budgets not being prioritised for areas of deprivation which exacerbate long-term issues of drug deaths and low life expectancy.

Many services are set up to support people using opiates and they cannot easily adapt to providing care for other substances (stimulants, cannabis). Cuts to other public services e.g. youth services reduces opportunities for prevention and tackling the problem upstream.

“ Resources are just not there to meet the level of need. ”¹⁷



ii. Service Provision

It was reported that it can be difficult to find services and groups as they are not well advertised or visible, with people often relying on word of mouth and relationships for connecting to support. GPs tend to rely on the medical model and are often unaware of the range of services that exist within their own communities.

“ Sometimes it’s hard to know where to turn for help. ”¹⁸

“ Some people might not know what services are available to them, how to access these services or that they are eligible for these services. ”¹⁹

“ More promotion of services that are available would make a huge difference, such as posters in pharmacies for instance. ”²⁰

Accessing and contacting services online is available for many individuals. However, for some people affected by substance use, using the internet to access service information, or to make appointments is a challenge.

“ When people are living in difficult situations appointments don’t work - we need flexible drop ins and choice for people ”²¹

“ Digital poverty is a massive barrier – no phones, laptops, don’t know how to use etc. ”²²

The provision of virtual support for individuals has become normalised since 2020 during the Covid 19 pandemic, and this is challenging for people affected by substance use in community justice settings, with participants stating that individuals in crisis need face to face engagement.

Many participants highlighted that typical opening hours of Monday-Friday, 9-5pm, could be a significant barrier and that more out of hours services are required, e.g. 24 hour/weekend services. The importance of outreach services was also recognised to be able to ‘meet someone where they are’.

“ There is also very limited out of hours services across the board. ”²³

“ We need services that are available late at night, not just during the day. ”²⁴

Established working practices (described as silo based) limit the ability to develop continuation of care between different health and social care settings.

“ We currently are getting it wrong in trying to 'fit' the individuals to the existing services rather than the services being available, accessible and holistically available to suit the needs of the individual. ”²⁵

Participants note that when a service cannot or does not meet the needs of service users, poor attendance, or missing appointments is common, and this can be interpreted as a lack of engagement:

“ In Scotland if someone is late for a prescription appointment, they can be left without access to medication, this does not happen with other health conditions ”⁷

Participants also refer to individuals affected by substance use who fail to comply with treatment rules - being discharged is a practice that requires review.

“ Substance use is the only health condition in a community setting that you can't get access to medication at the weekend and could potentially put a person at harm ”²

Travel difficulties were frequently reported as a significant barrier to accessing support to maintain good health and visit foodbanks.

“ People cannot afford travel ”²⁶

This was even more challenging in rural and island locations.

“ Rural and island challenges, lack of public transport, location of services, “how long does it take to visit, how far away are centres, how to get there? ”⁹

However, there were several reports of good practice in relation to access:

“ Kilmarnock provide people with weekly bus passes, makes travel easier ”¹³

Medication Assisted Treatment (MAT) Standards

Participants state that Medication Assisted Treatment (MAT) Standards have made positive changes in relation to recognising their right to drug treatment and support, however the MAT Standards are not fully implemented in all community and justice settings.

“ Services are clinical and based on their needs rather than users' needs, one size does not fit all ”⁹

The emerging trend of increased cocaine use presents a challenge to existing services to provide suitable medically assisted treatment and or psychosocial interventions for all drug use patterns.

“ MAT (Standards) should be made available for all substances not just opiates ”¹⁶

Treatment and support for non-opiate substance use vary in quality and accessibility across Scotland. However there are signs of change in justice settings:

“ In some areas this is far more developed than others therefore people’s rights are not being met nationally, it’s a postcode lottery. I do think MAT standard implementation in custodial settings is changing this ”¹⁶

Mental Health Service

There are challenges in accessing mental health treatment and support for people affected by substance use. Individuals report having to meet certain conditions specifically prior to accessing treatment and support. Participants refer to a requirement to stop the use of non-prescribed medication as well as opioid substitution therapy to access mental health services.

“ Can’t get access to my Mental Health team because I’m on methadone. ”²⁷

A lack of integrated approaches between mental health and alcohol and drugs services is commonly reported.

“ Need to address policy and legislation, but also need to crack attitudinal change from service providers, particularly the dual diagnosis of mental health and addiction; people are being bounced around like pinballs in a pinball machine and then we wonder why they disengage. ”¹⁵

Criminal Justice Services

While there are reports of good practice within custody settings, this is inconsistent.

“ Medicines are fairly available in custody although the wait to be seen in police custody can be excessive, but doctors are keen to prescribe medicine to keep people in addiction safe. ”²⁸

There is a lack of equivalence of support in custody settings when compared to community service provision. Access to healthcare is described as variable, despite some improvements:

“ Within the Prison estate it depends on where you are as to what medication you receive. The fact that each prison is run by the respective NHS... makes the access to medication tricky. ”¹⁶



iii. Workforce

Primary Care services including General Practitioners (GPs) were viewed as both facilitators and gatekeepers to accessing healthcare for people affected by substance use.

GPs are often the first point of contact but can lack training in recognising substance use as a health condition.

The relationships between people affected by substance use and prescribers was largely positive, however this was not consistent throughout Scotland.

Whilst duty bearers refer to being trauma informed, participants do not consider this the same as trauma responsive.

“ Trauma informed practice is misleading – staff are trauma trained... but not actually trauma responsive... ”¹⁴

Several community conversations highlighted that staff recruitment is an issue for people accessing support for substance use within community and criminal justice settings. It is noted that knowledge of rights by staff could be improved.

“ People in criminal justice system don't know their rights – needs to be more training at national level to get rights recognised (for individuals, and for services e.g. police service, prisons) ”¹⁶

There are significant challenges in some prisons as staff are recruited on a temporary basis with an increasing reliance on bank nursing staff. This limits the ability to have a dedicated workforce trained in understanding people affected by substance use.

“ Nurses who aren't experienced or skilled to support people with SU can work in prisons, they are desperate for staff...no specialist training is required ”¹⁶

iv. Complaints

Making complaints was considered a challenging process, with a distinct lack of information on how to do this or to participate in making suggestions for improvements.

“ Staff aren't trained on resolving issues, so won't publicise pathways to raise complaints ”¹⁶

While there are forums to raise concerns, individuals engaging with services are prevented from having agency to resolve and fix personal or service delivery issues.



“ It’s one thing knowing rights are being breached but how do you actually take that to the next stage? ”⁷

It was reported that people within community and criminal justice settings are unable to challenge decisions and resolve the problem.

Complaints processes in some prisons involve having to ask prison officers for the complaint form. This is a barrier as people fear punitive consequences.

“ Challenging decisions made are treated as disruptive, and people fear reprisals if they even bother to complain ”²⁸

The fear of punitive consequences for making a complaint was also reported in the community.

“ Fear that making a complaint will affect my healthcare. ”²⁹

In addition, participants and family members report being unable to challenge decisions that affect them, particularly if they struggle with language or literacy issues.

“ Who do you complain to? ”³⁰

v. Monitoring and Evaluation

In relation to evaluation, regulation and inspection, there was a perception that the inspections/scrutiny system is very disjointed and people highlight limitations of self-reporting. Self-reported evaluation may not seek the opinions of people using services.

“ Inspections (are) required to drive up quality ”²

“ 3rd sector services are very regulated but statutory sector are not regulated in the same way or subject to the same scrutiny. ”⁶



Participant examples of good practice

- The contribution of third sector services that create time and space to build trust and engage in therapeutic relationships in community services.
- Community based hub style interventions where duty bearers deliver holistic support beside recovery communities in community settings.
- Assertive Outreach and mobile harm reduction approaches.



Non-discrimination

In the PANEL Principles, all forms of discrimination must be prohibited, prevented and eliminated. People who face the biggest barriers to realising their rights should be prioritised.

There exists a range of stereotypes that negatively label people affected by substance use, and their families who require help and support. These labels can enable discrimination and this can occur in many settings. Women affected by substance use can be described as unfit mothers, and opiate users known to services can be denied access to pain medication.

As possession of controlled substances is an offence within the Misuse of Drugs Act 1971, people affected by substance use risk a criminal record which can lead to discrimination and impact on many aspects of their lives, including jobs, and participating in wider society.

The following themes are presented:
(i) stereotypes and stigma (ii) overdose (iii) accessing medications (iv) right to privacy (v) women and children affected by substance use, and (vi) justice settings.

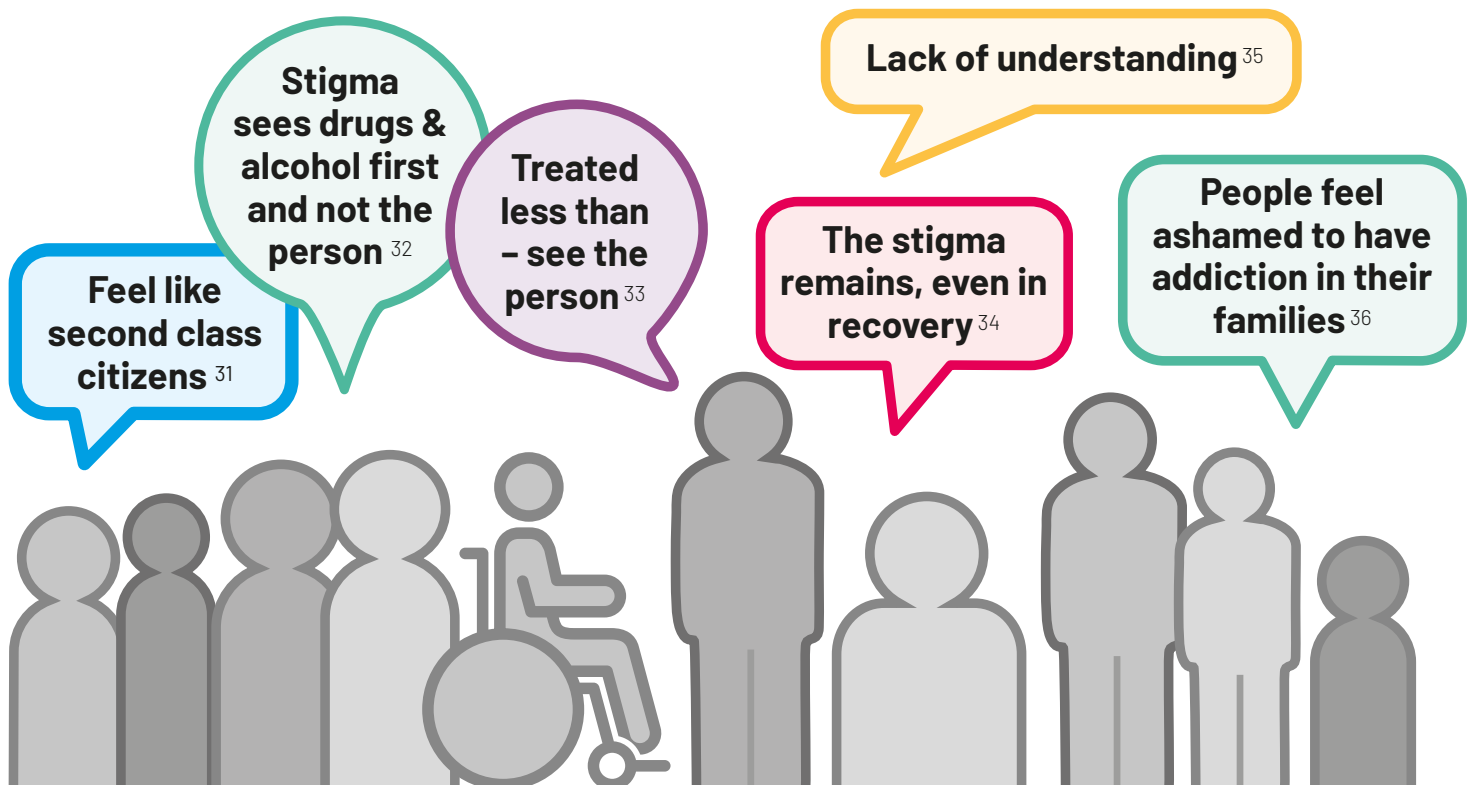
i. Stereotypes and Stigma

People affected by substance use can be negatively labelled and experience stigma and discrimination when engaging with their communities, when accessing health care and when engaging with welfare, housing, employers, and education or training providers.

“ You need to constantly ‘prove’ to services that you are in crisis to get support. ‘You need to jump through hoops like a circus performer’ ‘being told to play up to services’ to hit a trigger point where support can be accessed ”²¹

Barriers exist within wider healthcare when substance use is mentioned and people report being treated differently when this information is shared.

Participants describe class differences heightened by literacy and numeracy inequalities



that act as (perceived and actual) barriers to a full and active part in seeking information, and when in consultations and meetings.

Participants noted that attending some services is difficult because there is a perception that everyone knows where they are located, feelings of shame act as barriers to attending.

Within General Practitioner's (GPs) surgeries and other medical settings not all individuals with medical training have sufficient knowledge and expertise in recognising substance use as a health condition. People who use substances are commonly unwilling to talk to their GP about mental ill health, and report anxiety that this will involve changes to their medications. An emphasis on substance use means that things can be missed e.g. mental health, treating pain. Reporting pain, if known to be a person affected by substance use, can be perceived as drug seeking behaviour. Pain medication can be refused if a person is known to have issues with opiates.

Pharmacies were also reported to be particularly stigmatising as people regularly have to queue outside; medications, for example methadone, can be given in view of others resulting in a lack of privacy and a loss of dignity; some individuals collecting methadone are not allowed to be accompanied in pharmacies; individuals known to be affected by substance use report negative experiences when collecting prescriptions for themselves and for others. Bail conditions sometimes mean people are banned from accessing the pharmacy closest to them.

Accessing suitable accommodation to encourage behaviour change and recovery was commonly referred to as a significant challenge. Participants gave examples where they believed that housing staff did not always support applications for social housing.

“ Housing must not be dependent on abstinence – families struggle with the choice between making their loved ones homeless or having them live with them ”¹¹

“ Housing may deem a person ‘not ready’ for a tenancy. ”³⁷

Inequalities in accessing services that understand sexual identity and substance use problems were reported.

ii. Overdose

The Misuse of Drugs Act 1971 criminalises possession of controlled drugs and places those witnessing a near fatal overdose at risk of being considered to be involved in the supply of substances.

People who witness an overdose are reluctant to telephone for an ambulance for fear of being implicated in the overdose.

“ We phoned and we left ”¹⁶

Individuals in homeless accommodation who suffer overdose are moved to another room to avoid implicating others living within the premises.

“ People at the scene of an overdose are automatically questioned. ”¹⁶

Hostels and homeless accommodation providers send mixed messages by having policies for no drugs/alcohol and conducting checks for drugs whilst also providing safe needle exchange facilities.

Participants believe that long waiting time responses to overdose in the community may be due to reports of some Scottish Ambulance Service personnel being wary of attending specific community locations. Ambulances may not respond quickly because an address has been blacklisted as 'not for entry without police presence'.

iii. Accessing medications

There is a significant gap between policy and practice in relation to public health and human rights approaches to substance use.

Risk averse attitudes to OST in police custody suites limits access to medical professionals who can prescribe essential medications.

Transitions between prison estates and lack of information sharing can lead to gaps in timely access to medication.

Access to medications in justice settings can be based on judgement rather than following established treatment protocols:

“ ...When a resident requests a specific medication it is noted as ‘drug seeking behaviour’ rather than them trying to access help and support. ”¹⁶

Accessing pain relief by people affected by substance use is commonly reported as a challenge:

“ People waiting for dental treatment being given paracetamol which didn’t touch the pain but were not offered anything else as they were a registered drug addict ”²⁸

iv. Right to privacy

There is a lack of privacy reported when accessing medication within a pharmacy setting.

“ Stigma in pharmacy, no privacy when you go in for an exchange ”¹³

There were instances of people reporting being banned from chemists, and having to use ‘dirty’ needles. Also reports of chemists having separate entrances for people accessing daily methadone.

There is a general reporting of lack of information sharing that occurs in specific services. Participants also describe instances where personal and confidential information is shared without permission.

v. Women and children affected by substance use

In all health and social care settings, including those aligned with Social Work and Criminal Justice, the assessment process for people accessing support is described as a major barrier.

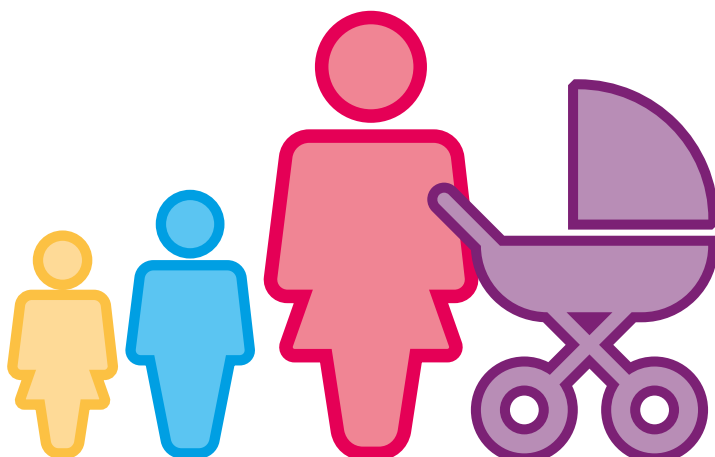
“ One key worker should be given – not several as retelling the story over again ”⁹

This is specifically the case with mothers with children who seek help in relation to substance use.

“ How many women have actually spoken out and then their children have been removed? ”¹

When they disclose they have children, a range of child protection services as duty bearers become involved.

“ Women feel scared to come forward for support and help over fear of children being removed from their care. ”²¹



A class disparity in how duty bearers engage with people affected by substance use is commonly reported in relation to women who use substances:

“ GIRFEC? It should be getting it right for every family. Need to shift the paradigm – middle class families get CAMHS, working class get social work. There is a real class disparity in how we support poor families ”¹⁴

In issues of child custody, workers struggle to respect the rights of the child, while attempting to recognise the rights of mothers and other family members.

“ Always contentious issues in family support – how do we do that with care and compassion and on a relationship basis? Work in this area can feel complicated as everyone has individual needs. Can experience high levels of conflict if people don't agree. People in recovery need to focus on themselves and their journey which can be challenging with a child ”¹⁴

Child protection also highlighted the concerns of workers, who consider prevention work essential in this area of service:

“ Early intervention would stop families going onto child protection register. The model of funding needs to change, but our care system (commissioners, public sector, Scottish Government) need guidance to help us get from crisis/chaos/insecurity to a preventative, holistic early intervention approach ”¹⁴

vi. Justice settings

Prisoners on remand, who have not been sentenced were reported as being less able to access rights to healthcare within prison settings compared to convicted prisoners.

Accessing wider services to support good health is problematic on release from prison and is believed to contribute to discriminatory practices by duty bearers.

“ Communication needs improved between prison services and support organisations...what happens in the prison seems to stay in the prison...support organisations need information to identify correct support ”¹⁶

Participants in community conversations note some positive aspects of service provision:

“ CJS are starting to ask the right questions: 'what' and (the) 'why' people are using substances and reasons for becoming substance users in the first place ”²⁸



Good practice

- Public awareness of stigma campaigns were noted as encouraging improvements; however some highlight that the efficacy of this approach is not known.



Empowerment

While there are some overlaps with this section and the right to participation section, there were discrete themes that emerged: (i) individual empowerment (ii) local decision making and policy development, and (iii) being paid for lived experience knowledge, skills and experience.

i. Individual Empowerment

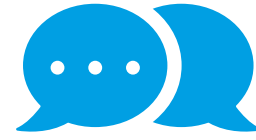
Advocacy was widely recognised for individuals and families as key to navigating the complex systems and processes and helping to uphold people’s rights.

“ Independent advocacy can help people be heard ”³⁷

In addition to a Scottish Families Advocacy Service, SFAD run a ‘My family, my rights’ program for families to develop skills and increase knowledge and understanding of their rights. This can then help families to advocate on behalf of themselves or their loved one.

In relation to self-advocacy, accessing advocacy training was considered a way to educate people about their rights so they can advocate for themselves.

“ Need to increase education so people know the right language etc and benefit from better services. ”¹⁵



ii. Local decision making and policy development

Although involvement of local people is a step in the right direction, there is a perception that LLE panels may be selected by services and or Alcohol and Drug Partnerships (ADPs) to make sure that messages communicated by them adhere to what services and ADPs require.

“ People on panels can be hand-picked. ”¹

It was reported that there are often requests for people with lived experience to consult on things but no outcomes seem to come from the discussions which take place. Additionally, it was highlighted that people need to be supported and informed in order to contribute meaningfully.

“ ...people with lived and living experiences are ‘divorced’ from mainstream service planning. If services are to be fit for people and designed with purpose, this needs to be reversed with people with experience included in decision making processes and planning across other non-addiction services and within addiction services ”¹²

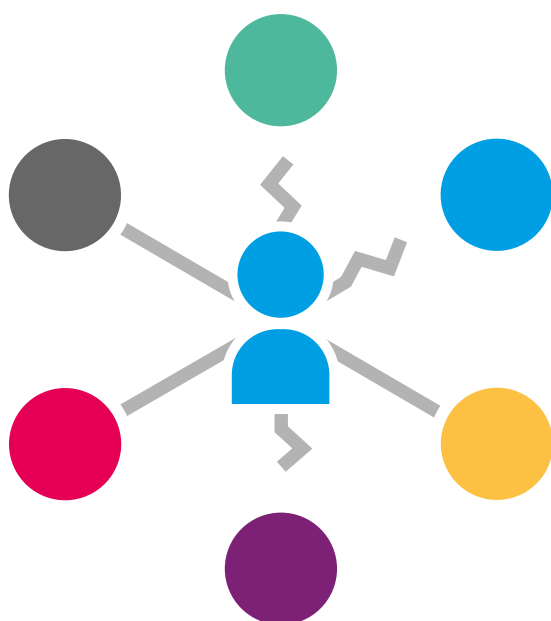
“...people with lived experience are often not offered enough development opportunities to understand what they’re being consulted on.” ³⁸

Experiences of participation were sometimes described as tokenistic and lacking in feedback of contributions made. The lack of feedback was also reported as a challenge for lived/ living experience communities being unable to actively participate as equal partners.

“Tokenistic at times due to lack of feedback loop of information – what is happening with the information shared? Has it had any impact?” ¹

The conversations gave the sense that people want to be empowered to understand their rights and therefore be able to realise them.

“About us but never without us..” ³⁹



iii. Being paid for knowledge, skills and experience

Participants highlighted a need for LLE individuals to be paid for their time to meaningfully engage in capacity building, and make contributions to local decisions that affect them.

“Incentives are important – training and being paid for time. There’s a sense of dignity in giving people money, not vouchers – not judging people for what they will spend it on.” ¹

There were conversations that noted the challenge in finding work after recovering from being affected by substance use.

“Should be considering the workforce as well. People have human rights but are being pushed into insecure work through their lived experience... We should be training people up to be lots of things, not just be support workers – should be encouraging people to have jobs in other sectors and getting practical skills” ⁴⁰

Participant Suggestions for Change

These suggestions for change and improvement are summarised from the analysis, and presented using the PANEL principles.

Participation

- Good practice examples should be advertised across Scotland to raise awareness of what meaningful participation looks like in practice.
- Advocacy should be 'opt out' rather than 'opt in' to ensure meaningful participation.
- Improve the capacity for family members to be fully involved in the care of a loved one.
- Include 'seldom heard' voices to increase participation: provide parenting groups, gender specific spaces, childcare, out of hours support, effective use of technology, and provide mother/children rehab approaches.

Accountability

- There should be improved independent regulation and inspection of all alcohol and drug services.
- All duty bearers should be mandated to ensure their workforce are appropriately trained in rights-based approaches to service delivery.
- All advocacy services providers should undertake nationally recognised vocational rights-based qualifications.



Non Discrimination and Equality

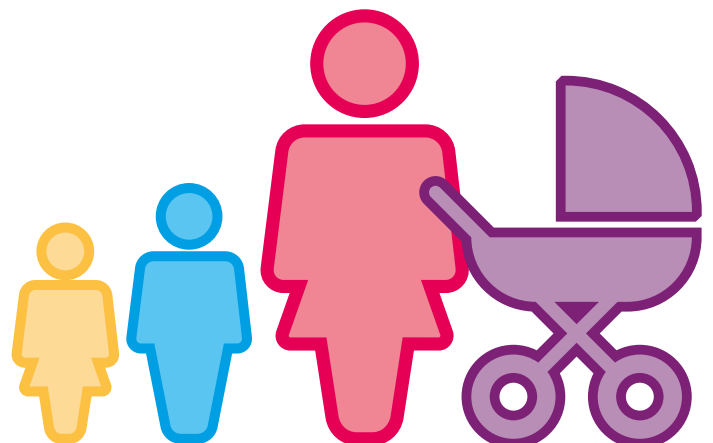
- Evaluate the impact of GIRFEC on families and women who are affected by substance use and if required review approaches are compatible with human rights approaches for women and children.
- Provide equivalence of support for people on remand within prisons.

Empowerment and Capacity Building

- The 'you said/together we did' approach should be adopted across all duty bearers in relation to offering opportunities for feedback on complaints and responding to suggestions for improvement.
- Ensure LLE panels are fully developed to ensure their views are properly acted upon.
- A welcome pack should be provided for all people seeking treatment and support for substance use to explain what is expected when they access support, and an explanation of their rights and responsibilities.

Legality

- Maximise existing legislation to target funding to address inequality, for example 'The Fairer Scotland Duty'.



Next steps

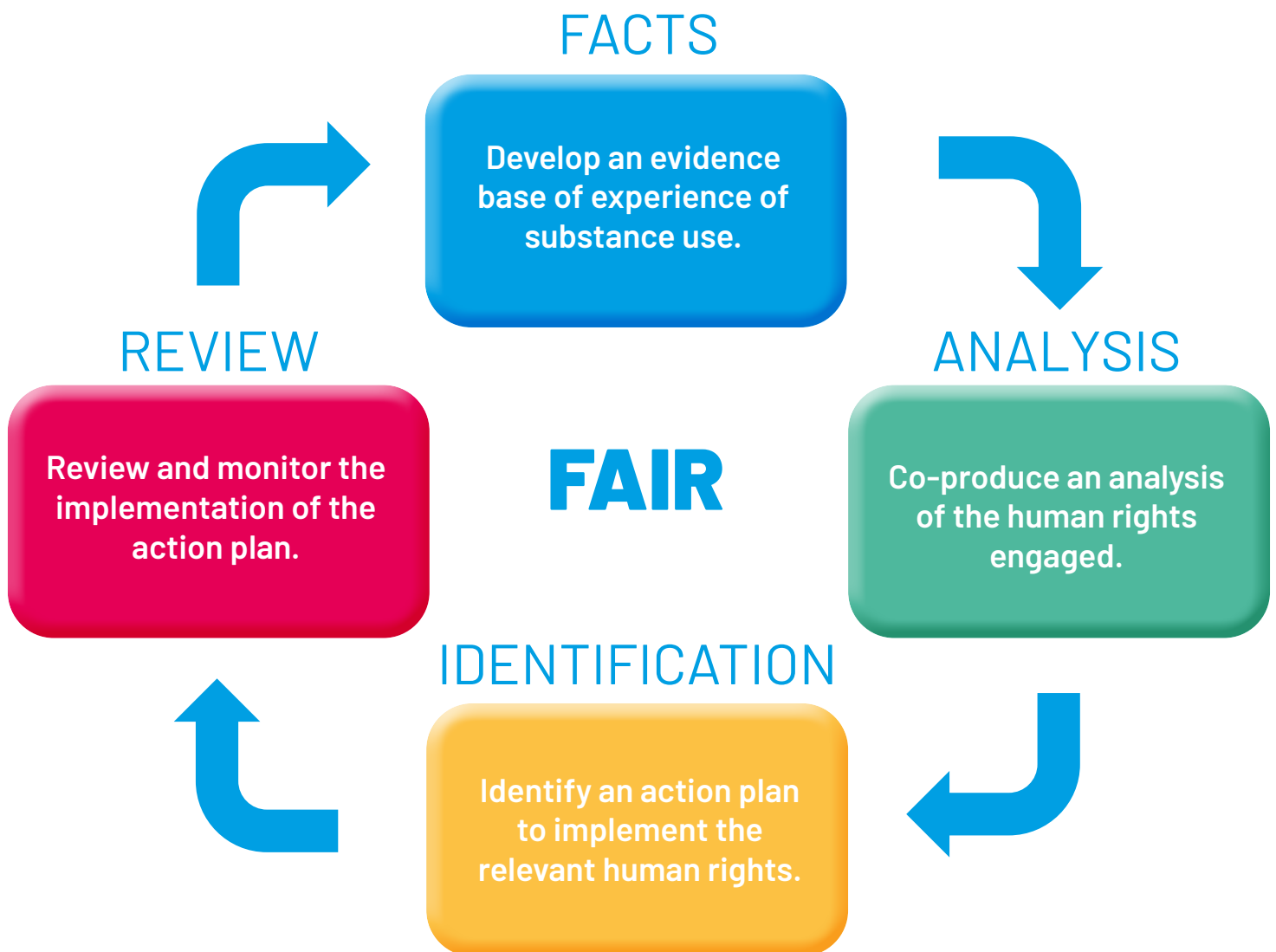
The common themes identified form the first stage of the human rights-based approach being taken by the National Collaborative to contribute towards improving and saving the lives of people affected by substance use.

This approach is outlined in its Roadmap at www.alliance-scotland.org.uk/lived-experience/engagement/national-collaborative/ and it

draws upon the human rights-based UN Panel Principles of **P**articipation, **A**ccountability, **N**on-discrimination, **E**mpowerment and **L**egality as previously referenced in this report.

The National Collaborative is applying the Panel Principles through the FAIR model process as indicated below:

The **FAIR Model** follows the process indicated below:



Acknowledgements

The National Collaborative would like to thank everyone involved in this Call for Evidence who attended sessions or responded to the survey - including all the individuals and the numerous organisations and groups, of which there are too many to list.

Special thanks go to the many organisations and groups who hosted conversations to ensure their communities could participate and have their voices heard, as listed below:

Ref No	Ref No
1. Right to Participation deep dive, Dundee	22. General rights, NC on-line session
2. Right to Health deep dive, Glasgow	23. Glasgow's Helping Heroes
3. General rights, NC session, Inverness	24. Alliance gambling forum
4. SRC National Recovery Advocacy Network	25. Alliance members
5. South Ayrshire ADP Families Group	26. LLERN Shetland
6. Family Related Rights Deep Dive, Kilmarnock	27. Patchwork Recovery Community
7. Reach	28. PING Peer Support Group, South Ayrshire
8. South Lanarkshire ADP	29. CGL West Lothian recovery service
9. Scottish Families Affected by Alcohol and Drugs (SFAD)	30. Chance 2 Change
10. Mental Health Advocacy Project	31. Bridge Recovery Café Macduff
11. SFAD Families on the Frontline Conference	32. Lomond & Argyll Advocacy Service and We Are With You
12. North East Health Alliance	33. Integrated Drug & Alcohol Recovery Team, Perth & Kinross
13. SDF Engagement Groups	34. GIVIT, South Lanarkshire
14. Corra- grant holders of National Drugs Mission funds & related	35. FASD Scotland
15. Criminal Justice Voluntary Sector Forum	36. SFAD Routes
16. Criminal Justice Related Rights deep dive, Lanarkshire	37. Right to Health - Social Determinants deep dive, Edinburgh
17. Harm Reduction Champions Network	38. SRC Lived Experience Recovery Organisation Leadership Group
18. Circle, East Lothian	39. Alcohol Focus Scotland and Recovery Coaching
19. Scottish Psychedelic Research Group	40. Cyrenians / Homelessness Network Scotland - All in for Change Team
20. Individual survey response	
21. Simon Community Women's Steering Group & Development Mentors	Advocard
	West Dunbartonshire ADP LLE panel

Glossary

ADP	Alcohol and drug partnership
CAMHS	Child and adolescent mental health services
CJS	Criminal Justice System
FAIR model	Facts, Analysis, Identification & Review
GDPR	General data protection regulation
GIRFEC	Getting it right for every child
LE	Lived Experience (of substance use)
LLE	Lived and living experience (of substance use)
MAT	Medication assisted treatment
NC	National Collaborative
OST	Opiate substitution treatment or therapy (OST), also known as ORT opiate replacement treatment or therapy.
Recovery	recovery is defined differently by people with different experiences.
SU	Substance use
Substance	alcohol and drugs
UN	United Nations

Deep Dive Workshop Questions

Right to Health

1. In Scotland, what stops people from using services and support for people affected by substance use? (including health and social care services, prevention, harm reduction, rehabilitation, recovery and other services)
2. Are these services: available, easy to find and use, good enough? If not can you tell us why? What could change to make it better?
3. Are there examples where things are being done well which could be used to help make things better?
4. Are these services delivered in a way that is fair and available for everyone who needs them? If not could you tell us about that? Is there anything that could make this better?
5. Do these services keep people's personal medical history private?
6. Do they ask for people's views and are these respected? Is the situation/treatment etc. explained in a way that people can understand and is the understanding checked? If not, what do you think could help this?
7. Are people affected by substance use able to speak about issues they find unfair (such as where the right to health is not fulfilled as it should be) and are they able to fix/resolve these? If not, what are the problems, and what do you think needs to change?

Right to health – social determinants

1. In Scotland, what stops people affected by substance use from accessing things that support good health (e.g. education, employment, leisure, adequate food and housing) in the same way as other people?
2. Are things that support good health (e.g.

education, employment, leisure, adequate food and housing): available, easy to find and use, good enough? If not can you tell us why? What could change to make it better?

3. Are services that aim to support good health delivered in a way that is non-stigmatising? If not, could you tell us about that? Is there anything that could make this better?
4. Are there examples where things are being done well which could be used to help make things better?
5. Are people affected by substance use asked for their views on decisions about the determinants of health, and are these respected? Is the situation explained in a way that people can understand? If not, what do you think could help with this?
6. Are people affected by substance use able to speak about issues they find unfair and are they able to fix/resolve these? If not, what are the problems, and what do you think needs to change?

Right to Participation

1. In Scotland, are people affected by substance use supported to meaningfully participate in decisions affecting them and to influence outcomes?
2. Are families of loved ones affected by substance use supported to meaningfully participate in decisions affecting them and to influence outcomes?
3. Are LLE Panels supported to meaningfully participate in the decision-making processes of ADPs and influence outcomes?
4. What stops people affected by substance use participating meaningfully and what could be done to make this better?
5. Are there examples of good practice that could be built upon?

6. What would help to hear from the voices that are the most seldom-heard, including women and children?
7. Where people affected by substance use are not able to meaningfully participate in decisions affecting them and to influence outcomes are they able to effectively challenge that and resolve the issue? If not, what are the problems and what do you think needs to change?

Family Related Rights

1. In Scotland, is there understanding and respect for the rights of family members and loved ones who support somebody with their substance use? If not, how not? What needs to change?
2. Are families of loved ones affected by substance use supported to meaningfully participate in and influence decisions affecting them or their loved ones?
3. Are families and loved ones affected by substance use able to take part in the development of policy and practices which affect their lives?
4. Are services and support delivered in a way that is non-stigmatising for family and loved ones?
5. If not, could you tell us about that?
6. Is there anything that could make this better?
7. Are families and loved ones able to speak about issues they find unfair and are they able to fix/resolve these?
8. If not, what are the problems, and what do you think needs to change?
9. Are there examples where things are being done well which could be used to help make things better?

Criminal Justice Rights

1. In Scotland, is there understanding and respect for the right to liberty for people affected by substance use? If not, what needs to change?
2. Are people at risk of criminal prosecution for being victim of or witness to an overdose or other injury occurring due to substance use?
3. Are controlled substances used as medicines available and accessible for people affected by substance use in custodial settings including during transition periods?
4. Do people in custody, affected by substance use, have access to health services equivalent to those available in the community? (Including access to essential medicines, harm reduction and treatment services)
5. Are substance-related health care services in prisons provided by qualified medical personnel who are specifically trained in substance treatment and harm reduction?
6. If people in custody, affected by substance use, are refused access to essential medicines, are they able to effectively challenge that decision and secure a remedy?
If not, what are the issues, and what needs to change?

Summary Report



Video Summary



Easy Read Summary



National Collaborative



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[www.alliance-scotland.org.uk/lived-experience/
engagement/national-collaborative/](http://www.alliance-scotland.org.uk/lived-experience/engagement/national-collaborative/)