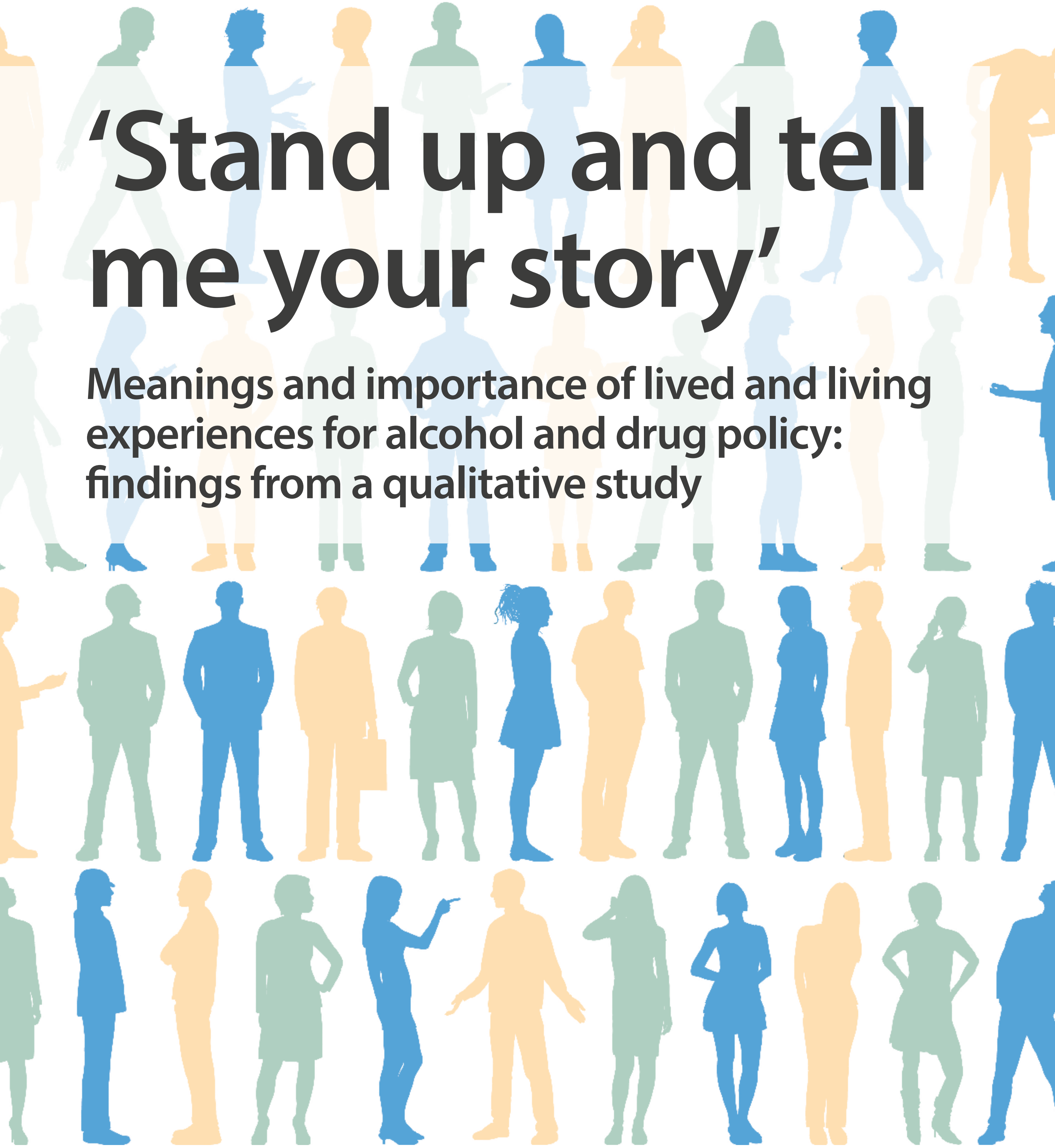


‘Stand up and tell me your story’

Meanings and importance of lived and living experiences for alcohol and drug policy: findings from a qualitative study

SHAAP
SCOTTISH HEALTH ACTION ON ALCOHOL PROBLEMS
www.shaap.org.uk

Scottish Health Action on Alcohol Problems (SHAAP) provides the authoritative medical and clinical voice on the need to reduce the impact of alcohol-related harm on the health and wellbeing of people in Scotland and the evidence-based approaches to achieve this.

SHAAP was set up in 2006 by the Scottish Medical Royal Colleges and is based at the Royal College of Physicians of Edinburgh (RCPE). SHAAP is advised by a Steering Group made up of members of the Scottish Royal Colleges, the Faculty of Public Health in Scotland and invited experts.

SHAAP works in partnership with a range of organisations in Scotland and beyond. Key partners include Alcohol Focus Scotland, the British Medical Association (BMA), the Scottish Alcohol Research Network (SARN), the Scottish Recovery Consortium, the Alcohol Health Alliance, the Institute of Alcohol Studies, Eurocare, the European Public Health Alliance (EPHA) and the World Health Organization (Europe).

‘Stand up and tell me your story’

Meanings and importance of lived and living experiences for alcohol and drug policy: findings from a qualitative study

Dr Eric Carlin, Dr Briege Nugent, Ruth Moulson MPH

February 2020

CONTENTS

1. INTRODUCTION AND OVERVIEW

This study draws on interviews carried out in 2019 with representatives of non-governmental agencies in Scotland who are concerned with supporting the development, implementation and evaluation of Scotland's 'refreshed' Alcohol Framework 2018 (Scottish Government, 2018a) and the Scottish Government Alcohol and Drugs Strategy 'Rights, Respect and Recovery' (Scottish Government, 2018b). The latter document talks about understanding and using voices of lived experience 25 times, usually but not always also utilising the term 'living experience' alongside this (20/25 mentions). The Alcohol Framework 2018 (Scottish Government, 2018a) only uses the term lived experience once, and this is when citing another publication[1]. In the literature review, we have focussed mainly on interpretations of lived experience, but we also explored the notion of living experience in our interviews with stakeholders. Our intention is to supply Government and relevant stakeholders with suggestions about how such engagement might support the development, implementation and evaluation of the Alcohol Framework 2018 and 'Rights, Respect and Recovery' (Scottish Government, 2018a, 2018b).

2. STRUCTURE OF REPORT

We will briefly describe the methods employed. We will then summarise key points from literature reviewed and draw on our analysis of thirteen semi-structured interviews with managerial level staff from seven organisations to explore:

- Meanings of lived and living experience
- What they can say to policy makers and service planners
- How narratives of lived and living experience can be captured
- How this can help to effect meaningful change

We will acknowledge the limitations of this study but then draw some conclusions, specifically thinking about the Scottish Alcohol and Drug Strategies (Scottish Government 2018a, 2018b). Finally, we will provide some recommendations as policy makers develop and implement action plans.

3. METHODS

Purposive sampling of seven organisations spanning both the drugs and alcohol field took place, with thirteen individual interviews being conducted. The organisations were Scottish Health Action on Alcohol Problems (SHAAP), Alcohol Focus Scotland, the Scottish Recovery Consortium, Scottish Families Affected by Alcohol and Drugs, LEAP (Lothian and Edinburgh Abstinence Project), CREW and the Scottish Drugs Forum. Interviewees had a good overview of the perspectives of their organisations, as well as an ability to

---

[1] Warren, F. (2016) *'What works' in drug education and prevention?* Scottish Government, Edinburgh, http://www.gov.scot/ Publications/2016/12/4388

help guide their direction. In varying ways, each of the organisations has a national remit and perspective. We are very grateful to all for generously giving their time and for their openness and honesty in sharing their perspectives.

Interviews lasted between around one hour fifteen minutes and two hours. Transcription was undertaken confidentially by a professional external service and coded using a grounded theory approach, being open and making sense of phenomena through systematic coding and recoding (Charmaz, 2006; Strauss and Corbin, 1998). Our research methods have been phenomenological, in the sense that our analysis focusses on subjective reflections by ourselves as the researchers about what we read and what we were told in interviews.

The interview schedule is presented in Appendix A and revolved around the four key areas described above. The analysis is ultimately subjective, based on the researchers' assumption of having 'a superior insight' (Travers, 2001: 114). We made personal notes after each interview, reflecting on key themes that emerged, so that the analysis would include some of our reflections on what we had been told. It was agreed with the research participants that we would take all reasonable measures not to identify individuals in our report, although the agencies would be named.

4. LITERATURE REVIEW

'Rights, Respect and Recovery' (Scottish Government, 2018b) states that the reduction of alcohol use, harm and related deaths can only be achieved by working together. The partners specified are 'people with lived and living experience, delivery partners, service providers, decision-makers, funders and the research community'. The strategy discusses lived and living experience as:

- being used to inform approaches (Scottish Government, 2018b: 4),
- being put on the same level as 'experts, supporting the development of plans to address stigma' (Scottish Government, 2018b: 19)
- enabling children and young people affected by others' alcohol and drug use to make a direct contribution to national and local developments (Scottish Government, 2018b: 43).

User involvement encapsulates a range of different ideas, from active participation at the micro-level of individual decision-making, to more macro-level involvement in service planning and evaluation as well as in the training and research arenas (Millar et al., 2015). The intention to utilise lived and living experience in 'Rights, Respect and Recovery' (Scottish Government, 2018b) appears to be far more ambitious than this, potentially opening the door to reframe how we view and respond to issues, without necessarily being constrained by historical antecedents or existing organisational structures. However, and similar to broader discussions in the academic literature (for example, McIntosh and Wright, 2018), what lived or living experience specifically means within 'Rights, Respect and Recovery' (Scottish

Government, 2018b) is open to different interpretations. The claim is made that hearing the voices of those with lived and/or living experience is central to the Scottish Government's work, to develop, design and deliver treatment and recovery services, interventions and approaches. The strategy recognises that this may lead to differences of opinion and challenging of embedded approaches in service planning, delivery and evaluation.

Lived Experience: Meanings and value

Van Manen (2004) suggests that the first systematic explication of lived experience and its relevance for the human sciences dates back to the 1980s. Sandhu (2017: 4) offers a fairly simple definition, stating that it is:

> *the experience(s) of people on whom a social issue, or combination of issues, has had a direct personal impact.*

According to Williams (1984), beliefs about the cause of illness need to be understood as part of a larger interpretative process. How people make sense of illness is within the context of their personal biographies, and in turn this must invariably be influenced by, and meshed with, the cultural values of the society in which they live (Nettleton, 2013). Illness narratives, including narratives of recovery, can contribute to an understanding of how people experience, make sense of, and incorporate their illness into their identity (Hyden, 1997). They also afford insights into the cultural and social factors that shape, or give rise to, people's experiences (Nettleton, 2013).

Arguments for the development and use of narrative inquiry come out of a view of human experience in which humans, individually and socially, lead storied lives (Connelly and Clandinin, 2006). By interpreting their past in stories, the future is also shaped. Frank (1995) suggests that there are three typical illness narratives: Restitution, whereby a sick person seeks help and recovers; Quest, whereby a person seeks for some meaning to be gained by the illness experience; and Chaos, whereby the experience seems to have no clear beginning or end. People with lived and living experiences typically will have stories that exhibit categories of each, with intersectional influences related to their social and economic contexts, as well as issues such as their gender, ethnicity and age. There is some discussion in the literature about how, in contexts such as people dealing with mental health issues – and it would be reasonable to apply this also to substance use -, lived experience might often be the same as living experience, in the sense that the problem and risk of harm never goes away. However, engagement with lived experience specifically promotes an optimism about potential recovery from what might appear to be otherwise hopeless situations (Byrne, 2017).

Bury (1982) evolved the notion of chronic illness as a biographical disruption, whereby individuals adopt either the 'Parsonian' role of being sick and submitting to help to be cured or a more interactionist perspective whereby they operate strategically to identify and manage symptoms so as to recover (Parsons, 1975). This theoretical perspective can apply to experiences of alcohol and drug harms, whether or not people identify as addicted. However, lived and living experience tend to be defined with a lack of consistency within social policy and allied disciplines, the third sector and at governmental level (McIntosh and Wright, 2018).

The real value of lived experience lies in its ability to connect people, helping others to understand and emphasising the humanity that binds us all (Chen et al., 2016), building empathy and hope (Byrne, 2017). Working with those with lived experience can provide a platform for those who are marginalised to be heard (Johnson, 2016; Neale, 2016; Nel et al., 2017; Tilikainen and Seppanen, 2017). Engaging with people with lived experience can ensure that policy making does not become victim to stereotyping and assumption making (Wright, 2012) about them. This can lead to policies that are realistic, responsive and likely to be effective (Rogotff et al., 2018).

The subjective accounts that are expressed by people with lived experience can provide 'a window into instances of the *shared typical'* (Garthwaite, 2016: 12) and flatten power disparities, widening the net of recognised expertise (Faulkner-Gurstein, 2017; Hankins, 2008; Voronka, 2016). Abbot and Wilson (2014) argue that the inclusion of lived experience can lead to innovation, inviting policy makers to 'tap into a wealth of creativity' (ibid: 9). In addition, they argue that this approach can gain public acceptance for, and understanding of, potentially controversial interventions. Lived experience is evolved knowledge from individual and collective agency, which enables reflection, engagement with other people and other knowledge, so that actions can be taken in response (Abbott and Wilson, 2014). As an example of this, a review of patients' experiences of compulsory detention highlighted the potential for co-production between people who access services, their supporters, and professionals to improve treatment (Ford et al., 2015).

Challenges

It is important to recognise some of the challenges related to engaging with people with lived experience. Voronka (2016) suggests that people who self-identify as having lived experience and who want to talk about their experiences may be privileged in having their say in policy discussions. Other marginalised and minority groups may be excluded. This raises the concern that having lived experience in ways that are useful to influence policy could unintentionally lead to stigmatisation of others. McIntosh and Wright (2018) argue that lived experience can speak to a set of sensations that are wholly individualised. As a result, there is a danger that lived experience is being appropriated to serve the interests of the most powerful groups (Novotna et al., 2013; Voronka, 2016) and also that structural inequalities may be ignored.

Chen et al. (2016) contend that those sharing their lived experience need to have distance from the experiences they describe to where they are now. They also argue that capturing lived experience requires investment in supporting individuals both to have personal resilience and an ability to present so as to challenge what might be perceived stereotypes. They (Chen et al., 2016: 284) describe a successful speaker with lived experience as someone who is:

> *ready to share their personal story, is well equipped with knowledge and skills to deliver the presentation, and is able to act as a role model to embody recovery characteristics. In other words, a speaker must actively disconfirm the stereotype of mental illnesses such as being unkempt, dangerous, incoherent or intellectually limited by demonstrating a demeanour appropriate to the situation. This requires a well-designed training program that psychologically and technically supports the speakers.*

Sandhu (2017) argues that those with lived experience are expert citizens and promotes the idea of creating a partnership of equals. However, creating what could be said to be hierarchies of knowledge could easily become barriers to inclusion for others, particularly those who feel especially marginalised, and less likely to view themselves as expert citizens. As well as this, some researchers (for example, Byrne et al., 2016) argue that professionals who hold power may not wish to share it with people with lived experience. From such perspectives, the recovery approach and the medical model are seen to be diametrically opposed, whereby the medical model supports paternalistic approaches with patients, and the recovery model collaborative partnership and shared decision-making (Byrne et al. 2016). The medical avoids taking positive risks, and continues to do for, instead of with those it supports, fostering dependence on the system (Charles et al., 1997; Gravel et al., 2006).

Abbott and Wilson (2014) suggest that what are considered to be scientific forms of knowledge tend to be prioritised over and set up in opposition to lived experience. Notwithstanding this, at the other extreme, Novotna et al. (2013) found in a study of 26 professionals working in the area of addiction in Canada with women, that they prioritised lived experience inputs above all other evidence. In a previous study, exploring contributory factors to alcohol-related deaths in Scotland, we have sought to steer a middle way, drawing together individual narratives and epidemiological evidence to support our analysis, without favouring one form of evidence over another (SHAAP, 2018). However, in research as in policy making, there is no such thing as objectivity and what is prioritised is related to broader power relations within society.

Capturing and utilising narratives

Novotna et al. (2013: 140) argue for ‘Evidence-informed decision-making (EIDM)’ as the identification, appraisal and use of the best available scientific evidence along with other factors, such as, in their case, clients’ preferences for treatment in health care decision-making. Lived experience, at its most effective, can be a way of bridging the lives and stories of individuals with the understanding of larger human and social phenomena, and be politically useful, and valuable to all, not just the interests of certain groups (Kim, 2008). This encouragement of new ways of thinking, acknowledging diversity and contested prioritisation of knowledge sources, has been described as a ‘public action approach’ (Mackintosh, 1992 cited in Abbot and Wilson, 2014: 13). Abbott and Wilson (2014) argue for the creation of spaces for active engagement where different forms of knowledge inform discussion and debate. Narrative accounts can be captured in many ways. For example, Photovoice, photography, artwork and virtual spaces afford opportunities for engagement (Hardey, 2002; Nettleton, 2013; Reid and Alonso, 2018).

Murinas (2017: 1) argues that,

> *Sometimes people with lived experience have to get this done themselves, because the organisations they want to get involved with don't believe in them. There can be a lot of fear, people questioning whether service users know what they're talking about. Well, yes they do. They're on the end of these decisions and live them every day.*

Barriers to engagement of people with lived experience can include lack of information, financial and time costs, concerns over notions of representativeness and resistance to the idea of users as experts (Tait and Lester, 2005). Sandhu (2017) challenges this and makes the case that policy makers need to rebuild systems and structures around lived experience expertise, to radically rethink, revise and reform approaches, practices and cultures. If the intention is honestly to utilise lived experience to improve policy and/or services, there needs to be a genuine and supportive organisational culture (Morgan and Lawson, 2015). Bee et al. (2015) also note that the values and interpersonal skills of individual practitioners can facilitate successful engagement. Employment of people with lived experience can also be beneficial in supporting cultural change within and beyond organisations (Griffiths and Hancock-Johnston, 2017). White et al. (2017) emphasise the need for clarity in knowing how much you can ask from people with lived experience, as well as ensuring that they are protected in the sharing process.

Health contexts of lived experience

Increasingly, in a range of health-related areas, advocates have argued that having the voices of lived experience inform service development is important. For example, Dy et al. (2017) describe patients with experience of lung cancer as being on a journey of wanting to 'Live, Learn and Pass it on', with 'Live' relating to their own determination to do more than just survive, 'Learn' describing their quest for knowledge, empowerment, and skills, and 'Pass it on' describing wanting to make a difference through guiding others, building awareness, and community support. They argue that lung cancer survivor–advocates can provide crucially important perspectives that can inform the shaping of support services that improve people's quality of life, including involving them in shared decision-making.

In the area of mental health, the importance of using people with lived experience to inform service development has grown over several decades, growing out of earlier discourses that emphasised service user involvement, which is a more limited concept. Over several decades service user involvement in mental health was born out of anger by advocates against the biomedical model, psychiatry and institutions (Millar et al. 2015). This approach recognises that everyone has assets that they can bring (Walker et al., 2014: 134), with service users being ‘more than a mental patient’ and service providers being ‘more than a mental health practitioner’. Millar et al., (2015) argue that this involvement constantly re-educates policy makers and service providers about the uniqueness of users and validates a person-centred approach. However, even service user involvement in policy development, and/or in influencing service development has been limited in the mental health context (Bee et al., 2015); Tait and Lester, 2005). Stigmatising attitudes continue. It would be reasonable to theorise that people with substance-related problems, brought in to share their lived experience would run the risk of being similarly labelled by their illness.

Drugs and Alcohol Lived Experience

Williams (1984) discusses narrative reconstruction of accounts of chronic illness. If we consider drug and/or alcohol-related problems as symptomatic of an illness, people with lived experience will undertake a cognitive organisation (Williams, 1984) of the meanings of their illness, as well as reconstructing accounts to explain the genesis of the problems that they experienced and their recovery. However, Darke and Torok (2013) highlight the under-acknowledgement of lived experience from individuals with substance-related issues in shaping current policy debates. Unlike policy discussions surrounding mental health, lived experience from individuals with substance-related issues still is yet to be fully appreciated as valuable in planning acceptable drug and alcohol treatment programmes, and in helping to better understand the social context which surrounds one’s substance problem (Zakrzewski and Hector, 2004).

Goffman (1963) describes the phenomenon and lived experience of stigma as perceiving others or oneself as different, tainted, and leading to what he describes as a disgraced sense of identity. People with lived and/or living experience of alcohol and/or drugs problems experience significant stigma and a sense of personal shame (Lancaster *et al*., 2015; Room, 2005). This stigma can both mask and define individuals’ identities as ‘treatment users’ or ‘addicts’ as opposed to other health-related discourses where individuals are labelled as ‘as person who *has* cancer, or the cold’ (Lancaster *et al*., 2015). Stigmatisation of problem drug users is common, not only among the general public, but also within healthcare settings and pharmacies, creating barriers to accessing services and treatment (Lloyd 2013; Treloar and Rhodes, 2009). The way policies are created also position and identify individuals in a certain way within society (Lancaster *et al*., 2015). For example, the criminalisation of illicit drug use means they are labelled as ‘deviant’ and ‘criminal’. Parker and Aggleton (2003) argue that stigma can act as a form of symbolic violence which is internalised by vulnerable groups, can facilitate ‘risky’ behaviour and can reinforce the acceptance of risk.

In countering these situations, telling personal stories can be beneficial for individuals, as well as for policy and service development. Zakrzewski and Hector (2009) conducted research into the lived experience of members of Alcoholics Anonymous. They found that supporting individuals to tell their stories and experiences with alcohol helped them move towards recovery. Lived experience can also help in assessing the quality, acceptability and accessibility of alcohol and drug services and can also be used as a way of introducing and exploring new issues about which researchers and policy makers may not be aware (McAuley, Munro and Taylor, 2018). For example, in Collins's (2016) qualitative research examining recovery amongst individuals with lived experience of homelessness and alcohol use disorders, they found that participants valued services for reasons unintended by providers. These findings resulted in services tailoring their programmes to better fit the needs of individuals, which would not have been possible without gaining the perspective of individuals with lived experience.

Conclusion

In summary, the literature emphasises the value of lived experience, but also that what constitutes lived and living experience is ill-defined. Overall, it is clear from research that engaging with lived experience can connect people, build empathy, hope, flatten power disparities, promote inclusion, innovation and produce responsive and reflective policy. Engaging with lived experience has the potential to improve the quality of current services and policy. This approach widens the net of experts, promoting taking positive risks and doing with rather than for those who have lived and living experience.

5. ANALYSIS OF INTERVIEWS

This section presents the analysis of 13 semi-structured interviews carried out between February and April 2019 with representatives from national organisations that work in the field of drugs and alcohol in Scotland.

RESEARCH QUESTION 1: WHAT DO WE MEAN/UNDERSTAND BY LIVED EXPERIENCE?

Interviewees tended to have a vague recollection of where and when they had first heard the term lived experience. Some suggested that it was a recent idea, others that it originated in the 1990s, possibly connected to mental health and/or criminal justice contexts. It was argued that the Scottish Government is probably unclear itself about what it means.

> *I don't think they (the Scottish Government) know. Well, you know, I'm being blunt but I really don't think they know. I think it is back to the…it's the term of the moment…so much of the strategy reads like that, it's the right language…that works to our advantage in a way because we help them…elaborate what it means in a meaningful way. (P1)*

All people felt that the stated centrality in 'Rights, Respect and Recovery' (Scottish Government, 2018b) is a positive step, supported by good intentions to promote a rights-based approach.

Who has lived experience?

As indicated in the literature (Chen et al., 2016), several interviewees suggested that lived experience entailed having some distance between substance use that was experienced as harmful and one's current situation.

> *It means people who have experience of being addicted either to alcohol or drugs, and that they hopefully are in recovery and bringing themselves and their knowledge of how they recovered, to help others who are searching for recovery. (P3)*

All participants argued that lived experience can usefully draw on personal accounts in constructive and purposeful ways to set strategic priorities. However, as indicated in the literature (Voronka, 2016), some people urged caution in prioritising those who self-define as having lived experience, with the potential that others may be excluded.

> *I think the danger is that we end up with people who are used to, are confident about taking part in consultation, and I think the danger is that, you know, we could be tempted to go to the same people all the time and end up with an echo chamber. (P11)*

Some interviewees were concerned that lived experience could be used to pit people against each other, such as those in recovery and those not, those abstinent, those not, medical professionals versus those in recovery. It was also felt that it is important to recognise that different individuals have different experiences, and that capturing one person's lived experience may not necessarily imply representativeness of a broader population.

> *People are given extra credibility because of their lived experience or only they can have a view. And I feel that's not always that helpful because actually, we all bring experience and we all bring knowledge and expertise and there shouldn't be a hierarchy. (P5)*

Several interviewees were concerned that accounts of lived experience might be skewed by an over-emphasis on hearing extreme stories, from people who are often abstinent. It was felt that policy based on this will be imbalanced. It was suggested that, for some, lived experience could become an exclusive label, with hierarchies being created, whereby abstainers were considered as 'better than well', and certainly better than those who are not deemed to be in recovery.

Some people did, however, argue strongly that it was important to seek the views of people who continue to use alcohol and/or drugs in harmful or hazardous ways and who do not self-define as being in recovery.

> *It's about that voice, that missing voice, which is people who are living and experiencing these issues in relation to services, or not services because 60 per cent aren't accessing those services. (P7)*

> *They could be in the middle of it…so I suppose it's a spectrum, depending on where people are in the process. And it could be…I'm thinking about this context, but in a kind of more coalface treatment service, people with lived experience might be people with experience, maybe drug users, people with experience of using drugs could be lived experience…we were talking about vague terms. Recovery itself is poorly defined or at least multiply defined, so the answer to your question is no, I don't think you need to be in recovery to have lived experience. (P9)*

Some interviewees also argued that there are differences between lived experience of legal and illegal substances:

> *I think with the drugs it's difficult because drug dealers will really pursue you and your whole network of friends are maybe still involved in that and so people do reinvent themselves, don't they, and get this whole new network of friends or no friends. But with alcohol, there's something about the fact it's absolutely everywhere, every day. Even if you stay in the house, you can't avoid it because it's on the telly and, you know, just the sort of everyday drinking in dramas and soaps. You know what I mean? It's absolutely everywhere. So, very difficult to avoid. (P5)*

Alcohol is used by the majority of Scots, whereas drug use is still a minority activity. One person suggested that hearing the narratives of people with lived experience was especially important for people, perhaps the majority, who are able to consume alcohol without any seriously harmful consequences:

> *People go, well I drink, I haven't…never done that. You know, I don't have…you know, I drink socially, so how could somebody end up like that, you know. (P9)*

It was also suggested that prioritising the views of people defined as having lived experience defies the fact that alcohol (and possibly drugs) affects everyone in Scottish society. The entire community, not just those who self-define as having lived experience needs to be engaged in agreeing strategic priorities, including for prevention and early intervention:

> *There's no reason why we can't invite people across the spectrum of lived experience or even just members of the public as well, why don't we speak to people who haven't necessarily ever touched drugs and ask them what they think as well, because we're all part of a community. (P11)*

RESEARCH QUESTION 2: WHAT DOES LIVED EXPERIENCE TELL US AND WHY IS IT USEFUL?

All interviewees agreed that including lived experience in policy making widens the definition of 'expert', helping to shape policies and services that can be realistic and responsive, meeting people's needs (Nel et al., 2017). This brings insights into the lives of others and in some cases challenges pre-conceived notions.

> *I think until you actually engage with it and are prepared to listen to what could potentially be quite difficult stuff, and even the natural thing is to potentially be a bit defensive – and I think that's why, as I said, there needs to be the real commitment…so this isn't tokenistic…you know, we kind of need to speak to these people because we kind of have to and actually these people have fundamental insights that are really valuable to us. (P2)*

Interviewees were asked if there was an expiry date on lived experience. There were differences of opinion on this. Several argued that, in relation to policy making, the stage at which the person is at in their lives, and the context of their story should be taken into account.

> *I don't think it necessarily has an expiry date, but I think if we're going to do intelligent policymaking, we should be putting the lived experience into context and we should be evaluating it for what it is. So if someone can tell us where they are now compared to 20 years ago, if they can tell us the things that helped them get to where they are now, because obviously if they're having that conversation with us, hopefully that means something is going really right. But at the same time if somebody is in the middle of a drug crisis at this point in time or has just come out of treatment, they will give us something slightly different. So I think it's important to listen to everybody, but to evaluate the input based on context. (P11)*

All interviewees agreed that the evidence gathered from lived experience needs to be weighted alongside other evidence (Novotna et al., 2013).

> *I suppose that's always the risk isn't it, like...around the table at that recovery event where somebody is, like, actually quite angry about another type of service and another type of approach. And I suppose that's the kind of role of the slightly more dispassionate advocate or researcher is to be able to kind of step back from that and go, okay, I understand why somebody might say that but I don't think that that should necessarily go, right, well, we're cancelling that service because this one person thinks that that's inappropriate. (P1*)
>
> *I would say all evidence is treated with value and interrogated just the way that any other evidence is interrogated. (P7)*

Some interviewees referred to SHAAP's previous investigation into contributory factors to alcohol-related deaths in Scotland (SHAAP, 2018) as providing a useful template by presenting lived and living experience narratives as equivalent evidence to epidemiological research in providing evidence to formulate conclusions and recommendations. Several interviewees suggested that the Scottish Recovery Consortium provides a useful platform to support the engagement of people with lived experience in policy discussions, including those not engaged with services. However, the entry routes and the responsibility for advocacy should not be limited to one organisation. Policy makers need to gather lived experience accounts from different people in different contexts as part of ongoing conversations; however, this could have substantial resource implications.

> *So, I think that's part of it. Not giving it to one organisation to sort of...'Right, you're lived experience, everybody else is other' stuff. And just by keeping a whole process of engagement all of the time. So, the people who develop policies, I'm thinking about at government level, they need to be a lot more out and about, they need to be engaging with all of this stuff all of the time, not just occasionally dipping in. (P5)*

RESEARCH QUESTION 3: HOW CAN WE CAPTURE LIVED EXPERIENCE NARRATIVES?

All respondents felt that the process of capturing narratives was challenging. Some interviewees argued that a fundamental barrier to capturing lived experience narratives can be that health professionals, especially doctors, can be unwilling to consider these as useful evidence to inform decision-making (Byrne et al., 2016).

> *The scientific paradigm, it's such a narrow view of science, such a narrow view of what's valid, such a narrow view of the evidence-base. And I think that's the other thing as well, that's our challenge as people who are coming from that sort of lived experience background, is we're saying, well hang on, these things are important. Emotion, love, all those things are important. You can't build a system that doesn't have those things in them. (P7)*

> *My experience of professionals is, they fall broadly into two camps when lived experience is mentioned: Some people recognise the value of it in a professional setting and other people are terrified of it, because they think, well, I can't ever learn this, and it somehow devalues me…I'm talking about that vested interest, rigidity of thinking, unwillingness to accept new information, that I think is the biggest barrier. (P13)*

It was also suggested that the emphasis on lived experience could make people feel pressurised by those who self-define as being in recovery to share personal experiences with others when they do not want to do so.

> *I wouldn't want it to get to the point where people would feel obliged that they have to be outed for having lived experience as well I think, and that's a bit of a strange kind of spectrum. (P4)*

Time and again, it was stressed that, for lived experience to be valued, understood and taken on board, it is crucial that all parties approach the process with openness (Abbot and Wilson, 2014), and also respect one another and the knowledge they bring.

> *I think the culture, the dominant culture in the NHS is very, very hierarchical…It is interesting those hierarchies though because actually if we're being serious about this, you need to just let all that go…But some peoples' egos are a little bit too fragile or some people have had to fight to where they get, and if people are in that culture where you have to sort of establish yourself in a hierarchy, it's very difficult to think outside that box. (P12)*

One person expanded the discussion to suggest that engaging with lived experience improves scientific rigour by including additional, highly relevant evidence.

> *I think that, like in many fields, we learn something, we learn about models, we learn theories, we put them into practice, and then something new comes along. Now, true scientists are able to accept the new information and then alter their stance accordingly. A lot of people aren't and they feel threatened by that, and so they don't want new information to get in the way of a good assessment. (P13)*

Even within what is widely considered to be the recovery community, there are many intersecting and dynamic relationships between individuals and across populations (Vrady et al., 2015). Some of our interviewees suggested that those who offered themselves to provide input from lived experience perspectives could be exploited. Interviewees reflected on their experience of people with lived experience being brought into meetings with professionals, in an intimidating atmosphere, to tell their story, listened to politely as they emptied their soul, asked to leave the room and then promptly ignored.

> *When people say they're hearing their stories of people in recovery, they mean, 'Stand up and tell me your story'. And what we do is, we go,*
>
> > *'That's a very interesting story. Actually I found that quite moving.' And it is very enlightening. Thank you very much. If you'd just like to leave the room now and we'll get on with our business.*
>
> *But what actually happens is, these people who apparently have this massive insight are then packed off back to wherever they came from, somewhere in the West of Scotland and he goes back to St Andrews House or wherever he works and you think, well what actually happened, what was the communication there? Where, who was empowered by that? And there's a whole class element in this as you'll appreciate, where people don't want to have complex conversations with people who've got a very different experience of formal education and/or have come from a very different postcode. (P9)*
>
> *It's been a problematic thing, I think, for governmental policymakers to*

> *try and involve people meaningfully. One, you've only got one representative of a huge population of experience and recovery, different sorts of recovery, two, the stage that they're at, it might be too much for them, and my experience of sitting in rooms with people that have been brought in for lived experience has not been great, particularly because they're not familiar with the sort of structure of meetings, how meetings work, and they're certainly intimidated by the professionals in the room…So that's a real problem, I think, because it's tokenism. (P10)*

In order to make engagement with lived experience more meaningful and ethical, interviewees emphasised the importance of providing support, with preparation including making participants fully congruent with what is going to happen and how their contribution should be used. One person argued that someone's 'whole story' rarely has to be shared and it would be better if people were directed to decide for themselves what is relevant to inform the specific issues being discussed. The well-being of individuals is paramount, so that they do not get 'burnt out', which could potentially put them at risk of health harms, including relapse.

> *So, there's something about that and again, it's getting back to these people, the people that were repeatedly put on a pedestal and were asked to share their story. What is that actually doing to people's psyche and how they're processing what's happened? (P5)*

Several interviewees emphasised the need to hear the voices of all people in communities, some argued that special efforts were required to enable the most marginalised people to be included.

> *Often it's people who are most isolated or marginalised who we're not bringing into the conversation. So it's about actively making the investment of time and effort to seek out voices who don't normally get an opportunity to be heard, but whose experience is kind of vital if we're going to ensure that we're meeting the currently unmet need, or we're tackling the currently unaddressed problems. (P1)*

> *Unless we've got a really wide pool of individuals from a variety of different experiences who've used different drugs, who've used different services or not used services, there are loads and loads of people who recover from drug use, whether it's problematic or recreation drug use that's got out of control, there are loads of people who recover on their own. So we need to speak to them as well, and they're much harder to engage with because if they don't belong to a specific recovery community or a fellowship group, it's not going to be as easy to engage with them, they're not necessarily going to feel as safe coming to an event with other people from their networks. And they may not want to be identified as well. (P11)*

RESEARCH QUESTION 4: HOW CAN THESE NARRATIVES EFFECT MEANINGFUL CHANGE?

All interviewees felt that lived experience can effect meaningful change, if there is openness and consistent commitment to the process, including monitoring and evaluating processes and outcomes.

Interviewees also argued that inclusion of a range of perspectives, not just people who have had fairly extreme experiences, could usefully move the conversation beyond a discussion of crisis services and towards prevention. Working in this way can help create a culture of openness, enabling all sides to reduce professional barriers and to recognise common humanity.

> *For me when I go to some of these government civil service things, the people that I see in that meeting are completely bloody different to the people I know outside of that meeting. So is there something going on in our definition of professionalism...And it means that you can't be human…I hate to tell you this – but we're all actually human beings. We're all emotional and stuff and it's not bad… And I think that's probably why we have a lot of issues, is because of this strange measure of professionalism. (P7)*

Lived experience can bring people together, closing the distance between 'them' and 'us', building empathy, understanding and compassion.

> *The difference between that lived experience and the public is the public don't understand that and a large number of the public – and this is part of the problem we face in terms of stigma…those of us that have not been there, some of the…us struggle to understand that, you know, dependency (P9)*
>
> *If we want to make an impact, we have to be radical. I'm very, very big on social networks as a way of reducing problem severity. (P10)*

Including a broad spectrum of voices in policy making could also help shape and guide the research agenda.

> *Because if you're only designing those questions and formulating those issues from a more removed perspective, then you might be asking the wrong things or focusing on the wrong things. (P1)*

Engaging with lived experience could influence public discourse in Scotland to question a culture that is so focussed on alcohol use as a norm. It could also help to understand and respond to emerging issues, such as the development of new psychoactive substances, the problematic use of stimulants and new ways of marketing illegal drugs.

It was observed that those with lived experience are often strong advocates for change; passionate, driven and 'doers'.

> *I don't want anybody who's starting out on their journey now or coming to the realisation that they have problematic substance misuse to ever have to go through some of the situations that I and my friends and people I love and care about have been through. (P7)*

One respondent felt that as well as listening to people with lived experience, they should take the lead in policy making.

> *I think it's very useful, but I think it's really important to define it clearly and to problematise it and think about the relationships of power and think about what would be a token effort at listening to lived experience and what would actually be giving power to people with lived experience and letting them lead at the other end as well. (P11)*

As discussed in the literature review, this points to the idea of a public action approach, so that there is ongoing dialogue between policy makers and all parties.

> *I guess what I think, is that yeah, ultimately, the civil servant who's employed to implement the strategy, is the person who makes the call on this, but it should be informed by those kind of interactions that should be going on all the time, and there ought to be some way of making sure that you haven't just got somebody sitting in St Andrew's House, writing something and not being connected. (P6)*

Ultimately, engaging with lived experience in policy making, recognising and prioritising the diversity and complexity of voices and accounts, could help the whole of society, communities, and have revolutionary potential.

> *Actually this is about making it better for everybody. This isn't about making it better for people with drug and alcohol problems or their families or whatever. The fact is our services are failing, and there must be…it can't be beyond the wit of all of us to bring all those experiences together and say, what might it look like if it was a little bit better? And we know those things. We've seen an improvement in the last ten years but it's been fought. We've had to fight to get screens taken down in waiting rooms. We've had to fight for all these tiny, little things. And no-one is saying, we expect our voices to change everything. But listen to us, and if you think it's pants, fair enough, but listen to us first, and equally we will listen to you. (P7)*

> *I think as well that lived experience is going to be broad, it's going to be diverse, it's going to challenge a lot of the things that have taken quite a long time to come into our collective thinking…But that's the work, isn't it, it's the complexity and we shouldn't shy away from complexity because unless we engage with it properly we're never going to come out with something that's actually effective. (P11)*

6. LIMITATIONS OF THIS STUDY

In undertaking this review, we are conscious of its limitations, given that it draws on views from a small number of individuals in agencies with a national focus, which may or may not include people with lived or living experience.

We did not have the capacity at this stage to undertake research with members of Twelve-Step agencies or people who used services which support recovery from drugs or alcohol problems.

As well as this, agencies with more of a focus on alcohol were overly represented and the discussions focussed more on alcohol than on illegal drugs.

We reached a degree of consensus in understanding the importance of engaging with lived experience. Having recognised that one has had a significant problem with alcohol and/or drugs and being engaged in something that could be deemed to be a recovery process, seems to be central to the definition. However, for at least some of these interviewees, what is meant by living experience, whether it is different from lived experience, whether it is useful for policy making and if so, in what ways, was contested.

Our recommendations therefore relate to engaging with lived experience, with a suggestion that further work needs to be done to interrogate meanings and potential usefulness of living narratives.

7. CONCLUSIONS

The fact that lived and living experience are mentioned in the Scottish Government Alcohol and Drug strategies (Scottish Government 2018a; 2018b) is a positive step. This review highlights the value of lived experience as a human rights approach to policy making, gaining meaningful insights into lives, the pain faced, and bring to the fore the impact of structures and environments in a way that may otherwise remain hidden. It brings to light the uniqueness of voices, emphasising humanity, to deepen understanding, and in this context to change and develop policies, services, environments and structures accordingly.

Capturing narratives is challenging. As well as hearing from those who are part of networks and recovery communities, i.e. people with lived experience, policy makers and planners need to engage with the broader population, including people who might be defined as having living experience, i.e. with the problems continuing, whether they recognise this or not.

Policy makers and planners need to ensure that those with lived experience with whom they engage are well supported. The sharing of stories should be purposeful. Their perspectives should genuinely be listened to and seriously considered, for the right reasons, and without tokenism.

The inclusion of lived experience in policy development, implementation and evaluation can help us examine environments and how these can be changed to support effective prevention and support for recovery.

Policy should be constantly responsive and dynamic to needs and learning. If taken seriously, lived experience could lead to a radical rethinking, if not an overhaul of current systems and structures. A public action approach is advocated for here in policy making, that acknowledges diversity and contestation of knowledge and is committed to shifting power structures where required.

One thing that becomes apparent from this study is that positioning lived experience to effect meaningful change requires bravery, not just from those telling their stories but also from those who are listening.

8. RECOMMENDATIONS

OVERALL AMBITION

To engage at all levels of policy making and implementation with people with lived experience of alcohol and drug problems to co-produce plans and embed actions that prioritise prevention and support recovery.

RECOMMENDATION ONE

The Scottish Government should make a meaningful plan to implement its commitments in relation to engaging with lived and living experience. This should include:

- Allocating a named lead officer at senior level in Government and tasking this officer with establishing a fully costed action plan that will:
- Define what the Government means by lived and living experience, with a commitment to principles of co-production.
- Establish a plan for engagement with measurable outcomes to bring people with lived and living experience into policy planning, implementation and evaluation at national, regional and local levels.
- Ensure that the plan includes support for people engaged in the process, encouraging co-production and innovative approaches that draw on existing evidence-based approaches and also supports the emergence of new evidence to shape the future.
- Include in the plan a strategy across all areas of Government for gathering input from the wider population, including families, people who may be affected by drug or alcohol use (their own or others'), but are not in recovery and young people.
- Establish a time frame within which the Scottish Government will lay out its vision about how lived experience will be defined, utilised and supported, with responsibilities, engagement plans and monitoring and evaluation clearly defined.
- Include plans for using new and emerging technology to engage with people with lived experience and to co-produce plans with them.

RECOMMENDATION TWO

The agencies involved in this review should convene a ‘reflect and learn’ seminar to explore these issues further, including with people with lived experience, to make recommendations to Government about meaningful ways forward.

RECOMMENDATION THREE

The Scottish Alcohol Research Network (SARN) and the Scottish Drug Research Network (SDRN), or other relevant research-focussed bodies should be tasked with establishing a research plan to propose to the Scottish Government to:

- Clarify issues that we have identified as remaining unclear, e.g. living experience and how to engage with it and how to weight different sources of evidence
- Synthesise evidence of best practice
- Find out more from people with lived experience in Scotland.

RECOMMENDATION FOUR

Alcohol and Drug Partnerships should be encouraged and supported to develop policies and practices across the communities for which they are responsible to engage with lived experience as a core ‘modus operandi’ embedded throughout systems. Their annual reports to Government should be required to demonstrate this, as well as providing evidence of what has changed as a result.

REFERENCES

Abbot, D. and Wilson, G. (2014) Climate change: lived experience, policy and public action, *International Journal of Climate Change Strategies and Management,* 6(1): 5-18.

An Roinn Slainte, Department of Health (2017) Reducing Harm, Supporting recovery. An Roinn Slainte, Department of Health: Dublin.

Bee, P. Brooks, H. Fraser, C. and Lovell, K. (2015) Professional perspectives on service users and care involvement in mental health care planning. *International Journal of Nursing Studies*. 52: 1834-1835.

Brady, G. Lowe, P. and Olin Lauritzen, S. (2015) Children, health and well-being: policy debates and lived experience. *Sociology of health and illness monographs; Vol. 37, No. 2.* Wiley Blackwell.

Brown, K. (2017). The governance of vulnerability: Regulation, support and social divisions in action. *The International Journal of Sociology and Social Policy, 37*(11-12), 667-682.

Byrne, L. (2017) Promoting Lived Experience Perspective: Discussion paper prepared for the Queensland Mental Health Commission (Available online).

Byrne, L., Happell, B., & Reid-Searl, K. (2016). Lived experience practitioners and the medical model: World's colliding? *Journal of Mental Health, 25*(3), 217.

Charles *C*. Amiram G. and Whelan T. (1997) Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Social Science and Medicine*, 44(5):681-92.

Charmaz, K. (2006) *Constructing Grounded Theory.* London: Sage Publications.

Chen, S., Koller, M., Krupa, T., & Stuart, H. (2016) Contact in the classroom: Developing a program model for youth mental health contact-based anti-stigma education. *Community Mental Health Journal, 52*(3), 281-293.

Collins, S. E. et al. (2016) ‘In their own words: Content analysis of pathways to recovery among individuals with the lived experience of homelessness and alcohol use disorders’, *International Journal of Drug Policy*. 2: 89–96.

Darke, S. and Torok, M. (2013) ‘Attitudes of regular injecting drug users towards the legal status of the major illicit drugs’, *Drug and Alcohol Review*. 32(5): 483-488.

Dy, S. M., Janssen, E. M., Ferris, A., & Bridges, J. F. (2017) Live, Learn, Pass It on: A Patient Advocacy Engagement Project on the Lived Experience of Lung Cancer Survivors. *Journal of Patient Experience*, *4*(4), 162–168.

Faulkner-Gurstein, R. (2017) ‘The social logic of naloxone: Peer administration, harm reduction, and the transformation of social policy’, *Social Science & Medicine*. 180: 20–27.

Ford, S., Bowyer, T., & Morgan, P. (2015) The experience of compulsory treatment: The implications for recovery-orientated practice? *Mental Health and Social Inclusion, 19*(3): 126-132.

Garthwaite, K. (2016) 'Stigma, shame and 'people like us': an ethnographic study of foodbank use in the UK', *Journal of Poverty and Social Justice*, 24(3): 277-289

Gillard, S., Foster, R., Gibson, S., Goldsmith, L., Marks, J., & White, S. (2017) Describing a principles-based approach to developing and evaluating peer worker roles as peer support moves into mainstream mental health services. *Mental Health and Social Inclusion, 21*(3), 133-143.

Goffman, E. (1963) Stigma: Notes on the Management of Spoiled Identity. New York: Simon & Schuster.

Gravel, K. Légaré, F. Graham I. (2006) Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. *Implementation Science,* 1:16

Griffiths, C. A., & Hancock-Johnson, E. (2017) The experiences of paid formal lived experience workers within a secure mental health service. *The Journal of Mental Health Training, Education, and Practice, 12*(5), 313-322.

Hankins, C. (2008) 'Sex, drugs, and gender? High time for lived experience to inform action', *International Journal of Drug Policy*. Elsevier, 19(2), 95–96.

Horn, J. and Brysiewic, P. (2014) "Lived Experiences of HIV Community Workers Participating in a Community Empowerment Programme." *Curationis* 37(1):1-7.

Hyden, L. (1997), 'Illness and Narrative', *Sociology of Health and Illness, 19*(1): 48–69.

Inglesant, P. and Sasse, A. (2007) "Usability Is the Best Policy: Public Policy and the Lived Experience of Transport Systems in London." *Electronic Workshops in Computing* (Available Online).

Johnson, H. (2016) Exploring the Lived Experience of People with Dementia Through Interpretative Phenomenological Analysis. *The Qualitative Report*, *21*(4), 695-711.

Kolind, T. (2007) 'Form or content: The application of user perspectives in treatment research', *Drugs: Education, Prevention and Policy*. Taylor & Francis, 14(3), 261–275.

Lancaster, K. *et al.* (2015) 'Stigma and subjectivities: Examining the textured relationship between lived experience and opinions about drug policy among people who inject drugs', *Drugs: Education, Prevention and Policy* 22(3), 224–231.

Lloyd, C. (2013) ‘The stigmatization of problem drug users: A narrative literature review’, *Drugs: Education, Prevention and Policy*. Taylor & Francis, 20(2):85–95.

McAuley, A., Munro, A. and Taylor, A. (2018) ‘“Once I’d done it once it was like writing your name”: Lived experience of take-home naloxone administration by people who inject drugs’, *International Journal of Drug Policy*. 58: 46–54.

Mcintosh, I. and Wright. S. (2018) "Exploring what the Notion of Lived Experience offers for social policy analysis." *Journal of Social Policy* 48(3) 1-19

Millar, S. Chambers, M. Giles, M. (2015) Service user involvement in mental health care: an evolutionary concept analysis. *Health Expectations*. 19(2): 209-221.

Morgan, P., & Lawson, J. (2015) Developing guidelines for sharing lived experience of staff in health and social care. *Mental Health and Social Inclusion, 19*(2): 78-86.

Murinas, D. (2017) Putting People with Lived Experience in the Lead. London: *New Philanthropy Capital*.

Neale, B. (2016) Introduction: Young fatherhood: Lived experiences and policy challenges. *Social Policy and Society, 15*(1), 75-83.

Nel, K., Vawda, N. B. M., Mbokodo, L. H., & Govender, S. (2017). The lived experiences of black undergraduate lesbian students at a rural South African university. *Gender & Behaviour, 15*(3):9708-9721.

Nettleton, S. (2013) Sociology of Health and Illness. 3rd ed. Cambridge: Polity.

Novotna, G., Dobbins, M., Jack, S. M., Sword, W., Niccols, A., Brooks, S., & Henderson, J. (2013) The influence of lived experience with addiction and recovery on practice-related decisions among professionals working in addiction agencies serving women. *Drugs: Education, Prevention & Policy, 20*(2):140-148.

Parker, R. and Aggleton, P. (2003) ‘HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action.’ *Social science & medicine*, 57(1): 13–24.

Parkin, S. (2013) *Habitus and Drug Using Environments.* Burlington: Ashgate Publishing Ltd.

Parsons, T. (1975) The Sick Role and the Role of the Physician Reconsidered. *The Milbank Memorial Fund Quarterly. Health and Society* 53(3): 257-278.

Paynter, S., & Rivers, C. (2015) Making use of elephants: Lived experience and organisations. *Mental Health and Social Inclusion, 19*(3), 148-154.

Reid, C., & Alonso, M. (2018) Imagining inclusion: Uncovering the upstream determinants of mental health through Photovoice. *Therapeutic Recreation Journal, 52*(1):19-41.

Roberts, G. Good, J. Woolridge, J. Baker, E.(2011) "Steps towards "putting recovery at the heart of all we do": workforce development and the contribution of "lived experience"", *The Journal of Mental Health Training, Education and Practice*, 6(1):17-28,

Rogoff, B. Dahl, A. and Callanan. M. (2018) "The importance of understanding children's lived experience." *Developmental Review* (50):5-15

Room, R. (2005) 'Stigma, social inequality and alcohol and drug use', *Drug and Alcohol Review*, 24(2):143–155.

Sandhu, B. (2017) The Value of Lived Experience in Social Change: The Need for Leadership and Organisational Development in the Social Sector.

Schweizer, R., Marks, E., & Ramjan, R. (2018) One door mental health lived experience framework. *Mental Health and Social Inclusion, 22*(1): 46-52.

Scottish Government (2018a) Alcohol Framework. Edinburgh: Scottish Government.

Scottish Government (2018b) Rights, Respect and Recovery. Edinburgh: Scottish Government.

Scottish Health Action on Alcohol Problems (SHAAP) (2018) Dying for a Drink. Edinburgh: SHAAP.

Strauss, A. and Corbin, J. (1998) Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. London: Sage Publications.

Suomi, A. Freeman, B. and Banfield, M. (undated) Framework for the engagement of people with a lived experience in program implementation and research: Review and report prepared for the LifeSpan suicide prevention project. Canberra: Australian National University.

Tait, L. and Lester, H. (2005) Encouraging user involvement in mental health services. *Advances in Psychiatric Treatment 11(3): 168–175.*

Tiilikainen, E., & Seppänen, M. (2017). Lost and unfulfilled relationships behind emotional loneliness in old age. *Ageing and Society, 37*(5), 1068-1088.

Treloar, C. and Rhodes, T. (2009) ‘The Lived Experience of Hepatitis C and its Treatment Among Injecting Drug Users: Qualitative Synthesis’, *Qualitative Health Research*. SAGE Publications CA: Los Angeles, CA, 19(9): 1321–1334.

Van Manen M. (2004) "Lived Experience" in Lewis-Beck, M. Bryman, A. Futing, T. and Book, L. (Eds.) *The SAGE Encyclopedia of Social Science Research Methods*. London: Sage Publications.

Voronka, J. (2016) The Politics Of 'People With Lived Experience': Experiential authority and the risks of strategic essentialism. *Philosophy, Psychiatry & Psychology 23*(3): 189-201,325-326.

Walker, L., Perkins, R., & Repper, J. (2014) Creating a recovery focused workforce: Supporting staff well-being and valuing the expertise of lived experience. *Mental Health and Social Inclusion, 18*(3): 133-141.

White, H., Price, L., & Barker, T. (2017) Exploring the impact of peer support in early intervention in psychosis. *Mental Health and Social Inclusion, 21*(2): 102-109.

Williams, G. (1984) ‘The Genesis of Chronic Illness: Narrative Reconstruction’, *Sociology of Health and Illness, 6:* 175–200.

Wright, S. (2012) Welfare-to-work, agency and personal responsibility. *Journal of Social Policy, 41*(2): 309-328.

Zakrzewski, R. F. and Hector, M. A. (2004) ‘The Lived Experiences Of Alcohol Addiction: Men Of Alcoholics Anonymous’, *Issues in Mental Health Nursing*. Taylor & Francis, 25(1): 61–77.

APPENDIX A: TOPIC GUIDE

SHAAP Lived Experience Research Project, January – March 2019

Give them the information sheet and explain: SHAAP is supporting a short term piece of research, to be concluded by end March 2019, to feed into the Government's strategic planning, as well as our own strategies and work programmes, to explore meanings of the concept of lived experience.

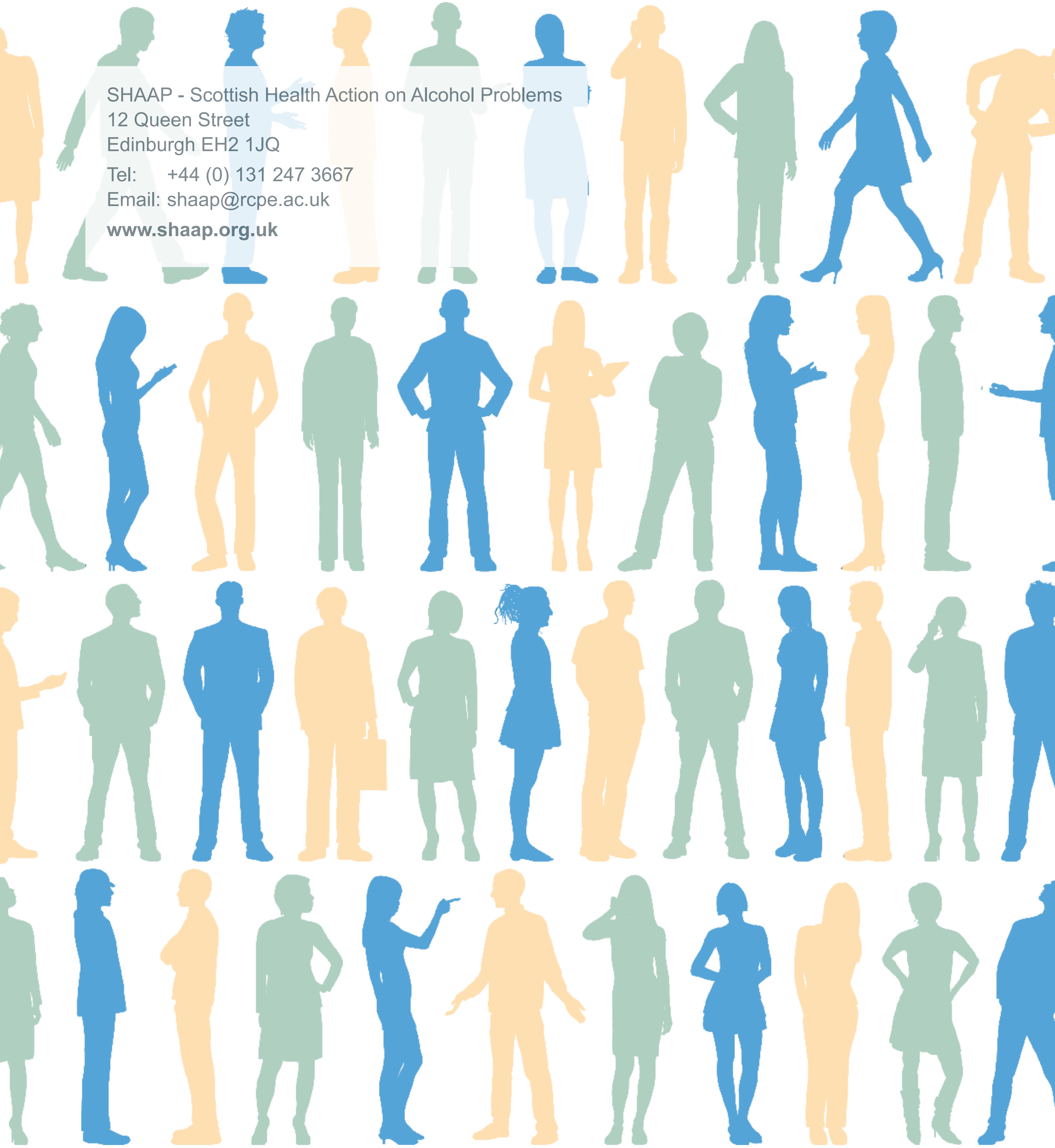
Administrative details:

1. Record date and time
2. Record name and pseudonym for anything to be shared
3. Describe organisation briefly
4. Record gender
5. Explain confidentiality arrangements
6. Agree interview can be recorded
7. Get consent form signed
8. Check if any questions before starting

Research areas to explore:

1. Are you familiar with the term lived experience?
2. Who has lived experience? (Who doesn't?)
3. What exactly does the concept mean for you?
4. Are there specific meanings in relation to alcohol?
5. Where did it come from?
6. When did you first hear it?
7. How is it used by others?
8. Do you think that the concept is useful? Why?
9. How could it be more useful?
10. How can we capture lived experience narratives?
11. Can we use these narratives to effect meaningful change?

12. How can we use them to effect meaningful change?
13. How do we weight lived experience against other evidence? Who decides?
14. Does lived experience have an expiry date?
15. Are they brave or are they victims?
16. How we do avoid exploiting them?
17. Who else do you think we should be talking to? Why?
18. Who should we be sharing this research with? Why?
19. Is there anything else you think we should be thinking about?



SHAAP - Scottish Health Action on Alcohol Problems
12 Queen Street
Edinburgh EH2 1JQ
Tel: +44 (0) 131 247 3667
Email: shaap@rcpe.ac.uk
www.shaap.org.uk

SHAAP

SCOTTISH HEALTH ACTION ON ALCOHOL PROBLEMS
www.shaap.org.uk