Northern Ireland Alcohol and Drugs Alliance: Service users experience during lockdown

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Foreword

2020 has been blighted by a global pandemic for which the outcome and extent for all of us is still unknown. However, even the most difficult of times can offer the opportunity to learn and grow. NIADA were gifted such an opportunity by Queens University's Centre of Evidence and Social Innovation (CESI). The opportunity to take a snapshot in time and record the behaviour and trends of a range of service users, across Northern Ireland, who were participating in the substance use services and interventions of NIADA members.

Thanks to CESI this short survey has provided NIADA with a range of valuable information upon which members, policy makers, influencers and others can utilise to plan and improve services as we strive to meet service users complex and diverse needs post-COVID.

This vital information could not be more timely as the Department of Health, responsible for leading and co-ordinating action on Northern Ireland's new substance use strategy, issue **'Making Life Better – Preventing Harm and Empowering Recovery: A Strategic Framework to Tackle the Harm from Substance Use'** for public consultation. The first critical review in nearly 10 years.

I wish to thank all those who took part in this survey, particularly the service users. I commend the NIADA members for committing to the process and for reviewing and commenting on this report during a very trying and stressful time for their staff. I am extremely grateful for all your efforts and applaud you all for **stepping up and standing out**.

NIADA's services users experience and feedback, documented in this report, will galvanise NIADA's resolve to ensure the right services are available throughout Northern Ireland, in the right place, at the right time.

Anne-Marie McClure
Chair - NIADA

Introduction

The Northern Ireland Alcohol and Drugs Alliance (NIADA) is a group of voluntary and community sector organisations that provide support to those affected by alcohol and drug use, and their families. Their members include organisations that provide a range of services to children, young people, individuals and their families. Organisations vary in size and focus. Larger organisations for example, deliver many services, with drugs and alcohol being only one of many aspects of provision. Specific organisations may focus primarily on the needs of children and young people, including their mental health and overall wellbeing. Smaller organisations may focus more on drugs and alcohol (or other addiction) related need. Importantly, NIADA facilitates a coordinated approach for all these organisations to raise awareness and influence policy and practice on the impact of alcohol and drug use on individuals, families and communities.

As part of the public health response to the Covid-19 pandemic, stringent restrictions on physical contact introduced by the government, required organisations to reduce one to one contact to a minimum. For drug and alcohol services, this meant putting in place emergency response plans to ensure that service user needs continued to be met. This often called for evolving news ways of working to comply with national guidance while maintaining communication. Among the challenges for service organisations was the unparalleled nature of Covid-19, the fact that no examples of good practice existed and determining how people experiencing issues related to alcohol or drugs were being affected by the health pandemic.

Organisations recognised the need to better understand how their service users were being impacted by coronavirus. For example, ASCERT conducted a survey in April 2020, with plans to follow-up in May (ASCERT, 2020). A co-ordinated effort was made by NIADA to gather information across their organisations that would augment what was already known. Queen's University Belfast assisted NIADA with their work.

Sincere appreciation and thanks goes to everyone who took the time to complete the questionnaire and to the organisations that participated in the research.

NIADA survey

A short survey was distributed by NIADA in mid-May 2020, asking organisations to encourage their clients to participate. This was when lockdown was fully in place. The survey aimed to build on the important information that had already been collected by ASCERT. In addition to the survey, organisational leads were asked to maintain a diary over a four to six week period (from late May to the end of June 2020), noting their observations, thoughts on whether and

how Covid-19 was impacting on people's experience of drug and alcohol use and noting anything of concern/interest/change in patterns of use. To avoid placing additional work burdens on organisations, diaries were deliberately short and concise, with people recording their reflections in the way that suited them best.

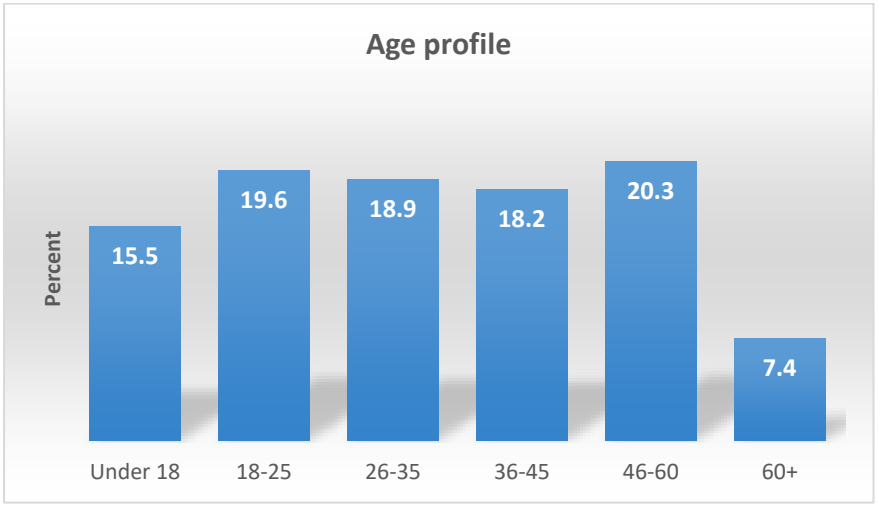
Five organisations kept diary entries during this time. As noted above, these organisations vary in size and focus. The diaries revealed some common themes that aligned with information revealed in the survey. When considered alongside the survey results, the diaries provide additional context in relation to the experiences of individuals, their families and service providers during this period.

Demographic information

A total of 149 people took part in the survey. Over two-thirds of respondents were male (64%). This is broadly reflective of published information on people presenting to services with problem drug and/or alcohol use where the majority of clients were male (DoH, 2019).

The age of people who responded to the survey ranged between 14 years and 71 years of age (see Figure 1). Fifteen percent were under the age of 18 years, which is higher than numbers usually recorded in official statistics. This is likely to be reflective of the range of services offered by individual organisations who engaged with the study and the higher likelihood that younger people were in contact with these organisations.

Figure 1: Age of respondents



Pattern of use

Of the 149 respondents, 17 did not report substance use at the time of the survey, the majority of which were young respondents (aged under 18). More than half of those taking part indicated that alcohol was their main substance (58%).

Table 1: Main substance used

Main substance	(n)	%
Alcohol	86	58
Benzodiazepine	6	4
Cannabis	15	10
Meth/Chrystal meth	2	1
Cocaine	10	7
Opiates (inc codeine)	3	2
Opioids (inc heroin)	7	5
Porn	1	1
Pregablin	1	1
Tobacco	1	1
None	17	11

Alcohol use was particularly high among older respondents. For those aged 46-60 years, more than four-fifths (83%) indicated that alcohol was their main substance. The percentage was even greater for those aged older than 60 years of age, with all respondents in this age group reporting alcohol as their main substance.

Official statistics for the UK show a similar pattern, with increases in the frequency of alcohol consumption by older people (ONS, 2018). Research suggests that the interaction between alcohol and older people's increasing use of multiple medicines (Moriarty et al. 2015) leaves them particularly vulnerable to physical and mental health harms and alcohol-specific death (Comiskey, 2020; Holton et al. 2017).

Cannabis was the next most common main substance, reported by 10% of respondents. Again, there was an age gradient noticeable, with younger respondents more likely to report cannabis as their main substance. The 18-25 age group were the most likely to report mainly using cannabis (40%), while no one in the oldest two age groups said cannabis was their main

substance. Again, this is similar to other research showing increased use of cannabis among young adults (DoH, 2015; EMCDDA, 2019).

People were also asked whether they used a secondary or any other substance. Over half (57%) did not name any other substances, other than their main substance. For the remaining 43%, a range of other substances was mentioned, with respondents sometimes recording two, three or more other substances (polydrug use). Other substances mentioned included a mixture of prescription medication (e.g. pregablin, tramadol), opioids (e.g. codeine, fentanyl), cocaine, cannabis and alcohol.

Change in use

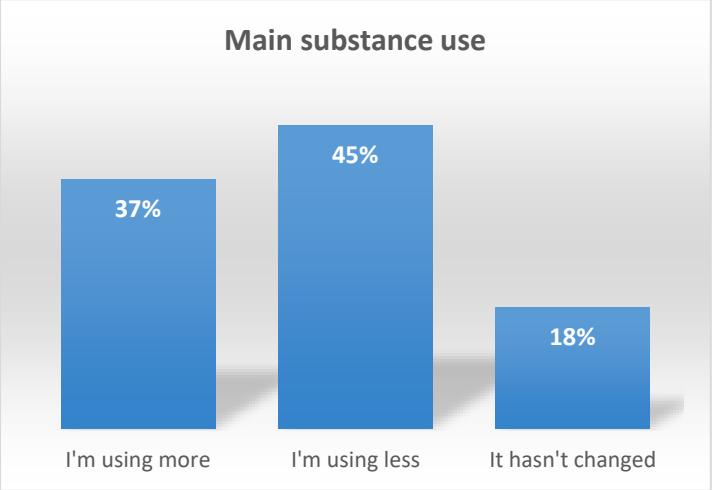
To get a picture of how and if people's substance use habits had been affected during the time when lockdown restrictions were at their height, people were asked:

'*Has your main substance use changed in the past 4 weeks?*' Responses were:

I'm using more
I'm using less
It hasn't changed

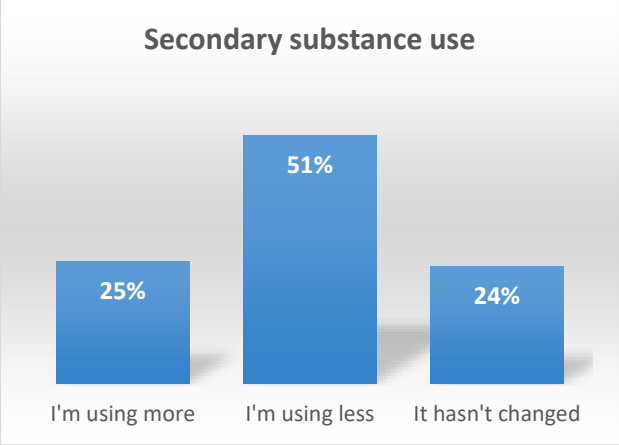
At the time the survey was carried out, over a third (37%) of people who named a main substance said they were using more, 45% said they were using less, for 18% of people it remained the same. See Figure Two.

Figure 2: Main substance use in the past 4 weeks



Of those people who were using secondary or multiple substances, a quarter (25%) said they were using more additional substances. Just over half (51%) were using less, with almost a quarter (24%) saying it had not changed. See Figure Three below.

Figure 3: Secondary substance use in the past 4 weeks



The decline in substance use is similar to findings investigating the effects and implications of Covid-19 across European countries during the first 3 months of the pandemic (EMCDDA, 2020).

There was a statistically significant link between the way people were using their main and secondary substance - people who reported using less of their main substance, were almost all likely to be using less of their secondary substance/s, if they were using other substances. For those who were using more of their main substance, almost half (48%) were using more of their secondary substance too, indicating the existence of an intensified cohort of clients.

Of those who reported using a main substance, the majority (83%) had not changed the way they used their substance. For the remaining 17% who said they had changed the way they were using their main substance, examples of change included moving from beer to spirits, smoking rather than sniffing (or vice versa), trying cannabis edibles, swapping smoking heroin for injecting. However, the numbers are very small and no main conclusions can be drawn. Very few people (6%) who were using additional substances had changed the way they were using them.

Very few respondents had tried a new substance in the past four weeks (11%). Of those that had, it was mostly a different type of their usual substance – for example a different type of alcohol, or prescription drug or different form of the same drug, for example crack cocaine as opposed to cocaine. Reasons for use were mainly that their regular substance was not available and to try something new. Other reasons included feelings of isolation, lack of routine and because others were using it. Again, numbers are small and no clear patterns emerged. Similar findings were recorded from the ASCERT survey of service users (n=97) in April 2020.

Health status

People were asked how their physical and mental health had been recently. The majority of respondents reported 'good or very good' physical health (55%). This might be due to the higher than usual number of younger respondents aged under 18 years, given that younger people were more likely to rate their physical health as good or very good.

However, fewer people reported positive mental health; 65% said their mental health was 'poor or very poor' with just over a third (35%) describing their mental health as 'good or very good'. While young people under 18 years of age were the least likely to say their mental health had been poor, it was still the case that 39% of young people said they experienced poor or very poor mental health recently. [1]

Figure 4: Recent physical health

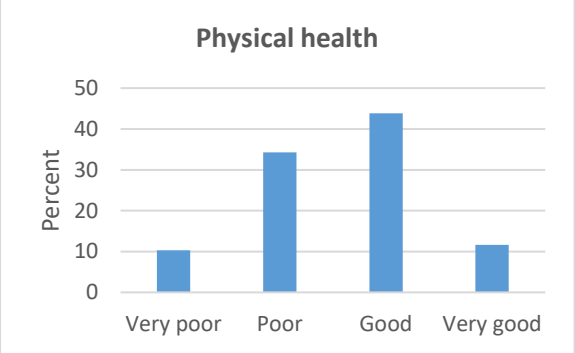


Figure 5: Recent mental health

Follow up questions asked if people had received any support that helped them cope better with their physical and/or mental health over the past four weeks and to say where that support came from. Respondents could select more than one option and there was an 'other' category if support was received from a different source. Two-thirds (66%) of respondents with poor/very poor physical health said they received support recently that helped them cope with their health issues. Support came from a variety of sources, but was mainly from a medical professional (e.g. doctor, nurse, social worker). The next significant source of support came from a community/voluntary/charity organisation. Very little support came from any 'other' source, although two people added 'personal trainer' as an additional source.

[1] In the ASCERT survey, 68% of respondents said their physical health had been affected 'a little or a lot' by the coronavirus pandemic, while 89% said their mental health had been affected 'a little or a lot' by the pandemic. There was a smaller percentage of younger people in the sample.

Most people who described their recent mental health as poor/very poor had received support that helped them cope better (81%). Overwhelmingly, that support came from a community/voluntary/charity organisation, with 70% people saying they got help from this source. Reliance on the voluntary and community sector (VCS) for support for mental health support draws attention to the dual diagnosis issues of clients and how their needs are less likely to be addressed within primary care or acute services.

The next significant source of support for mental health issues came from a family member (36%). The findings underline the importance of the VCS and the role that family play in providing mental/emotional health. It also highlights the fundamental importance of sustaining the ability of the family to continue in their supportive role.

A question was included at the end of the survey asking if there were other types of support that would have helped people cope better during this time. Just over a third of respondents answered this question (n=52). Comments mostly clustered around continued access to drug and alcohol services and better/easier access to mental health services and primary health services as mechanisms for helping people cope better. A summary of responses is provided in Table Two alongside the number of people who specifically mentioned this source of support (simply to indicate frequency of issues raised within comments).

Table 2: Support to help people cope better

Other support that would help you cope better at this time	Number of people who said this
Better access to mental health services/primary health services (e.g. GP appointments, medical consultation, access to opioid substance therapy)	24
Continued access to drug & alcohol services	18
Financial/legal aid	5
Help with housing issues	5
More social contact with family and friends	3
Help from social services	3
Sporting activities	2

Better access to mental health and primary health services during lockdown and continued engagement with addiction services were the main forms of support most cited as helping people to cope better. Difficulties getting a GP appointment or not being able to consult with a specialist or discuss revision of medication were among examples given. Six people

specifically mentioned that easier/increased access to opioid substance therapy (OST) would have helped them cope better during lockdown. Again, this is similar to other findings where clinicians in a number of European countries highlighted increases in emergency presentations for mental health problems (EMCDDA, 2020).

Regarding continued engagement with substance use services, some people stated a preference for personal engagement/contact (either face-to-face or in a physical group) and wished that organisations were open again. Others preferred one to one contact, but this could be personal, online or by phone. One person hoped that the online meetings would continue after lockdown while another person said they had declined online meetings. No single form of contact emerged as preferable. Neither was there any general link between age and preference for form of contact. These are a sample of the suggestions made for continuing access to services:

> *Set up small group meetings. Maybe use larger rooms using masks*. (Female, aged 63)

> *That online meetings could be continued after lockdown*. (Male, aged 47)

The ASCERT survey highlighted similar findings about clients expressing difficulties accessing mental health and primary care services and continued contact with substance use services as significant forms of support for coping better (see ASCERT, 2020).

Diary entries

As explained above, five NIADA organisational leads agreed to maintain a diary over this time, noting their observations, thoughts on whether and how Covid-19 was affecting people's drug and alcohol use and noting anything of concern/interest/change in patterns of use. To avoid placing additional work burdens on organisations, diaries were deliberately short and concise, with people recording their reflections in the way that suited them best. The diaries revealed the emergence of some common themes and patterns across the various organisations which both strengthen the survey findings and provide an additional perspective on substance use related experiences of individuals, their families and services providers during a period of lockdown.

Increased demand

All organisations recorded increased demand on their services and additional pressure on available resources. In terms of drug and alcohol use, much of the demand was driven by an upturn in the number of clients relapsing and the subsequent increased intensity required to re-engage with clients, just to get them back to their original starting point. For older clients,

increased demand was observed by an increase in the number of re-referrals from other agencies/sources. This required a doubling of efforts by the organisational team, simply to re-establish the status quo.

As reported in the EMCDDA 2020 study, decreasing substance use was also noticed in the earlier weeks of this research gathering exercise. However, higher incidents of relapse, particularly among younger clients, were recorded in the later weeks. Higher rates of Covid-19 infections in the general public during the earlier weeks were thought to have helped act as a deterrent against high-risk drug and alcohol use. There was a suggestion that clients (mostly younger clients) were more wary of overdosing, which might increase their risk of hospital admission and, consequently (they believed) increase their risk of exposure to infection of Covid-19. However, once infection rates in the community began to decrease, the fear of risk of infection in this way diminished, stimulating more dangerous usage, which brought with it increased risks of relapse. Relapse is expected, particularly when dealing with new circumstances or when circumstances are out of a person's control and is recognised as part of the recovery cycle. The need to deal with relapse and prevent clients becoming disengaged or 'harder to reach' became a fundamental concern for staff.

For some particularly vulnerable clients (e.g. among homeless heroin users), higher rates of Covid-19 infection among the public during the earlier days of lockdown were thought to have helped reduce regular substance use. However, the stimulus for change was different, with an empty city centre diminishing a source of income. One organisation noted a heightened risk of withdrawal symptoms and a loss of tolerance among this population.

For many clients, existing issues (e.g. poor mental and physical health) were noticeably more intensified and complex. Feelings of isolation and loneliness were major contributing factors for deteriorating mental health including depression and anxiety and other co morbid conditions. Some clients who were shielding due to serious physical health conditions had heightened fears and anxiety regarding their risk of contracting Covid-19, exacerbating co-existing emotional and mental health issues.

The observed increase in deteriorating mental health is in line with recent studies suggesting that pre-existing mental health conditions could have been exacerbated by lockdown and concerns about COVID-19 (Chatterjee et al., 2020; WHO, 2020). Factors causing concern were similar as those found here and included loneliness, fear of contracting the virus and worry about vulnerable family members or close friends.

This type of complex demand had a 'ripple effect' manifesting in concurrent and increasing demand in the number of client families requesting help. Organisations offering family support reported a greater uptake of family services and increasing numbers of unscheduled family

support during this time. Depression, anxiety and helplessness, heightened by feelings of isolation, were also common experiences among families who turned to the organisations for help, irrespective of whether their family member was receiving treatment or not.

Observations on usage

In terms of usage, a number of organisations observed that cannabis appeared more difficult to obtain. The general sense was that available supply was becoming more expensive and was of dubious quality. An increase in the use of substituting one substance with another was a pattern noted by staff. For instance, a rise in the use of prescription medication and cocaine was noted by more than one organisation, a pattern echoed in the ASCERT 2020 survey findings and in the EMCDDA 2020 study. While not a common observation, there was a slight increase noticed in changing routes of opioid usage – where a small number of clients had moved from swallowing or inhaling towards injecting, and in the case of the ASCERT survey findings, with increased incidence of groin injecting reported by some organisations.

A few organisations noted a growing number of incidents of the emergence of non-prescribed and 'fake' Benzodiazepines, particularly visible among those in temporary accommodation. One organisation had sent pills off for testing, all of which came back positive for Flualprazolam content, raising concern due to the higher potency, the increasing availability of this compound in UK markets and its involvement with 12 flualprazolam-associated deaths in the UK reported in March 2020 (ACMD, 2020).

Some of the recorded side effects of Flualprazolam (e.g. increase in seizure, aggression, increased anxiety, violent behaviour, loss of impulse control, irritability and suicidal behaviour (ACMD, 2020)) were reported by organisational staff as being visible among clients. These effects were particularly noticeable in clients who were taking what they believed to be 'blues' (Diazepam) but were actually taking Flualprazolam.

Of note here is that although the survey findings showed that 45% of people were using less of their main substance, the dairies suggested that this might have been a temporary feature, with people returning to previous patterns of use quite quickly, once Covid-19 infection rates began to decrease and/or once issues of supply and access were resolved. As noted by EMCDDA (2020), the true impact will only become evident in time.

Mainly, demand on existing services can be viewed in terms of depth as well as breadth: *Depth* because responses to individual clients' needs required much more intense efforts by staff to deal with the situation. Re-engagement for example, required time, determination and endurance. Problematic access to mental health and primary care services put greater strain on community organisations' resources. *Breadth*, because some clients' existing conditions became more complex. Families and the wider family circle were experiencing deeper and

greater levels of need because of trying to cope with their family member's more complex situation. All of which added pressure on finite resources.

Support services

Following lockdown, support organisations had to reconfigure quickly their existing services to comply with Covid-19 restrictions. In place of physical contact for example, services had to convert to online and/or other forms of socially distanced communication. There was no precedent for this way of working and organisations had no way of knowing how individual clients might respond. Therefore, all information on client response to different methods of communication is beneficial for future learning.

One common message was that keeping lines of communication open on a regular basis was critical. The regularity of being able to 'check-in' with a member of staff was of significant importance to clients, be that via a telephone call or a text message. Staff noted that regular 'check-ins' provided a level of reassurance and, importantly, client accountability. This supports the survey findings that showed the significance of maintaining contact, in whichever form.

Limitations

These findings are based on a short survey carried out at one point in time during an unparalleled health crisis. The research was in response to concerns about meeting the needs of clients and their families during Covid-19 restrictions, and learning about the most effective ways to deliver services and continue giving support that would help people cope better. NIADA wanted to coordinate all information that was available, with the aim of recording the experience for future learning.

The questionnaire collected data at one point in time. It was very brief to cause as little burden as possible to respondents, particularly given already high levels of existing need and challenging circumstances brought about by lockdown. Although the survey was carried out with existing clients, it was anonymous and no unique identification code was used. Therefore, there is no opportunity to follow-up on the findings or make comparisons with previous data. This limits the amount of information that was collected and the capacity to address any other questions posed by the findings.

It also raises the tension between an ideal scenario whereby individual unique identifiers are attributed to clients, allowing for the collection of baseline data and respondent follow-up - with a less ideal but practical scenario whereby research is carried out in challenging real life circumstances.

However, it still provides a valuable snapshot of the experiences of people reliant on drug and alcohol services, and their families, during lockdown. The findings also provide some useful messages for future learning, particularly in light of the unpredictable nature of Covid-19 and related regulations on public behaviour.

Thoughts/reflections

The survey findings suggested that, at the time the survey was completed, a large percentage of people said they were using less of their main substance. However, this was a short, quick survey taken at one-point-in-time. Observations noted in the diaries suggest that this might have been only temporary, changing as the risk of infection from Covid-19 lessened and/or supply and access issues were resolved. Additionally, erratic usage during lockdown may possibly have had unforeseen consequences in terms of increasing demand due to more complex needs.

The reliance on the voluntary and community sector for mental health support draws attention to the dual diagnosis issues of clients. Problematic access to mental health and primary care services reported by respondents underlines how these issues are less likely to be address within primary care or acute services. It also demonstrates how lack of access to health services affected organisations in terms of additional demand on their services.

Relapse is not unexpected, particularly when dealing with new circumstances or circumstances out of a person's control. Relapse is part of the recovery cycle and is recognised as such by substance use services. It is not failure if, and when, dealt with in treatment. Organisations were constantly alert to the need to deal with such situations, especially during lockdown, intensifying efforts required.

A core message was that consistent contact – in whichever form – was significant to help people cope and/or help them maintain stability.

The survey and diary entries both underline the key role of the family. Family support is a pre-requisite for ongoing recovery to ensure capacity is available within the home when treatment/support ends. Therefore, maintaining the ability of the family to carry on in their supportive role is also fundamental.

Unique clients numbers are necessary to track and trace clients - not only for research purposes but to also create coherency in terms of referral pathways, assessment, sharing of information, treatment/support , follow up and relapse prevention – all of which will improve the client experience and ultimately provide better outcomes in terms of substance use and mental health

There was no unifying system of identification coding used across organisations. Adoption of universal processes by all substance use organisations, in tandem with primary care and acute services, to include unique personal identification numbers and assessment/outcome tools,

would greatly enhance information and knowledge. This would require additional government resources and investment.

Services need to be flexible and well resourced to offer the level of engagement clients require. Vulnerable clients are usually dealing with chaos. This snap shot during lockdown offers us the opportunity to see how chaotic behaviours manifest. It would have been very useful to track and follow up on these clients post lockdown.

This research is timely as consultation on a new Substance Use Strategy (SUS) is imminent.

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