Service User & Lived Experience Engagement Project

KETAMINE LIVED-EXPERIENCE FINDINGS IN NORFOLK

NORFOLK RECOVERY COMMUNITY

together FOR MENTAL WELLBEING

prepared by SULE

for Public Health Ketamine conference

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About SULE and the Recovery Community

The SULE Norfolk Recovery Community

The SULE Recovery Community provides safe, inclusive and non-judgemental spaces for anyone in Norfolk affected by drugs or alcohol, whether through their own use or as an affected other. Rooted in lived experience, the project began with large-scale peer research and has evolved into a peer-led, co-produced community that centres connection, empowerment and hope.

The community offers peer-support spaces designed by members, both online and face-to-face, enabling people to share experiences, build relationships and access recovery-focused activities. These spaces foster belonging and reduce isolation, ensuring no one feels alone. Members help shape what's offered, from recovery groups to member-led fundraising that sustains community spaces.

Joining the community begins by sharing lived experience through accessible engagement options such as online surveys and face-to-face conversations. This insight plays a crucial role in shaping local treatment systems. Members can also participate in focus groups, expert panels and development opportunities, including becoming Recovery Community Champions, with training in facilitation, public speaking and project support.

At its heart, SULE is building a movement where lived experience becomes a powerful driver of positive change, strengthening both individual recovery and the wider system's ability to respond to people's needs.

NORFOLK RECOVERY COMMUNITY

National & Local Strategic Context

The UK Government's 10-year drugs strategy, From Harm to Hope (2021–2031), sets out an ambition to reduce drug-related harm by developing a high-quality treatment and recovery system. It emphasises the use of evidence and lived experience voice, alongside stronger local partnership working through Combating Drugs Partnerships. The strategy also includes significant new investment and responds directly to the recommendations of Dame Carol Black's Independent Review of Drugs.

Public-health commentators have welcomed the renewed funding and system-wide focus, while highlighting the need for a more health-led, harm-reduction and trauma-informed approach to effectively prevent deaths and tackle inequalities. Recent progress reports underline the importance of robust multi-agency collaboration, strong local leadership and consistent delivery across services.

Overview

In response to increasing concern about ketamine-related harm, the team conducted a dedicated ketamine survey and focus group. This targeted work was designed to provide greater understanding of ketamine users' experience of the treatment system and to discover what supports or hinders engagement.

Findings from the ketamine-specific work reveal that ketamine use often begins in social settings where it feels normalised but can escalate into dependency, and significant physical and psychological harm. Participants described delays in being taken seriously within healthcare settings, limited professional knowledge of ketamine-related bladder and pain issues, as well as inconsistent aftercare.

Across the broader project and the ketamine-focused study, participants identified clear priorities for improving the treatment system:

- Better-informed professionals who recognise ketamine-related harms and respond appropriately.
- Consistent workers who build trust, reduce the need for retelling traumatic histories and support sustained engagement.
- Trauma-informed, non-judgemental, peer-led spaces where people feel safe, understood and able to disclose honestly.
- Earlier intervention points, with clearer referral pathways to prevent escalation of harm.

The insights gained do not claim to be exhaustive but they provide a helpful starting point for ongoing conversations about how services can become more responsive, trauma-informed and grounded in lived experience.

Methodology

Data collection methods

During Year One of our project we conducted extensive outreach (>400 contacts) and completed 271 one-to-one peer-led interviews.

This report integrates three sources: Analysis of Year One interview data to ensure fidelity to lived voices and accurate framing. A dedicated ketamine survey on initiation, harms, service access and support needs; A targeted focus group exploring emergent themes.

Analysis followed a thematic approach across sources; limitations include non-probability sampling and self-report bias.

Ethics and Safety

Participation was voluntary, with clear participant information and consent. All engagement followed trauma-informed practice, safeguarding protocols and confidentiality standards. Facilitators received supervision and wellbeing support throughout.

#	Questions
1.	Why people start using ketamine
2.	How use changes over time
3.	Physical, psychological and social harms
4.	Barriers to accessing healthcare and support
5.	Experiences with treatment services
6.	What people feel would genuinely help
7.	What recovery looks like and what makes it possible

Understanding Ketamine Use and Motivations

Motivations for Starting Ketamine Use

Initial motivations for ketamine use were described as strongly shaped by social and environmental factors. Participants commonly reported first encountering ketamine in recreational settings such as raves, festivals or gatherings where peers already considered ketamine an accepted element of their social culture. This normalisation reduced perceived risk and contributed to a sense of belonging for individuals seeking connection.

Several participants explained that the availability and acceptance of ketamine within their immediate peer groups made early experimentation appear harmless, particularly when use was encouraged by friends or partners. Over time, these environments facilitated a rapid shift from occasional recreational use to more regular and habitual consumption, with individuals increasingly relying on drug-using groups for routine, validation and social structure.

> *"I first started using ketamine while out with friends. K was handed to me, I tried it and liked it."*

Co-dependent dynamics were also evident, with some personal relationships reinforcing ketamine use as part of shared behaviour. These patterns illustrate that ketamine initiation is rarely an isolated decision; rather, it is embedded within broader social norms and community behaviours. Understanding these influences challenges the assumption that ketamine use begins through individual choice alone. It highlights the importance of interventions that address peer-group culture, promote safer social environments and provide targeted harm-reduction messaging for young people and nightlife settings.

> "I first started using it when I went to a rave... I didn't feel pressured by friends to use it, it was my own free will."

Key Insight

Initiation is socially embedded and normalised—often in nightlife and peer contexts—lowering perceived risk and accelerating escalation.

Changes in Motivation Over Time

Over prolonged use, motivations for ketamine consumption undergo significant transformation, often driven by shifts in mental health, dependency and personal circumstances. Many participants recalled an early period in which ketamine provided escape, euphoria or companionship. However, as dependency deepened, they experienced diminished self-motivation, loss of purpose and growing difficulty maintaining daily routines. Basic activities such as eating, cleaning, sustaining social connections or attending work were increasingly neglected as ketamine use began to dominate daily life.

Participants frequently described pivotal turning points, often referred to as "penny-drop moments", that interrupted this cycle. These moments were commonly linked to medical emergencies, clear warnings from healthcare professionals or profound emotional events such as bereavement. Such experiences often catalysed a shift from avoidance-driven use toward a desire for recovery, structure and improved well-being.

> *"I basically got told you're gonna go into liver failure if you carry on using K... That was a moment for me... this is not good."*

Key Insight

Motivation often shifts from escape or social connection to dependency until a health crisis triggers a "penny-drop" turn toward recovery. Whilst relapse risk remains high amid stigma and inconsistent support.

> "Reflecting on past relapses, I recall a period of hopelessness where I felt my bladder was so unwell that I might as well continue using ketamine until it killed me."

Despite increased motivation to change, relapse remained common. Individuals described recurring periods of hopelessness, influenced by physical decline, internalised stigma and inconsistent support from services. This evolution in motivation highlights the complex interplay between dependency, life events and external support. It also underscores the importance of consistent, empathetic and knowledgeable services in fostering and sustaining recovery motivation.

Support Needs and Service Gaps

Support Needs Identified by Participants

Participants identified several critical support needs that, if addressed, could significantly improve outcomes for people using or recovering from ketamine. A key priority was the need for better-informed healthcare professionals, particularly GPs, who were often perceived as lacking specific knowledge about ketamine-related harms. This gap in understanding limited their ability to recognise symptoms, provide appropriate treatment or make timely referrals. Participants emphasised that clinical awareness of bladder injury, mental-health deterioration and the complexities of long-term ketamine use is essential for improving care.

In addition to clinical knowledge, participants highlighted the importance of structured, empathetic peer support systems. These environments provided non-judgemental spaces where individuals felt safe to share their experiences. Peer support not only offered emotional grounding but also strengthened community resilience, giving people a sense of belonging that is often lost during periods of dependency.

> "Education and warnings about ketamine should be brought into schools. We need to be explicit about the risks and harms."

> *"GP's knowledge of K is so basic or they don't really want to know... I've had more success from nurses... I don't bother now going to talk about anything."*

Consistency in support workers was another major theme. Frequent staff turnover required individuals to repeatedly recount traumatic histories, which participants found distressing and demotivating. Stable relationships with workers were seen as vital for building trust, maintaining engagement and reducing the risk of retraumatisation.

Finally, early intervention, particularly through education in schools, was regarded as essential for preventing harm among younger people. Participants expressed concern about the growing normalisation of ketamine use within increasingly younger age groups. They also emphasised that proactive, accessible education could help reduce future dependency and associated harms.

Key Insight

People want ketamine-literate clinicians, structured empathetic peer support, consistent workers, and early education, especially in schools.

Gaps in Services and Barriers to Access

Despite the availability of multiple support pathways, participants described substantial gaps in services that continued to hinder recovery. Many reported that healthcare professionals, from GPs to specialists, lacked sufficient understanding of ketamine-related harms. This lack of clinical awareness contributed to missed diagnoses, delayed referrals and inconsistent or inadequate follow-up. Aftercare was frequently described as fragmented, with support often reduced or withdrawn once initial improvements were observed. As a result, some individuals felt pressured to downplay progress in order to retain essential care.

> *"I felt like I had to pretend I was worse than I was just to keep getting help... It's like they only want to help you if you're at rock bottom."*

Mental-health follow-up was highlighted as particularly inconsistent. Several participants explained that they received no contact after critical incidents such as overdoses or episodes of self-harm, leaving them without support during periods of heightened vulnerability. Systemic delays, experiences of stigma and being labelled "too complex" further discouraged people from seeking help. Stigma emerged as a recurring issue, with some individuals denied appropriate pain management due to assumptions of drug-seeking behaviour, leading them to unsafe forms of self-medication.

Key Insight

People encounter knowledge gaps, stigma, delayed referrals, fragmented aftercare and weak post-crisis mental-health follow-up, all of which undermine safety and trust.

> "I was in real pain, but they just assumed I was looking for drugs. It made me feel like I had to find my own way to cope, which wasn't safe."

Long waits for referrals, especially to continence, urology or mental-health services, meant that urgent medical needs often went unmet, exacerbating physical and psychological harm. Collectively, these gaps demonstrate the pressing need for coordinated, informed and compassionate care pathways that recognise the complexity of ketamine-related harm and prioritise continuity, timely intervention and anti-stigma approaches.

Health, Social Harms and Daily Life Impact

Health and Social Harms

The harms associated with ketamine use described by participants were severe, multifaceted and often life-altering. Physically, individuals frequently reported rapid bladder deterioration, including urge incontinence, urinary retention, chronic infections and long-term damage leading to significantly reduced bladder capacity. These symptoms often required repeated hospital admissions and ongoing specialist care. Additional medical complications included kidney and liver damage, extreme weight loss, cessation of menstruation, hair loss and chronic pain. Many participants explained that these physical changes developed gradually, making it difficult to recognise ketamine as the cause and delaying access to appropriate treatment.

Key Insight

Harms are severe and multi-system with profound daily-functioning loss and isolation; many initially misattribute symptoms which delays care.

> "I overdosed in September on pregabalin because I was fed up with the pain of K cramps... I couldn't take it anymore... Still never heard back from the mental health team."

> *"My period stopped when I was doing that... My hair was falling out because I wasn't eating anything. Malnutrition had set in. I was seven stone back then."*

Social harms were equally significant. Individuals described increasing isolation as they withdrew from relationships, employment and daily responsibilities. Risk-taking behaviours, such as drug driving or self-medicating with unsafe substances became more common as dependency deepened. Some participants described experiencing emotional numbness and psychological distress, which were often exacerbated by stigma from healthcare providers and their wider social networks.

These combined harms highlight the need for early detection, specialist training for clinicians and accessible, integrated support systems capable of intervening before health and social consequences become irreversible.

Impacts on Daily Life Functioning

Everyday functioning was significantly disrupted for many participants during periods of heavy ketamine use. Pain, incontinence and physical deterioration forced some individuals to become housebound or even bedbound, leading to unemployment, financial instability and a loss of social engagement. Basic hygiene and nutrition often declined: participants described eating infrequently, neglecting hydration and lacking the emotional energy required for self-care.

Managing physical symptoms became a constant challenge. Some individuals attempted bladder retraining or self-diagnosis due to limited access to appropriate healthcare support. These ongoing difficulties frequently created a cycle of shame, secrecy and further isolation, making it harder for individuals to seek help or maintain routines.

The loss of structure, identity and independence contributed to worsening mental health. Several participants reported reaching crisis points without receiving adequate follow-up support from services. The combined impact of physical and psychological decline highlights the urgent need for robust aftercare systems, practical day-to-day support and psychological services tailored to the specific challenges associated with ketamine-related harm.

> *"I had to leave work and now wear incontinence pads, having previously spent 80% of the day on the toilet. I became bedbound due to pain, cramps, bladder and kidney problems, also losing my appetite and emotion."*

Key Insight

Heavy ketamine use severely disrupts daily functioning, with pain, incontinence and physical decline leading to isolation, loss of independence and worsening mental health. These combined harms highlight the need for strong aftercare, practical day-to-day support and tailored psychological services.

> "I've had to cut off every single person who's like that. No offence to them, but I can't be a part of that anymore if I want to do better in my life."

Recovery Approaches and What Works

Effective Support Approaches

Despite the challenges described, many participants identified clear factors that supported sustained recovery from ketamine dependency. Small support groups were highlighted as particularly effective; their intimate size fostered trust, privacy and deeper conversation, enabling individuals to share difficult experiences without fear of judgement.

Peer-driven recovery models were also highly valued. Participants noted that the flexibility, warmth and lived-experience knowledge within services, such as CGL, created a safe and supportive environment for change. This peer-led approach was seen as central to helping people feel understood and less isolated.

Internal motivation emerged as another critical element. Participants emphasised that lasting recovery required personal commitment, behavioural change and, in many cases, the painful decision to cut ties with social networks where ketamine use had been normalised. For many, distancing themselves from using peers was essential to reduce the risk of relapse.

> *"Peer support, where you can lean on one another, is important... I come here and I feel safe."*

Across accounts, participants described how a combination of structured peer support, trauma-informed facilitation, consistent workers and opportunities for skill-building contributed to long-term improvement. These insights suggest that recovery is most successful when support systems are empathetic, peer-informed, and focused on empowerment rather than judgement.

> "Having a consistent support worker is important to build trust and avoid repeating my story."

Key Insight

Recovery is supported by small, peer-led groups, psychological safety, consistent workers, and behaviour change—often including distancing from using networks..

In Summary

This lived-experience insight shows a consistent pattern: ketamine use in Norfolk brings serious health and social consequences, while gaps in understanding, stigma and fragmented pathways often prevent people from getting timely help. At the same time, participants are clear about what genuinely supports change, knowledgeable clinicians, continuity and safe peer-led spaces that build trust and stability.

Key Points at a Glance

- Social normalisation, in nightlife and friend groups, lowers perceived risk and leads to rapid escalation.
- Motivations shift over time, moving from escape and social connection into dependency and routine.
- Severe health harms include bladder injury, chronic pain, malnutrition, liver/kidney issues and being housebound or unable to work.
- Social impacts include isolation, loss of relationships, loss of routine and unsafe coping strategies when services fall short.
- Barriers to support include limited ketamine knowledge among clinicians, stigma, delayed referrals and inconsistent follow-up after crises.
- What helps is consistent: small peer-led groups, trusted workers, ketamine-literate clinicians and trauma-informed approaches.
- Recovery is possible when people feel understood, supported consistently and able to distance themselves from using networks.

In Conclusion

As a peer-led project, we are privileged to hold people's stories with care. Across Norfolk, individuals have shown honesty and courage in sharing how ketamine has affected their health, relationships and daily lives.

Their trust in us reflects what peer-led, trauma-informed spaces make possible: safety, understanding and the confidence to speak openly.

The themes in this report highlight a simple truth, people engage and begin to recover when support feels consistent, compassionate and informed. Small peer-led groups, trusted relationships and workers who understand ketamine-related harms create the conditions for hope and change.

As we continue building the SULE Recovery Community, our focus remains on ensuring people feel seen, heard and valued, with lived experience continuing to shape how the system responds.

Thank you!

We would like to thank all participants who took part in our research and focus groups

Contact Details

Jamie Barnes
Project Coordinator SULE
jamie-barnes@together-uk.org
07521 430272

Claire Woodcock
Service Manager SULE
claire-woodcock@together-uk.org
07880 191236