

Cross-Party Group Minutes

Meeting Minutes:

Cross Party Group Title:	Substance use and addiction
Date of Meeting:	29.01.2025
Location:	Seminar Rooms, Pierhead Building and Teams

In attendance:

Name:	Title:
Peredur Owen Griffiths MS/AS	Plaid Cymru Member of Senedd for South Wales East
John Griffiths MS/AS	Labour Member of Senedd for Newport East
Jane Dodds MS/AS	Liberal Democrat Member of Senedd for Mid & West Wales
Jo Moore RGN, Guest Speaker	Registered Manager of Birchwood @ Kaleidoscope House Detox and Rehabilitation facility
Peter Furlong, Guest Speaker	National Harm Reduction Lead, CGL
Martin Blakebrough, Facilitator	CEO, Kaleidoscope
Cris Watkins, Secretary to the CPG	Executive Assistant to the CEO & Board, Kaleidoscope
Eleri Morgan, Translator	Senedd Staff
Sector Wide CPG Distribution List	
Gareth Llewellyn	Senedd Staff
Mark Tudor	Mark Tudor Consulting
Rachel Martin-Suarez	CAVDAS
Ruth Bowley	RD&I Lead, Kaleidoscope
Thomas Lavery	The Wallich
Sioned Hughes	Kaleidoscope Campaigns & Communications Lead
Amy Gillard	Barod CYP & Family Intervention Team Leader
Geraint Davies	Substance Misuse & Harm Reduction Coordinator
Danielle John	Cyfle Cymru C&V Team Leader
Anthony Vaughan	Head of PIE Operations & Therapeutic Services, The Wallich
Andrew Misell	Director for Wales Alcohol Change UK
Nev Brooks	Powys APB
Dee Davies	Nurse Manager Alcohol Team Cardiff CAU
Rosey Stonehouse	CAVDAS
Ross Woodfield	CAVDAS
Joshua Hapgood	Barod Recovery and Prevention Team Leader
Louise Edwards	Healthcare Development Manager, Ethypharm



Becky Twose	Policy Advisor Dyfed Powys OPCC
Neil Harding	CAVDAS Service Manager
Jan Melichar	Chair of the RCPsych Wales Addictions Faculty
Gareth Morgan	Commissioning Manager: Substance Misuse Harm Reduction & Intelligence CAVUHB
Andrew Cresswell	Cardiff University, School of Pharmacy and Pharmaceutical Sciences
Zoe Jenkins	Salvation Army - Programme Manager
Hugh Carter	Salvation Army - Service Manager
Zoe Low	Salvation Army - Outreach Worker
India Taylor	Peer Mentor - Cyfle Cymru/CAVDAS
Martin Canning Matthews	AFYX
Jon Findlay	Waythrough National Harm Reduction Lead
Caroline Davies	Adferiad - Head of Treatment Services
Jane Turner	Adferiad - Treatment Services
Luke Jones	GDAS Treatment Practitioner
Donna Brown	GDAS Peer Volunteer
Rhys Morgan	GDAS Peer Volunteer
Jane Mudd, PCC	PCC for Gwent
Elwyn Thomas	Kaleidoscope National Co Production Lead
Rick Stephens	Director Phoenix Heroes
Lisa Buckley	CGL National Detox & Rehab Lead
Rondine Molinaro	Head of Service, GDAS
Nicola Cook	Swansea Bay UHB
Vicky Williams	Co Production Coordinator
Mark Tudor	Mark Tudor Consulting
Rachel Martin-Suarez	CAVDAS
Ruth Bowley	RD&I Lead, Kaleidoscope
Thomas Lavery	The Wallich
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Amy Gillard	Barod CYP & Family Intervention Team Leader
Geraint Davies	Substance Misuse & Harm Reduction Coordinator
Mat Jones	Voices Action Change Rep
Online	
Alison Chapman	Post Graduate Researcher, USW
Rachel Axon	Barnados CYP Substance Misuse Service
Amy Williams	Substance Misuse Project Manager
Vicki Hillier	Dyfodol Service Manager Western Bay
Elizabeth Bond	BCUHB
Nicky Evans	Team Leader, YP Drug & Alcohol Team

Alaw Thomas-Davies	PHW Senior Public Health Practitioner
Oliver Townsend	Platform Policy Development Lead
Sian Roberts	Barod Operations Manager
Robert Green	CTMUHB Consultant in Public Health
Huw L Williams	CTB Substance Misuse APB
Ben Langwith	Powys Co-Production Coordinator
Louise Channon	Cardiff CAU
Kelly Arnold	Interim Service Manager Harm Reduction & Helpline Services
Zelda Summers	CAVUHB Consulting Psychiatrist
Kirsty Jones	Barod Early Intervention & Engagement Team Leader
Luke Ogden	BCUHB Helplines Wales
Kerry Bailey	Consultant in Public Health - PHW
Euan Hails	Adferiad Clinical Director
Claire Morris	Drug Poisoning Prevention and HR BCHUB
Kirsty Brooke	Drug Poisoning Prevention and HR Lead BCHUB
Paul Firth	Flintshire CC - Regional Commissioning and Development Officer
Sian Bunston	RCT APB
Hannah Phillips	RCT APB
Cath Nolan	Adferiad
Gary Evans	Swansea Bay UHB Nurse Specialist NMP
Gill Rafferty	Swansea Dept of Psychiatry Substance Misuse Clinical Nurse
Emma Adams	CDAT Specialist Clinical Nurse
Greg Robinson	Senior Nurse CTMHUB Substance Misuse Services
Leanne Dalton	AHB APB Substance Misuse Team
Maria Evans	AHB APB Substance Misuse Lead Officer
Emily Dibdin	Clinical Lead for Secure Environments and Substance Misuse
Sarah Hanson	Substance Misuse Nurse Swansea Bay CDAT
Emma Adams	Substance Misuse Nurse Swansea Bay CDAT

Summary of Meeting:

CPG AGM (followed the initial presentations outlined below, but presented first for clarity)

Peredur Owen Griffiths welcomed both in-person and online attendees to the Annual General Meeting.

Peredur Owen Griffiths stood to be Chair. Senedd Members attending confirmed there were no other nominees. Peredur Owen Griffiths was duly elected by a show of hands.

Peredur Owen Griffiths proposed that Kaleidoscope continue to provide Secretariat support to the CPG.

The group approved the nomination by a show of hands. (Crispin Watkins from Kaleidoscope to act as Secretary)

Peredur Owen Griffiths (PG) suggested this group can help driving positive change in Wales especially in terms of the NHS and Social Care. This can be achieved through providing input to Welsh Government but also as a Cross Party Group by helping inform manifestoes. So for example today via Peredur Owen Griffiths (Plaid Cymru), John Griffiths (Labour) and Jane Dodds (Liberal Democrats). All parties have an opportunity to recognise the importance of Harm Reduction in our health and social care services, and informing our approach through active engagement with those with Lived Experience.

Martin Blakebrough (MB) reminded the Cross Party Group that no one party nor any one provider determined the agenda for these meetings and invited all participants to consider topics they felt might be worthy of bringing to the CPG's attention during 2025 and beyond.

Lot of love in the room

PG noted he has been talking to the new Minister to get her to the next meeting so she can hear the Lived Experience directly. This group has always provided an opportunity for Senedd Members and Ministers to get direct understanding of that experience in a kind way (rather than berating them for 'not doing something'). PG stated the hope that Sarah will come to next meeting to discuss some of the challenges facing Wales in terms of substance use and addiction.

Jane Dodds (JD) asked about gambling-related Harm Reduction methods and asked if we could do a joint group to present to the Senedd looking at the cross over between both areas.

MB noted Adferiad who are also a partner agency have a specialist unit for gambling.

ACTION: Secretariat to approach the Gambling CPG to explore this possibility.

The AGM closed with PG expressing thanks to all participants for another session of positive engagement.

CPG Meeting Opening remarks and formalities

Peredur Owen Griffiths MS welcomed everyone to this Cross Party Group on Substance Use and Addiction.

This event sought to explore the dramatic rise in ketamine use and ketamine related harms and harm reduction, as well as the unique challenges faced by providers of detox and rehabilitation services to the most badly afflicted.

Summary of Speakers:

Peter Furlong, National Harm Reduction Lead, Change Grow Live (CGL)

Peter spoke to his slide deck. A key theme with ketamine is that Services are not seeing people until too late. Today is first of many events across the UK exploring the rapid rise in ketamine use and associated harms.

Peter commenced by saying he personally could not see the reason for the proposed reclassification of this drug to class A as other such reclassifications have brought no benefit in terms of reduces usage but does result in an increase in criminalising users. Criminalising drug users has been consistently demonstrated to increase rather than decrease the harm of substance use.

In terms of ketamine in England there is a clear escalation in use in young people and children, from age 13 upwards.

ONS statistics suggest circa 300,000 users. These are English figures but seem to be replicated across the UK. 15-18 year olds are the biggest user group.

One of the drivers appears to be a 'post pandemic hangover' of use and behaviour. During the pandemic party drugs weren't the thing. 'Users didn't want to take MDMA in their house during lockdown' so moved to drugs with related but distinctive effects. This is where the rise in ketamine use really started.

In recent months Peter has been working with Harm Reduction leads in CGL, Turning Point and Way Through to compare experiences, and these data in the slides reflects this common experience.

Ketamine is like a 'new heroin' in terms of the widespread use and impact. A key issue is that 'it is socially acceptable' compared to other drugs. So, for example, within the substance using communities cocaine users can sometimes be regarded as 'a bit shady' but ketamine use doesn't carry the same stigma. The fact there is no comedown experience for users is a key driver of this perception.

Relative price is also a factor. For example it is currently as cheap as £10/g Liverpool with an average of £20/g and peak as much as £25/g. Cocaine by comparison can be £30-£50/g. Ket is 'okay to buy' unlike other drugs. Users clearly think the lack of comedown means that people feel they are 'getting away with it' and there are no consequences.

In the student population in Manchester ketamine is also cheaper than other substances, both legal and illegal and the lack of comedown, especially compared to beer, is often cited as a benefit of the drug.

Ketamine is also used by students to help with anxiety. Some cite it as 'really useful' for their experiences and pressures of University life, and in the absence of substantial mental health support for young people ketamine is used for self-medication.

Peter spoke to the quotations from users in the presentation – for example “thing is the next day I’m going to feel completely fine, there’s not gonna be a repercussion in that way like not even close to a hangover!” (23-year-old male, Salford).

Critically in terms of the rise in usage Drug and Alcohol Services are not seeing people until it is too use. GPs need to be asking ‘are you using ketamine’ to detect the source of bladder problems etc. that might be presenting in surgeries. Users are bypassing Tier 1 and Tier 2 services and ending up directly in detox and rehabilitation services.

Useful Links:

- Website:
<https://www.changegrowlive.org/ketamine-uk-advice>

Jo Moore RGN, Registered Manager – Birchwood @ Kaleidoscope House Residential Detox and Rehabilitation facility

Jo started by stating she has seen the escalation in use described in Peter’s slides over the last two and a half years in terms of patients coming in to detox and rehab. ‘The pace of change is something I’ve never seen before in health and social care.’

Jo’s slides started with photographs of service user’s urine (images provided with consent) to show what the quantity of blood in the urine looks like. Consent was given by service users who are trying to help educate others as to the consequences and risks.

Before continuing Jo gave a Content Warning in terms of images and descriptions that would follow.

JM spoke to the extensive physical complications detailed in the slide deck.

From a detox perspective the Birchwood staff’s experience is that GPs aren’t always asking the correct questions to help refer service users to drug and alcohol services and detox/rehab facilities early enough.

As a consequence of this late referral and the severity of impact of excess ketamine use ‘I’ve not heard the shouts that I’ve heard before of the people who are passing these blood clots in our treatment facility’. The passing of these clots can lead to prolapse.

‘Can you imagine an 18 year old presenting to services with a prolapse? And identifying as doubly incontinent?’ The severity of the physical impact of use sometimes over just a one to two year period is leading also to a deterioration in the relative mental health of residential patients.

‘We see people who too late to help.’

Residential inpatient facilities provide the best results in general in terms of both drug and alcohol detox and rehabilitation as they take service users away from the communities in which the substance in question is used.

For ketamine in-patients pain management and incontinence are the two biggest issues faced.

Long term sobriety is the goal. However, services need to be wrapped around them to support them going back into the community environment.

Sometimes our facility is told by referral agencies that 'they haven't even lost their bladder yet' which is a sign that people are being referred to us too late and the understanding in referring agencies can be limited.

There is a cost to primary NHS care on a long term basis, often for the rest of their lives, of late detection and referral.

'We've seen heroin users of 20 years experience and not seen as much damage as a ket user of 2 years.' Service users have been known to advise each other that 'its better to take Heroin than ket'.

Jo presented data on the last 33 ketamine users who attended Birchwood. It is an older demographic than shown in Peter's data, which is not unexpected as the impact of prolonged usage can come a little later.

There is very limited instances of poly drug use.

There is an issue about how few users access rehabilitation post-detox? These people often need prolonged care yet less than a quarter access residential rehab post-detox. Referral agencies often underestimate the importance of rehabilitation for this cohort of users, whose physical impacts can be life changing.

Relative to other substances there is reasonably low unplanned self-discharge of patients from the facility, and the two examples shown in the last 33 attendees were readmitted.

What can GPs surgeries do? Firstly educate the front line receptionists in GPs about ketamine. Some front line staff report to users 'it isn't addictive' but that is incorrect. Combined with this lack of information the lack of stigma around usage (in other circumstances it is a medically prescribed drug) mean there are no barriers to use.

Jo noted that Birchwood sometimes has CYP referrals but it is an adult service so has to quickly hand off to other parties – however there are only 2 sites with a combined 5 places for 16 to 18 year olds in the entire UK who handle young people's referrals for ketamine.

As ketamine itself isn't an opioid drug and alcohol services often don't give out naloxone however ket is often mixed with synthetic or plant opioids. 'I have had families desperately running around pharmacies looking for naloxone' as a result.

The conversation around ket needs to be normalised to remove barriers to access services.

It would be good to have someone in each area who is up to date with the trends in substance use and telling peers.

Jo reported 'I've been in A&E twice this week to explain to Doctors and Nurses what we do in an inpatient service as the knowledge level is very low.'

Another challenge in terms of dignity and stigma is that incontinence pads are really expensive. Again NHS services require the knowledge of ket to ensure these pads are made available to patients.

In one case a mother found 6 bin bags of incontinence pads in the wardrobe in the bedroom as the first sign their child was using ket.

ENT is a service attended for nasal collapse due to the nature of the crystals which can be sniffed. Some users refer to it as like 'sniffing broken glass'.

Generally urology won't touch a ket user for 6 months of abstinence. But what happens in the interim? The pace at which lasting harm can hit a user is huge, and the harms are substantial. Increased testing for urology and hepatology is needed. A 6 month wait to be seen is too late. In some cases a service user will be dead by then.

Users will not stop until they can access inpatient treatment so harm reduction advice is key. For example there are increased deaths post bathing.

Testing kits are vital to find nitizine, fentanyl xylacine

Jo presented a case study. The service user used pads to urinate and pass clots on the floor in a squatting position because he couldn't stand up to urinate.

When he entered the facility he was bed bound. He has now moved to a wheel chair and is just starting to relearn how to walk. He had previously been a body builder. It is hard to get physio referrals to come to an inpatient unit as they are unaware of the cause and need and question if they should be attending such a location to provide assistance.

Jo showed a number of images of a service user who wished his case study to be used as a communication tool with others. 'I thought when I set eyes on him I'd seen the worst. But it is already getting worse than this.'

Useful Links:

- Birchwood @ Kaleidoscope House Residential Detox and Rehab facility:
<https://birchwood-detox-rehab.com/>
- YouTube Video – Service User Story – **CONTENT WARNING** – contains graphic images and descriptions of the physical impact of excess ketamine use:
<https://www.youtube.com/watch?v=Sb-RBYCSG9Y>

Summary of Questions, Comments and Suggestions Raised:

PG started the Q&A session by stating 'That was harrowing and fascinating. What we try to do is learn from your experiences and see what we can replicate here in Wales and what we are and aren't doing here by comparison.

What struck me is 'in all your years working in the field the dramatic nature of what is happening' One question is 'why now'. Just post pandemic? Is there an issue of high availability?

Jo Moore (JM) replied Self-esteem, depression and anxiety are all factors. It is a 'good' drug to use alone, per the service users reports. It was a party drug but quickly becomes someone in their bedroom using alone. I have looked on Snapchat and Tiktok and if you want it is there, and there in 5 minutes. Cheaper than alcohol. So availability is a factor.

PF One of the main things is that people who use it think they are getting away with it. Can wake up next day and go to work/school/college. Can sleep on it. It is cheaper than cocaine. Anxiety is a BIG issue in Manchester University and John Moores. It is replacing Xanax as the substance of choice to deal with that issue. Anxiety is a big thing for young people in general and in the absence of decent mental health services service users find this is a cheap quick fix to that.

PG what about the change to class A?

PF – it went from C to B and use went up. All you get at class A is criminalising young people. Not sure what the ACMD will do with a referral on this decision but the evidence suggests it would be a bad idea to change the class further.

Rondine Molinaro (Gwent Drug & Alcohol Service) I agree with PF re: reclassification. Seeing similar patterns in Wales and Gwent. We had first ket death recently – a 25 year old girl. Used pads which were all over her accommodation. She had been evicted from several premises due to the smell of urine. Didn't attend urology appointments - unknown as to why – perhaps pain? A question for me is there resource there in primary health care to educate staff and in turn guide patients appropriately? We need a message out there for users to go to their GPs as early as possible.

JM – We need to get GPs to ask parents to leave room to facilitate a 'very honest conversation with the client' due to the age of clients.

PF – Another factor is that in urology there is a lengthy waiting list but the GP referral says ket is referenced it will accelerate the client up the list – but the GPs aren't referring to ket use so people aren't moved up the list.

Elwyn Thomas (Kaleidoscope Co Production Lead) – In Bridgend at present you can get ket 70/30 mixed with coke £25 for 3.5g or a tenner a gram. The price doubles going to a club. On the street £10. In years past it would be cooked. Now it is coming from synthetic labs where it is concentrated and strengthened. It is stronger today than it was 17 years ago when it first arrived.

JM Ket is so normalised that women in particular are putting it in tea for weight loss.

Comment from the audience – There is availability in the internet enabled market. I could order today for next day delivery online. Could order on the normal internet (not dark web) and order several kilos. I've met young people who are playing computer games whilst on ketamine. The way people use drugs has changed. People now are having drugs delivered to their bedrooms but still connecting socially (digitally). Harm reduction advice needs to go online to engage with people. There is a fear that we shouldn't put our information on those platforms. The young people I work with don't Google things, they use TikTok and social media apps. No one talks to Frank or Dan (the public drug healthlines). We need to move our harm reduction advice to where the users are. There are Tiktok channels for people going around toilets in the UK getting 20 million hits talking about the best toilets to snort coke in.

PF I know a 26 year old who doesn't use ket and states 'the young ones use that, then have a tablet (of ecstasy) before going into town'. I asked what do the older ones like you use and was told 'Coke'. How do we get to these young people? My own service CGL cant use TikTok because the Ministry of Justice say that software would invalidate our contracts.

MB Is there a point that across the UK Harm Reduction leads need to come together and ignore boundaries but go onto these platforms to share experiences. Maybe some charities can go on behalf of the whole movement in this time of crisis.

PF Yes we need to come together as a sector – if we can't do it in England but you can in Wales then by coming together we can help everyone'

Audience question: The Leah Betts one tablet kills you message doesn't work. We need to find out how much real drug causes harm

JM we still don't have the data on how much causes harm but it depends on their physical health as well and what they've already done to themselves.

Audience question: If the bad results don't come through scare tactics do we need more evidence?

PF affordability and price is a big thing.

Audience comment: a night out versus heavy use needs to be better understood by HR advisors to be able to speak the language

Elwyn Thomas: We have an opportunity through lived experience peers to provide advice based on experience that people will listen to.

Andy Westwell – Cardiff University School of pharmacy – Chair of the advisory group for WEDINOS. Ketamine hasn't really showed up much in testing which suggests we are just catching the tip of the iceberg and we aren't really engaging with this world at the moment. I agree with there being no sense in reclassification as it won't change the nature or use of the drug or help people. We are really interested in dosage and purity. It sounds like what people are buying pretty pure ketamine that is almost essentially 100% ket. In terms of the engagement that harm reduction messaging is clearly key. We have to get people somehow away from this substance.

PF we are not going to stop ket use. We need to involve that wider system – GPs and primary care – anyone who gets UTIs on a common basis primary care has to recognise that's not normal and ask about ketamine.

Caroline Phipps (CEO Barod) - In Barod we've developed some interactive and digital methods in the Children and Young People's service using the voices on YP who've used it and getting those messages to professionals and older people like us to need to hear the messages.

JM Seems to me that as I talk to service users I learn more from them than anywhere else. Professionals will listen to me but people who use the substance only listen to peers.

Question online – What are the rates of relapse after detox?

PF limited understanding but I believe rates are quite low, due to the intensity of the experience.

MB – Drug and alcohol services typically see 75% men. But in the ket field it looks like 50/50. So we need to think a lot more about engaging with women?

Often our videos are men speaking and we need more voices of women speaking to women.

PG interesting that the poly drug use is almost zero. How do we communicate across the generational gap? And how do we get the message to Welsh Government around development of policy in NHS to highlight this? Good to see John Griffiths in the room here today MS for Newport to work out how to engage with the Minister.

MB There is an online question about what should we do about under 18s? Birchwood is looking at under 16s.

There are only 2 detox/rehabs in UK with 5 places between them for 16-17 year olds.

ACTION CW to share slides

PF It is so important to get GPs to ask the question 'do you use ket?'

Rondine Molinaro asked - Does Birchwood see people with engaged family members or are they are often in care or something else?

JM Mostly it come from family members as referrals. Currently setting up a family group using the 'bag for life' logo as a hard hitting image targeted at adults who need the impact and advice to get youngsters to GPs urgently.

Audience question: I'm getting GPs and A&E discharging people as soon as they know ket is involved.

JM Yes that stigmatising needs to end

Question Regarding taking ket then a tablet before going out. In Wales how about renting or posting in public transport and trains (most come in to the city centres by public transport). Might be a subliminal way of getting that information to young people.

Audience commence: Also toilet doors

PF yes getting someone to think for one minute is key

MB just to assure people online we will take some of those questions are record them and share with the speakers so they can give some answers.

PG summarised the conversation. 'There are some really hard hitting conversations but that talks about what's affecting our communities and making it a live issue rather than a dry report. Thank you to the speakers and to those here and online.'