

Luminus

Quarter 2: Insight for Combating Drugs Partnership Board Public Involvement

October 23



● Shining a light on what matters to people.

Quarter 2: Insight for Combating Drugs Partnership Board Public Involvement

October 2023

If you would like a paper copy of this document or require it in an alternative format, please get in touch with us.

Involvement Strategy 23-24

Shining a light on what matters to people.

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- Public involvement**
Led by the Engagement Manager and Engagement Officer we will deliver a programme of face-to-face activity across Surrey.
This will entail 4-5 events per month in community settings, groups or clinical break out spaces to speak to those most at risk of health inequalities.
We will focus the engagement to support the CDP in delivery of their objectives.
- Whole system working**
Developing and nurturing stakeholder and provider relationships.
Stakeholder mapping, regular networking and meeting to ensure cohesive working.
- Signposting**
Ensure our signposting information is up to date, accessible and available to people wanting to access services. Highlight any gaps in signposting.
- Comms and awareness**
Using our established channels to communicate our service and call for evidence and experiences.
Develop literature and marketing materials to hand out to public and share with stakeholders.
- Reporting**
We will produce a quarterly insight report to share with commissioners and the wider CDP. We will also use our insight to feedback to those that have shared experiences with us.

Communications

Some examples of the literature we produced to promote our service during Q2:

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We are an independent service, listening to people affected by substance use and their experience of treatment, recovery and support services.

This includes people with lived experience, their families and networks, individuals impacted by the effect of substance use through their communities and those who have been victims of drug-related crime.

We are also keen to hear from people with lived experience who choose not to access treatment services so we can understand barriers to accessing help and support.

0303 303 0023
07592 787533 (text only)
info@luminus-cic.uk
<https://luminus-cic.uk/services/public-involvement-for-the-combating-drugs-partnership/>

Luminus - shining a light on what matters to people

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Thank You

Thank you for sharing your experience of treatment, recovery and support services with the our engagement team.

Feedback is shared anonymously to help providers of services and decision makers understand what they are doing well and what might need to change.

For further information and advice, or if you or someone you know wishes to share another experience, please contact:

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07592 787533 (text only)
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<https://luminus-cic.uk/services/public-involvement-for-the-combating-drugs-partnership/>

Examples of the social media activity during Q2



Ensure the voices of a range of members of the public are heard:

Our area of focus for Q2 was supporting the CDP to achieve their ambition in response to a governmental drive to increase numbers in treatment.

We aimed to:

- To understand barriers to accessing treatment, what can be done to overcome these barriers from the perspective of the individuals and their families/networks.
- To raise awareness of our new public involvement service through communications, engagement and stakeholder meetings.
- Signpost individuals/their families to services when on engagement.

Public involvement activity in Q2

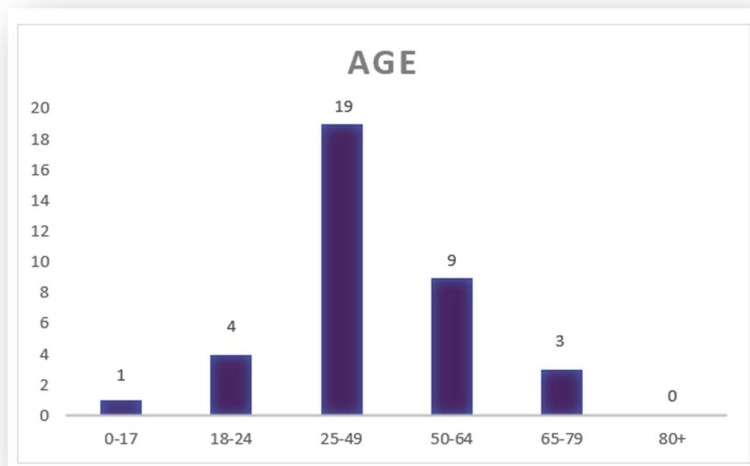
We spoke to **87** people about our public involvement service and **36** individuals shared in-depth experiences with us.

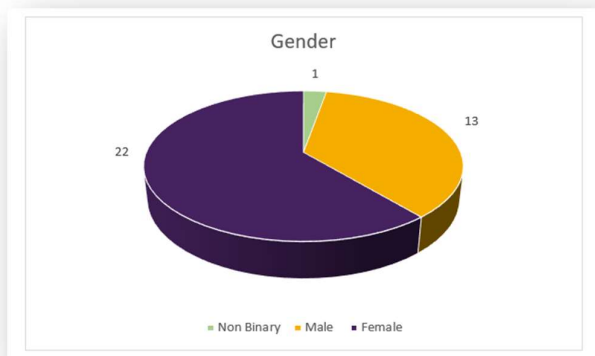
During the quarter, we visited the following places;

Quarter	Month	Where we went	Town
Q2	July	Carers Fair	Guildford
Q2	July	Al-Anon	Farnham
Q2	August	Twister	Twister
Q2	August	Veterans Hub Guildford	Woking
Q2	August	St Saviours	Sunbury
Q2	September	Freshers Fayre	Redhill
Q2	September	CDP Engagement	Guildford
Q2	September	Merland Rise Foodbank	Tadworth
Q2	September	Social Media Poll	Online
Q2	September	York Road Project	Woking
Q2	September	Holy Trinity Food Club	Woking

Demographics

We collected the demographic information for the 36 people that shared their in- depth experiences with us.





What we have heard in Q2

There were a number of key themes that emerged from our public involvement this quarter:

- Barriers to access
- Communication & signposting
- Mental health and substance use
- Continuity of care & establishing trust

Barriers to access

People have us told us about different barriers to them accessing treatment and support services, these include:

- **Stigma:** not wanting to acknowledge a problem for fear of repercussion/people finding out.

"Never in a million years would he go to the GP about his problem." Female, White British, 25-49

- **Treatment/support:** not meeting the need/expectation of the individual.

"I tried AA but didn't like the group environment, I need 1:1." Male, 50-54, White British, Foodbank

"AA doesn't work for me. You start to realise that most are opposite a pub. I went to two different ones and ended up across the road drinking. I had to leave." Male, 25-49, White British, Food bank & homeless

"I know I must sort myself or I will be back inside. I did attend an AA meeting in prison. But I couldn't really say much. Inside, you must be tough, not show weakness or vulnerability." Male, 25-49, White British, Homeless

- **Treatment time:** not long enough / no follow-up / individuals dropping out of the system while waiting from referral to treatment.

"I was given 12 hours by Talking Therapies. I was pleased at first, but I had just started to trust this counsellor and unpick my issues and my hours were over." Male, 25-49, White British

"To be honest I feel I-Access is like a drug dealer, it's just another drug. My drug dealer asks me more questions and is friendlier than I-Access! It isn't person centred at all. I am a tick box, don't feel like anyone cares about me at all. Methadone is harder to get off than crack! I do everything old school, I am in my 40's. I don't use social media or snapchat this and that. I contact people via text. It's so bloody expensive. One good thing I-Access did do, is refer me to social services [with my permission] to get some help. It's taken 13 months to get someone in to assess me." Male, 25-49, White British, Foodbank

"With I-Access, there is no follow-up. Once you've engaged with them, that's it." Female, White British, 25-49, Probation

- **Rigid processes:** to access some services doesn't work for all. e.g. probation, domestic abuse, mental health.

"There is a 3-week window often to wait after initial contact with treatment services, until treatment. No one keeps an eye on these people during this time, so it is down to other services to hand hold / stay in touch." Female, 25-49, White British, Surrey Police

- **Mental health:** not acknowledging there is a substance problem as their mental health issue is not being addressed and the substance is being used as a coping mechanism.

Historical experience: past experience or perception of a service can make people reluctant to re-access.

"I have tried this in past, but they wanted total abstinence. I don't want to do that. I want to cut down from 8 cans a day to 4. I also struggle with people and wanted it to be remote and they said it was ok." Male, 18-24 White British, Food club

Communications & signposting

We have heard a number of experiences about the challenges people face trying to get up to date and correct information to access support and treatment services (both PWLE and VCSE orgs). This includes:

- **People not knowing how or where to find information**
- **Individuals not knowing they can self-refer to services.**
- **Frontline workers, e.g. GPs, not having (or not giving) the signposting information**
- **Individuals and VCSE/support organisations having to work to pull together information themselves about the services available.**

"I didn't know where to get information from so I researched myself online." Male White British 25-49

"We had no information about treatment or recovery support organisations. I found out about Al-Anon through a friend". Male, White British, 25-49

"I didn't know I could self-refer. My GP referred me to I-Access 2/3 weeks ago. I have a telephone appointment in a few days." Male, 18-24 White British, Food club

"I wish my GP had told me about this service, I'd have come sooner." Female, White British, 25-49, Al-Anon

I don't think all health care professionals are aware that you can self-refer. Your information and knowledge is only as good as the person you are dealing with." Male White British, 50-64

"After my ex called me saying he was going to die, I tried every service available: Samaritans, Police, AA. I felt that everyone pushed me onto a different service." Female, White British, 50-65

"We need more cohesive working and clearer information for people to see their treatment options." Male, White British, 25-49,

"I've researched a lot of addiction websites and resources, a lot of them have hotlines that are not even open when you might be really in need." Female, White European, 25-49, Foodbank

Mental health & substance use

Building on what we heard in Q1, more people have told us about the challenges faced accessing services when experiencing both mental ill health and substance use issues (Dual Diagnosis). When an individual needs treatment for both, but this cannot be done at the same time, they can end up bouncing between services and help for either issue is then not accessed. Also, we have heard from people when they can't get help for their mental health condition, they use the substances as a coping mechanism so don't want to stop and this prevents them seeking help.

"I went to the GP about 2/3 weeks ago to ask for help in reducing my drinking. I have tried to use them before, but they wanted me to totally stop, and I can't and don't want to. This time round they said they will work with me to reduce my intake. That is what I want. I have drunk more in the last 7 years because my parents died. I didn't get any help at the time, and it's really affected me. I struggle with people and prefer remote. They are calling me in 2 days time and say they can work with me remotely, so this suits me. I didn't know I could self-refer. I am struggling with my mental health. My church near me, help support me and give me strength to cope with my mental health". Male, 25-49, White British, Foodbank

"Being sent to prison, [Send] saved my life. I got 1:1 therapy and diagnosed with borderline personality disorder. Mental Health won't touch you, until you've accessed treatment for substance misuse. I drank with medication, and it was intentional. I have overdosed twice on my medication due to hip pain and anxiety. I still self-harm but I don't do drugs now. I do drink to block stuff out." Female, White British, 25-49, Probation

"I have suffered with my mental health for years due to trauma and military. I was referred to Farnham Road, but my psychiatrist didn't even turn up. I was sober for 5 years, lost my license due to drink driving. I went to rehab. But with the pain I have, I now feel bullied at work. I drink most days." Male, 25-49, White British, Veteran

"My daughter drinks to black out. She associates with the wrong people. Last year she got raped on a date. There is a question mark over if she is Bi-Polar or not." Female, White British, 50-64, Foodbank

"I am constantly moving, and my head is active. I realise now that I probably have ADHD and that may explain some things especially the addiction side. York Rd is helping me getting a diagnosis. We went to see Dr Khan at Southview and he mentioned 'Right to choose' which might help us Fastrack an appointment out of county. This is hopefully going to help me understand my compulsions and possibly help me cope better. I may even be medicated as I lose concentration easily. Dr Khan is also helping me apply for some anger management but the course of treatment I'd like is not readily available in Surrey or on NHS." Male, White British, 25-49, Homeless

Continuity of care & establishing trust

Individuals have told us the importance of continuity of care when establishing trust, opening up and seeking help.

"I find it hard to trust people and be open. With my probation team, [name] really helps me. At one point she went off for 2 weeks and I would not talk to anyone else. I also think dealing with someone who has lived experience is so much better because they are relatable. But if I must change who I speak to, it's so triggering. I trust one person and build a rapport and then to start again is so hard. York Rd is trying to build my resilience and encourage me to share with a few people, not just one, but it is hard." Male, White British, 25-49, Homeless

"I have engaged with I-Access myself once. I was doing well but then the lady moved Redhill location to Essex, she is still with I-Access. I was drinking a litre of Vodka per day and 6 cans of high strength lager. Now I am on 4-6 cans of normal strength lager per day. She helped me cut down. I just don't seem to do well with staff changing all the time. It's not necessarily their fault but the man that replaced her wasn't nice. I was discharged from the service 4 months or so ago for DNR. I know I have no excuses for missing the appointments. If you want reality, I was off my face on booze. I know I have to re refer myself again. But I just want to do it in Essex so I can meet with the person that was helping me. I need to trust someone and get on with them. They have said they are considering letting me go if I can cover the travel, it's about budgets and stuff." Male, White British, 25-49, Food Bank

"Are you with the police? Or Council? I will speak with you if not." Male, 25-49, White British, Foodbank

"For information I wouldn't really use the internet or read up. I would only ask a trusted person like [name] at York RD or my probation lady. But I think a one stop shop flyer would work if it showed me all my options." Male, 25-49, White British, homeless

Cuckooing

"I have fallen prey to people who have come in to my privately rented flat in Redhill and run their drugs from there. They are savvy, they befriend multiple people and stay a few days at several places. They wanted me to do their running for them. They gave me some stuff for free which last like minutes and then wanted me to do all the work. I refused and luckily I was able to get them out. I know others that have lost their accommodation because of it." Male, 25-49, White British, Foodbank

Positive feedback

We have also heard examples of how important the services can be for those who do access them. The right support can be life changing for the individual and their networks.

"Catch 22 helped me so much. I am 5 years sober thanks to them." Non-Binary, 18-24, White British, LGBTQ+ group

"I-Access worked with me in prison [Bronzefield] to put me on a Methadone programme to reduce my intake." Female, 25-49, White British, Probation

"The person at I-Access was great and had lived experience themselves which helped reassure me." Female, White British, 25-49, Probation

"My Dad googled where to go for help and self-referred to I-Access. He found them really good." Female, 25-49 White British, Foodbank

"Fortunately, I was given a probation officer who seemed to actually care, he was like a mentor." Male, 18-24, White British, Student Fair

Case studies from Q2



41, White British, Female, Woking – Probation coffee morning

"Three years ago, I went to prison for a 1st offence. I am a mother of 3. I was charged on the Monday and sent to prison on the Wednesday. I didn't get to say goodbye to my children. It was so quick. My two youngest were picked up from school and taken into care. I am beginning contact with them again currently. I get information about how they are doing. They are actually living on a farm, experiencing things I could never provide for them. So, in some sense, it is better.

My husband was abusing my child, and I didn't report it and I was using drugs to cope. The drugs were helping me to get through a very hard time, in a very abusive relationship. I took drugs every single day. Speed and MDA mostly. We got done for the drugs and the abuse came out. I admitted my guilt immediately as yes, I knew and was 'protecting my ex' but it was such a complicated situation, he was abusing me too. It was a domestic violence situation, and I couldn't seek help easily.

I would say that being sent to prison did save my life. It enabled me to reflect and take advantage of study time and rebuilding. I was given a place on the Nexus Hub at Eastwood Park Prison, where I was sent initially. I got 1:1 therapy here and got diagnosed with borderline personality disorder. I still self-harm a lot. But I don't do drugs now. It was something just to get me through. I do drink though to block out stuff. If I needed help, I'd speak to someone at the women's centre [Women's Probation group, Woking], or from their SMART programme. I have overdosed twice on my medication for my hip pain and my back pain and anxiety.

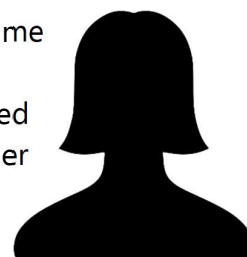
I was in [hospital] for 3 days. The mental health team referred me to I-Access. The person there at I-Access was great and had lived experience themselves which helped reassure me. I did the course I had to and go to the SMART group meetings and am now a peer mentor for the women's centre. I also did the 'Freedom' project which helped me recognize domestic abuse. I would say that with I-Access, there is no follow-up. Once you've engaged with them, that's it. And mental health won't touch you until you've accessed treatment for substance misuse.

I am now on mood stabilisers which are helping me and been on these since January this year. I have come off the anti-depressants. I have also done Dialectical behavioural therapy (DBT) whilst in prison. I probably would go to the support worker at Women's centre for support in first instance. Where I am living now isn't great. It's a tiny studio flat and my eldest child is living on the sofa with me, so we have no space from each other. I can't afford hobbies. I come to the women's centre for socialisation. I really want to work but I am now on the sex offenders register for life. It's stigmatising. I have just finished all my probation meetings so am now 'free!'"

Alice*, 46, White British, Female, Farnham – Al Anon

I have been coming here [Al-Anon] since January. I wish my GP had told me about Al-Anon as would have come sooner.

I've seen a big change in myself since coming. I'm calmer and have accepted I do not control situations and do not have the power to change my other half. I was making myself ill and miserable by trying constantly to fix him or solve it. Constantly exhausted and at a low ebb and I couldn't think positively about my life. I like a drink or two myself but no more than that.



I did used to smoke and have managed to stop myself after trying for years. I have more joy for fitness, my skin and hair have improved, and I have been telling my husband of the benefits of giving something bad up, but it fell on deaf ears.

Al-Anon, is powerful as it has created a change in our relationship and his attitude with drinking. I do believe in a higher power and think this time was meant to happen now as it's only the right time now to be able to change the addiction.

My partner has been sober for 4 months.! This is the longest time in 10 years.

His Dad died this year from Alcoholism and that and the fact that I have been going to Al-Anon, has triggered a change in him to want to stop for himself.

Nothing has worked before; he hasn't wanted to or been in right place. He hasn't taken it seriously. He did about 100 Zoom calls with AA before he went in person. Often, he'd attend those online meetings whilst drinking a beer. I staged many interventions, but it only made things worse. He would never in a million years go to the GP either. We had no information about treatment or recovery support organisations. I found out about Al-Anon through a friend.

But now he attends an AA meeting every day in person and his sponsor calls him twice a day. It is a tough bumpy journey, but I hope this is going to be our life now. He feels so much better in himself. The chaos is clearing. However, with the chaos that was, it has left some mess that was being avoided which needs to be cleared up and tackled. My husband has got us into a lot of debt which means we will have to sell our house and move to a cheaper one, but we will just have to accept that.

The 12 steps are now engrained in both of our lives.

He has had a difficult relationship with his twin children which can now start to be rebuilt.

I am also a carer for my mother-in-law who has Alzheimer's. We get some care in via Adult Social Care and rest we do ourselves.

George*, 54, Guildford Veteran

I was a serving member of the British Army. I've been sober for 5 years. I got a bike in lock down, with the cycle to work scheme. One day while I was cycling my leg stopped working. I went to my GP (Woodbridge Hill) and they said I needed a CAT Scan. I went to the RSCH for the scan and somehow the scan was lost between the GP and RSCH.



I contacted the military doctor with the support of a peer support worker from Mind Matters, SABP. I was referred over to a pain clinic (through the military). The military doctor said I need a steroid injection in my back, but he can't do any procedures, he can only diagnose and stick me back into the NHS system for the procedure. So I went back to my GP, they told me that

the referral for the injection had not been sent over to them. I feel let down by them (GP at Woodbridge Hill) again.

I have suffered with my mental health for years (trauma from youth and military) I was referred to the Farnham Road hospital to see a psychiatrist and let down- psychiatrist didn't show up. I said I was sober for 5 years, I lost my license for drunk driving. I went to rehab after losing my license, my choice. But with the pain I have and now I feel bullied at work I drink most days. I'm a driver, that's my job. After, my time at rehab, I know exactly how much I can drink and how much time needs to pass so that I can still do my job and pass a drug or alcohol test. I'm registered with I-access. A lady called [name] rings me a every couple of weeks and checks in, we've never met in person. I don't really see the point.

When I moved to Guildford from Scotland, I was put up in a Halfway house. I almost got sent to jail, it was filled with druggies, totally off their heads. I had a couple of the other people staying there ask me to look out for them because they didn't trust some of the others in the house.

***names have been changed to protect identity**

Feedback from frontline staff

DNA / Leaving treatment early

"We take a view that we understand that domestic abuse and addiction has a serious impact on your life. We know you will miss an appointment, not get to the door because maybe you needed a drink to get through the door. We call, we talk. We don't send a DNA letter. I believe with treatment; you only get 2 opportunities to engage and then you are DNA."
Women's Centre

We do refer to I-Access often/ But because the mental health isn't addressed at the same time, people don't always follow the whole treatment course, they are still needing the crutch of the addiction. They don't know other coping mechanisms because they haven't yet unpicked why they drink or use ultimately." York Rd Project

We see a lot of people that dip in and out of treatment. The process and journey is quite ridged and the type of people accessing aren't really ideally suited to that. So we hear about DNA a lot." Guildford Action

Trust & Consistency of staff

"A lot of people come here for lots of reasons. We give them advice regarding substance use treatment and recovery, sexual health, mental health. We often are the most trusted people to our young people attending." Twister LGBTQ+

“Continuity of staff is key to success. People want to stay on their journey with the same person the other end.” Guildford Action

Across system working

“We would love to work closer with I-Access to help make a more joined up service, but we need more funding. More of an understanding of specialist services like us would help. Work together to underpin the trauma. We invite team members here, but they don't engage with us and we have to find our own information. With I-Access, I don't find them responsive. For them it feels like the client is a number not a person.” Women's centre

“Probation chuck people out of prison on a weekend with £47 in their back pocket and guess what? They go straight to the pub or score. At the point of release from prison, they are in a traumatic state and not in the right head space to access treatment services.” York Rd Project.

We do have a very good relationship with I-Access. [name] comes in for a weekly chat with individuals and it helps to build the trust. They must not be ready to take treatment straight away. Here we also do a lot of hand holding, which is needed.” Guildford Action

Dual Diagnosis

“I've tried to refer people to Talking Therapies but as soon as they hear they have substance use issues, they won't help. Everyone then keeps 'self-soothing'. When will Surrey recognise Dual Diagnosis.” York Rd Project

Stakeholder meetings

We met with the following stakeholders / service providers to understand what it is they do, explore ways to work together and hear from them, what things are working well and what could be improved.



Luminus signposting and safeguarding

On engagement, our team always signposts to appropriate support and care services. For example, if someone is struggling with finding a dentist, they will be given information for Dentalchoices.org. Support services are given where relevant; I-Access, Catalyst, Mind Matters (if mental health exclusively), The Hope Hub, Renewed Hope, York Road Project etc., Al-Anon, AA etc.) We check in with community leaders if someone has said something we are unsure of or concerned about to ensure that the person is being supported and not alone.

We have signposted this quarter to;

- Al Anon & AA
- Citizen Advice – Housing
- Richmond Fellowship
- The Useful Wood Company
- Women's Centre
- SW Domestic Abuse Service
- The Solace Centre, Cobham
- ESDAS

- DWP
- I-Access
- Catalyst
- Mary Frances Trust
- Smoking Cessation service – One You Surrey
- Action for Carers
- Catch 22
- Marie Curie Bereavement counselling

Social Value

We have had requests from two individuals who have been through the prison system and would like to volunteer. We are identifying people through our engagement that could work closely with us as part of our special interest group (SIG).

We are also in discussions with the manager of Woking's women centre, to offer a volunteering scheme to women who enter the SMART programme.

Planning for Q3

For Q3 our comms/engagement activity will incorporate:

- Digital and social media
- Face-to-face activity
- Printed material
- Internal communications

Looking at the insight we gathered in Q2 we were able to look at gaps in demographics to identify places to visit in Q3. We hope to speak to individuals /their families and networks that haven't accessed any services or may not realise they have a substance use problem. There are some areas we have highlighted for our Q3 work:

Hospitals: those who don't identify as having a substance use issue or unknown to services, arriving at A&E as their first access to services maybe because they haven't realised that they have a substance use problem. To work with the Hospital Alcohol Liaison nurses to find best ways to engage.

Domestic Abuse: Family centres to work with vulnerable families / single mothers /parents.

Urban / Rural areas: High footfall – areas at lunchtime or commuting times - train station / shopping centres

We are planning to visit the following places this quarter.

Quarter	Month	Where are going	Town
Q3	October	Redhill DWP Job Fair	Redhill
Q3	October	Direct Pharmacy - Madrid Rd	Guildford
Q3	October	Guildford Action Community Event	Guildford
Q3	November	Lighthouse	Woking
Q3	November	Family Centre	Camberley
Q3	November	Redhill Probation coffee morning	Redhill
Q3	November	Mary Frances Stigma around addiction group	Surrey Downs
Q3	November	Narcotics Anonymous Open group session	Sunbury
Q3	December	Train Station engagement	Guildford
Q3	December	Hospital engagement	Location tbc possibly East Surrey, Redhill
Q3	December	Train Station engagement	Woking
Q3	December	The Square / Atrium shopping Centre	Camberley

Areas of focus for Q3 to be discussed in the contract monitoring meeting.

Feedback from CDP meeting on areas of focus:

Alcohol risk reduction

Women in treatment/accessing treatment.

Contact us:

Contact us through any of the channels below.

We'd love to hear from you:

-  Web: luminus-cic.uk
-  Telephone: 01483 301448
-  Text: 07592 787 533 (SMS only)
-  Email: info@luminus-cic.uk

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