



# Understanding Service User Engagement in Camden

The perspectives of mental health and substance misuse service users

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# Executive Summary

TONIC were commissioned by Camden and Islington Public Health department on behalf of Camden Council to offer service users of mental health and substance misuse services an opportunity to comment on the current operating model of service user involvement in the Borough of Camden.

Since 2014, an external provider has held the contract for service user engagement in Camden across both substance misuse and mental health fields. The vision and aim of this contract was to empower service users to continue to build on existing achievements as well as develop and grow new opportunities for service user engagement. This includes strengthening and developing the breadth of opportunities available across the Borough.

## Our Approach

TONIC offered service users a variety of ways to engage. There were four site visits conducted across the Borough, telephone interviews, online and paper surveys. Relevant services were contacted across the Borough to promote the opportunity to their client base. Through this, we heard from 123 service users across mental health and substance misuse fields.

## Key findings

The findings centre around four key themes; (i) The breadth of service user involvement, (ii) the range of opportunities, (iii) promotion and communication, and (iv) the challenge of independence.

## The Breadth of Service User Involvement

Some people that took part had heard of and worked with the incumbent provider and gave favourable reviews of their approach. However, not everyone was aware of the opportunities

available (e.g. CBUG, Frontline, Patients Council, Sunday Club). The work highlighted specific groups that are not necessarily accessing opportunities for service user involvement as much as other groups (e.g. young people, BME, street homeless groups). This suggests a need to involve new individuals with recent lived experience.

## The Range of Opportunities

There was a real appetite and motivation to be involved in service user engagement. Whilst there are good examples of service user engagement in the Borough already, which are valued by those that use them, feedback from service users was that they desired more opportunities to engage with. Importantly, there was a desire for a range of opportunities; moving beyond forums and newsletters.

## Promotion and Communication

The work highlighted an opportunity for better promotion of opportunities, as mentioned in theme 1. Service users highlighted their desire for varied communication and promotion methods to appeal to a range of cohorts including face to face visits to service providers to promote opportunities. Service users also expressed a need to understand what was on offer, how they could take part, how their contribution would be meaningful and what would or could happen next. Service users explained they did not know what happened to their feedback after it had been given and they sometimes felt like an afterthought or their contribution was tokenistic. This did not empower or motivate individuals to contribute in the future.

## The Challenge of Independence

Service users struggled to identify 'the model' and its current structure. They discussed the extent an organisation, funded by the council, could be truly independent whilst still having to collate commissioning data. Concerns were also expressed over the remit of the current specification and whether it was too broad by covering substance misuse and mental health under one contract. Service users were clear they valued independence but simultaneously asserted they desired less 'us' and 'them' and distance between commissioners and service users.

## Conclusions

The key findings were as follows:

- Service users noted that opportunities were currently accessed by a small group of individuals, with little scope to attract new people. There were also cohorts of individuals who were less likely to access service user engagement e.g. young people.
- There was an expressed desire for more opportunities; an increase in number, breadth and diversity
- Promotion of current opportunities needed to be strengthened and appeal to a range of individuals (including face to face promotion to services)
- Feedback following service user input was highlighted as an important component of service user engagement that was currently lacking.
- Independence was valued but there needed to be a clearer remit and scope for a service user engagement provider and assurances that council funded initiatives retained autonomy.

## Next Steps

It is clear that, notwithstanding its strengths, even if the current commissioning model is maintained, there are areas for improvement and future development. There are also opportunities to discuss differential commissioning structures in order to best meet the needs of service user engagement.

**Option 1:** Refine and review the current specification. Commission an independent organisation to co-ordinate service user involvement across the Borough for mental health and substance misuse. This service would operate as the 'go to', impartial, service for service users to share views, or for the council to seek input for consultations.

- 1a: Commission two separate independent organisations to co-ordinate service user involvement; one for substance misuse and one for mental health.

**Option 2:** Offer independent funding directly for service user groups (e.g. directly from the council to service user groups e.g. CBUG)

- 2a: Stipulate in new contract with independent provider that some of the budget should be retained for service users to apply for grant funding for new initiatives.

**Option 3:** Contract with a current commissioned provider to provide and co-ordinate independent service user involvement activity across the cohort (either substance misuse or mental health). Key to this option is that service users feel confident that their views will not affect their care from said provider and this function is seen as an adjunct to the other activities offered.

**Option 4:** Do not commission an independent service user involvement service outside of the current service providers, as they already promote service user engagement as part of their individual contracts. This would, however, not benefit from a resource to pool together all of the separate service user engagement and feedback into one place for providers and commissioners and service users may be concerned they cannot give honest feedback to the service providers about their care/treatment.

# 1. The Task

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In November 2017, TONIC were commissioned by Camden and Islington Public Health department on behalf of Camden Council to engage with substance misuse and mental health service users across the Borough to inform the development of service user engagement services. As the current contract for service user engagement services is due for recommissioning in 2019, the Council want to ensure that service users, with experience of mental health and substance misuse difficulties, had an opportunity to inform, influence and have a strong voice in the future service model.

Specifically, the council were seeking insight from service users into:

- their experience of the current service model,
  - suggestions on potential key priorities,
  - areas for development, and
  - the scope of a future service model.
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## Background to the Current Service

Commissioned from an external provider since 2014, the current service aims to operate as an independent organisation which hosts, supports, capacity builds and transforms the service user involvement function for Camden's mental health and substance misuse services. The service was intended to build on Camden's existing achievements (which included the service user groups Camden Frontline, Camden Borough Users Group and Camden Mental Health User Involvement Service) and provide an effective and supportive new platform for the function. The service specification states 'it will empower service users to evolve the service user involvement function into a service user run organisation, operating independently as a social enterprise or similar model, in line with the aspirations of the service user community'.

The key aims of the service are to:

1. Empower mental health and substance misuse service users to consolidate and build on existing achievements and work together effectively across Camden.

This includes acting as a vehicle through which the CCG and Council can engage with mental health and substance misuse service users, influence practice and policy, keep service users up to date on developments, empower service users to train peers and professionals

2. Promote wider and more diverse user involvement across Camden

This includes increasing the number of people who are engaged and involved in service user engagement opportunities including those who are in regular work and are of different ages, genders, ethnicities and stages of recovery including those who are unrepresented such as those from Asian communities, offending cohorts and young adults.

3. Strengthen service user involvement in the planning, commissioning, delivery and monitoring of services in Camden

This includes enabling mental health and substance misuse service users to inform the decision-making processes and to be integrated into the planning, monitoring and evaluation of mental health and substance misuse services and help service users to represent the views of others which may not be the same as their own.

In part, the work offered an opportunity for service users to express the extent to which they perceived these aims and objectives had been met.

#### 4. Promote inclusion and challenge stigma and discrimination

This includes normalising mental illness and substance misuse problems, promoting positive messages and challenging taboos.

#### 5. Enable service users to help others to achieve recovery

This includes, raising awareness and uptake of personal budgets, establishing links with other peer led and mutual support groups, locally and nationally, promoting the transition from using services to peer mentoring, training and employment.

#### 6. Facilitate institutional development of the service user involvement function

This includes the potential to become a service user run organisation, operating independently as a social enterprise or similar model.

In commissioning this service, Camden Council expressed a vision 'for our service users to achieve wellbeing, to be empowered to influence local strategies and service delivery; to gain skills and confidence, to help to achieve recovery for themselves and play an instrumental role in supporting their peers to achieve this goal'. The service specification is also clear that service user involvement extends to individual level, service level, commissioning level and national level and that all mental health and substance misuse service users [should] feel represented and have a voice.

## 2. The current offer

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As a snap-shot, provided by the manager of the incumbent service in January 2018, of what is currently on offer for service users in the Borough includes the following:

### Mental Health

- Monthly service user forum: Camden Borough User Group (CBUG)
- Monthly Patients' Council ward inspections
- Weekly peer-led drop-in service at the Hub
- Mental Health newsletter
- CBUG website

### Substance Use

- Monthly service user forum: Frontline
- Weekly peer-led drop-in service at 184 (Sunday Project)
- Weekly Hep C support drop-in at hostels in Camden with support available to get people into testing and treatment (restarting)
- Frontline newsletter
- Frontline website

### Cross Cutting

- Training and supervisions for service users involved in above activities
- Outreach activities to promote service user involvement (recruiting service users to hold stalls at events held by different service providers, support the running of certain awareness raising events such as Camden events for World Mental Health day, supporting Camden substance use service users to attend the Drink Drug News conferences).
- Recruiting and supporting service users to participate in the following activities: Tendering, Contract-Monitoring, Interview panels as needed
- Focus groups: As and when requested by commissioners and service providers
- Peer research projects: Roughly one per year (Most recent include hostels pathway and supported living pathway research)

## 3. Our Approach

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Service users were invited to take part through a number of routes, including: via an online survey, paper survey, telephone interviews and through a number of site visits. The survey and interview topics were written in consultation with the commissioners and with reference to the service specification. on

Supported by commissioners, TONIC contacted a range of relevant service providers in Camden to inform them of the different ways that service users could be involved.

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This included third sector providers working in both mental health and substance misuse sectors as well as statutory healthcare providers (e.g. the Camden and Islington NHS Foundation Trust). Service providers were sent the online survey link, a 'blurb' to disseminate through social media and contact lists, as well as wallet-sized 'business cards' which could be given to service users at drop-ins or during appointments which gave details of the survey link and contact number to arrange a telephone interview. As an incentive to encourage participation, there were 4 x £50 vouchers being given away in a prize draw for those completing the survey and those who took part in a phone survey received a £10 high street voucher.

Questions for site visits and telephone interviews centred around the following headlines:

- What opportunities are there to be involved and engaged as a service user? What opportunities are you involved in?
- How do you experience these opportunities?
- How do you find out about them?
- What other opportunities would you like?
- What feedback mechanisms are there?
- Are there any barriers to engagement?

23 telephone surveys were completed. This included 13 women and 10 men. 17 people identified as having been affected by a mental health problem, < 5 people identified as solely having substance a misuse problem and < 5 people identified as having dual diagnosis.

We heard from 42 people through the online survey, although 69 further individuals made attempts to start the survey but did not submit their response. The largest age group of respondents was 45-54 years old and respondents were mainly female.

We conducted four site visits, which included CBUG (a mental health forum), Frontline (a substance misuse forum), CGL (third sector substance misuse treatment provider) and Spectrum (third sector homeless drop-in provider). As part of this, we had support from TONIC's colleagues with lived experience of mental health and substance misuse services, from Essex and Medway, who also conducted interviews on site. Through these visits, we were able to consult with a further 58 individuals.

In total, we heard from 123 people service users in the Borough. In addition, we discussed the project with 8 professionals from local services and 3 commissioners.

# 4. Findings

## Key themes arising from discussions with service users



### 4.1 Quantitative Findings from the Survey

46% of the 42 people completing the survey stated they would know how to share their views of services if they wanted to. 29% said they were not sure if they knew how to share their views. 51% said they had been asked their views on services (this includes in-house service user consultation).

30% of respondents had heard of Frontline, 36% had heard of CBUG, 29% had heard of Patients Council, 14% had heard of mystery shopping, 19% had heard of being supported to attend strategic meetings, 19% had heard of taking part in procurement exercises but 29% had not heard of any these opportunities.

Email was the preferred method of communication selected by respondents in terms of learning about opportunities available (from service providers to service users), text message was 2nd popular, followed by posters and flyers in a service. The three most popular ways of being able to share views and engage (from service user to service providers) were; focus groups, forums and by email.

The findings from the quantitative elements of the survey indicate that the majority of service users know how to share their views if they chose to, although it is unclear whether this is within services or across the system as a whole. A minority of respondents had heard of the independent service user opportunities, and well-established, long running forums were most likely to be known about compared to more innovative

opportunities such as procurement and strategic engagements. No-one noted that they would like face to face promotion of opportunities and both email and text messages rely on a degree of technological advance that not everyone may have access to.

Qualitative comments supplied by participants in the survey are included in the following analysis.

### 4.2 Qualitative Findings

It is important to note, that the findings presented here are an aggregate collation of discussions, observations, survey comments and feedback across a 6-week period. Eligibility was broad; any service users with mental health and/or substance misuse problems across the Borough of Camden. Therefore, statements about demographics that are not currently being reached or accessing service user involvement opportunities, e.g. homeless populations or BME communities, were not specifically explored. Instead, feedback is mentioned here because individuals raised these as issues or we noticed a consistent absence across those completing surveys and attending groups.

Findings are discussed under four thematic headings that emerged across the data collection: (i) The breadth of service user involvement, (ii) the range of opportunities, (iii) promotion and communication, and (iv) the challenge of independence.

## (i) The Breadth of Service User Involvement

There were some people that took part that had heard of and worked with the incumbent provider and gave favourable reviews of their approach.

*'They are caring and reliable, easy to get hold of and have a very good relationship with CBUG members. They have trained people in minute taking and website design. The peer mentoring service is very good too.'*

*'I've been involved with them for the past 4 years and they really listen and believe in the service users involvement'*

However, many of those contributing had not heard of the incumbent service provider nor were they aware of the opportunities to be involved such as CBUG or Frontline. These were people who were affected by mental health or substance misuse problems, in receipt of services, who did not know about an independent service user involvement organisation in the Borough. This feedback therefore seemed to highlight a significant gap in those who take part in service user involvement. Feedback indicated 'those who know, know and outside of this, no-one new really comes in'.

Particular cohorts who seemed not to know about service user involvement opportunities were those accessing third sector mental health services (e.g. Mind), those in acute wards (although some did know about Patients Council when prompted) and street homeless populations. At Spectrum, only one attendee had heard of the current service provider and two had heard of Sunday club. Whilst there were a significant number of homeless attendees at Frontline, their level of engagement was limited and some admitted they were there to receive the reimbursed train fare, even if this meant they had to pick a used ticket off the floor at St Pancras station. Therefore, the homeless community remains a group of hidden voices with

seemingly limited integration between support services and service user involvement. Those in active use and without a fixed abode may find it harder to access groups due to the chaotic nature of their lifestyles, but this also perhaps indicates a need to conduct outreach or offer more accessible opportunities for this cohort.

One telephone participant also remarked that there was a distinct lack of culturally appropriate opportunities for BME individuals within the mental health sphere. Others completing the survey remarked that LGBT and over 60's were not being engaged in service user involvement opportunities.

Young adults (those under 35) were another noticeably absent cohort. This was evidenced in particular from the site visits where older adults dominated engagement. There was recognition amongst service users that more needs to be done to make opportunities attractive to younger people.

*'It's the same old people doing the same old thing – we need new blood'*

There was recognition amongst professionals and service users that often forums were led or carried by one or several motivated individuals which placed the forums at risk if this person became unwell, stepped down or left. Further, there was also acknowledgement that many of those engaging in service user involvement were 'professional service users' who may have been engaging for decades and not necessarily accurately representing the views of more current service users. This gives rise to a discussion about promotion and how new people from new cohorts can be engaged which will be addressed shortly.

## (ii) The Range of Opportunities Available

The work highlighted a real appetite and motivation to be involved in service user engagement. In line with this, there are positive examples of service user engagement operational in the Borough including CBUG, Patients Council and Frontline. However, people called for greater variety and breadth of opportunities to be involved in. The sentiment from individuals was that they would like more of a say, and more opportunities to shape provision.

It was observed that CBUG and Patients Council are important tools to the service user involvement sphere and that cannot be minimised. Patients Council offers an opportunity for those who are acutely unwell to have a say on their care, it is an important resource for a hard to reach cohort. One member of Patients Council remarked 'changes can be grindingly slow but they do happen'. Without the Patients Council, several patients that engaged in the telephone interviews indicated they had no other way to 'have their voice heard'

CBUG received favourable feedback in its ability to operate as an independent entity.

*'They're very well run, committed, sincere people, no uncomfortable politics, we want to do our very best for the people we work with and for. It's very inclusive, it meshes together so well, we are all from different directions and backgrounds'*

However, one service user commented that CBUG was not suited to everyone and, as one of the main forums within the mental health sphere in Camden, this left little alternative for those who wanted to be engaged. This leaves scope for more creativity in how service users can be engaged outside the forum structure.

At both CBUG and Frontline there was a good level of attendance. CBUG in particular seems to be cohesive, with an agenda and minutes being disseminated to attendees on the day. Several CBUG members stated this could be

strengthened further, by having the agenda disseminated ahead of the next meeting with speakers announced in advance so people can prepare adequately. One person completing the survey remarked that service user engagement opportunities do not always have to be formal and social activities, such as barbecues, could also be organised as a way of promoting engagement, involvement and discussion.

There was an observed willingness and motivation to make and contribute to change and CBUG members expressed a wish for a guarantee and similar commitment from the council in terms of investing in service user involvement.

Linking with the previous theme, even if people did not know about the opportunities available to them, there was certainly an appetite to be involved and a desire for more opportunities to do so.

Frontline and CBUG seemed to have their own identity and history which is important, but beyond these groups, the reach of the current service provider was seemingly limited. It was unclear what else was on offer or what had evolved for service users to take part in, although the Sunday club had now resumed. Opportunities for service users to be part of panels or consultations were said to be advertised but service users remarked they were notified at too short notice and 'they go like hot cakes'. There was a desire for clearer transparency over how people can be involved once they've heard about opportunities.

*'There is definitely a lack of awareness of what's available, you tend to only be recruited if you're on a network but this limits the quality of people that are involved'*

Significantly fewer service users with solely substance misuse problems contributed. From those we did speak to, it seemed there were less opportunities and relative disparity between the opportunities presented to individuals experiencing mental health problems and those with substance misuse problems.

*'We used to do contract monitoring meetings this has died down, a newsletter four times a year, this has also not happened. We've only had one this year, it feels like it's being run down. All the groups we did have going, like the HEP C group, we wanted this to be reinstated. It would have been nice to keep this up. Our women's group, the relapse group, they've all disappeared. It just feels like there's an unwillingness to do anything new. It doesn't feel there's any service user input into what runs or happens. Now it's just the forum and the Sunday group for us'*

*'I am so upset what's happening to Frontline, the council are spending the same money but it's going on admin and rent for the incumbent provider'*

It was also observed that, compared to CBUG, those attending Frontline were at the earlier stages of recovery and some in active addiction. It was observed; 'there was a strong impression people were there for the train fare and the sandwich and not to give their opinion or affect change'

Whilst it is encouraging that Frontline is able to appeal to a broad range of individuals within the substance misuse sphere there should be a clear pathway or channel of communication which allows feedback to be heard by commissioners and therefore for attendees to contribute to change. In contrast to CBUG, it seems that Frontline operates as a 'place to be' rather than 'a space to do'.

### **(iii) Communication and Promotion**

This theme transcends two key issues raised by service users. The reach of service user involvement and engagement opportunities was limited; not enough people knew about what was on offer. How best to communicate and promote opportunities, especially to a range of individuals with a range of needs was highlighted as challenging. Secondly, communication and feedback about what changes had taken place following engagement or involvement were also limited and this affected people's willingness to engage in the future. Input from service users

suggests there needs to be a clear offer and a drive to reinstate confidence in service users that their contribution is valued and can contribute to change.

In terms of promotion, as previously noted, many people engaging in the phone interviews had not heard of the incumbent service provider nor CBUG or Frontline.

*'The fact I don't know a lot about [incumbent provider], and I have been in post for 6 months, says a lot'*

One on site visit to a substance recovery service, attendees had not heard of the service user involvement opportunities and there was a perception that the Sunday club, run from those premises was 'not for us'.

*'It's diabolical, no-one has heard of it - why haven't we heard of it? Is Frontline a dog flea medication? Word of mouth should have reached us by now'*

This finding promoted a discussion about the best ways that opportunities could be advertised. Many individuals within services said they wanted someone to physically come in and tell them about the opportunities available, breaking down barriers and promoting face-to-face communication, rejuvenating interest and enthusiasm. This was especially important where posters were said to be ineffective and service users often changed their phone numbers.

*'They need to work harder on getting a wider range of people involved. Be visible. Be a face'*

Other ideas included a broader range of places to highlight the forums and opportunities e.g. at pharmacies, gyms and GP surgeries. One service user reflected word of mouth was the strongest resource available, especially in homeless or substance misuse circles where people may not have access to technologies, but only if enough people bought into the concept.

*'A good thing never needs advertising. When a good thing is going, the people will come – it's just the right people who are fronting it'*

There was an acknowledged difficulty in catering for communication preferences. Young people may be more technologically minded but other individuals suggested a need for alternatives for those who did not have smart phones to access texts, emails or social media.

Linked to the concept of promotion was the need for service users to understand what was on offer, how they could take part, how their contribution would be meaningful and what would or could happen next.

*'I have not got feedback apart from a word of gratitude for taking part and the promise that my input will be used to help my make improvements to services'*

*'In general the feedback is at the time... A 'thank you for filling in form or participating in...but I find that's as far as it goes...Disappointing'*

There was therefore an overwhelming lack of clarity from service user's perspective on how their concerns and views were carried forward.

*'There is too much tokenistic work. Nothing much gets done after we've been consulted, they talk the talk and walk the walk'*

Service users were dubious or unclear on how the current service provider supported involvement as a vehicle for change.

*'Please help us to have our voice heard – to understand how difficult life is for all of us'*

There was a prevailing sense of distrust amongst service users about what changes could actually occur following service user involvement and consultation. Service users reported they either did not know what changes had occurred following

consultations or providing feedback.

*'We do our best but we don't any information back about what's changed'*

Service users, especially those within substance misuse or homeless circles, reported that they felt their views were 'pointless' because 'nothing will change anyway'. This clearly acts as a barrier to engagement in service user involvement and does little to provide incentive or motivation to be involved.

*'I don't see a lot of changes happening. We are powerless to make changes because we don't control the purse strings'*

Service users reported a sense that exercises to seek their views were part of a 'tick box' exercise or 'tokenistic'. Service users stated consultations were undertaken once the outcome had already been decided leaving them with little opportunity to influence systems or services. This had a disempowering affect.

*'We don't want to be treated as an afterthought, or sent someone who just says I am not the person who can make that decision'*

*'It was a frustrating experience, he just said I am here but I can't do anything about it, so why did he come at all?'*

As a 'quick win' and remedy for this, service users were keen to hear back about what changes had been made as a result of their input, or at the very least why certain changes could not be made.

There was also some debate around reward, recognition and incentivising. Service users on panels and boards, especially those engaging at a National level, stated they liked the fact they were financially rewarded as it made them feel valued and that their views were respected. Achieving this at a more local and generic level was said to be more challenging.

*'We aren't being paid, our views are not being valued –what we're giving needs to be more respected'*

Reward and recognition policies were said to be useful in terms of increasing footfall but also risked attracting individuals who did not want to shape services and share their views but instead attain a train fare, a free sandwich or a voucher.

#### **(iv) The Challenge of Independence**

Service users were ultimately asked to reflect on the current model in operation in Camden, and the extent they valued having an independent organisation overseeing and supporting service user involvement across mental health and substance misuse arenas. Some service users, as mentioned earlier, were unsure on the 'service' that was being provided and by who.

*'To my knowledge I haven't had any contact with this organisation. This is one of the problems. I find that over a period of time things change, that's understandable, but it feels like to me that things are ALWAYS changing so patients like me and other health care professionals too I'm sure... aren't always clear on who is covering or taking the lead in a specific area'*

In addition, service users struggled to identify 'the model' and its current structure and it was challenging to encourage service users to answer this question. The model was described as being a 'dysfunctional kitchen' and 'not bottom up enough'.

*'There isn't a model! There's different groups, different emails, it's a hotch potch. We aren't clear what's included under engagement or involvement, the council need to decide what is meant by those parameters'*

Despite this, service users were able to discuss the concept of an independent organisation facilitating service user involvement. Concerns were expressed around the extent an organisation, funded by the council, could be truly independent whilst

still having to collate commissioning data. The need for the service provider to provide numbers and reports back to commissioners was said to be at odds to equipping groups to be independent.

*'Service User involvement should be independent and not monitored by the council'*

There was positive feedback about the current provider, but a small number of individuals felt they were not wholly service user orientated and were 'driven by business opportunities and chances to further or promote the brand'

*'They are not here for me, they are here for the money'*

*'The service is dominated by paid workers...and that controls some of their actions and cuts across what they should be doing'*

Some service users felt the current service provider lacked the right ethos or approach for the task.

*'They aren't nurturing, developing or fostering independence.'*

*'The model can only be as good as the people running it. They need an interest and an understanding of how service users operate, they need insight, they have the authority but aren't fit for purpose'*

*'They have other agendas as far as I am concerned. They are just using it as a platform to further whatever else they're doing – their finger isn't on the pulse at all and when they do try and get the right people they pick the wrong people'*

The incumbent provider were criticised for not listening to or acting on the views of service users. One example included the desire for CBUG to have 'hot topics' each month, which would allow a more concentrated attendance based on specific interests.

*'As a service user involvement organisation – they aren't even listening to service users!'*

Others recognised that any organisation would face similar challenges resulting from having to navigate and promote engagement across such a broad cohort. The breadth and variety under each umbrella of mental health and substance misuse is arguably too much for one organisation to unify and co-ordinate across the Borough.

*'I think they are doing a good job as it is. They have been given a hard task'*

*'It's good to have an independent collective voice but you lose too many fish by having such a big net'*

When asked what suggestions there might be to improve the current commissioning arrangement, one service user stated 'how do you find your way out of a mess?'

Service users were clear they wanted independence but simultaneously asserted they desired less 'us' and 'them' and distance between commissioners and service users. This relates to the earlier discussion about seeing changes come into affect. Despite expressing concerns over the current model, some service users also acknowledged that it may be too challenging to be solely service user led.

*'The model isn't perfect, I like [incumbent provider], it's difficult for them as a 3rd sector provider, having to bid for work all the time but it is better to have them doing it rather than the service users themselves. It's better to have an intermediary to avoid money issues, often when service users manage things and money is involved, things go missing, would people stay well to provide the continuity? It would be cheaper but maybe not so organised'*

Service users expressed a desire to interview any proposed contractors for independent service user involvement and this was felt to be particularly important if 'they're going to hold the pot of money for us'.

# 5. Summary & Conclusions

Several pertinent ‘needs’ emerged from the themes identified:

## Key Themes

### The need for more promotion about what is already available

Many service users had not heard of the forums and opportunities available, suggesting a need for these to be more widely promoted and accessible for people. Means of promotion need to accommodate the preferences of different demographics and service users especially advocated having face to face promotion, visits to services as one valuable tool.

### The need for new opportunities

Feedback that suggested a ‘lack of new faces’ may be inherently linked to a paucity of creativity and dynamic opportunities for service user engagement. Largely opportunities are forum based and fairly formal. Moving forwards, a breadth of opportunities could encourage new and more engagement from service users. A rejuvenation of opportunities could occur alongside a strengthening and maintenance of well placed forums such as CBUG and Patients Council.

### The need to involve different cohorts of people

Opportunities that are currently available are not reaching into each pocket of mental health and substance misusing communities. More needs to be done to be inclusive and appealing to young people, BME groups, street homeless as well as older adults.

### The need to see change after feedback has been given

One ‘quick win’ to support and promote better levels of service user engagement would be to ensure clear lines of communication and feedback loops once service users have given input to commissioners. This ‘what next’ question is important for service users to remain engaged and feel their contribution is worthwhile.

### The challenge of independence

Service users valued the opportunity to be independent but the ‘model’ certainly needs some strengthening and clarifying. The task for any service provider to unify, co-ordinate and build service user engagement across the Borough and across two distinct groups is vast. Service users desired transparency over who was funding service user involvement and reassurance that commissioners retained interest but not mastery over opportunities. Some service users did express a desire for more independence but acknowledged the challenges in managing financial and administrative tasks.

With these in mind, it is clear that there are pockets of good work and valued opportunities in the Borough of Camden for individuals with substance misuse and mental health needs to engage, however the remit and scope of these opportunities is not yet far reaching enough. In part this may be a reflection of the scale of the task given to the incumbent provider and the fact that the ‘net is too wide’.

Those that engaged wanted to be involved in shaping provisions, there was a real appetite and motivation for engagement, but the council's vision of giving everyone a voice to shape service provision at an individual, service, local, regional or national level is not yet realised and there are challenges in recruiting and involving new people, especially from specific groups (e.g. young people, BME, street homeless, primary care, acutely unwell individuals).

The current review has presented discursive opportunities as to how the current model should be continued, refined and adopted in the future. In any commissioning structure, there are certain elements that need to be retained and others that require adding.

### What should be retained?

- Positive components of the current system and service include; CBUG, Patients Council and Frontline with associated newsletters and websites; although each of these can be strengthened and more widely promoted.
- Service users valued assurances of independence when giving feedback and an environment that nurtured this sense of freedom of engagement and a space to air concerns, fears, disagreements without concern of this affecting their care or treatment.

### What should be added?

- A broader, more innovative range of opportunities for service users to be involved in (beyond forums and newsletters)
- More strategic leadership and steer from the Council on how they define and what constitutes service user engagement
- Visible engagement and strengthened outreach; 'taken to' services with a more physical presence to promote involvement
- Better integration with other commissioned service user groups (e.g. from drug treatment service providers and CANDI).

- A focus on involving new individuals in service user engagement with recent lived experience

### Specific Recommendations and Actions:

#### For commissioners:

- Review and refine specification, with particular focus on clarifying what is meant by service user engagement and how the service fits with other roles and organisations in the Borough. Commissioners need to be clear on the purpose of the service and what it adds to what is already in existence
- Consider whether the remit is too broad for one organisation
- Ensure clear feedback and communication pathways with service users following consultation (even if this involves informing them of why something cannot be undertaken)
- Seek to offer a range of opportunities for service users to be involved in (e.g. interviews, panels, commissioning boards, procurement, contract reviews)

#### For future service providers:

- Offer a range of opportunities; move beyond forums and newsletters as a method of engagement and involvement
- Ensure cohesion with other service user groups and resources in the Borough
- Be visible and promote opportunities widely, with a focus on recruiting new individuals
- Ensure there are consistent feedback loops following feedback and consultation so service users feel their contribution is meaningful and worthwhile
- Address the issue around reward and recognition so that service users are rewarded for their input but people don't just attend for financial gain

## 6. Next Steps

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# What options are there moving forward?

There are a number of potential options to discuss with commissioners moving forwards, outlined below:

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**Option 1:** Refine and review the current specification. Commission an independent organisation to co-ordinate service user involvement across the Borough for mental health and substance misuse. This service would operate as the 'go to', impartial, service for service users to share views, or for the council to seek input for consultations.

- **1a:** Commission two separate independent organisations to co-ordinate service user involvement; one for substance misuse and one for mental health.

**Option 2:** Offer independent funding directly for service user groups (e.g. directly from the council to service user groups e.g. CBUG)

- **2a:** Stipulate in new contract with independent provider that some of the budget should be retained for service users to apply for grant funding for new initiatives.

**Option 3:** Contract with a current commissioned provider to provide and co-ordinate independent service user involvement activity across the cohort (either substance misuse or mental health). Key to this option is that service users feel confident that their views will not affect their care from said provider and this function is seen as an adjunct to the other activities offered.

**Option 4:** Do not commission an independent service user involvement service outside of the current service providers, as they already promote service user engagement as part of their individual contracts. This would, however, not benefit from a resource to pool together all of the separate service user engagement and feedback into one place for providers and commissioners and service users may be concerned they cannot give honest feedback to the service providers about their care/treatment.

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