

# My Say: a Service User Feedback Project

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February 2019.



**My Say Project**



**cavamh**

Gweithredu dros Iechyd Meddwl Caerdydd a'r Fro  
Cardiff and Vale Action for Mental Health

Sefyll is part of cavamh, Registered Charity No. 1148312 / Company No. 8000094

The My Say Project was funded by MHCB, Cardiff and Vale UHB.



# Introduction

The views of people who use of Community Mental Health Team (CMHT) services are increasingly used to help service providers and decision makers evaluate, plan and shape services offered. Indeed, the NHS constitution (updated 2015) commits to the inclusion of service user views to refine and improve service.

Cardiff and Vale University Health Board (UHB) commissioned Cardiff and Vale Action for Mental Health (cavamh) to undertake an engagement exercise with current users of Cardiff and Vale CMHT services to determine their subjective experience with services to date and assess the quality of provision via the views of 'experts-by-experience'.

The aim of the current project was to determine: (i) what is most valued about current services (i.e. what works); (ii) what people want to see happen more often or start happening (i.e. gaps in current provision) and; (iii) what is happening that people feel shouldn't happen or should happen less (i.e. what is not working nor valued by service users)

The structure of this report is as follows:

## Method

- Research methodology
- Sample characteristics and considerations

## Results

Results are broken down into the following sections:

- The experience of having an assessment at a CMHT
- Treatment and care in the community: Communication between CMHTs and service users
- Treatment and care in the community: The accessibility of the CMHT offices
- Treatment and care in the community: The quality of treatment and care with a CMHT
- Treatment and care in the community: Experiences of accessing care in a crisis
- Treatment and care in the community: Holistic support
- Co-location to Barry Hospital - service user experiences

## Conclusion

## Method

### Research methodology:

We engaged with users of Cardiff and Vale CMHT services in a number of ways. The findings of this report are a result of speaking to over 100 people between November 2018 and January 2019.

The inclusion criteria for taking part in the study were:

- People who have been assessed and accepted into CMHT treatment and care (or those having the assessment on the day of interview) in Cardiff and the Vale.
- People who have received treatment and/or care from a Cardiff and Vale NHS mental health service in the community in the last 12 months
- Be aged 18 and over

Data was collected by the Project Manager - Dr Jacqueline Campbell - and five Peer Researchers. Peer Researchers are people with both lived experience of mental health conditions and receiving treatment at a local CMHT - they are experts by experience.<sup>1</sup>

Questionnaires were constructed to meet the research brief and piloted with service users before use. There was an online version as well as an abridged 'hard-copy' version specifically for face-to-face use with people receiving treatment and care with their local CMHT. A further questionnaire was designed for use with people attending the CMHT for an initial assessment on the day of interview.

Data was collected in the following ways:

- Researcher presence at the following CMHTs: Vale Locality Mental Health Team (Barry Hospital); South West Cardiff (Hamadryad Centre) and; North East Cardiff (Pentwyn Health Centre). Paper copies of the questionnaire were also left at North West Cardiff (Gabalfa Clinic)
- Researchers also collected data at other locations in Cardiff and the Vale such as: Mind in the Vale; FourWinds; Ty Canna; the Crisis Recovery Unit at Heath hospital; as well as using a snowballing technique through personal contacts.
- The online survey was disseminated widely to stakeholder contacts and service user networks

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<sup>1</sup> Peer Researchers attended a Peer Research and Interview Skills training course at Shelter Cymru in advance of data collection. Training was delivered by a specialist in peer involvement in research.

Through our comprehensive sampling method, we collected the following data:

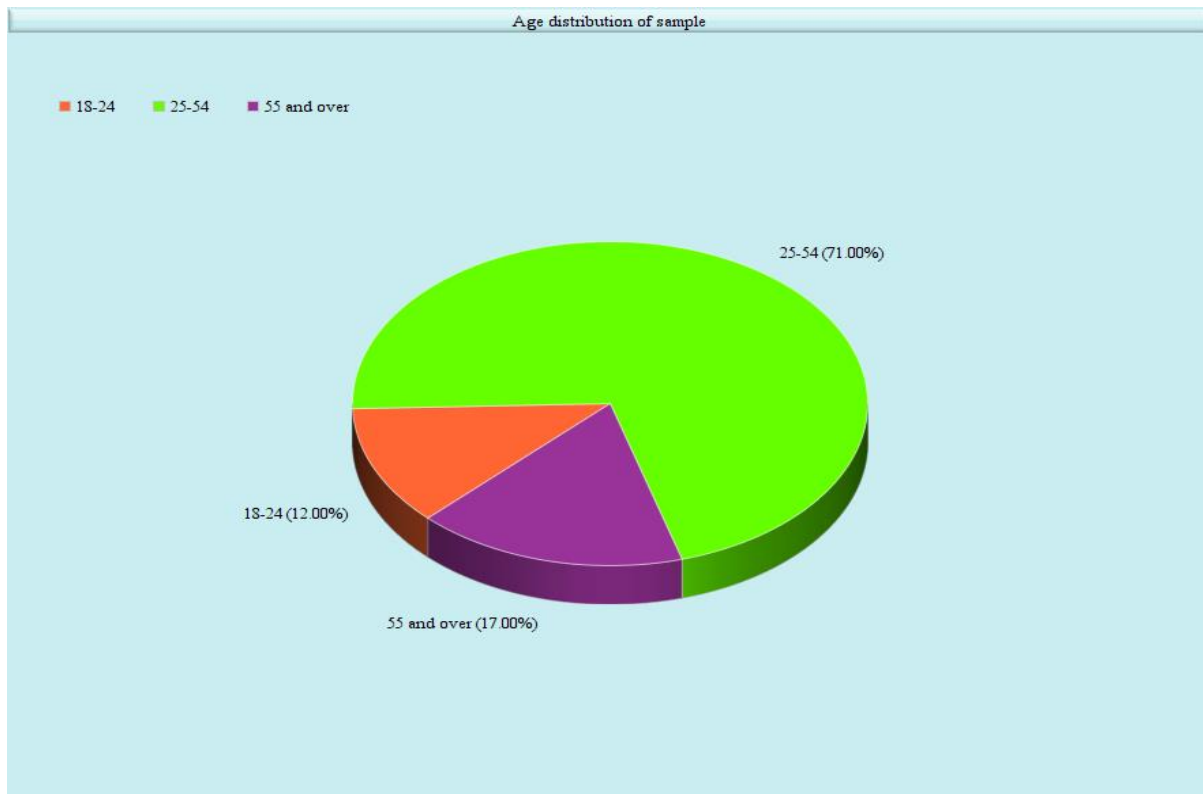
- Eighty-four responses to the treatment and care hard-copy survey (completed face to face as an interview with researchers or alone by service users). An additional three responses were received after the cut off date and the qualitative data from these surveys were included in the thematic analysis but not the quantitative considerations.
- Nineteen responses to the online survey
- Eight responses to the assessment questionnaire (completed face to face as an interview with researchers or alone by service users)
- A focus group with four people (including one carer) in the Vale; A second focus group with five service users in Cardiff and; a final focus group with an additional five service users in Cardiff
- Illustrative case study interviews with three service users

Sample characteristics and considerations:

The research team collected demographic information from survey respondents so that we could monitor sample characteristics and ensure, where possible, that we were speaking to a diverse sample that accurately reflect the population. Nevertheless, despite attempts to ensure the survey was distributed to a wide demographic - including dissemination to specific support organisations that work with minority groups - 93% of our survey sample selected their ethnic background as White British. These demographic inequalities could be a result of our narrow sampling time frame or it could be symptomatic of a reported disparity in accessing mental health treatment between Black, Asian and Minority Ethnic groups and the general population (NICE, 2018). Either way, it is recommended that further work is done to ensure a representative view of all demographic groups in Wales.

Other sample characteristics include:

- The majority of the sample was aged between 22 and 54 (Figure 1.)
- Sixty-seven per cent identified as female, 32% as male and 1% preferred not to say.
- One person identified as trans in our sample, while another two people told us that they preferred not to say
- Eighty-three per cent of people identified as heterosexual
- Twelve per cent have been receiving treatment and care with their CMHT for less than 12 months, whereas 56% said they had been in contact for over five years



*Figure 1. Age distribution of the sample*

During the research we spoke to people who attended the following CMHTs: South West Cardiff (Hamadryad Centre); North West Cardiff (Gabalfa Clinic); West Cardiff (Pendine Centre); South East Cardiff (Links Centre); North East Cardiff (Pentwyn Health Centre); Vale Locality Mental Health Team (Barry Hospital). Thirty-eight per cent of treatment and care survey responses were received from the Vale Locality CMHT, owing in part to the increased footfall of service users on those premises during data collection sessions. Please note that no attempt has been made to make comparisons between experiences at various CMHTs as numbers are too low for meaningful comparisons. The survey was only one of many ways we gathered survey user views and taken in isolation does not give an accurate reflection of experiences at individual CMHTs. Results are illustrative of a sample of service users at one point in time - they are not intended to be generalised beyond the sample.<sup>2</sup>

Finally, a point raised by some people during the course of the research was that there is a paucity of research on people who feel that they *should* have access to secondary mental health care services but do not - essentially those that feel they have 'slipped through the net' - and those that have been discharged back to primary care over 12 months ago but still

<sup>2</sup> Not all service users answered all survey questions - either because the questions varied depending on whether they were completing the online or face to face version of the survey or because they chose to omit a question as per their right to do so. Attempts to amalgamate question results have taken place where appropriate and percentages are based on the number of people who provided a response on that topic (n=).

want to have their say on mental health services. Both topics were outside the scope of the current research but provide avenues for future research.

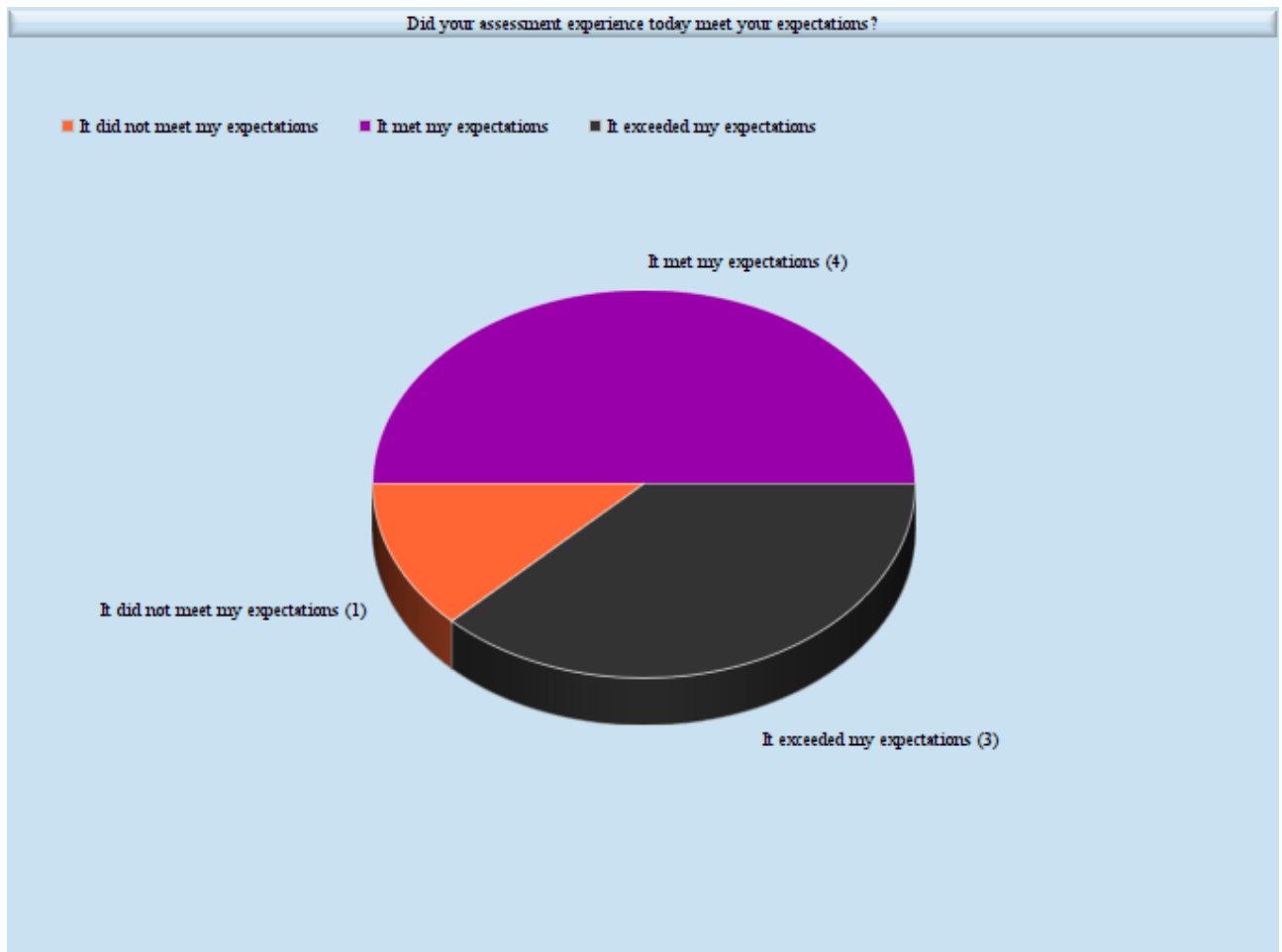
## Results

### The experience of having an assessment at a CMHT

Please note that despite results being presented in percentages in places, we only spoke to eight people having their mental health assessment with a local CMHT. As noted in the above method section, results are illustrative and not intended to be representative of general experiences of assessment appointments with Cardiff and Vale CMHTs.

Most people we spoke to were female (75%) and were referred for assessment by their GP (75%). One person told us that they had re-referred themselves under Part 3 of the Mental Health (Wales) Measure. Half of people were not having their first CMHT assessment and most people having repeat assessments (75%) told us that their last assessment was less than a year ago. Participants were either having their assessments at Barry Hospital or Pentwyn Health Centre.

Overall, 75% of people were very satisfied or were satisfied with their assessment experience and two people said that they felt neither satisfied nor dissatisfied. No one said that they were dissatisfied. Only one person said that the assessment appointment did not meet their expectations with four people saying that it met expectations and three people saying it actually exceeded their expectations (Figure 2.).



*Figure 2. Did your assessment experience today meet your expectations? (values)*

"The assessment was good, felt like everything was covered that was needed to be. Friendly ladies made me feel comfortable" (Service user)

People told us that they were generally happy with how the referral process had been communicated to them - half of participants rated communication as good or very good and no one rated communication as poor.

People can experience anxiety in advance of their appointment due to fear of the unknown and concerns over the process and outcome of the procedure. Results suggest that people value being treated with dignity and respect by CMHT staff. One hundred per cent of people who answered this question felt that they were treated with empathy, dignity and respect. To help with anxiety over the assessment procedure, people also value a welcoming waiting.

People say it is important to them that the CMHT office building is easy to travel to, but only half of those we spoke to said that they found it easy to travel to their appointment. Differences in service user experience of ease of access is likely down to whether the person has their own transport, i.e. a car, as opposed to relying on public transport which



can significantly increase travel time. Additionally, if it is a person's first time visiting the offices then they might not be aware of public transport options.

People told us that they valued someone explaining to them in advance what was going to happen during their assessment appointment. This happened for half of the people who all stated it was very useful. The remaining people said an explanation of what was going to happen was not offered but they would have found such an explanation very useful.

One hundred per cent of people agreed that they felt listened to by the people (or person) doing their assessment. Everyone also agreed that the assessment took into consideration all aspects of their lives and personal circumstances. All but one person agreed or strongly agreed that they had a say in decisions made about them.

Three people stated that during the appointment they were told of other organisations (for example, charities, voluntary organisations or help lines etc.) that could help them with their mental health and that this was valued. More than half of respondents were given information about how to self manage their mental health problem which they valued and others said they were not given information on this but would have liked it.

Seven out of eight people having an assessment told us that they now know who to contact if they were to have an emergency mental health crisis.

Key findings: Most valued in current provision and good practice

- Overall, people had a very positive assessment experience at their local CMHT with evidence of good practice
- People value being treated with empathy, dignity and respect during the assessment procedure
- People value information on travel options to the CMHT in advance. Including local public transport information in the referral letter warrants exploration
- People value an explanation in advance of what they can expect to happen at the assessment appointment in order to reduce anticipatory anxiety
- People having their assessment value useful signposting to a comprehensive range of third sector organisations and resources that could help them to manage their condition. Ways to achieve this include (i) arming assessors with a range of leaflets that could be handed to people during their appointments and (ii) posters of third sector organisations and services such as MIND, 4Winds or Ty Canna could also be displayed in the waiting room
- People want to be given useful information about how to self manage their mental health. An A4 list of available websites and help lines handed to service users following their assessment appointment could be helpful in achieving this
- People having their assessment value being told who they should contact in the case of an emergency mental health crisis.

## Communication between CMHTs and service users

We spoke to people about how satisfied they are with how their CMHT communicates with them. Overall, 54% of people who answered this question (n=74) rated communication as either 'good' or 'very good'.

Analysis of the qualitative data revealed deeply mixed communication experiences and satisfaction amongst service users. Some people were very happy with the level and method of communication between themselves and CMHT staff:

"I like the way I am listened to and treated as a human whose preferences matter" (Service user)

"I am happy and communication is fine" (Service user)

Good communication from the CMHT boosts service user satisfaction with their CMHT treatment and care.

People value:

- Reliable, consistent communication where clear information is given in advance regarding what appointments will involve (for example, medication review, routine check-up, depo etc.)

"More explanation of what's happening would really help lower the anxiety levels." (Service user)

- Clear, non-jargonistic explanations of a person's diagnosis and treatment
- CMHT staff that are willing and able to listen to people and allow the user to express themselves. People accept there is limited resources but appreciate it when professionals listen and do not rush them during appointments. Many people spoke to us about the value of Community Psychiatric Nurses (CPNs) who they feel can give more of their time to listen than Drs can due to the nature of their job role.

"Talking therapy really helps. I need to get a lot off my chest but there is no one to talk to" (Service user)

- Being communicated with in a style that treats the service user with empathy, dignity and respect. In our study 73% (n=73) of people told us that CMHT staff communicate with them with empathy dignity and respect.
- Timely access to their care provider; however, only 45% (n=75) of people agreed they are seen often enough by their mental health team to meet their current needs and many felt that they have to wait too long between appointments.

Although good practice in communication style is certainly happening for some people, there is great variability in experiences and clear opportunities to boost satisfaction with CMHT communication. Analysis of the research findings allowed us to identify areas where communication can be improved in order to maximise service user satisfaction of their CMHT service.

Just under a third of people (n=19) people feel that they are not listened to by their care provider and just under half (n=20) feel that they do not have enough time with the member of staff to fully discuss their needs. The feeling of not having enough time to discuss what is personally important impacts on the extent to which a person feels like they are being listened to. In a climate of limited resources, and where waiting lists for talking therapies are long, it is essential that service users are signposted to other support organisations and given the number of local or national help lines that they can contact when they need to feel listened to.

“I try ring for help but I miss the office hours. I just want someone to talk to.” (Service user)

Just over half of people (n=73) agreed that the CMHT team communicates with them in their preferred way. However, some people would value more flexible options of communication when arranging appointments.

“Having an option to text and not phone would be really helpful when I’m very unwell”  
(Service user)

“Phone-calls are my least preferred method of communication as it raises my anxiety”  
(Service user)

Some people told us that they receive a text reminder of their appointment which they find useful.

A basic thematic analysis revealed that there are two key issues that lead to a poor communication experience for people:

(i) Failure to communicate, and/or inconsistent communication between the CMHT and service user

“I was told someone would call be back but they never did” (Service user)

“On a number of occasions I have taken time to arrange a meeting in my home with my CPN and he has not turned up. This is very frustrating and has made me feel anxious” (Service user)

Even in the event of unforeseeable circumstances or routine breaks in usual care, for example, staff holidays etc., then continuity of communication remains essential.

(ii) A lack of communication between internal teams and external stakeholders

Joint working and communication between team members and external stakeholders was flagged as a concern for service users. People do not want to repeat their personal information unnecessarily for various staff members - they want effective communication and joint working between teams, wider stakeholder and themselves.

“There needs to be much more joined up working between all the areas involved in my care, both physical and mental health” (Service user)

“My mental health condition makes it hard for me to engage in physical health services and attend much needed scans and tests. There is no communication between the sectors so I end up risking my health and going without. It makes me so depressed” (Service user)

“It is vital that there is excellent communication between everyone, including and most important, the service user but too many times this falls completely, inadequately short” (Service user)

Key findings: Most valued in current provision and good practice

- Our research highlighted variations in the quality of communication between staff and service users who receive ongoing treatment and care at CMHTs
- A significant proportion of people feel that communication needs to improve
- People value a communication style that is empathetic and conveys respect to the service user
- People value being listened to
- People value being made aware of agencies external to the CMHT that they can contact if and when they want to talk through their problems
- People value communication that is clear, timely and, where possible, respects the preferred mode of communication of the service user
- People want consistent communication and joint-working between mental health workers, the service user and wider stakeholders, especially care providers who work in physical health
- People value good communication and every effort should be made to gather ongoing feedback from service users from across Cardiff and the Vale CMHTs. Ideally data should be collected by someone independent from the CMHT to ensure that people can talk openly and honestly about their experiences. Trained peers with lived experience of mental illness could be ideal in this role.

### The accessibility of the CMHT offices

This section of the report explores how easy and comfortable it is for people to attend appointments at their local CMHT. Overall, 98% (n=65) of people rated their CMHT building as ‘somewhat’ or ‘very’ accessible.

Some people told us that they find it easy to get hold of the CMHT team via telephone with only 17% (n=18) of people saying they find it difficult to get through this way. Fifty-six per cent of people (n=75) felt that the opening hours of the CMHT suited their needs. Those that disagreed expressed a desire for a service that can accommodate people during evenings and weekends.

Just under 1 in 4 people find it difficult to travel to their local CMHT office. Difficulties arise for a number of reasons:

- (i) those relying on public transport for travel to the CMHT and find this difficult due to (a) the time and/or effort it takes to travel to the CMHT office or (ii) those unaware of feasible local public transport options
- (ii) The presence of mobility issues or physical disability
- (iii) Those who find travel uncomfortable due to their mental health condition

“Having a centre where bus travel is practicable with a minimal walk would be good” (Service user)

“The office is easily accessible but parking can be a problem at times, especially disabled” (Service user)

“Fine if you have a car but difficult for those without.” (Service user)

People value CPNs that can visit them in their own home:

“CPN will visit at home where I am more relaxed and able to discuss in a comfy environment” (Service user)

“I would like to see more CPNs employed. They are overstretched and overworked” (Service user)

The atmosphere of the waiting room can make a difference to the experience of those attending appointments. People told us that a welcoming atmosphere shows people that they are valued and that effort has gone into making their experiences as comfortable as possible.

Twenty-nine per cent of people (n=73) do not find the waiting room of their CMHT welcoming. Some people expressed concern that waiting rooms can be too ‘sterile’, ‘formal’ or ‘crowded’. While many CMHTs are restricted with how much they can change the layout of the waiting area, they should nevertheless ensure the following where possible:

- Provide a water machine for refreshments
- Clearly signpost toilets and exits
- Provide reading material/leaflets for people to browse, including material on local third sector and wider support organisations
- Provision of a private room for people in distress

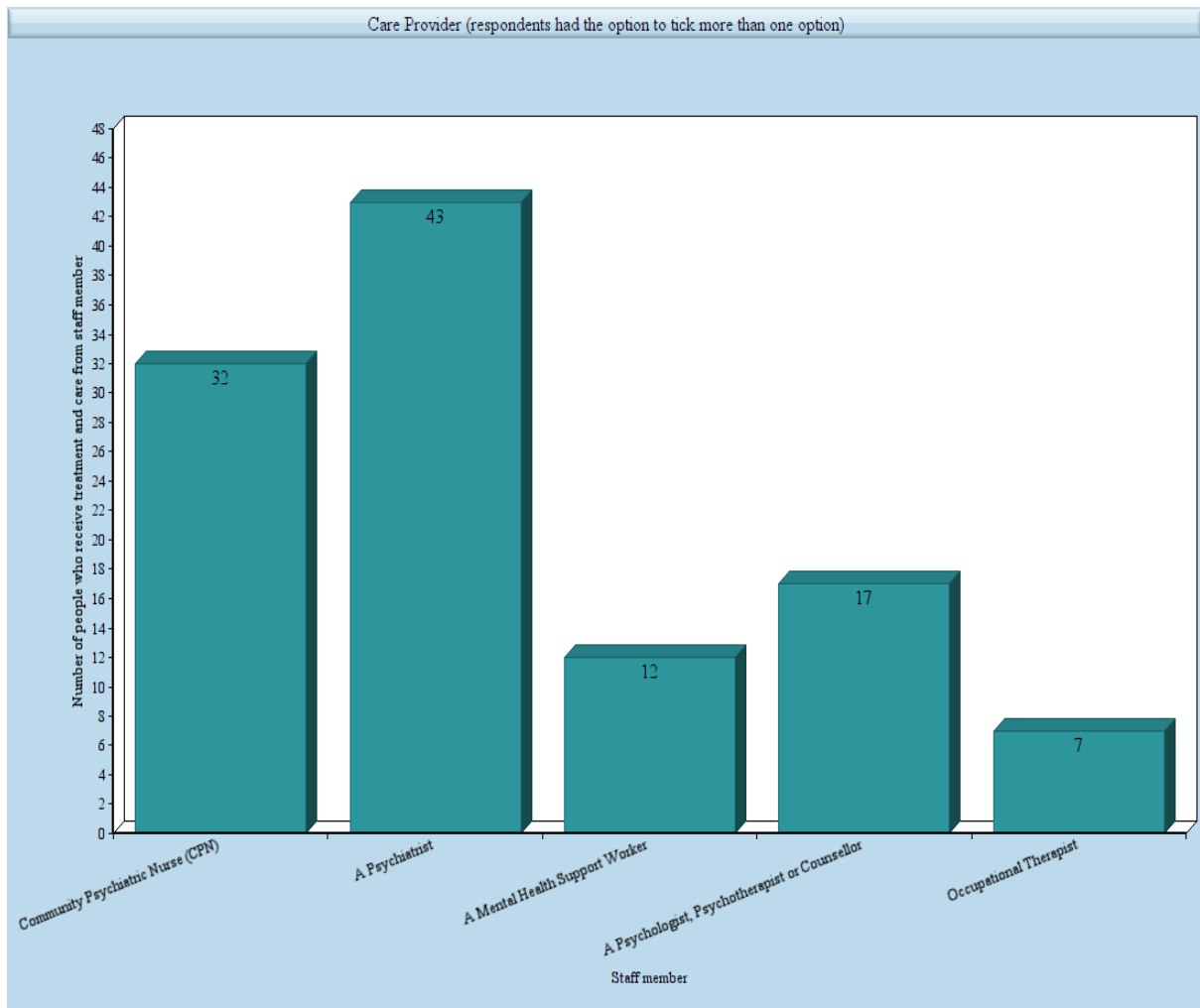
“Waiting rooms can be sterile and intimidating if lots of people are there. I have to go outside if there are lots of people.” (Service user)

Key findings: Most valued in current provision and good practice

- Overall, people find their local CMHT building accessible, but there are ways to boost ease of access by considering any travel barriers and ensuring that waiting rooms are welcoming
- People value being able to access help outside of office hours. All service users should be given details of who to contact if they require support and advice outside of CMHT working hours (e.g. out of hours GP service, Community Advice Listening Line details, NHS Direct etc.). A wallet sized card containing essential numbers and an up-to-date directory of local and national 24 hour help lines would be helpful
- People value efforts to ensure travel to the building is made as straightforward as possible. This includes the provision of adequate parking space, especially disabled spaces. Ensuring all service users are aware of local public transport options for travel to the CMHT building maximises the accessibility of the CMHT
- When people find it difficult to travel to the CMHT, they value CPNs and home visits

### The quality of treatment and care with a CMHT

We asked people who usually provides their treatment and care at the CMHT. The most popular care providers are displayed below in Figure 3.



*Figure 3. Who usually provides your treatment and care? Most frequent shown*

Over half of people (n=71) stated that they were satisfied or very satisfied with the treatment and care they are receiving from their CMHT. Qualitative data painted a variable picture with some people being extremely satisfied with service provision:

“I have been looked after extremely well” (Service user)

“Excellent service, should have more money!” (Service user)

Case study: "I have experienced mental health problems since I was a child but I didn't get referred to my CMHT (Hafan Dawel) until I was in my thirties. I remember being really nervous going for my assessment but the two people who undertook the screening were really friendly and welcoming which meant a lot. They told me that I would receive an appointment with the psychiatrist shortly after my appointment. Two weeks later I had my appointment with a wonderful psychiatrist and we worked together to try different medications to help me to control my symptoms. It was a long wait (two years) but I have now been able to have psychological therapy, too. My therapist was great, and has helped me understand myself and my illness and explore better ways of relating to myself and my symptoms. I do not have a care plan, as far as I know, but the team have always included me in what medication I try and worked with me to tailor therapy to my difficulties. I most value having someone to talk to who understands how my illness impacts my life. Both my Psychiatrist and therapist were always willing to listen to me and I never felt rushed or unheard. I still have symptoms of mental illness but I am learning to live with them and lead the best life possible for me and my family."

Some service users told us that they were very unhappy with the quality of treatment and care they are being given, with satisfaction with the service reduced for one or more reasons. Analysis has allowed us to identify the factors that boost service user satisfaction with the quality of treatment and care provided as well as areas that reduce satisfaction. The rest of this chapter explores these drivers and barriers to a positive experience and satisfaction.

In many instances people told us that their dissatisfaction with the service is not to do with CMHT staff, and more that mental health services are squeezed with nowhere near enough resource to meet demand. More than three quarters of people we spoke to felt that they have had to wait too long for treatment.

"Almost all the people are nice; it seems the system limits what support they can offer."  
(Service user)

"The individual people I see are very warm and personable" (Service user)

Nevertheless, there are clear opportunities to maximise satisfaction within the current system of services by ensuring a consistent standard and replicating the good practice that is already happening for many service users.

People value access to knowledgeable staff, and 61% of the sample (n=75) agreed that their mental health team is knowledgeable.

"I see one of the best psychiatrists I have ever met" (Service user)

People want access to staff that have specialist knowledge in their particular condition, regardless of how rare. One person explained how she feels her care provider does not understand the intricacies of her binge eating disorder and this leaves her feeling misunderstood and alone.



Some people explained to us that they find only find certain members of their CMHT team knowledgeable. It was also interesting to witness people in a focus group having very different views on their satisfaction with particular members of staff- thus highlighting the very heterogeneous nature of people's subjective opinion of care quality.

Importantly, people told us that being treated with empathy, dignity and respect is just as important as having access to staff they deem knowledgeable.

"[I want] More understanding from the psychiatrist - often feel like she thinks I'm a time waster and can't wait to get me out of the room - she literally stands to open the door for me to leave while I'm still sitting and asking questions." (Service user)

People value early intervention before they reach crisis point. There was strong recognition that when correct treatment and care is in place at the earliest opportunity there is a decreased risk of people spiralling towards a mental health crisis situation:

"I feel alone and there isn't any preventative support" (Service user)

"Although not suicidal, I needed out of hours care but no one got back to me after I left a voicemail message. By the time someone could see me - days later - I was too ill to respond to the level of care they offered me. I had continued to spiral into poorer mental health alone and needed more comprehensive support by the time anyone saw me. It was too little and too late, I have never really recovered back to where I was before" (Service user)

"Early intervention is key. Crisis care is improving which is great. Services are getting much better - the mental health measure/charter has helped with this." (Service user)

People value consistency with their care providers, with whom they build up a relationship of trust. One service user, Carys (pseudonym), told us how she once had a valued relationship with a particular CPN:

"I could finally open up and be vulnerable with someone. She knew all my secrets"

Carys turned up for her routine appointment one day only to be told that the CPN had left post and she never saw her again. This left the Carys feeling hurt and confused that the relationship was broken without notice or explanation. Carys' experience was not an isolated incident during the research...

"I had a great CPN but then they left" (Service user)

Seventy-seven per cent of people told us that it is extremely important to them to see the same person for their care and treatment and the remaining 23% said it was somewhat important. Despite the importance of continuity, over half told of our sample told us that the person providing their care had changed in the last 12 months and in 47% of cases the change was not the choice of the service user. Where changes to trusted relationships are unavoidable, it is clear that people value prior notice and reassurances of what the change means for their care and treatment.

“I have seen 3 different psychologists in the last 12 months or so” (Service user)

“I am on my 4th rotation of consultant, my third cpn all under two years.” (Service user)

Some people expressed continuity concerns over being discharged from CMHT back to primary care, despite the right to right to re-refer themselves to mental health services under part three of the Mental Health (Wales) Measure. In addition, less than a quarter of people (n=19) we spoke to told us that they were aware of their right to re-refer themselves to mental health services under part three of the Mental Health (Wales) Measure.

“changes [that mean] we can only access help when in crisis - there will be no continuity of care and the care providers will not know us or what we are usually like and there will be no trust in them !” (Service user)

Under Care and Treatment Planning in Part 2 of the Mental Health Measure, secondary mental health service users have the right to an individual and comprehensive Care and Treatment Plan (a Plan) to assist their recovery. In our sample only 49% of people (n=72) told us that they were aware that they had a Plan.

"I was promised a care plan, I don't know if I have one" (Service user)

We questioned a small sample of people regarding details of their plan. Of those that had a plan, 67% said that they had as much involvement in developing their care plan with their care provider as they wanted; 67% said that the care plan took into consideration all areas of their life; and 78% said that they find the care plan somewhat or very useful.

“There should be much more focus on the care treatment plans rather than them hastily being done years ago and left in a drawer!” (Service user)

“Good to know your rights and what to expect. It's proof. It's like a receipt” (Service user)

Of those that had a Plan, 89% had viewed it but over a half were not given a copy to take away.

Just over half of people (n=69) have regular meetings to discuss their treatment and care, which mean just under half of people do not. Opportunities to tailor treatment and care to a person's current life situation as well as opportunities to identify deterioration in mental health are being missed.

“I don't have regular meetings. I am left to my own device, which means I don't always do what is right for me” (Service user)

“It (the Plan) is not being followed by my mental health team” (Service user)

The value of having a Plan to service users is clear and, when done correctly can serve as an empowering tool for service users to help them understand their rights and what they can expect from treatment. People do not want a token Plan; they want a meaningful record of

where they are now in terms of their goals and where they want to be. To maximise the effectiveness of the Plan:

- Ensure they are co-produced with service users so that all salient life points are covered
- Review at appropriate points ( and at least annually) to ensure relevance and assess progress towards treatment goals

Just over half of people (n=67) agreed that their mental health team help them with what is personally important to them. Working towards recovery goals that are personally meaningful to the service user boosts satisfaction in the service and the co-produced Plan is an obvious opportunity to ensure that initial goals between staff and service user are aligned.

The right to regular monitoring and review (including a formal annual review) should be vocalised to service users and they should be supported to enforce their rights under the Mental Health (Wales) Measure. Indeed, only 29% of people told us that they know their rights when it comes to their care and treatment. Some people told us that the system of services is complex and without advocacy it can be difficult to navigate, understand and, if need be, make a complaint. Only 16% (n=19) told us they were aware of the CMHT complaints procedure. People want access to trained advocates to help them understand and, when needed, enforce their rights.

“Get an advocate involved otherwise you get walked over sometimes” (Service user)

"I don't feel heard" (Service user)

“When you complain formally, you are made to feel a trouble maker, the Trust defends all staff and nothing really is changed” (Service user)

Finally, but importantly, people value shared decision-making and having a say in their own treatment and care. More than half of people told us that they have as much involvement and say as they want in the treatment and care they are given. Many people told us that, given the nature of their condition, they don't always get to choose the medication they take but nevertheless report joint-working with their team to trial medications and they felt listened to by their care provider. However, this still leave a significant minority that would like more involvement in their treatment and care.

A small sample of people were asked to elaborate on their experience of shared decision making on medication and only one in four people said the advantages and disadvantages of particular treatments had been fully explained to them in a way that they can understand. Further analysis of the qualitative data revealed more than one disturbing example of where the full potential risks of particular medical treatment was not explained to the person in advance. This coupled with a lack of therapeutic drug monitoring for toxicity led to irreversible damage to physical health.

“I want more say in my treatment with other options explained and discussed openly” (Service user)

## Key findings: Most valued in current provision and good practice

- Over half of people are satisfied with the treatment and care they are being given but a significant proportion feel improvements could be made
- People value access to knowledgeable staff, including those with specialist knowledge in the illness they experience
- People value being treated with empathy, dignity and respect
- People value early intervention and support before they reach crisis point
- People want continuity of care and when that is not possible they want to be provided with a full explanation and implications for their care as soon as possible
- The full potential of care plans are not being realised in many cases
- People value a holistic, non-tokenistic care plan that is regularly reviewed and updated as is people's right under Part 2 of the Mental Health Measure
- People value shared decision-making and having a say in their treatment and care. A significant proportion of people we spoke to want more say and involvement than they currently have
- People value having the pros and cons of medication explained fully to them so that they can make an informed decision. Where indicated, any potential side-effects need to be monitored to identify any potential issues early
- People value being empowered to know and understand their rights and have access to independent advocacy to enforce these rights when needed
- People value being made to feel like their voice matters

## Experiences of accessing care in a crisis

Just over half of people (n=74) told us that they knew who to contact out of hours if they have a mental health crisis. Although numbers are too small to make a comparison, this figure appears significantly lower than the seven out of eight people having their assessment who knew who to contact during an out of hours crisis.

We spoke to a smaller sample of people who had been through the process of crisis assessment locally (n=11). Three people told us that they found it difficult or very difficult to get hold of crisis support. Four people said they were not seen quickly enough for their needs and only half felt supported by staff during the crisis assessment and felt they were given clear information on the outcome and next steps. However, seven people said they found crisis care either somewhat or very useful.

“Very helpful, got me out of the hole I was in at the time” (Service user)

Most valued by people in crisis care is timely access to crisis and recovery support.

“Wheels moved very quickly as I was a suicide risk” (Service user)

However, some people we spoke to feel there need to be more intensive/crisis support for those that are not suicidal.

“People who need immediate treatment are not always suicidal” (Service user)

“Unless one is actively suicidal it is incredibly hard to access crisis care and they have no doctors working at weekends” (Service user)

People told us that having a mental health crisis and accessing support can be anxiety-provoking. A key element of helping people feeling more comfortable with the process is for staff members to explain to the person what is going on and what the next steps will be.

Move on from crisis care and/or hospital is very important to people. Some felt that discharge and aftercare was chaotic with little information filtering through to the service user. Places like the Crisis Recovery Unit at the Heath were praised for their work. People would like to see these services receive more financial support and their services advertised more widely.

People want more than short-term planning after recovery from a crisis.

“They took all my tablets but no follow up support. I would have liked follow up support” (Service user)

“Short-term positive but I relapse quite quickly” (Service user)

Key findings: Most valued in current provision and good practice

- A significant proportion of current CMHT service users do not know who to contact out of hours in the event of a mental health crisis
- Current users of CMHTs require up-to-date information on who to contact in a crisis  
Small wallet sized ‘business cards’ with crisis care numbers on could be useful to achieve this aim
- Most valued by people in crisis care is timely access to crisis and recovery support
- People want understanding that being in crisis does not always mean feeling suicidal
- People value transparent communication of the crisis procedure and expected next steps
- People value both short and long-term planned discharge from crisis care and/or hospital with follow-up monitoring.

Treatment and care in the community: Holistic support

Wider support needs:

We asked people “in addition to your mental health needs, has your team told you about how to access advice and/or care for any other life areas?” Answers in this area were varied and many people we spoke to said they did not require advice or care in any other area. For those that did, the most common area people received signposting was how to access care for physical health issues. Access to physical health services was also rated highly in terms of where service users would like more assistance and support to access. Other people said they would find it useful to get more assistance and signposting in areas such as finance &

benefits; relationships; alcohol and drugs; housing and relationships. The Care Plan is an excellent opportunity to identify and monitor ongoing wider support needs.

Self-help and recovery journeys:

People want to be given information on resources to help them to manage their own mental health problems in addition to more formal care and treatment. Forty-one per cent of people said that they have been given information on how to self-manage their mental health which they find helpful, and another 35% told us that they did not receive information on this but would have liked to have. Nevertheless, it is clear that while some people are willing and able to explore and utilise such resources, others require further support to access such services, especially when they are unwell:

“When I am really ill I cannot look up things for myself on the internet” (Service user)

“I look self-sufficient but I need help. Even though I look strong, I am not” (Service user)

The role of third sector organisations can play an essential role when it comes to addressing wider support needs and undertaking self-management of mental health conditions. Just over half of people told us that they have been given information about services provided by charities and voluntary services and found it helpful, while 35% have not yet received this information but said that they would have found it helpful. Throughout the study period people told us how much they valued the support and help that organisations outside the CMHT can offer them. The help most valued is:

- Speaking to someone who has time to listen and respond with empathy and understanding
- Direct access to courses and resources run by the organisation
- Support to access wider support needs and advocacy
- Meeting other people with lived experience of mental health issues who can empathise.

“They tell you about wider issues like benefits and will come with you and support you” (Service user)

Examples of places valued by service users are:

MIND

Ty Canna

4WINDS

Crisis Recovery Unit

SHEDS (service for high risk eating disorders)

“I think everyone who has access to CMHT should know about all organisations and charities helpful to them, irrespective of whether the person giving treatment thinks that person is well enough to benefit/not benefit. Better to know than not.” (Service user)

“I enjoy reading and have been able to join a book club at 4winds” (Service user)

“Put up posters about relevant mental health organisations. I have been involved with 4 Winds recently and finding it massively helpful. I heard about them from my support worker outside of CMHT and was surprised there were no posters nor was I made aware of 4 winds while accessing treatment” (Service user)

“Someone to help with day to day stuff like CV writing would be helpful. There should be more resources available for people to go to a safe environment with service users and professionals (<run by) when you feel wobbly” (Service user)

Nevertheless, not all service users want to access third sector organisations. Reasons given include:

- Group work being difficult or unappealing for some people
- Feeling ‘fobbed off’ and preferring treatment and care only with a CMHT

“They just want you to do courses these days” (Service user)

- Lack of standardisation and consistency of courses and support between external services so you cannot guarantee quality

Thus it is imperative to tell service users about such resources, but ultimately up to the individual if they feel it would be helpful to their personal recovery journey.

Recovery journeys:

Thirty nine per cent of people we spoke to (n=19) said that they have discussed their recovery journey with their mental health team and found it useful - another 39% said they haven’t but would like to have this discussion. Twenty-two per cent of people didn’t know what we meant when we talked about their ‘recovery journey’. People want to have a discussion about what recovery means to them as part of a holistic mental health service.

We explored the Mental Health Charter with a smaller sample of people and 63% said that they were aware of the charter. Of those aware of it, 82% think it is somewhat or very useful. People would like to see it advertised more and given the recognition it deserves.

“Professionals especially should be much more aware and adhere to it even when short staffed and under-resourced.” (Service user)

Peer Support:

Nineteen per cent of our sample have been told about ‘peer support’ delivered by other people who have used mental health services and found it helpful while 50% said they have not been told about peer support but would like to know more.

We spoke to a small sample of people (n=16) about whether they had been offered skills training delivered by other people who have also experienced mental health issues. Three

people said they had and it was helpful, one person said they had been told but it was not helpful, nine people said they had not been told but it is something they would be interested in and three said they had not been told and would not like this.

Responses to whether people value peer support - either in the form of skills training delivered by experts-by-experience or more informal support- was varied.

Those that value the inclusion of peers in their recovery cited a variety of reasons including boosting optimism about recovery and increased empathy:

“I take great strength from people who have lived experience” (Service user)

“You can speak to people and they can relate to what you’ve been through” (Service user)

“For me, knowing others can get through it and help other people makes me feel like there is some hope for me and maybe I can help people if I get through this” (Service user)

However, those that did not welcome peer support cited reasons such as:

- Concerns about quality of courses if not delivered by trained professionals
- Privacy

“No, I like to keep my problems personal” (Service user)

Service user involvement in the design and delivery of services:

People want the chance to feed in their views to evaluate services. In addition, people want the opportunity to become more involved in the design and delivery of mental health services. Thirty one per cent of people told us that they have been given information about ways in which they can get involved in shaping the delivery or evaluation of local mental health services and found it helpful, while 50% said they have not received this information but would like to know more. Nevertheless, it is imperative that involvement is meaningful and not tokenistic. Service users need to feel empowered to have their say in how services are run and see evidence that their views are being listened to and make a difference.

“Would be nice to be more involved but I kinda feel that nothing I say will be listened to” (Service user)

Key findings: Most valued in current provision and good practice

- People want to be asked if they require signposting and/or support to access other wider support agencies

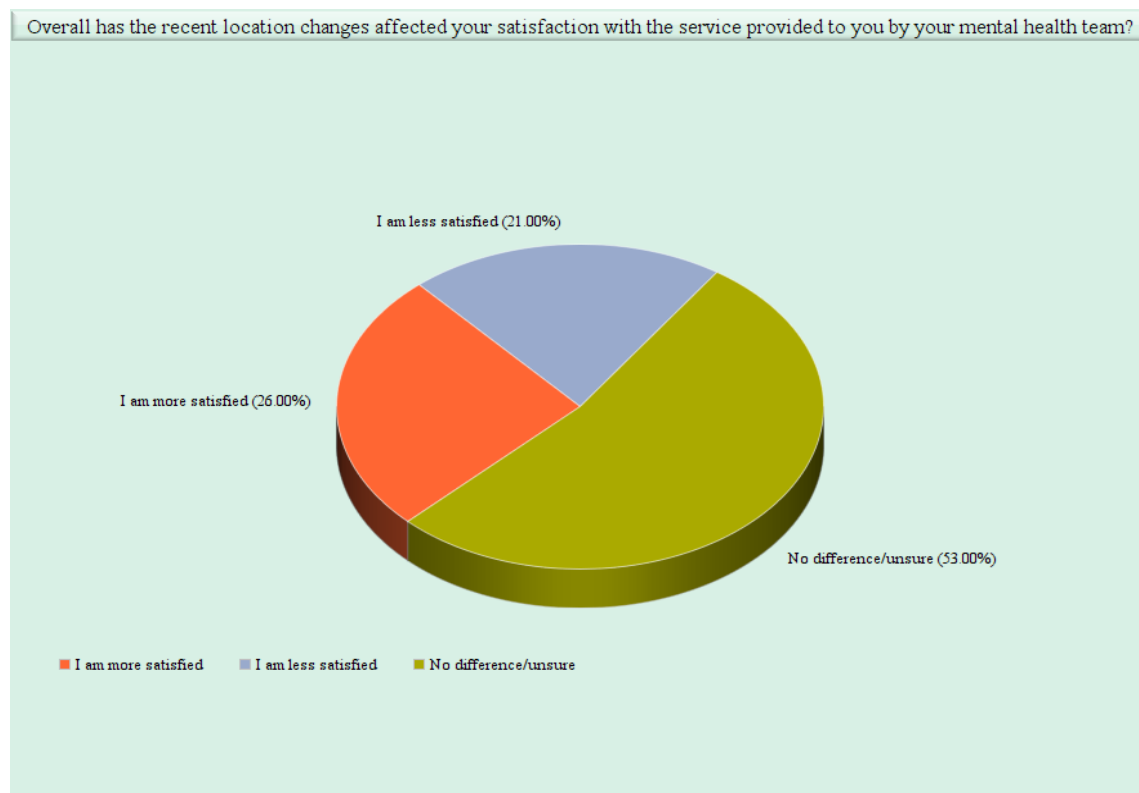


- People value being told about third sector organisations that can help people access help for wider support needs or more informal support with recovery journeys - even if they choose not to use them
- People want to have a discussion about what recovery means to them as part of a holistic mental health service
- People value the Mental Health Charter and would like to see it advertised and understood more widely
- People want to be told about available peer support - this could be courses run by experts-by-experience or more informal support - in case they wish to utilise it
- People want a range of ways in which they can be involved in evaluating and shaping the delivery of CMHT services
- People want to be empowered to have their voices heard and see evidence that their views are being listened to and making a difference

### Co-location to Barry Hospital - service user experiences

We spoke to a sample of people (n=19) who had been affected by the merge of the former three Vale CMHTs (Amy Evans, Hafan Dawel and Western Vale), which co-located to Barry Hospital (Vale Locality Mental Health Team).

The majority of people told us that, at present, they were unsure if the merge had impacted on their satisfaction with the service provided to them by their mental health team.



Just over a quarter said their satisfaction has increased, while just under a quarter said it had decreased. Further investigation highlighted the factors that have led to these variable results.

It was clear that for many it is too early to fully assess whether the co-location has impacted on their satisfaction with their care. Nevertheless, there was palpable unease around the move that centred on the key theme of uncertainty - uncertainty over what the change meant/means for (i) the accessibility of the CMHT and (ii) the relationship with their care provider. The anxiety surrounding this uncertainty was exacerbated by a lack of communication in advance of the change.

Some people told us that they did not receive a full explanation of the co-location in advance:

“I didn't have much notice of the change. I was worried about travelling to the new location” (Service user)

“It was never explained. Is it cost cutting?” (Service user)

Some people had concerns around what the change would mean for continuity of their care and loss of trusted, personal relationships which are valued.

“As long as patient care is not neglected by having a larger team. Don't want to lose the personal team, but good that we have more resource” (Service user)

“A very awkward location change, no consultation before move. Now unsure if I have a named member of staff in the new location” (Service user)

Some people explained that travel could be a concern for those without their own transport.

“Fine as I have the car but I wouldn't want to travel to Barry by bus. It would take up time I do not have.” (Service user)

However, overall, people are hoping that the merger will lead to greater pooled resources which will, in turn, result in improved quality of service. Some users pointed out that regardless of the perceived negatives of co-location, the quality of staff remains high; and, as we have seen elsewhere in this report, how people are treated by CMHT staff impacts on their overall experience of treatment and care.

“Slightly less accessible and slightly longer waits but unchanged in professionalism and caring disposition” (Service user)

Key findings and lessons learned:

- People do not feel the recent co-location in the Vale was effectively communicated to them in advance

- People value significant changes communicated at the earliest opportunity, particularly: (i) reasons for any change and (ii) clarification around continuity of care.
- People value consultation on changes to the location of the CMHT and understanding for their concerns about travelling to a new location.
- Ultimately, with reassurance, service users are optimistic that co-location can result in the same, if not better, standard of service. Indeed, this is apparent with the 26% of people who told us that they are more satisfied with their treatment and care since the co-location to Barry Hospital happened.

## Conclusion

This report provides an illustrative snapshot of over 100 service user experiences at Cardiff and Vale CMHTs during late 2018. Overall, the results demonstrate a variable picture of experience and level of satisfaction with the treatment and care provided. From the findings we have been able to identify (i) what about current provision people most value and; (ii) what could be improved or changed to maximise service user satisfaction and optimise positive experiences. We have provided insights into several key themes involved in the CMHT experience including: having an initial assessment; communication; accessibility of the building; treatment and care; access to crisis care; holistic support and service user involvement and; how co-location can impact on satisfaction with the service and good practice.

We hope that the results can offer a useful insight for UBH and other interested stakeholders into what is most valued by people using their services, as well as providing a roadmap on potential ways to improve service user satisfaction.

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**MySay: A Service User Feedback  
Project  
Executive summary**

## Summary

Cardiff and Vale University Health Board (UHB) commissioned Cardiff and Vale Action for Mental Health (cavamh) to undertake an engagement exercise with current users of Cardiff and Vale Community Mental Health Team (CMHT) services to determine their subjective experience with services and to assess the quality of provision via the views of 'experts-by-experience'.

This report provides an illustrative snapshot of over 100 service user experiences at Cardiff and Vale CMHTs during late 2018. Overall, the results demonstrate a variable picture of experience and level of satisfaction with the treatment and care provided. From the findings we have been able to identify (i) what about current provision people most value and; (ii) what could be improved or changed to maximise service user satisfaction and optimise positive experiences. We have provided insights into several key themes involved in the CMHT experience including: having an initial assessment; communication; accessibility of the building; treatment and care; access to crisis care; holistic support and service user involvement and; how co-location can impact on satisfaction with the service and good practice.

We hope that the results can offer a useful insight for UBH and other interested stakeholders into what is most valued by people using their services, as well as providing a roadmap on potential ways to improve service user satisfaction.

## Key findings: Most valued in current provision and opportunities for improvement

### Assessment experience

- **Overall, people had a very positive assessment experience at their local CMHT with evidence of good practice**
- People value being treated with empathy, dignity and respect during the assessment procedure
- People value information on travel options to the CMHT in advance. Including local public transport information in the referral letter is worthy of exploration
- People value an explanation in advance of what they can expect to happen at the assessment appointment in order to reduce anticipatory anxiety
- People having their assessment value useful signposting to a comprehensive range of third sector organisations and resources that could help them to manage their condition. Ways to achieve this include (i) arming assessors with a range of leaflets that could be handed to people during their appointments and (ii) posters of third sector organisations and services such as MIND, 4Winds or Ty Canna could also be displayed in the waiting room
- People want to be given useful information about how to self manage their mental health. An A4 list of available websites and help lines handed to service users following their assessment appointment could be helpful in achieving this
- People having their assessment value being told who they should contact in the case of an emergency mental health crisis

### Communication

- **Our research highlighted variations in the quality of communication between staff and service users who receive ongoing treatment and care at CMHTs**
- **A significant proportion of people feel that communication needs to improve**
- People value a communication style that is empathetic and conveys respect to the service user
- People value being listened to by staff
- People value being made aware of agencies external to the CMHT that they can contact if and when they want to talk through their problems
- People value communication that is clear, timely and, where possible, respects the preferred mode of communication of the service user

- People want consistent communication and joint-working between mental health workers, the service user and wider stakeholders, especially care providers who work in physical health
- People value good communication and every effort should be made to gather ongoing feedback from service users from across Cardiff and the Vale CMHTs. Ideally data should be collected by someone independent from the CMHT to ensure that people can talk openly and honestly about their experiences. Trained peers with lived experience of mental illness could be ideal in this role.

### Accessibility

- **Overall, people find their local CMHT building accessible, but there are ways to boost ease of access by considering travel barriers and ensuring that waiting rooms are welcoming**
- People value being able to access help outside of office hours. All service users should be given details of who to contact if they require support and advice outside of CMHT working hours (e.g. out of hours GP service, Community Advice Listening Line details, NHS Direct etc.). A wallet sized card containing essential numbers and an up-to-date directory of local and national 24 hour help lines would be helpful
- People value efforts to ensure travel to the building is made as straightforward as possible. This includes the provision of adequate parking provision, especially disabled spaces. Ensuring all service users are aware of local public transport options for travel to the CMHT building maximises the accessibility of the CMHT
- People value home visits when they find it difficult to travel to their local CMHT

### Quality of treatment and care

- **Over half of people are satisfied with the treatment and care that they are being given, but a significant proportion feel improvements could be made**
- People value access to knowledgeable staff, including those with specialist knowledge in the illness they experience
- People value being treated with empathy, dignity and respect
- People value early intervention and support before they reach crisis point
- People want continuity of care and when that is not possible they want to be provided with a full explanation and implications for their care as soon as possible
- **The full potential of care plans are not being realised in many cases**
- People value a holistic, non-tokenistic care plan that is regularly reviewed and updated as is people's right under Part 2 of the Mental Health Measure



- People value shared decision-making and having a say in their treatment and care. **A significant proportion of people we spoke to want more say and involvement than they currently have**
- People value having the pros and cons of medication explained fully to them so that they can make an informed decision. Where indicated, any potential side-effects need to be monitored to identify any potential issues early
- People value being empowered to know and understand their rights and have access to independent advocacy to enforce these rights when needed
- People value being made to feel like their voice matters

#### Access to crisis care

- **A significant proportion of current CMHT service users do not know who to contact out of hours in the event of a mental health crisis**
- Current users of CMHTs require up-to-date information on who to contact in a crisis. Small wallet sized 'business cards' with crisis care numbers on could be useful to achieve this aim
- Most valued by people in crisis care is timely access to crisis and recovery support
- People want understanding that being in crisis does not always mean feeling suicidal
- People value transparent communication of the crisis procedure and expected next steps
- People value both short and long-term planned discharge from crisis care and/or hospital with follow-up monitoring

#### Holistic care

- People want to be asked if they require signposting and/or support to access other wider support agencies.
- People value being told about third sector organisations that can help people access help for wider support needs or more informal support with recovery journeys - even if they choose not to use them
- People want to have a discussion about what recovery means to them as part of a holistic mental health service
- People value the Mental Health Charter and would like to see it advertised and understood more widely
- People want to be told about available peer support - this could be courses run by experts-by-experience or more informal support - in case they wish to utilise it
- People want a range of ways in which they can be involved in evaluating and shaping the delivery of CMHT services

- People want to be empowered to have their voices heard and see evidence that their views are being listened to and making a difference

#### Impact of co-location

- **People do not feel the recent co-location in the Vale was effectively communicated to them in advance**
- People value significant changes communicated at the earliest opportunity, particularly: (i) reasons for any change and (ii) clarification around continuity of care.
- People value consultation on changes to the location of the CMHT and understanding for their concerns about travelling to a new location
- Ultimately, with reassurance, service users are optimistic that co-location can result in the same, if not better, standard of service. Indeed, this is apparent **with the 26% of people who told us that they are more satisfied with their treatment and care since the co-location to Barry Hospital happened.**