



The Advocacy Project

User Focused Monitoring Evaluation Report

Loneliness and Social Isolation

Mental health service users' experiences and views

November 2018



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Acknowledgements

The User Focused Monitoring (UFM) team would like to thank the people who have used mental health services who agreed to be interviewed, for their time and commitment in sharing their experiences with us.

UFM would also like to thank the managers and staff North and South in both Kensington and Chelsea and Westminster boroughs at the Woodfield Road, Pall Mall, Vauxhall Bridge Road and 1 Nightingale Place Community Mental Health Teams (CMHT). We very much appreciated the help from staff who actively promoted the evaluation to service users and facilitated access to confidential meeting space.

Thank you to the Campaign to End Loneliness for allowing us to take part in the informative and inspiring conference this year. Thank you also to Healthwatch Central West London for the update on the 'Meeting the needs of socially isolated older people in the Royal Borough of Kensington and Chelsea' report which helped shape our evaluation.

And last but not least a big thank you to the UFM members for their ongoing input and commitment to UFM.

Document details

Document Name	Loneliness and Social Isolation - Mental health service users' experiences and views		
History	Date Published Dec 2018	Date of last review Dec 2018	Date of last updates Dec 2018
Approval Authority			
Responsible Office	UFM Katja Huijbers		


Scope: Views and experiences of loneliness and social isolation, by people who use Mental Health services in both Kensington and Chelsea and Westminster.

Reason for the document: To understand the experiences of local people and make recommendations for improvements.

Who should read this document: Commissioners of health and social services, providers of mental health services, providers of community services, managers of community projects and groups. People who use mental health services.

The Advocacy Project

Loneliness and Social Isolation

1 Include loneliness and social isolation in care and discharge plans, and discuss at each review 

Professionals, should make time to discuss loneliness, mental health and medication impact with clients **2** 

Offer support to people less likely to attend groups to overcome barriers and engage **4** 

5 

3 Signpost people to a diverse range of activities and groups 

- Overcoming barriers**
- Someone to travel with to attend the first few sessions
 - Interpreter
 - Communication support expert
 - Support around building relationships
 - Explore other options to reduce feelings of isolation

Fund a diverse range of accessible regular community groups that offer people safe spaces

6 Increase therapeutic access for people who would benefit 

Key themes

Settings

- Safe spaces
- Engagement with mental health and community
- Living with others does not equate to being less lonely

Activities

- Diverse choice of groups
- Remove barriers
- Professionals facilitating access and engagement

Therapy/ treatment

- Medication impact
- Therapies and treatments to help with loneliness
- Skills and strategies

People

- Access to a trusted professional
- Time with professionals
- Access to other networks
- Access to networks and peers

Contents

Acknowledgements	2
Document details	2
Introduction	5
Recommendations	7
Background	8
User Focused Monitoring	8
Current evaluation - Methodology	8
Evaluation design	8
Data Collection.....	9
Data Analysis.....	9
Findings and discussion	10
Feeling a lack of companionship	11
Contentment with friendships and relationships.....	14
Asking for help.....	16
Feeling isolated	19
Feeling left out.....	21
Demographics	23
Summary and discussion	25
Settings	25
Activities	25
Issues around activities.....	26
Therapy/treatment	26
People.....	27
Appendices	30
UFM: What we do	30
Aims	30
Impact	30

Introduction

Loneliness and social isolation are issues that have received increasing media attention in the last few years. There is wide recognition that loneliness has a negative impact on wellbeing. The minister for loneliness, Mims Davies, writes 'Loneliness is one of the most pressing issues our society faces and it impacts upon millions of lives. Now, we need swift movement on implementing the loneliness strategy.'

The definition of loneliness used first by Perlman and Peplau¹ and adopted by The Campaign to End Loneliness and the Government strategy for tackling loneliness is:²

'A subjective, unwelcome feeling of lack or loss of companionship. It happens when we have a mismatch between the quantity and quality of social relationships that we have, and those that we want.'

Social isolation is about the number of connections people have or don't have in their lives and while this is not the same as loneliness it is recognised that practical measures to reduce isolation can also help to tackle loneliness. Loneliness is damaging to society, it decreases wellbeing and as the Campaign for Loneliness states 'it is harmful to our health: lacking social connections is a comparable risk factor for early death as smoking 15 cigarettes a day, and is worse for us than well-known risk factors such as obesity and physical inactivity. Loneliness increases the likelihood of mortality by 26%.'³

Jo Cox, MP worked to inspire a legacy of powerful calls to action and initiatives to make people's lives less lonely, she said, "loneliness is an urgent but solvable issue" The government strategy for tackling loneliness sets a framework that cuts across health, local authorities, businesses and the voluntary sector, as well as communities and individuals, to support people's social connection Despite both long-standing and new initiatives – e.g. day centers, peer support workers, service user groups and community

¹ Perlman, D. and Peplau, L. A. Chapter 2: *Toward a Social Psychology of Loneliness*, in Duck and Gilmour (eds.) 1981. *Personal Relationships in Disorder*. London: Academic Press.

² https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/750909/6.4882_DCMS_Loneliness_Strategy_web_Update.pdf

³ <https://www.campaigntoendloneliness.org/loneliness-research/>

navigators – contributing to the prevention of loneliness, recent research has shown that the problem is escalating and costly.

Research published in September 2017 from the LSE estimates the UK's "epidemic of loneliness" costs £6,000 per person for a decade of an older person's life in health costs and pressure on local services.

However, they also say that for every £1 spent on preventing loneliness, there's the potential to save £3.

This report is published at a time of increasing pressure on health and social services to do more with less. UFM findings show that practical steps for preventing or decreasing loneliness can involve different ways of doing things, many not related to cost.

There is an expectation, which is for the recommendations to work, there needs to be a community infrastructure in place. People will continue to need:

- a choice of places to be signposted to
- activities to be on offer
- professionals and peers to talk to
- time with professionals to build trust and strengthen skills

The UFM team hope that this report will inspire continued support for and future investment in the groups, safe spaces and therapies that already work and those that can be set up to prevent or deal with loneliness and also save money in the long run.

This evaluation sought to establish the views and experiences of people with mental health issues about loneliness and social isolation. In addition to this, opinions were sought from the participants about what had worked to help prevent or reduce loneliness and any suggestions for how this could be improved.

A total of 56 people who have experience of secondary mental health services provided feedback. The participants ranged in age from 18 to 75+ and were residents of Kensington and Chelsea or Westminster.

Four key themes emerged from the evaluation findings.

1. Settings:
 - a. The importance of safe spaces
 - b. Increased engagement with and inclusion in the mental health and wider community
 - c. Not making assumptions about living arrangements, living with others does not always equate to being less lonely
2. Activities:
 - a. Having a diverse choice of groups
 - b. Removing barriers to participating in group or other activities
 - c. Having professionals who actively facilitate access and engagement in groups/activities

3. Therapy/treatment:
 - a. Medication can have an impact on feelings of social isolation and loneliness
 - b. Various therapies and treatments were considered beneficial in helping people prevent or deal with feelings of loneliness
 - c. Helping people develop and grow skills and strategies for creating and maintaining relationships
4. People:
 - a. Access to a trusted individual (professional) who knows the person well and who can be relied on
 - b. Time with professionals
 - c. Access to other networks (As well as mental health/peers)

We hope that the report will help shape future provision for people who use mental health services and services that prevent or reduce loneliness and social isolation.

Recommendations

The four key themes led to the following recommendations:

1. Include a section on loneliness and social isolation in people's care plans and discharge plans, and discuss at each review.
2. Mental health professionals, GP's and social workers should make time to actively discuss loneliness with their patients/clients and establish if and how mental health and/or medication is having an impact on their client in forming or maintaining relationships.
3. Ensure people using mental health services are actively signposted to a diverse range of activities and groups.
4. Ensure people who are less likely to attend groups are offered extra support to overcome barriers and engage - e.g someone to travel with them and attend the first few sessions, an interpreter, a communication support expert, or support around building relationships - if they would like or need this prior to going to a group. If people do not like groups explore other options to reduce feelings of isolation.
5. Fund a diverse range of regular groups that offer people safe spaces to attend activities or talk. Ensure people can attend these in the community and evaluate the groups or activities regularly from the perspective of the people who use them.
6. Increase therapeutic access for people who would benefit in relation to forming or maintaining relationships and thus preventing or dealing with loneliness and social isolation as early as possible.

The above recommendations align with the work done by the Campaign to End Loneliness and described in their recommendations guidance for commissioners for a strategic approach.⁴

The UFM recommendations also fit with evidenced practical approaches that place emphasis on the following key points to reduce loneliness:

- Start with individual – their interests, the type of experience they are facing: isolation or loneliness?
- Involve each person in shaping the activity
- There is more academically-robust-evidence that group interventions work at present, yet individual activities should still be tried and tested further⁵.

Background

User Focused Monitoring

User Focused Monitoring (UFM) is a method of service evaluation that puts service users at the heart of the process.

The UFM programme in Kensington, Chelsea and Westminster was the first of its kind, set up in 1996 at the Centre for Mental Health by Professor Diana Rose, a long term user of mental health services.

UFM adds value as a model that is proven to provide quality user feedback to help shape services. UFM is independent, user led at each stage of the evaluation process and rigorous, ensuring quality evaluation of services.

Please refer to the appendices for more details about the methodology.

Current evaluation - Methodology

Evaluation design

The evaluation method and design of the interview was decided and developed by the UFM team.

The interview schedule was designed by the User Focused Monitoring team members. The development of the questions was influenced by 'The Campaign to End Loneliness Measurement Tool' and associated resources,

⁴ <https://campaigntoendloneliness.org/guidance/strategic-approach/>

⁵ <https://www.campaigntoendloneliness.org/loneliness-research/>

as well as the 2017 Healthwatch report 'Meeting the Needs of Socially Isolated Older People in RBKC'.

The UFM team pre-tested the questions and refined the questionnaire based on the results.

Data Collection

The User Focused Monitoring (UFM) project interviewed 56 people who use mental health services about their thoughts on and experiences of loneliness and social isolation.

Interviews were conducted face to face at the north and south Community Mental Health Teams in both Kensington and Chelsea and Westminster. The team also interviewed people at the Oremi Centre and other locations throughout the two boroughs according to the interviewee's preference.

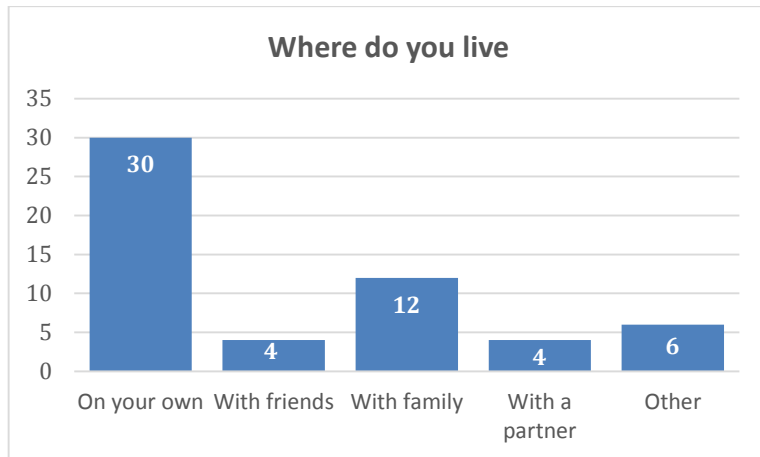
Data Analysis

The UFM team used thematic analysis – looking at patterns in the data - to draw out emerging themes. The narrative discussion of the findings was developed during UFM team analysis meetings and forms our user led perspective to this report.

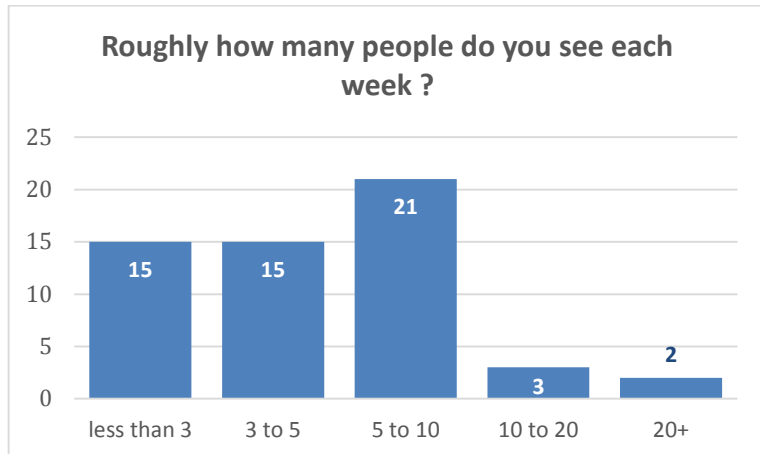


Findings and discussion

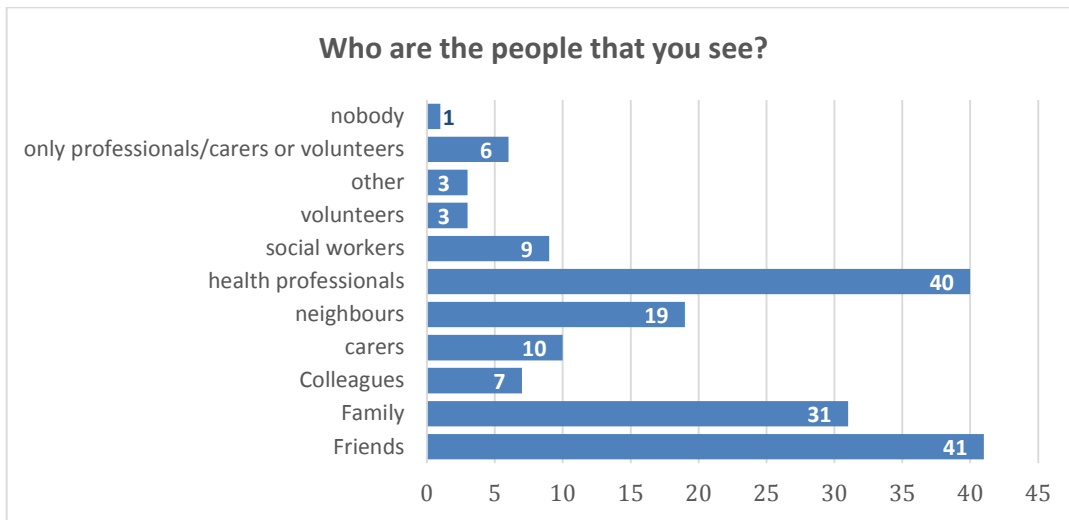
The findings are the result of 56 face-to-face interviews. Quotes are written in italics and are verbatim.



Just over half of the people we interviewed (n=30) lived on their own. The second largest group (n=12) live with family. Living with family or others is not a determinant for prevention of loneliness as many people we interviewed commented on feeling lonely despite living with others.

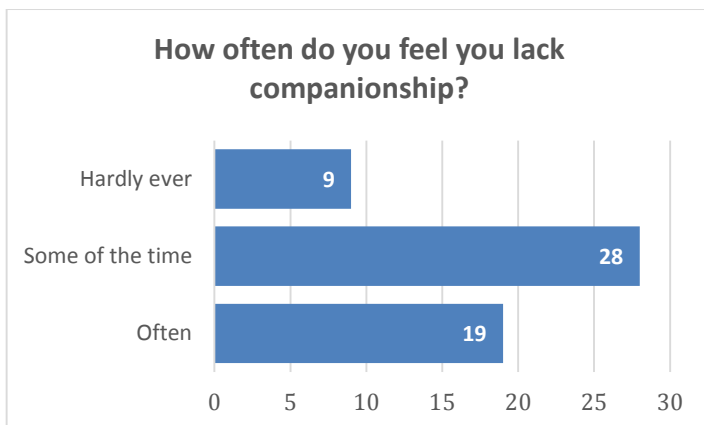


Just over a quarter of the people we interviewed saw less than three people per week.



People were able to select more than one category for the above question. Friends and health professionals were seen most frequently by most people interviewed.

Feeling a lack of companionship



People who answered 'often' could be grouped into three categories:

1. People who lack companionship and experience stress in developing or maintaining relationships:

"I feel very nervous about having to deal with people."

"I feel stressed, I am not able to relax."

2. People who expressed an external reason for their lack of companionship: loss, trauma or as a result of their ill health/disability:

"Always sad, lonely. I lost my family. I have to live without them. I am sad every day."

"I had a companion, ex-partner who mentally and physically abused me. I was isolated with him he was controlling. I had no friends. He decided what I ate and how I dressed."

"I have psychosis and physical disability. I cannot have children. I cannot work, I cannot have sex, this illness has taken so much away from me."

3. People where lack of companionship has become the accepted norm, which can be either a positive or negative experience:

"I have the companionship of my dog so don't feel lonely. I don't have much human companionship though."

"I tend to isolate myself."

"Because I live alone I feel very isolated and lonely."

There was a perception that other people are busy and do not have the time for them and that being lonely often wasn't about being alone.

One person who is a carer described how having to chase up and coordinate things for their parent has meant they have no time to spend with their friends and often leads to them feeling isolated:

"Because I am a sole carer everything falls on me to do. People don't know things so I am always coordinating and following up. I'm spending a vast amount of time repeating myself when I could be carrying on with my life."

People who answered 'some of the time'

Many people described feeling lonely even when around people, with contacts they do not see often or those who they live with but do not feel relieved of loneliness by.

"Even in my relationship I can feel alone."

"It's easy to feel alone even if surrounded by people."

"When I finish work my son is in his room, I am alone. He is doing his own thing as he is older."

This is linked to some people who described low self-esteem or confidence about having anything to offer.

"Sometimes I feel I have nothing to offer them. I don't feel sad. I want to offer them something. I want to make new friends."

"I have a few friends but I do not see them all the time as they are very busy."

Some people talked about having anxiety around others which led to people isolating themselves from others.

"I get anxious being around people for a long time."

Environment was mentioned as a factor. Some commented in terms of people attributing loneliness to living alone:

"When I close my door that is it. I am on my own. I do see my daughter sometimes but she has her own life. She does see to my needs."

And others commented that even living with people in a busy place (hostel/family home or even London as a big city) did not make them feel less lonely.

"Sometimes my sons may go to their girlfriends for a couple of days so I am in the house on my own. I also have a grandson who sometimes may see me."

"London is particularly big and a lonely place."

People who answered that they 'hardly ever' lacked companionship

People who described themselves as 'hardly ever' lacking companionship appeared content with the amount of companionship they had, even when for some this was limited or they had no companionship from others. Some talked about the factors that helped them personally e.g. participating in activities or having a belief system.

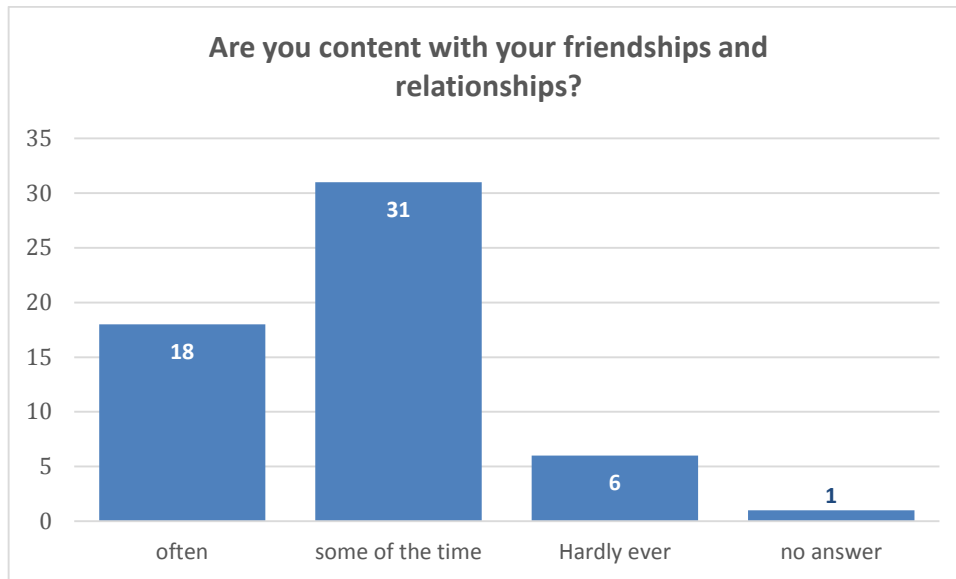
"I don't like companionship. I grew apart from my family years ago."

"I am content to be seeing few people."

"To keep myself busy I am in two choirs."

"Because people I need to see I see, and then if I am at home alone I chose to be. I am very religious so I don't feel I am alone, alone."

Contentment with friendships and relationships



For people who answered 'often' to the question 'Are you content with your friendships and relationships', the responses could be split between people who:

- Were content
- Wanted more

A common theme was the value of having someone to trust and the quality of their relationships.

"The friendships I have now are solid. I am no longer fearful. I do not have many friends but I trust the friends that I have."

"I have one female friend who is a very good friend of mine. We talk and sometimes have a meal or chat."

"I have some very good friends. They are always there for me and I for them."

"I'm in a good relationship."

"All are happy it is going well, ticking over."

"Very content. I have a craving for more friends. At the hostel I am content but I want more."

"Sometimes it is hard to tell if someone is a true friend."

"Friendships and relationships, it is very difficult finding someone."

"My friends come and talk to me there are some around me sometimes you don't want to talk to them about serious matters as you don't want to worry them. When they are at work is when I am

most lonely. My grandson is very helpful I can reach him by phone."

People who responded by saying they were content 'some of the time' with their friendships and relationships mentioned multiple factors that affected their level of contentment:

Some talked of family tension and expectations.

"I have certain disputes with my family."

"Due to work commitments I don't get to see family as often as I would like. Due to people not understanding my mental illness this creates friction with the family - I cannot always do what they want me to do."

Several people stated their experience of mental health issues had an impact on their friendships and relationships, which sets them apart from those people who they initially were friends with.

"My friends come and talk to me. There are some around me sometimes you don't want to talk to them about serious matters as you don't want to worry them."

Other factors were reflecting on friendships in the time before they experienced mental health issues as more positive:

"I don't think I have strong connections with people that I used to have back in the days."

Concerns around trust and not feeling 'strong' enough to build connections were mentioned.

"I find it difficult at the moment and don't feel strong enough to maintain friendships and relationships."

"Disappointed in some people but don't know if this is true or in my head."

"I have trust issues. With my bipolar I was giving money away and I was in debt."

"Not enough caring and loving attention, it's just when my friends want something."

Some people have difficulty making friends and would like more but have grown used to their current situation as 'normal'.

"I would like to see more people but I've been like this a long time and am quite used to it."

Others identified that their situation is related to their mental health directly – that it changed their friendships.

"Since mental health lessened, friends have lessened also."

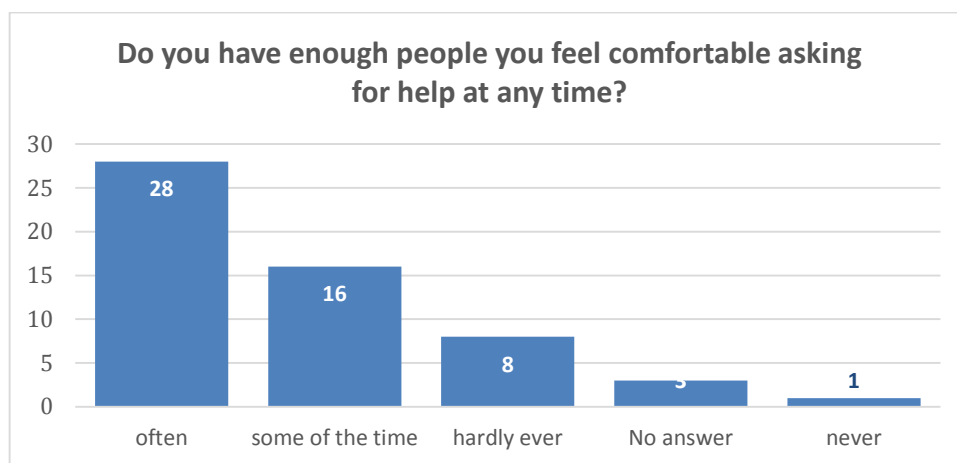
Some of the participants who said they **'hardly ever'** were content with their friendships and relationships, talked about an external cause (loss and grief or trauma in a past relationship) as the reason for their lack of friends.

"Lost my wife 5 or 6 years ago. Been lonely since then."

"My dad ruined friendships I had."

Asking for help

For this question it is helpful to remember that the people we interviewed were already engaged with services (CMHT or day centres).



Regarding people who answered **'often'** to the question 'Do you have enough people you feel comfortable asking for help?' all had easy access to either a known and trusted professional, a family member or a friend.

"Friends and family are very supportive."

"I have access to a lot of different people who I can tell how I am feeling."

"I have enough people I am comfortable, If I need anything it is there I am blessed."

"Friends and family in addition to my wife."

Having professionals and a network of support was important when it came to asking for help.

"Key worker at the Grove helps me."

"When I am in crisis my keyworker deals with the problems straightaway. There was also a benefit officer who also tried to help me but I am not sure if he works at K&C mental health unit."

"The Single Point of Access number."

"The support worker, also my doctor and case worker are there for me."

"I have quite a lot of people I feel comfortable talking to, my GP and wonderful friends."

"If I need help I will come to Pall Mall. They make assessments of me. Staff are very helpful without them I do not know what I'd do. The Grove is very helpful for me. I go to art therapy."

"Good support network, Pall Mall is really good."

"Health care professionals."

"I want relationships. I am here at Pall Mall every Tuesday and at Hestia 3 or 4 times a week."

People who stated that 'some of the time' they felt they had enough people to ask for help commented about a sense of control, being able and having people or networks they could ask.

"Mainly my partner."

"My daughter is there. She helps out a lot and my granddaughter and of course I have Oremi and my keyworker there."

"Sometimes I might need cigarettes and there is no money. At the end of the month if my family have any money left over they help me."

"I would ask if I needed help"

"My mum has been very helpful, coming with me to meetings now. She was aware of my mental health. Due to my loneliness I was taking Spice."

The people we interviewed held diverse views about asking for help:

"Sometimes I want more people to help me out, like with my boyfriend."

"I speak up when I want something, Im not a shy person. I don't feel isolated - that's too extreme. I feel lonely."

"I don't like to ask - but often my daughter helps."

"I would ask if I needed help."

A lot of people again mentioned professionals who provided help and who they could trust:

"I love Oremi they are always very helpful towards me and my social worker at Woodfield road is also someone I can come to for help and assistance."

For those people who 'hardly ever' feel they have enough people they feel comfortable to ask for help this seemed to result from a lack of knowledge of where to access help as well as a barrier such as a language barrier and/or a feeling of deficiency in some way:

"I didn't speak English very well I find it hard to tell people how I am feeling or how to help me."

"I don't have much support I have to do everything by myself."

"People see my situation and laugh."

"None since services have lessened."

"Probably because it is hard to know who or where to ask for help. I am a person not used to talking about myself, my issues but may be its because you feel let down by the service because I don't look like someone who needs help but that makes it difficult to ask for help."

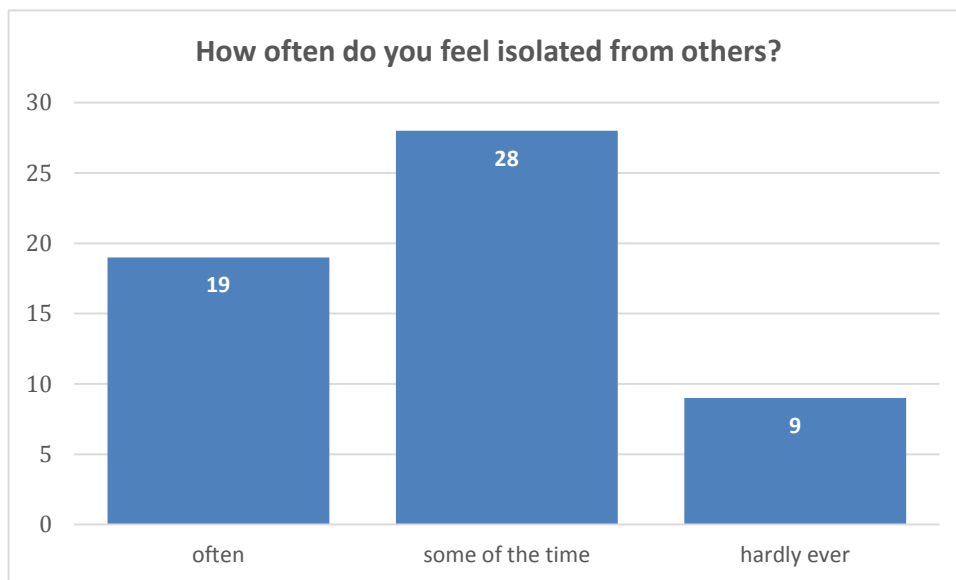


Feeling isolated

People who said they **'often'** felt isolated from others talked about having difficulties socialising, which sometimes they attributed to themselves:

"Most of the time I find it hard to socialise with people."

"I have a sense of loneliness about me that I cannot 'feel'. I am not very sociable like I used to be. I have become a lot more quieter and have lost a lot of my social skills."



Some felt they were in isolation due to their finances or to their environment.

"When I am shut indoors in my room, my finances can affect if I invite others."

"My friends live quite far away and I can't see them as much as I would like to."

Feeling isolated from others was talked about in relation to mental health:

"Interaction with people is difficult."

"I spent nearly a year in hospital while they tinkered with my medication, I was quite institutionalised and had issues when I came out."

People who responded they **'sometimes'** felt isolated from others:

People isolating themselves, wanting to be apart from people and avoiding people when mentally unwell was a key theme:

"When during psychosis. I go through complete isolation. I distance myself from people. I realise I am not the only person to go through this."

Some people felt others do not understand them and were also less confident to interact with others:

"My illness makes me lonely."

"Lack of understanding. Others' time constraints they have their own things going on."

"People I know are lovely but haven't been through what I have been through."

"I am sometimes scared of people."

Struggling with feeling isolated was also talked about in relation to choosing to be independent and alone:

"I want to be independent, live my own life. I am a young man. I can isolate myself I keep myself to myself."

"I isolate myself a lot from people."

Comments relating to having strategies to deal with this included:

"If I feel lonely I go to bed and sleep or go to the TV room and watch television."

"Sometimes I move around to talk to people."

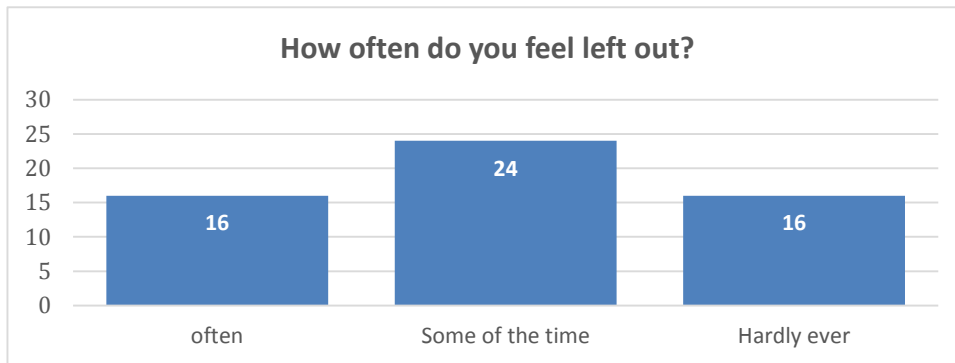
People who reported they 'hardly ever' felt isolated from others had the following comments:

"I often ask my sisters not to visit me when I am on my own."

"I enjoy a bit of space, seclusion and peace and quiet."

"If I get the feeling of isolation I choose to go out. If I cannot travel on the bus, I sit in the square or go to Oremi."

Feeling left out



People who responded they 'often' feel left out

People who said they often felt left out had a sense of being 'apart' from social and family groups:

"I feel I have no one to hang around with. My family are usually out; my sister looks after me."

"I'm not part of society eg Christmas and things like that."

Similar to an earlier question about how often people felt socially isolated the barriers to making friends and having relationships were attributed to a lack of finances/resources and having mental health issues.

"A lot of the time I don't have the resources to meet my needs which would enable me to see family and friends more, like a car."

"With friends come a reality check, friends are active, working at various places, off to universities at various places. I'm stuck with my mental health issues."

"With the money I am getting I cannot socialise. I'm grateful for the money i get but after bills I cannot save and spend. I get about £433. Most of that is food and bills My disabilities also prevent me from concentrating and meeting people."

"Family dynamics do not run smooth and are usually quite negative. They do not understand. As it is negative it often impacts on me."

It was even more difficult to start making new friends for people who had multiple or complex issues such as coming through the criminal justice system or using drugs and alcohol.

"I don't know how to be sociable since I have had my mental illness. I have given up a lot of friends due to their lifestyle. I have had to give up my best friend. They have gone on with life without me."

Having suffered loss or trauma impacted often on feelings of loneliness:

"I feel down. I worry other times. When I lost my family, my life is very hard and difficult at times."

People who said they feel left out 'Some of the time' also talked about not belonging, not feeling part of or being actively excluded from the group or family and related this to their mental health

"Usually at family meetings and group chats. They don't tell me anything. I think I am always last to know. They don't want to worry me."

"With my friends I feel as though I am not part of a family. I feel like a spare wheel and I don't want to be there."

"When there is a family gathering my family don't invite me because of my mental health."

"I feel pushed away sometimes by my family. They have high expectations of me."

Lack of confidence or lack of skills in making or maintaining relationships also featured in people's comments.

"I get invited to things but I am not confident enough to go even though I would enjoy if I attended."

"Sometimes I have been invited somewhere but I don't go and then I regret it."

"Lack of relationships, Lack of positive confidence, I'm left out as I'm lonely bored lazy and upset."

Loneliness was also associated with depression:

"When I get depressed, I feel more left out then."

"Sometimes it is depressing."

People who told us they 'hardly ever' feel left out made the following comments:

"I have a few good friends who I trust and know they are not ignoring me."

"Sometimes my mind is elsewhere when I am with people but other people don't leave me out."

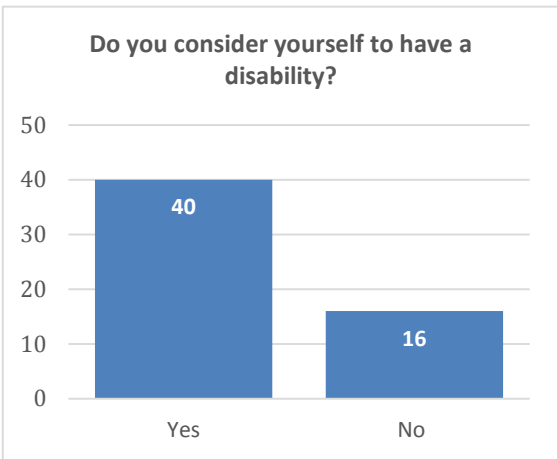
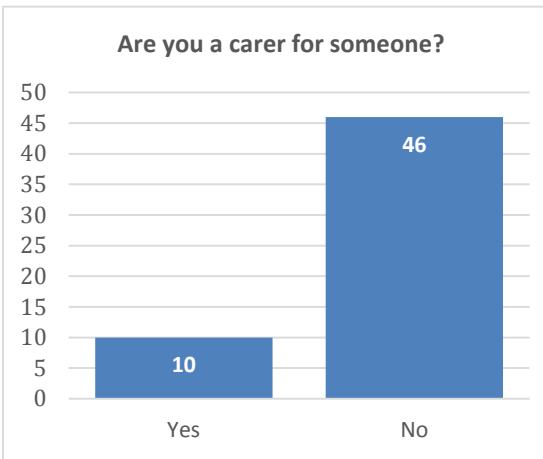
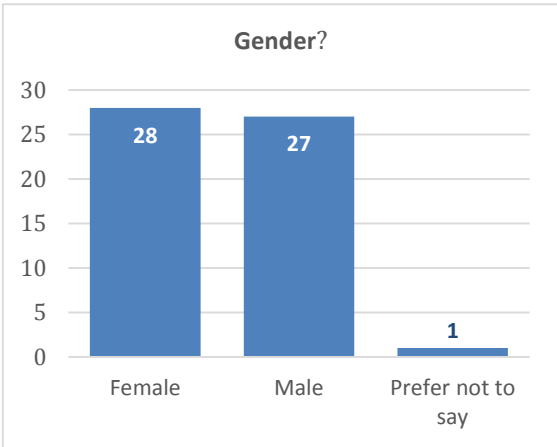
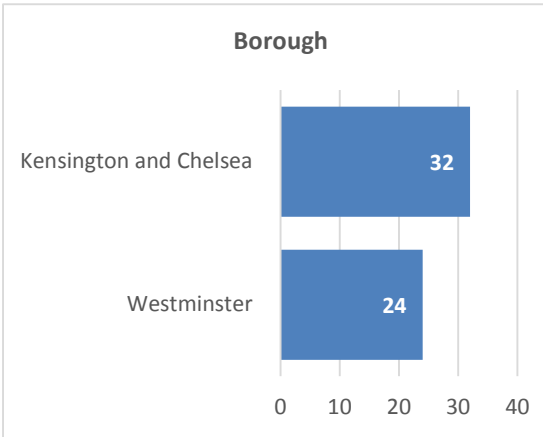
"Sometimes I like to have some time to myself."

"I don't feel left out."

"I am like I am lonely by choice."

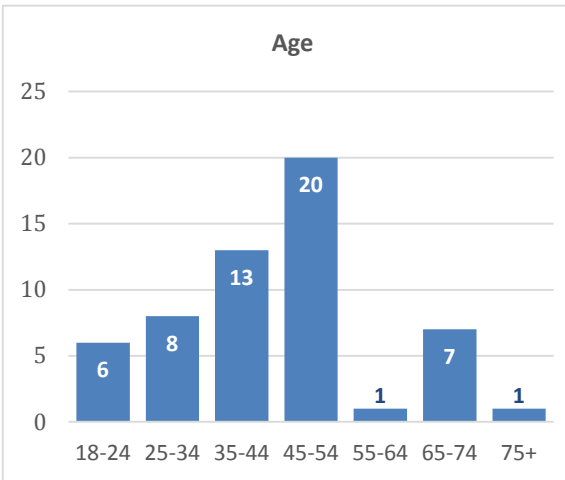
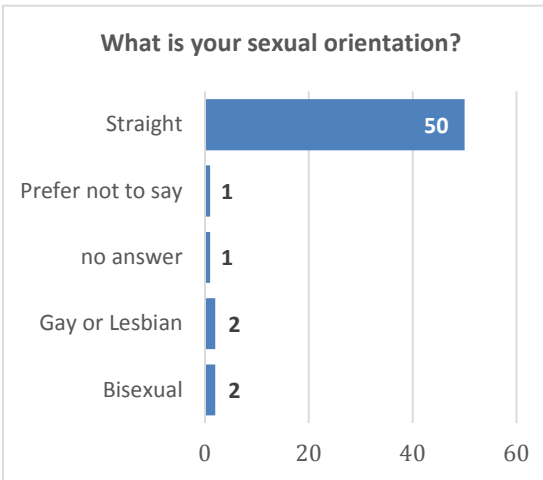
"I see people usually twice a week, it's part of my job."

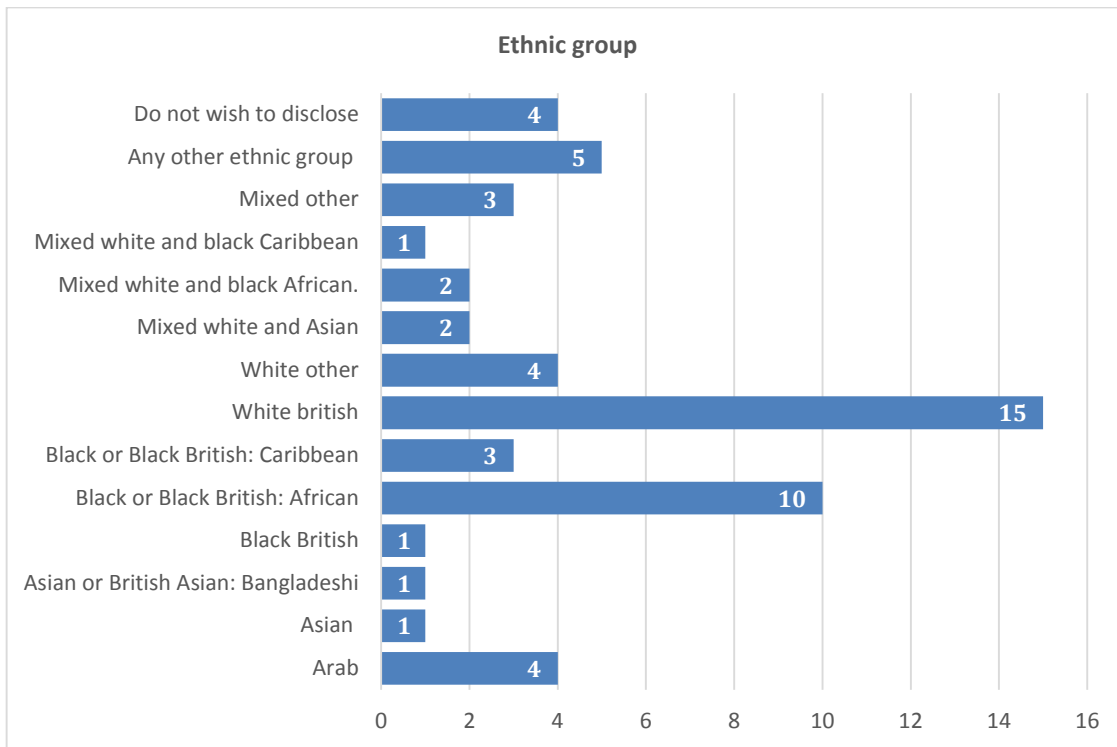
Demographics



18% of the people we interviewed were a carer for someone

70% of the people we interviewed considered themselves to have a disability





The two largest self-selected groups of interviewees were 23 percent of people who self-identified as white British and 18 percent of interviewees who self-identified as Black or Black British: African.



Summary and discussion

Four key themes emerged from our analysis.

These four themes all centre on people's ability to understand their options, have access to and choose what is meaningful for them in reducing loneliness.

The recommendations set out in the introduction to the report serve to address these themes on a practical level.

Settings

Some people had a very strong sense of belonging to a centre or group which they identified as a safe space and which helped when they were feeling lonely or to prevent loneliness.

"At Oremi they are like my family. I don't have to hide my feelings there I feel like I am part of the family."

"The Grove, Harrow Rd Art Therapy - the Waterview Centre. I go to the above places, we talk about life and how we deal with it. They provide me with a safe space I can talk freely. I look forward to attending and being active there."

Others felt that inclusion in the wider community beyond mental health related activities was also important for a sense of belonging.

"May be group discussions, not too dramatic but a chance to meet. I don't think I would focus it around mental health but something else like a museum visit or coffee because it might be scary otherwise. May be even a reading group or something."

Where people live can make a big difference to having access to people and support but does not mean it reduces loneliness.

"I am in 24 hr supported housing where the job is to give support."

"I have a craving for more friends. At the hostel I am content but I want more."

"It's easy to feel alone even if surrounded by people."

Activities

People valued groups where they could meet people. Group activities helped some people reduce isolation/loneliness:

"They provide activities where I live (hostel) Like jewellery making, sewing, singing. Different people come and use the service."

Having choice about how many and the types of groups available to join was important - some people wanted therapy groups, others excursions out of London, others a book club, walking group or women's group:

"It would help if there were more groups where there were more things to do."

The findings highlighted the importance of actively helping people find things to do and places to go. This meant having a trusted professional who explores the person's interests, has a good local knowledge and can work with the person to plan to access activities or therapies. For some people to overcome barriers to participation this would need to include support to travel to and take part in activities.

"The lady I see here at the CMHT has helped me feel less isolated. She pushes me to do things, helps me move away from my sad issues. I was encouraged to do yoga, to walk for one hour each day as well."

"My key worker has recommended that I do a computer course with Mind. I am on the case it has helped me a lot. I am with Hestia, attending has helped me I went on day trips with them. It was mingling with other people that got me out of the haze."

"If there was money to be spent it should be on people's routines, actively doing things, getting back into the community. She is attending a choir but apart from that there are a lot of other things, she just needs someone to go with her and take her a few times."

Issues around activities:

Local places and free/cheap outings are important:

"Coming to the Oremi has helped me meet people and make friends, they are helpful and I like to join the groups and have a meal in the café with other people. If I did not eat at the Oremi I would probably eat alone at home."

Some people are happy alone and not lonely:

"I am on my own largely by choice so I can't really answer that."

"I am content seeing few people."

This is not to be confused with the fact that some people withdraw when feeling unwell and would like someone to go to them rather than be expected to ask for help.

"If people checked in with their friends like how are you, how's your day been. How's things going for you? That would help. When you're depressed and lonely it's difficult to make the first move."

Therapy/treatment

Cognitive Behaviour Therapy, Dialectical Behaviour Therapy (DBT), one-to-one and group therapy are examples of some of the therapies people had

accessed. People talked about the value of one-to-one therapy to help them feel less alone as well as group therapy, peer groups, learning to deal with relationships and self-reflection opportunities:

"The care I received has helped me deal with others, go out by myself and not be scared and so on."

"I was in DBT in CAMHS and was in a group with people going through the same stuff."

Having the ability to develop and maintain skills around forming relationships was important to some people:

"I have a sense of loneliness about me that I cannot 'feel'. I am not very sociable like I used to be. I have become a lot quieter and have lost a lot of my social skills."

"I think I am learning more because I am becoming more aware of other people's needs as opposed to my own."

Waiting time to access therapy was a difficult period for some people:

"Lessen waiting times. My GP referred me more than 6 months ago and I have only just started seeing someone."

The need for more and ongoing access to one-to-one therapy and group therapy was expressed by many participants:

"Therapy groups, there are less of these now. Day centres and one to one services help me but there are less of these now."

"More groups at CMHT. Nice to see other people are going through the same thing."

"Peer groups"

Most of the people we interviewed took medication for their mental health issues.

People

A lot of participants talked about the value of having access to a trusted professional who knows them well. The experience is of fast staff turnover which is an issue especially for people who find it harder to trust.

"...my doctor is soon to go and I have extreme trust issues as part of my illness so it may take me another year to trust which will leave me vulnerable."

When asked if the participant felt comfortable to call on people for help, many participants found this very difficult.

People faced difficulties asking for help and preventing isolation from friends and family as well as professionals when experiencing a decline in mental health.

"When during psychosis. I go through complete isolation. I distance myself from people. I realise I am not the only person to go through this."

"My illness makes me lonely."

Asking for help was more complex when, in addition to declining mental health, people also had other diagnoses, disabilities or were dealing with addictions or homelessness. Having someone dedicated to helping you who understood your issues was mentioned frequently:

"For the key worker to have a key session with patients. People with drug issues could be helped more."

"The SHP shelter for homeless people I had a floating support worker there."

Time with professionals was important. Some people would value the opportunity for longer interactions with mental health professionals:

"Probably I would say more social workers or nurses so they are not so snowed under and they can see you more often than once every two weeks or once a month or only in an emergency."

"I find the Home Treatment Team not very useful they can only see you 15 minutes at a time or they drop meds off and they can't see you."

"They used to be more caring and attentive under the services. The professionals see us less now. I Don't blame them though; the funding has changed."

People who had been discharged from secondary mental health services to primary care talked about the following issues in relation to loneliness.

Needing to 'do more' to access services or groups:

"Being in primary care has made me realise I need to put more effort into helping myself."

"I've got to help myself. I've got to attend those therapy classes. Mind are based at the hostel. Poetry Singing workshops, art. There are flyers to let you know what is going on. The homeless project - it's all good. I have got a positive mental health attitude. Word of mouth is good - it helps."

For some people having to do more to get to the groups or activities was problematic when information about accessing them was not readily available or there was a waiting list.

"When I was in the Gordon there were services and groups. I am still waiting for emails to access the (therapy) groups. I go to the walking group, one of the best ones at Mind."

Having gained a different perspective on people after becoming more well and less fearful helped some people with their relationships:

"I have been stepped down to primary and this has changed the way I see people or groups. I feel more clear headed not so paranoid and fearful. I realise people care about me."

Feeling more alone after therapy finishes was a reality for others:

"I used the NHS and a gay charity called 'Living Well'. I have been referred to CMHT via GP - it hasn't impacted on my loneliness coming here. You get your 12 sessions then they ask you to leave and they can't extend and you feel even worse."

When asked 'what else could help people feel less lonely' the following were mentioned:

- Day centres – access to places where you find people who understand
- Outings/day trips or holidays
- Help understanding and forming relationships
- Having a routine
- Encouraging self-motivation
- More group therapy and individual therapy
- Having a professional you can trust and more time with professionals
- Less waiting time for therapy
- Peer groups

Much is written about the pros and cons of groups versus individual initiatives to combat loneliness. Taking a broader view of the steps to prevent or treat loneliness and social isolation means making things personal for each individual.

Professionals can reach lonely people by actively asking the questions in interactions with each of the people they work with, without making assumptions.

Where this had been done people felt understood and had been able to explore person centered solutions to address loneliness. For some this had meant having support where needed to access these services they were signposted to.

Related links

<https://hansard.parliament.uk/Commons/2017-11-15/debates/D2106C26-6821-445C-8666-4F8D3445FFDA/LonelinessAndLocalCommunities>

<https://www.jocoxloneliness.org/>

<https://www.gov.uk/government/publications/a-connected-society-a-strategy-for-tackling-loneliness>

Appendices

UFM: What we do

The UFM Programme gathers the views and experiences of mental health service users in the community and in inpatient settings in Kensington and Chelsea and Westminster. The team is made up of interviewers who have all used or continue to use local mental health services, bringing valuable knowledge and experience to their work. Interviewees talk more freely about their experiences to UFM interviewers in the knowledge that the person has had experience themselves of using services, and is independent from other services.

The depth and quality of the information collected is further improved by use of two interviewers per interview to increase rigour and reliability.

When evaluating services, UFM interviewers devise a variety of evaluation methods including interviews, site visits and focus groups. Data collected is analysed to develop a report and recommendations.

Aims

User Focused Monitoring has four essential aims:

- To give a **voice** to patients and service users
- To ensure patients and service users **actively influence** service planning and delivery
- To provide **ongoing, user-led monitoring** of mental health services
- To recommend **positive changes** in mental health services based on service users' feedback.

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The depth and quality of the information collected is further improved by use of two interviewers per interview to increase rigour and reliability.

When evaluating services, UFM interviewers devise a variety of evaluation methods including interviews, site visits and focus groups. Data collected is analysed and written up into a report with recommendations.

Impact

Reports and recommendations are presented to the UFM steering group. Action plans are developed based on the recommendations and populated by the lead 'champion' for each evaluation. The steering group monitors the action plans for updates and improvements to enable mental health services to better meet the needs of their users.

Essentially what UFM provides is a rigorous and insightful process that helps gather quality feedback from people who use local services.



We hope this report provides useful insight

For more information, please contact

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