

Users' experiences of community based NHS mental health services:

Survey findings

Women's Resource Centre

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LONDONASSEMBLY

This survey was undertaken by the Women's Resource Centre on behalf of the London Assembly

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Executive Summary

The majority of the 287 survey respondents were satisfied with the quality of the mental health services they had received. 77 per cent said the services they received had helped them deal with their mental health problems, and only 6% stated that services had not helped them at all. However, respondents identified a number of barriers to accessing NHS mental health services as well as issues regarding their care and treatment.

Accessibility

The survey found a number of issues that created barriers to accessing mental health services including:

- Lack of information about services available and how to access them (including private and voluntary sector organisations)
- Long waiting lists for services, particularly GPs, Community Mental Health Teams and counsellors/therapists based outside GP surgeries
- Problems getting to or from services due to expense, distance and reliance on public transport
- Inability to get to appointments at suitable times (e.g. outside of working hours, problems of child care or homelessness)
- Lack of support in accessing services for individuals whose first language is not English.

Needs

Respondents wanted quicker access to appropriate services. They reported that an average of three 'social issues' were impacting on their mental health, most often as a result of relationship of family problems, financial problems and physical ill-health. Themes which emerged included:

- Service users should be able to access support which can acknowledge and meet multiple needs in one place, rather than just being referred to another service or offered medication
- Services should acknowledge that recovery is a) possible but b) does not necessarily occur within a pre-defined timeframe
- Information should also be made widely available on the causes of mental health problems and promotion of good mental health (including self help information, local community groups).

Choice

The main choices offered to respondents were regarding whether to take medication or type of service or treatment they wanted. Eleven per cent stated that they had received no choice and 24% failed to respond to the question. Additional comments from respondents that were analysed found that:

- Respondents want to be empowered and informed about all aspects of their mental health problem and how to manage it
- Health professionals should be able to support service users to choose appropriate services and/or treatment and help them manage their mental health problems whilst they are waiting for a service e.g. by providing self help information or referring to voluntary or community organisations.

Quality

Respondents felt that the quality of mental health services needed to improve, particularly in terms of their relationships with mental health professionals. As service users, they wanted professionals to treat them with respect and empathy, to listen to them and understand their experience. This may require all of the above and:

- An increased focus on the impact of social issues on mental health and recovery.

Mental health problems affect one in six people in the UK and up to 16% of the population have a common mental health problem such as depression or anxiety¹. There is much evidence to suggest that social factors have a significant influence on mental health and the survey findings corroborate this. Mental health services need to adapt in order to meet this need, which means moving beyond a medical or 'disease' model of mental health which focuses purely on treatment, to one which takes account of the broader social context of service users' lives. Whilst policy has been progressive in this area, particularly in terms of improving services for BME communities and women, translation into practice is patchy.

Clearly, the majority of respondents to this survey are willing (and able) to take an active role in recovering from their mental health problems. From their point of view, the role of GPs and mental health professionals (as well as other agencies) is to empower and support them by providing empathy, information and choice, to receive the most appropriate support for their needs.

¹ Department of Health (1999) *National Service Framework for Mental Health Modern Standards and Service Models*. Department of Health. London

Introduction

This report outlines the methodology and findings of the *Have Your Say* survey. The aim of this research was to:

- Find out what service users think about NHS community mental health services in London, in particular how easy it is to access services appropriate to their needs and to highlight access to suitable services for different groups
- Ascertain the 'pathways' by which people find out about and use NHS community based mental health services in London.

The questionnaire asked for people's views and experiences on four key themes:

- | | |
|---|------------------------------|
| 1) Quality of the service | 3) Access to services |
| 2) Whether the service/s met their needs | 4) Choice of services |

The target audience for the survey was people aged 18-64 years who had used a NHS community based mental health service, in London, in the past 12 months.

The *Have Your Say* survey was conducted by the Women's Resource Centre and commissioned by the London Assembly. The research will inform the Health and Public Service Committee's investigation into community based mental health services in London.

Respondents' profile

Of the 287 respondents:

- 54% were women and 46% were men.
- 10% were aged under 24 years, 65% were aged 25 to 49, and 22% were 50+.
- 67% described themselves as heterosexual, 16% as lesbian, gay, bisexual or transgender (LGBT) and 17% preferred not to say.
- 37% described themselves as disabled and 14% considered themselves to have a learning difficulty.
- 49% described themselves as belonging to a BME community (including Irish) and 47% described themselves as being "White UK".

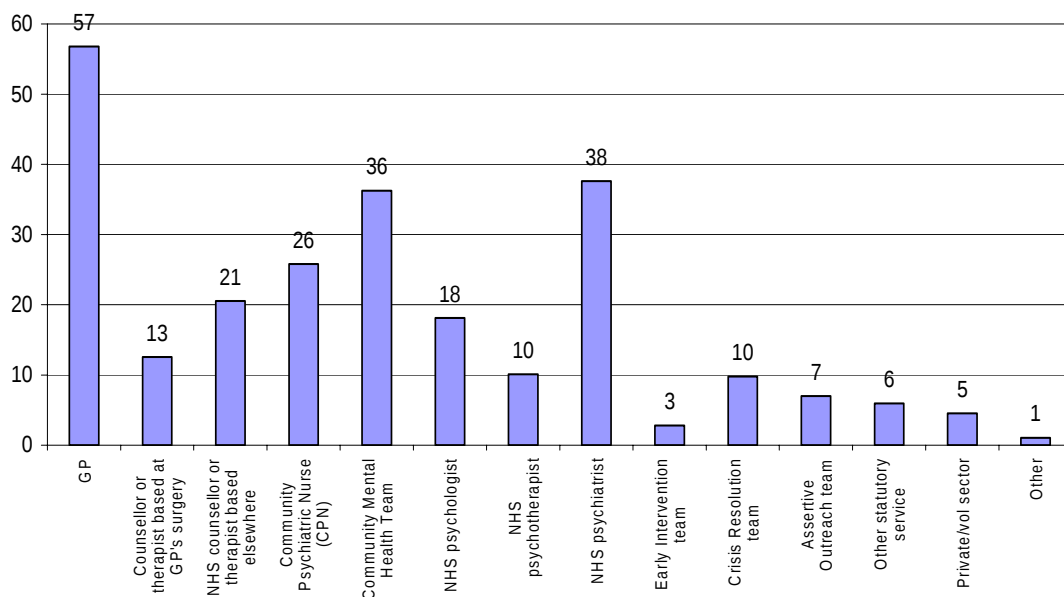
Disabled people, people with learning difficulties and people who describe themselves as lesbian, gay, bisexual and transgender were over-represented in the sample, when compared with London's population.

Survey findings

Q1 Have you seen any of the following people about your mental health in the last 12 months?

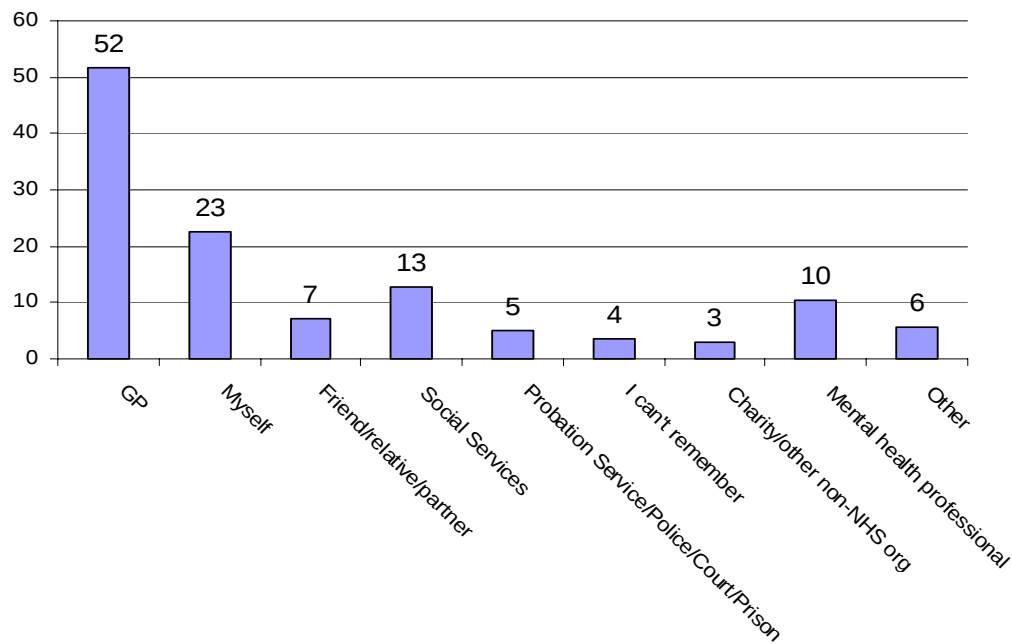
- Overall, respondents were most likely to have reported that they had seen their GP (57%), about their mental health in the last 12 months than any other service, followed by a NHS Psychiatrist (38%), and Community Mental Health team (36%).
- Respondents had used an average of 3 different services in the past 12 months

Percentage of respondents who had accessed NHS community based mental health services

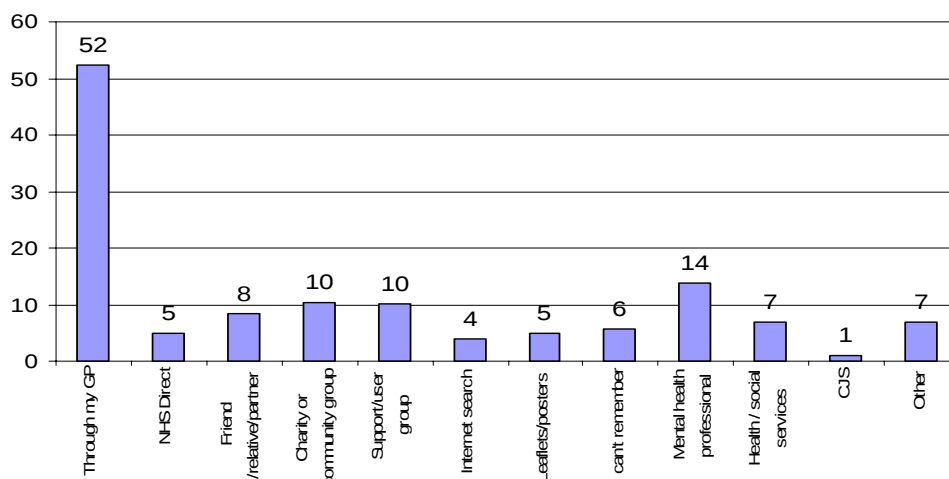


Q2 How did you get an appointment with the person/people you ticked in Question 1?

- GPs were the main source of referral (52%), followed by self-contact (23%). Social services were the next highest category at 13%.
- On average respondents obtained appointments or were referred through 3 different sources.
- GPs were most likely to have referred respondents to a NHS psychiatrist, then Community Mental Health team or NHS counsellor or therapist (not located in GP surgery).

Percentage of respondents by source of referral**Q3 How did you find out what community based mental health services and treatments were available on the NHS?**

- On average respondents found out about available mental health services through 4 different sources.
- The most commonly used sources for information on mental health were GPs (52%) other mental health professionals (14%), charities/community groups (10%) and support/user groups (10%).

Percentage of respondents who found out about NHS community based mental health services by source

- Six respondents to this question cited specific difficulties in finding out about services (see Q4 for detail) and other, despite having accessed services in the last year, were still unaware of support available to them. Comments included:

"I am still unaware of support that I could access to help me with day-to-day living with my mental health. As I work I can't attend user groups/ events that happen in the daytime. There must be stuff that I can go to in the evenings and weekends."

"When I first had problems I didn't know where to go. It was difficult finding out. Even on the internet."

"Training [for health professionals] on recognising mental health issues and where to refer, mainly for families of people with mental health issues. Do not presume everybody knows where to go when an acute situation arises."

"I would have liked to have been able to access information on all that was available and choose what was right for me – instead I had to find out the information myself and ask my GP if I could have it"

- BME respondents were more likely than White UK respondents to find out about services through a charity or community group or support/user group (32 compared to 21).
- In the cases where surveys were carried out on a face-to-face basis with a translator, it was clear that respondents whose first language was not English were less likely to be aware of services available (for example, anything beyond the support of a GP).

Q4 Do you feel you were given enough information about the range of community based NHS mental health services and treatments available?

- Over half of respondents did not feel they were given enough information about support available (57%).
- Although BME respondents reported similar levels of satisfaction to White UK respondents in terms of information, those who were dissatisfied with went on to say that there was a lack of culturally appropriate or sensitive information about what services were available.
- 39% of disabled respondents felt that they had not received enough information.

Types of information

Respondents wanted access to information about:

- alternatives to NHS support such as voluntary and community or private sector services.
 - how long they would have to wait for services and what options they had for obtaining support in the meantime (including self help) or as an alternative and how to get help in a crisis.
 - the types of medication available to them, the side effects, how it would affect medication they were already taking and support when ending medication.
 - alternatives to medication such as psychotherapy or alternative therapies.
 - practical support, such as which benefits they were entitled to and home support:
- "Financial information, availability of benefits to people with mental illnesses is not sufficiently well publicised."*

Format of information

In addition, respondents wanted:

- Clear information available in different languages.

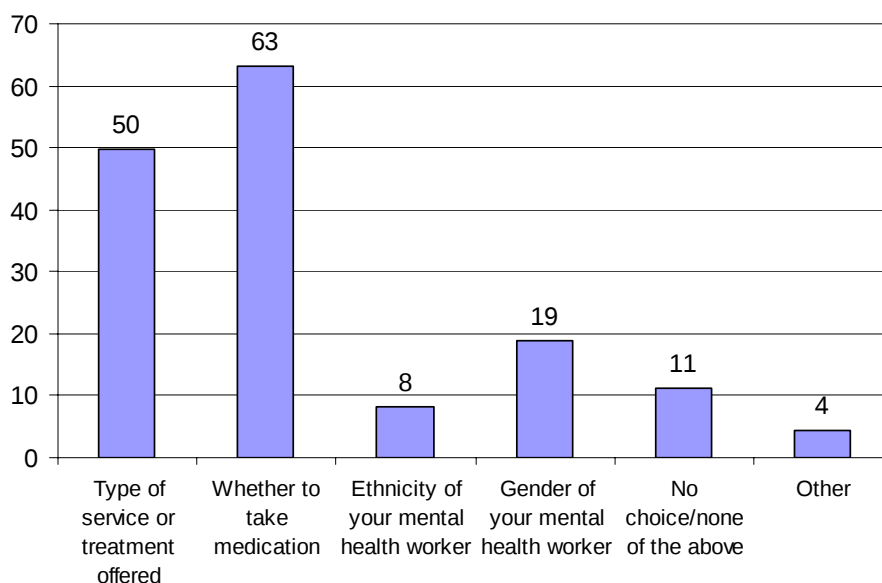
“Due to my language barrier, I am unable to understand the information I have been given.”

- Information in different formats and British Sign Language.

Q5 Were you given a choice about any of the following?

- 63% of respondents were given a choice about whether to take medication and 50% on the type of service/treatment.
- Respondents were more likely to be given a choice about the gender of their mental health worker (19%) than ethnicity (8%).
- 11% of respondents used the free text box to state that they had been offered no choice (therefore it included in the chart below).
- 24% respondents failed to answer the question; which could indicate that the question was irrelevant to them as they hadn't been given any choices.
- Respondents from BME communities were more likely to be given a choice about the ethnicity or gender (27%) of their worker than White UK respondents (15%).

Percentage respondents offered a choice with regard to their service or treatment

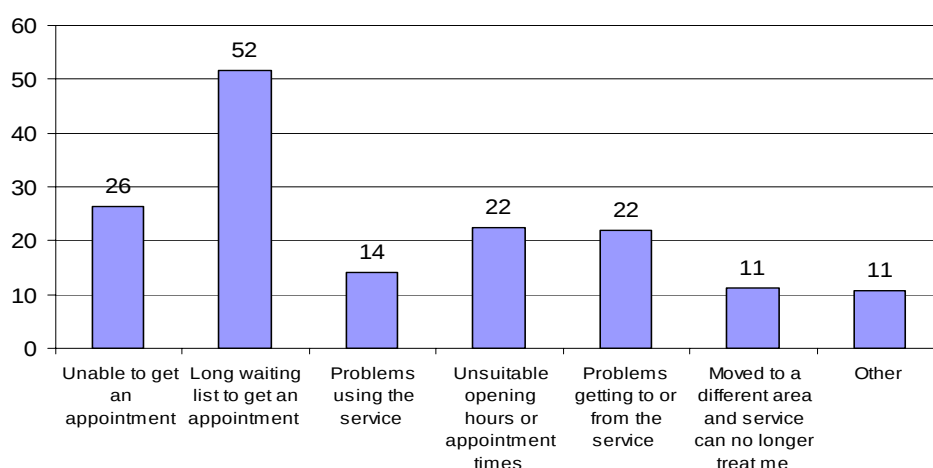


Q6 Have you had any of the following problems accessing community based NHS mental health services in the last 12 months?

- 39% of respondents described a problem with accessing a service and 23% had experienced two or more problems accessing services.
- 38% had not responded to the question, although, again, it is not possible to determine whether this was because they had not experienced any problems accessing a service or did not wish to answer the question.
- “Long waiting lists” was the most frequently cited issue (mentioned by 52% of those who had access problems), followed by difficulties in getting an appointment (26%)

followed jointly by “Unsuitable opening hours” (22%) and problems getting to or from the service (22%)

- Respondents from BME communities were more likely to be given a choice about the ethnicity or gender (27%) of their worker than White UK respondents (15%).
- People who had problems getting to or from the service cited public transport and distance to services as the main reasons. More specifically, some respondents thought that public transport was too expensive or due to their mental health problems were frightened of using it.
- “Other” difficulties accessing services varied widely and included:
 - Homelessness
 - Language barriers
 - Lack of childcare
 - Worries and anxieties over state intervention into their lives
 - Not ‘getting on’ with their mental health worker
 - Change in their mental health worker
 - Worsening mental health
 - Support only available for a short period of time
 - health professionals changing appointment times, sometimes to deal with more ‘urgent’ cases
- Women respondents (59%) reported a higher of problems in terms of accessing mental health services than men (35%).
- The survey found no differences between BME and White UK respondents, however, open-ended comments and face to face surveys revealed a number of problems for BME respondents in accessing services:
 - Unaware of support available beyond a GP
 - Difficulty in arranging appointments due to language barriers and lack of support from reception staff
 - Difficult and time consuming to co-ordinate arranging an interpreter as well as an appointment
 - Lack of clear referral information for service user and professionals – who they were referred to and why
 - Lack of choice about the support they could access
 - Problems not taken seriously by (mental) health professionals.

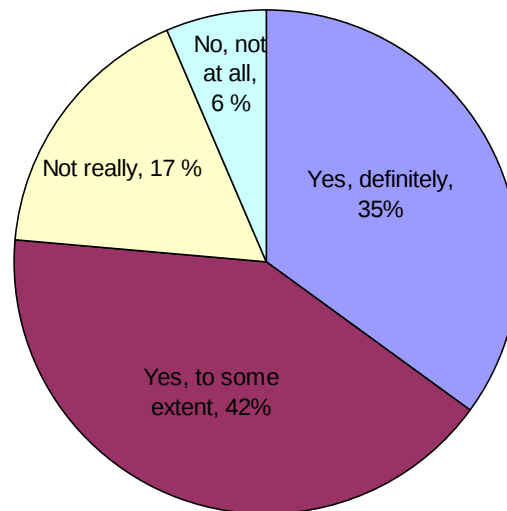
Percentage respondents experiencing problems accessing servicesServices where problems cited

- Respondents had most difficulties getting appointments with GPs, Community Mental Health teams and counsellors/therapists based outside GP surgeries.
- Long waiting lists were most often cited in relation to counsellors/therapists based outside of GP surgeries, psychiatrists and social workers/care co-ordinators.
- Unsuitable opening hours/appointment times and were most likely to be experienced with counsellors/therapists based outside of GP surgeries, Community Mental Health Teams and psychiatrists. Specific problems that were described included childcare, and lack of services out of working hours.

Q7 Overall would you say that the support you have received from the NHS in the last 12 months has helped you deal with your mental health issues?

- In spite of reported problems, there was generally a high level of satisfaction with services. The majority of respondents stated that the support they had received had "Definitely" (34%) or "To some extent" (41%) been helpful. Furthermore, there were numerous positive comments from respondents who felt that they had received good NHS mental health services, particularly those who needed intensive support.
- Only 6% stated that NHS services had not helped "At all".
- Of respondents who stated that the service/s had not helped "At all", 72% were women and 2% were men.

Percentage respondents' response to whether the support received from the NHS in the last 12 months has helped them



Positive comments included:

"The psychiatrist, community nurses and outreach team are all excellent at helping people with their problems."

"[The] staff...are brilliant. I [was] self harming, was homeless, epileptic. All staff and start team brilliant. And [I've] stopped self harming."

"I have been very well supported by my GP, who is monitoring my current medication and well-being..."

"I have been very happy that the NHS - despite a lack of funding as promised by the government - can provide such a top class service."

Other respondents felt that there was still room for improvement:

"Within the last twelve months each area of my care has been ok. However, when first taken into the NHS system, it took ten months to come to a correct diagnosis."

"GPs and psychiatrists, in my experience, tend to prescribe anti-depressants automatically without discussing the full range of other options. They seem to have little contact with other services... They rarely know about Day Centres or voluntary organisation facilities and drop-ins."

"I have suffered all of my life with mental health issues and last year suffered a severe brain haemorrhage and feel very let down by the lack of support I have NOT received. The mental health service is deteriorating and it is a major concern for people such as myself."

"My GP is useless and doesn't want anything to do with my mental health problems... A gay group would be good..."

Q8 Apart from this survey have you ever been asked to give your views about the community based NHS mental health services you have used?

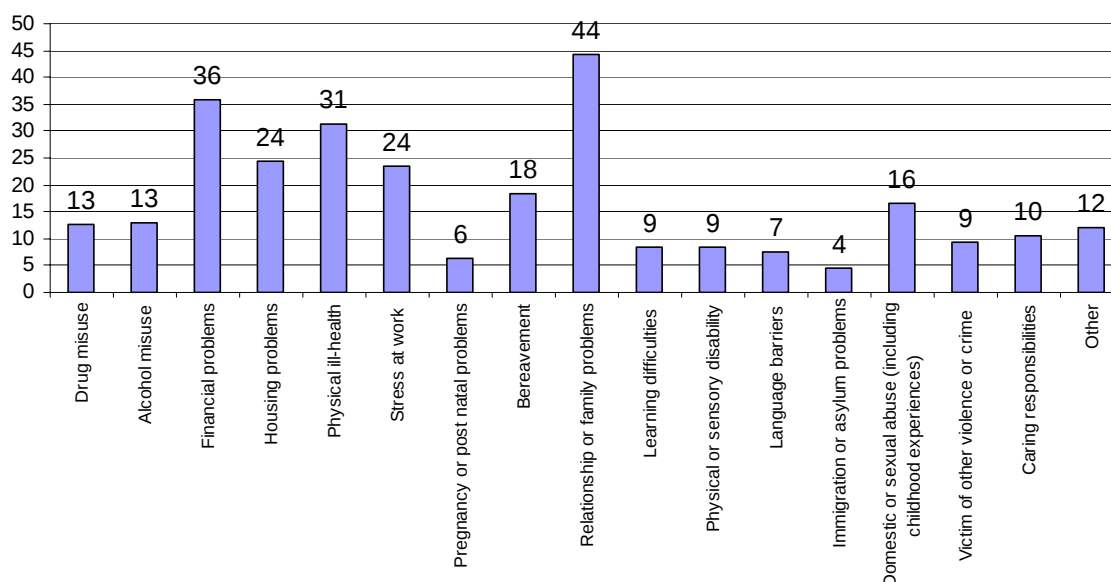
Respondents were asked to select one of the listed answers only.

- 54% of respondents had “Never” been asked their views on services they’d used.
- 24% had been asked “Once or twice” and 4% had been consulted on “Several occasions”.
- BAME respondents were slightly more likely than their White British counterparts to have been asked to give their views about NHS mental health services (53% compared to 41%).

Q9 Have any of the following issues affected your mental health over the last 12 months?

- 28% of respondents reported having experienced at least one problem and 25% said at least two of the issues were impacting on their mental health.
- 40% said that three or more of the problems were having an impact. The average number of issues impacting on a respondent’s mental health was three.
- The most frequently cited were relationship/family problems (44%), followed by financial problems (36%) and physical ill-health (31%).

Percentage issues affecting mental health

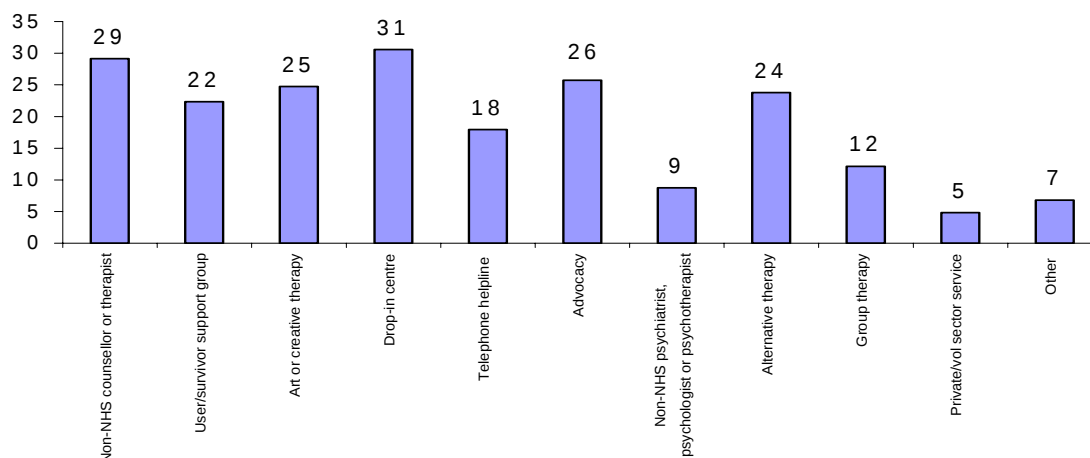


- 63% of women reported relationship/family problems as impacting on their mental health compared with 33% of men.
- Women (25%) also reported significantly higher levels of domestic violence or sexual abuse than men (5%). Of female respondents, one in four experienced gender based - consistent with estimated national figures for the general female population.
- Most respondents are seeing someone who is helping them with the identified issues, although 87 respondents were not, of which 69% (60) of these respondents do not know where they could go for help.

Q10 Have you used any non-NHS services to help you with your mental health?

- Drop-in centres (31%), non-NHS counsellors or therapists (29%) and advocacy (26%) were the most cited non-NHS services which respondents had also used. Just under a quarter of respondents had also used alternative therapies (24%).

Percentage of non-NHS services used by respondents

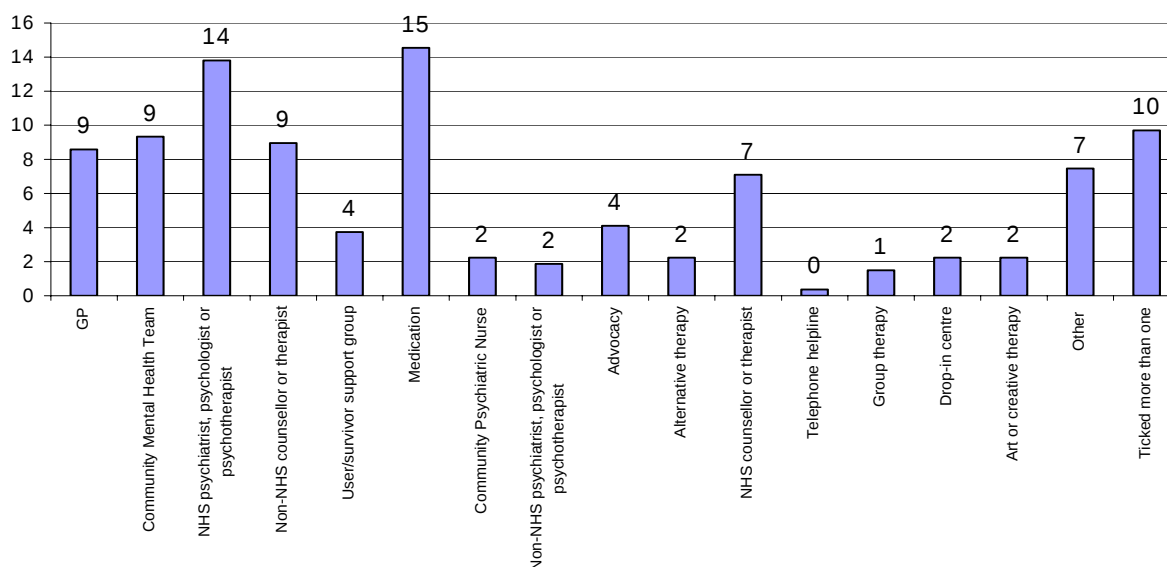


Q11 Which ONE of these services or treatments would you say has helped you the most?

The most cited were "Medication" (15%), followed by "NHS psychologist, psychiatrist and psychotherapist" (13%). Charities and community groups were cited by a number of respondents (18) in the "Other" category.

Despite over half of respondents accessing GP services in the last 12 months, only 9% cited them as the most helpful service/treatment.

Services which had helped the most (percentage of respondents)



In spite of specifying that only one option should be ticked for this question, a number of respondents (10) stated that more than one service had helped them. As one respondent said:

"Only ONE option is limiting and restricts relevance of answer - medication AND contact with family AND creative writing AND seeing a psychologist regularly."

This illustrates the often holistic needs of users (i.e. the need for multiple interventions), hence respondents asking for services which are better co-ordinated to meet their, often multiple needs.

Q12 What one thing do you think would make the most difference in helping people get the mental health services they need? and

Q13. Any other comments?

The findings of questions 12 and 13 are reported together due to the considerable overlap in type of response. As the questions were situated next to each other on the questionnaire they were often used interchangeably.

Respondents provided a wealth of information and suggestions in response to these questions which revealed a number of common themes.

1. Values/philosophy of care

Relationships with staff and services were a high priority for respondents. Essentially, respondents wanted mental health services to empathise with them but often felt, (particularly if they had additional needs such as a learning disability or drug or alcohol problems) that they were a burden or that their problems weren't taken seriously.

"Listen to the patient - not the - them and us approach. Be considerate to dual diagnosis."

Specifically, respondents stated that they wanted to "feel that they are believed", "nurtured", "understood", "respected", "listened to", "supported", "encouraged" and "given hope". They wanted mental health services to believe in their ability to recover; to achieve goals and to have respect for service users' own insight.

"More understanding of people with learning difficulties."

2. Choice

For service users to have 'choice' they need to be provided with information and where possible be supported to find the most appropriate service for them. Many respondents were unaware of what they could access or how to seek help (particularly those whose first language was not English). They expected health professionals to be able to inform them of the range of services available although the reality was that they often had to find out themselves. For people already unwell and vulnerable, this was considered to be a challenging and unwelcome task.

The theme of choice has been broken down into 'Information' and 'Accessibility'.

Information

"Without proper advice and information patients cannot make informed choices regarding their care."

"Also required is more information on what is available, how to access the services, choice of location and times. A specific benefit as a single parent working full-time would be access to services outside of normal working hours (i.e. after 5 pm - at weekends, etc)."

Respondents were in agreement that information should be made widely available both within and outside of mental health services.

In addition, they specified different types of information needed including:

- Medication, including options, side effects and coming off medication
- The various NHS and non-statutory services and treatments available including talking therapies, alternative therapies, self help and support groups
- Who to contact in a crisis, including non-statutory services
- Where to go for practical support, such as housing and financial matters
- Information to be accessible to all communities and therefore available in different languages/formats (including British Sign Language).

Accessibility

As demonstrated in question six, the overwhelming issue identified was waiting lists. Respondents stated they wanted "earlier referrals", "quicker access to services" and "no waiting lists".

Respondents whose first language is not English wanted more support in making and attending appointments, particularly in terms of arranging for an interpreter. More generally, respondents wanted more rapid access to services and at an earlier stage to prevent escalation of problems.

Some felt that it was only at crisis point that a service could be obtained or that they found out about what was available.

"The only way I found out was through being admitted to hospital."

"I would quite like to know what's available. The only way I know how to see a psychotherapist is to get admitted as an inpatient into the hospital."

It was felt that if long waiting lists were inevitable, then health professionals, such as GPs, should be able to provide information on alternative forms of support, such as voluntary sector organisations or self help approaches.

3. Type of support/service

Many respondents stated that they wanted more support in the community:

"Home support for basic problems/intensive support to rehabilitate people (greater communication with other community services) – so service users have a stronger network to tackle areas which may trigger relapse."

"We are left to fend for ourselves in the community with little or no support at all. Treatments are not offered and no information is given on what is available. The same goes for medication, no choice is given and medication is forced on patients regardless of side effects etc"

"Care in the community concept is a joke – in very poor taste – just to save money. Isolation is the worst way to treat anyone with mental health problems."

"There's a considerable lack of support in the community. The only available day centres are ghettos for the mentally ill and I'd rather not access them as they're depressing places to go."

Other respondents wanted less emphasis on medication and more focus on the wider aspects of their lives. For example, they wanted services to be able to meet *all* of their needs, including social and practical, or at least for services to be better co-ordinated so that service users have a smooth transition between services, without, for example, having to constantly re-tell their story to different professionals.

Respondents wanted services which were flexible, not only in terms of appointment and opening times (which were also important) but in terms of acknowledging that service users cannot, as one respondent put it, "spontaneously recover". The process of recovery doesn't necessarily fit in with a timescale, such as six sessions of therapy.

"Although I am having help...at the moment, my last session...is next. I feel that I have no option now but to pay for more counselling – with someone else which means 'starting again' to give them the background I have already covered with NHS counsellor."

4. Communication

The theme of 'communication' was quite common, however only a few respondents elaborated on what they meant by this.

Several respondents wanted, as mentioned above, better communication between services and professionals and reference was made to the need for 'holistic' and 'continuous support'.

"There needs to be better communication between GPs, the Community Mental Health Team and hospital-based services."

Lack of referral information between professionals was a source of frustration for several respondents. One respondent felt let down, at a time when they were most vulnerable, by poor communication,

"I was on a waiting list for a psychotherapist for approximately seven months. I saw several different counsellors, doctors and therapists between two different services. They didn't communicate with one another about my case. One practitioner actually sent my private health records to the wrong address. My new GP office doesn't take my condition...seriously and merely signs off on antidepressants. I don't know why I am still alive today."

5. Prevention/early intervention

A number of respondents were keen to know about alternative ways that they could help themselves, rather than simply waiting for a service. They wanted to know what was available in terms of self help, drop in centres, support groups, leisure activities and social events and as discussed earlier it was felt that health (and indeed, other) professionals should be able to support individuals with this.

"A focus on prevention and looking after one's mental health would be good."

Other issues that were raised included the need to ensure that mental health professionals were given enough time to assess people to ensure they were correctly diagnosed and assessed.

As illustrated in the quote earlier, service users felt they were more likely to recover if they felt that mental health (and other relevant) services were able to provide co-ordinated care across teams and departments/services.

Case studies

Whilst there is no single profile of a mental health service user, or respondent to this survey, these case studies provide a brief summary of individuals' 'pathways' into mental health services, and in most cases a combination of services, and their experience of those services.

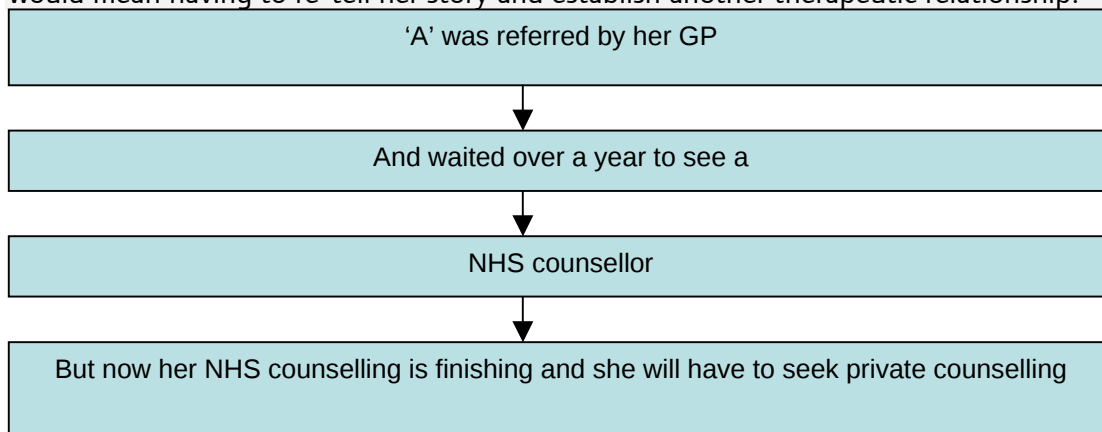
'A'

'A' is a 40-44 year old, heterosexual Irish woman. In the last year she has been in touch with a NHS counsellor (based outside of her GP surgery). She was referred to the service by her GP and found out about mental health services from both her GP and a friend/relative/partner.

She had to wait over a year for her first appointment with the NHS counsellor and felt that the GP practice could have supported her more during the time she had to wait. For example, by providing her with information about how she could help herself or groups that she could join.

'A' reported that physical ill health and pregnancy or post natal problems were impacting on her mental health. Overall, she feels that NHS community based mental health services have helped her 'to an extent' with the problems she was experiencing.

However, she is coming to her last session with the NHS counsellor and does not feel ready to stop. She says she will have no option but to pay for more counselling, which would mean having to re-tell her story and establish another therapeutic relationship.



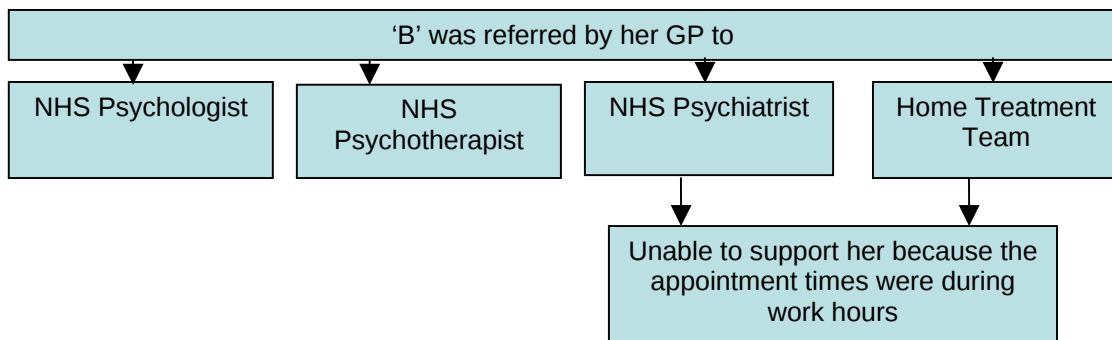
'B'

'B' is a White UK, heterosexual woman, aged between 25 and 29. She has been in contact with her GP, a NHS Psychologist, Psychiatrist, Psychotherapist and a Home Treatment Team in the last year. She was referred by her GP.

A number of issues were impacting on her mental health, such as, financial and housing problems, stress at work and relationship or family problems.

She said that she was given enough information about mental health services and was offered a choice of the type of treatment or service she could have, however, did not feel that the service had really helped her.

The main reason was that appointments and treatments were inaccessible to her as she worked full time. 'B' was told by both the psychiatrist and the Home Treatment Team that they would be unable to support her because of this. She felt that it was assumed in the NHS that you cannot have mental health problems and also be employed full time.

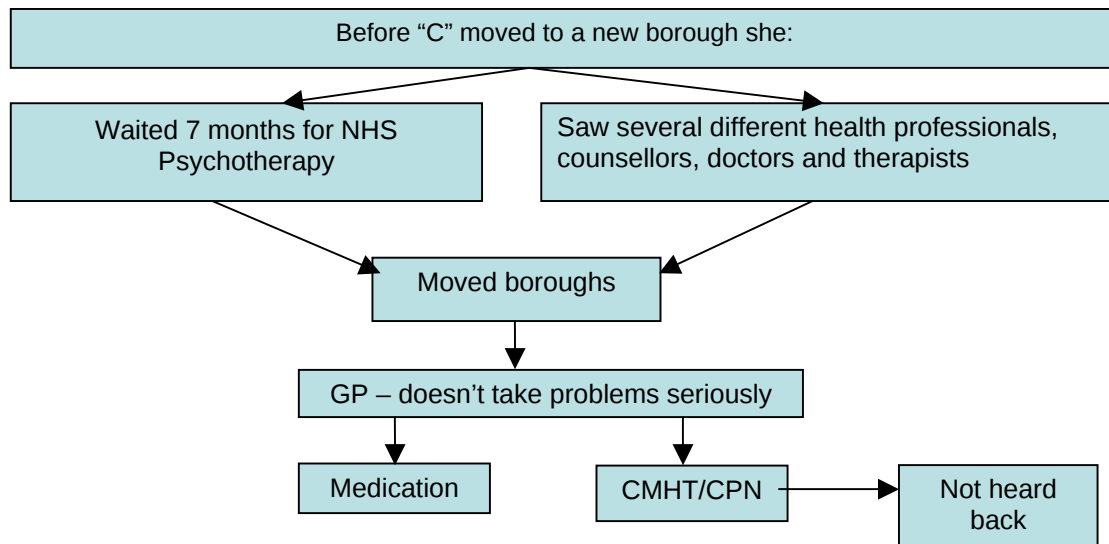
**'C'**

'C' is a Black American heterosexual woman aged 35-39. In the last 12 months she has seen her GP, Community Psychiatric Nurse and Community Mental Health Team. She was referred by her GP.

'C' found out about services via her GP, Internet search and the Accident and Emergency department. She would have liked more information about what services were available, the process for accessing them and the average waiting time.

'C' said that issues of drug misuse and relationship or family problems were impacting on her mental health and that NHS mental health services haven't helped her at all.

She described her experience as 'abysmal'. Prior to moving to a different borough she had been on a waiting list for seven months to see a psychotherapist. She had seen several different health professionals, counsellors, doctors and therapists, between two different services but they didn't communicate about her case. 'C' feels that her new GP doesn't take her mental health problems seriously and just prescribes medication. In addition, she hasn't heard back from the Community Mental Health Team. She said she doesn't know how she is still alive today.



Appendix: Methodology

Steering group

At the beginning of the project, a Steering Group of voluntary and community sector (VCS) mental health workers, including service users, was established to provide guidance, advice and assistance on the survey methodology, dissemination and analysis. Steering Group members included:

- Revolving Doors
- Newham Asian Women's Project
- Greater London Domestic Violence Project
- Social Perspectives Network
- Shaping Our Lives
- National BME Mental Health Network

As the Steering Group was made up entirely of workers from voluntary and community organisations (VCOs), reimbursements were made available to acknowledge both the time and expertise given in support of this project.

Literature review

A literature review was conducted to identify current data on London's population, mental health prevalence, access to services and mapping information on both NHS and third sector mental health services in the community. This information was used to inform the development, dissemination and analysis of the *Have Your Say* survey.

Focus group

Current mental health service users were invited to take part in a focus group to explore the four themes and test possible survey questions. The main issues raised by the focus group, and which were incorporated into the survey, were:

Access to services

- Long waiting lists to get an appointment
- Problems getting to/from the service
- Unsuitable opening hours or appointment times
- Environment 'not conducive to healing' which impacted on engagement with the service
- Better choice of types of services/ treatments
- Lack of information
- Attitude of health professionals

Choice of services

- More choices about medication (whether or not to take, types of medication available etc)
- Better choices of types services/ treatments
- Lack of information
- Lack of continuity e.g. service users having to repeat history to different staff members

Meeting needs

- Not feeling listened to
- Attention paid to symptoms rather than underlying causes
- Services not dealing with multiple needs
- Lack of appropriate services e.g. culturally specific

Quality of services

- Improved relationships/trust between service user and service provider/health professional
- Feeling 'listened to'
- Independence of information/ treatment given

There were six participants – five men and one woman – plus the facilitator note-taker. Participants were from a variety of backgrounds and included people from White, BME and disabled communities. Given the limited time available, participants were recruited through Steering Group members and other Women's Resource Centre (WRC) connections in the VCS.

The focus group was held on a weekday evening and lasted approximately an hour and a half. With the consent of participants, the focus group was tape-recorded and later transcribed. Participants were reimbursed for their time and travel.

Survey

The survey was developed in conjunction with the Steering Group and the project lead for the London Assembly. Comments from the focus group and research from the literature review also informed survey questions.

At the suggestion of the Steering Group, a prize draw was used as an incentive to complete the questionnaire. Steering Group members commented on 'research fatigue' amongst mental health service users and felt it important that at the start of the questionnaire, clear information about what would happen to the information should be included, along with a statement from a London Assembly member.

Each of the mental health trusts and a foundation trust in London was contacted for support in distributing the survey to their clients. Of the ten trusts contacted, five agreed to disseminate questionnaires. Postal surveys were also distributed amongst VCOs and via networks of Steering Group members. The survey, including the link to the on-line questionnaire, was publicised via extensive email networks, posters and the WRC website.

People were able to complete questionnaires through free post, on-line and free phone. Researchers also went to VCOs to support people to complete the survey, particularly where people's first language was not English. An interpreter was arranged to facilitate this. The questionnaire was available in Braille and large print.

Only people aged 18-64 years who had used a NHS community based mental health service, in London, in the past 12 months were eligible for the survey.

A total of 298 surveys were submitted. However, eleven questionnaires were removed from the survey because the respondents had not stated they had used a community based NHS mental health service in the last 12 months – the primary criteria. The total number of eligible questionnaires was 287 for analysis.

The response rate to the survey was low (16%) in spite of a variety of methods employed to try and ensure the survey was well publicised and easily available.

Postal surveys proved the most popular method of responding, accounting for 79% of the surveys received, although of the 1,885 questionnaires sent to mental health and foundation trusts for distribution, only 12% were returned.

Over 200 organisations were emailed with the link to on-line survey and 49 on-line questionnaires were completed.

Two questionnaires were completed via free phone and 13 were completed on a face-to-face basis with the researcher and/or interpreter.

It was hoped that the incentive of a prize draw would encourage people to participate, but, interestingly, 33% chose not to participate in the draw. Twenty- two per cent asked to be sent a copy of survey findings.