NHS Long Term Plan Engagement

A focus on Mental Health

Shaping the future of our NHS in North West London

healthwatch

“I was able to access the Crisis Team very quickly.

Staff were knowledgeable and offered constructive help.”

Local resident and service user

Contents

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What is the NHS Long Term Plan?

With growing pressure on the NHS – people living longer, more people living with long-term conditions, lifestyle choices affecting people's health – changes are needed to make sure everybody gets the support they need.

The Government is investing an extra £20 billion a year in the NHS. The NHS has produced a 'Long Term Plan' setting out the things it wants health services to do better for people across the country.

This includes making it easier to access support closer to home and via technology, doing more to help people stay well, and providing better support for people with long-term health conditions.

Engaging Local People

Whilst the national plan has set some clear goals, it's up to local areas to decide how they're achieved – that means engaging with local people and listening to their experiences and expectations of current and future services.

Healthwatch organisations in North West London, alongside the national Healthwatch network has collected local views on the Long Term Plan through surveys, focus groups and events between April and June 2019, to give tens of thousands of people the opportunity to help local hospitals, GP surgeries and community services hear about the changes people would like to see.

In this report, we look at experiences and expectations associated with Mental Health.

What matters most to people in North West London?

Engaging with 46 people – service users, families and carers we found that:

Summary: Mental Health Services

GP Services
When talking about local GP services, people cite good levels of empathy from GPs, however treatment is not always effective. Some patients comment on feeling unsupported, with GPs showing 'little interest' in their personal or social circumstances – this can affect ongoing care and early intervention. One patient had to 'persuade' the doctor that he was ill, while others say that assistance is only offered in potentially suicidal cases.

Generally it is felt that mental health specialists at GPs 'are not best equipped' to help and it was also agreed that the ten minute consultation period was not sufficient. Long waiting lists are a common theme, with people receiving little or no support in the interim.

Digital technology was seen as a good way to make online appointments but there is not enough direct marketing of the service.

Community Mental Health Services
We heard reports of attentive and thoughtful psychiatrists at the Child and Adolescent Mental Health Services (CAMHS). People were also complimentary about community services and hubs.

Some people comment on a lack of personalisation, in some cases leading to social isolation. For counseling, it is reported that the number of sessions on offer is not always effective, particularly for those with 'complex needs'. Waiting times are also cited as an issue, with some services not responsive following referrals.

Hospitals
People commented on good levels of empathy and support, and timely services. However, we heard experiences of poor staff attitude, a lack of quiet space or privacy on wards and an environment not conducive to recovery.

It was also suggested that cuts to community services have increased demand on hospital beds. Waiting times are also cited as an issue, particularly for Psychiatric Liaison.

Being accompanied by a partner, family member or carer can make the experience more comfortable for all. Views about mixed-sex wards differ – some people prefer them while others do not, therefore a choice would be equitable.

Summary: Mental Health Services

SPA (Single Point of Access)
Many people commented that the service is 'not empathetic' and offers advice of little value - such as 'make a cup of tea, listen to music or go for a walk'. Telephone access and waiting times for callbacks are also noted as issues.

To improve understanding and empathy, it was suggested that staffing should include people who have had similar mental health illnesses.

Recovery Team
We heard accounts of compassionate staff, however people note the service is 'over stretched'.

Many people experience poor telephone access, with one person trying to make contact for one week. It is also reported that communication and liaison between services and GPs is poor.

Coordination between services
People commented on administrative problems, poor communication and liaison between services plus a 'postcode lottery' across boroughs. The complexity of referral pathways can also delay treatment.

Travel and Transport
In one experience, a journey to visit a partner involved 3 buses – each way. Other people cited financial cost and waiting times as issues. By one person, the Freedom Pass was regarded as 'a lifeline'.

Co-morbidities
When talking about co-morbidities we detected a sizeable theme on medication. People cite a lack of alternatives to medication, side effects and complications with other medication. Some people also comment on a lack of information and signposting from their GP.

Learning from Discussion (Checklist)

GP Services – local people would like:

- Good levels of support and engagement.
- To be listened to, respected and involved.
- Specialists that are knowledgeable and empowered/equipped to help.
- Timely access to services and support while waiting.
- Optimum use of digital technology.

Learning from Discussion (Checklist)

Community Mental Health Services – local people would like:

- Holistic treatment and care, with 'real choice'.
- Good levels of support (example increasing number of sessions).
- Timely access to services.
- Services that are responsive.

Hopsitals – local people would like:

- To be treated with dignity and respect.
- An environment conducive to recovery (with privacy and quite space).
- Timely access to services.
- Option of same or mixed-sex ward.

SPA (Single Point of Access) - local people would like:

- To be treated with dignity and respect.
- A good level of information and advice.
- Good telephone access.
- Services that are responsive.
- To be understood.

Recovery Team - local people would like:

- Adequate staffing levels
- Good telephone access.
- Good liaison and communication between services.

From Diagnosis to Ongoing Care

Assessment, Diagnosis and Treatment
It was felt that assessments should include a 'risk assessment', and that only Mental Health professionals should be authorised to diagnose. A good level of training was emphasised across the board – from school staff to GPs. People also stressed the importance of contact with peer workers who have recovered from similar conditions.

Follow-up treatment and support should be tailored and personal, and alternatives (such as laughter therapy, music therapy and exercise) included in the mix of options, as appropriate.

At one event, a number of people felt the 'only way to access emergency treatment' was through the police and that this was inappropriate.

From Diagnosis to Ongoing Care

Prevention and Early Intervention
Discussions emphasised the importance of education for new mums, children and young people, and school staff. People said that GPs should have a 'broader understanding' of mental health issues. There is also a need to educate the wider community so that people with mental health issues do not feel any different and can seek support (break down the taboo factor about mental health).

It was felt that good levels of specialist support are vital, including for continued access, and people should not be discharged prematurely.

Lack of community based projects, poor levels of information & signposting and use of 'jargon' were also cited as challenges.

Ongoing Care and Support
The ability to build relationships is considered important - a named, consistent contact (such as a care navigator) would be useful for both patients and families and volunteers could be trained to befriend and offer peer support. Carers also need greater levels of support – suggestions include drop-in centres and peer support groups.

People would also like subsidised travel, greater choice of treatment and therapies and practical support – such as assistance in applying for benefits or completing forms. It was felt that medication 'should not always be the go to approach'.

At one event, young people use the word 'frustrating' as it is felt that help 'simply isn't there' for them.

Learning from Discussion (Checklist)

Assessment, Diagnosis and Treatment – local people would like:

- Assessments that include a risk assessment.
- Diagnosis by Mental Health professionals.
- Training for medical and other professionals.
- Access to peer support.
- Holistic follow-up treatment and support, with alternative options.

Learning from Discussion (Checklist)

Prevention and Early Intervention – local people would like:

- Education for new mums, children and school staff.
- Training for GPs.
- Awareness within the wider community (break down the taboo).
- Good levels of specialist support.
- Appropriately timed discharge.
- Access to community based projects.
- Clear, and good levels of information.

Ongoing Care and Support – local people would like:

- A named contact (such as a care navigator).
- Befriending and peer support.
- Support for peer support carers.
- Subsidised travel.
- Choice of treatment and therapies.
- Practical support (such as help to apply for benefits).
- Alternatives to medication.

Communication and Engagement

Finally, we asked people how engaged they would like to be, and whether they would like to be involved in designing new services. As part of this, we asked them which aspects of communication and engagement could be improved.

It was felt that public meetings should be well communicated, to maximise turnout. Consideration should be given to having meetings at different times in the day, including evenings, so that people can attend.

Patients also need encouragement and support to get involved in engagement – Healthwatch could be useful, particularly in raising awareness, harnessing skills and building networks. Outcomes of meetings should be widely communicated and actions reported back – to keep people engaged.

Learning from Discussion (Checklist)

Communication and Engagement – local people would like:

- Good awareness of public meetings.
- Choice of times (morning, afternoon and evening).
- Good levels of engagement.
- Updates on how their feedback has/has not been used.

What did people tell Healthwatch?

Here, we take a more detailed look at the top themes emerging from discussion. Generally we asked people what they feel works well and what could work better.

1. GP Services

This section explores top themes around GP services.

1.1 What works well?

People comment on good levels of empathy from GPs, however treatment is not always effective.

GPs - what works well?

Selected comments:

"Reception staff and duty officer at Claybrook centre considered to be constructive and knowledgeable." [Hammersmith & Fulham]

"Personal touch from GPs - one participant said: "she hugged me". However, ultimately was unable to help in any meaningful way." [Hammersmith & Fulham]

"GP admitted gap in Mental Health knowledge and expressed willingness to learn more and also in alternative therapies such as music therapy." [Hammersmith & Fulham]

1.2 What could work better?

Patients comment on feeling unsupported, with GPs showing 'little interest' in their personal or social circumstances – this can affect ongoing care and early intervention. One patient had to 'persuade' the doctor that he was ill, while others say that assistance is only offered in potentially suicidal cases. Generally it is felt that mental health specialists at GPs are 'not best equipped to help' and it was also agreed that the ten minute consultation period was not sufficient.

Long waiting lists are a common theme, with people receiving little or no support in the interim.

GPs - what could work better?

Selected comments:

"Not taking early intervention seriously enough - Mental Health crises/eating disorders only addressed when they are extreme." [Westminster]

"You have to persuade the GP or doctor about that you are ill. You have to lie,

otherwise you are not taken seriously. I was really depressed, had anxiety, couldn't open my post, couldn't leave the house. I forced myself to go to the GP to get help, they asked if I was suicidal. I had not felt suicidal that week so I didn't get any help. Another time I had to lie and say I was suicidal and a danger to other people. If I didn't add any colour to my story nothing would happen." [Ealing]

"Services always ask if you are thinking about ending your life. It's the first thing they ask. If you say yes they take you seriously, If you say no you get nothing." [Ealing]

"One person had been transferred back to the mental health worker at their GP, who told them that they couldn't help with certain things because it was out of their jurisdiction. They felt like they didn't see the point of having someone there who was not equipped to deal with mental health issues." [Ealing]

"Waiting time from seeing the Dr to getting a proper diagnosis and specialised treatment can be a long time, some quoted 9 months and were not signposted to any help in the meantime." [Ealing]

1.3 What could easily be improved?

Digital technology was seen as a good way to make online appointments but there is not enough direct marketing of the service.

2. Community Mental Health Services

This section explores top themes around Community Mental Health services.

2.1 What works well?

We heard reports of attentive and thoughtful psychiatrists at the Child and Adolescent Mental Health Services (CAMHS). People were also complimentary about community services and hubs.

Community Mental Health Services - what works well?

Selected comments:

"Able to access Crisis Team very quickly and staff were knowledgeable and offered constructive help." [Hammersmith & Fulham]

"'Back on Track' self-referral allows service users to take control of their own care." [Hammersmith & Fulham]

"Recovery hub is brilliant, but they haven't done anything else. There was also regret expressed for the lack of funding for Mind services like 'Heads Up'." [Hammersmith & Fulham]

2.2 What could work better?

Some people comment on a lack of personalisation, in some cases leading to social isolation. For counseling, it is reported that the number of sessions on offer is not always effective, particularly for those with 'complex needs'.

Waiting times are also cited as an issue, with some services not responsive following referrals.

Community Mental Health Services – what could work better?

Selected comments:

"Claybrook uses a model of therapy that doesn't work for all - it's based on Borderline Personality Disorder, but what if you don't have that? I've had to help myself and still find myself isolated." [Hammersmith & Fulham]

"Isolation is part of the illness, it is hard to approach someone who is depressed - inreach and outreach is the key." [Hammersmith & Fulham]

"There is 'little or no structure' in group therapy sessions for the most vulnerable." [Hammersmith & Fulham]

"The gap between in-patient and community support is too big/wide." [Brent]

"It would be much better to have fewer more highly functioning specialist mental health centres - I would be prepared to travel" [Hammersmith & Fulham]

"Counselling is seen as a negative (even though it is good that we have it) because the contracted periods are too short for people with complex needs. [Westminster]

"Long waiting times (no interim measures in place while waiting for appointments)". [Hillingdon]

"One participant mentioned that their GP had referred them to IAPT, who did not reply to them for two months and then failed to keep in touch." [Ealing]

2.3 What could easily be improved?

In one case, service users have been inspired to 'take the initiative' and forge support networks. This has including pooling of personal budgets to book particular actitivities.

Community Mental Health Services – what could easily be improved?

Selected comments:

"Service users have worked together to create a network to seek out help from charities where there are gaps in the NHS." [Hammersmith & Fulham]

3. Hospitals

This section explores top themes around hospital services.

3.1 What works well?

People commented on good levels of empathy and support, and timely services.

Hospitals – what works well?

Selected comments:

"Lakeside (mental health unit, Hounslow): I was in taken to Lakeside last year as there was no room at Ealing Hospital. A nurse stayed with me up until 11pm. She made time for me and sat with me to make sure I ate. I felt somebody cared." [Ealing]

"I had a voluntary admission. Help and support at the hospital was quick." [Ealing]

"PALS worked OK when they missed an appointment at Hillingdon Hospital." [Hillingdon]

3.2 What could work better?

We heard experiences of poor staff attitude, a lack of quiet space or privacy on wards and an environment not conducive to recovery.

It was also suggested that cuts to community services have increased demand on hospital beds. Waiting times are also cited as an issue, particularly for Psychiatric Liaison.

Healtwatch Ealing makes an observation about mixed sex wards (St Bernards Hospital). "Service users mentioned that some wards are mixed and some are same-sex, depending on the severity of people's illness. They mentioned that on one hand it can feel unsafe to be in a mixed ward and that they needed more support from the nursing staff than they were receiving as a result. On the other hand, some participants felt as if being in a mixed ward was better for them. They agreed overall that would like to have an option to choose what type of ward to be admitted into as part of their care plan."

Hospitals: what could work better?

Selected comments:

"Staff are cold towards families and carers on the wards." [Hammersmith & Fulham]

"Wards lack quiet space for recovery and respite." [Hammersmith & Fulham]

"Thought that it wasn't a good environment to recover in; there are no windows, it looks like a prison, is unhealthy." [Ealing]

"Having multiple people in consultation rooms could be very uncomfortable for some, and they often do not feel like they have a choice but to allow this - it's often student doctors. They feel as if there needs to be a relationship built with a person before they can divulge sensitive information around them. [Ealing]

"Mental Health in-patient service is like a revolving door when there is insufficient support in the community." [Brent]

"So demands for beds outstrips needs because the support in the community doesn't work. There are people who need to be hospitalised." [Brent]

"Psychiatric Liaison service at Ealing Hospital: I had to wait for 4 hours. Another person identified only waiting 20 mins recently." [Ealing]

3.3 What could easily be improved?

Being accompanied by a partner, family member or carer can make the experience more comfortable for all.

Views about mixed-sex wards differ – some people prefer them while others do not, therefore a choice would be equitable.

Hospitals: what could easily be improved?

Selected comments:

"One person said that they benefitted when their partner was transported there with them and was not separated from them." [Ealing]

4. SPA (Single Point of Access)

This section explores top themes around SPA (Single Point of Access).

4.1 What works well?

We heard one account of a good, helpful service.

SPA (Single Point of Access) – what works well?

Selected comments:

"SPA played a role in getting me the help I needed. The first call was not good. The second call was very helpful." [Ealing]

4.2 What could work better?

Many people commented that the service is 'not empathetic' and offers advice of little value - such as 'make a cup of tea, listen to music or go for a walk'. Telephone access and waiting times for callbacks are also noted as issues.

SPA (Single Point of Access) – what could work better?

Selected comments:

"Not very empathetic when people phoned up feeling suicidal, they were giving useless advice such as "watch TV, listen to your favourite music or go for a walk", therefore people questioned whether or not they are even trained. Some people have had experiences of being automatically signposted rather than SPAs helping them deal with the situation. Many people said they would rather use the Samaritans because they are more empathetic and supportive - "you get the feeling that they actually want to talk to you"." [Ealing]

"I had a 10 minute call. I felt rushed. She left me crying on the phone." [Ealing]

"Can't get through on the phone. Have to wait too long." [Ealing]

"They left me in a worse state when I got off the phone. They told me the clinician would call back in 20 minutes. 12 hours later they finally called back." [Ealing]

4.3 What could easily be improved?

To improve understanding and empathy, it was suggested that staff should include people who have had similar mental health illnesses.

SPA (Single Point of Access) - what could easily be improved?

Selected comments:

"It was suggested that the staff employed by phone services should be people who have had similar mental health illnesses to them because people who have not gone through it themselves do not understand their situation. This suggestion was a two-fold solution 1) to help recruit more understanding and helpful staff 2) Most mental health SUs do not have employment and this could be a way to help them regain confidence and self-respect, and therefore improve their mental health." [Ealing]

5. Recovery Team

This section explores top themes around Recovery Team services.

5.1 What works well?

We hear accounts of compassionate staff, however people note the service is 'over stretched'.

Recovery Team - what works well?

Selected comments:

"Staff are good and compassionate but people do not see them often, and the staff seem overstretched, which means that they lack a proper human connection." [Ealing]

5.2 What could work better?

Many people experience poor telephone access, with one person trying to make contact for one week.

It is also reported that communication and liaison between services and GPs is poor.

Recovery Team - what could work better?

Selected comments:

"Many phone call services do not pick up their phone lines - especially detrimental as people usually call when they are in a crisis. One SU called the Limes as we spoke and only got through to the answering machine." [Ealing]

"One person has been trying to contact for one week - impossible to get through!" [Ealing]

"Communication between Avenue House and the GP is poor." [Ealing]

"When you go and see the duty team at Avenue House the information does not get logged. I have no confidence in the service. I'm not being listened too." [Ealing]

"Staff are always rushing at Avenue House. It makes you feel like an inconvenience. There are not enough CPNs there. CPNs have been cut and the workload has gone up. They have no time. They have just paperwork and deadlines. Even getting allocated a social worker is difficult." [Ealing]

5.3 What could easily be improved?
It was felt that home visits for the housebound would be a good idea.

Recovery Team – what could easily be improved?

Selected comments:

"There should be a home visit service for people unable to leave home." [Ealing]

6. Co-ordination between services

Trends were also established on service coordination. We heard accounts of administrative problems, poor communication and liaison between services plus a 'postcode lottery' across boroughs.

The complexity of referral pathways can also delay treatment.

Co-ordination between services

Selected comments:

"Since 2013, patients have been referred for Cognitive Behavioural Therapy then to secondary care and then on to primary care - there seems to be an issue with information not being sorted/archived correctly." [Hammersmith & Fulham]

"Postcode lottery for treatment of mental health." [Hammersmith & Fulham]

"Lack of coordination with/access to out-of-borough Mental Health services; lack of community support." [Westminster]

"Services not working in an integrated way (having to tell my story more than once)." [Hillingdon]

"Feeling that services were passing the buck and blaming each other." [Hillingdon]

"There is also a lack of communication between GPs and other services; GPs are not getting records from Avenue House - again this can cause a problem between medications." [Ealing]

"The layers that exist between you and getting help need to be removed. You go from the GP – consultant – psychiatric nurse – psychiatrist back to consultant etc. It takes months in between each appointment and every time it's a new person." [Ealing]

7. Travel and Transport

In one experience, a journey to visit a partner involved 3 buses – each way. Other people cited financial cost and waiting times as issues.

By one person, the Freedom Pass was regarded as 'a lifeline'.

Travel and Transport

Selected comments:

"My partner doesn't drive and it took him 3 buses to come and see me at West Middlesex hospital every day. The travel took a lot out of him (more so as he has back problems). The distance of treatment to where your family/support network is makes all the difference to your recovery and their ability to support you." [Ealing]

"The financial cost of travel for partner/family/support network limits the support they can provide." [Ealing]

"Ealing hospital transferred me to Lakeside. The longest wait was for the transport. They took my partner with me in the transport. This was a massive help and very reassuring. The services were quick, but the transport slow. This was a voluntary admission." [Ealing]

"The freedom pass is a lifeline." [Ealing]

8. Co-morbidities

When talking about co-morbidities we detected a sizeable theme on medication. People cite a lack of alternatives to medication, side effects and complications with other medication. Some people also comment on a lack of information and signposting from their GP.

Co-morbidities

Selected comments:

"People said they would rather get therapy than take pills, and felt that medication was overprescribed, however in some cases people have waited for over 2 yrs for a therapist." [Ealing]

"There is too much medication. Everytime you go they give you something new. There are too many side effects and too many problems caused by the medications." [Ealing]

"I am not getting my diabetes medicine as I am on too many other medications, 12 all together. My daughter is a doctor. She helps and advises me." [Ealing]

"The GP and Psychiatrist do not understand each other's medicine. It's dangerous." [Ealing]

"One person has learning difficulties as well, and therefore they find it hard to find information about services, and about their mental health. Therefore they need more support from Drs than they are getting, just someone to give them proper face-to-face information and signposting." [Ealing]

From Diagnosis to Ongoing Care

We talked about various aspects around assessment, diagnosis, treatment, early intervention and ongoing care and support.

9. Assessment, Diagnosis and Treatment

It was felt that assessments should include a 'risk assessment', and that only Mental Health professionals should be authorised to diagnose. A good level of training was emphasised across the board – from school staff to GPs. People also stressed the importance of contact with peer workers who have recovered from similar conditions.

Follow-up treatment and support should be tailored and personal, and alternatives (such as laughter therapy, music therapy and exercise) included in the mix of options, as appropriate.

At one event, a number of people felt the 'only way to access emergency treatment' was through the police and that this was inappropriate.

Assessment, Diagnosis and Treatment

Common themes:

Assessment:
An assessment should involve a comprehensive risk assessment before crisis point. Any non-specialist staff involved should be trained to spot the signs and this should be the protocol across the boroughs. School staff should be trained to spot the signs of mental health so that it could be identified before becoming a crisis. Training should also be provided to GPs and/or their staff to help identify issues and to have a better understanding of how to manage the person/patient.

Specialist Diagnosis
Only a Mental Health professional should be authorised to provide a diagnosis with a full evaluation of environmental and familial factors included with an emphasis on the cause, not the effect. These diagnoses should also be earlier rather than at crisis point - there is anecdotal evidence that incorrect assumptions by non-specialist staff can lead to misdiagnosis and unsuitable treatment.

Peer Support
Participants stressed the importance of contact with peer workers who have recovered from similar conditions.

Follow-Up
People agreed that follow-ups should be tailored to the case. For example, it may be necessary to follow up once a day for some patients and once a month for others. Isolation is often part of the illness in mental health cases, but attempting to contacting patients via various means of communications is important. One participant suggested follow-up calls should have a caller ID so patients know who the call is coming from even if they are unable to answer.

Alternative Treatment
Popular examples include laughter therapy, music therapy and exercise should be considered viable options for treatment.

Assessment, Diagnosis and Treatment

Summary of other popular themes:

- **GP Support:** The GP turns people away unless the situation is life threatening. It feels like this pushes people to hurt themselves.
- **Diagnosis:** Advice should be given at the point of diagnosis as well as guidance to how better to manage while waiting for appointments. This would help the patient to cope better.

- **Treatment:** Emergency metal health needs should be accessible without having to contact the Police. There needs to be a way of accessing treatment after the short-term Cognitive Behavioural Therapy (CBT) and Talking Therapy as when these have stopped it can have devastating effect for some people. More specialists are needed to resolve the waiting time issue.
- **Protocol:** Should be more awareness that some unwell patients are unable to manage schedule of appointments and travel to services and that this needs to be a joined-up, team effort between patient and service provider.
- **Gateway to Treatment:** Treatments other than CBT should be available, but a risk assessment and proper diagnosis are needed first.

10. Prevention and Early Intervention

Discussions emphasised the importance of education for new mums, children and young people, and school staff. People said that GPs should have a 'broader understanding' of mental health issues. There is also a need to educate the wider community so that people with mental health issues do not feel any different and can seek support (break down the taboo factor about mental health).

It was felt that good levels of specialist support are vital, including for continued access, and people should not be discharged prematurely.

Lack of community based projects, poor levels of information & signposting and use of 'jargon' were also cited as challenges.

Prevention and Early Intervention

Common themes:

Further Training
Discussions emphasised the importance of education for new mums, children and young people, GPs and school staff. Children should be educated to understand feelings and emotions and how to manage them. There is also a need to educate the wider community so that people with mental health issues do not feel any different and can seek support (break down the taboo factor about mental health). GPs should have a broader understanding of mental health issues e.g. triggers and support needs for different conditions.

Specialist Support
Having more specialists to reduce waiting time is crucial both in terms of treatment, early intervention and prevention. Within this aspect of the service having a continued access to the healthcare professional is crucial. Not being discharged too early from treatment is important.

Community
There is a 'dearth' of projects within communities. More accessible activities are needed to combat isolation and prevent crises recurring.

Service Signposting
There needs to be better mapping of available services in local areas and a directory of services in surgeries and practices, and in the community.

Jargon
Language of othering e.g. DNA (Did not attend) and 'flow' as a synonym for patients is not helpful and should be stopped – patients who do not attend appointments may not have been able to due to factors like severe isolation and fear so more teamwork is required in ensuring patients get the correct and timely treatment.

Prevention and Early Intervention

Summary of other popular themes:

- **Role of GPs:** There was a strong view that patients with health care should be informed of any GP/s in their practice with specific knowledge of mental health.
- **Tackling Conditions Early**: An early recognition apparatus needs to be instated for particularly complex/serious cases to trigger a package of services and care as early as possible.
- **Navigating Crises**: Crisis/recovery cafes in the community that are periodically staffed with mental health and peer support workers.
- **Monitoring:** For those people who don't meet the threshold would help people who are close to crisis point. Parents and carers should be trusted more when they report their concerns about an individual.

11. Ongoing Care and Support

The ability to build relationships is considered important - a named, consistent contact (such as a care navigator) would be useful for both patients and families and volunteers could be trained to befriend and offer peer support. Carers also need greater levels of support – suggestions include drop-in centres and peer support groups.

People would also like subsidised travel, greater choice of treatment and therapies and practical support – such as assistance in applying for benefits or completing forms. It was felt that medication 'should not always be the go to approach'.

At one event, young people use the word 'frustrating' as it is felt that help 'simply isn't there' for them.

Ongoing Care and Support

Common themes:

Trusted Connections
One point of contact (such as a 'trusted' care navigator) would help with on-going care and support and this should not be the GP. There should be a process of checking up on the clients so that it is not always the client chasing up issues related to appointments and medicine needs. This would help reassuring patients who are having to wait a long time for support. Patients need more regular monitoring that is currently available.

Volunteers and Befriending
Training for volunteers on how to befriend patients taking in to account their specific needs and triggers. Volunteers should commit to regular, timetabled interactions to provide consistency and continuity and build trust with the patient.

Family Guidance
Families need guidance and support on how to negotiate and manage certain situations – there is a massive divide between what family and patient understand to be real and how to communicate.

Support for Carers
We need more support for carers who are caring for long term mental health service users. There should be support groups for carers specifically focusing on mental health. There should be drop-in centres for people particularly for males who are 50+ after the meds have been prescribed. Support should also be available via websites which would also allow people to keep in touch. Families should be involved in on-going care of patients.

Flexible Travel
Subsidised travel should be available for most ill/vulnerable.

Choice
A more diverse selection of therapies should be available, such as music therapy, exercise and laughter therapy and more investment in social prescription.

Practical Help
Further help is needed with practical tasks like filling out PIP and benefits forms. Mind provided this service in the past but it has been cut – it should be an NHS service!

Medication
Need for specialist mental health pharmacist who understands the complexities of multiple prescribing and can offer a person-centred approach as medication should not always be the go-to response.

Ongoing Care and Support

Summary of other popular themes:

- **Pro Choice:** Established specialist centres - service users and care navigators should be given option to choose centre based upon Ofsted-like ratings.
- **Improved Outreach:** Peer support workers should be available around the clock to offer support advice to patients and their families when it is needed most.
- **Practical Considerations:** The standard twelve appointments for long term mental health conditions is not enough and should be person-centred.
- **Quality of Service:** There is a concern about the quality of services in different parts of the country (postcode lottery). One person was concerned about her impending relocation to another borough whether the care and support would be continuing, who to contact and the quality of communication between the services. Shortage of staff particularly when patients are seeing different professionals has an impact on the quality of care and support.
- **Admissions:** There is a need for more long-term beds for those with mental health particularly for teenagers. There needs to be some transport support to get people home from hospital particularly when they have been referred to out of Borough hospitals. There is a need for some form of support for teenagers who have been diagnosed with mild mental health conditions.

12. How could communication and engagement be improved?

Finally, we asked people how engaged they would like to be, and whether they would like to be involved in designing new services. As part of this, we asked them which aspects of communication and engagement could be improved.

It was felt that public meetings should be well communicated, to maximise turnout. Consideration should be given to having meetings at different times in the day, including evenings, so that people can attend.

Patients also need encouragement and support to get involved in engagement – Healthwatch could be useful, particularly in raising awareness, harnessing skills and building networks.

Outcomes of meetings should be widely communicated and actions reported back – to keep people engaged.

How could communication and engagement be improved?

Common themes:

Attendance and Representation
Meetings should be 'better communicated' so that patients and carers can attend. One 'critical meeting' was not communicated adequately to the people who need it most, therefore it was poorly attended - it was suggested that Healthwatch could be a vehicle for creating awareness of meetings. Consideration should be given to having meetings at different times in the day, including evenings, so that people can attend.

Closing the 'Feedback Loop'
Outcomes of meetings should be widely communicated and actions to be reported back. Some people wanted a follow-up event where they could get feedback on how the information and ideas they came up with during the focus group was used. They want to know whether or not their feedback has reached the right people and why/why not it was taken on board.

Decision Making
Those with mental illness and supporters of better care for mental health need to be more political in their approach to influencing policy and services – these are the people that should be part of any decision that is taken.

How could communication and engagement be improved?

Summary of other popular themes:

- **Meetings:** There should be more of these types of meetings with key decision makers in attendance (commissioners, services, police and social services and other Local Authority representatives). One group suggested three monthly meetings.
- **Database:** Should be available that shows what meetings are taking place, what these are about and who is attending.
- **Patient Power:** Need to be at the centre of the treatment, more focus groups are required and advocated with lived experience – service users should be involved at every level.
- **Using Skills:** Healthwatch should utilise skills of the Discussion Group and members, capturing their expertise and using them as expert contributors in future groups and discussions.
- **Community Forum:** Healthwatch should consider creating forums open to all with access to expert advice and services and an option to add friends in need.
- **Follow-Up:** People also wanted to be included in the write-up process before the report is disseminated to make sure that it is a proper reflection of their ideas and experiences.
- **Official Representation:** Some people would like to sit on official boards and committees, to be 'genuinely involved' in decisions.

13. Case Study on Good Practice – The Solace Centre

The Solace Centre is an out of hours community service in Ealing, and regarded as a centre of good practice.

The Solace Centre

Selected statements:

- Staff treat everyone like human beings, they feel as if they are a family unit. People can discuss problems and get help from staff. It is an environment in which everyone is respected.
- It's open 365 days a year, and long hours (4pm - 7.45pm and weekends). Its open on Christmas day and the staff drive around and pick people up to bring them here for Christmas when there are no buses running to get there by yourself.
- The centre provides many services including cooking, washing. There is a book club, a women's group, a men's group, a baking group, a wellbeing group, benefits help, advice around budgeting.
- The Solace Centre has Saturday meals and discussion which people find important especially if they do not have other family. The centre is open on Christmas for people to come to.
- The service gives you "the power and means to make connections" - very important as many people have lost touch with family and friends.
- Also because they see same people, do not have to repeat their story again and again, and risk triggering.
- Several service users highlighted the woman's forum, describing it as "empowering" and "refreshing".

Glossary of Terms

CAMHS	Child and Adolescent Mental Health Services
CPN	Community Psychiatric Nurse
CWL	Central West London
IAPT	Increasing Access to Psychological Therapies
NHS	National Health Service
LTP	Long Term Plan
PALS	Patient Advice and Liaison Service
SLaM	South London and Maudsley NHS Foundation Trust
SPA	Single Point of Access

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Distribution and Comment

This report is available to the general public, and is shared with our statutory and community partners. Accessible formats are available.

If you have any comments on this report or wish to share your views and experiences, please contact us.

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“Young people with mental health issues feel life has no value.

We [the system] need to act to inspire them”.

Healthwatch official


healthwatch