Themes emerging from Healthwatch Southwark's engagement on mental health

Mental health was identified as a priority area for Healthwatch Southwark (HWS) through public and stakeholder consultation. Our evidence on this topic is collated here from the many engagement activities where people have told us about their experiences, between HWS's beginning on 1st April 2013, and 25th February 2016. It is arranged thematically, roughly following a pathway through services from access to discharge. Whilst we do hear of some very positive experiences, we naturally receive more contacts from those who are unhappy. We believe that every voice counts and even one person's negative experience needs to be addressed.

Our engagement activities

Public forums

Healthwatch holds **quarterly public forums** on different themes. At some forums, members of the public have raised mental health services spontaneously or discussed them in a more directed way:

- December 2013: Directed tabletop discussion on each of our priorities, including mental health, amongst people with experience of relevant services.
- July 2014 forum on social care: Questions and anecdotes were raised about the role of care coordinators for people with mental health difficulties.
- November 2014 update on our priorities: Several people raised the topic of discharge, including for mental health patients.
- June 2015 updates on health and social care integration: Discussions touched on mental health topics.
- September 2015 forum focused on equalities: Questions raised by the public.

Focus groups

Healthwatch runs **focus groups** with members of seldom-heard communities. Again, participants may discuss mental health issues spontaneously or after prompting:

- In discussions with Somali women and Bengali women (June 2014), both groups raised mental health spontaneously amongst more general consideration of primary and secondary care, cultural needs, and long-term conditions.
- Discussion with people aged 16-25 at a mental health support group (February 2015) focused on sexual health but also we also asked about mental wellbeing.
- Our focus group with Vietnamese and Vietnamese-Chinese mental health service users attending the Vietnamese Mental Health Services (VMHS) community organisation (October 2015) focused on different levels of mental health care.
- A carers' focus group (January 2015) touched on the impact of caring on people's own mental health.

Information and signposting service

We run an **information and signposting service**. Many queries also highlight problems with services and we receive other contacts from people who simply want to share their experiences. All contacts are logged so that we can identify themes emerging. During this period 46 contacts have mentioned mental health issues and services. Where not otherwise referenced, evidence collated below is from our signposting function.

As well as the themes discussed in detail below, we have provided assistance regarding:

- Information on where to go for mental health support, how to register with a GP in order to get help, or access mental health advocacy and legal advice
- How to access records for a mental health patient whose surgery had closed
- How to follow up on an IAPT referral into secondary care
- Contact details for CAMHS supported housing.

Engagement prior to Care Quality Commission (CQC) inspection of the South London and Maudsley Trust

Prior to the CQC's inspection of the local mental health trust, South London and Maudsley (SLaM), in September 2015, HWS collaborated with Healthwatches in other affected boroughs to **actively seek feedback from the public and patients about SLaM's services.** This included call-outs for comment via email, website and e-newletter, and visits to groups such as the Cuckoo Club (Southwark and Lambeth Mind) and the Dragon Café. The feedback was submitted to the CQC to inform inspectors' investigations.

Enter and View

HWS has the statutory right to visit publicly funded health and social care services, observe the environment and activities and talk to patients. We have conducted these 'Enter and View' visits at two mental health facilities – Aubrey Lewis 1 (March 2014) and the Snowsfield Unit (March 2015), both provided by SLaM. Reports on these visits can be found at our website here: http://healthwatchsouthwark.co.uk/reports. As they refer to very specific services, the findings of these visits are not incorporated into this report.

Timely access to appropriate services

Education, preventative and community support

People are worried that **preventative and community support** for those with mental health problems is inadequate and threatened. Some forum participants argued that cuts to services such as Mental Health Day Centres leave people vulnerable and undermine the prevention agenda.[1] An email contact agreed, saying that *"mental health and other invisible disabilities are being unfairly and disproportionately targeted"*, and that not everyone feels able to go to a statutory service. Another was concerned about support for minorities, saying funding for an advocacy project had been withdrawn 'because there is no concept of advocacy in Vietnamese culture/language.'

In a focus group with young people, 12 of the 13 participants said that young people can access mental health services without fear of judgement. However, they felt that in sex education there was an emphasis on physical health rather than 'emotional support'.[2]

Waiting times

[1] HWS public forum, June 2015
[2] Focus group with young people aged 16-25, February 2015

Concerns have often been raised about **people with mental health problems having to 'jump through a lot of hoops' and wait a long time to get support**.[3] During our engagement prior to the CQC inspection of SLaM, people raised long waiting lists to get onto developmental courses like mindfulness which were themselves seen as excellent (and the need for a good GP who could push for the patient), and long waiting times following referral to a Community Mental Health Team (CMHT). People cannot access Improving Access to Psychological Therapies (IAPT) treatment or be on its waiting list until their CMHT referral is accepted or rejected, so they may have no support and face two separate waiting periods.[4] One contact referred from practice-based counselling to Southwark Psychological Therapies Services (SPTS) had not heard anything in six months, despite his counselling being discontinued. It is felt that often people do not get support until someone gets hurt.[5]

There have also been some problems with **referrals getting 'lost' or people being unable to contact a service** about referral, and being discharged without care.[6] Patients would like to be involved and updated throughout the referral period.

Triage has been described as a 'lottery' which can miss some people with real needs.[7] Some people are **refused particular treatments** which professionals feel will not be successful, or because they are 'not sick enough' (the person reporting this later presented at A&E).[8]

Access to the right kind of talking therapies

People are particularly concerned with being **offered the right type of support, including talking therapies**. Bengali women told us they were concerned about the abundant use of medication to treat illnesses like anxiety. They felt that medication tends to make people tired, which can interfere with their responsibilities, and that talking therapy would be better.[9] Somali women with long-term conditions told us that they are keen to be offered psychological therapies to manage pain, and it would be good to have counselling provided at the GP surgery.[10] We had contact with a patient on lithium who was unhappy about not having a Community Psychiatric Nurse (CPN) – they were told by the CMHT that this was not available due to the change in government.

Even when talking therapy is offered, it is not always the right kind. Participants at one forum felt that while programmes such as IAPT were helping more people access therapy, access to more specialist help might be getting worse. They said patients were often offered short-term Cognitive Behavioural Therapy (CBT), which was described as a 'sticking plaster', and that when this was not the right approach for the individual it could be damaging.[11] Another person contacted us for help as he had been referred to group therapy at IAPT and felt this was not suitable for the issues he needed to discuss.

[3] Focus group with Somali women, June 2014
[4] Callout for evidence prior to CQC inspection of SLaM mental health trust in September 2015
[5] HWS public forum, June 2015
[6] Callout for evidence prior to CQC inspection of SLaM mental health trust in September 2015
[7] HWS public forum, December 2013
[8] Callout for evidence prior to CQC inspection of SLaM mental health trust in September 2015
[9] Focus group with Bengali women, June 2014
[10] Focus group with Somali women, June 2014
[11] HWS public forum, December 2013

May people spoke to us with high praise for the psychologists and therapists who have helped them, but it is also important that people feel able to speak up if they do not get on well with an **individual therapist**, as those who cannot engage with their practitioner will have poorer outcomes.[12]

Language barriers

Language is a particular barrier to accessing good mental health support. A Deaf forum participant told us about the impact of this: *"High numbers of Deaf people have poor mental health because of barriers they face with communication - they can't access services to talk about their problems. When their physical health gets worse, their mental health gets worse too."*[13]

At our focus group with Vietnamese/Vietnamese-Chinese mental health service users, participants agreed that language is the main barrier for them in accessing services. Even some who normally or previously spoke good English may struggle to do so when unwell or may lose the ability due to their illness.

Most of the Vietnamese-speakers we talked to had not accessed mainstream **health information**. Some had not received help until in a crisis because of this – *"no idea, no help, no contact"; "By the time you [get] it is when you're sectioned".*[14] Two people said that if the VMHS voluntary organisation was not there, they would rely on friends and word of mouth for information. Two said that it would be very difficult and that they did not know where they would be able to get information. Two said it would lead to crisis for them, *"I'm in hospital, definitely", " Hospital for an emergency".*[15]

Some **GP surgeries** are not meeting the need for interpretation. Making GP appointments was agreed to be a problem for many in the group, largely in connection with the language barrier – this has been reported in more detail in our GP access report. Interpreters were sometimes also required for **talking therapy** (as also discussed at a previous forum[16]); we did hear a couple of examples of this being provided.[17]

Pressure on care coordinators

There is some indication of mental health **care coordinators being overstretched** – one forum commentor said that coordinators do not have the time to do what they need to for people being assessed for personal budgets; another that one care coordinator failed to respond to emails and calls from a person whose mental health was deteriorating.[18]

Attitudes in primary care

Being listened to and taken seriously

[12] SLaM CQC callout
[13] HWS public forum, September 2015
[14] Focus group with Vietnamese and Vietnamese-Chinese patients, October 2015
[15] Focus group with Vietnamese and Vietnamese-Chinese patients, October 2015
[16] HWS public forum, December 2013
[17] Focus group with Vietnamese and Vietnamese-Chinese patients, October 2015
[18] HWS public forum, July 2014

People with mental health conditions do not always feel that primary care staff support them well. Whilst some people at our Vietnamese focus group felt understood by their GP, one participant told us, *"The GP doesn't have enough time to listen to our problems. I feel like they don't want people with mental health [problems]. They think we talk too much silly things, and say 'quickly, quickly'. They give medications and that's it. I feel like I don't have enough time to explain my problem…No, they don't understand."*[19]

In one discussion, 6 of 8 participants were unsure whether their GP took their emotional wellbeing seriously and 2 disagreed that they did – people said this very much depends on the individual GP.[20] One caller with mental health issues felt her GP was 'sarcastic'.

Beyond attitudes, the **set-up of GP practice** can pose challenges for those struggling with their mental health – some feel that ten-minute appointments are not enough to discuss these problems, and that the need for a long-term relationship with a named GP is not always fulfilled.[21]

All primary (and secondary) health care staff need to be aware of the impact of people's mental [ill] health – one person who waited a very long time at the foot clinic felt that staff there were unsympathetic to the impact on his anxiety and agoraphobia.

Tension between mental and physical health needs

We have had two calls from people worried about physical symptoms who **felt dismissed by their GP's focus on their mental health** and anxiety. One of these people said that she thought racial stigma was playing a role.

Medications

Discussions at one forum revealed that many **patients do not feel aware of how to manage their conditions well with medication, and about possible side effects** – the one out of eight participants who said patients *were* aware was referring only to children. People were not sure what counted as 'a good result' from psychiatric medication. The participants all felt **GPs needed more training about the drugs** and their side effects, and more communication with CMHTs about how people are getting on with their prescriptions.[22] It was suggested that pharmacists could run sessions at GP practices about this, as they do in mental health inpatient wards.

HWS has received a few contacts about **psychiatric medication errors and mistakes** – one psychiatrist prescribing the wrong medication, one medication change being missed due to the patient's GP surgery closing, and one person feeling that the GP had given her the 'wrong' medication - a foreign brand. Presumably the drug is generic but this may indicate a need for patient education.

[19] Focus group with Vietnamese and Vietnamese-Chinese patients, October 2015
[20] HWS public forum, December 2013
[21] HWS public forum, December 2013
[22] HWS public forum, December 2013

Crisis care

Crisis care was much discussed during our engagement around the CQC inspection of SLaM. The clinical care provided by the psychiatric liaison team at King's A&E was described as very good and helpful by four people who had presented there. One patient said the two doctors were *"very good and very sure of themselves"* which she needed when she was unsure herself. They also explained the process well.

However, significant unhappiness was raised around the use of A&E for mental health crisis. Common across the accounts were the long waits to be seen. Two people found it hard to sit among those who did not have a mental health crisis, and said the environment could be confusing. One person said *"the ambulance just dropped me off at the entrance hallway, nothing else"* which was daunting. A father disliked the use of police vans to escort his daughter to A&E, and the waits there, '*I was in tears the other day, watching her being escorted out of her house into the cage of a police van - the ambulance service being too busy… I didn't realize she would still be sitting in A&E ten hours later, still waiting for a bed.*

Suggestions for improving the experience of going to A&E for mental health problems included:

- Written information to be provided after A&E presentations outlining patient details, the process and next steps. Patients may not remember the detail of what happened.
- Light refreshments of food/water as people will arrive at A&E having not taken care of themselves [and this will only increase their unwellness].
- A separate space away from other patients.
- Option of a volunteer or professional advocate to sit with or talk to patients.
- All mental health patients to have clear discharge plans and crisis plans (circulated to family members as well), to help avoid A&E where possible.

Quality of inpatient care

Many people have highlighted **positive traits in staff** at Maudsley Hospital, such as empathy, attentiveness, appropriate introductions, calmness and confidence. Some families feel well-involved in their relative's care and people appreciate help with practical social matters like paying bills during their stay.

However, we have heard of problems with both **staff capacity and the personalisation and coordination of care in inpatient services**.

One person very unhappy with her care in the Maudsley Hospital (EC1) told us that staff had too little time to help – she was given only five minutes to talk to a doctor, who was not a good listener. She had no care coordinator, and felt there was no collaboration between staff. A separate caller who had been sectioned at the Maudsley said she had been given medication but had not seen a doctor in her several days there.

Reports from a voluntary organisation about the experiences of other Maudsley patients tell us that it seems often generic care plans are used, and they are not clear to patients. Also, a lack of staff capacity means people cannot always take full advantage of their leave, causing loss of contact with family and friends. (In another hospital this impacted on people's ability to exercise which may also be a problem here).

Appropriateness and safety of inpatient and supported accommodation environments

Being admitted to hospital is obviously stressful and some people find the **ward environment** can make the experience frightening and possibly harmful. A former Maudsley inpatient recounted her experience where she felt *"frightened"* on the ward and alleged she had been attacked many times by other patients.[23] We have heard from a person who found Maudsley EC1 a scary environment with verbal abuse and door slamming from other patients. Another said that the Maudsley Intensive Care Unit was an 'inappropriate environment' for her daughter, due to constant loud reggae music making her daughter feeling isolated as the only white person present. Another mother informed us of her son being given illegal drugs by other patients in Maudsley AL3.

Relatives of patients in Maudsley AL3 said that the inside garden was *"neglected, with dead plants and rubbish"* which was interpreted this as implying the inpatients' *"life was less valued"*. However, the activity room at this ward was praised as helping take the pressure off relatives and giving families a place to spend time together.[24]

We also heard from a previously homeless person with mental health difficulties who found the environment in his **supported accommodation** (for people with mental health or substance misuse problems) very distressing. He said he was surrounded by drugs and alcohol and felt it was bad for him.

The Mental Health Act, Deprivation of Liberty, and restraint

Fears as an inpatient can be exacerbated by the actions of staff, who may need to use **restraint**. One contact was upset at nurses allegedly shouting, throwing her on the bed, twisting her arms and holding her wrists tightly enough to leave bruises for two weeks.

A voluntary organisation has also told us that there is inconsistent practice on hospital wards with not all staff aware of patients' rights under the **Mental Health Act**. As mentioned above, a patient who had been sectioned was unhappy at being prescribed medication and not having seen a doctor. The patient unhappy with the use of restraint said that her sectioning kept being extended, but that she and her family didn't know why. Communication with patients on this matter is very important.

Discharge and ongoing support

[23] Callout for evidence prior to CQC inspection of SLaM mental health trust in September 2015
[24] Callout for evidence prior to CQC inspection of SLaM mental health trust in September 2015

In one forum discussion, discharge was recognised as an crucial period. It is important to look at how **carers are involved** at the point of discharge.[25] We have heard cases which indicate possible failings in **risk assessments** and in **aftercare**.

Discharge from hospital

During engagement around CQC inspection, a family told us that their relative with schizophrenia was inappropriately discharged from Maudsley Hospital in 2012 without them being informed. Another family said that when their son was transferred from the Maudsley to Ladywell Unit, there was little information or willingness to involve relatives.[26] Three individuals also contacted us independently about issues around their discharge from Maudsley Hospital AL3. One had not had their records sent to their GP and so could not be prescribed medication; one had had a discharge meeting without an advocate/friend present; another implied that if discharged he intended to kill himself as he was not ready to leave but was not being listened to (it appears his stay was extended).

Discharge from the Community Mental Health Team (CMHT)

A distressed and possibly suicidal person contacted us about his discharge from the CMHT in Camberwell as he had missed an appointment for which he had not had the invitation in time. He felt 'I am crying for help and no one is helping me'. We confirmed that he had been discharged but the team agreed to contact him for further support.

Support after discharge from hospital or the CMHT

We have heard from a voluntary organisation that many service users do not have enough support after discharge from hospital, and return on a regular basis. Some people have complained of abrupt discharge from the CMHT, lack of clarity about post-discharge support (and long waits) and time-limited interventions without any follow up.[27] One person told us that after discharge from the CMHT she had been waiting a month so far for contact from the Wellbeing Hub.[28] Support needs to be in place before discharge and stepped down gradually to ensure patients can remain stable. Those who have received support from community care nurses and the Home Treatment Team often say this is very helpful, with staff listening to them and helping with social issues.

Integration and coordination across services

Our engagement work prior to the CQC inspection of SLaM highlighted that patients find it stressful and frustrating to have to **repeat information and assessments** when accessing different services. More coordination across local services would help with this issue. One father told us his daughter had presented to services from St Thomas' A&E to triage wards in Lambeth, Bethlem and Bromley, to inpatient wards in Lambeth and Maudsley, to the local home treatment team – each involving a new assessment. It was confusing in terms of who to call, and highlighted **fragmented and siloed working**

[25] HWS public forum, November 2014
[26] Callout for evidence prior to CQC inspection of SLaM mental health trust in September 2015
[27] Callout for evidence prior to CQC inspection of SLaM mental health trust in September 2015
[28] Focus group with Vietnamese and Vietnamese-Chinese people with mental health difficulties, October 2015

structures. We raised in our response to SLaM's Quality Accounts 2015 the lack of consistency of service across the four boroughs where SLaM operates.

Transitions from children's to adults' services

During our engagement work prior to the CQC inspection, transitions between child and adult services were consistently raised as an issue. The treatment and environment for children and adults is significantly different and there is a lot of understanding and trust to be rebuilt after transition. Relatives and patients highlighted a lack of robust handovers and became less confident in the care received as an adult.[29]

Privacy and confidentiality

Given the stigma that still surrounds mental illness, **privacy and confidentiality** for patients is particularly important. We have been informed of two concerns about this, with one visitor to King's College Hospital having overheard someone's mental health assessment taking place at ward level, and one woman's GP having passed information about her mental health to housing officers.

Cultural understandings of mental illness

Understanding and interpretations of mental ill-health vary across Southwark's diverse cultural groups and this needs to be recognised in order to provide appropriate help.[30]

Stigma around mental illness

Participants at some of our focus groups recognised that their cultures traditionally placed stigma on mental illness: *"In Vietnam there is bad talk about people with mental health [problems]. They don't want to believe what you say. They laugh behind you"; "We don't like to talk to strangers about our problems such as marriage problems"*[31] Stigma can take many dimensions – for example Somali women told us that mental illness may cause someone's faith to be questioned, and that they are expected to suppress postnatal depression due to a cultural image of the 'strong Somali woman.'[32]

Impact of culture on mental health treatment outcomes

People's cultural background also influences their approach to self-help and their experiences of treatment. One Somali woman told us that she considered reading the Qur'an to be 'psychological therapy'.[33] At our focus group with Vietnamese/Vietnamese-Chinese service users, many said that they felt understood and some appreciated the

[29] Callout for evidence prior to CQC inspection of SLaM mental health trust in September 2015
[30] HWS public forum, December 2013
[31] Focus group with Vietnamese and Vietnamese-Chinese people with mental health difficulties, October 2015
[32] Focus group with Somali women, June 2014
[33] Focus group with Somali women, June 2014

regular support provided by their CMHT.[34] However another participant in the same group felt strongly that they were not understood by white British professionals: *"I don't think they understand our religious background and problems... They give medication that doesn't work; I need Vietnamese medication…They are understanding, yes, but not for mental health. They can't just section us for months when they don't understand our beliefs…I don't want to be sectioned, I want to be among Vietnamese people. They know a Muslim needs a prayer mat and to pray [but]…they don't understand my religious needs."*[35] This person said that people's experiences as refugees impacted on the way they needed to be treated. He wanted more people from ethnic minorities to be trained as mental health staff in order to help their communities.

Consultation and complaints

Healthwatch aims to promote the public voice, and sometimes people do not feel they have been **listened to**. There has been recent widespread concern about the closure of voluntary-sector-run mental health services and day centres and their replacement with a Wellbeing Hub, as described above. Some feel that the changes were made too rapidly and without consultation, and announced in a way that would shock many vulnerable people relying on the services. We have also heard from a person who complained to SLaM but the complaint was not accepted as it did not contain the word 'formal'; after being resent no response had been received within 28 days.

Social causes and exacerbators of poor mental health

Whilst we are not able to delve deeply into the social and root causes of mental ill health, members of the public are concerned that these are addressed – we have heard particularly about the impact of housing problems, difficulties with finances and benefits, the experiences of refugees, and digital exclusion.[36]

Some root causes of mental ill health can be addressed within the health and social care system itself. A forum attendee questioned how much **education about mental health and drugs was provided in schools**.[37] Discussion at a focus group highlighted that carers' health and wellbeing can suffer greatly due to the overwhelming **pressure of caring and lack of time**.[38] We have received three contacts from people whose **poor experiences in maternity and obstetric care** had led to mental health deterioration. This is a pertinent issue especially given the increased focus on perinatal mental health.

[34] Focus group with Vietnamese and Vietnamese-Chinese people with mental health difficulties, October 2015
[35] Focus group with Vietnamese and Vietnamese-Chinese people with mental health difficulties, October 2015
[36] Focus group with Vietnamese and Vietnamese-Chinese people with mental health difficulties, October 2015
[37] HWS public forum, September 2015
[38] Focus group with carers, January 2015