

## Medication and mental health recovery



Tower Hamlets peer led survey of mental health user views of medication.



Healthwatch Tower Hamlets is an independent organisation led by local volunteers. It is part of a national network of Healthwatch organisations that involve people of all ages and all sections of the community.

The Healthwatch Tower Hamlets Mental Health Task Group encourages proactive engagement of those that use mental health services in influencing their quality and commissioning. It provides a space for people to hear about the differing experiences of service users and discuss what is working or not so well. It is run on the principles of co-production and providers' work alongside users to improve services and outcomes for local people.

[www.healthwatchtowerhamlets.co.uk](http://www.healthwatchtowerhamlets.co.uk)

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## Executive Summary

Healthwatch Tower Hamlets surveyed over a hundred mental health service users between October and November 2016.

Overall service users gave very positive feedback on medication. The majority of people surveyed seemed happy with their current medication. They felt that medication is necessary and beneficial for them and allows them to function on a day to day basis. It gives them control over their life and without it they could relapse and their mental health worsen.

Although most of the service users felt that medication was necessary to maintain their mental wellbeing for day to day functioning, they also felt that an holistic approach to recovery should be proactively promoted by health professionals. This could include recovery support such as talking and complementary therapy (yoga, massage etc.); physical activity and sport; work and volunteering opportunities; and involvement in social and group activities. Medication is an important part of a range of support and coping mechanisms.

Most service user cited 'side effects' of medication as their main concern with medications.

Weight gain, feeling lethargic, drowsy and sleepy were generally reported as the most common side effects of taking medication. These side effects can have a huge impact on service user's ability to lead a normal life.

Most service users said they feel comfortable talking to a mental health professional about their medication and that mental health professionals listen to their needs. Most of the people that approached a mental health professional in

relation to concerns around side effects of medication said that they were offered alternative medicines or help to deal with the side effects.

Service users feel that mental health professionals, GPs and Pharmacists should proactively provide better information on the side effects of medication and offer help and advice around it.

We recommend that:

1. GPs, mental health professionals and pharmacists work together more effectively to explain and manage the common side effects of medication to mental health users and to signpost them to reliable sources of further information.
2. That mental health service providers monitor user feedback on their experience and side effects and these are reviewed for improvement.
3. Mental health professionals proactively offer information and access to other sources of therapeutic recovery, exercise and social activities available in the community (better signposting to services).
4. Community pharmacists have the opportunity to improve their knowledge and skills in dealing with the side effects of mental health medication and to signpost to other services.
5. Consideration is given to developing community pharmacists with a specialist knowledge of mental health and mental health medication.
6. Health professionals and community pharmacists visit community groups and community centres to talk about medications and their side effects.

7. More proactive support is offered to mental health users to tackle weight gain such as exercise and sports activities and weight loss groups.
8. Mental health users are supported to develop and lead their own sports and physical health programmes e.g. yoga, tai chi, football, walking, Pilates etc.
9. Mental health users are specifically considered as part of the local authority's sports and physical activity strategy.
10. A collaborative quality improvement group is established with mental health users to look at how the management of side effects of medication can be improved. .

## Why we undertook the project

Our aim was to find out how service users felt about their medication and the positive or negative impacts that it had on their quality of life and their recovery. And to present those views to mental health commissioners and providers in order to improve services and outcomes for users.

The Healthwatch Tower Hamlets Mental Health Task Group held a number of workshops with users and stakeholders to identify potential project areas for in-depth work to understand the needs and views of mental health. They identified medication as a potential area as some felt that mental health professionals prefer prescribing medication as opposed to other forms of treatment that can assist service users in the recovery process.

User members commented that their medication can:

- make them feel lethargic to the point that they don't feel like doing anything;
- make them gain so much weight they no longer recognise themselves; and
- reduce their sex drive

As these views cannot be generalised members suggested that Healthwatch undertake a survey with a wider range of mental health service users to gather their views on medication.

## How we undertook the project

### Working Group

A service user led working group consisting of eight Mental Health Task Group members met regularly to decide:

- the key issues around medication and areas to consider in data collection;
- how feedback should be collected;
- how many service users should be engaged;
- where to gather the information;
- the questions and format of the questionnaire; and
- how to make sure the information would have an impact.

### Questionnaire

The Working Group agreed that service user feedback would best be collected using a **questionnaire** combining closed and open ended questions (see Appendix 1). The questions were **coproduced** by service users and mental health professionals from East London NHS Foundation Trust.

A **pilot outreach session** with six service users at Pritchard's Road Day Centre was used to test the questions (key concerns were: length of time to complete the survey, if questions were easy to answer or relevant). Feedback resulted in additional questions being added to the survey, the language of questions being simplified and additional response boxes being added.

### Recruitment

Participants were engaged through existing voluntary, community and statutory mental health service providers and groups including:

- Inpatient wards at Tower Hamlets Centre for Mental Health (Mile End Hospital)

- Community Mental Health Teams (Bow, Poplar, Stepney and Wapping)
- Pritchard's Road Day Centre (Bengali Men's Group, World Mental Health Day, Drop in sessions)
- Mind in Tower Hamlets and Newham (Somali Group, Bengali Men's Group)
- Bow Haven (Kushi Group)
- Look Ahead (World Mental Health Day, Look Ahead Support staff completing surveys with their clients)

As a small peer led piece of engagement 'Sampling' methods were not practical. The key selection criteria was service users that had had experience of medication in the last 12 months.

### Peer Led

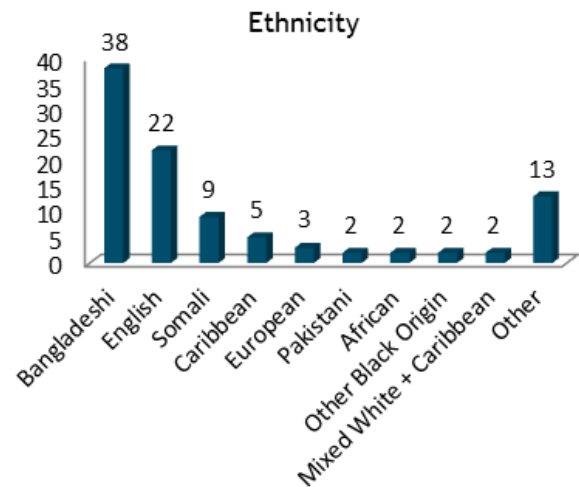
The Working Group agreed that members of the Mental Health Task Group, the Working Group and other Healthwatch volunteers should be given the opportunity to lead the engagement and survey work. This allowed the work to be peer led and provided training and skills development for members. It was agreed to offer an incentive of a £20 gift voucher and training and skills development. Overall 10 volunteers undertook the fieldwork.

### Limitations

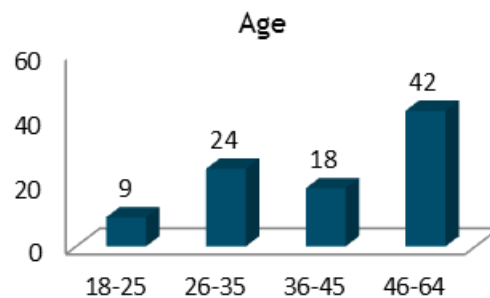
The venues in which the surveys were conducted mean that participants may have tended to be more psychotic and to have a higher appreciation of the benefits of medication. Being interviewed in a service provider may also have influenced them to be more positive about the treatment they were receiving.

### Who we talked to

We surveyed 105 service users between October and November 2016. 62 of the respondents were male, 36 were female and one was transgendered. The ethnicity of respondents was largely Bangladeshi (38%) and White English (22%), with members of the Somali community (9.2%) the third highest.



84.8% of service users were surveyed in community settings and the remaining 15.2% service users were surveyed at the different inpatient wards at the Tower Hamlets Centre for Mental Health (Mile End Hospital). It was difficult to ensure that the survey feedback was representative of the community in terms of age, as we did not have capacity (resources and staffing) or opportunities (established networks) to reach out to older people and young people within the timeframe of this work. The survey was essentially carried out with service users categorised as 'Adults of Working Age'.



The period over which participants had been taking medication for their mental health ranged from within the last six months to over 30 years.

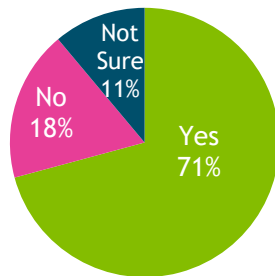
### Key Findings

#### Views on medication

Contrary to the perceived negative experience of medication raised by the

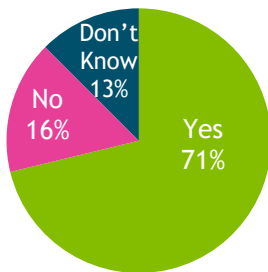
Mental Health Task Group the majority of health medication and felt that it had improved their quality of life.

Are you happy with your current mental health medication?



The majority of respondents were happy with their medication and believed that it improved their **quality of life**.

Do you think your mental health medication has improved your quality of life?



### Positive impact of medication

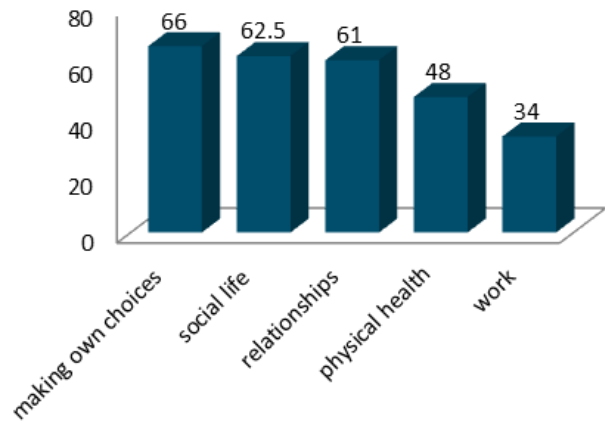
Respondents were asked to select survey response scales (e.g. very positive, very negative) on the **impact of medication** on aspects of their life.

Overall the majority of respondents believed their mental health medication has had a **positive** or a **very positive** impact on relationships, social life and their ability to make own choices.

The impact on **'physical health'** was not as clear cut with a substantial number of respondents (30%) feeling that medicine

service users were happy with their mental

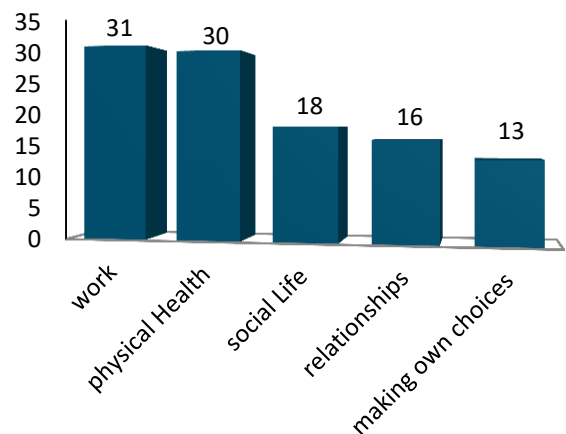
### Positive or very positive impact



had had a **negative** or **very negative** impact on their health.

The impact of medication on **work** received a more varied response, 34% felt it was positive or very positive, 31% said the impact was either negative or very negative and 33% was neutral. Some respondents commented that taking the medication allowed them to live a normal life and hence they could go to work, others commented that the **side effects** of their medication and their current mental state would not allow them to go to work.

### Negative or very negative impact



*'I can work, as it takes away the aggression and helps me to relax.'*



*'medicine is necessary, but I don't feel happy, the medicine makes me tired and lethargic...I have to force myself to work...working is good, if I did not work I would feel worse.*

The 'neutral' respondents said that they could not comment on this as they were not able to work due to their mental health.

Overall there were 88 qualitative comments in response to the question of whether medication had improve life quality with 74 of them being positive.

The most common benefit mentioned was that it improved their **sleep**

*It helped cure my insomnia and I experience less up and downs in my mood. It makes me better able to function.*

*Makes me feel relaxed and calm. I have control of my life, more focus. I can tell if I am becoming unwell. It keeps me well, it helps me sleep at night..I wake up in the morning and I feel happy.*

Many also commented that it helped them to feel **calm and relaxed** which improved their relationships

*My mood is better, It makes me more calm and relaxed...I don't feel hyper.*

*If I don't take my medication I am more violent and angry toward my family plus I talk too much when I take my medication it improved my quality of life and I am more happier.*

*I feel far less stressed.*

It also enabled them to feel a greater **stability** which enabled them to manage their lives better.

*It stabilizes my mood; I am able to function on a day to day basis*

*It has made me stable and kept me well and better.*

*It keeps my mind stable, if I don't take it I might end up in A&E. the medicine allows me get around and maintain a normal life.*

Another key benefit was that it made want to get out and **socialise** which had additionally benefits for their mental health.

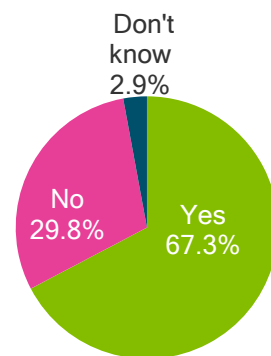
*Stops me from depression. I can go out, can socialise.*

*I am feeling better, talking more, getting involved with other people.*

*My mood is better, I get out more, and I am more sociable*

## Side Effects

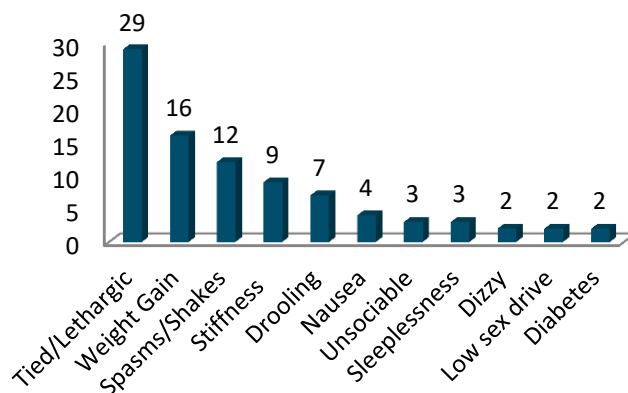
Have experienced side effects from mental health medication



NB: 104 people answered this question, 1 skipped.

The majority of respondents said that they had experienced side effects as a result of taking their prescribed medications. There were 71 qualitative comments in response to this question. They broke down into these general areas.

## Side effects



By far the most common side effect was feeling very tied and lethargic often combined with increased appetite and weight gain.

*I sleep a lot, I can't stop eating. I have put on 5 stones.*

*I sleep too much. I can't study or work due to this tiredness.*

*It makes me sleepy and drowsy. I cannot concentrate on day to day things sometimes.*

*It has increased my appetite and I have excessive saliva during sleep.*

It was also common for people to experience shakes or spasms or conversely stiffness.

*The only problem I have with my medication is shaking all the time all day long. I get some rest but not much.*

*This is very stressful for me, the side effects is getting bad the first medicine prescribed had lots of side effects e.g. my arms get stiff, my legs use to twitch. I felt restless and tired. I was also bloated*

*My hands shake or become stiff and I experience dribbling.*

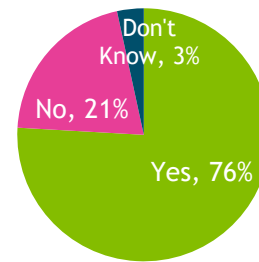
*I suffer from stiffness, unrewarding sensation, drowsiness and erectile dysfunction.*

Volunteers undertaking the survey had the impression (through discussion) that the side effects are service users biggest concern with mental health medication. However, **30%** (31 respondents) said that they have not experienced any side effects, this highlights that not everyone's reaction to medication is the same. It should be noted that the sample included service users who had taken a range of different medications for different times.

It is important to highlight that the majority of the participants (**74%**) that said they experienced side effects also said that they either approached a mental health professional or a GP to discuss the side effects of their medication.

The majority of these participants also commented that once the side effect issues were raised with the relevant doctor/consultant, they were offered a change of medication, offered side effect medication or were provided advice to help overcome the side effects (e.g. physical exercise).

Concerns about medication or side effects were listened to by mental health professional.



A few mentioned that the doctors and consultants did not listen to their concern or that the advice and alternatives offered did not help, but the overall feedback was positive.

*'They changed the medication, the new medication is ok, it has not given any side effects. it makes me feel normal'*

*'They let you talk about it and change it. I have changed my medication a few times'*

*'The doctor reviewed the medication and changed it to ensure the dosage is right for me'*

**NB:** This question was only answered by people that said they experienced side effects, **58** people responded to this question

## Health Professionals

Overall **75%** of respondents said that they feel mental health professional **listened** to their concern about their medication and its side effects once they had been raised. However, **20%**, said that their mental health professional did not listen to their concerns.

**61.5%** of respondents said that they were told about the possible side effects of their mental health medication when they were first prescribed it by their **doctor/consultant**. However, **30.8%** said that they were not told about the side effects of their mental health medication by their doctor. The percentage of people not being informed about the possible side effects seems quite high. Informal discussions with service users suggested that a majority would prefer that doctors always inform them of possible side effects



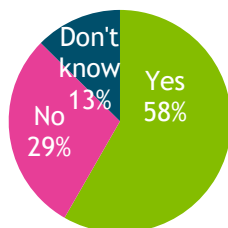
at the initial stages of prescription and that they let them know what actions to take if this happens. This should be standard protocol.

It is also important to highlight that a substantial majority of respondents (83%) said that they felt **comfortable** talking about their medication with their doctor or consultant. This could suggest that service users and consultant/doctors have an established relationship that allows service users to express themselves and be confident around them. From discussions with some respondents, it appeared that they are also not afraid to ask questions or challenge the doctor/consultants if necessary.

We asked whether **Community Pharmacists** provided information on medication and its side effects when dispensing. **57%** said that Community Pharmacists **did not** tell them about the possible side effects of the medications they were being prescribed. On a slightly more positive note, **33%** said community pharmacists **did** inform them of the possible side effects of their medication. On the whole service users felt that Community Pharmacist should do their best to always educate mental health service users about their medication and its side effects and always inform them what actions to take if the side effects occur and persists.

## Other support

Do you feel medication is the best option to help with your recovery?



The respondents that said 'No' (29.1%) to this question were asked to **tell us what other option (s) would best suit them and why**. The majority of their feedback was centered on being able to receive a more holistic approach to recovery, which

includes being offered other opportunities such as sports, therapy, complementary therapy/ medication, better social life opportunities, work or volunteering opportunities.

*Complimentary medication CBT, Quiet Meditation, Yoga*

*I think new friends will help, better social life, someone to support me like a support worker...It's something I need to do to change my life.*

*Holistic approach is the best way. Sport therapy is the best for me. I am not shut in, I am out on the open playing football, I am able to see the world.*

*Holistic approach is the best way plus activities to get me moving. I am being held down by medication, medication everything is medication.*

*I would rather see somebody and talk about my condition rather than take the medication*

*I feel that I can look at other areas of my life and take a holistic approach in order to improve my mental health. For example, if I were to get a job, it would increase my self-esteem and therefore improve my mental health.*

*Support from other people is important, I get a lot of support from my support worker at Look Ahead. Also praying helps.*

Respondents who did not feel medication was the best option mostly cited the **side effects** as the reason:

*'I am sleepy all the time'*

*'The medication makes me feel very sick, weak and dizzy'*

*'It's too strong and it makes me ill such as tired and slow'*

*'The medication changed me. I became someone who I never knew before'*

The survey asked service users if mental health professionals offered them other forms of therapy or support in addition to being prescribed medication. e.g. talking therapy, CBT, or referral to social, community, sport or exercise groups. Almost 55% of respondents (56 people) said

they were not offered any other forms of support or treatment when first prescribed medication. There was a large number however, at 38% (39 people) that were offered alternative means of support or treatment. This ranged from being referred to talking therapies, counselling, mindfulness, CBT, and group activities. Most respondents that received other support or treatment in addition to medication found this support very helpful. One service user said that receiving different support in addition to medication helped them a lot. The general feeling from the majority was that providing alternative support in addition to medication is necessary and important to recovery.

## Physical Health

On a very positive note the majority of respondents (88%) said that GPs and Psychiatrist asked about their **physical health**, this is important as there have been concerns that GPs and mental health professionals can neglect asking about physical health to mental health patients. To validate this further it would have been useful to ask the respondents when they last did a physical health check, unfortunately this question was not included in the survey.



## Summary

Overall service users gave very positive feedback on medication. The majority of people surveyed seemed happy with their current medication. They felt that medication is necessary and beneficial for them and allows them to function on a day to day basis. It gives them control over their life and without it they could relapse and their mental health worsen.

*'I used to be afraid to leave bed in the morning because when I walked around I thought that someone was following me.'*

*Since being on the medication for a while now, I have been doing things that I haven't been able to do in a long time like going places and meeting people and being more social. This gives me the feeling of empowerment, that I have control over my mental illness with the help of my medication, and strength that I am able to do the things I love, like dance.'*

Although most of the service users felt that medication was necessary to maintain their mental wellbeing for day to day functioning, they also felt that a holistic approach to recovery should be proactively promoted by health professionals. This could include recovery support such as talking and complementary therapy (yoga, massage etc.); physical activity and sport; work and volunteering opportunities; and involvement in social and group activities. Medication is an important part of a range of support and coping mechanisms.

*Less medication and more holistic approach is much healthier for me. The consultant needs to look at each patient and treat them differently'*

*The holistic approach is the best one for me because I have physical illness as well as a mental illness. Doing things that make me feel good such as listening to music and watching movies. They should look at other things besides medication. A more holistic approach than a medication one'*

Most service users cited 'side effects' of medication as their main concern with medications.

Weight gain, feeling lethargic, drowsy and sleepy were generally reported as the most common side effects of taking medication. These side effects can have a huge impact on service user's ability to lead a normal life.

Most service users said they feel comfortable talking to a mental health professional about their medication and that mental health professionals listen to their needs. Most of the people that approached a mental health professional in relation to concerns around side effects of medication said that they were offered alternative medicines or help to deal with the side effects.

Service users feel that mental health professionals, GPs and Pharmacists should proactively provide better information on the side effects of medication and offer help and advice around it.

## Recommendations

We recommend:

1. GPs, mental health professionals and pharmacists work together more effectively to explain and manage the common side effects of medication to mental health users and to signpost them to reliable sources of further information.
2. That mental health service providers monitor user feedback on their experience and side effects and these are reviewed for improvement.
3. Mental health professionals proactively offer information and access to other sources of therapeutic recovery, exercise and social activities available in the community (better signposting to services).
4. Community pharmacists have the opportunity to improve their knowledge and skills in dealing with the side effects of mental health medication and to signpost to other services.
5. Consideration is given to developing community pharmacists with a specialist knowledge of mental health and mental health medication.
6. Health professionals and community pharmacists visit community groups and community centres to talk about medications and their side effects.
7. More proactive support is offered to mental health users to tackle weight gain such as exercise and sports activities and weight loss groups.
8. Mental health users are supported to develop and lead their own sports and physical health programmes e.g. yoga, tai chi, football, walking, Pilates etc.
9. Mental health users are specifically considered as part of the local authority's sports and physical activity strategy.
10. A collaborative quality improvement group is established with mental health users to look at how the management of side effects of medication can be improved.

# Appendix 1

## MHTG Medication Survey

### About the Project

Healthwatch Tower Hamlets is gathering mental health service users feedback on the 'medication' they take for their mental health. Healthwatch Tower Hamlets would like to present the findings of the survey to key stakeholders such as a mental health professionals.

We would appreciate if you can share your feedback. The information you provide will be treated as confidential.

**NB: In order to take part in this survey you must be taking medication for mental health or have done so in last few years.**

1. Source of outreach session

Community

Inpatient

## MHTG Medication Survey

### Section 1: Your Feedback on Health Services

2. How long (months; years) have you been taking medication for your mental health?

3. Who prescribed your medication for your mental health at first instance? (Please select one of the choices below)

Hospital

RAID Team/ A&E

GP

Can't Remember

Psychiatrist

4. Are you happy with your current mental health medication?

Yes

No

Not Sure

5. If you have answered 'No', please tell us why are you not happy with your medication ?

6. Do you think your mental health medication has improved your quality of life?

- Yes
- No
- Don't Know

Please tell us why?

7. How much of an impact has Psychiatric/mental health medications had on the following aspects of your life?

	Very Positive	Positive	Very Negative	Negative	Neutral
Relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social Life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical Health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ability to make own choices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

8. Have you experienced any 'side effects' as a result of taking medications for your mental health?

- Yes
- No
- Don't Know

If you have answered yes, please tell us the side effects you experience and how this impacts on your daily routine.

9. If you have suffered any side effects of medication, have you approached anyone for help?

- Yes
- No
- Don't Know

10. Who did you approach for help? (only answer if you said 'Yes' on Q8)

- Mental Health Professional
- GP
- Pharmacist
- Family/Friends
- Support Workers in community services

11. If you have asked for help in relation to 'side effects', what was the outcome? e.g. change of medication,

12. If you have raised any concerns about your medication or its side effects with a mental health professional (e.g. Psychiatrist, Care co-ordinator) , do you feel they listened to your concerns

- Yes
- No
- Don't Know

13. Do you feel 'confident' about asking questions about your mental health medications to doctors generally or Psychiatrist?

- Yes
- No
- Don't Know

If you have answered no, please tell us why?

14. When you were prescribed your current medication, did the doctor/consultant provide you information about any possible 'side effects' of the medication?

- Yes
- No
- Don't Know

15. When you collected your recent supply of medications from the pharmacy, did the pharmacist explain any possible side effects of the medications?

- Yes
- No
- Don't Know



16. When you were first prescribed medication, were you also offered others forms of support/treatment (e.g. CBT) in addition to being prescribed medication?

- Yes  
 No  
 Don't Know

If yes, please tell us what other therapy or support you were offered?

17. Are you asked about your 'physical health' when you come in contact with your GP, mental health professional/ Psychiatrist ?

- Yes  
 No  
 Don't Know

18. Do you feel medication is the only best option to help with your recovery?

- Yes  
 No  
 Don't Know

If you have answered 'No', please tell us what other option (s) would best suit you and why?

19. Please use the box below to provide your other comments/views on your mental health medication (anything not covered in questions above).

## MHTG Medication Survey

### Demographic Data

#### Equalities Information (Optional)

20. Do you live in Tower Hamlets?

- Yes                       No                       I'd prefer not to say

21. What gender are you? (Please tick)

- Female                       Male                       Transgender

22. What is your age group?

- 18-25  
 26-35  
 36-45  
 46-64  
 65+

23. What is your sexuality?

- Heterosexual (Straight)  
 Bisexual  
 Homosexual (Gay)  
 Homosexual (Lesbian)

24. Do you have any disability?

- None  
 Mental Health  
 Learning disability  
 Physical disability  
 Long term health conditions  
 Sensory Impairment  
 I'd prefer not to say  
 Other (please specify)

25. Please choose which specific ethnicity you identify with

- |  |  |  |
|--|--|--|
| <input type="radio"/> English                | <input type="radio"/> Pakistani          | <input type="radio"/> Mixed White + Asian              |
| <input type="radio"/> Irish                  | <input type="radio"/> Chinese            | <input type="radio"/> Mixed White + African            |
| <input type="radio"/> Scottish               | <input type="radio"/> Vietnamese         | <input type="radio"/> Mixed White + Caribbean          |
| <input type="radio"/> Welsh                  | <input type="radio"/> African            | <input type="radio"/> Mixed white & other black origin |
| <input type="radio"/> European               | <input type="radio"/> Caribbean          | <input type="radio"/> Mixed white & other              |
| <input type="radio"/> Bangladeshi            | <input type="radio"/> Somali             | <input type="radio"/> Rather not say                   |
| <input type="radio"/> Indian                 | <input type="radio"/> Other Black Origin |  |
| <input type="radio"/> Other (please specify) |  |  |

This project was developed and the interviews conducted by Healthwatch Tower Hamlets Mental Health Task Group volunteers. We would like to thank all them for giving up hours of their valuable time to undertake this important work.

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