



# Open Public Services Network & Mind

## Mental Health Data focus group

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## Background

The Open Public Services Network (OPSN) approached Mind when they started working on a project to make publically available data around mental health care and outcomes accessible to people with lived experience of a mental health problem. They had identified that despite there being universal agreement that the best care should be patient centric, openly available health data indicates that patients with mild, moderate and severe mental health concerns alike are not provided equal access to care across the country. In particular, there are vast differences in physical health screenings, GP prescribing behaviours, access to IAPT and finally, patient preferences dictating care pathways

OPSN intended to help service users access and interpret information that would potentially mean they could take more control of their care pathway. It was important to them that the data be presented in a user friendly way in order to ensure it was accessible, meaningful and could lead to people taking more control of their care. The OPSN were planning on embedding this data in a website where people across the country could input their postcode and understand how care in their area relates to other care across the country.

Mind believes that people with lived experience of mental health problems should have the opportunity to influence and guide work that affects them. To this end Mind recommended a series of engagement<sup>1</sup> events to help the OPSN understand the perspective of people with lived experience in order to better analyse and present the data in the way which would be accessible and informative.

## Engagement activity

Mind carried out two focus groups bringing together people from across the country who have lived experience of mental health problems and also used paper information and / or the internet to find out more about their health and services they could access.

Focus groups were held in London and Birmingham, the locations where chosen in order to provide as wide a group of people as possible the opportunity to take part without having to travel vast distances. Participant selection was based on experiences, gender, location, internet access as well as other demographic information. This gave us the opportunity to hear a broad range of views so that themes could be drawn to give guidance during the development of the website.

The groups lasted three hours and explored the following:

- Participants' views on the areas / topics where mental health data is being analysed for this project
- What participants felt they would do with information nature
- What areas participants felt have been missed and why

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<sup>1</sup> Mind defines Engagement as: 'The active participation of a diverse range of people with experience of mental health problems in Mind's governance, strategic and operational activities and in shaping the development of the organisation.'



- Define how the information being analysed by ZPB / OPSN could be presented

Our discussions were structured around the areas OPSN were analysing data in and were presented using the following questions / headings.

1. How well do GPs look after physical health when I have a mental health diagnosis?
2. Psychological Therapies
3. Prescribing of anti-depressants
4. Living well with your conditions

What follows is the write up of both focus groups including all insights drawn from the feedback. This report was made available to OPSN before development of the website started to ensure all work designing and structuring this was guided by the feedback received.



## Open Public Services Network – Mental Health Data focus group write up

Birmingham = Blue      London = Dark green

### What is Information?

**Signposting** – indicating access to where you can get more information

**Old** – 2/3 years out of date is not helpful

**Quality** – updated, relevant, accessible

**Accessible means** – Plain language, comprehensive but not overly academic, clear direction, done differently for different audiences, format is important, translatable is also important whether in print, online or by family members. Language needs to be kept straightforward to allow this.

**Propaganda** – set out to mislead or make people fail. This is not helpful. It's not easy to identify when information is of this nature.

Information comes from many different perspectives

Information comes in a wide variety of formats including written, printed, online, pictorial, slides, graphs and videos. It's important to use a variety of these as this makes information more interesting and easier to understand.

Contains facts; but not too many that can be overwhelming.

Easy to follow, engaging, relevant, useful, focused

Relevant to individual

Description of what you're looking for

Signposts you to other places

Takes you in a new direction

Knowledge

Guidance

Never ending – infinite

Makes you more aware

It's a form of advice

Method to inform self and others

Words / figures / pictures

Dynamic – Moving and changing (or it should be!!)

Educational

Only as good as the person giving it

Journals / Research

Propaganda

Form of learning

Find pros & cons

Primary and secondary information

Information changes depending on where it's from – source is important

People can perceive it differently

Evidence based

Where has the information come from?

Information can be formal or informal

Can be overwhelming when there's too much to take in or presentation is bad

What makes information helpful or unhelpful?

Helpful	Unhelpful
<p>Clarity x3</p> <p>Avoid jargon especially medical x2</p> <p>Charts – distribution in % with comparisons</p> <p>Video format with audio x2</p> <p>Up to date; includes publication date</p> <p>Publication source is included = credibility</p> <p>Face to face</p> <p>Self-help groups and information</p> <p>Mind information</p> <p>Straightforward layout x2 paper &amp; online</p> <p>Bullet points or short statements</p> <p>Signpost to charities etc.</p> <p>Easy read x2</p> <p>Presentation is clear and interesting</p> <p>Relatable – to my situation</p> <ul style="list-style-type: none"> <li>- Can pass to friends / family</li> <li>- Actionable easily – do something with</li> </ul> <p>Practical – gives tasks or other places to go for more information</p> <p>Free x4</p> <p>Independent – reputable – Trusted</p> <p>States where information has come from</p> <p>Advice that comes recommended</p> <p>Interactive</p> <p>Multi-lingual at the click of a button</p>	<p>Too much jargon or academic wording</p> <p>Information overload</p> <p>Biased information – prejudiced, inflammatory, stigmatising, discriminatory, full of stereotypes</p> <p>Out of date information</p> <p>Poor layout</p> <p>Limited formats</p> <p>Propaganda</p> <p>Irrelevant information or information that requires decoding to understand</p> <p>Complicated presentation</p> <p>Large chunks of text</p> <p>Misleading pictures</p> <p>Cost to access</p>

Simplicity  
 Transparency  
 Accessibility – Language, Individual needs,  
 Choice of words, Make own decisions from  
 Open information – doesn't lead you to a  
 conclusion  
 Must include pictures  
 Led by lived experience  
 Written or compiled by expert in the field  
 Needs to be trusted  
 Tailored to the audience – focus on the  
 positive  
 Gives clear messages  
 Factual and up to date  
 Progressive  
 Internet – accessible, infinite and uncensored  
 Encouraging, clear and concise  
 At the right time  
 Simple language  
 Signposts on where relevant  
 Transparent – must include pictures, be  
 interactive, information from a wide variety of  
 sources, includes lived experience  
 Wordful – appropriate words used in the  
 appropriate way not overly wordy or  
 academic  
 Must be – Happy  
     - Successful  
     - Trusted  
     - Truthful

Jargon!!!!  
 Crammed / overloaded  
 Unclear / messy  
 Biased  
 Vague / blurred  
 Broken links  
 Not updated  
 Too academic  
 Hard to extract to actual information you want  
 from it  
 Too deep / complex vocabulary  
 Lies  
 Not transparent / no source  
 Hidden agendas  
 Incomplete  
 Too much in one space  
 Negative or stigmatising graphics eg. Head  
 clutcher, piles of tablets, scales  
 Telling us how bad, unless when it's wrong  
 Untold

**Insights**

For information to be helpful it needs to be

- Engaging - From a trustworthy source - Informative - Clear - Interactive

Contain – Pictures and words - but no jargon – simple accessible language – no excessive  
 use of words – translation buttons if possible

Videos are helpful to engage and explain – they give context

Messages must be clear; it must be comparable to other information and a baseline given

Information needs to come in a variety of formats – as this will be web based, when a page is  
 printed it must still look good, the formatting must remain as good as it is online.

It cannot be overwhelming, cluttered or too academic. It needs to be kept up to date.

Feedback per data area

How well do GP's look after physical health when I have a mental health diagnosis?

**Birmingham**

Linked to NHS choices data  
 Explanation of what health checks are  
 Worried about reliability of this data as had had experiences of checks not being completed properly or by practise manager  
 Source of data needs to be available  
 Does this include data from annual check up's? What's included in an annual check-up?  
 Does everyone have these?  
 Many illnesses are not detected  
 GP's are not checking on physical health of patient with mental health diagnosis; they are assuming this is done in secondary care

Would like to know about links of medication to physical health eg. On cholesterol, to diabetes, smoking reducing the effect of meds

Can GP's relate to needs of patient with mental health problems – severely paranoid patient – if not they won't bother to do physical health checks  
 This applies especially to people with a learning disability or autism

**London**

Linked to NHS choices  
 Able to comment  
 Online chat with medical professionals  
 A bit like NHS 111 but with a person  
 Need another way of getting help  
 Feedback to GP's needed to anonymous  
 Diabetes is important – can get this as a side effect from medications but you're not told.  
 More information on this and how you can help yourself is needed.  
 Compulsory health checks for people with a mental health diagnosis – publicity about what these are – currently don't know what should be checked!  
 Open discussion / interactive – about being physically healthy  
 Dentists – dental information should be included – lots of people with mental health problems have very bad teeth (fall out)  
 Information about service user involvement at GP practises – this isn't publicised enough  
 Training, design, delivery, educate  
 Would want to know why!  
 Contact information for relevant CCG so can follow up – ask for an explanation

**Insights**

Both groups felt it would be interesting to be able to understand whether their GP practise completed health checks.  
 They wanted more information on what these are.  
 Information or links to the health conditions the checks related to eg. Diabetes, cholesterol, weight management – this needs to be in relation to mental health “It is much harder to manage your weight if taking anti-psychotic medication – how can I do this? Who can help me except the GP?”  
 Links back to NHS choices for advice. Could also be specific health charities. Need to be reputable and trusted.  
 NHS Choices widget to be included here so people can write comments

This information needs to be presented in a way that is easily digested and related back to their experiences. Explanations need to be given regarding health checks.

## Psychological Therapies

### Birmingham

Could be titled 'Talking Therapies'

Use agreed definition of talking therapies

Choice – to have choice we need options and need to understand what each option is – Informed

The group were interested in understanding the data in more depth.

Waiting time and outcome were interesting however they also wanted to know about types of talking therapy offered and outcomes in relation to this.

Discussed how some areas are offering therapy in groups, sometimes very large groups. Participants questioned how good the outcomes for this type is vs 1:1 therapy.

Travel distance – how far are people having to travel to access talking therapies?

There is a change in the type and level of service offered when transferring from children's & YP services to adult services.

What about talking therapies in secondary care? Waiting time? Outcomes?

Data comparing voluntary sector providers of talking therapies to NHS provider

Waiting time in weeks to receive first IAPT session in all areas – comparable

Information around who can provide talking therapies

Can be 'old news' if no one checking on any advancement / improvements of therapy especially if given by third sector.

### London

We want information of how many CMHT's are referring not just GP's.

How many are referring back to GP because of lack of funding / resources in secondary care?

Referral rate and waiting time is just the beginning of the story, useful information to know but not enough.

There is restricted time for very limited amount of sessions.

There is nothing for people who have complex / long term needs. How many people are rejected as not suitable because they are more complex? What happens to them?

Secondary care psychological therapies data would be helpful too

Quality of psychological therapies

Monitoring effectiveness – How? Who's perception?

Choice and control – what about the types of therapies offered? Is there a choice? Is there a choice of therapist? This is interesting information.

Always available but some are not well heard of

### Insights

This was an emotive topic for participants, the data currently being proposed to be displayed was seen as only the beginning. Both groups were interested to hear about waiting times and access but thought this was a start point. They were very interested in hearing about choice of therapy vs outcomes as well as format of therapy vs outcomes eg was it 1:1 or in a large group.

Felt this was a bit limited as it only focused on IAPT psychological therapies. Many people wanted to know the same information proposed and explained above for secondary care. They felt people were spending a long time waiting for services here because they had been told to complex for IAPT.

Choice and control were strong themes here. People's experiences of talking therapies had not given them this and they were interested to hear / see if others had.

Data you do have should be displayed broken down into specific headings. This should then be comparable across areas eg. Waiting times in Sussex Vs waiting time in Yorkshire.

There was a little interest in looking at waiting time vs outcome of treatment; this stemmed from participants feeling that the longer someone waits the more unwell they will be when receive treatment therefore likely to have less of an impact.

## Prescribing of anti-depressants

### Birmingham

Choice – to have choice we need options and need to understand what each option is – Informed

Information about what's out there; rates will be interesting however how will we know what choices people are being offered behind the numbers

Diagnosis can change access to treatment – it can improve or limit what you are able to access

Care in the community – Looking at medications being reduced over a period of time – too much medication can make you not be able to function properly and affect your health – drowsiness / faint / blackout

Many GP's are not willing to use newer drugs – anti-depressant

GP's aren't willing to initiate anti-psychotics.

GP's / Psychiatrist cannot navigate the NHS system to help patient's access 3<sup>rd</sup> sector organisations to refer onto. This can especially be difficult for individuals not trained in the UK as they are even more unfamiliar with the system.

### London

What is the average prescription rate?

We will need context and additional information in order to understand what the information means.

What is the timeframe the prescription rate is being analysed in?

What about peer support or self help?

Are GP's prompting and / or supporting people to decrease their meds at a time that suits them?

Prescription rate for other things eg. Anti-psychotics, anti-anxiety medication

Adult services prescribe less than children and young people's services in my (participant) experiences – Comparisons across age would be interesting

Social prescribing / Gym prescriptions

More information on what brings on mental ill health and what will help. Nutrition, classes as prescription (Recovery college), positive thinking, self-esteem, anger management, stress management, sleep support, well-being information. GP's shouldn't just rely on medication and talking therapies.

All pieces of the puzzle need to be thought about by the GP.

Some doctors will allow you to give an opinion on use of anti-depressants; there is a time and a place for them.

Need more information from the GP about the different types so an informed choice can be made.

## Insights

Context and baselines need to be included. 'What is the average prescription rate compared to what my GP practise is doing?' this to be followed up with information about medication vs talking therapies prescribing. There was interest in this being comparable across chosen areas and the UK.

The theme of choice came up here a lot as well.

From this information how will people know if choice has been given in terms of talking therapies or medication? And then within that choice over what therapy and / or medication. What types of anti-depressant / mental health medication is being prescribed. Is there a reluctance to use newer medications? Why?

This was seen as interesting but again just the beginning.

Lots of interest in information and data around other types of prescribing. Other types of medication but expanding that to social prescribing, gym prescriptions and referring onto third sector services. There was a feeling that GP's may not think beyond what the NHS offers however this doesn't mean they shouldn't.

Interest in diagnosis in relation to what prescribed.

## Living well with your conditions

### Birmingham

Agreed the title made sense; though suggested 'Living Well' could also be used.

This kind of support is patchy – it's a postcode lottery!

Need to breakdown the area's that are included – figures for each area that could be compared across the country

Cuts in funding impact on this

Funding issue – local authority cuts – mental health funding is not ring fenced.

Having to wait days to see the crisis team – will crisis team figures be included / available?

No support to complain about your situation as less CAB services are available.

How do you know what you should be receiving? Not enough information available.

Patients don't know what they are entitled to so can't ask!

Information on side effects of medication.

Free bus pass – indication of support to live well – this is different across the country – harder and harder to get.

Can't receive if have a provisional drivers licence, sometimes means you still need to pay for travel but a carer can travel free.

Use of specialist clinics – ie clozapine clinic

Severe side effects – information about – creates drowsiness / faints that are ignored by team – can't live well when feeling this way.

### London

This is a good indicator to see if the other services are working.

Some people can't work, including work is a difficult one. Whose perceptions are being used to define who is able to work and then looking or in employment?

Living well doesn't necessarily include employment – it could also be attending classes, volunteering or looking after your family

This is about being able / happy to cope with all aspects of your life.

Fulfilment / contentment/ achievement

Groups that work for your different 'days'

This could also be called 'Living well' – meaning living that life that is right for you

What about stable relationships

Breakdown of what's included in this area – what are you looking at to get this information? Figures displayed separately as well. Contact information in order to follow up with the relevant authority.

Having a choice – being presented with one as well as the information needed to make a decision

Doing what you are naturally best at.

What about alternative healing? – Sound therapy, Tai chi, mindfulness, music?

Is information from day services included?  
 Services similar / like Local Minds? How will this information be displayed? Individual service or as a group of services across an area?  
 Can information about services available be included? Contact and what they do.  
 Recovery model – patient / service user should be listened to – can information / data about how listened to people feel they are be included?  
 Real services – that actually exist!

### Insights

This was a complex area that generated much discussion and many differing opinions. Overall participants wanted to see an overall rating that was then broken down to explain what created the rating / score. Eg. 'Enfield offers good support to people with mental health problems – 40% of population ...; 22% are in work related activities; 70% of people applying for supported housing are placed within 6 months of application.

Baseline of what to expect should be included so they would know if the figures were good or bad. Participants felt very strongly about services under these categories as these were ones having their funding reduced however gave them most support in more areas of their lives.

This breakdown was felt to be very important as areas could be fantastic at supported housing but not delivering personal budgets.

The definition around the work element was also highlighted and created much discussion. Who is defining people as ready / able to work? Themselves? Clinicians? Work capability assessments?

Does the work element include other meaningful activities eg. Voluntary work – this was felt as just as important and may be what the person feels they are able to do.

Living well (with your conditions) was felt to be a subjective area. We will all define how we do this differently and it will change over time. What is being measured / reported on here needs to be clearly explained as does the source of the information.

It was felt that this could be an area that could be expanded on over time.

Support in these areas is variable across the country. It was hoped that information under this category could be displayed in a way that was comparable therefore demonstrating the differences across the country. This would then allow people to campaign for different services. – “How do I know what support I should be receiving if I don't know what's out there or I'm meant to be able to access”

Quality was of importance to participants and it wasn't clear how / if this would be reported on. Figures on services user's perceptions of the quality of services was suggested.

### Additional areas of interest

Information about whether choice was given and if so was information then given to inform choice.

In patient data

Unit's you can be sent to - No' of people sectioned, re-admissions within a fixed time period

This should extend to workers / nurses / psychiatrists – Rating system

Rate my psychiatrist – listening skills, choice offered

Time spent in crisis suite (136 suite / place of safety) before responsible team arrives

Lack of beds - admission rate in relation to community services – people not being able to access a bed if they need one but also being in need of beds more frequently because the support in the community was not adequate.

Open dialogue – not really acknowledged

Move away from diagnosis

Limited signposting

Question around quality

GP's doing health checks will depend on the GP – some are scared of mental health, they wouldn't do checks as would need to engage for longer

Map of services – All types – Including third sector not just NHS services – more information needed than just the address

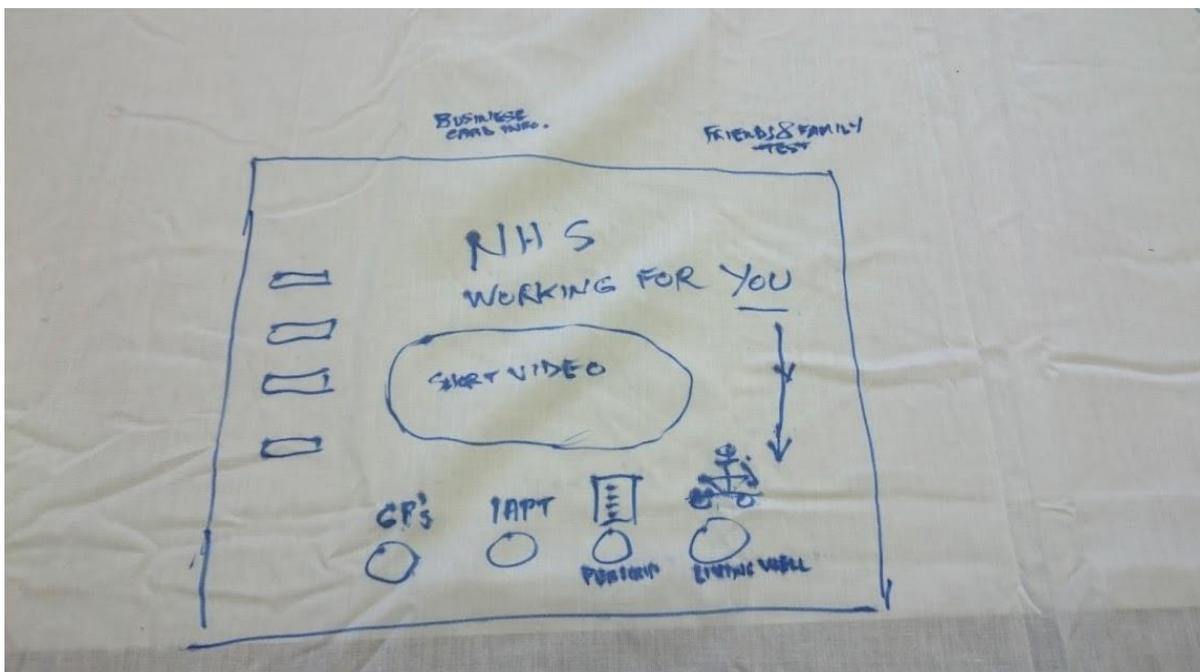
Comparison is really important – across county and country – need to understand the baseline

Comment boxes need to be included

Could ask GP for health checks once I know what I should be offered.

Information can be explained to family members / friends in their own language; informing them of what they can expect.

What would the presentation of this information look like?





WHAT TYPE OF SERVICE TO EXPECT FROM DIFFERENT PROFESSIONALS  
 RATING DIFFERENT PROFESSIONALS  
 INFO ON HOW TO CHANGE CMHT  
 LINKS TO KEEP OUR NHS  
 PUBLIC GROUPS TO  
 INTERNATIONAL COMPARISONS WITH  
 OTHER COUNTRIES RATIO OF MEDICAL  
 PROFESSIONALS

MENTAL HEALTH SERVICES, VALUE FOR MONEY, TOTAL NUMBER OF DIFFERENT WORKERS IN EACH AREA OF THE NHS. WHAT SERVICES, CHECK WBS SHOULD AN AVERAGE NHS USER GET IN A YEAR, WAITING TIMES DATA, WHAT TO DO IN EMERGENCY, WHAT MEDICATION TO HAVE IN SPECIFIC CONDITIONS, SO THAT IF YOUR NOT GETTING MEDICATION THAT SEEMS SUITABLE YOU CAN QUERY IT

NUMBERS TO RING  
 FREE PHONE NUMBERS

