

NSUN Member Survey Report 2017

Summary of Findings

- **107** NSUN members completed the survey.
- **77%** of respondents have a **positive perception** of NSUN.
- **76%** of respondents agreed (or strongly agreed) that they **felt connected** to a wider network of people as a result of being an NSUN member.
- **75%** agreed (or strongly agreed) that they were **more informed of their rights**.
- **75%** agreed (or strongly agreed) that they were **more aware of opportunities** to engage and influence policy and the design, delivery, commissioning and auditing of services.
- **71%** agreed (or strongly agreed) that they felt **more able to and prepared to get involved** to influence service design, policy makers, commissioners and/or others.
- **62%** agreed (or strongly agreed) that they had **taken up involvement opportunities**.
- **76%** recognise the value they can add to bring about change to services and resources.
- **66%** said that NSUN had **helped them to speak out/up in their personal life/community**.
- Respondents continue to value NSUN's ability to **keep members informed of the latest information and developments** (eg. welfare cuts).
- Respondents also continue to value NSUN's **user-led ethos and the sense of solidarity and community** within the network.
- NSUN needs to **improve information for members (especially new members)** with regard to how to get involved.

"I feel part of a supportive, understanding, community of peers. The resources shared provide the info I need to quote. The community provides the support I need to feel 'part of something'".

Top 10 Issues

1. **Access to timely and appropriate treatment and support**
2. **Genuine co-production and empowerment**
3. **Welfare reforms and social inequalities faced by people with lived experience**
4. **Rethink the medical model/use of medication**
5. **Improve and develop services** - through person-centred, holistic models of care
6. **Raise awareness** – challenge stigma and discrimination
7. **Wellbeing** – care of self and others
8. **Funding for services**
9. **Human Rights**
10. **Parity of esteem with physical health.**

This report sets out the key findings emerging from the Members Survey 2017. The findings are discussed in relation to NSUN's strategic aims and outcomes. These are:

Networking

- Improved connection and peer support amongst membership
- Increased regional presence
- Enhanced awareness and reputation of NSUN.

Capacity Building

- Stronger service user voice
- Increased regional presence
- Members are empowered to inform and influence and address the things that are important to them.

Involvement and Influencing

- Stronger service user voice
- Members have the opportunity to be involved (including excluded/ marginalised groups) locally and nationally

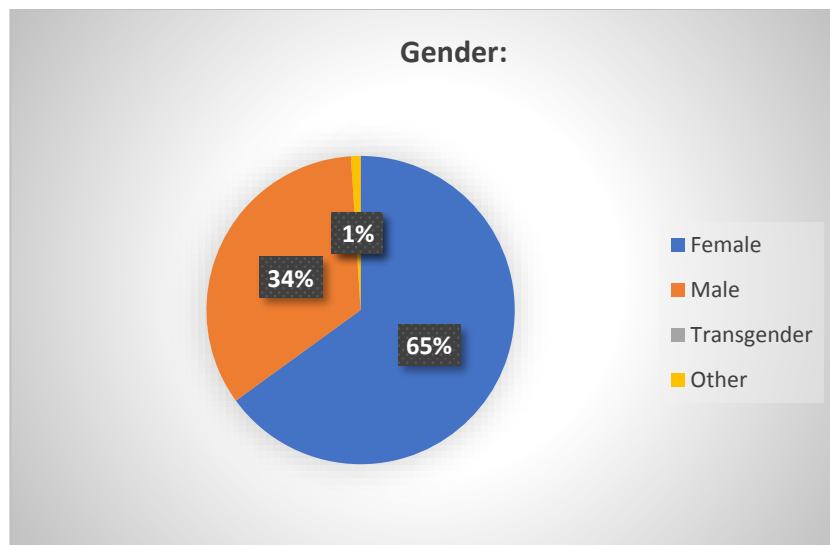
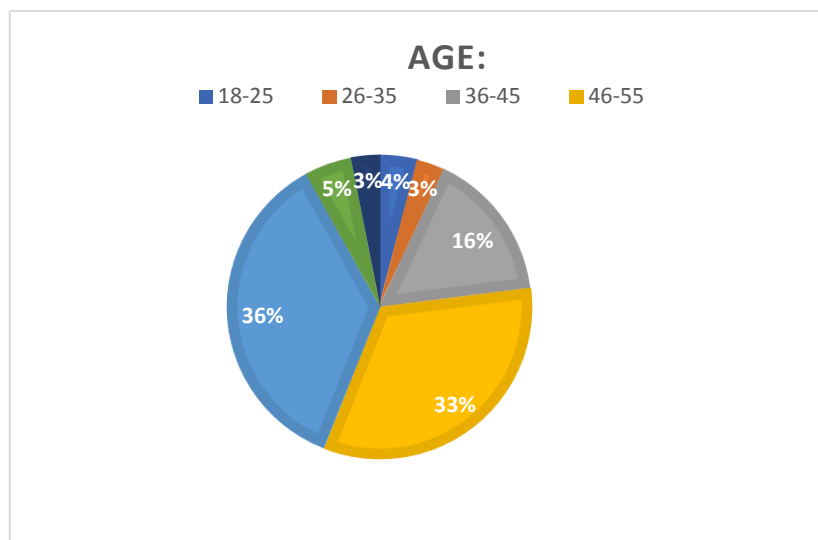
- Members have influenced local and national decisions as a result of NSUN activity.

About the respondents

107 NSUN members completed the survey (compared to 80 respondents in 2015/16, 110 in 2014 and 180 in 2013).

58 respondents provided contact information for a follow up telephone call/focus group.

The following tables set out information gained from the member survey with regard to the age, gender, ethnicity and sexual orientation of respondents.



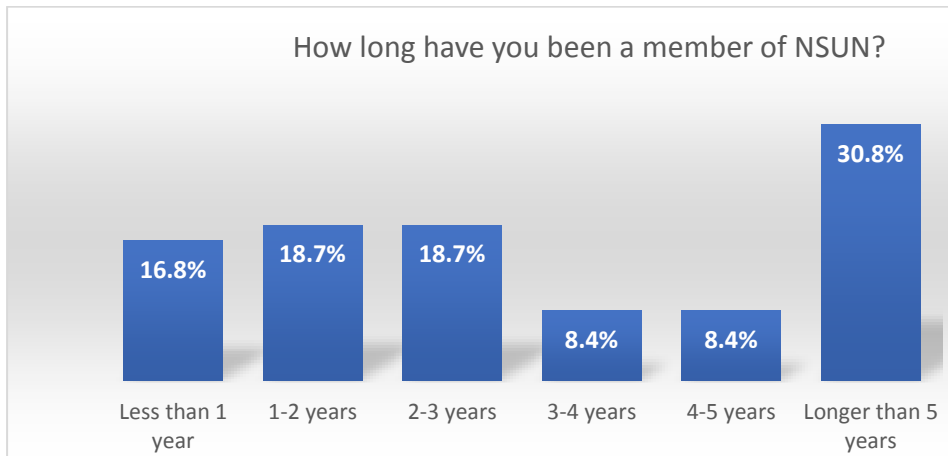
Ethnicity:

Ethnicity:		
Answer Options	Response Percent	Response Count
Asian or Asian British (*Bangladeshi *Indian *Pakistani *Other Asian background)	6.9%	7
Black / Black British / African / Caribbean (*African *Caribbean *African Caribbean *Other Black background)	5.0%	5
Chinese (*Chinese British *Other Chinese *Other)	0.0%	0
Mixed / Multiple Ethnic Group (*White and Black Caribbean *White and Black African *African Caribbean, *White and Asian *Chinese British *Other Mixed *multiple ethnic background)	3.0%	3
Other Ethnic Group (*Arab *Irish *Other)	4.0%	4
White (*British *English *Welsh *Scottish *Northern Irish *British Irish *European)	72.3%	73
I do not wish to declare my ethnicity	8.9%	9
answered question		101
skipped question		6

Sexual Orientation:

Sexual orientation:		
Answer Options	Response Percent	Response Count
Heterosexual	72.0%	72
Bisexual	6.0%	6
Gay Woman/Lesbian	9.0%	9
Gay Man	0.0%	0
Transgender	0.0%	0
Other	6.0%	6
Prefer not to say	7.0%	7
answered question		100
skipped question		7

As with previous member surveys the majority of respondents were in the 36-45, 46-55 and 56-65 age categories and there were very few respondents in the younger and older age categories. **65%** of respondents were women (a slightly higher proportion than previous years), **72%** were heterosexual and **72%** of respondents were white. **31%** of respondents had been NSUN members for over five years. It is not possible to assess the representativeness of the respondents in relation to the overall member demographic because we do not gather this information when recruiting new members at present. **107** NSUN members completed the survey – a higher number than last year, when 80 members responded. However, this is still a very small proportion of the total NSUN membership (over 4,000 individual members and 600 groups). All findings should therefore be interpreted in the light of this information and as a reflection of this specific group of self-selecting NSUN members.



What does NSUN do well?

- 1. Information Sharing** – communicating with members through the weekly e-bulletin, social media and website. Keeping members informed about local and national issues, campaigning activity and involvement opportunities.
- 2. Networking** - connecting members, professionals, organisations.
- 3. Campaigning** - lobbying, representing and promoting the voices of people with lived experience. *"Campaigning for true service user involvement in service improvement"*.

AND...

- *Surviving in a climate of economic hostility*
- *Being a critical voice*
- *Unafraid to protest against injustice*
- *Empowering members*
- *Staying true to service user values*
- *Remaining a genuine grassroots organisation*
- *Being an advocate for change*

Networking

Connection and Peer Support amongst membership

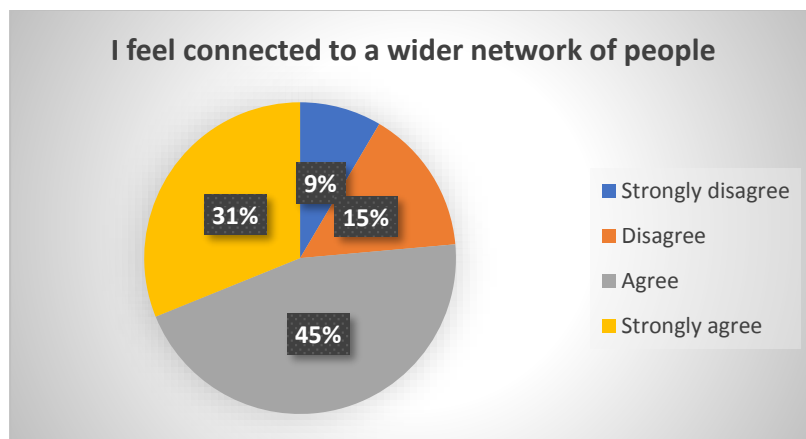
"NSUN makes you realize you are not on your own".

"I feel as if I am not alone! I love the signposting, shared information and the feeling that we are fighting together!"

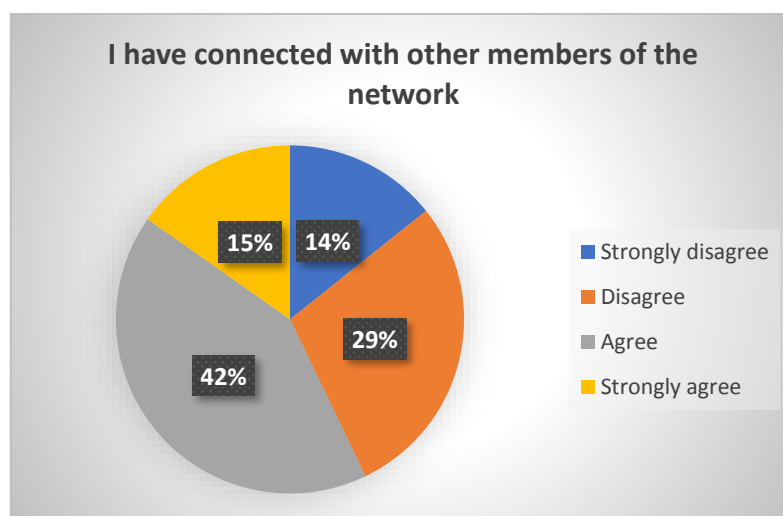
"Having my voice heard in a supportive manner is great".

In previous years the survey has asked 'are you a member of a local group?' This has led to some confusion about whether local NSUN groups exist. In 2015/6 only **39%** of respondents stated that they were a member of a local group. In 2014, **50%** replied that they were connected to a local group. However, having rephrased the question in the survey this year to ask whether respondents were connected to other mental health groups or organisations in their local area, **80%** stated that they were (see appendix A). This finding would indicate that NSUN's current role may be less about connecting individuals with other people in their local area (as discussed in the survey last year) but instead may play a greater role in connecting people who are already involved at a local level with a national network.

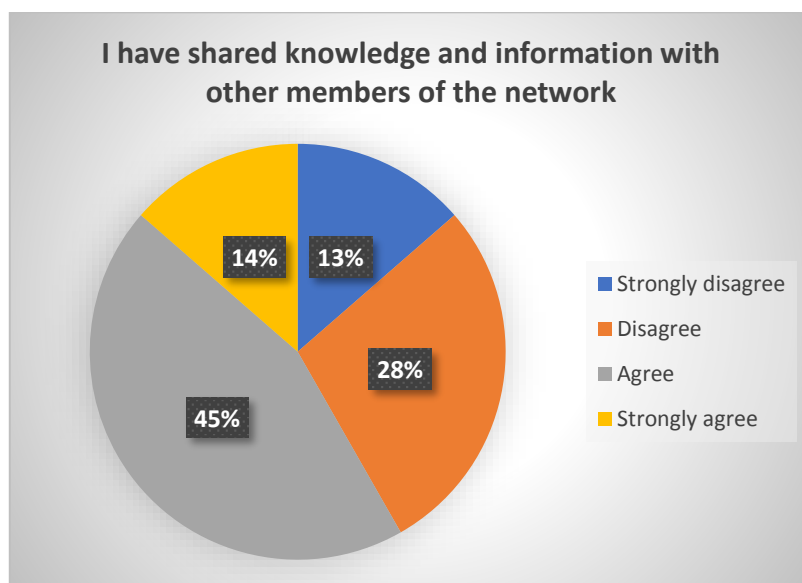
76% of respondents agreed or strongly agreed that they felt connected to a wider network of people by being a member of NSUN (compared to 83% last year and 82% in 2014).



67% agreed or strongly agreed that they had connected with other members of the network (compared to 65% last year and 62% in 2014).



59% agreed or strongly agreed that they had shared knowledge and information with other members of the network (compared to 68% last year and 61% in 2014).



As with previous years there continues to be a greater feeling of connection to a wider network than an actual practical connection. Moreover, a greater number of respondents strongly agreed that they felt connected (31%), whereas only 15% strongly agreed that they had connected with other members of the network. Many of the respondents mentioned the importance of feeling connected to the network:

NSUN makes you realize you are not on your own.

I feel as if I am not alone! I love the signposting, shared information and the feeling that we are fighting together!

However, a significant number of NSUN members (43%) have not connected with the network and 24% do not feel connected:

I don't really feel a part of something bigger, other than the newsletter, I'm not sure I feel connected to the work NSUN is doing? It feels quite London based and maybe in the South East people feel more a part of a wider network?

Several respondents stated that there were limited opportunities to get involved with NSUN activities (particularly in their own local area):

There is no real opportunity to get involved.

Is a bit unfair - I can post a blog but then that seems to be all. Feels like there is no real participation.

Would like to have more opportunities to be involved.

A couple of respondents stated that it was difficult to get involved because NSUN felt 'exclusive':

I was impressed with the soap box at the AGM but there is a "glass ceiling" in NSUN and it was difficult to join ...

Value the news updates at a national level but strong positioning of NSUN does not represent my views and often feels exclusive.

Other respondents stated that they wanted to become more actively involved with NSUN's activities but did not know how to go about doing this:

Not been involved for that long... Not sure how to get more involved as yet.

This sense of confusion from some respondents was also corroborated by the number of people who - when asked what NSUN needed to improve - stated that clearer information was required for how members could get involved:

Clearer info on how service users can get involved.

Clearer information of how to get involved and how to contribute.

Make it easier to contribute.

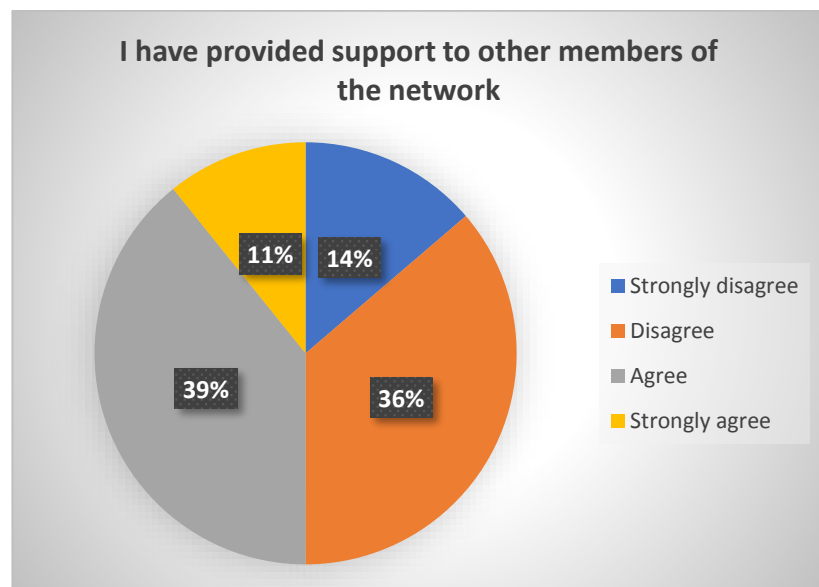
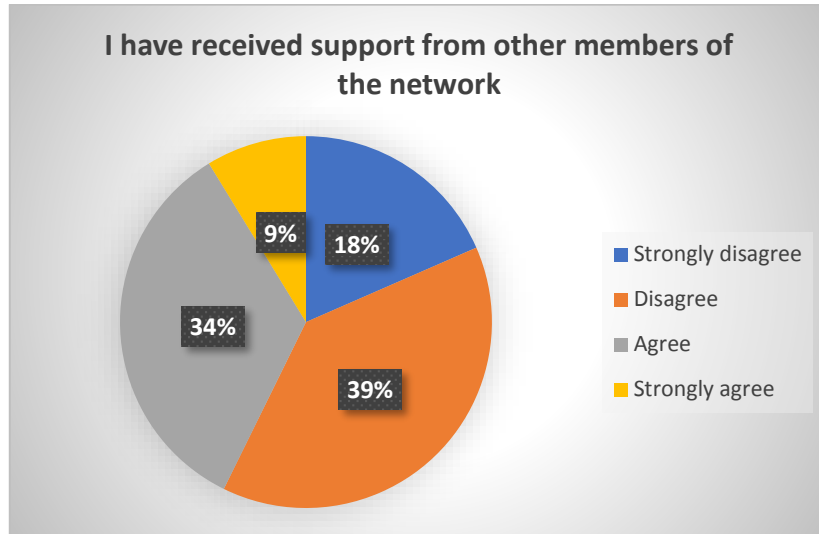
Being clear about what is on offer.

Directing new members about how to use the network to the full potential.

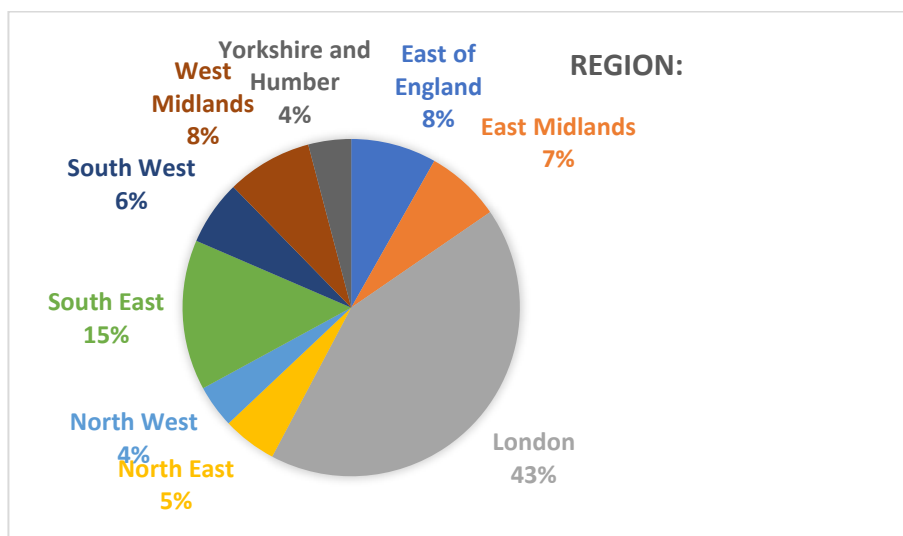
It will be important for NSUN to find ways of harnessing the energy of members in order for them to connect further with the network and become more actively involved. A straightforward way of doing this would be (as respondents suggest) to develop an information pack for members (particularly new members).

"I believe it's really important to have a user-led group doing this sort of work. I see our greatest challenge as translating our knowledge, expertise and passion into working influence at all levels that leads to measurable improvements in services. This is what I am particularly keen to help with".

With regard to respondents receiving support from, and providing support to, other members of the network, **42%** agreed or strongly agreed that they had received support from others. **50%** agreed or strongly agreed that they had provided support to other members. As with previous surveys, there is scope to improve these figures and explore how best to create better connections and opportunities to receive and give support within the network.



Regional presence



43% of respondents were from the London area and **15%** from the South East. These are higher figures than previous years and may reflect the way in which the survey was shared and promoted amongst members (eg. to people involved in specific projects such as the S136 work in London).

Although NSUN has attempted to address feedback relating to being 'Londoncentric', for example, by sharing information in the bulletin from different parts of the country, some respondents still feel that NSUN is not doing enough in local or regional areas outside of London:

Very "London" focussed

Events and opportunities are London centred.

There is nothing really in Kent that I know about, with 1 exception when Saz did a tour of some of the projects, that was several years ago & I am unaware of anything they have done since.

Would be nice to have a group in West Norfolk. Can feel very cut off from Londoncentric stuff.

NSUN has done good stuff nationally but feel it hasn't helped with local user-led survivors groups having a say and sometimes marginalised them.

Although NSUN works across England (but not in Scotland or Wales) it was also interesting to note that this year, for the first time, several respondents mentioned a lack of work in Wales:

I don't think that NSUN in Wales has fully developed yet.

Not much on offer for Wales But it does give me general info.

No has done little if any work in Wales hope it will do better from now on.

This point also relates to feedback about what NSUN needs to improve on. In addition to the request for clearer information for members about ways to get involved, some respondents also stated that NSUN needed to be clearer about its identity (who we are and what we do/don't do):

Being clearer who does what and who to contact for xyz.

Their identity ie. are they England only or across the other parts of the UK.

As such, as part of an information pack for members, it may also help to include information (re)introducing the organisation and its remit, staff members etc.

NSUN needs to improve...

1. Clarity of information (re. NSUN's identity and how to get involved)

- *Their identity ie. are they England only or across the other parts of the UK.*
- *Being clearer who does what and who to contact for xyz.*
- *Getting info across on how we can get more better involved.*
- *Clearer information of how to get involved and how to contribute.*
- *Make it easier to contribute.*
- *Clearer info on how service users can get involved.*
- *Being clear about what is on offer.*
- *Directing new members about how to use the network to the full potential.*

2. Regional/Local Work

- *Less Londoncentric*
- *Local involvement opportunities*
- *Build structures and processes that will lead to improvement at local level.*
- *Local connections.*
- *There needs to be more information about local campaigns.*
- *Provide opportunities for members to meet one another in local groups.*

3. Diversity of membership and work with marginalised groups

- *Diverse voices*
- *More BME women voices*
- *LGBT service user members.*
- *More disabled people's voices.*
- *More for disabled people.*
- *More diverse narratives/lived experience.*
- *More young people's voices.*

AND

- *Campaigning against funding cuts / benefit cuts.*
- *Bringing user groups and individuals together.*
- *Stronger presence and visibility*
- *Sometimes things take to long or don't end up happening at all (eg. involved in making video)*
- *More dialogue between members.*

Awareness and reputation of NSUN

77% of respondents had a positive perception of NSUN. Information sharing continues to be the area in which NSUN is most valued and has a good reputation. As in previous years, the e-bulletin (sometimes referred to as the 'newsletter' by respondents) was frequently praised by respondents:

Excellent newsletter which is both broad, informative and inclusive in its remit.

They keep you informed of the latest information especially regarding Welfare Benefits.

Gives information from all over the country. A variety of topics and mental health issues, variety of forums to get involved and very informative and great visually.

Very glad to be kept in the loop re mental health, activities projects & relieved as someone on low pay, to receive some emails re some paid opportunities.

Respondents also continue to value NSUN's user-led ethos and the sense of solidarity and community within the network. Increasingly respondents are also valuing NSUN's 'critical voice':

NSUN is critical of treatment, mainly medication, which in my experience is a nightmare. Medication dominates mental health. Any organisation which tells the truth about the damage it does I support whole heartedly.

Campaigning for true service user involvement in service improvement.

Unafraid to protest against injustice.

"Being service-user led and interested in our views, NSUN is right on the ball where mental health is concerned".

"I believe NSUN does some really great work. It works alongside some of the major organisations to make improvements, and give service users an opportunity to make a real difference".

22% of respondents had a neutral perception of NSUN and **3%** had a negative perception. A wide range of reasons were given as to why this was the case:

It doesn't have the impact and excitement that it used to have for me. Maybe because I am getting older. Perhaps because I get similar information from other mental health newsletters and pamphlets.

Newsletter is "fussy" and complicated and hard to read on my mobile phone Don't have PC etc.

Just doesn't seem quite right. Too complicated but somehow at the same time too vague or disjointed.

NSUN "talks a good talk", but it is careless in accepting people & organisations who are not really what they pretend they are!

I think NSUN is hierarchical and does not support citizen participation.

One theme to emerge however was NSUN's increasingly critical political perspective. Although some respondents praised this 'critical voice' and ability to be 'inclusive of all service users despite radical views', others felt that there had been a loss of balance with regard to the presentation of perspectives:

It seems like a political movement. Don't really get how NSUN is supporting better mental health and involving people. Seems like NSUN is stuck in the past.

The newsletter is a vital source of information but the organisation feels like it aims to represent a specific view point. Almost all of the blogs and position pieces are openly disparaging of psychiatry and of the view that user-led narratives and provision is superior. This fails to reflect that users define their experience in many different ways and often gives the impression that many of these ways should not be supported. NSUN speaks very effectively to a specific group of people but does little to challenge this and reflect the views of a wider population.

Relentlessly critical with little balance of perspective.

I would value a greater balance of perspectives and wider representation.

I do think there is more negative than positive info.

One specific view of psychiatry (usually bad).

However, others felt that NSUN should be more openly critical.

Useful for info sharing but not strong enough on political activism or challenging PD label.

If NSUN had the resources, it should be more active politically, via campaigning.

In addition to clarity of information and improved regional work, respondents also felt that NSUN needed to improve the diversity of its membership and its work with marginalised groups. Specific groups mentioned included BME women, LGBT members, disabled people and young people.

What do people value about NSUN?

Information and communication (through e-bulleting, social media and website)

- *You bring together so much great information*
- *Provides lots of helpful information and resources.*
- *I like to be kept informed of developments in mental health service provision that places service users at the centre of the service.*
- *Excellent news and views with a political edge. Thank you!*
- *Succinctly put information with links to greater details.*

NSUN's ethos

- *You are exactly opposite of standard mental health services: you don't label, judge and spread the stigma.*
- *Uniquely service user orientated. Smart, active, meaningful. Interactions add to quality of life and progress.*
- *It is run by a very committed team who feel strongly about supporting service users to be heard.*
- *They are always encouraging voices of lived experiences. Highlighting issues where we cannot always campaign for ourselves.*

Solidarity and community within the network

- *I feel as if I am not alone! I love the signposting, shared information and the feeling that we are fighting together!*
- *We are all passionate to bring about change.*
- *Without stealing a cliché 'Unity is strength' and god knows we need to stick together as the attack on user groups is relentless We have spent so much time trying not to be swallowed up! We need a 'National' organisation to bring us all together and that is what NSUN does in the best way!*

Lobbying and campaigning – critical voice

- *Has lobbying power and is at the cutting edge of mental health research and survivor movement.*
- *NSUN is critical of treatment, mainly medication, which in my experience is a nightmare. Medication dominates mental health. Any organisation which tells the truth about the damage it does I support whole heartedly.*

Capacity Building

Stronger service user voice

This outcome is explored in the following section on involvement and influencing.

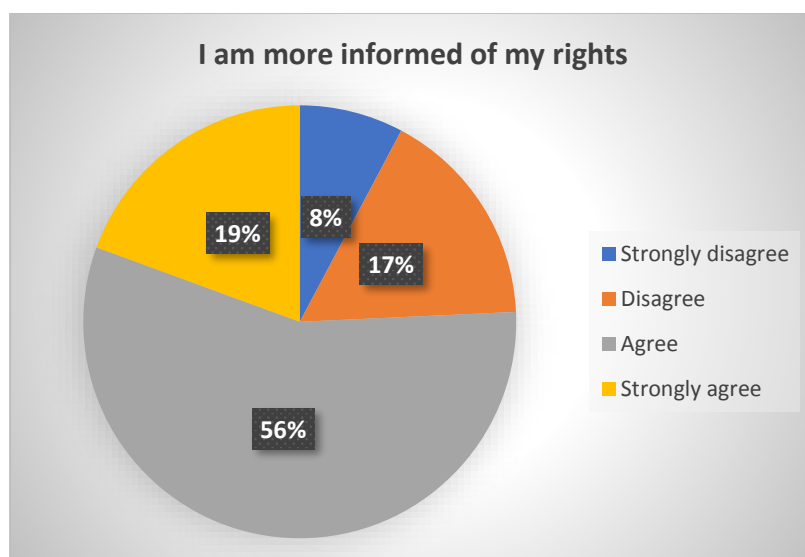
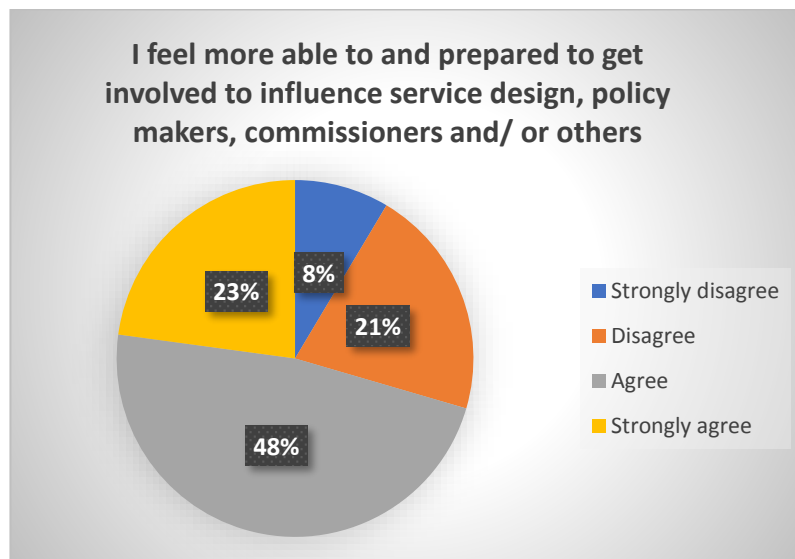
Regional presence

This outcome has been discussed in the previous section. Previous member surveys have highlighted the need for further capacity building in local areas.

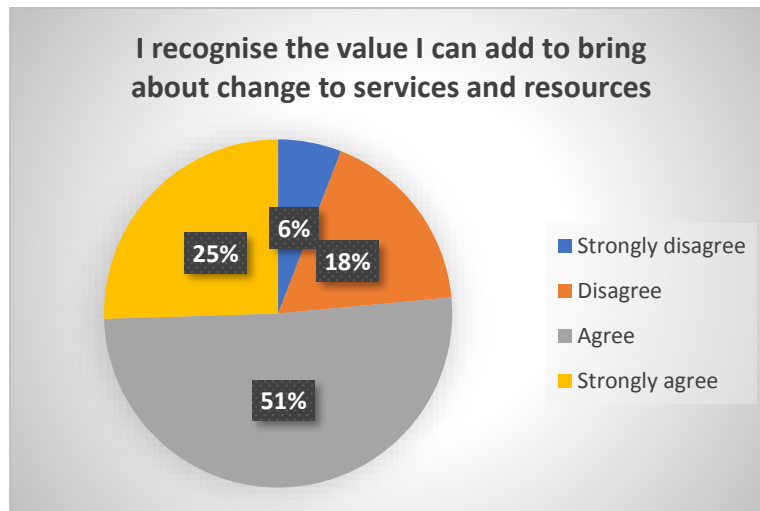
Members are empowered to inform and influence and address the things that are important to them.

"I am more confident. I am more able to be assertive, both within involvement opportunities, in my own care and within my life generally".

71% of respondents agreed or strongly agreed that they felt more able to get involved to influence service design, policy makers and commissioners as a result of being an NSUN member. This is a slightly lower figure than last year (78%). However, **75%** felt that they were more informed of their rights as a consequence of being a member of NSUN which is slightly higher than last year (72%).



76% of respondents felt that as a member of NSUN they could add value to bring about change to services and resources.



Survey responses would appear to indicate that NSUN is providing less support, advice and guidance over the past couple of years. **30%** answered 'yes' to this question in the 2017 survey, compared to **36%** in 2015/6 and **43%** in 2014. However, when answering the question 'Does NSUN support you/your local group to be more informed and influence the services you receive and/or your local services?' **54%** of respondents answered yes, and gave a range of positive examples:

NSUN has been instrumental in their support of my user group.

NSUN User Research reflected in University of East Anglia research projects I've been involved with.

I have recently used the statistics, you provided, on the decline of funding and demise of other service user organisations. I am currently embroiled in a battle (again!) to stop us being 'merged' by hanging future funding over our heads on a premise of 'partnership working'.

The news from other groups and regions is a valuable reference point when discussing strategic developments in our area.

More specifically several respondents praised NSUN's work with the MAD Alliance:

It helped form MAD Alliance, it's training 'Creative Leadership' has been invaluable.

Networking with the NSUN Mad Alliance.

Throughout MAD Alliance facilitation, it was excellent.

Some respondents felt less supported, or were unaware that support, advice or guidance was available to them:

While I do feel more informed through being a member of NSUN I don't feel supported to engage with the opportunities offered, but this may not be due to lack of support but my lack of engagement. Who knows.

Leeds area is a little lacking in support. Please help me develop.

Other respondents were more critical of NSUN's position with regard to local groups:

It "blanks" CTA & SELDAN, but gives credence to some very dubious people.

The biggest joke was the way NSUN treated "Southwark Mind" as a "User run, User led" body, when it was the only Mind to be kicked out for failing to be that !!!!

51% of survey respondents stated that they had attended and/or been involved with events organised by NSUN. Many respondents mentioned the AGMs when discussing events:

AGM - really great event, motivational, inspiring, militant! More gatherings like this would help to bring about more of a feeling of a movement.

AGM Birmingham, great local to me and I was able to talk about research and meet friends, what could be better.

Took part in all AGMs. Great energy, you feel the strength of the network.

Those who were more critical mentioned the lack of follow up after events, the fact that some events were too far away:

One which was with RCP but led nowhere.

A couple of AGMs. Ok, but no real follow up.

No because they are too far away, & there is nothing in it for me personally.

A few & I felt an atmosphere of denial about NSUNs shortcomings.

With regard to the **expectations of respondents and their reasons for joining NSUN**, a wide range of reasons were given, but focused mainly on the need for up-to-date information, the potential for connecting with others and the opportunity to become more empowered and bring about changes in the system:

To be in touch with what is happening in the wider community of mental health activists and keep up to date with opportunities for involvement, mainly in research. To keep to date with what is happening nationally.

Keeping up to date on news that affects service-users, gaining easier access to research and initiatives/actions about the current workings of the mental health systems.

CONNECTION, communication and campaigning. To get up to date info of what's going on who can help. My part in getting things changed for the better.

As a mental health survivor how we can bring about change for services users.

Wanted to influence changes following a poor experience of mental health services.

To help speak out about the ongoing political injustices.

To become Empowered and more assertive especially when dealing with mental health professionals.

"I believe NSUN champions those that society seems to neglect and marginalise, it gives them a voice and a vehicle through which to express their feelings and experiences of injustice and poor treatment. It is not afraid to stand up for them and campaign for their true involvement in the improvement of their services and to protest at unfair policies".

A wide range of responses were also evident with regard to whether respondents felt as though they had got what they expected/hoped for from NSUN. Although many stated that they were satisfied ("*Yes and I am delighted to be constantly informed, challenged and valued for my experience*") some felt as though the benefits were limited (or non-existent):

Expect for nothing and you won't get disappointed.

Only limited benefits to my local area.

Only the newsletter which covers out of Area, so it's not much use.

A couple of respondents mentioned that they had hoped NSUN would be more able/inclined to hold organisations to account:

I don't have expectations of any organisations unfortunately, because the real problems lie with failing trusts (poor culture - not necessarily lack of funding), the CQC, PHSO, etc. and no one ever seems to want to take them on.

1) Holding NHS ENGLAND and CCGS to account for involving (relevant, not always the usual-same) experts by experience in service redesign/ outcomes etc 2) I'd hoped for more on alcoholism and dual diagnosis issues/reducing this awful stigma (exists in psychiatry!)

Other respondents were more satisfied and made suggestions for further work:

Yes, but would like more activism regarding benefits cuts and campaign to change the difficulties people are having with their claims and constant fears and despair.

More BME narratives and voices: lgbt service users/ blogs please.

I think some members may like to speak to other members but not sure they really get the opportunity other than if they sign up for involvement work for instance or go to the AGM. I would like to have the opportunity to informally meet other members locally on occasion or regularly to discuss current issues.

Involvement and Influencing

Stronger service user voice

66% of respondents stated that NSUN had helped them to speak out and up in their personal life and community. For those who answered 'yes', some gave examples of how being an NSUN member had inspired and motivated them to work on specific projects/events:

A group of us went to DRUK to speak at their AGM. We started a National Dementia Policy Think Tank as a more effective way of getting heard.

Provides me with the opportunity to work with other organisations (eg. NHS England) in focus groups to impact on the project and the care and experiences of other service users.

I have been asked to give a talk about Section 136.

Particularly helpful have been the e-bulletins with job opportunities, research summary links, current affairs etc. I have gained several posts and suchlike from these.

At a personal level some said that they felt more confident and empowered as a result of being an NSUN member:

I think the workshops have empowered me more.

I'm learning little by little to gain inner confidence.

Having knowledge gives me confidence.

It gives me information I need to be empowered.

Respondents referred to sharing the information they received from NSUN as being one of the key ways in which they were speaking out:

I learn a lot from NSUN from bulletin and share info to others.

Any useful info I then talk about in my groups.

Opportunity to pass on useful information to friends and members of the support group.

The information in the e-bulletin was also frequently referred to as one of the main ways in which NSUN had helped them to do this, by providing 'backing' and 'credibility', for example when attending meetings with mental health workers and commissioners:

I have quoted directly from the newsletter to illustrate points at meetings and to defend our local organisation. I am always informing my friends within and outside of my organisation about items I have read or events, legislative changes etc. from the newsletter.

Gives me things to quote from, to tweet, etc.

Newsletters and various pieces of research on the NSUN website absolutely vital for up-to-date info, and in dealing with mental health care workers and commissioners.

Info directing me to which relevant orgs that may help. Very difficult sometimes to speak up alone so with your backing it helps.

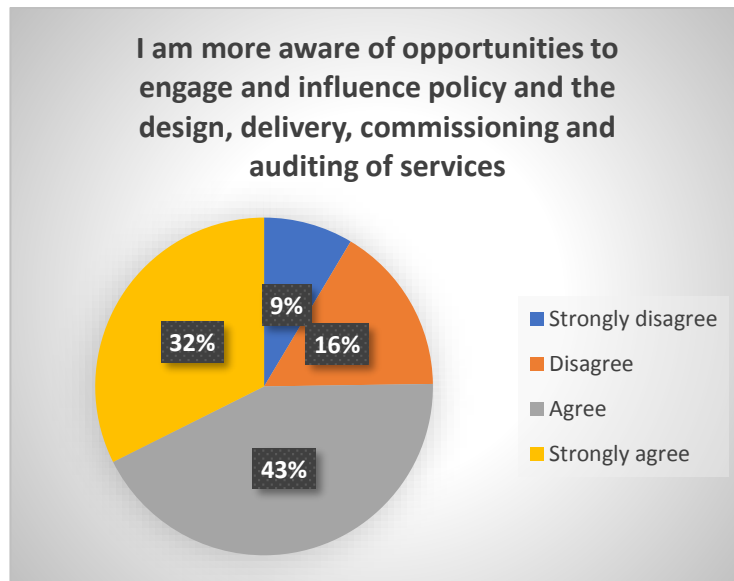
Gives me credibility.

"It has grown and developed over the years since the inaugural event in Birmingham I attended into a robust lobbying and support network with national relevance for its members and wider communities".

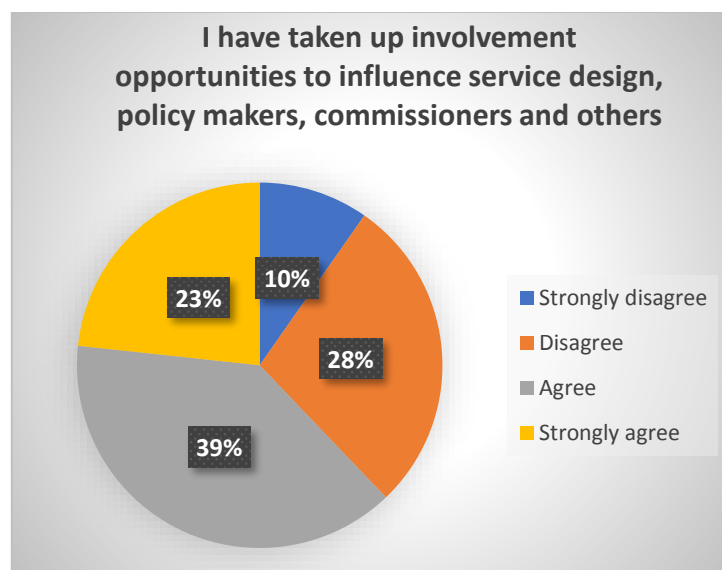
Members have the opportunity to be involved (including excluded/marginalised groups) locally and nationally and have influenced local and national decisions as a result of NSUN activity

75% of respondents agreed or strongly agreed that they were more aware of opportunities to engage and influence policy and the design, delivery, commissioning

and auditing of services. However, this is a significantly lower figure than last year (91%) and 2014 (80%).



62% agreed or strongly agreed that they had taken up involvement opportunities to influence service design, policy makers, commissioners and others.



Although some respondents gave examples of the kinds of activity they had been involved with as a result of being an NSUN member (see section above) there continue to be significant barriers to successful involvement and many of these issues (eg. the lack of genuine co-production) were discussed in response to the question 'what is the single most important issue for you in mental health?'

Top 10 issues arising from the Members' Survey

(NB: These issues reflect the concerns of the survey respondents and should not necessarily be viewed as representative of the wider NSUN membership).

1. Access to timely and appropriate treatment and support

- *Challenging the way mental health services deliver care.*
- *Provision of support.*
- *Lack of available help especially in Kent*
- *Better support.*
- *Lack of support.*
- *Status of the 'discharged' patients ... left to get on with it!*
- *That everyone can access the effective services when help is needed. Not get stuck in the services for the whole lifetime.*
- *Informed choices and accurate information.*
- *Getting the right information.*
- *Clear and honest information.*
- *Support in employment*
- *The lack of support for Education or even training for a job.*
- *Accessing appropriate services via NHS for AL conditions, as this is not happening at the moment. My area provides no specialist support at all for adult ADHD*
alcoholism, dual diagnosis and the stigma which exists in psychiatry NICE GUIDANCE CG115 is not enforced (to advice the value and benefit of AA to anyone seeking help with drinking). They ignore the drinking issue but we cannot engage in treatment until the alcoholism is addressed and alcoholic cannot simply 'cut down'.
- *Getting more MBCT courses commissioned so that GPs can prescribe them, see papers on www.sectco.org.uk, and section 9 of www.reginaldkapp.org*
- *More beds in hospitals. Especially to prevent people being sent out of their district to get a bed.*
- *The prescription and use of the correct medication for its treatment.*
- *Sharing experiences and learning what is being done throughout the NHS*
- *Independent advice of mental health.*
- *Integration with neuroatypicality.*
- *Food intolerance diagnosis for all mental illness sufferers.*

2. Genuine co-production and empowerment

- *I honestly don't believe that mental health services will change unless the people who use services have the power to monitor behaviour/attitude of staff (including their reviews/appraisals) – from top down. Service users need the power to ensure services is accountable to them. They need the power to genuinely recruit and discharge staffs (including managers) who fail to do what they say they do. They need the power to be a part of the complaint procedure and to ensure that organisations cannot hide behind statutory.*
- *Citizen power.*
- *To paraphrase Rogers, that it is the client who is the expert, the one who knows what hurts and ultimately, the one who knows the way forward...*

- *Remembering we all need to be treated as individuals! And have equal rights with a need to be heard.*
- *Lack of service user voice in services and all areas of mental health.*
- *More user led groups and support.*
- *Peer support.*
- *Having voice heard legitimately.*
- *Using service user experience to inform practice, policies and learning from what went wrong as well as what went right.*
- *Users having their voice heard.*
- *Trying to influence local services to involve its patients and carers more in service design.*
- *Valuing me as a carer for two complex health conditions...*

3. Welfare reforms and social inequalities faced by people with lived experience

- *Austerity, we are attacked from all angles, discharged from services, sanctions, humiliating work capability assessments, all wrapped up in a bow of "recovery" and "personal responsibility".*
- *The toxic social climate created by austerity.*
- *Austerity/neoliberalism.*
- *Change the Governments mental health policy.*
- *Benefits changes and distress caused.*
- *Not to be victimised by society, trying to shame us, due to mental illness. It fall outs in discrimination, benefits, housing, work, etc.*
- *GETTING THE RIGHTS OF USERS LEGALISED IN LAW AND KICKING OUT THE TORIES!!*
- *My welfare benefits! I'm constantly terrified of losing my money and of them being reduced! And the way the 'system' treats us with MH problems. PLEASE HELP US!*
- *DWP assessments and their impact.*
- *An organisation that will get to grips with where the system is failing to protect vulnerable people.*

4. Rethink the medical model / use of medication

- *Alternatives to medical model.*
- *Prevention. Relegating the medical model and the dishing out of drugs like sweets to history. Waking everyone up to common sense that social, physical and environmental factors have a HUGE part to play in preventing poor mental health. Until society recognises this and genuinely seeks to address it, we're a long way off improving the nation's mental health.*
- *The almost universal use of toxic medication which causes physical, mental and psychological damage and early death. Highlighting the way greedy multinational drugs companies have taken over the treatment of mental distress and doctors disregard the suffering this is causing as they are only interested in controlling patients whatever the cost.*
- *More people are being sectioned than ever before but there are less NHS beds in local areas so many people are being hospitalised in out of area private sector hospitals. The medical model is clearly ineffective and*

unsustainable. Consequently we need to develop and embrace proven alternatives such as Peer Supported Open Dialogue approach.

- *The risks of medication.*
- *How important is medication, given that there're variable side-effects, & if it can be dispensed with: are the alternatives sufficient for health.*
- *Medical research leading to improved medications with fewer side effects.*
- *Empowering self-management strategies that can help us live without medication and health inequalities and premature death caused by medication, e.g. diabetes, obesity, dementia.*
- *Personality Disorder labelling and welfare.*

5. Improve and develop services (through person-centred, holistic models of care)

- *Improving services nationally.*
- *Probably helping to build organizations that can produce better understanding of mental illness in all its forms.*
- *Improving UK mental health service delivery.*
- *Awareness, changing attitudes and encourage open and honest communication, person-centred care and make sure staff are aware that some of the small things they do can make a huge difference to someone's life - good or bad.*
- *Redesigning treatment pathways to reflect the needs of service users, changing the status quo as necessary.*
- *That mental health services focus on all aspects of individuals' wellbeing including to enable them to deal with what is contributing to their mental health issues as opposed to a 'mental illness'.*
- *I want to recover, so what is the best treatment for my unique needs and a personal support plan that looks at me holistically.*

6. Raise awareness (challenge stigma and discrimination)

- *Reduce stigma (x 4)*
- *Increasing public and institutional awareness and accurate understanding of mental health matters (prevention, disease, treatments, accommodation in everyday life, etc.) and eradicating stigma.*
- *Restoration of self-esteem, requiring debunking of stigmatising myths, providing quality of employment, and enforcing reasonable adjustments in the workplace.*
- *Public awareness.*
- *Society openly connecting and/or reaching out to each other as mental wellbeing should not be a selfish characteristic, should be an act of kindness or selflessness everybody takes ownership of. Everybody has some level of psychological or physical disability or ability it's part of being human and depends on perspective.*
- *That it is sound and the stigma surrounding mental ill health will have vanished*

7. Wellbeing (care of self and others)

- *Independence and self-help coping strategies.*

- *Learning variety of ways to calm whilst parenting my daughter as single parent important support for families supporting their children.*
- *Better wellbeing.*
- *Self-care/recovery.*
- *Recovery.*
- *Being able to feel that life is worth living.*
- *TO LEARN AND IMPROVE MY LIFE AND THE CHANCES OF OTHERS IN MH.*
- *Creating a world where people don't suffer anymore.*

8. Funding for services

- *The lack of funding.*
- *Funding!*
- *Underfunding.*
- *Funding for care and support.*
- *Cuts to benefits and services*
- *More funding for mental health.*

9. Human Rights

- *The Mental Health Act and state coercion.*
- *Stop doping us and start healing us!*
- *Incarceration.*
- *The fact that I always feel doctors are lying to me and covering for the mistakes of others such as a surgeon who harmed me in the operating theatre in 1980. Doctors are even prepared to lie in court under oath!*
- *Following up new legislation and the general consensus like now.*

10. Parity of esteem with physical health

- *Parity of Esteem between mental and physical health.*
- *Parity of esteem and parity of funding.*
- *Parity of esteem with 'other' areas of health and social care.*
- *Making a reality of parity of esteem between physical and mental health, opens lots of doors to implementing UNCRPD and equality in benefits entitlement etc.*

Appendix A – List of Local Groups

Respondents were connected to the following mental health groups/organisations in their local areas:

- *The Haven Project, Colchester*
- *Carers Network Beethoven Centre, London*
- *Waltham Forest Bipolar UK Support Group*
- *Harmony Health Hub, Waltham Forest*
- *Chapter, Cheshire*
- *Mind*
- *Time to Change*
- *Barnet Voice for Mental Health*

- *Dragon Cafe, London*
- *Capital project, West Sussex*
- *Mind Cymru Npt Cvs Participation Cymru Disability Wales, Bridgend Coalition of Disabled People (BCDP) Hafal member*
- *Together, Equal lives, Norfolk*
- *Kindred Minds, Lambeth Healthwatch*
- *Caerphilly Borough Mind, South East of Wales.*
- *Bristol independent mental health network, Bristol survivors, Bristol hearing voices group*
- *Healthy Minds, Calderdale Well Being*
- *London Depression & Associated Problems meetup*
- *ASK service user group*
- *LAMP and Network for Change in Leicester*
- *TEWV Experts by Experience group - North East*
- *Autscape peer support group for adult autistics in Reading, Reading and Wokingham CMHT*
- *Mind, Sure Search, Birmingham leisure forum, NHS*
- *AA (alcoholics anonymous)*
- *MindSet*
- *Stockport Progress and Recovery Centre; Stockport MIND; Stockport User-Network Service; and Stockport User-Friendly Forum.*
- *Healthwatch and RBKC MIND*
- *FEEL-Campaign, Mental Health Resistance Network, Dragon Café, Cool Tan Arts, Hammersmith and Fulham Mind, Hoarding Peer Support Group, Crisis Skylight Wellbeing Forum. All in Greater London.*
- *Mind Neath Mental Health Matters, Bridgend Sun Group Neath Port Talbot*
- *Together, Equal Lives, West Norfolk Mind, Family Action*
- *Abergavenny User Group - Wales*
- *SANE in London, Islington.*
- *West London Mental Health Trust*
- *Community Support Network South London (CSNSL), a mental health advocacy organisation*
- *Together in Hastings and Bexhill*
- *Milton Keynes Mental Health Board Meetings*
- *Cooltan Arts, South East London Direct Action Networks*
- *Drop the Disorder*
- *Young Dementia UK Alice's Tea Party*
- *Campaign to Save Mental Health Services in Norfolk and Suffolk; Equal Lives, Norfolk.*
- *Arts and Health South West*
- *Making a Difference Alliance*
- *Sussex Partnership Heads On, Time to Talk, Mind*
- *Reachout in Kent*
- *North East Together*
- *Mind, Heads-Up Ealing and the West London Collaborative*
- *Women's strategy group*
- *Brent Mental Health User Group, also a MAD Alliance advisor for north west London*

- *Mind Westminster*
- *Camden and Islington Foundation Trust*
- *Mind both in Westminster & Wandsworth, UFM, under umbrella of Advocacy Project Nth Kensington, little connection to MAD Alliance in CNWL area*
- *Westminster Mind*
- *Making a Difference Alliance, Rethink, Mind*
- *Ekta under Mind organisation, Housing, Bridge, Carers*
- *Daventry Mind*
- *FEEL RITB MHRN DPAC Survivors History Group*
- *Wiltshire Mind Richmond Fellowship*
- *Lincolnshire Partnership NHS Foundation Trust*
- *Gateway Centre, Rathmines, Dublin, Ireland*
- *Camden CCG Service User and Carer Working Group, Service User Research Forum at UCL Camden Borough Users Group. The Side By Side Network (primary care) Evolution (clinical strategy) GP 's PPG group.*