

NSUN Member Survey Report (2015)

Summary of Findings

- **80** NSUN members completed the survey.
- **81%** of respondents have a **positive perception** of NSUN.
- **83%** of respondents agreed (or strongly agreed) that they **felt connected** to a wider network of people as a result of being an NSUN member.
- **77%** said that NSUN had **helped to strengthen the service user voice**.
- **91%** 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.
- **78%** 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.
- **68%** agreed (or strongly agreed) that they had **taken up involvement opportunities**.
- **72%** agreed (or strongly agreed) that they were **more informed of their rights**.
- NSUN **needs to improve its regional presence and representation**, lobbying and campaigning work, diversity of membership, funding/resources and communication.
- Respondents value NSUN's ability to **share and communicate information** through the weekly bulletin, website and social media.
- Respondents also value NSUN's **user-led ethos** and **sense of solidarity and community** within the network.

"The training I received from NSUN has been a terrific help. I feel better in myself, more relaxed and at ease. I feel more confident".

"I get so fed up with a lot of the professional 'spin' stuff that goes on. NSUN talks my language!"

Top 10 Issues in Mental Health

- 1. Access to timely and appropriate treatment and support**
- 2. Funding cuts to services**
- 3. Genuine co-production and empowerment**
- 4. Welfare reforms and social inequalities faced by people with lived experience**
- 5. Raise awareness** – challenge stigma and discrimination
- 6. Human Rights** – freedom from coercion, forced medication and the use of the mental health act
- 7. Rethink the medical model**
- 8. Better service provision for specific groups** – young people, mothers, older people and BME communities.
- 9. Parity of esteem with physical health** – particularly with regard to funding, support and waiting lists.
- 10. Early intervention and prevention**

This report explores the main findings emerging from the Member Survey 2015 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

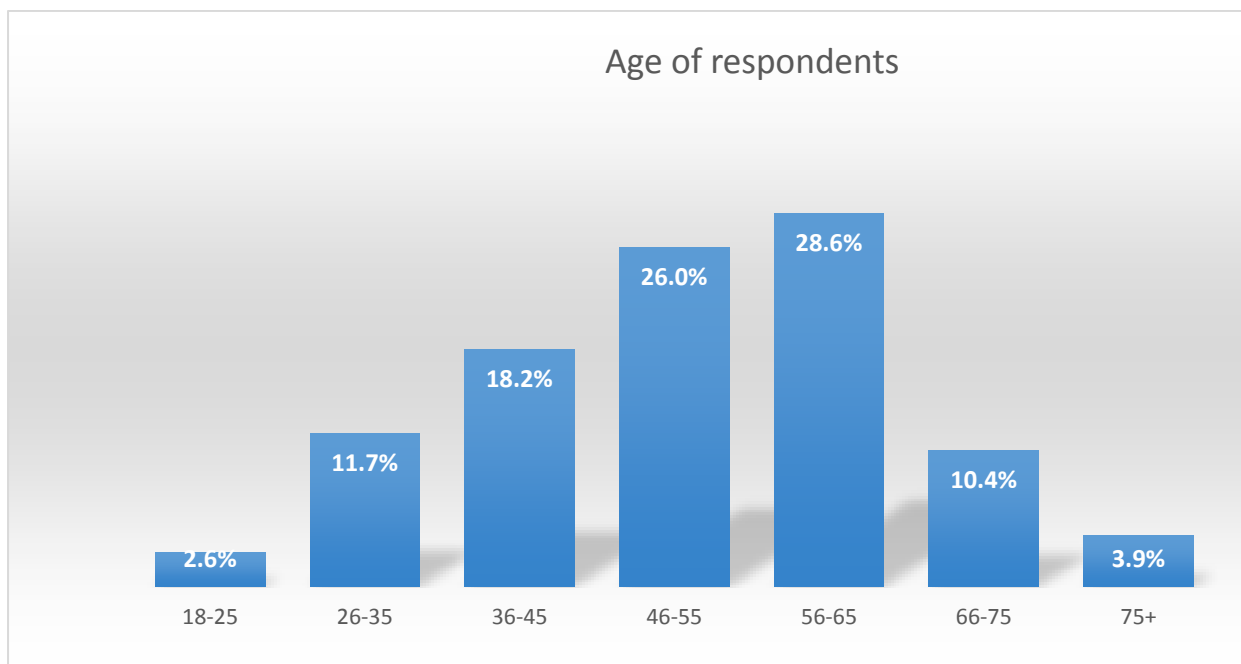
- Members have the opportunity to be involved (including excluded/ marginalised groups) locally and nationally
- Members have influenced local and national decisions as a result of NSUN activity.

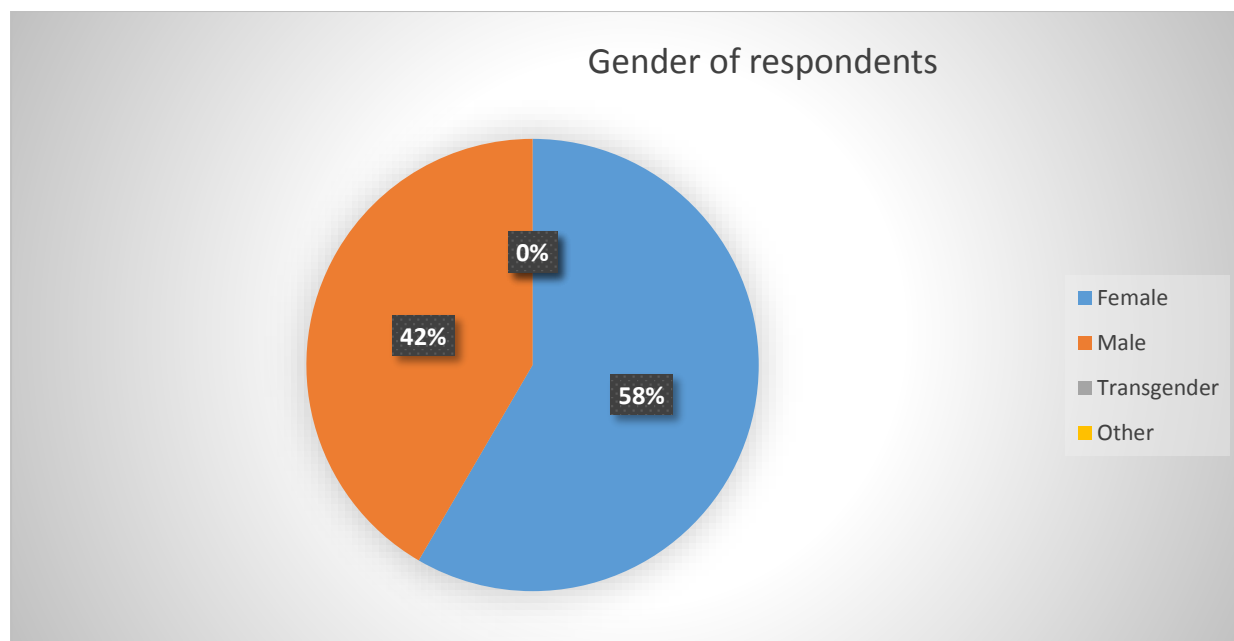
About the respondents

80 NSUN members completed the survey.

53 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 sexuality of respondents.





Sexuality

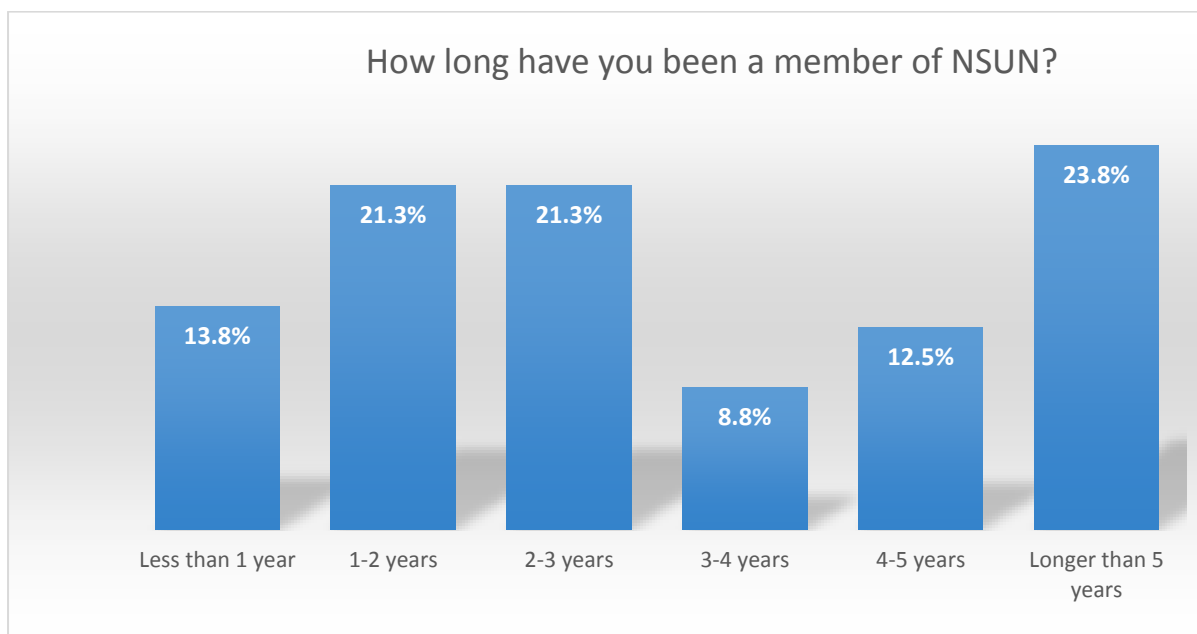
Sexual orientation:		
Answer Options	Response Percent	Response Count
Heterosexual	74.0%	57
Bisexual	9.1%	7
Gay Woman/Lesbian	9.1%	7
Gay Man	0.0%	0
Transgender	0.0%	0
Other	5.2%	4
Prefer not to say	5.2%	4
<i>answered question</i>		77
<i>skipped question</i>		3

Ethnicity

Ethnicity:		
Answer Options	Response Percent	Response Count
Asian or Asian British (*Bangladeshi *Indian *Pakistani *Other Asian background)	1.3%	1
Black / Black British / African / Caribbean (* African *Caribbean *African Caribbean *Other Black background)	3.9%	3
Chinese (*Chinese British *Other Chinese *Other)	1.3%	1
Mixed / Multiple Ethnic Group (*White and Black Caribbean *White and Black African *African Caribbean, *White and Asian *Chinese British *Other Mixed *multiple ethnic background)	1.3%	1
Other Ethnic Group (*Arab *Irish *Other)	6.6%	5

White (*British *English *Welsh *Scottish *Northern Irish *British Irish)	82.9%	63
I do not wish to declare my ethnicity	3.9%	3
answered question		76
skipped question		4

The majority of respondents were in the 36-45, 46-55 and 56-65 age categories. There were very few respondents in the younger and older age categories. **58%** of respondents were women, **74%** were heterosexual and **83%** of respondents were white. It is not possible to assess the representativeness of the respondents in relation to the overall member demographic at present because we do not gather this information when recruiting new members. **80** NSUN members completed the survey which is 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 etc.
- 3. Raising awareness of mental health issues** – campaigning, lobbying, representing and promoting the voices of people with lived experience.

AND...

- Supporting service users and survivors
- Engagement with service users, professionals and organisations
- Inclusive and accessible ethos
- Influencing policy at national level
- Advertising and creating involvement opportunities
- Championing the rights of mental health service users
- Organising events and meetings
- Opportunities for participation in research.

"The organisation is friendly and non-judgmental".

"A sense of solidarity out there beyond the immediate experience of services".

"...individual service user voices are valued – not a token person being the 'service user voice' for everyone".

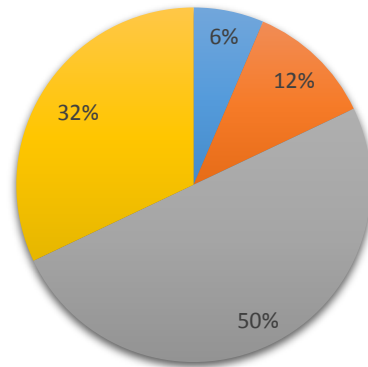
Networking

Connection and Peer Support amongst membership

Only **39%** of respondents stated they were members of a local group (which is a decrease from last year by 11%). Although it is possible that respondents could be interpreting this question as being a member of a 'local NSUN' rather than a local service user group (see discussion in the survey report from 2014) this continues to be a noteworthy finding regarding the importance of NSUN's role in connecting individuals who may not be connected with other people with lived experience in their local area. (A table of which local groups the survey respondents were members of can be found in Appendix A.)

83% of respondents strongly agreed or agreed that being a member of NSUN made them feel connected to a wider network of people.

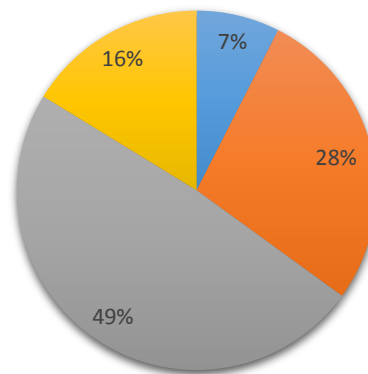
I feel connected to a wider network of people



Strongly disagree Disagree Agree Strongly agree

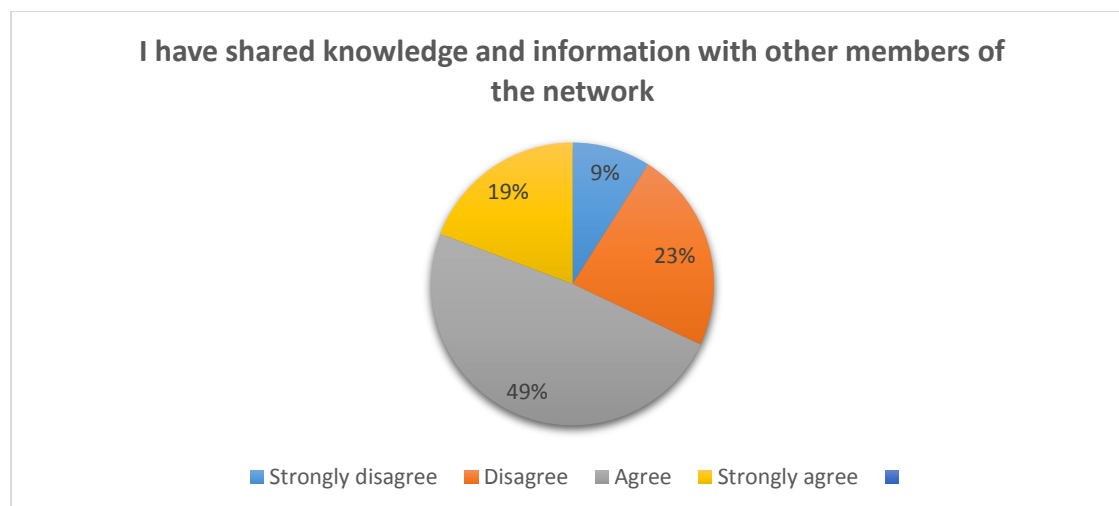
65% strongly agreed or agreed they had connected with other members of the network.

I have connected with other members of the network



Strongly disagree Disagree Agree Strongly agree

68% strongly agreed or agreed that they had shared knowledge and information with other members of the network.

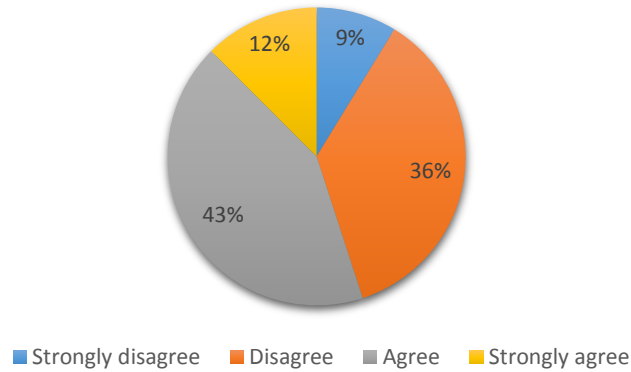


These figures are very similar to those from last year. Once again, there appears to be a greater *feeling of connection* to a wider network than an actual practical connection. Although **83%** of respondents feel connected to the wider network, it is also important to continue to explore why some members do not feel connected (eg. due to lack of regional presence), how members can take greater ownership of the network, and also to improve the ways in which NSUN can facilitate further connections and knowledge sharing between members (eg. through events and meetings as well as online).

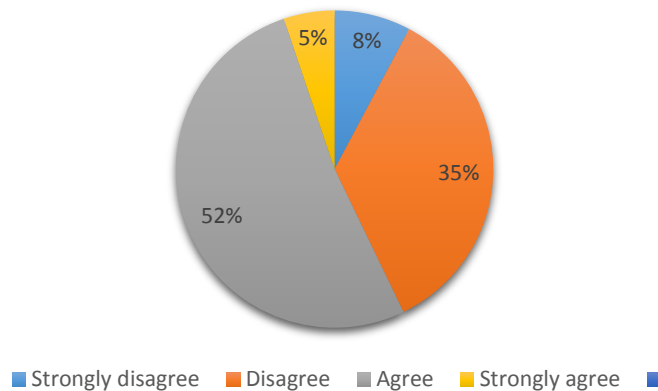
In the 2014 Members' Survey, 42% of respondents disagreed and 12% of respondents strongly disagreed that they had received peer support from other members of the network. However, other findings indicated that NSUN's atmosphere was seen as supportive and that members' were connecting with each other, which was possibly at odds with these findings. This raised the question of whether respondents were interpreting the phrase 'peer support' within the formal definition of the term as opposed to more informal, mutual support. Follow up telephone interview data appeared to confirm this, as several members who had disagreed with the statement 'I have received peer support from other members of the network' confirmed that they had interpreted this as formal 'peer support' (eg. through a specific programme or project) and that they *had* received informal support from other members of the network.

As such the statements in this section were rephrased this year to 'I have provided support to other members of the network' and 'I have received support from other members of the network'. **55%** agreed or strongly agreed that they had received support from other members of the network. **57%** agreed or strongly agreed that they had provided support to other members of the network.

I have received support from other members of the network



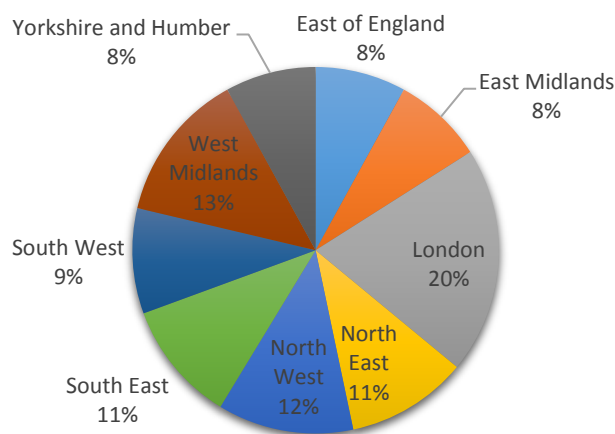
I have provided support to other members of the network



There is scope to improve these figures and explore within telephone interviews about how best to create better connections and opportunities to receive and give support within the network.

Regional Presence

Region



20% of the respondents were from the London area, however the percentage of respondents from other areas ranged from **8% - 13%**. Survey respondents outside of London were therefore fairly evenly spread across the country.

82% of respondents did not think that NSUN had a strong enough presence in their area. Some respondents also commented that NSUN continued to be too 'Londoncentric'. This finding has been consistent in all NSUN member surveys to date.

You are LONDON based!

Not a lot outside of either north or London.

It's very southern orientated and the north west very rarely gets a mention.

No groups or activities in the East Midlands.

Birmingham, not really.

Maybe if I lived in Newcastle...

Not aware of anything beyond e-mail contact this year.

In a similar manner to the survey findings last year, several respondents mentioned that there wasn't a 'local group' they were able to join in their area. Others were aware of NSUN activities that were taking place in their local area, but living in a rural location meant that they were unable to travel there. Many respondents also highlighted the need for NSUN to be promoted more widely:

Not sure if our CCG, Mental Health Trust and London Borough are aware of it.

I have never seen an NSUN poster in any NHS waiting room.

Every time I mention it I have to explain what it is.

Not enough is known by others.

I don't think many people in my area have heard of NSUN, maybe it would be a good idea to raise awareness among professionals as well as service users and carers.

Still only limited profile unfortunately.

Perspectives varied as to whether responsibility for regional presence and promotion rested mainly at an organisational level, or with the membership (with support from NSUN). For example, one respondent stated:

Somehow your presence is not noticed you need to promote yourselves in day services, mental health units.

Other members volunteered to organise local activities and promote NSUN's work, but needed support to do this:

I am willing to organise a local group.

Let me be this for you in Yorkshire.

I expect as a service user to represent NSUN and this is what I am trying to do but I would like the process to be more official.

In Oxford, I feel really isolated regarding user involvement! I am working on trying to form an independent, funded user-led group here and would welcome some support from NSUN.

It will be important to speak to these members and follow up their requests for help and support at the telephone interviewing stage of this evaluation.

A few respondents also recognised that current resource limitations were hindering regional activity:

Because it doesn't have enough funding! It does have a good presence and connections considering what it has had to work with. The government and funders really need to embrace the health and wellbeing potential of NSUN's ability to develop empowerment in individuals and involvement/coproduction approaches in organisations.

I am aware that NSUN has been involved in events in Sheffield. I think there is more scope for NSUN to work in partnership with user controlled groups in the area but I think that this activity would require resources that are not currently available.

These responses, particularly with regard to local groups and regional promotion highlight a possible need for NSUN to explain to members what the current limitations on the organisation are (eg. staff numbers, no regional offices etc.), what members can do in their local area, and the kind of support NSUN is currently able to offer.

NSUN needs to get better at...

1. Regional/Local Work

- Better regional and local representation
- Improve regional presence outside London, the south, large population areas etc.
- Work in partnership with local groups
- Help local groups survive
- Facilitate regional group networking
- Enable local activism outside London
- More person to person contact, hold events.

NSUN needs to get better at...

2. Lobbying and campaigning

- Influence government
- Strengthen political stances
- Challenge the government
- Co-ordinate campaigns
- National campaigns re benefits and welfare assessments
- Effective representation on public bodies
- *"Some initiatives are somewhat skin deep ie lack depth – although meant well".*
- *"Training for me to go and promote NSUN work"*

3. Diversity of membership and work with marginalised groups

- Regional and local diversity
- Become more nationally real and representative
- BME issues
- Look at marginalised groups eg. wheelchair users and rural areas.
- Focus on specific groups of service users
- Involve more young people.
- *"Start taking a good hard look at what you have contributed to mental health and service users. We have become a study group for you. Nothing has shifted in terms of race, forensic mental health. Nothing this year you lose my vote of confidence... Get some experienced black empathic workers who can advocate for change".*

4. Funding and Resources

- *"Please survive and have a plan B or plan C to make sure the skills and resources you have built up have a way on continuing, growing in some form".*
- *"If it had more resources it could get on and improve. It just keeps coming back to resource starvation! Find a really wealthy trust fund benefactor!"*
- *"It needs to find a way to secure core funding so it can be stable longer term".*

5. Communication

- *"I think I've had two members of staff promise to get back to me and haven't, which impacts on self worth".*
- *"The colours of the fonts on the e-mail messages. The black background is fine, but the links lack contrast and are difficult to read".*
- *"Update the website, especially local information".*

Awareness and reputation of NSUN

81% of respondents stated that their overall perception of NSUN was positive. **52** of the 80 participants stated that **'information' (collecting/sharing/sending)** or

'communication' (through the weekly e-bulletin, social media and website) was first on the list of what they thought NSUN did well. Other respondents noted it as second and third on the list of what they thought NSUN did well. This was also supported in the answer to the question **'what do you value most about NSUN?'** where many of the respondents mentioned the information and communication with members:

The weekly newsletter keeps me updated.

I really like the news bulletins.

Information from the website is the best.

It tells me what is happening all around the country.

Comprehensiveness – even Gov.UK is represented!

The information NSUN collected and shared was seen to be valuable because it:

- Raised awareness
- Kept members informed about regional activity and current issues in mental health
- Provided opportunities for involvement
- Provided information on policy changes
- Promoted the service user voice
- Made links and connections across the country
- Influenced national work and policy.

The information/communications were described as being "*clear and concise*", "*clearly written*", "*accurate*", "*reliable*" and "*accessible*". Overall, there was a clear feeling that the weekly collection and sharing of information was NSUN's greatest strength and this was closely linked with respondents' positive perception of the organisation.

"The NSUN bulletins point to up-to-date projects, work and research happening in the UK – so each area in the UK doesn't have to 'reinvent the wheel' and we, service users can learn from each other and benefit from learning from each others' experience".

Respondents also referred to **NSUN's ethos**, that promoted a **sense of solidarity** within the network. Several also noted the importance of a national network that **promoted and represented user voices**.

19% of respondents had a neutral perception of NSUN and **3%** stated that they had a negative perception. As discussed in the previous section, the main criticism of NSUN was the lack of local involvement outside of London and lack of regional presence. Other respondents felt that it was important for NSUN to improve its lobbying,

campaigning and political stance, to have a more diverse and representative membership, and to focus more on BME issues and specific groups of service users (eg. young people, wheelchair users, people in rural areas). Several people mentioned problems with communication – that it was difficult to get in touch with staff members in the office, or that requests for information (eg. for groups) were not put on the website. This has been an area of concern in previous years and something that could damage NSUN's reputation. A couple of respondents also felt that NSUN had become a 'clique' of service users with one describing the organisation as *"a club for white academics"*. This feedback needs to be followed up at the interview stage of this evaluation.

What do people value about NSUN?

Information sharing & communication (through e-bulletin, social media and website)

- *"Its ability to co-ordinate and effectively distribute information".*
- *"Information resource, and realisation that I don't stand alone".*
- *"The up to date information about MH events etc. most IMPORTANTLY it has a 'user' feel to it. I get so fed up with a lot of the professional 'spin' stuff that goes on. NSUN talks my language!"*

NSUN's ethos

- *"The organization is friendly and non-judgemental"*
- *"Its honesty and integrity"*
- *"The commitment, professionalism, humility, courage, respect and value"*
- *"Ethos, community feeling, aims, goals and objectives, interest in promoting user voices".*

Solidarity and community within the network

- *"A sense of solidarity out there beyond the immediate experience of services".*
- *"The feeling of community"*
- *"A network of like-minded people"*
- *"Being part of a collective"*

Promoting user voices at a national level

- *"Bringing a strong user voice and understanding the complex systems we need to work within"*
- *"Equality, having a voice, different perspectives valued, individual service users voices are valued – not a token person being the 'service user voice' for everyone".*
- *"The psychiatric authorities cannot dismiss service users' appeals and petitions so easily when they are formally and officially organised".*

That NSUN still exists

- *"That a user body exists"*
- *"Being there, keeping going"*
- *'That it's there, that it is independent'.*
- *"The dedication of staff, trustees and members".*

Capacity Building

Stronger service user voice

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

Regional presence

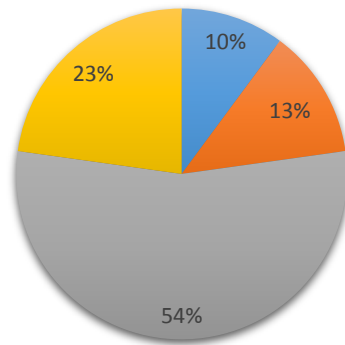
This outcome has been discussed in the previous section. Previous member surveys have highlighted the need for further capacity building in local areas.

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

"I feel like I am better able to understand and use the language/acronyms used by professionals. I am involved in steering groups, working parties, interviewing, conferences, training and much more".

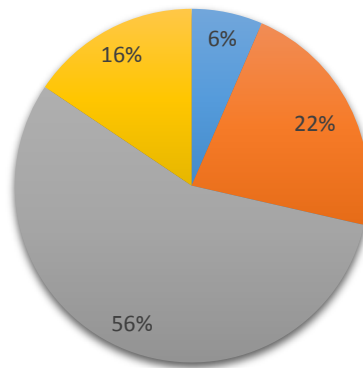
78% of respondents strongly agreed or agreed that they felt more able to get involved to influence service design, policy makers and commissioners as a result of being an NSUN member. **72%** felt that they were more informed of their rights as a consequence of being a member of NSUN. These figures are slightly higher than last year.

I feel more able to and prepared to get involved to influence service design, policy makers, commissioners and others.



■ Strongly disagree ■ Disagree ■ Agree ■ Strongly agree ■

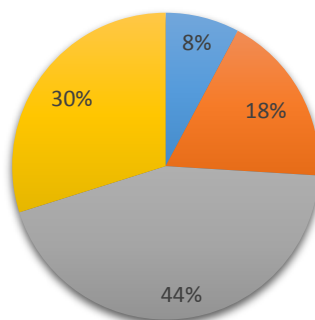
As a member of NSUN I am more informed of my rights



■ Strongly disagree ■ Disagree ■ Agree ■ Strongly agree ■

74% of respondents felt that as a member of NSUN they could add value to bring about change to services and resources.

I recognise the value I can add to bring about change to services and resources



■ Strongly disagree ■ Disagree ■ Agree ■ Strongly agree

36% of respondents stated that they had received support, advice or guidance from NSUN.

Have you and / or your group received support, advice or guidance from NSUN?		
Answer Options	Response Percent	Response Count
Yes	35.6%	26
No	47.9%	35
n/a	19.2%	14
If yes, please provide details and if you were satisfied:		22
answered question		73
skipped question		7

In terms of the structure of the survey, we asked 'Have you/your group received support/advice/guidance from NSUN? If yes, please provide details and if you were satisfied'. One respondent stated:

This survey is very leading... come on I thought you had expertise in research... You don't have the expertise I needed also at times difficult to get hold of anyone.

The survey will be changed next year to read 'please provide details and if you were satisfied', rather than 'if yes, please provide details' so that respondents can feel more able to be critical of NSUN's support, advice and guidance. Feedback on communication and responding to individual requests has already been mentioned in the section regarding NSUN's areas for development.

Although fewer people stated that they had received support from NSUN this year (a drop of 7% from last year) a range of positive examples were offered:

Satisfied with support surrounding a MH lobbying issue.

4Pi gave us credibility at University of Worcester with a generic SUAC service user and carer group.

Payment information for involvement and how this might affect benefits.

I included Chief Exec in to Gov. correspondence. Positive response from NSUN. Signposting for maternal mental health services and how to involve service users – very satisfied.

I have discussed the possibility of developing training based on the 4Pi standards. I was satisfied with the response to my initial proposal to discuss this idea.

I've been involved in developing a project and have looked to them for advice and input. I found Sarah and Naomi's support in particular very helpful.

As discussed in the section on regional presence, some respondents stated that they wanted more support to represent NSUN/set up local groups in their area. One respondent stated that they had not received the support they asked for:

Net Together is very satisfied with support. My local group has had no support or encouragement. When I contacted NSUN about my local group I was asked to send information for the NSUN website which was never posted. I felt discouraged from contacting NSUN again about my work across Teesside. NSUN seem to be able to work better in the south around London.

55% of respondents stated that they had participated in events involving NSUN. The majority mentioned AGMs, but there were also other mentions of:

- Faculty of public health conference
- Kent event
- Crisis summit
- MAD Alliance leadership training
- Human Rights; Gov.interface
- Event in London (Waterloo) two years ago
- Eastbourne service user WMHD events
- Peerfest

There were not as many comments within this section compared to last year which may be a reflection on the fact that NSUN has organised fewer events this year. Several respondents provided positive feedback. One stated that the AGM they had attended had been “enjoyable and challenging”. Two respondents were more reserved, stating:

*Very good and inspiring but hard to keep up the enthusiasm.
AGM, EQUALITY AND DIVERSITY, VALUES. Partially satisfied as no follow up or feedback.*

These findings will require further follow up discussions at interview stage to explore this area in more detail.

Expectations/Reasons for Joining NSUN

Respondents gave a wide range of reasons for joining NSUN but mainly focused on **knowledge, networking** and **connecting** with others, **opportunities for involvement** and **campaigning**:

"To value and promote the voice of lived experience. To support the empowerment of those with lived experience".

"I want to be part of a positive movement for change based on lived experience not just of service users and carers but also of those who deliver services".

"To understand issues across a wide mental health spectrum and access opportunities which may not be available otherwise".

"To make a difference to services locally and nationally".

"To be connected and aware of different opportunities".

60% of respondents felt that their expectations had been completely or mostly met. **29%** stated that their expectations had been partly met and **11%** felt that their expectations of NSUN had not been met at all:

"Tend to feel NSUN is a consultation body. Used by who can pay the bills rather than I suppose a radical strong user voice. Very academic based again service the powers that be. Networking good but overall a bit of a clique for specific users".

"We used to campaign against mental health/diagnosis now you have accepted it... you have become the friendly psychiatrists who purport to be service users... doing research on us. What challenging reports have you written. None. You have become the system that oppresses us. A network a clique. You are a major disappointment. What could have been a dynamic force is a club for white academics".

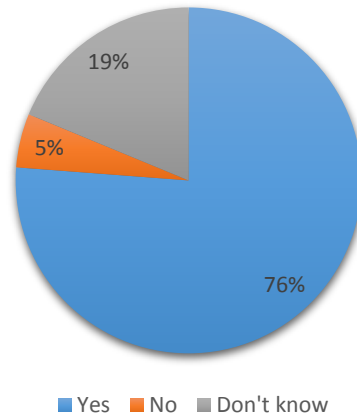
"I wanted to be connected to a wider network but beside Naomi and Sarah I don't really feel that I am connected beyond the region. I also expected more help developing a local voice – more opportunities to network and share experience with other people across the country".

Involvement and Influencing

Stronger service user voice

76% of respondents answered that NSUN had helped to **strengthen the service user voice**. 19% did not know and 5% felt that it had not.

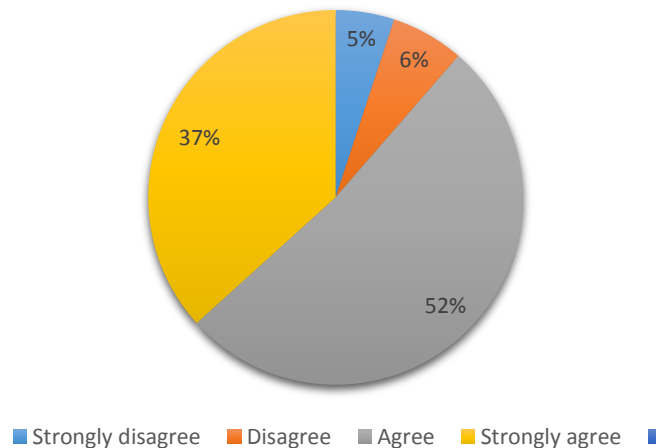
Has NSUN helped to strengthen the service user voice?



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

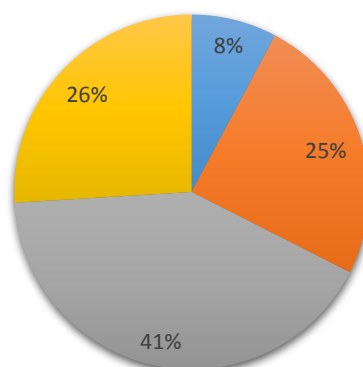
91% of respondents strongly agreed or agreed that they were more aware of opportunities to engage and influence policy and the design, delivery, commissioning and auditing of services.

I am more aware of opportunities to engage and influence policy and the design, delivery, commissioning and auditing of services.



68% strongly agreed or agreed that they had taken up involvement opportunities to influence service design, policy makers, commissioners and others.

I have taken up involvement opportunities to influence service design, policy makers, commissioners and others.



Strongly disagree Disagree Agree Strongly agree

68% of respondents stated that they or their group were more able to inform and influence the things that mattered to them as a consequence of being an NSUN member. Respondents offered a wide range of positive and specific examples relating to further training, project involvement, speaking at conferences etc. For example:

The Irish equivalent of NSUN known as the National Service Users' Executive (NSUE) allowed me to inform service users in South West Dublin of their rights and options in hospital. It also acted as an organisational platform for service user's concerns and recommendations for themselves to management with a hospital in Dublin.

As a result of NSUN I have been employed as a co-designer of mental health and made an impact in my borough. Now a committee rep for 200 service users.

Helping to develop an on-line tool for depression (LSHTM). Helping to advise NHS on psychosis services (McPin)

Norman Lamb's legislation on access times Children's Mental Health Transformation Plan fund.

Respondents stated that they felt more confident and better informed (with regard to their own health but also with regard to influencing services) as a result of being a member of NSUN:

I feel more confident to talk about my mental health.

Gained confidence and know where the most up-to-date information is.

It gives me information which I can use whilst taking part in comments in meetings or on documents.

Can refer to national initiatives when talking about local issues.

I can ask for information about issues that matter to me (e.g. surveys, events, blogs) to be put in the newsletter which is really helpful and I can see what else is happening across the service user network.

Thanks to NSUN I have now skills and reasons and I know ways to influence the system.

The training I received from NSUN has been a terrific help... A positive spin off from the training has been coming into contact with mental health professionals who are very engaged and positive about working with service users and carers. This has given me confidence that the system can be changed to reflect the needs of the service users and not the policy makers and bureaucrats...

Respondents also mentioned some of the difficulties and barriers to successful involvement (often due to the current political climate):

We tried to keep the Joseph Whitworth Centre open, but unfortunately were unsuccessful.

I used to be locally involved but have been removed as a Trustee of my local group after raising concerns re. Governance. I has & continues to be a nightmare.

Tory barriers at every turn. Dismayed even if there is 100,000 people telling them to change policy they don't listen and close their minds.

Influencing a mental health system in which power is absolutely vested and entrenched is, however, hugely problematic. Rattling its cage very loudly is really the best that can be done.

When it comes to Black user involvement or tackling issues of race/discrimination services close shop.

This final quote is particularly important as the data gathered does not specifically address whether marginalised and excluded groups have had the opportunity to influence at local and national levels. This continues to be an area that needs to be explored further.

Top 10 Issues in Mental Health

1. Access to timely and appropriate treatment and support

- *75% of people are currently receiving no support regardless of severity*
- *Appropriate treatment, whether that is medication, talking therapy, peer support or a combination*
- *Recovery and services to support that*
- *Access to appropriate treatment*

- *Access to services without having to jump through endless hoops to qualify. Assessments without all the form-filling. Having a sense of security instead of living in constant fear of future changes that impact negatively.*
- *Need to respect people's needs, lack of appropriate evidence-based services*
- *The bed crises.*
- *Treatment of people in mental health crisis, inpatient care*
- *Improved access to services*
- *Crisis care (or lack of)*
- *How to beat chronic depression especially every morning*
- *Getting support be it OT, SW therapy, medication, GP*
- *Getting CCGs to invite tenders for interventions such as the NIUCE recommended Mindfulness Based Cognitive Therapy (MBCT) 8 week course.*

2. Funding cuts to services

- *Challenging cuts to services (particularly beds)*
- *Funding the voluntary sector*
- *For me in Oxford it is increasing REAL involvement here. Services are being cut and many people I know have been discharged even though they still actually need support. I feel passionately that what we need here is a user-led group run on the lines of Capital or other groups in England.*
- *CUTS TO EXISTING SERVICES THAT PUSH PEOPLE TO SUICIDE!*
- *Cuts to services and misguided rearrangements*
- *Cutbacks and the closure of day centres.*
- *Austerity and effects on people and mental health services*
- *Lack of services*
- *Inadequate services.*

3. Genuine co-production and empowerment

- *Taking the power back from the professionals it is my health – which is more important than their career.*
- *I want to see the development of services and support delivered by people with personal experience of mental health issues for people with personal experience of mental health issues*
- *Connections, meeting quality people (service users and decision makers) with whom I can start to make real change happen.*
- *Service users' experiences need to be listened to and valued by professionals and carers, not ignored or brushed aside.*
- *Challenge tokenism*
- *Having a voice*
- *Fund empowerment practices.*
- *Humanity has been replaced by a malign 'business' model that commodified its service users and dispenses care from a spreadsheet. Front line staff are also regarded in the same way and join service users in being disempowered, disrespected and unsupported.*

4. Welfare reforms and social inequalities faced by people with lived experience (eg. housing, employment, social isolation)

- *Addressing the inequalities faced by those with mental health problems*

- *Benefits cuts*
- *Employment and tokenism*
- *Having a clear mind and stable to address my benefits, housing and responding to letters.*
- *Obtaining stable, sustainable accommodation*
- *Social activity/employment opportunities*
- *Reduce isolation for people, communicate to each borough why buildings are needed. Promote social activities for service users and campaign for them.*
- *Meeting others.*

5. Raise awareness (challenge stigma and discrimination)

- *Discrimination by services, public, friends and family*
- *The way the causes of mental health are understood*
- *Discrimination and stigma brought about and reaffirmed in the discourse/language by government/department of health, psychiatry, society.*
- *Ending discrimination, helping to support those in need and raise awareness in the community to end stigma.*
- *Stigma within mental health services of those who use such services, especially those detained under the Mental Health Act.*

6. Human rights

- *FORCED MEDICATION – hindering recovery*
- *Use of the mental health act, human rights, CRPD*
- *Freedom from coercion. I want the same rights to liberty as members of society that haven't been psychiatrised and I want control over what I put in my body. And I want that for everyone else too.*
- *Medication should not be forced on patients against their will.*

7. Rethink the medical model

- *Abolish the biomedical model*
- *Advice concerning psychotropic medication*
- *Rethinking psychiatry*
- *Medicalisation*
- *The way the causes of mental health are understood.*
- *For in the final analysis our biologies are not our biographies and the definer is not the defined.*

8. Better service provision for specific groups

- *Getting more help for young people who have been subject to violence and sexual abuse. I would like that all young people in care and particularly transitions like late entry get a complete health check including emotional and mental health well-being and that they take part in developing an individual health and well-being plan.*
- *Provision for help for the under 25's and stopping arrests and detention in police cells.*
- *For mothers to access specialist perinatal mental health community services wherever they live in the UK and to be kept with their baby.*

- *Provision for older people all concentrated on dementia, to detriment of those with other mental health issues, IAPT services not age relevant.*
- *BME groups*
- *Forensic mental health services*

9. Parity of esteem with physical health

- *Nationally it is about more real funding being put into MH. Parity of esteem!!!*
- *Need for parity of esteem with physical health – and parity of general/physical health outcomes for people with mental illness*
- *Parity of esteem regarding funding, support, waiting lists etc.*
- *Lack of thought into the relationship between physical and mental health, not enough partnership working (eg. training A&E staff) and too much focus on money.*

10. Early intervention/prevention

- *Early intervention*
- *Prevention must become stronger*

Next Steps

The next stage of this evaluation will be to create a topic guide for member interviews based on the findings of this report and to follow up on specific requests from members (eg. support for setting up local groups).

Appendix A – List of Local Groups

Respondents were members of the following local groups:

- The Bridge Collective, Devon
- Birmingham Mind positive mental health group
- Suresearch (Birmingham)
- Calderdale Well Being (Healthy Minds)
- Barnet Voice for Mental Health
- Oxford Campaigners for Change
- Rochdale Boroughwide User Forum
- DMHCIP, West Midlands
- SUNS, Stockport.
- Worcester Survivors West Mids
- North Derbyshire Mental Health Carers Forum
- Mad Alliance
- CAPITAL Project Trust, South East
- BIMHN Bristol Independent Mental Health Network
- Bristol Survivors
- Hearing Voices Network
- Mind

- Community lived experience organisation, Greater Manchester
- North East Together (NEt, North East)
- Pathways (London)
- Tees Esk & Wear Valleys NHS Foundation Trust (North East)
- SUST, Yorkshire and Humber
- Mental Health Service-user Forum, Lancaster and Morecambe District
- Revision, Liverpool
- Voices for Choices