

Member Survey 2014 Analysis

The following analysis explores the key findings that emerged from the Member Survey 2014 in relation to NSUN’s strategic aims and outcomes as set out in our new evaluation framework. 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.

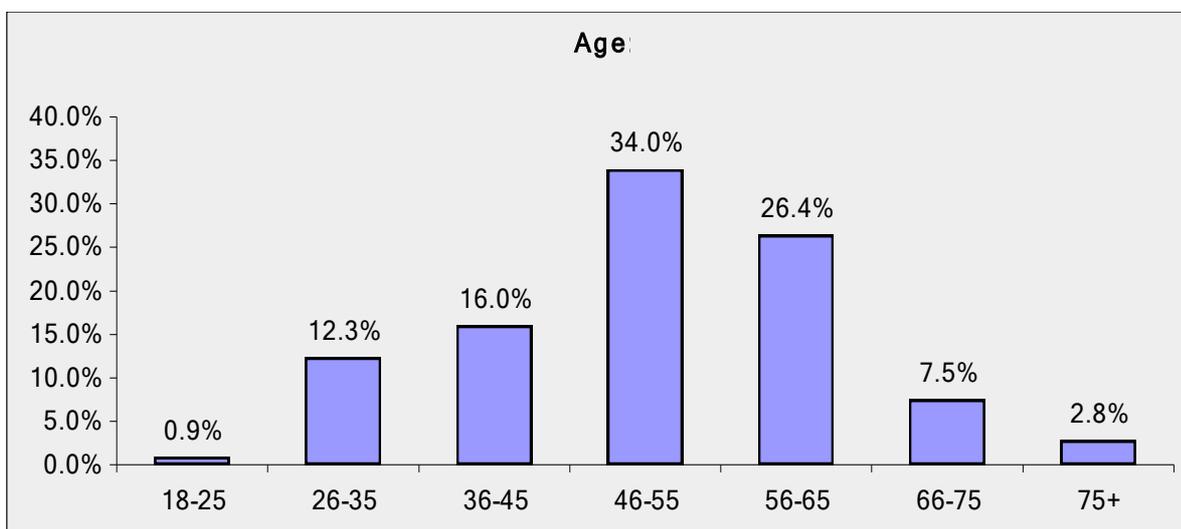
About the respondents

110 NSUN members completed the survey.

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

The tables below set out information gained from the member survey with regard to the age, gender, ethnicity and sexuality of respondents. At present we are unable 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. What follows is the only demographic information NSUN collects in relation to its members.

Age



Gender

Answer Options	Response Percent	Response Count
Female	55.8%	58
Male	44.2%	46
Transgender	0.0%	0
Other	0.0%	0
<i>answered question</i>		104
<i>skipped question</i>		6

Ethnicity

Answer Options	Response Percent	Response Count
Asian or Asian British (*Bangladeshi *Indian *Pakistani *Other Asian background)	2.8%	3
Black / Black British / African / Caribbean (* African *Caribbean *African Caribbean *Other Black background)	2.8%	3
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)	2.8%	3
Other Ethnic Group (*Arab *Irish *Other)	1.9%	2
White (*British *English *Welsh *Scottish *Northern Irish *British Irish)	80.2%	85
I do not wish to declare my ethnicity	9.4%	10
<i>answered question</i>		106
<i>skipped question</i>		4

Sexuality

Answer Options	Response Percent	Response Count
Heterosexual	80.2%	85
Bisexual	6.6%	7
Gay	1.9%	2
Woman/Lesbian	0.9%	1
Gay Man	0.0%	0
Transgender	0.9%	1
Other	9.4%	10
Prefer not to say		
<i>answered question</i>		106
<i>skipped question</i>		4

How long have you been a member of NSUN?

Answer Options	Response Percent	Response Count
Less than 1 year	14.7%	16
1-2 years	18.3%	20
2-3 years	21.1%	23
3-4 years	11.0%	12
4-5 years	13.8%	15
Longer than 5 years	23.9%	26
	<i>answered question</i>	109
	<i>skipped question</i>	1

What does NSUN do well?

1. **Information Sharing** - communicating with members through the weekly e-bulletin, keeping them informed about local and national issues, campaigning activity, volunteering and employment opportunities.
2. **Networking** - connecting people to other service users, organisations, services etc.
3. **Influencing policy** - lobbying, campaigning and gathering service user opinions and experiences and representing these voices at national level.

AND...

- Providing support
- Meetings, conferences and events
- Empowering service users and enabling service users' voice to be heard
- Listening
- Encouraging/providing opportunities for involvement
- Dissemination of information and the production of guides eg. 4PI, Mental Healthwatch, VbC
- Raising awareness of mental health issues/putting mental health on the public agenda
- Promoting equality and diversity.

****79% of respondents have a positive perception of NSUN****

"NSUN enables me to feel part of a whole".

"Keep the genuine unfiltered service user voice being heard".

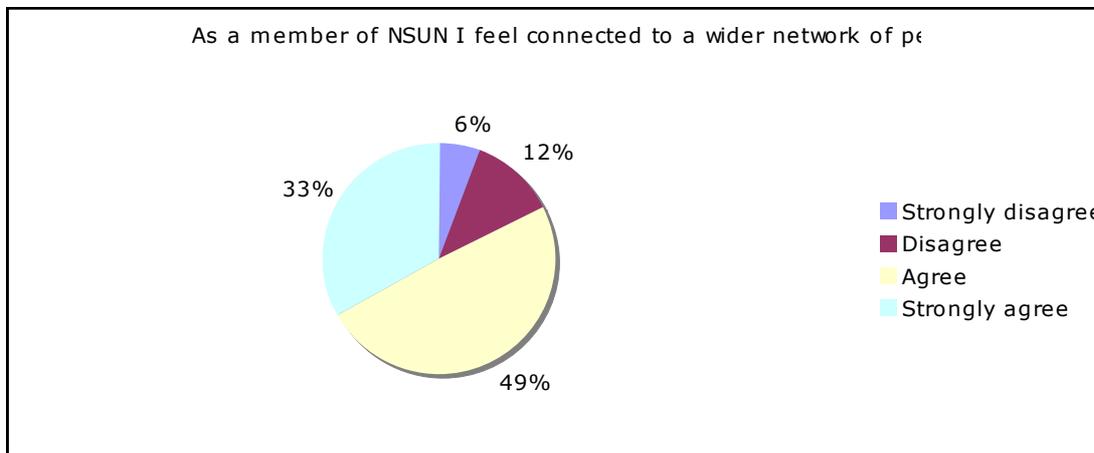
"NSUN has some fantastic members of staff - they are a credit to the organisation".

Networking

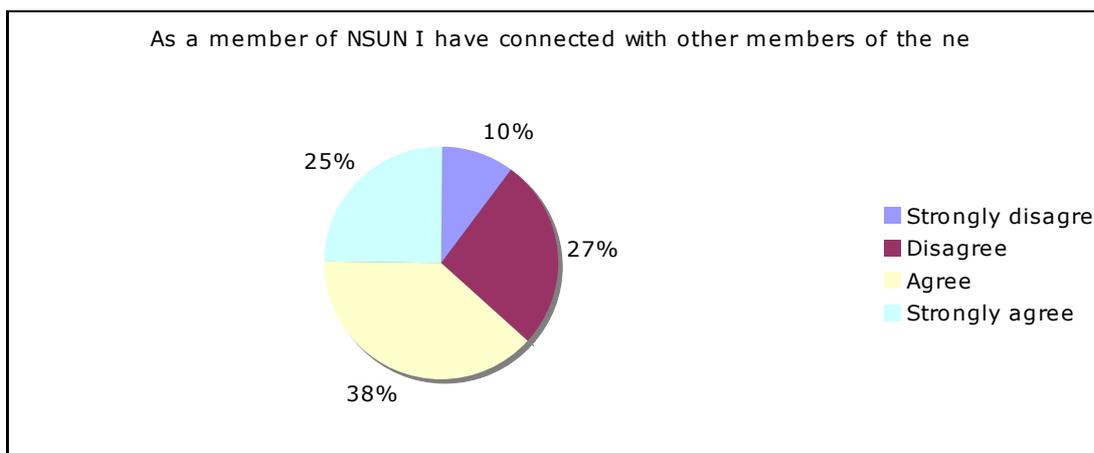
Connection and Peer Support amongst membership

Only **50%** of respondents were members of a local group. This is a potentially noteworthy finding in relation to the importance of NSUN's role in connecting individuals who may not be connected with other service users/survivors in their local area. A table of which local groups the survey respondents were members of can be found in Appendix A.

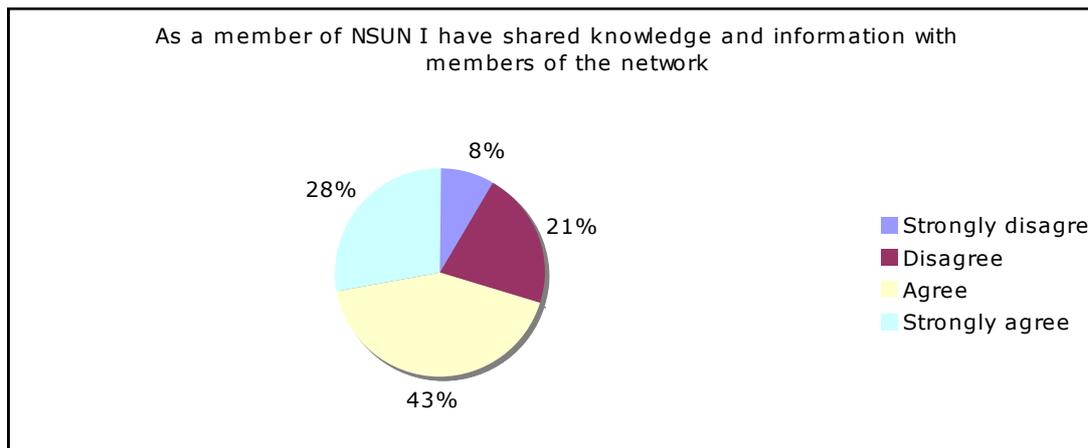
82% of respondents strongly agreed or agreed that being a member of NSUN made them feel connected to a wider network of people.



62% strongly agreed or agreed they had connected with other members of the network.



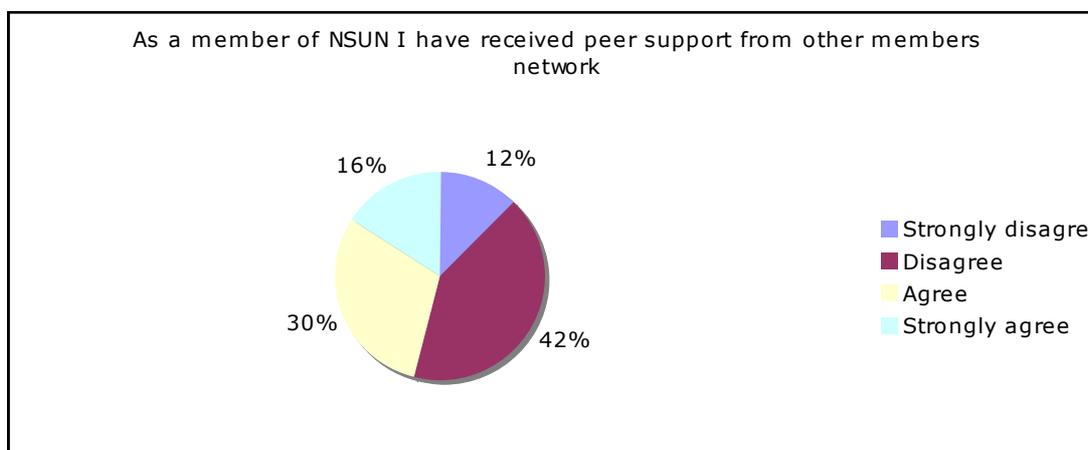
61% strongly agreed or agreed that they had shared knowledge and information with other members of the network.



Among respondents there appeared to be a greater *feeling of connection* to a wider network than an actual practical connection. Although it is encouraging that many members feel connected to the wider network, it would be worthwhile exploring why some members do not feel connected and also to improve the ways in which NSUN can facilitate further connections and knowledge sharing between members.

With regard to **peer support**, **42%** of respondents disagreed and **12%** of respondents strongly disagreed that they had received peer support from other members of the network.

This finding is particularly interesting when compared with other findings (explored later in this document) that highlight NSUN’s supportive atmosphere and indicate that peer support is taking place between members. It is possible that people interpreted the phrase ‘peer support’ within a formal definition of the term. For example, our AGM evaluation did not refer to the term ‘peer support’ but instead asked people to respond to the statement ‘I feel I received support from my peers’. Of the 31 respondents, only 4 disagreed and no one strongly disagreed with this statement. These findings may require further investigation within focus groups and individual interviews.



Regional Presence

34% of the respondents were from the London area and **14%** from the South East, which may reflect the level of local work that has been done in these areas. The percentage of respondents representing other areas ranged between **5%** and **8%**.

82% of respondents felt that NSUN did not have a strong enough presence in their local area. Many felt that it was too Londoncentric:

In spite of my own efforts there has been a lack of engagement in the north and more effort is needed to stop NSUN becoming too Londoncentric due to lack of funding.

Mainly London based.

Everything is down in London.

A number of respondents also noted the lack of NSUN work in their own local area and comments were made along the following lines:

Could do more in s.yorks

I don't hear anything much about Nottingham.

We seem to be out on a limb in N. Lancs.

No presence at all and no user group at all in East Lancashire.

I would like to see more happening around Teesside, I didn't know about NSUN until I was at an event in Newcastle.

There also appeared to be a degree of confusion with regard to whether there were 'local NSUN groups' that people could join:

I live in London SE1 and have been a member of a number of local mental health service user groups and no other member or staff member has mentioned the local NSUN. I would be like to join.

I only chanced upon NSUN and I don't know where to go for a meeting there is no very local group.

As far as I know there are no local groups in Southampton.

Unable to find group. Essex quite rural and I rely on public transport.

No local groups in Camden or North London as far as I know.

Although some respondents may have been referring to 'local groups' more generally, NSUN may need to raise awareness amongst the membership with regard to its aims and intentions with regard to local work (i.e. not to establish NSUN groups, but

working partnership with local service user groups that are already established in local areas).

NSUN needs to get better at...

1. Regional/Local Work

- regional activity and regional representation
- local face to face meetings
- the facilitation of networking between local groups and individual members in local regions.
- listen more to the voices of members from the regions on local needs
- respect user groups
- trust the network to share/run the work on its behalf.

2. Lobbying and campaigning

- be more outspoken and radical
- stay out of the sphere of influence of the RCP
- be more vocal in support of the Critical Psychiatry Network – outside the mainstream.
- Challenging political and psychiatric oppression,
- present advocacy issues more forcefully.
- More direct action re government and psychiatric practices.
- Challenging those in power more.
- Advocating for social justice. Links to disability organisations.

3. Administration, communication and funding

- Be more responsive to e-mails
- Update database records
- Better communication from those leading the organisation
- Newsletters are too business like and can be confusing/ not accurate,
- Make drop down menus on website readable.
- Seek further financial backing for security of the organisation
- More use of social media
- Employ volunteers in regional areas
- Better promotion of NSUN's work.

4. Involvement

- Dissemination of info back to groups after consultations
- involve people earlier in the project process so they can take part more fully, better notice given for events and surveys,
- payment for involvement
- leadership training options
- real/long term opportunities for involvement and participation.

Awareness and reputation of NSUN

79% of respondents stated that their overall perception of NSUN was positive. One of the most common reasons cited was that of NSUN's role in **sharing information and opportunities** to get involved, particularly through the weekly bulletin:

I like the weekly bulletin as it keeps me up to date with all that is happening in mental health activities. The links to other interesting articles are helpful.

From shaky beginnings it has developed into a valuable support and resource full of news, views and important info that we "must have".

It is great to be able to network with people across the country. The weekly bulletin is really informative.

Many respondents also referred to NSUN's **supportive and inclusive atmosphere** that led to people feeling **valued and empowered**:

They have created numerous opportunities for me to be involved in various activities and they have supported me to throughout. They make me feel valued and through NSUN I have met some wonderful people.

I have been listened to and empowered to do work in what I am passionate about.

So far I have met some fantastic people and have been made to feel very welcome, respected and supported at all events I have been part of.

A vibrant organisation with lots of creativity, drive and energy. Feel better for the future of the SU involvement movement after attending one of their events.

Several respondents also praised the staff team:

The integrity and passion of NSUN workers shines through!

The team always very professional and friendly and knowledgeable.

It takes members interests and views seriously. I have found the office to be extremely helpful when I have rung for advice/support.

Respondents also appreciated NSUN's **user-led ethos** and the importance of having a national network that represented the **service user/survivor 'voice'**:

I feel it is unique in providing a direct national voice of survivors.

A voice for service users directed towards the 'so called' professionals is a MUST.

A national network that strengthens our voice.

The survivor voice needs to be heard. Rethink and MIND have sold out.

It gives service users a voice.

NSUN consistently supports service user led initiatives across England.

A few respondents also referred to specific pieces of work such as Healthwatch and the 4PI standards.

What do people value about NSUN?

- **The weekly e-bulletins**

- **The sense of solidarity and community within the network**

It's existence. Knowing that I'm not alone.

- **Having a 'national voice'**

Being able to have the potential to influence the service user/carer voice from a grass roots level to a collective at a national level.

It's national, it has national influence is recognised by other national organisations and is increasing its reach.

- **Being involved and being heard**

The opportunity to be involved and get my voice heard.

Being heard and being valued for the unique person I am.

It's access to such a wide range of people giving a voice to those with lived experience of mental health difficulties.

- **Supportive and friendly**

People I have met and those I contact on line are warm, friendly and helpful.

That you were there for me and held out some kind of hope. I have been able to ask for advice, guidance and support and it has always been helpful. In turn, being able to give something back by way of getting involved locally has been enormously empowering for me.

They are professional, welcoming and non-judgemental. Well connected to decision making processes in London and held in high regard deservedly.

- **Opportunities to participate**

The information, friendship and support I have received, plus the opportunities to participate in initiatives to shape the health system and policy.

They provide fantastic opportunities and are very supportive.

Being connected to others outside of my areas and the variety of opportunities available.

Challenging mental health professionals, talking to policy makers and commissioners.

19% of respondents had a neutral perception of NSUN and **3%** stated that they had a negative perception. Some responded that they were unable to form a judgment about NSUN because they were new members and either did not have enough knowledge to make an informed decision or had not had any direct involvement with NSUN activities.

One of the main criticisms of NSUN was the **lack of local involvement** outside of London and the South of England:

I don't hear enough about local events.

There is not much going on in my area that NSUN is involved with.

Nothing ever gets reported about Lincolnshire.

Too restrictive to London area.

Doesn't reflect where I live - not your fault, I know.

The perceived 'London bias' led one respondent to see NSUN as 'not accountable' and 'unrepresentative'. Several respondents felt that NSUN had more work to do with regard to **communication, partnership working** (both locally and nationally), and **lobbying** the government:

There is always room for improvement. The NSUN message of our mission, vision and profile has to be understood locally and nationally.

Little progress on national change and still local groups get missed out in terms of recognition more work to do on this and lobbying and independence.

I think there is more to do working in partnership with local groups and user and also concerns re lack of challenge of government.

With regard to challenging the government, a couple of respondents also specifically stated that they were keen for NSUN to be more forthcoming in challenging the bio medical model and the political issues of psychiatry.

Capacity Building

Stronger service user voice

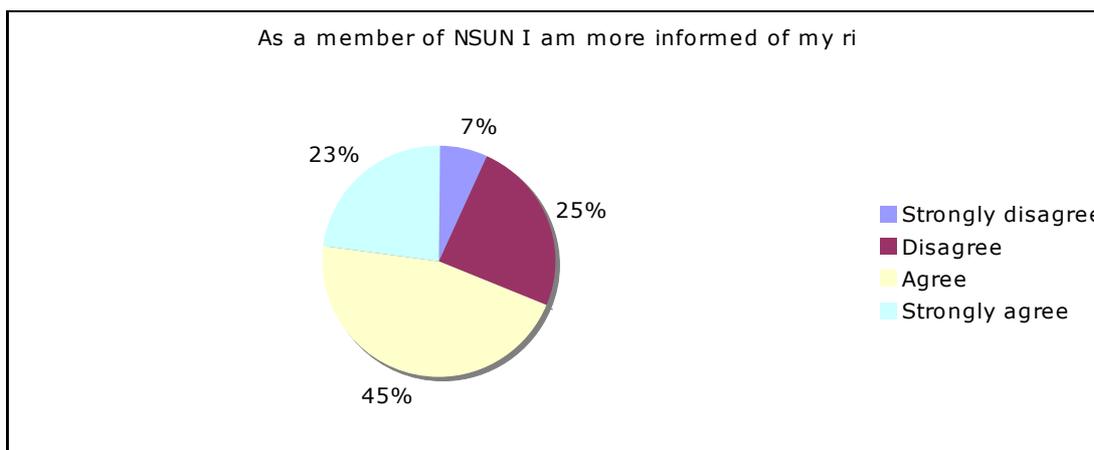
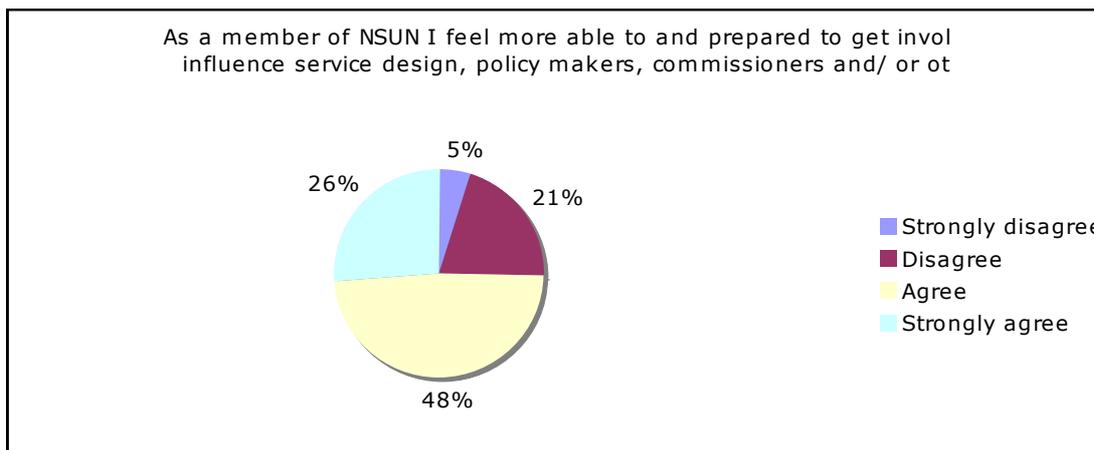
This outcome is explored in the following section on involvement and influencing.

Regional presence

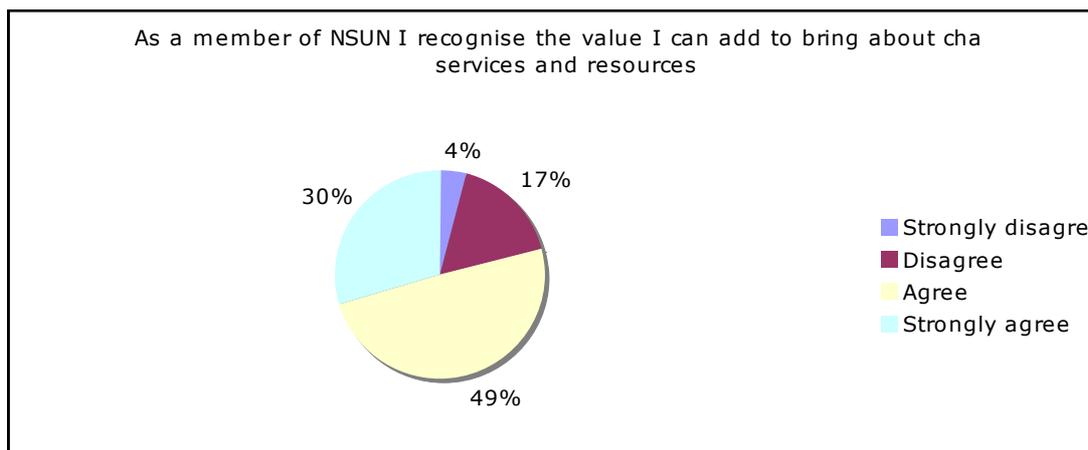
This outcome has been discussed in the previous section. Previous member surveys have highlighted the need for further capacity building in local areas and this is something that NSUN will be focusing on in the next few years.

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

75% of respondents strongly agreed or agreed that they were more able to get involved to influence service design, policy makers and commissioners as a result of being an NSUN member. **68%** felt more informed of their rights having joined NSUN.



It was also encouraging to note that **79%** of respondents felt that as a member of NSUN they could add value to bring about change to services and resources.



44% 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	43.7%	45
No	40.8%	42
n/a	18.4%	19
If yes, please provide details and if you were satisfied:		36
	answered question	103
	skipped question	7

Examples were given from personal support and encouragement, to practical support and advice for groups. Here are just a few examples:

I did a course on peer support/counselling with NSUN, which gave me skills to take back to my group.

I am being supported to progress in my career in mental health as an expert patient. It is very inspiring and grounding to be part of NSUN.

We were given support when we took part in Consultation Events and in relation to other potential projects. We have received financial support, which enabled us to take part on a number of occasions, this is important when people are often living on severely reduced budgets.

Support with events and publicising projects and help with working with national orgs, very satisfied.

The majority of respondents gave very positive feedback and stated that they had been satisfied with the help they had received. However, one respondent stated that after initial encouragement they would have appreciated further dialogue. Another said that the support had been 'OK, but wasn't really understood and NSUN more interested in their own work'.

Also:

I expected to be empowered about my negative relationships to profession of psychiatry and able to stand up to the oppressors to stop using us as guinea pigs for pharmaceutical companies – also wanted to start up local survivors group in Camden but no encouragement.

62% of respondents stated that they had participated in events involving NSUN. The following is a list of events that were mentioned:

- NSUN AGMs
- Peerfest (Birmingham)
- Mental Healthwatch Launch (Lambeth)
- MAAT PROBE (Sheffield)
- London Leadership programme
- Creative leadership course (Newcastle)
- East of England events
- VbC Conferences (London and Manchester)
- Sheffield Sharing Knowledge
- Creating Connections Conference (London)
- International Service User Leadership and Peer Support Festival
- Crisis Care Concordat
- Local events and consultation exercises

Many respondents were satisfied and provided positive feedback:

National enquiry into unsafe discharge from hospital – I felt very well supported and appreciated. I was involved with the creative leadership course in Newcastle, I found this useful, enjoyable and hugely beneficial to me personally and also to my involvement in the future.

Played music at event, and spoke, very happy to be involved.

NSUN have been fantastic, I wish I'd known about them years ago.

However, several respondents were more reserved and made statements such as 'sort of satisfied' and 'they were OK'. This may require further follow up discussions to find out about which aspects of particular events worked well and which did not. Those who were less satisfied with events gave feedback as follows:

London leadership – employed for a year but not given a role which could be regularly deployed. NB – also no strategy for personal projects

Not satisfied. They organised local event, took things over not enough local expertise.

User consultation requested by CCG in Avon and Wiltshire regarding Trusts bidding to provide services. Felt that NSUN were too much on the side of the mental health trust and not willing to transcribe fully enough our concerns.

These comments need to be explored further in interviews and focus groups.

Expectations/Reasons for Joining NSUN

▪ Knowledge/Information

I joined believing I would become more informed. Since then I have become part of a rights movement.

▪ Connections

I was excited it existed. I hoped to find local people near to me and attend events and meet more people.

To feel more widely connected to similar groups and thus have a wider support network.

▪ Involvement opportunities

Opportunities to get involved in shaping future mental health services and support.

▪ Campaigning and Influencing – an active voice

I joined NSUN to try and influence services on a higher level. I want to challenge the views of the people who make the policies that affect those with mental health problems.

That this would give a national voice to service users, bringing groups together to make for a stronger, united voice on the issues that matter.

▪ Support (individual and/or group support)

I felt that I might be able to gain further support and connections for our user-led organisation.

Although the majority of respondents felt that their expectations had been 'completely', 'mostly', or 'partly' met, 9% of respondents stated that their expectations had not been met at all:

[The expectation was] *To feel connected and supported which I do not.*

It is all we have. No alternative and hoped for better but realise difficult. Not enough challenging of recovery being promoted by services.

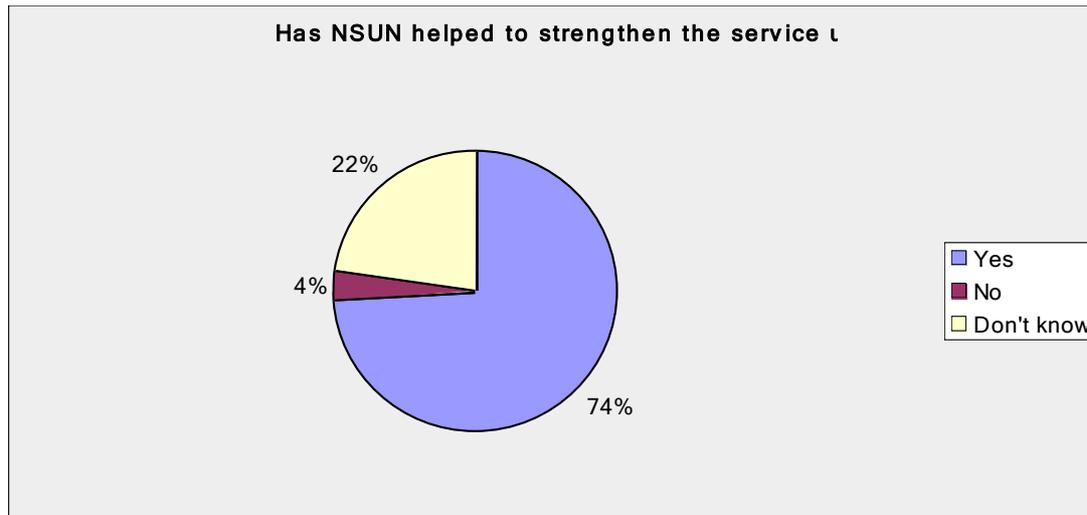
I wanted to join a larger group that would help me with my work and keep me up-to-date with both local and national news. Yet I do not know how to join up with other members locally as I do not know where they are.

Further analysis needs to be done with regard to expectations when running interviews and focus groups.

Involvement and Influencing

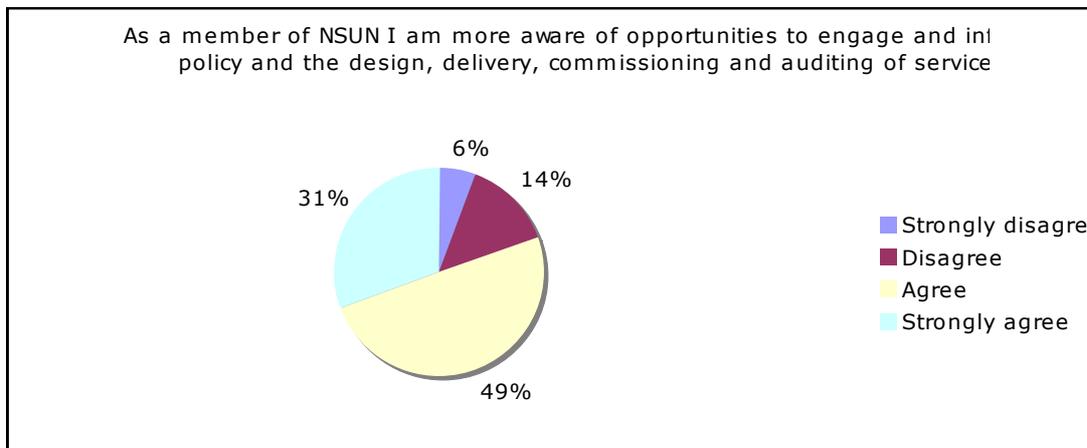
Stronger service user voice

74% of respondents answered that NSUN had helped to **strengthen the service user voice**. 22% did not know and 4% felt that it had not.

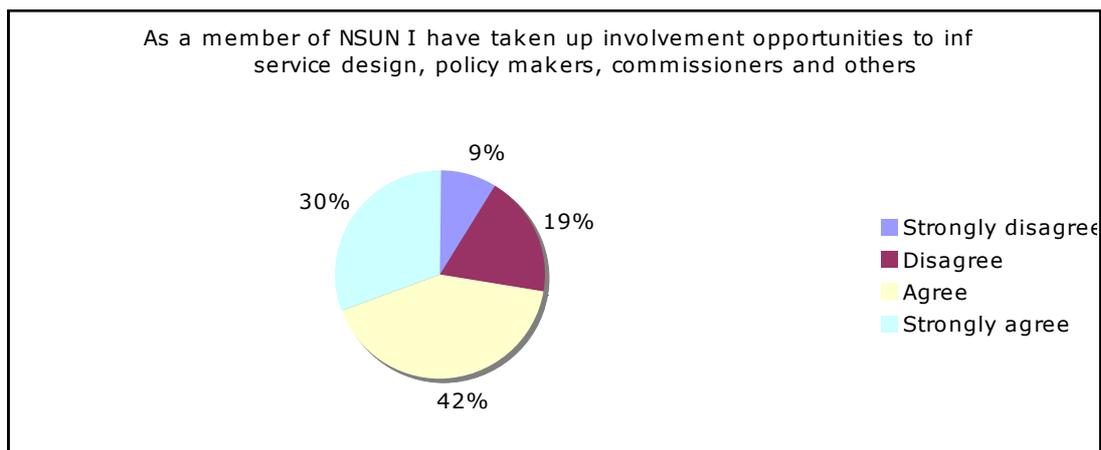


Members have the opportunity to be involved (including excluded/ marginalised groups) locally and nationally and have influenced local and national decisions as a result of NSUN activity

80% 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.



72% strongly agreed or agreed that they had taken up involvement opportunities to influence service design, policy makers, commissioners and others.



When respondents were asked if they or their group were more able to inform and influence the things that mattered to them, **74%** answered ‘yes’ and gave a wide range of examples. Several respondents reported that by being an NSUN member they had grown in **confidence** and that it was helping their **personal recovery**:

I have gained the confidence to attend high-level board meetings through the support of NSUN.

The knowledge that I'm not alone and that there is a 'movement' out there, has given me more confidence to self-advocate in my own care and even to successfully blow the whistle on harmful and dangerous practices in the supported accommodation where I live.

I now am not afraid to give my opinion and be heard as a service user.

I have grown in confidence and am willing to put myself out there more.

I have secured employment with a national service user panel, through responding to adverts on the weekly e-bulletin. It's really helping me to recover personally, and help shape services too.

Others gave examples of how NSUN was helping them to **share information through their own networks**:

I let people in my network of peers know about conferences, training events and other opportunities.

Told my members of Bipolar self help group about this email and the wealth of information. Happy that newsletter covers more activities outside London than in previous years. Regularly knowing about reports and up to date campaigns, job opportunities, developments & social groups and training is fantastic. Thank you.

NSUN’s sharing of information both regionally and nationally was also helpful for some members when speaking to professionals (eg. CCGs) in local areas:

I can always bring in perspectives into various parts of my work and point to the

collective voice and opinions.

I can comment on issues that have been reported on NSUN and refer to the evidence base.

There were also many examples of how individuals (and/or their group) had felt more able to **campaign on specific issues** and **make changes in their local area**:

Input from NSUN at the launch of our Welfare Reform Action Group gave us a national picture and lots of ideas around how we can campaign.

We have had conversations with local MPs including James Morris who is the Chairman of the Commons all party Mental Health group.

I got the daily newspapers delivered to the wards at Lakeside MHU at West Middlesex Hospital.

Bristol Independent Network had a voice in the new set-up in Bristol.

Involved in shaping events like local celebration of World Mental Health Day and Community Connections initiatives.

There are monthly forums now in MK specifically for service users.

Influencing commissioners, retaining day services, opposing bed cuts, mixed wards, anti-stigma forums.

Commissioning of services, payment for involvement.

More informed of our rights as service users.

We have been able to influence our strategy more.

Those who felt that they were not able to influence the things that mattered to them cited old-fashioned attitudes and the professionals/government not listening to the service user voice:

Don't always feel heard and listened by services, who are selective as to what they hear!

I think Government still listens to Rethink and MIND.

Council budgets still tend to cut Mental Health services before others.

Poor networks within Leeds - 1980's thinking/methods.

Sadly not enough professionals are aware of NSUN.

The data gathered does not specifically address whether marginalised and excluded groups have had the opportunity to influence at local and national levels and this is an area that could be explored further in the focus groups and interviews.

Appendix A – List of Local Groups

Respondents were members of the following local groups:

- Bristol hearing voices group
- Bristol independent mental health network
- CAPITAL Project Trust
- Dorset Mental Health Forum
- Service User Network Stockport
- MIND (Kensington and Chelsea)
- Rochdale Boroughwide User Forum
- North East together
- Launchpad (Newcastle)
- Friends of East End Loonies (FEEL)
- Healthwatch (Hackney)
- Mind (Hackney)
- Hounslow Service User Forum
- Suffolk User Forum
- Healthy Minds Calderdale Wellbeing
- Sheffield - CCG partnership board
- Rochdale Mind
- HEAR US (Croydon)
- CAPITAL
- Local Survivors in Partnership (LSIP)
- IMAGINE Mental Health (Manchester)
- CAMHS Youth Group
- Viewpoint (Hertfordshire)
- West London Collaborative
- Hammersmith and Fulham Mind
- SSNMH (South Staffordshire Network for Mental Health)
- Birmingham Mind
- TEWV experts by experience (Tees, Esk and Wear Valley)
- SUN:RISE (Sheffield)
- Sheffield Mind
- Speak Out Against Psychiatry
- Developing Partners CiC
- Clevedon 1in4
- Clarity at Weston
- BIPED
- Shine Lincolnshire
- Sutton Users Network
- People in Mind (PIM), Sandwell
- SUTRA - Service User and Training Association (Waltham Forest)
- Lambeth and Southwark Mind
- Mental Health Reference Group Herefordshire
- Suresearch (Birmingham)
- Paranoia and Schizoid Affective Disorder Support Group, Nottingham