



## Membership Survey 2013 Evaluation

***“Membership survey needs to have an impact on all aspects of the work”***

NSUN grant report: March 2013- September 2013, p4.

### ***1. Membership Survey: issues and potential redesign***

The Membership Survey forms part of NSUN’s evaluation framework and serves multiple functions including:

- Satisfying specific funders and showing that certain strategic objectives are met (i.e. evidencing effectiveness and impact on specific areas such as supporting networks and supporting involvement and influencing etc).
- Informing future projects and practice
- Identifying areas of strength and weakness and driving improvement.
- Evaluating effectiveness of different elements of NSUN’s work i.e. modes of communication (reviewing website, ebuletin etc).
- Evidencing growth and quality of engagement – reflected by increased response rate (particularly in previously less active geographic areas) and higher ratings of authenticity (in terms of user led-ness etc).

Given the importance of the survey with regard to informing NSUN’s work we need to ensure that the data generated is reliable and valid. As NSUN moves towards more structured monitoring through the development of the new evaluation framework, this is a good opportunity to critically assess the membership survey and consider how it can be improved for 2014.

Some issues have emerged with regard to design and delivery that include the following:

- Several different versions of the 2013 survey were in operation at the same time. There is a need for standardisation. Online and paper copies of the survey should be exactly the same otherwise the data will be unreliable and difficult to analyse.
- Paper copies were uploaded onto survey monkey and this introduced additional issues. The numbering and ordering of questions on survey monkey did not correspond directly to the numbering on the paper copy, which was not ideal.
- On the paper survey (2013), many respondents had left blanks, and some had not completed the second side of the questionnaire. Survey monkey, however, does not allow you to skip certain questions. Therefore the only way to upload members’ data was to tick the N/A box for ‘multiple choice’ responses, which

were left black. As such, it has not been possible to draw any conclusions from the N/A box.

- The design of some of the questions could be improved upon. For example, Question 6 asks respondents for their membership status. However, survey monkey only allows respondents to select either 'individual', 'group' or 'ally' membership status, when these are not mutually exclusive categories, so the numbers of members in each category are likely to be underestimates.
- Qualitative questions are excellent for gleaning rich and detailed data, however, the wording of some could be improved and respondents have found them confusing (see Rachael McGill's Survey Analysis for 2012). Concerns relating to specific questions have been discussed in sections 2 and 3 below.
- Although improving, the membership survey response rate is still poor (180 people), representing only a small fraction of NSUN members. This will inevitably be skewed by selection bias (eg. self-selection of participants) and is therefore low in external validity (affecting our ability to apply any findings across the membership more widely). Response bias (in this case the desire to provide an 'acceptable' or positive response) may also be an issue due to the lack of anonymity of responses, as respondents who wish to be included in the prize draw have to list their name and address. Therefore the surveys are not truly anonymous.

Due to the above issues, the data generated from the 2013 survey cannot be relied upon. It is therefore not possible to produce an effective or valid analysis of the results. Bearing this in mind, the results of the survey are tentatively discussed and reflected upon in Sections 2 and 3 of this document.

In order to improve the overall reliability and validity of the survey for future years it needs to be extensively overhauled and redesigned.

It may be helpful to consider these questions as part of this process:

- What are the aims of the membership survey? What do we want to find out? How will it be linked to NSUN's evaluation framework? *(The answers to these questions will help us to make decisions about the type of data we collect, the wording of questions, analysis etc.)*
- Who is our target audience? *(At the moment this is undefined and both NSUN members and some staff have participated in the survey.)*
- How will it be rolled out? Where and when will the surveys be completed and distributed?
- How will the different forms of data (quantitative and qualitative) be analysed? *(The analysis should be congruent with the overarching methodological framework and approach.)*
- How will the data be used and how will it inform our future work? *(Standardising the design, methods, and analysis of the survey will enable us to make more reliable comparisons over time.)*

## 2. Summary of findings

- 80% of survey respondents have a positive perception of NSUN.
- Respondents see us as being a good, reliable source of information and particularly value our communication via the weekly e-bulletin.
- They also value NSUN's networking opportunities, campaigning voice, user-led ethos, and approachability.
- The key issues for members are:
  - *Access to timely and appropriate treatment*
  - *Stigma and discrimination*
  - *Changes to the benefits system and welfare reforms*
  - *Funding cuts/lack of resources*
- Our reputation is that of being helpful, friendly, supportive, and hard working.
- Although we are seen as having 'good intentions' we are also thought to have 'poor visibility' in a number of local areas.
- Many respondents were keen for us to develop our work by supporting local organisations, building capacity for local groups and holding more regional events.
- People are most likely to describe us to others as 'a national mental health network', 'a network of service users/survivors', 'a user/survivor-led organisation', 'a campaigning organisation', and 'an information provider'.
- Issues that could potentially damage NSUN's reputation are a) giving the appearance of taking credit for local work, b) not getting the balance right between our contact with 'bigwigs' and members, and c) poor communication (specifically, not getting back to people and not responding to e-mails).
- We need to think very carefully about how we develop our regional presence and support service user groups/activities in local areas (which survey respondents were keen for us to do) without giving the impression of being a '*national group who piggyback on local efforts*'.

## 3. Findings from the 2013 Survey

## Respondents

180 people completed the 2013 Membership Survey. With regard to 'membership status', 151 people stated that they were completing the survey as an individual member, 12 were completing on behalf of a group and 3 respondents were NSUN allies. 13 respondents were not NSUN members. As previously stated, these categories are not mutually exclusive, however survey monkey only allowed respondents to select one of the categories.

Due to the way in which the survey was designed and administered, demographic data was collected for some versions of the survey, but not others. At the time of writing it is unclear as to how much demographic data is available for analysis. As such, it has not been possible to analyse or comment upon this data.

The largest numbers of respondents were from London (27%, 49 people), the North West (20%, 36 people) and the South East (17%, 31 people). All other areas had between 7 and 15 respondents (see table below).

**Table 1**

London	27% (49)
North West	20% (36)
South East	17% (31)
East Midlands	8% (15)
West Midlands	7% (13)
South West	6% (11)
North East	5% (10)
Yorkshire and Humber	4% (7)
East of England	4% (7)

## Perception of NSUN

The overall perception of NSUN continues to be positive.

132 people (80%) had a positive perception, 28 people (17%) were 'neutral' and 4 people (2%) had a negative perception.

## Issues Raised

The question, 'Are there any particular issues you face as an individual or a group that you would like to share?' existed on one of the two electronic versions of the survey that appeared to be running at the same time. It is therefore important to bear in mind that these findings are only a possible indication of issues faced by members and are not to be relied upon.

The findings for this question have been merged with the question, 'What is the single most important issue for you regarding mental health?' because the responses were very similar. This question could be improved by offering selected categories (with an 'other' option for qualitative comments) so that members can circle the most resounding option. It would then have the potential to produce more meaningful results that could be reported on more emphatically.

Bearing this in mind, the issues identified were:

- Improving access to timely and appropriate treatment
- Reducing stigma and discrimination
- Changes to the benefits system and welfare reforms
- Funding cuts/lack of resources
- Self-defined recovery and self-management
- Education
- Peer support and self help groups
- User involvement
- Recognition of (and support for) carers
- Challenging the medical model

**Access to services, stigma and discrimination, changes to the benefits system and funding cuts** were the issues that were most often mentioned by respondents.

With regard to accessing services, some respondents were not receiving the right kind of support because they did not 'fit' into the necessary criteria:

*'I find that I am hindered because I don't fit into the major categories.'*

*'I have health needs that do not fit into their limited criteria – so some of my issues are not treated & so I am forced to go on without support.'*

Others struggled to access talking therapies (particularly long term talking therapies) through the NHS, or were not made aware of more holistic forms of treatment (such as access to exercise) that they could have been referred to by a GP. A number of people mentioned the funding cuts within the NHS, the lack of adequate crisis care, the reduced number of inpatient beds and the lack of suitable alternatives.

Accessing appropriate treatment and support was particularly difficult for some of the BME survey respondents who wrote of their experiences of trying to access mental health services within a context of stigma and discrimination:

*'I am an African woman, aged 54 years old and have mental health problems. As a BME I face daily discrimination because I am a migrant, and have suffered Race Hate/Harassment for many years... The mental health system stigmatizes us and does not treat us with the respect and dignity that we deserve – just like any other citizen in Britain who has a disability. Access to every service is fraught with barriers that exclude us at every turn!'*

*'Inability to access person centred care as a mixed race person.'*

*'I am on a therapeutic programme it took me to get on after being severely ill. Nobody listened until I broke down. When the therapy ends in early March I will be left with no support again. In my area I am the only Asian-British woman'*

*and have been referred to as the coloured girl. It is sad that one need's to be on death's door to be taken seriously'.*

Another respondent also highlighted the continued discrimination that mental health service users from BME communities continue to experience:

*'Over representation of BME communities in the mental health system AND institutional racism by police, psychiatric treatments, mental health system including the staff.'*

Many respondents identified the need to reduce stigma and discrimination, and improve understanding amongst employers, commissioners, mental health professionals, GPs and the media:

*'I face prejudice when volunteering, if I mention mental health problems, I'm generally not even considered for an interview. People don't want to know. Discrimination in the work place and when looking for jobs'.*

*'The hierarchy staffing culture in NHS, and Berlin wall between staff and service user 'roles' fuels open and subtle stigma problems for service and ex service users and carers'.*

*'The issue of stigma in society. There is still too much misunderstandings and bad press around people with certain illnesses'.*

The two other major issues to be mentioned by respondents were the changes to the benefits system and funding cuts. A number of comments were made along the following lines:

*'Supporting people with benefits is becoming more and more complex with the changes and cuts (I'm a service user but also work in the sector) and outcomes are getting worse for the individuals involved'.*

*'The misuse of WCA interview system to bully and sanction people suffering from mental health through inappropriately sensitive staff, lack of understanding'.*

*I am a member of staff working within mental health and at present the difficulties I am having are due to a lack of funding. It is difficult to get the services and treatments my clients require in a timely fashion'.*

*'Peer mental health group I was involved in lost its funding and had to close. Very difficult now to get the right help'.*

These four key areas relating to accessing services, stigma and discrimination, welfare reforms and cuts to funding are very similar to McGill's findings from the 2012 and 2011 surveys.

**What do you value most about NSUN?**

The question ‘What do you value most about NSUN?’ might benefit from providing specific categories that respondents can circle in order to produce more targeted results. An ‘other’ box could be included to allow for qualitative feedback.

151 answered this question, although many people mentioned more than one thing (see table 2 below). Above all, members really valued regular, **up-to-date information and communications**. 69 people said that they valued NSUN as a good source of information, with 19 specifically mentioning the weekly e-bulletin, 7 mentioning the Network newsletter, and 2 the website.

*‘I value the weekly e-mails – finding out more of what is going on. Looking at things I can work towards’.*

*‘Quality communication through frequent newsletters’.*

*‘Regular communication weekly. Really feel that NSUN is acting on behalf of users and is building momentum strategically and also on the ground’.*

**Table 2: What do you value most about NSUN?**

Info/Communications	69
Connecting people/networking opportunities	16
Campaigning voice/lobbying	13
User-led	11
Approachability/supportive/listening/friendly staff	11
National reach	9
Policy voice/influence	9
Strengthening the service user voice	8
Encouraging meaningful involvement/empowering/combats apathy	7
Events	7
Opportunities for involvement	4
Positive approach	3
Training opportunities	2
Radical	2
Focused/clear strategy/outcomes	2
Inclusive/non-judgmental	2
Nothing/very little	2
The fact it exists	1
How hard it works	1
Trustworthy	1
Mental Healthwatch	1
Regional work (eg. in Leicester)	1

Respondents also valued NSUN’s **networking opportunities, campaigning voice, user-led ethos, and approachability**:

*'I appreciate its friendly and easy attitude. Good staff. The unification of service users under one umbrella. Its influence with the Government. First class regular newsletter'.*

Several respondents also commented on how important it was to have an organisation with **a national reach**:

*'I like it that they cover a wide region of the UK. This seems important as we can share good practice ideas with each other & so help make services for people better. Its been useful having the newsletters & finding out about events & campaigns. I like that they are run by service users & help stand up for service users'.*

*'NSUN provides opportunity to have a collective voice for ALL people with a mental health condition, regardless of where they live in England'.*

*'Being able to take grassroots problems to a national level'.*

### **How relevant do you feel NSUN is to your local area?**

This question would benefit from rewording or adding a short list of specific categories. Rachael McGill provided a critique of this question in her analysis of the 2012 Membership Survey that is worth quoting in full:

*'There were problems with this question in that people interpreted it differently. The lack of clarity is also evident in the large number of 'don't know' answers. Some responded to whether NSUN was doing enough in their region, some to whether the issues championed by NSUN struck a chord locally. Some answered yes or no, but it was unclear whether they saw local relevance as important or not. Some just described the situation in their local area. Unfortunately I think the lack of uniformity about what people actually meant when they answered 'relevant' or 'not relevant' makes these results fairly meaningless. In future, a multiple choice question along the lines of 'no, NSUN needs to do more', 'no, but it is not NSUN's job to do more' etc. might be clearer. Alternatively the idea of **whether** NSUN is relevant needs to be separated out from **what NSUN is doing** in order to be relevant'.*

This question was not altered for the 2013 survey, so the same issues arose. We need to take the feedback from previous surveys on board and redesign this question for the 2014 survey. With regard to the data that was collected, 150 people answered and 30 people skipped this question.

**Table 3: How relevant do you feel NSUN is to your local area?**

Very relevant	34
Relevant	15
Quite/fairly relevant	9
Not very relevant	14
Not relevant	21
Don't know	13

Maybe not in my specific geographical area, but still relevant to me	8
NSUN is more concerned with national relevance	5
Not relevant, but it is the responsibility of members to share information	2
Good London Network	7
London bias	3
Relevance in local areas could be improved upon	9

Specific areas mentioned as not having an NSUN presence locally were:

- Yorkshire/Humber
- Greater Manchester
- Northwest/Lancashire
- Exmouth & Exeter
- Essex
- Worcestershire
- Hounslow
- Nottinghamshire
- Gloucestershire
- Southampton
- Romford
- North West
- Tower Hamlets

Some of the qualitative comments indicated that people living in the London area were more likely to feel that NSUN was relevant to them:

*‘Living in London I feel the whole of London is my local area and NSUN’s relevance a given’.*

*‘Very important in London. It keeps us informed’.*

*‘Very, when London is 1 hour away by train’.*

### **Is there anything you would like NSUN to do that it doesn’t do currently?**

131 people answered and 49 people skipped this question.

One of the themes to emerge from the data related to the **development of local work**. Suggestions include the following:

- Support and develop service user groups and activity in local areas (specifically, the North West, Greater Manchester, Yorkshire and Humber, North East, West Midlands, Channel Islands, Isle of Man and London suburbs).
- Make active links with local organisations and build capacity for local groups
- Hold more local/regional meetings and events across England

- Raise NSUN's profile amongst asian and black organisations in regional areas.
- Get funding for local networks - local NSUN representatives/regional co-ordinators.
- Connect regional hubs to share common themes and pick up new ideas
- Create a list of local NSUN members (who have given permission) so they can get together locally
- Continuing to build and expand in areas of the country where NSUN is already active
- More opportunities to profile local initiatives
- Publicise where we are in local communities

However, at other points in the survey some respondents were critical of NSUN's relationship to local groups:

*'NSUN should be very careful not to imply or take credit for the local initiatives and SU groups who are working in the regions'.*

*'Please give appropriate credit to local groups'.*

*'We have been increasingly concerned about NSUN activities that do not have regard to local groups and could potentially put local groups at risk. NSUN could do much more to use its local groups and not to threaten their existence by seemingly offering the same access and information. We used to consider the value of NSUN was its national relevance and links into policy. Increasingly we are concerned that it could be seen as a potential alternative provider of what us as a local group have spent years developing and building'.*

*'I had great hope for the organisation but as someone working full time in involvement I have yet to see any benefits of their existence locally and when I have asked for help the response had been inconsistent. I have concerns that those working as representatives are doing so in a void with no responsibility to feedback to the wider mental health community or to represent their views and opinions – if this is being done I wonder why a large organisation such as the one I work for is not consulted'.*

Once respondent also warned that staff members needed to get the balance right between 'contact with members and bigwigs'. Perhaps the most critical comment of this nature was the person who answered 'how would you describe NSUN to someone who asks you what it is?' with 'a national group who piggyback on local efforts'. As such, NSUN needs to think very carefully about how work in local areas is planned and delivered.

Other themes to emerge in response to how NSUN can develop its work in the future included:

### **Campaigning on particular issues**

- Welfare reforms and Work Capability Assessments
- Issues relating to employment eg. applying for jobs
- The number of deaths in mental health services
- Locked wards
- Bipolar

### **More work with specific groups**

- BME engagement
- Carers (and a stronger carer voice within NSUN eg. staff member)
- Young people (children and adolescents)
- PTSD and veterans
- Condition specific subgroups

### **Member support/development/training**

- Self-development days (mindfulness/assertiveness)
- More meetings for members other than the AGM
- Support with specific activities eg. to take Mental HealthWatch forward, help to open a drop in centre in Horley, Surrey
- Put on events outside working hours to that people who are working can attend
- Involving people without e-mail addresses
- *'Train me to be a voice for local city/county/service users'*.
- *'Support service users to make the case for service user involvement and link up work that is happening across the country so we can all learn and share'*.

### **Working together and sharing good practice**

*'NSUN could make much more use of its groups and allies to bring in cohesive arguments about national policy drivers that affect all service users – it could do much more to use us to strengthen its position'.*

*'I think NSUN needs to maintain on-going contact and visits to grassroots projects and speak to our members in smaller groups/staff/workers and figure out the many ways NSUN could offer (bespoke) support like small user-run project Kindred Minds. Sometimes it appears NSUN are there to collect membership contacts at big events/conferences but not clear what else is being offered... NSUN have a large database and it would benefit us all if there was some sort of co-ordination of us to group together in order to stay supported – practically financially, spiritually, being acknowledged etc.'*

### **Communication with members**

Respondents were asked to rate their contact with NSUN as 'very good', 'OK', 'poor' and 'N/A' with regard to the following forms of communication: website, telephone, e-mail, e-bulletins, Network magazine, event, and presentation/workshop. There was also an 'other' category, but no opportunity

for members to state what they were referring to when they ticked 'other'. Therefore it is not possible to analyse the data in this category.

The e-bulletins are the most highly rated form of contact, with 94 of 153 people selecting 'very good'. The website and e-mail contact was also highly rated.

	Very Good	OK	Poor	N/A
Website	72	47	1	33
Telephone Contact	37	28	6	82
E-mail Contact	67	37	10	39
E-bulletins	94	29	3	27
Network Magazine	63	64	4	22
NSUN event	47	37	0	69
Presentation/ workshop	31	32	2	88

*'Your people on the phone are really helpful'.*

*'The NSUN website contains lots of useful information eg. about what's going on nationally and locally'.*

*'NSUN have always been helpful in anything I have asked/enquired about and I have never felt anything less than valued for any contribution/attendance at an event I have made on behalf of NSUN'.*

*'Very helpful – staff have been inclusive and supportive and as a new member I have found this very useful'.*

*'My dealings with NSUN usually by e-mail have always been top class'.*

*'I found their workshops and training extremely helpful. I met some lovely people, whom I am still in contact with'.*

*'When I asked for help the person on the phone was really supportive and calm'.*

However, 10 people also thought that our e-mail contact was poor and 6 people stated that our telephone contact was poor. The most common complaint was of **staff members not responding** to queries or requests:

*'I have contacted a couple of people in NSUN via e-mail and had to 'refresh' their memories that I had contacted them... I do know and appreciate people are busy but for me it was a missed opportunity for NSUN'.*

*'I did contact NSUN about getting involved with a piece of work and no one got back to me, which is a real shame and not very professional'.*

*'The London address doesn't answer you'.*

A couple of respondents found our publications difficult to read due to presentation and print colours and one person stated that due to the over subscription of our workshops they had been left out on several occasions.

### ***Has your contact with NSUN improved any of the following areas?***

This question would also benefit from being simplified, possibly restricting the answers to a simple 'yes' or 'no' dichotomy in the first instance. The areas that have been included would benefit from further consideration. For example, Rachael McGill states in her analysis that 'I'm not sure why 'attending events and training', 'attending meetings/groups' and 'online activity – website/social media/forums' were included here – these are simple outputs about involvement in NSUN activities, not outcomes about the effect on groups...'. Furthermore, the question does not allow for clarity about whether respondents sought or expected help from NSUN in these areas. Rather than having an 'N/A' option, it might be better to state that people should only rate a service if they have looked to NSUN to provide it. This question could potentially be redesigned in the light of the Evaluation Framework (for example, focusing on the connection amongst members, opportunities to get involved, links to national and local government and commissioning).

153 people answered and 27 skipped this question. By far the most popular response to this question was that NSUN was improving 'awareness and knowledge of what other service users and/or service user groups were doing' (70 selecting 'a lot'). This was followed by 'understanding policy' (42), 'campaigning/lobbying' (41) and 'research' (40). These results are very similar to last year. Areas where more people selected 'not at all' more than any other option were 'local networking' (41) 'fundraising' (36), 'running meetings/groups' (36) and 'running events/training' (35). Once again these results are very similar to those last year.

### ***How do you describe NSUN to someone who asks you what it is?***

This question elicited a wide range of responses. The most popular responses related to NSUN as 'a national mental health network', 'a network of service users/survivors', 'a survivor-led organisation' and 'a campaigning/lobbying organisation' (see table below). Respondents described NSUN in a variety of ways:

*'An organisation that attempts to represent service users nationally and produce information, guidance and support as well as campaign on 'hot topics' and important issues'.*

*'A brilliant small mental health charity that reaches far afield. By service users for service users. Inclusive and effective. National presence despite small group'.*

*'It's like starting on the first rung of the ladder to getting well'.*

*'A service user organisation with good intention, but with poor visibility, especially locally'.*

**Table 4: How do you describe NSUN to someone who asks you what it is? (137 people answered and 43 skipped this question. People may have mentioned more than one point)**

A national/mental health network/umbrella body	28
A network of users/survivors	20
A user/survivor-led organisation	16
A campaigning/lobbying organisation	16
An information provider	13
Mental Health Charity	9
Working to improve mental health services	8
Represents service users/strengthens service user voice	7
Promoting/supporting user involvement	4
Empowering	4
Brings together service users, providers etc	3
Refer them to the website	3
Raising awareness	3
Don't know/difficult to say	3
A support network	2
A magazine	2
Independent	1
A radical group	1
A website	1
Tackling stigma	1
Refer them to the magazine	1
Nice people who care	1
A way of finding out about involvement opportunities in mental health across the country	1
Promoting good practice	1
A London organisation	1
I don't	1

Comments also tended to move beyond the descriptive and include what people considered to be the qualities and values of the organisation:

*'A well organised and loud network of service users'.*

*'An organisation that works hard to educate people about mental health, empower mental health service users to take a real role in their care and work as a partner rather than patient'.*

*'NSUN is a somewhat mysterious team, though I do sense a strong holding of something that is possible for all of us to be engaged in and supported in around making social changes and liberating ourselves from the oppression of the mental health systems'.*

## **Conclusion**

Due to a number of issues relating to the design and collection of data from the 2013 survey, it has not been possible to produce an effective or valid analysis of the results. As such, this report has been compiled with a view to collating the available information rather than providing a detailed analysis of the data. If any clear conclusions are to be drawn, it is that the 2014 survey needs to be redesigned in relation to the evaluation framework, and consideration given to the methods of data collection and analysis.

With regard to the findings of the survey, one of the key themes appears to be around the development of work in local areas. Although many respondents were keen for NSUN to have a stronger presence in regional areas (particularly in the North West and Yorkshire) some were also critical that NSUN had appeared to take the credit for local initiatives. It will be important to consider these issues when planning and delivering local work in the future.

The majority of respondents continue have a positive perception of NSUN and value our weekly e-bulletin, networking opportunities, campaigning voice, approachability and user-led ethos.

*'I think NSUN is a huge information and support resource – it is also very inspiring and empowers those facing challenges and those in recovery and living with challenges'.*

*'Being a member makes me feel involved and part of something that is both caring and influential. A big THANK YOU to all'.*