



**Independent analysis of NSUN 2012 Members' Survey:** Rachael McGill

**Summary of the survey responses**

**Respondents**

123 people completed the survey.

The largest numbers of respondents were from London (29 people, 23.6%), the North West (27 people, 22%), and the South East (20 people, 16.3%). The other areas all had between 4 and 11 respondents. The North East was the lowest, with 4 (3.3%).

**Perceptions of NSUN**

98 people (79.7%) had a positive perception

23 neutral (18.7%)

2 negative (1.6 %)

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

(some people mentioned more than one thing, so total responses were 151)

**Info/Communications: 55**

Of which 17 specific mentions of the e bulletin, 9 of the newsletter, 4 of the usefulness of also getting postal information and 2 of the website.

Range of issues covered, topicality and practical usefulness were all highlighted.

**User-led: 13**

**Connecting people/networking opportunities: 12**

**Radical perspective/campaigning voice/rights approach: 11**

**National reach: 10**

**Policy voice/influence: 7**

**Fresh approach/new ideas/forward-thinking/proactive: 7**

**Positive attitude: 6**

**The fact it exists: 4**

**Approachability/supportiveness/listening: 3**

**Opportunities for involvement: 3**

**Regional work: 3**

**Awareness-raising: 3**

**Practices what it preaches/authenticity: 2**

**Use of recovery model: 2**

**Events: 2**

**Accessibility: 2**

**Media work: 2**

**Advice: 2**

**Independence: 1**

**Establishing national standards: 1**

### **Quotes**

'Depth and breadth of information, radical perspective and alternative views, not a corporate but grass roots image, an authentic user-led organisation.'

'Info bulletin, range of issues covered. I find bulletins from you absolutely brilliant. Lots of info in bitesize. Always several things to follow up. Great work.'

'Brilliant overview of the most important mental health news. Excellent.'

'The influence NSUN has with other organisations including the Department of Health.'

'That I am well informed regarding the key issues which are affecting all service users and the routes to ensure I am bending the correct political ears, whether local or national.'

'mental health info that is more accessible and seems more radical than other organisations, such as Mind. NSUN first came to my notice because of the judicial reviews they undertook on benefit cuts - excellent – proactivism.'

'New ideas and positive thinking.'

'Positivity: inspires hope for change and aids recovery through involvement and flexible, dynamic approach.'

'That a national organisation to help people with MH issues to have their voices heard actually exists.'

'You give us a stronger voice in shaping policy and services.'

'Friendly and supportive.'

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

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.

**Very relevant: 35**

**Not very, but not NSUN's fault: 5**

**Maybe not to my specific geographical area but still relevant to me: 3**

**More concerned with national relevance: 3**

**Quite relevant: 12**

**Little relevance: 28**

**Irrelevant: 5**

**Unhappy with local network: 1 (South East – no info received)**

**Only relevant to members: 1**

**Haven't explored local contacts yet: 2**

**Don't know: 11**

Specific areas mentioned as not having an NSUN presence locally were Wales (2), Dorset (2), Blackpool, Isle of Wight, London fringes, Central South, East Midlands and north west London.

A number of people suggested they were aware that things were changing, and that they expected a higher local profile for NSUN to come soon.

**Is there anything you would like NSUN to do that it doesn't do currently?  
( or 'that don't do currently', as the survey seems to read...proofread your survey questions, as a few people pointed out!)**

Some people mentioned more than one thing.

**No – happy with current activity: 16**

**Don't know: 6**

**More events/activity in specific local areas: 7**

**More regional networking: 5**

**Increase BME/hard to reach membership: 4**

**Regional member recruitment drives/more local outreach: 4**

**More opportunities for user involvement in NSUN's work: 4**

**Training and advice to local workers/activists: 4**

**More promotion of employment opportunities/employment success stories: 4**

**Mention of specific local services/issues: 3**

**Be more critical in policy work: 2**

**More work with other networks/organisations: 2**

**Provide funding for travel to events: 2**

**More events: 2**

**Offer advice and advocacy: 2**

**Anti-cuts campaigns: 2**

**Be more national: 1**

**More campaigning: 1**

**More grass roots: 1**

**Secret ballot for trustees: 1**

**Regional reps: 1**

**Prize draw/quiz: 1**

**Offender liaison: 1**

**Paid user focus groups: 1**

**Directory: 1**

**Include family and friends of service users: 1**

**More use of video: 1**

**More arts-based networking activities: 1**

**Support members instead of schmoozing policy makers: 1**

**More lobbying: 1**

**More detail about members so they can make links: 1**

**Feeding into Healthwatch: 1**

**More surveys: 1**

**Publicise activities more: 1**

**Better telephone availability: 1**

**Campaign around treatment of people with MH issues by employers: 1**

**Independent scrutiny of councils: 1**

### **Rating of NSUN activities**

**Positive**

The top rating was overwhelmingly for e bulletins, 83 people (74.8 %) rating them 'very good'. The next highest rating was for the website, 63 people (53.9%) rating it very good and only one person rating it poor.

'Network' magazine and e mail contact also had a high number of 'very good' ratings (52.5 and 50% respectively).

## **Negative**

Not so much negative as less positive, potentially benefiting from some investigation:

Less than half of respondents had had telephone contact, but those who had gave more 'OK' ratings (30) than 'very good' ratings (25).

32 people who had been to an event rated it 'very good' and 33 rated it 'OK.'

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

Notes on the question: 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. I will disregard them, as they don't fit with what the question is trying to establish.

The area where the biggest improvements were reported, with more people (49.1%) selecting 'a lot' of improvement over any other option, was 'awareness and knowledge of what other service users and/or service user groups are doing'.

This was followed by 'understanding policy', then 'contact with other service users/survivors', then 'research', then 'campaigning/lobbying'. However, in all of these categories, more people selected 'a bit' than 'a lot'.

The area where more people selected 'not at all' than any other option was 'local networking' (39 of the 91 who considered it applicable said 'not at all'). This was followed by 'fundraising', 'involvement in own care and support', 'involvement in LINKS/Healthwatch', 'running meetings/groups', 'running events/training' and 'presentations'.

However, the question does not allow for clarity about whether these people sought or expected help from NSUN on these areas or not, making the results unclear (it's not enough just to have a N/A option – you need to spell out that people should rate a service only if they've looked to NSUN to provide it).

## **Quotes**

### **Positive**

'finding out how things are done in other regions'.

'increased awareness of developments in policy, good practice in services in other areas'.

'improvements in communicating issues to other service users, because I have the information'.

'when I first joined as a member in 2009 there was minimal contact, but in the last year, with the recruitment of excellent staff, the support I've received has increased dramatically'.

'Has encouraged me to be more proactive'.

'More confident that we will get somewhere together'.

'NSUN campaigns give a feeling that something can be done'.

### **Negative**

'Disappointed there has been no contact'.

'Still awaiting response / contact further to registering interest'.

'I just don't have enough contact for it to make much difference. Also I do not receive e bulletins, despite being a member and having requested'.

### **What is the single most important issue for you regarding mental health?**

Some people mentioned more than one. Numbers are for times something was mentioned.

**Need for person centred/holistic care: 11**

**Cuts/lack of resources: 10**

**Access to mental health services: 10**

**Fighting discrimination and stigma: 9**

**Information/linking with others: 9**

**Benefits changes: 8**

**Staying well: 8**

**Prevalence of the medical model/labels/negative experiences of psychiatry: 7**

**Need for service user voice to be transmitted to policy makers: 6**

**System's reliance on medication/issues with medication: 6**

**Local peer support: 3**

**Awareness-raising: 3**

**Hostile government: 3**

**Need for real user involvement in all geographical areas: 3**

**Recovery: 3**

**GP commissioning/NHS changes: 3**

**Creativity/arts-based therapies: 2**

**Finding support to think positively/have confidence/somewhere to turn: 2**

**Poor quality services: 2**

**Need for better training for health professionals: 2**

**Equalities issues: 2**

**Being listened to: 2**

**Personalisation: 2**

**Commissioning systems leading to big providers hogging funding: 2**

**Debt: 1**

**Carers issues: 1**

**Employment/attitudes of employers: 1**

## **Quotes**

### **Holistic model**

'A move towards effective and positive holistic self management tools and techniques. Less emphasis on diagnostic labels and medications.'

'Being accepted as the person I am, not just a medical category.'

'Realigning power to service users away from medical model thinking.'

'The education of health professionals (GPs, etc.) to stop just handing out pills and listen to their patients sympathetically.'

### **Cuts and changes**

'Trying to stay out of debt while knowing MH services [are being cut] and vast differences in treatment and services before the cuts, as single mum with bipolar'.

'The cutbacks in services meaning more and more people fall through the net'.

'dissonance between government policy and actuality experienced which includes the inability to see that welfare/social policy etc affects mental health'.

'From what our service users are saying and experiencing in Hounslow, the Big Issue is benefits.'

### **Voice of users**

'Getting service users/ survivors and carers' voices heard at policy making stage'.

'That people with severe mental health problems get heard and an opportunity to speak up. That others don't speak for them too often.'

'That our voice is heard in the system'.

'Having a voice and being part of changes being made (service based, regional and most definitely national and policy related).'

'Having the voice of lived experience being heard, recognised and acknowledged as valid. often it is not given the value by professionals that it should'.

### **Linking**

'I think making better links with the huge variety of SUC groups and organisations that are around. Local people get to know about them, but it is hard to find them unless you live/work in the particular area.'

'sense of belonging'.

'That people suffering ill health can and should pull together rather than having people who say 'I was here first' or 'I know more than you' or organising stuff so that some people are excluded, belittled.'

### **Access to services**

'Prompt access to a range of services that focus on recovery.'

'Early intervention for better outcomes'.

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

People may have mentioned more than one point.

**A national mental health network/umbrella body: 21**

**An Information provider: 18**

**A user/survivor-led organisation: 12**

**A campaigning/lobbying organisation: 11**

**A network of users/survivors: 9**

**A linking organisation: 9**

**A support network: 7**

**An organisation that can influence policy makers: 5**

**A voice for mental health: 5**

**A good organisation: 5**

**A network of user/survivor groups/organisations: 4**

**Raising awareness: 3**

**Empowering: 3**

**Sharing good practice: 3**

**A forward-thinking/proactive organisation: 3**

**A website: 3**

**An organisation that listens: 2**



**A training organisation: 2**

**An independent organisation: 2**

**A radical organisation: 2**

**Like a union for people with mental health issues/a collective: 2**

**A regional network: 1**

**A new organisation: 1**

**A group of users who have got more well: 1**

**A caring organisation: 1**

**A research organisation: 1**

**Free to join: 1**

**A network of networks: 1**

**Fighting discrimination: 1**

**A London organisation: 1**

**Don't know: 6**

**I don't: 2**

### **Quotes**

'Network of supportive people with experience of MH issues and other life issues. A group of survivors!'

'Support network that listens to the views of users and tries to share good practice.'

'A network which represents the user voice, makes it louder.'

'National parent body of all the local user groups and forums.'

'Network for people with experience of MH problems: information sharing, campaigning, mutual support.'

'A coordinating body for collecting service user concerns, channelling those concerns to appropriate decision-makers, and supporting service user activity.'

'Campaign group for people with mental health illness who want to see the best treatment and care and dignity for all.'

'A caring organisation run by individuals who understand the problems of others and in many cases have personal experience and empathy to offer.'

'A highly respected and influential mental health charity with a genuine service user presence, strategically placed locally, regionally and nationally.'

'National Service User organisation - that should not be competing with local groups but compliment and support local activity.'

'A mental health organisation run by people with experience, not just white coats making decisions behind closed doors!'

'A news service for mental health industry.'

'Informative bulletin which gives weekly updates on local and national issues, invitations to attend meetings and also a very good source for job offers.'

### **Negative comments**

'I do not get asked at this time but try to tell users about it, but as it has no office or ever advertised in city of Salford.'

'It is OK for those that can access the internet or are in paid work; If not it is pointless being a member.'  
'A service user organisation that was meant to support and help develop other SU organisations, but has lost its way somewhat to its original mission.'

### **My analysis**

The number of respondents having a positive perception of NSUN and not wishing it to change in any way is very high, which is impressive.

For most people, NSUN is an information resource (many people see it only as that). Information services have a high profile, high levels of satisfaction, and were consistently praised, especially the e bulletin.

The next most important aspect of NSUN is its user-led nature. For many, this is what sets it apart from other organisations in the field, and gives it authenticity. Unlike in last year's survey, there were very few comments saying it is not user-led enough. There was a feeling that most members are proud of this aspect.

Complaints about lack of reach across the country were also notably fewer than last year. However, this still comes up as the main area of dissatisfaction (though a lot of members recognise its difficulty in practice). What people most want NSUN to do that it isn't doing currently is get out into more local areas.

Linking and networking functions, influence with policy makers and campaigning were all mentioned often and valued.

The reason why events had a relatively low satisfaction level needs to be explored further.

*Rachael McGill*

*April 2013*

NSUN is not principally seen as a capacity-building organisation, or used as such. There were some complaints about telephone accessibility. However, it is consistently seen as a supportive and friendly port of call.

This survey feels like a resounding vote of encouragement from members. NSUN has a strong identity and is on the right track, especially with the quality of its information. The future should look like more of the same, with some new projects and development of existing structures across the country if at all possible.