

The Survivor Researcher Network Survey

The Survivor Researcher Network (SRN), a network set up to support people with lived experience of mental distress with an interest in research, began as part of the Strategies for Living project in the late 1990s and was hosted by the Mental Health Foundation. It was moved to the National Survivor User Network (NSUN) in October 2011. NSUN wants to re-launch the network in order to continue supporting survivor researchers and to provide a platform for on-going discussions.

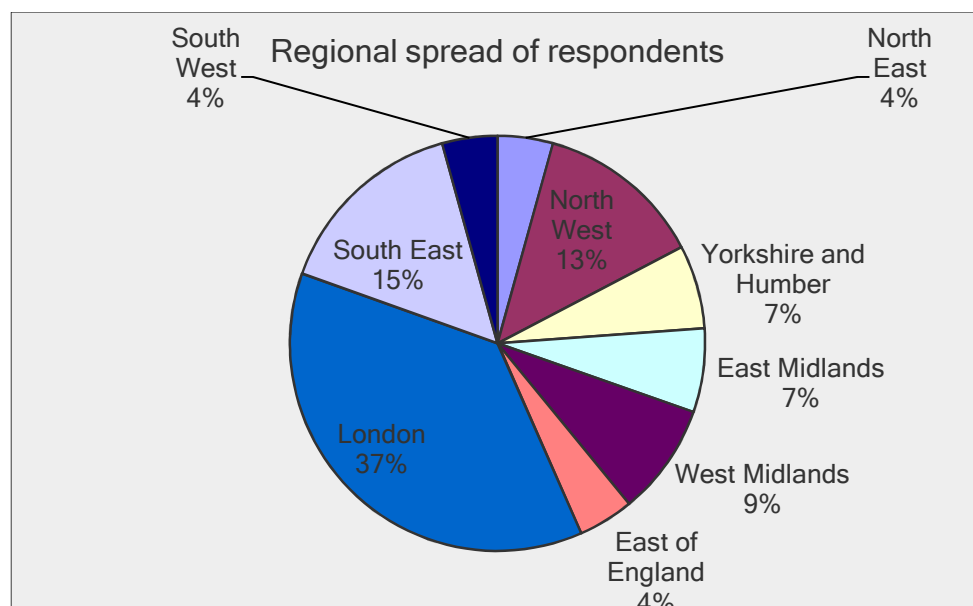
NSUN conducted a survey of SRN members and other members who were interested in research to get some ideas about what kind of support people would need and how best to offer this through the network. The aim was to have a better understanding of people's interests and skills in user/survivor research and to develop the objectives and work of the new research network. The survey was conducted using Survey Monkey, the link to which was disseminated to members of SRN, NSUN members who had an expressed interest in research and the members of Catch-a-Fiya, the national black and minority ethnic mental health service user network.

The following findings are based on the 46 responses we received to the survey.¹

1. The Responses

1.1 Regional spread of respondents

37 per cent (n=17) of respondents were from London; the rest spread across the other English regions. The following chart shows the regional spread.



¹ A total of 61 people accessed the survey to express their continued interest in SRN (by submitting their contact details), but only 46 answered the survey questions in full.

1.2 Involvement in research

63 per cent of the respondents were currently involved in research and 74 per cent said that they were involved in research in the past. All the respondents expressed interest in being involved in research in the future.

Some of the respondents were researchers by profession and training and had moved into mental health research because of their personal experience and identity as survivors/service users. For others, it was their personal experience that led them to pursue research as an activity and career choice through which to contribute their knowledge and skills to improving the understanding, attitudes and treatment. Some had several years of experience of working as survivor researchers while others were starting out and wanted to learn more about the processes. This wide range shows that the network members are well-placed to support each other and share experiences, ideas and skills, thus providing a research peer support and mentoring network.

Top among **the reasons for being involved in research**, both as researchers and as participants in research studies, were:

- Being involved in research that brings together the rigours of methodology and the uniqueness of personal experiences was seen as a way of making a difference to the lives of people and providing ideas and knowledge to other service users/survivors and providers of mental health services.

"Research provides opportunities for people to express their experiences of mental ill-health, how they manage it with or without the support of mental health services. The results often demonstrate the reality of the situation for most people living with mental distress which can then be used to support people. ... Research provides statutory services with the evidence of what is needed in regards to service planning, design and delivery."

"I really like feeling that my experiences and knowledge can be useful and may change things for others."

- The conviction that the power hierarchies within psychiatry and the mental health system needed to be challenged along with the predominance of clinically led research.

"We currently have a system which has used vast resources in protecting itself from some very fundamental shortcomings (such as no real evidence base for the structures and hierarchies within the system itself) and which has, by omission, provided a very partial and often very prejudicial picture of mental distress, its possible causes/contributory factors and the solutions to managing those individuals. It is time for the huge imbalances in research to be addressed."

"[...because of my] desire to re-balance the evidence base and enable survivor perspectives to exist equally with so-called 'established canons of research'."

"An impetus to increase the positive profile of service user research and to have it recognised as of equal status to traditional academic/clinical research."

- Survivor research was seen as a way to change attitudes and priorities with service delivery by focusing on people’s experiences of what works in mental health care.

“I believe it provides an evidence base for effective working, support for understanding and explaining issues, possible development of new ways of working with and supporting people.”

“As a service user I want to be able to use and produce research which informs better mental health practice - that is support which enables people to live their lives and achieve their goals and aspirations.”

“I want to see CHANGE in approaches and in treatment.”

- Documenting life stories and personal narratives was seen as an important part of the knowledge base on mental health, recovery and human rights, and survivor research was the ideal way of developing this knowledge base.

“To make sure excluded voices are heard. To ensure all perspectives are included.”

“I think that people should have the right to contribute to their records and that documenting life stories and opinions [also on film] can be therapeutic for the individual and reframe the relationship with professionals, enabling the voice of the service user to be heard in a new and more impactful way.”

“I hope to develop the service user voice in research as a leading voice and not as an 'add on' to the professional voice.”

1.3 Experiences and skills

Members of the survivor researcher community who responded to this survey have a wide range of experiences and skills. More people are involved and skilled in the delivery aspect of research, including conducting research, analysing data and writing reports, and as research participants. Just over half of the respondents are involved in developing and designing research and ensuring inclusion of marginalised groups, suggesting that there is scope for more work and support in this area. There are opportunities for further development, especially in training and teaching research methodologies, project management and more involvement in peer reviewing research proposals. The following table lays out the skills and experiences of respondents:

Experiences and skills of respondents	
Conducting research (e.g., interviewing, doing surveys)	74%
Participating in research as research subjects	65%
Analysing data (quantitative or qualitative)	57%
Writing research reports	57%
Advising research teams	54%
Designing research (e.g., writing proposals, preparing research tools)	52%
Involving marginalised groups in research (reaching out to those normally overlooked by mainstream research)	52%

Conducting literature reviews	48%
Project managing research	33%
Training researchers	28%
Teaching research methodology	17%
Serving on peer review and research ethics committees	9%
Acting as translators/interpreters	2%

The need to engage more with the ethical and legal aspects of conducting research was raised by one respondent. The small percentage of people involved in translation and interpretation also highlights the need for development as a way of reaching out to communities of non-English speaking service users/survivors who may currently be left out of research related work.

1.4 Areas of interest

We asked the members to tell us their three main areas or topics of interest in research. The responses are too numerous to list here.

Areas of interest specified by most number of respondents included:

1. Diagnosis and symptoms
2. Service user views on services, policies and organisational practice
3. Representation in user involvement and research
4. Evaluation and impact of survivor research
5. Recovery and empowerment
6. Institutional practices, including coercion, labelling and abuse
7. Changing service delivery and staff attitudes
8. Counselling and psychological therapies
9. Medication and its effects
10. Critiques of medical models of mental health care

Areas of interest specified by least number of people included:

1. Mental health law
2. Mental health and physical illness
3. Spirituality
4. Racism and mental health
5. Disability and mental health
6. Lesbian, gay, bisexual people's mental health
7. Early intervention
8. Mental health statistics
9. Genetics
10. Perinatal mental health

The priority list above seems to suggest that there are fewer people interested or engaged in researching the specific issues affecting marginalised communities. It may also suggest that there is a need to increase the diversity of people involved in the network through pro-

actively engaging survivor researchers working outside of the mainstream user/survivor forums and networks.

1.5 Support and opportunities expected

Over 80 per cent of respondents said that they would like the network to provide opportunities for collaboration and serve as a platform for networking. They also expected the network to be a forum for discussions and finding research opportunities and funding: “a nexus of resources and access to other research groups and individuals, as well as a hub for opportunities.”

Reflecting the areas of further development in the previous section, respondents hoped that the network would provide opportunities for receiving training in research methodologies, skills development and help with specific research projects. The main areas where support and opportunities are expected are laid out in the table below:

Support and opportunities expected	
Networking with other researchers	83%
Opportunities for collaboration	83%
A forum for discussion	78%
Opportunities for research work	78%
Finding funding for research	74%
Help with specific research projects	72%
Skills development opportunities	70%
Training in research methodologies	67%
Presentations of research work	52%
Delivering training on research	50%

Other areas for support indicated by respondents included training in working with people with complex communications needs in order to interview them successfully.

Some respondents would like support to explore what it means to be a survivor researcher and what that identity entails. Others said that the network could play a part in developing a body of work around survivor-led research and counter the current trend in research where survivor researchers are approached by other research leads only to ‘tick the box’ for fulfilling funding and policy requirements around user involvement.

The survey responses showed that survivor researchers worked in a variety of contexts: nationally funded research networks like the Mental Health Research Network, user-led sections of academic institutions like the Service User Research Enterprise at the Institute of Psychiatry, research and teaching staff and students at universities, NHS research and development departments, voluntary sector organisations, small user groups in a local community and self-employed independent researchers. The smaller groups expressed the need for more support from the network in terms of learning more about user-led research, finding funding and putting together research proposals.

"Having the skills to conduct research locally here in [place name] would increase by ability to have more people participate in [our group] ... and to produce documentary evidence on what is already known about service user needs. This would strengthen our position as an independent service user group. Knowing how to find funding for research is something I would like to learn in order to effectively challenge and hold to account local providers and commissioners based on inpatient and community service user surveys."

"Making connections with other service user research networks will be very valuable for [local user group name]."

"It is an art how to get an outline research proposal to the next stage for consideration. Where service users/carers are co-applicants for funding, it is important that non-NHS/university partners are involved and integrated into the overall research proposal and I would like to learn how."

Several of the respondents specified how they could contribute to the network and participate in strengthening survivor research as a whole and supporting individual survivor researchers and groups.

- Developing the concept, meaning, values and politics of survivor research
- Providing training in research methodologies
- Helping with research proposals, applications, analysis, writing up and dissemination
- Mentoring others and sharing experiences and skills
- Sharing information, opportunities and contacts
- Working on research projects (in both paid and voluntary capacity)
- Providing feedback on others' work
- Helping to understand and work out the requirements of research ethics committees and other statutory and funding bodies
- Bringing the experience of survivors from marginalised communities into mainstream survivor research. This was perhaps the least represented area, with only two respondents saying that there was a need for this specific contribution and that they were interested in contributing to developing knowledge, experience and interest in this area, although fifty two per cent said 'involving marginalised groups in research' was one of their areas of expertise and skills. (See section 1.3)

"As well as sharing lived experience of mental ill-health, as a black woman, I come from a marginalised group - certainly in terms of involvement in research and service improvement. Along with this, as a woman who lived with domestic violence, who struggled to bring up my children alone whilst being distressed, I bring with me a wealth of experience that can be translated into learning through research."

1.6 Practical suggestions for the functioning of the network

We asked the members to tell us their suggestions on how a national research network can work together. The following suggestions were made:

Regular communication:

- A dedicated website with member log in. The website could have forums on specific topics and interests, discussion forums and a resources section
- An e-newsletter that highlights opportunities for training, funding, collaboration, calls for proposals and papers, articles submitted by members etc.
- Dedicated section in NSUN's regular bulletin
- Using social media (Facebook, Twitter)
- (Depending on funding) a journal dedicated to survivor research

Meetings:

- Annual conference
- Occasional meetings (depending on funding available to support travel etc.) in different regions. The need to organise these in central locations where people from a specific region can travel comfortably was highlighted.
- Subject/topic specific seminars/meetings/webinars
- Conferences over telephone, Skype

Co-ordination:

- A dedicated co-ordinator and/or administrator
- Special interest sub-groups coordinated by members

Funding:

- Is the network funded?
- Explore possibility of regular funding

2. Points for Consideration by NSUN

2.1 Who are the members of the Survivor Researcher Network?

The survey was disseminated to 198 individuals including the database of members from received from the Mental Health Foundation, NSUN and Catch-a-Fiya members who signalled interest in research and others who were later added to the list. Sixty one people accessed the survey and left their contact details while 46 responded to the survey. NSUN may want to contact the initial list of 198 contacts to ensure that all of them are happy to continue as members.

2.2 Clarifying funding and management

Some of the respondents have asked for information on how the network is/will be funded and how it will be managed. NSUN may want to communicate this with the members. The indication from the survey is that members find NSUN to be an appropriate place for the survivor researcher network to be housed, but would welcome clarity of functioning.

2.3 Aims and objectives of the network

Based on the survey feedback described above, the following aims and objectives are suggested:

Overall aim of the network:

- To provide mental health service users and survivors involved and interested in research a forum for networking, sharing information and supporting each other.

Objectives:

- Act as a hub for resources, information, opportunities and support
- Work on a peer support model, in collaboration and partnership
- Promote the importance of concepts and evidence based on lived experience as fundamental to the knowledge base on mental health, human rights and social justice
- Campaign to rebalance the hierarchy of evidence currently existing in mental health research
- Influence mental health policy and practice through user/survivor-led research
- Increase the capacity, skills and knowledge of survivor researchers through mutual support, mentoring and, wherever possible, training and learning opportunities
- Work from a value base of inclusion, acknowledging the diversity of experiences, identities and backgrounds of survivor researchers

NSUN may want to bring together a working group from the members to further develop and concretise the aims and objectives outlined above and to work out a plan for launching the network.

2.4 Increasing the diversity of the network

NSUN may want to do further work to increase the diversity of the members of this network as it is clear from the responses to the survey that the representation of marginalised communities and areas of research addressing their specific needs and concerns are limited (See section 1.4). A targeted recruitment of survivor researchers working on issues affecting marginalised communities would be one way of doing this. Equally, the network will need to be promoted as an inclusive space and priorities set for work should reflect this.

2.5 Making a case for raising secure funds for the network

The responses section highlights the wide range of skills, knowledge, expertise and enthusiasm currently available among the members. Several of the members are well-established or have contacts with research departments within NHS, the academia, the third sector and have strong ties with their local communities. The network is well placed to call on these expertise and connections to provide feedback on government policies and to help develop future policy and practice development. The government's mental health policy claims to put great store in hearing from the people and evidence that is based on people's experience and the survivor researcher network will be able to provide that critical feedback.

By providing a forum for sharing ideas, developing skills and doing meaningful work, the network can also function as structure to support people's continuing wellbeing and empowerment.

2.6 Name of the network

While doing this work, there has been some confusion between 'Survivor Research' (an independent virtual collective of survivor researchers from marginalised communities), the Scottish Recovery Network (well-known as 'SRN' in mental health circles) and 'SRN' as the Survivor Researcher Network. The presence of the Scottish Recovery Network and Survivor Research seem to be well-established on the internet. Perhaps a renaming of the network is to be considered.