

Summary of Findings from the Survivor Researcher Network Members' Survey



A total of 61 people accessed the survey to express their continued interest in SRN (by submitting their contact details; 46 answered the survey questions in full. The report is based on these 46 responses.

Regional spread of members:

London: 37%	South East: 15%	North West: 13%
West Midlands: 9%	East Midlands: 7%	Yorkshire and Humber: 7%
East of England: 4%	North East: 4%	South West: 4%

Reasons for being involved in research:

- 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.
- 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.
- 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.
- 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.

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. 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.

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%

Areas of research interest:

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.

Support and opportunities expected from the Network:

Members expected the network to be a forum for networking, 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.”

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%

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.

Practical suggestions:

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

Aims and objectives:

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