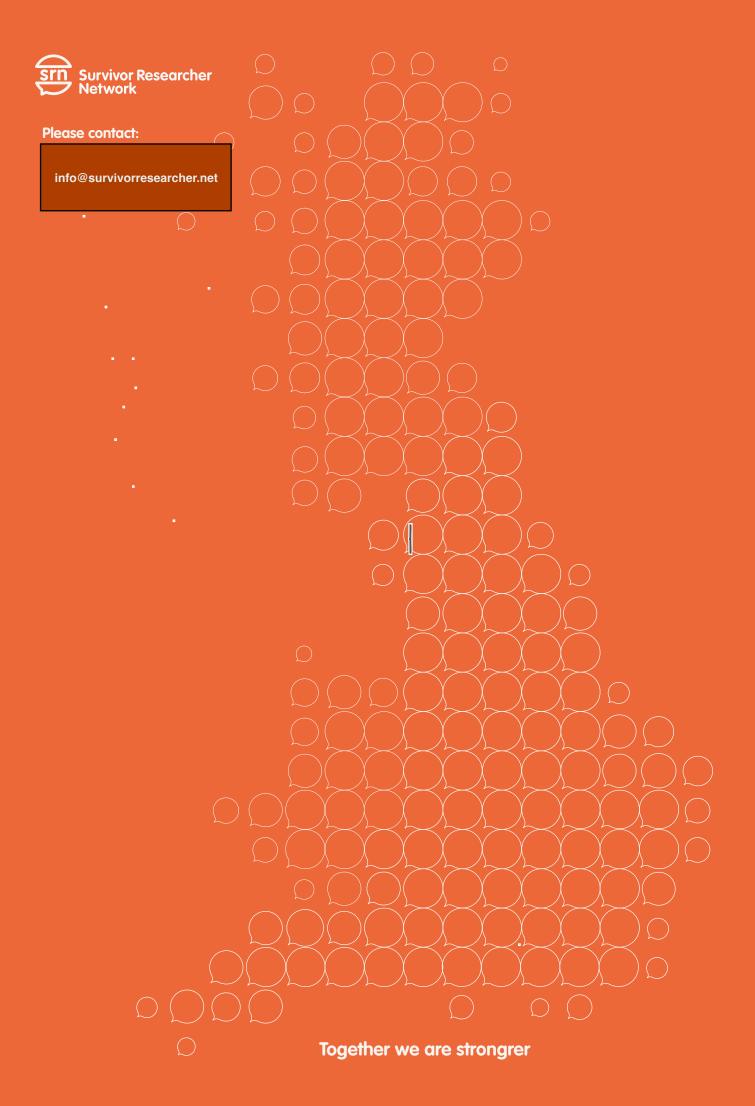# srn Manifesto

Survivor Researcher Network
Mental health knowledge built by service users and survivors

Written by Emma Ormerod

With Peter Beresford, Sarah Carr,
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Survivor Researcher Network

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Together we are strongrer

Contents

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This Manifesto was published in 2018 when Survivor Researcher Network was hosted by NSUN.

We are now an independent community interest company, Survivor Researcher Network C.I.C., and share information with network members via our newsletter.

For further information and to join the network, see our website at www.survivorresearcher.net

You can contact us by email at info@survivorresearcher.net

About us

The Survivor Researcher Network

The Survivor Researcher Network (SRN) is an independent, user-controlled and diverse network for all mental health service users and survivors who are engaged in or interested in research.[1]

The SRN was originally formed after the 'Strategies for Living' Mental Health Foundation project (1997-2003) and was hosted by the Mental Health Foundation until 2001. The network is currently hosted by the National Survivor User Network (NSUN), an independent charity led by survivors and service users that connects people with lived experience of mental distress. The SRN is currently unfunded and steered by a working group of nine volunteers from academic and independent survivor research backgrounds.

Survivor research

Survivor/service user research is carried out from the perspective of people who have experienced mental or emotional distress (Faulkner, 2004).[2] It is different from traditional user involvement in research because service users and survivors have control over the research process (Sweeney et al., 2009). This type of 'user-led' or 'user-controlled' research has grown and developed from the political roots of survivor activism that seeks to challenge the psychiatric system and collectively develop different forms of knowledge based on lived experience of mental distress.

Following on from the first survivor-led research work, Strategies for Living (Faulkner & Layzell, 2000) and *User Focused Monitoring* (Rose, 2001), survivor edited works such as *This is Survivor Research* (Sweeney et al., 2009), *Handbook of Service User Involvement in Mental Health Research* (Wallcraft et al., 2009) and *Mental Health Service Users in Research: Critical Sociological Perspectives* (Staddon et al., 2013) have been published. Alison Faulkner's *Ethics of Survivor Research* (2004) has also provided comprehensive guidance on the ethical issues to be considered for survivor research projects and training programmes.

Survivor/service user research has helped to foreground the perspectives of service users/survivors from black and minority ethnic communities (Kalathil, 2011) and LGBT people (Carr, 2013). Producing knowledge from the perspectives of people with lived experience of mental distress has allowed different kinds of evidence to emerge in areas such as experiences of recovery under the 2008 Care Programme Approach (Gould, 2012) electroconvulsive therapy (Rose et al., 2005), about different ways of understanding madness and distress (Beresford et al, 2016) and coercion and restraint (Rose et al. 2017). In addition to this, Mad Studies, a new emerging knowledge base, is also producing theories and evidence by service users and survivors (Sweeney, 2016; Russo & Sweeney, 2016; LeFrancois et al., 2013).

[1] People who have experienced mental or emotional distress define themselves and describe their experiences in a number of different ways. There is no consensus regarding terminology. However, we use the term 'survivor' to refer to people who have experienced mental distress and as a political term to refer to people who have survived the mental health system and societal oppressions. We use the term 'lived experience of mental distress' which includes people who have used mental health services and those who have survived trauma by using alternatives to mental health services. We also acknowledge that many people with lived experience of distress also have or have had experience of a caring role.

[2] Many terms are used to describe 'mental or emotional distress' including 'psychosocial disabilities', a term recognised under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and reflects the social model of disability

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Context

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Patient and public involvement (PPI) has become an essential component of NHS research, policy and practice in the UK (NSUN, 2015). An increasing number of users/survivors are now involved in research in mental health in England (Patterson et al., 2014). But service user and survivor-led research is an independent discipline in its own right. It is very different to and distinct from PPI and should not be conflated with it (Rose, Carr & Beresford, 2018).

There continues to be a huge difference between the rhetoric of 'co-production' within PPI and the often tokenistic reality (NSUN Manifesto, 2017). Genuine and meaningful involvement where people with lived experience of mental distress have real power within these processes is still sadly lacking (4PI National Involvement Standards, NSUN, 2015; Madden & Speed, 2017). Many people continue to be overlooked and marginalised within processes of involvement (including involvement in research) (Beresford, 2013). Service user and survivor contributions continue to be limited to advisory roles with the resources and power being held by non-user and survivor academic researchers (Rose, Carr & Beresford, 2018).

Mainstream mental health research also continues to be dominated by the medical model of mental illness and associated quantitative methodologies that position people with lived experience of mental distress as the objects of study (Rose, 2009). Within these clinical frameworks the voices and experiences of service users and survivors are marginalised and ignored.

In addition, the turn towards 'austerity politics' in recent years has led to devastating cuts in public spending (eg. to welfare benefits and local authority funding) that is causing harm to many people. It is disproportionately affecting BME service users, people from LGBT communities, disabled people and those who are already living on a low income. (NSUN Manifesto, 2017). Small mental health user-led groups have been forced to close due to lack of funds and in a recent survey, NSUN discovered that 160 of its 822 member organisations had closed since January 2015.

There is increasing competition for research funding and inequality of access to funds. Service users, survivors and their organisations are pre-defined as 'consultants' in research rather than being positioned as knowledge-makers or researchers themselves (Rose, Carr & Beresford, 2018). It is vital that service users and survivors are not marginalised, but are enabled to become leaders and instigators of co-production in mental health research, not only to provide alternative perspectives to mainstream mental health research, but as part of a wider social justice movement.

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Our aims

We aim to:

- Provide mental health service users and survivors involved and interested in research a forum for undertaking their work, networking, sharing information and supporting each other.
- Support new forms of knowledge making in mental health that are led by people with lived experience of mental distress.
- Challenge and broaden mental health research and explore alternatives to bio-medical 'illness' models and clinical methodologies.
- Promote first hand knowledge and experiential evidence as fundamental for the knowledge base on mental health, human rights and social justice.
- Set standards and promote good practice in service user and survivor research in mental health.

We will:

- Sustain and develop the Survivor Researcher Network (SRN) to provide survivor researchers a forum for networking, sharing information and supporting each other by:
- Challenging the hierarchy of evidence and promoting the validity of experiential and survivor knowledge(s), as well as qualitative, participatory and emancipatory research methods
- Promoting authentic and influential service user and survivor involvement and leadership in research
- Continuing to seek new partnerships with other organisations and institutions to increase opportunities for SRN members and ensure genuine, meaningful co-production and involvement in research.

srn Survivor Researcher Network

To join the Survivor Researcher Network, please contact:

info@survivorresearcher.net

Our values

The SRN is committed to working from a values-base that is:

Emancipatory

- addresses broad social issues of marginalisation, oppression, inequality, exclusion and impoverishment, and foregrounds the relationship between deepening inequalities and mental ill health in research and knowledge production.
- challenges the hierarchy of evidence that currently prevails in mental health research and the biomedical model of 'mental illness'.
- challenges the co-option of survivor knowledge by PPI (Patient and Public Involvement) in research agendas in mental health services and academia.
- campaigns for a redistribution of power within PPI and 'co-production' initiatives where the independence, agency and autonomy of service user/survivor researchers is being eroded or ignored.
- questions the idea that academia is the only place for 'valid' forms of knowledge production.

Experiential

- draws on our varied lived experiences of mental distress, psychiatry, mental health services, the welfare benefits system, societal structures and systems to create our own knowledge, theory and methodologies.
- promotes survivor knowledge(s) and research as credible, valuable, legitimate research evidence in its own right.
- produces and promotes standards and good practice in user-led/controlled research.

Holistic

- produces and promotes research that sees the whole person (their varied interconnecting identities and different aspects of their wellbeing) within a broader socio-economic, cultural and political context.
- promotes an alternative vision for mental health care that draws on the growing body of research into holistic understandings, methods, treatments, services and models of care.

Inclusive

- promotes knowledge and takes on board perspectives from the most powerless and marginalised groups in society including people with 'protected characteristics'

under the Equality Act (2010) and those living in poverty and experiencing multiple disadvantages.[3] Where possible we will also seek to produce knowledge from these perspectives.
- seeks to include people with a wide range of different experiences and opinions, recognising that sometimes our values will be in conflict, whilst also being consistent and clear about our purpose and what we stand for as a network.
- recognises and challenges the power relations that exist within less powerful groups (including the survivor movement itself).
- challenges the marginalisation of some communities in mental health research (including user-led research) in terms of access to resources, participation and leadership.
- lobbies funding bodies for the commissioning of studies which reflect the research priorities of people with lived experience of mental distress and are user-led.

Diverse

- acknowledges, values and promotes the diversity of experiences, identities and backgrounds of service user and survivor researchers.
- connects a diverse range of people from different communities, regions and backgrounds. Eg. people who are employed as 'service user/survivor researchers' (but who may be working in isolation) and those who are new to research and/or those who do not have formal 'research training' or background.

Respectful and anti-discriminatory

- emphasises the critical importance of clarity and transparency in our activities and working practices.
- challenges discriminatory practices.
- listens to the perspectives of others.
- creates a supportive space for members to share information, ideas and experiences.
- creates mechanisms to ensure we work to our values – eg. by having a truly diverse governance and constantly using critical reflection to examine our practices.

[3] The characteristics protected under the Equality Act (2010) are age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation.

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