

Anne Beales
Non-Executive Director SPFT
Chair of Heads On

I've been involved in research at a variety of levels:

- Capital Project, West Sussex, use of volunteers in local project, suicide prevention with Warwick university
- Project Board member at St Georges New ways of working in mental health services: a qualitative, comparative case study assessing and informing the emergence of new peer worker roles in mental health services in England
- As a commissioner of research:
 - The Freedom to be The Chance to Dream
<http://www.together-uk.org/wp-content/uploads/2012/09/The-Freedom-to-be-The-Chance-to-dream-Full-Report1.pdf>
 - Dancing To Our Own Tunes: reassessing black and minority ethnic mental health service user involvement
<http://www.nsun.org.uk/about-us/our-work/dancing-to-our-own-tunes/>

Messages from the Board

- With the tightening of budgets there will be increasing pressure on research funds
- The trust has an outstanding reputation for the research it does
- CAGS are slightly less about actual research instead they act as a link to the CDSs and must ensure they are offering up-to-date evidenced based treatments
- Research is everyone's business and it is essential in a healthy organisation
- My plea would be that research becomes more integrated with care
- The research in dementia must lead to a whole new strategy – even the possibility of it's own CDS

Discussed with: Sam Allen, CE,
Dr Rick Fraser, Chief Medical Officer,
Adam Churcher, Head Corporate Governance,
NEDs: Professor Gordon Ferns, Martin Richards, Lewis Doyle, Dianna Marsland

What we “believe” maddens us will move us in different directions of travel but should always be on an equal footing

Trauma

- Racism
- Homophobia
- Abuse
- Bullying



Chemical Imbalance
Physical Differences in the Brain
Illness
Treatment



Stress
Isolation
Desperation (not being listened to)

Biomedical Research – Clinical Practice

Messages about research from the board:

- We must know what the tangible benefits are for Patients (or carers) and what the wider Impact on society has been including the impact on the quality of clinical service, e.g. in dementia
- We must maintain our research focus as an organisation as this enriches the clinical programme, attracts quality staff and helps retain them
- We must create partnerships with scientists whose sole purpose is translating research into practice

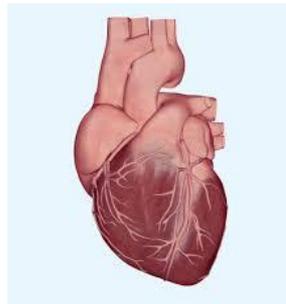
Medication: relapse or withdrawal?

Excellent work already – Research Magazine Issue 5

Brain and Body research

Scanning Patients at our Memory Clinics

Links between heart rate and anxiety



Neurobehavioural Clinic

The harnessing of diverse perspectives coming together at a particular point will combine the separate strengths into an irresistible force

- Service User Led Research - PPI
- Messages from the Board:
 - PPI is crucial
 - The LEAF group should be invited to speak at the board and describe
 - how research has improved the quality of care they have received
 - It would be wonderful to hear about the research work at board perhaps alongside the patients story
 - Patients should see how research meets their hopes and expectations



Excellent work already — Research Magazine Issue 6

Self Help – Youth Mental Health
MindSHINE PRODIGY EYE

The Air research theme

Learning from our experience of research (LETS)

Involvement in European Expert Patient Academy

Laura Lea part-time worker (MARS and SPRIG)

Section 136 Project



nsun manifesto

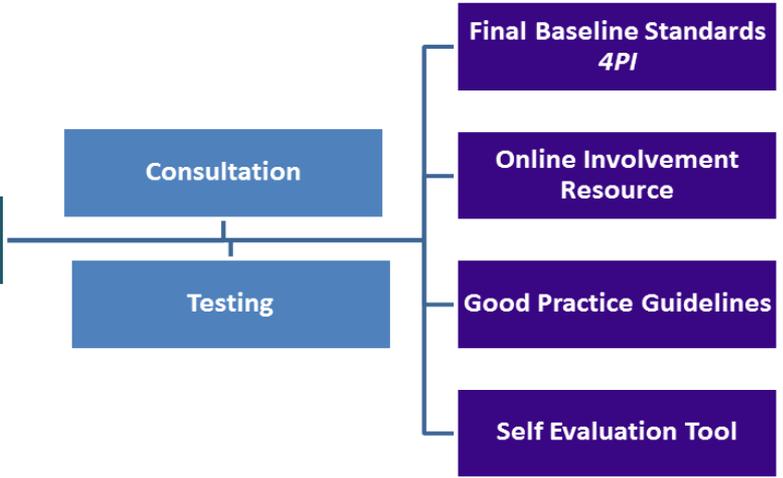
We aim to:

5. Challenge **institutionalised discrimination** and put equality back on the agenda for mainstream mental health services
6. Call for a **reform of the Mental Health Act 2007** to make it fully compliant with human rights legislation and ensure people are not harmed or abused
7. Reflect the **social model of disability** and promote **informed choice** and **alternatives to medication**
8. Reclaim, challenge and revive **survivor knowledge and research**

4pi National Involvement Standards



Historical References, Resources & Experiences



4pi National Involvement Standards FULL REPORT

This report sets out its main focus as developing national involvement standards in mental health and hardwiring involvement into the planning, delivery and evaluation of mental health services.

Involvement for influence

In association with: National Involvement Partnership | National Survivor User Network | Funded by the Department of Health

4pi National Involvement Standards

This compendium aims to provide an overview of service user involvement in health and social care policy and legislation. It functions as a companion piece to the 4Pi Standards for Involvement document and aims to enable readers to use it for reference purposes.

Service User Involvement in Health and Social Care Policy and Legislation

"Nothing about us without us"

In association with: National Involvement Partnership | National Survivor User Network | Funded by the Department of Health

4pi National Involvement Standards

This document has been written as a companion piece to the National Involvement Partnership: 4Pi Standards for Involvement. It aims to illustrate readers to the language of mental wellbeing by providing an overview of terms that have been, and continue to be used in this area.

The Language of Mental Wellbeing

"Nothing about us without us"

In association with: National Involvement Partnership | National Survivor User Network | Funded by the Department of Health

4pi National Involvement Standards

Good involvement has many benefits for all concerned - for individuals, communities, services, professionals and organisations. These are the benefits we identified in our main report Involvement for Influence: the 4Pi Standards for Involvement? (2014).

Why Use 4Pi National Involvement Standards?

"Because together we can get better..."

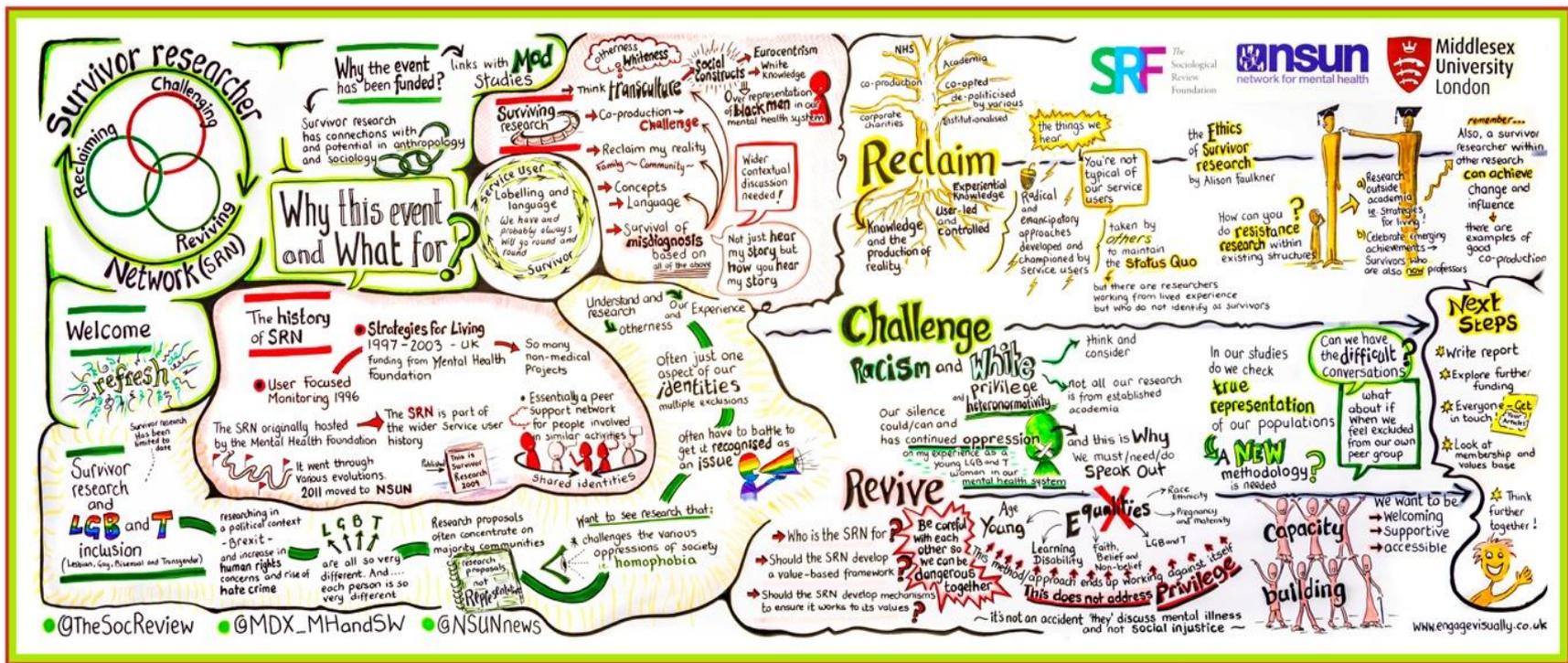
In association with: National Involvement Partnership | National Survivor User Network | Funded by the Department of Health



The Survivor Researcher Network (SRN), a network set up to support people with lived experience of mental distress with an interest in research was hosted by the Mental Health Foundation until recently.

It has now moved to the National Survivor User Network (NSUN).

Following a survey of members' NSUN re-launched the network in order to continue supporting survivor researchers.



In July 2016, members of SRN met for a seminar entitled **‘Reclaiming, Challenging and Reviving Survivor Research’**

Reclaiming survivor knowledge – how do we address the issues arising from the co-optation of ‘service user research’ into ‘public and patient involvement’ by the NHS, academia and large corporate mental health charities?

Reviving survivor knowledge – how do we address the broader social issues of marginalisation, oppression, inequality and impoverishment, and question the relationship between deepening inequalities and mental health?

Challenging survivor knowledge – how do we critically examine survivor research and knowledge itself, when much of the (known) history of the movement is white and ‘heteronormative’?

A new working group is now being established to take forward the work of the **Survivor Researcher Network**.

Carers Perspective and Contribution

Messages about Carer Participation from the board: PPI is crucial

Key messages from Involve – national institute for health research

To Gain Genuine Co-Production

- Agree a draft set of core PPI standards to include the rationale behind each standard, how it aligns to the values and principles for public involvement along with its importance
- Expand the core PPI standards and ‘sense check’ that they work with the everyday business of public involvement in research from research organisation, research project and individual (involved public and researcher) perspectives
- Consult on the draft core standards for public involvement widely for comment and feedback. It is anticipated that this will be in February 2017

Excellent work already – Research Magazine Issue 7

Collaborative Care Planning

Caring for Care Givers (C4C)



12–18 June 2017

Measuring Quality of Life in Dementia Carers



REACT Toolkit for carers of with psychosis or bipolar

Thank You and a Thought

Perhaps we could host a national BME survivors research conference to really place us on the map as leading around what is possible

To understand the impact of our research we must always look at it through the eyes of those who are most disenfranchised

Thank you for inviting me and for the contribution you all make

Anne.beales@sussexpartnership.nhs.uk