

Mental Health User/Survivor Research in the UK

A Policy Briefing (Extended Version)

INTRODUCTION

Since 1997 the Mental Health Foundation has played a key role in supporting and promoting user/survivor-led research in the mental health field across the UK through its *Strategies for Living* initiative. Phase I of the initiative ran from 1997-2000¹ and phase II² from 2000-03. This briefing:

- Provides a brief overview of the development of mental health user/survivor¹ research on mental health in the UK¹, with reference to the work of *Strategies for Living*.
- Outlines the extent to which the current research and policy environment in the UK supports user/survivor research in mental health.
- Recommends measures that would increase support.

MAINSTREAM RESEARCH ON MENTAL HEALTH

Most research on mental health problems/illness in the UK is defined and led by professional researchers/practitioners and is dominated by those working within natural science and clinical disciplines, with focus on disease and treatment issues. There is also a growing body of mental health research within social science disciplines but compared to clinical research this is less well developed and funded. This research relies heavily on experimental and quantitative research methods, with less emphasis on qualitative research. This reinforces the accepted hierarchy of evidence which gives high value and status to randomised controlled trials and systematic reviews, undertaken by professional researchers, with less value attached to qualitative research or research undertaken by service users/survivors.

Whilst much clinical research is extremely useful, informing improvements to services and treatments, this imbalance in the type of mental health research currently undertaken, presents several difficulties.

- It does not adequately address the wider range of key issues that are critical to mental health, especially social issues and complementary/alternative therapies.
- The research priorities and research process are controlled by professional researchers/clinicians where people with experience of mental health difficulties are usually passive research subjects.

MENTAL HEALTH USER/SURVIVOR RESEARCH

In response to these challenges, the mental health user/survivor movement in the UK has, over recent years, encouraged and supported the development of user/survivor research in mental health. The Mental Health Foundation's *Strategies for Living* initiative has played a significant role in supporting these developments across the UK, along with some other important initiatives, such as the Service User Research Enterprise (SURE) based at the Institute of Psychiatry, User Focused Monitoring (UFM) at the Sainsbury Centre for Mental Health and, more recently, Service Users Research Group for England (SURGE) supported by the National Institute for Mental Health England (NIMHE). This growing support for user/survivor research in mental health, has been informed by the experience of other political, emancipatory movements, especially anti-racism and feminism and informed by participatory, social science research approaches which have been developed on these and other issues over several decades. It has also been supported by a growing, generic movement to increase patient/public involvement in health research³, which in turn is linked to developments to increase public and patient participation in health and social care overall.

Value

Given the inherently subjective nature of mental health problems, users/survivors believe that defining and leading their own research can provide more insight into their needs and more accurately identify their views and experiences of effective support and treatment. In addition, users/survivors often find that ownership of their own research agenda and process is empowering.

This view is supported by the experience of the Foundation's *Strategies for Living* initiative as well as other initiatives such as SURE⁴, where it is evident that users/survivors prioritise different research issues to those selected by clinical academics or those determined by government policy^{5 6}. Users/survivors prioritise research into social issues surrounding mental health – such as social inclusion/justice, discrimination/stigma; and self-help and self-management strategies and alternative/complementary therapies. User/survivors research priorities demonstrate their interest in a more holistic view of mental health than that generally taken by clinical/academic researchers. Along with other 'standpoint' or emancipatory research models, user/survivor research also places a strong emphasis on the research process, from defining research priorities, research design through to dissemination of findings, with a concern to maximise user/survivor influence or control.

Approach and Support

There are some differences of emphasis with approaches to service user research. The Mental Health Foundation's *Strategies for Living* initiative supports user/survivor-led research whereby users/survivors:

- select research topics
- are steering group members
- design and undertake research
- ideally control research funding or, where this is not possible, have some influence over funding issues.

However, services users/patients can also be more *involved* in research undertaken by professional researchers through participation in discussions about research priorities, involvement in research design, delivery, write up and dissemination. The Foundation's *Strategies for Living* recognises there is a place for increased involvement of service users in professional research, a key challenge, however, is to ensure user involvement is not tokenistic – user led research avoids this difficulty. However, whilst user led research can be empowering and can provide powerful findings, there are many challenges to ensure suitable support for user/survivor researchers. If user/survivor-led research is to be effective, user/survivor researchers will require adequate funding and ongoing practical and emotional support, whilst inexperienced user/survivor researchers will require training in research methods. Even users/survivors involved in professional led research may need considerable support of this kind and professional researchers are also likely to require training in how to work effectively with users/survivors.

UK POLICY CONTEXT

The policy environment for strengthening mental health user/survivor involvement in research, including user/survivor led research, is generally favourable and is supported by four overlapping policy areas:

- generic health and social care
- mental health services
- patient and public involvement in health and social care
- research governance in health and social care.

Generic health and social care policies and plans and mental health strategies and service frameworks across the UK place the patient/service user at the centre. Each nation has user involvement as an explicit aim of their NHS plans^{7 8 9 10} and the National Service Frameworks for Mental Health for England¹¹, Wales¹², Scotland¹³ and Northern Ireland¹⁴ also put patients at the centre. Each nation has also established separate policies and structures to support general user involvement in the NHS^{15 16 17 18}, some of which encourage service user involvement in research as one of several 'involvement' strategies.

These developments reflect wide-ranging debate and struggle over patient and user empowerment and participation over many decades and there are now a plethora of initiatives in England, Wales, Scotland and Northern Ireland to make these policy commitments meaningful. However, despite these positive developments, there remain considerable barriers to ensuring health and social care services are genuinely patient/user centred and that public and patient participation is meaningful and not token – especially in mental health. There is not space here to explore these issues further, but the relatively slow development of person-centred planning and effective service user involvement in mental health services across the UK, is not only of considerable concern in its own right, but also hinders the effective development of user/survivor research.

However, research governance frameworks for health and social care increasingly support and encourage user/survivor research – although this is currently much more developed in England than elsewhere in the UK. The research governance framework for health and social care in England, for example, calls for user involvement at every stage of research and requires academic and clinical researchers to demonstrate in funding applications how service users will be involved. NIMHE is providing support for such developments in mental health in England, through its SURGE initiative (see above).

CHALLENGES

Whilst there is growing recognition of the potential value of user/survivor research, a number of major challenges remain, including:

- resources, capacity and infrastructure to provide necessary levels of support to user/survivor researchers
- involvement of a wider range of service users in research, including young people, older adults and people from black and ethnic groups
- greater acceptance by clinicians of the validity of user/survivor research and that it provides an essential and valid contribution to the evidence base within the mental health field
- improving the dissemination of user/survivor led research and its impact on policy, practice and services
- development of more effective links between user/survivor research, person-centred service planning and public and patient involvement initiatives.

The Foundation is keen to work with others across the UK in the medium to long term to address these challenges.

RECOMMENDATIONS

The Mental Health Foundation, informed by its *Strategies for Living* initiative, recommends the following action, which if implemented, would provide further support for mental health user/survivor research across the UK.

- Continued promotion of the value of user/survivor research by government, research/academic and voluntary organisations, including development of clear definitions and guidance.
- Equal involvement of users/survivors and users/survivor researchers in national and local health and social care research (including research ethics committees) and funding bodies, with guidelines to ensure their views are acted upon.
- More government funding to support user/survivor research, including funding for infrastructure support and training especially in Scotland, Wales and Northern Ireland, where user/survivor research is less developed.

- Appropriate changes to the criteria of relevant research and development bodies (e.g. Chief Scientist Officer (CSO) in Departments of Health, Medical Research Council (MRC), Economic and Social Sciences Research Council (ESRC)) to support more user/survivor research in mental health and to take more account of user/survivor views generally.
- Training for academic and clinical researchers to enable them to understand the value of user/survivor research and work effectively with user/survivor researchers.
- Changes to the peer review criteria and processes for journals to enable more user/survivor research to be published and to take account of their views with respect to other research.
- Development of effective dissemination and influencing strategies for user/survivor research, linked to public and patient involvement initiatives in health and social care as appropriate.

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I The term mental health service user refers to people with mental health difficulties who use NHS and other mental health services in the UK – this is the term most frequently used by service providers and government. However, many people with experience of mental health difficulties prefer to use the term survivor, referring either to their experience of ‘surviving’ mental health problems and/or ‘surviving’ use of mental health services.

II UK = England, Scotland, Northern Ireland and Wales.

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