

CARERS' RESEARCH PRIORITIES

FACTOR - Families/Friends And Carers Together in Research

National Institute for Health Research

Mental Health Research Network

Acknowledgements:

This document was written by Dr Juliana Onwumere and consists of an executive summary of the report on Carers Research Priorities prepared by Dr Geraldine Mason (FACTOR Coordinator), together with a review of the literature. We are grateful to Vanessa Pinfold (Rethink) and members of the FACTOR Advisory Board, and we acknowledge the contributions of carers in workshops and carers support groups to different aspects of the project.

1. Background

Changes in the National Health Service coupled with related social and political drives have demanded greater public involvement in all aspects of healthcare (e.g. Robert et al., 2003). Public involvement (i.e. non-professionals, non-academics) in setting research agendas is increasingly sought because their views are likely to differ from other subgroups (Townend & Braithwaite, 2002). Their contribution helps to ensure that research projects are designed to answer questions that are relevant and meaningful to the groups that are most likely to be directly affected by the findings (Chalmers, 1995; Hanley et al., 2001; Ross et al., 2005; Talloon et al., 2000). Therefore, public involvement forms a key feature of good practice guidelines and research governance (Department of Health, 2005; Hanley et al., 2003). Moreover, it remains a key objective for health service providers and funding bodies within the UK (Department of Health, 1999, 2001, 2002; Consumers in NHS Research, 1999; INVOLVE; Gooberman-Hill, Horwood & Calnan, 2008). The allocation of research funding has been increasingly linked to their relevance to the public (Maxwell et al., 2003). The last decade has witnessed a steady increase in the levels of public involvement in mental health research (Telford & Faulkner, 2004).

Current figures suggest there are an estimated 420, 000 carers¹ in the UK providing care for individuals with severe mental health problems. The research evidence confirms that carers play a central role in the recovery and community care of service users² with mental health problems. The following report describes an investigation to identify research priorities reported by mental health carers. The report was commissioned by FACTOR -Families/Friends And Carers Together in Research the carer involvement project in the National Institute for Health Research Mental Health Research Network (MHRN).

2. Aims:

The primary aim of the project was to draw on different sources to identify areas of mental health research in which carers would welcome research. The project relates

¹ Also commonly described as caregivers, supporters or relatives

² Commonly refers to individuals with mental health problems who use statutory or voluntary mental health services

specifically to carers of adult age (18-65) and excludes priorities relating to dementia disorders since these have been covered in a separate commissioned document.

3. Method

The method comprised five main strands.

- A literature review was undertaken to identify academic articles, including those from grey literature, that have specifically explored the research priorities reported by mental health carers.
- Research priorities were identified from five meetings held with different carer support groups across England and led by a facilitator from FACTOR.
- FACTOR held a conference in April 2008 on research priorities for carers. The conference comprised four different workshops that were led by an academic and required carers, as part of their workshop, to identify key research priorities.
- A postal scoping study³ of 161 carers, prior to FACTOR being set up addressing carers interest in research was commissioned by MHRN (Pinfold & Hammond, 2005, 2006).
- As part of their postal application process to join FACTOR, carers were asked to identify their priorities for research.

4. Main findings

4.1 Literature Review

In the last five years, there have been a few publications that have reported the research priorities of mental health service users (e.g. Rose et al., 2008; Thornicroft et al., 2002). The evidence suggests that service users want to be involved at all stages of the research process and are keen to observe greater research on social and welfare issues (e.g. psychological treatments), discrimination and abuse, and medication (Rose et al., 2008; Thornicroft et al 2002, Sainsbury Centre for Mental Health, 2006). By comparison however, there is a paucity of literature on the research priorities reported by mental health carers. The literature review identified only three *key* relevant publications.

³ The Carers and Families Scoping Exercise

1. The Sainsbury Centre for Mental Health (2006)
2. Griffiths, Jorm, Christensen, Medway and Dear (2002)
3. Owens, Ley and Aitken (2008)

i). The Sainsbury Centre for Mental Health (SCMH 2006)

The Sainsbury Centre for Mental Health (SCMH) undertook a national consultation of research priorities for service user and carer centred mental health services. The consultation comprised individual interviews, questionnaires and focus groups with service users and carers. The authors reported that there was some overlap between group members such that many carers also met criteria for service user. Carers specifically prioritised research projects that supported and empowered family members and carers. They wanted research that allowed services to provide better levels of information and support to families. The priorities identified across the whole sample, although they were not highly ranked, also included research on medication, care pathways, and service user and carer involvement in the conception and delivery of mental health services. It seems important to note, however, that the objective of the SCMh study was to determine stakeholder research priorities for services rather than research per se. Therefore, the conclusions that are drawn regarding carer research priorities are somewhat limited.

ii). Griffiths, Jorm, Christensen, Medway and Dear (2002)

Using an Australian sample, Griffiths and colleagues (2002) have undertaken one of the most comprehensive reviews, to date, of research priorities reported by different key groups including mental health professionals (e.g. psychiatrists, clinical psychologists), researchers, funding bodies, and service user and carer advocates⁴ drawn from mental health and advisory groups. Although the exact figures are unspecified, the study comprised responses from 173 service user and carer advocates in total. Using a highly structured questionnaire with *pre-determined* response categories, which had been designed specifically for the purposes of the study, respondents were asked to identify and rank research topics (e.g. psychological and

⁴ Individuals charged with the responsibility of *representing* the views of service users and carers rather than service users or carers

social treatments, drug treatments, genetic causes, evaluation of services). They were also asked to prioritise research across the following categories:

- disorders (e.g. affective disorders, eating disorders, schizophrenia); settings (e.g. hospital settings, primary care);
- populations (e.g. carers, children and adolescents),
- level of importance (e.g. financial implications to society, high incidence levels of the disorder, negative impact on patient/ family friends).

Schizophrenia, suicide and self-harm, and affective disorders⁵ were top research priorities for carers and were not dissimilar to the disorders that were highly rated by the other subgroups. Carers identified prevention and promotion, training and education of mental health staff, and drug treatments as important research priorities. Moreover, drug treatments were identified as a research priority by carers only. In terms of target populations, carers reported that children and adolescents, and carers were the key groups to focus research projects on. It was notable however, that carers were not considered a priority population by *any* of the other subgroups (e.g. service users, researchers, funding bodies). Carers believed that the potential for research to make a difference to the lives of many people should be a key factor in determining research priorities (Griffiths et al., 2002).

iii). Owens, Ley and Aitken (2008)

The Devon Partnership NHS Trust undertook a Trust wide consultation in which it explored the mental health research priorities of carers of individuals with mental health problems (N = 26) along with service users (N = 34), service managers (N = 23), and Mental Health Practitioners (N = 35, e.g. clinical psychologists, psychiatrists, nurses). The Delphi Survey technique⁶ was used to gather data (Moscovice et al., 1988). Carers were invited from a broader group that were known to the Trust and had previously expressed an interest in research, and from carer groups active within the geographical area covered by the Trust. Participants were

⁵ Full list comprised: affective disorders, anxiety disorders, childhood conditions, dementia, eating disorders, mental retardation, personality disorders, schizophrenia, substance use disorders, suicide & self inflicted injuries, other mental disorders

⁶ Questionnaires are sent to participants during a series of stages. During each stage, participants are asked to revise their feedback in the context of the results drawn from other participants.

initially asked to list up to five topic areas relating to mental health that should be priorities for research.

The authors found that carers tended to rate most items as being of ‘high priority’ and wanted to see research that related to seven main areas:

1. staffing issues (e.g. staff motivation)
2. stigma (e.g. strategies to challenge stigma)
3. causes, detection and treatments
4. quality of inpatient and residential care and alternatives to inpatient admissions
5. strategies for preventing and managing crises
6. promoting service user recovery
7. carer issues (e.g. respite, well-being, information, communication with professionals).

There were some areas of convergence between carer research priorities and those identified by the other subgroups particularly with their expressed need for research into promoting service user independence and recovery, psychological therapies, inpatient care, prevention of crises, and the relationship between physical and mental health. The authors noted that the research topics identified by carers, unlike those proposed by the other subgroups, tended to read as a ‘wish list’ with pressing calls for service developments and assistance that would benefit the patient they provided care for and themselves. Carers experienced significant difficulties in drawing distinctions between ideas for research and personal care related issues (Owen et al., 2008).

4.2 Carers’ support groups

The FACTOR coordinator attended meetings of five carers’ support groups. These are facilitated groups mainly run by voluntary sector carers’ centres (also one run by a local authority social services department) which provide a setting in which carers are supported to talk about their caring role. A diverse range of research priorities were identified from these meetings. The groups called for greater research into the causes of mental health problems, quality of mental health services, and the process of how professionals share information with carers. There was also considerable support for research into communication pathways between professionals and carers,

professionals' recognition of a carer's role, the relationship between professionals, service users and carers, and services for carers.

4.3 *'Factor Us In' conference*

The FACTOR conference ran separate workshops specifically to identify research priorities in the following areas:

- a. Supporting families
- b. Social care
- c. Communicating with professionals
- d. Recovery

Despite the different workshop themes, there was much overlap between the research priorities. The main priorities identified from all the workshops tended to relate to mental health services specifically in terms of the following:

- stage of provision (e.g. early intervention);
- point of access and degree of responsiveness to carer and patient needs (e.g. primary care);
- development of new services (e.g. carer friendly services, respite services);
- improving service quality for carers *and* service users (e.g. staff training on mental health issues, confidentiality).

All workshops, with exception of 'Social Care', prioritised research into professionals' relationships with carers particularly their attitudes towards carers and their role. Illness related stigma was also prioritised by all workshops with exception of 'Recovery'.

4.4 *FACTOR postal survey*

Carers who participated in the FACTOR postal survey identified a broad range of research priorities. These were primarily related to mental health causes; mental health treatments including medication and therapies; service user access to services; services for carers; and quality of services. Carers also expressed interest, albeit somewhat less, for research into communication styles between professionals and

carers; the attitudes of professionals towards carers and their role; confidentiality between services and carers, and stigma.

4.5 *Scoping review (Pinfold & Hammond, 2005; 2006)*

The results from the Rethink scoping review identified a broad range of research areas. There was support for research on mental health causes including the interplay between genetics and mental health problems; optimal treatments particularly medications, coping skills and general support for carers.

5.5 Limitations of methodology and data

One of the strengths of the current study is the use of different sources to identify carer research priorities (e.g. carers' support groups; postal survey). However, the data sets are not without their own limitations and thus, the findings should be interpreted cautiously. For example, it seems important to comment on the representativeness of the carers studied and the extent to which their priorities could be generalised to other carers. Most carers were white, female and middle aged. Moreover, the carers were either members of a support group, opting to become members of FACTOR and/or able to attend a one day conference in central London. These carers are likely to reflect a specific sub group of mental health carers. The Factor Us In conference offered pre-arranged workshops on research priorities. It remains unclear however, about the priorities that may have been identified if carers had not selected on the basis of the title of the workshop (e.g. recovery, causes). Further, it is possible that carers who tended to be outspoken were more likely to have their ideas for research prioritised within the workshops and the support groups. It was also evident that many carers, particularly those who participated in the support groups, tended to identify research priorities in the context of commenting on a specific issue related to their relative and/or themselves. Although similar observations have been reported in other studies (e.g. Owen et al., 2008), this meant their priorities were not always clearly identifiable. For example, as a research priority, one carer specifically talked about an issue related to the immigration service and the difficulty obtaining a British passport for her son, whilst another carer reported on the positive relationships they had developed with professionals over time. Despite these limitations, it seems important to note that there was a

considerable degree of overlap between the priorities identified using the different methods.

6. Summary, Conclusions and Recommendations

6.1 Summary of research priorities

The main carer research priorities identified from the study are listed below. The list is organised around themes rather than levels of importance.

- Improving carer functioning and well-being (e.g. access to support, coping skills)
- Developing carer focused and friendly services
- The interface between carers and services (e.g. communication pathways between carers and professionals; relationship between service users, carers and professionals; confidentiality)
- Illness causes, prevention and early identification
- Access and pathways to services, and responsiveness of services (e.g. for carers and service users)
- Improving quality of service provision (e.g. residential care)
- Inpatient admissions (including alternatives to inpatient admissions)
- Optimal medications and side effects
- Talking therapies
- Recovery and promoting service user well-being
- Staff training and education
- Intervening to prevent or manage crises
- Interrelationship between physical and mental health
- Stigma (e.g. impact on individuals and strategies to reduce stigma)

6.2 Conclusions

To date, there is limited literature on the research priorities reported by mental health carers. However, we know that mental health carers are enthusiastic about research, particularly where it has clear benefits for patient development and well-being, and a positive impact on their own lives (Pinfold & Hammond, 2005). Notwithstanding the

methodological limitations, there was consistency in the priorities identified from the different sources. Moreover, the evidence suggests that carer priorities are relevant and often consistent with national service developments and research programmes (e.g. recovery), and with reported gaps in the literature (Anthony, 1993; Ramon, Healy & Renouf, 2007; Department of Health, 2002).

6.3 *Recommendations*

Whilst similarities can exist, carer research priorities do differ from those identified by service users and mental health professionals. Therefore, carer priorities should be sought and considered separately. Further, carers are not a homogenous group; the research priorities identified by carer subgroups such as those from black and minority ethnic groups, young carers, and siblings should be identified. Finally, it seems important to note that the research priorities identified by carers may also reflect, in part, problems with disseminating research findings. For example, many carers requested research on medication, including side effects, and the efficacy of talking therapies. To date, there has been considerable research in both areas. It is possible that greater efforts will be required to ensure that carers and/or carer organisations are regularly kept updated on research developments in broad aspects of mental health.

References

Anthony WA.(1993). Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, 16, 11–23.

Chalmers I. (1995). What do I want from health research and researchers when I am a patient? *British Medical Journal*, 310, 1315-1318

Consumers in NHS Research (1999). R& in the NHS: How can you make a difference? Leeds: NHS Executive.

Consumers in NHS Research Support Unit (2001) Involving Consumers in Research and Development in the NHS: Briefing Notes for Researchers. London: Consumers in NHS Support Unit.

Corner, J., Wright, D., Hopkinson, J., Gunaratnam, Y.,McDonald, & Foster, J.W (2007). The research priorities of patients attending UK cancer treatment centres: findings from a modified nominal group study. *British Journal of Cancer*, 96, 875-881.

Department of Health (1999). The National Service Framework for Mental Health. Modern Standards and Service Models. London: Department of Health.

Department of Health (2000). Working Partnerships. Consumers in Research Third Annual Report. London. Department of Health.

Department of Health (2001). Research Governance Framework for Health and Social Care: London Department of Health.

Department of Health (2002). Strategic reviews of research and development-Mental Health Report Appendices
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4082809

Department of Health (2005) Research Governance Framework: 2nd edn, Department of Health: London.

Entwistle, V., Calnan, M., & Dieppe, P. (2008). Consumer involvement in setting the health services research agenda: persistent questions of value. *Journal of Health Services Research and Policy*, 13, 76-81

Entwistle, V. A, Renfrew, M. J, Yearley, S., Forrester, J., & Lamont, T. (1998). Lay perspectives: advantages for health research. *British Medical Journal*, 316, 463-466

Faulkner, A. (2004). The Ethics of Survivor Research: Guidelines for the ethical conduct of research carried out by Mental Health Service Users and Survivors. Bristol: Policy Press in association with Joseph Rowntree Foundation.

Gooberman-Hill, R., Horwood, J., Calnan, M (2008). Citizens' juries in planning research priorities: process, engagement and outcome. *Health Expectations*, 11, 272-281.

Goodare, H., Lockwood, S. (1999). Involving patients in clinical research. *British Medical Journal*, 319: 724-725

Grant-Pearce, Mills & Hills (1998). Mismatches in priorities for health research between professionals and consumers. Manchester: Policy Research in Engineering, Science and Technology, University of Manchester.

Griffiths, K. M., A. F. Jorm, H. Christensen, J. Medway, & Dear, K. B. G. (2002). Research priorities in mental health, Part 2: an evaluation of the current research effort against stakeholders' priorities. *Australian and New Zealand Journal of Psychiatry*, 36, 327-379.

Hanley, B., Truesdale, A., King, A., Elbourne, D. & Chlamers, I. (2001) Involving consumers in designing, conducting and interpreting randomised controlled trials: questionnaire survey. *British Medical Journal*, 322, 519-523.

Hanley, B., Bradburn, J., Barnes, M., Evans, C., Goodare, H., Kelson, M., Kent, A., Oliver, S., Thomas, S., & Wallcraft, J. (2003). Involving the Public in NHS, Public Health and Social Care Research: Briefing Notes for Researchers 2nd Edn, Eastleigh: INVOLVE.

Horsfall, J., Cleary, M., Walter, G. & Malins, G. (2007). Challenging conventional practice: placing consumers at the centre of the research enterprise. *Issues in Mental Health Nursing*, 28, 1201-1213.

INVOLVE. Promoting Public involvement in NHS Public Health and Social Care Research. www.invo.org.uk

Maxwell, J., Roswell, S., Forest, P-G (2003). Giving citizens a voice in healthcare policy in Canada. *British Medical Journal*, 326, 1031-1033.

Moscovice I, Armstrong P, Shortell S, & Bennett R. (1988). Health services research for decision-makers: the use of the Delphi technique to determine health priorities. *Journal of Health Politics, Policy and Law*, 2: 388–410.

Naylor CD, Wallcraft J, & Samele C. (2006). Research Priorities for Service User and Carer-Centred Mental Health Services: Summary of Findings from a National Consultation. London: Sainsbury Centre for Mental Health.

Owens, C., Ley, A., & Aitken, P. (2008). Do different stakeholder groups share mental health research priorities? A four-arm Delphi study. *Health Expectations*, 11, 418–431.

Pinfold, V. & Hammond, T. (2005). Mental Health Research Network: Carers and Families Scoping Exercise. Rethink.

Ramon S, Healy B, & Renouf N. (2007). Recovery from mental illness as an emergent concept and practice in Australia and the UK. *International Journal of Social Psychiatry*, 53, 108–122.

- Robert, G., Hardacre, J., Locock, L., Bate, P., & Glasby, J. (2003). Redesigning mental health services: lessons on user involvement from the Mental Health Collaborative. *Health Expectations*, 6, 60-71.
- Ross, F., Donovan, S., Brearley, S., Victor, C., Cottee, M., Crowther, P., & Clark, E. (2005). Involving older people in research: methodological issues. *Health and Social Care in the Community*, 13, 268-275.
- Rose D., Fleischman, P. & Wykes T. (2008). What are mental health service users' priorities for research in the UK? *Journal of Mental Health*, 17(5), 520-530.
- Spiers, S, Harney, K, & Chilvers, C (2005). Service user involvement in forensic mental health: Can it work? *The Journal of Forensic Psychiatry & Psychology*, 16 (2), 211 -220
- Talloon D, Chard J, & Dieppe P. (2000). Relation between agendas of the research community and the research community. *The Lancet*, 355, 2037-2040.
- Telford R & Faulkner A. (2004) Learning about service user involvement in mental health research. *Journal of Mental Health*, 13(6):549-559.
- Thornicroft, G., Rose, D., Huxley, P., Dale, G. & Wykes, T. (2002). What are the research priorities of mental health service users? *Journal of Mental Health*, 11(1), 1-5
- Townend, M. & Braithwaite, T. (2002). Mental health research-the value of user involvement. *Journal of Mental Health*, 11(2), 117-119.
- Trivedi, P. & Wykes, T (2002). From passive subjects to equal partners: qualitative review of user involvement in research *The British Journal of Psychiatry*, 181, 468-472.