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**Good Practice Guidance for Involving Carers, Family Members and
Close Friends of Service Users in Research**

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MHRN

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1. Introduction

1.1 Background

It is estimated that there are around 1.5 million family members, close friends and other informal carers who provide unpaid support for people with serious mental health problems (Princess Royal Trust for Carers, 2007). Over half of these people offer a wide range of practical and emotional support for more than 20 hours per week and 55% of them feel that their health, social relationships and lifestyle are significantly affected by their caring responsibilities. Yet their experiences are often overlooked both by mental health services and in the design and conduct of research. Repeatedly, studies of carers' experiences and views of mental health services paint a negative picture in which their role is neither acknowledged or valued (c.f. Arksey et al, 2002; Simpson & Benn 2007; Repper et al, 2008). Similarly, carers are rarely involved in the development of research questions, study design or implementation (Pinfold, 2006).

Although there is a significant body of research on family focussed interventions (e.g. psychosocial interventions with families, family therapy etc. [c.f. Forrest et al, 2004; Brooker & Brabban 2006]), these studies have largely been conducted *by* professionals *on* family members rather than *with* the involvement of family carers on the research team. In fact, despite assiduous effort to implement such evidence based psychosocial interventions, they remain available to only a small minority of families (Faddon, 2010), and day to day, practical support for family carers of people with mental health problems is largely neglected by researchers and service providers alike (Pinfold et al 2010).

Every intervention (biological, pharmacological, psychological or social) that is developed to help people who experience mental health problems has an effect on those who spend most time with them, yet researchers almost never seek the views of family carers on the impact of the intervention nor on the longer term outcome as perceived by those who often know them best. As a result, there is very little research evidence about carers' experiences of the interventions nor about their views of the approaches that have been found to benefit service users (c.f. Repper et al, 2008).

In recent years there have been a small number of participatory research studies undertaken in collaboration with carers to guide effective practice in which the needs of both people using services *and* their family carers are addressed. In addition, family carers have played a significant role in the design and implementation of several large trials, multiple case studies and smaller qualitative studies. Such endeavours demonstrate both the feasibility and the positive impact of working with people who bring personal experience to influence the research. These examples of good practice form the basis of these guidelines and are included as vignettes to illustrate specific points.

It is all too easy to assume that the involvement of carers in research follows exactly the same course as involvement of service users and that the same practices apply to all groups outside the professional research team. It is the case that good practice for involvement is founded on the common principles of clarity and transparency, respect, diversity, flexibility and accessibility (MHRN, 2010). It is recommended that readers consult generic documents for a more detailed understanding of consumer involvement, its meaning, role, purpose and impact (see INVOLVE 2004, Staley, 2009). However there are differences between the way these principles apply to people who themselves experience mental health problems, and those family members, close friends and informal carers who provide support. As Faulkner, (2007) states:

“Service users and carers share the experience of being low paid volunteers among groups of professionals, talking about personal and emotional issues with people delivering services. However, it is important also to acknowledge their different perspectives and their need to be supported by people who understand and share that perspective.” (p.17)

The different perspectives and experiences of service users and family carers are significant at every stage of the research process; from research priorities, to role and contribution, rights and principles of access.

“Whole bunch of different issues – some are similar, shared perspectives. However for carers there are some very different issues and to do justice to these need discrete time to work with carers and carer organisations... we need a dedicated person ‘walking the floor’.”
(Quoted in Pinfold and Hammond, 2005, p. 11).

The training needs of carers also differ: their caring role and experience may influence their understanding of research and application of research skills. They need to consider complex issues around what to disclose about their caring role and what impact this might have on the person they care for. It might be helpful for training to consider potential differences in perspective between members of the research team (including service users and carers) and how such differences can be managed throughout the research process. Research teams need to understand these issues, in particular the significance of family carers' role, the contribution that family carers can therefore make to research and ways of facilitating this most appropriately and effectively within the research process.

1.2 Terminology

The term 'carers' is used throughout policy documentation to refer to the family members and close friends who provide support for people with mental health problems. Whilst recognised by most professionals and service providers, this term is disliked by many of the people to whom it refers: they do not necessarily recognise themselves as carers but as parents, children, siblings or friends. It can also be offensive to the people who receive support; they may not perceive their so called carers as caring *for* them, but as friends or family members with whom they share a reciprocal relationship – they care *about* one another. In this paper, the term family carers is used as shorthand for all relatives, friends, colleagues and neighbours who provide significant support.

1.3 Aims and Objectives

Whilst it is apparent that wholesale change in the culture of services is required to shift carers from the margins to their deserved place as a partner in the provision and receipt of *services*¹, this paper focuses on the role of carers in mental health *research*. Reasons for the routine exclusion of carers from research include a lack of appreciation of the

¹for this purpose the recently published 'Triangle of Care' report from the Princess Royal Trust and MNHDU, 2010 is a good starting point

contribution that they can make at all stages of the research process, a lack of understanding of the value of collaborative research, and a lack of skill in practically facilitating meaningful involvement of carers in research. This guidance aims to address these three areas by providing practical, accessible guidance for researchers (including people who themselves experience mental health problems or who provide care and support to those who do) who seek to collaborate with family carers in research.

1.4 Examples

Throughout the guidance, short vignettes of good practice are included to illustrate the way that some organisations have implemented the principles and the impact that this has had upon the research. It is notable that such examples are currently extremely limited (c.f. Pinfold, 2005). However valuable lessons have been learnt in projects that have worked collaboratively with carers and these are included in relevant sections.

1.5 Consultation with carers who have experience of research

The guidance has been developed in collaboration with service users and family carers. Two discussion groups were held, one with The Newham Mental Health Carers Group, East London NHS Foundation Trust, and the other with SUGAR (Service User Group Advising on Research, City University London, which includes service users and carers). These were designed to explore their views and experiences of research. Specifically,

- i. essential similarities and differences in the nature and facilitation of collaboration in research for service users and carers
- ii. the specific challenges of collaborating with carers in research and how these might be overcome (e.g. identification of carers, access and consent)
- iii. carer relevant issues at each stage of the research process.

1.6 Structure

This guidance examines the potential role, contribution, and the impact of carer involvement in the research process - from capacity building and identifying research priorities, through to dissemination of the research findings. Discussion groups were based on the Toolkit for assessing consumer involvement developed by the Service user and Carer Reference Group at CLAHRC –NDL (2010, see Appendix 1). This draws on principles and guidance for good practice in collaborative research to provide an accessible tool for exploring all aspects of the research cycle including:

- i. Building capacity and capability amongst carer researchers (including identifying existing researchers who have experience of caring and enabling them to use that experience effectively).
- ii. Identifying/recruiting and selecting carers to work with the research team (including expertise, experience, cultural background)
- iii. Clarifying roles and responsibilities of all members of the research team including family carer researchers and emphasising the value of different perspectives and the importance of respect for each other's right to express their views.
- iv. Providing support (a) with caring role, b) through payment, c) by making role accessible by making necessary adjustments and providing flexibility), c) by providing training and ongoing supervision).
- v. Facilitating appropriate levels of collaboration in doing the research from planning and designing the study, to collecting data to analysis and interpretation of findings and dissemination. Family carers' role in diffusion, dissemination and implementation of research findings.

1.7 Using the guidance

This practical guidance is written to complement the MHRN Good Practice Guidance for Involving Service Users in Research (Faulkner, 2007) but readers are referred to the

publications of INVOLVE (www.invonet.com) for more detailed papers on all aspects of public and patient involvement, evidence of its impact, availability of training, payment and support .

2. Guidance for Good Practice

2.1 Why involve family carers in research?

Recent moves towards lay involvement in all aspects of healthcare lately ensconced in the slogan ‘nothing about us without us’ (DoH, 2011) reflect prevailing notions of democracy. At a minimum, since the general public ultimately provide funds, they should have a say in the healthcare they receive. This also applies to research; those who provide funding should have an influence, and those with personal interest and experience are well placed to inform the process. Family members, friends and others who provide unpaid care for people with mental health problems certainly count amongst these stakeholders. They bring a perspective grounded in daily experience to ask questions that are worth asking, about healthcare worth investigating and outcomes that matter (Chalmers, 1995).

2.2 When should family carers be involved in research?

The great majority of research undertaken in the field of mental health has an impact on the people who spend most time with those who experience mental health problems: their family members, close friends and unpaid carers. Changes in treatment or services might effect behaviour and mood of the person receiving support and so change the experience of family carers or alter relationships between them. So, family carers may provide a helpful perspective on what differences certain interventions make, to the individual and to those around them. Whenever research is planned, the team should include both service users and family carers from the very beginning. During the planning process, the team needs to work with both service users and family carers to discuss the possible impact and relevance that the proposed study has on the experience of family carers and whether this is something they wish to explore as part of the research. (See Box 1).

Box 1. By involving family members from the very early planning stages of research, their role and their contribution (to care as well as to the research) can be fully recognised.

In a recent programme grant planning meeting the whole research team, including three service users and one family carer met, for two days of intensive discussion about options, possibilities and eventually plans. On day 1, one of the three theme leaders stated that family carers were not relevant to the development of a tool to improve 'engagement with services'. However, by the end of the meeting it was agreed that a carer researcher would run a focus group with other family carers to generate ideas about ways in which a) engagement and motivation amongst patients might be improved, and b) engagement of family carers might be improved. These would contribute towards the construction of the engagement tool and the impact on both patients and family members would subsequently be assessed. Had carers not been present at this meeting, then the perspective of family carers would have been missed entirely.

It is not merely during the planning stages that family carers make a valuable contribution. Even if the research study is not specifically about their experience, role or contribution they bring a useful perspective on the acceptability and accessibility of the research (both the research intervention, and the way that intervention is assessed) to the people they support. Furthermore, involving carers in interpreting and making sense of research findings can often provide novel insights that help researchers develop their understanding and provide recommendations for practice that move beyond the academic and routine.

Family carers should therefore be involved in every research project, at the very least, on the advisory board.

2.3 The principles of good practice

The core principles of good practice for involvement in research are detailed by Faulkner (MHRN, 2004). There are aspects of these that apply particularly for carers:

Clarity and Transparency. It is helpful for family carers to know what is expected of them and what they can expect from others. Written contracts of agreement about roles and responsibilities can be helpful. Whilst it is relatively easy to define the contribution of a statistician, project manager or health economist, the contribution of family carers is less tangible. They therefore need to be clear about what they are able to offer (and training may well help them to define this with confidence) - and whether this is congruent with the expectations of the research team. This contribution is *primarily* based on their practical experience of providing informal support for someone with mental health problems rather than on any research skills they might bring. It is their practical experience that enables them to assess the relevance of such issues as the research question, the outcome measures being used, the focus of interviews; their own experience also enables them to judge the potential response of carer participants, the accessibility of written information and aspects of family carer experience which might be missed. If involvement is to serve any purpose then the research team needs to take the views expressed by the family carer researcher seriously. They need to be willing to negotiate and allow carers' views to influence the research.

Respect. Mutual respect for different views and experiences is essential if the research team is to work together productively. People have the right to express their views and others have the right to challenge these – with respect. It is such difficult conversations that can lead to creative solutions in studies which might otherwise represent only professional and managerial beliefs and assumptions. Once again, involvement will be meaningless and tokenistic unless the team is willing to listen and prepared to change plans to attend to diverse views.

Creating appropriate organisational structures may encourage and support the expression and consideration of diverse views: the whole research team can negotiate and agree ground rules for discussions and a nominated person to facilitate or chair meetings may provide gentle guidance to ensure different perspectives are taken into account.

Flexibility. It is clear from the preceding principles that there needs to be flexibility within the research methods to accommodate suggestions of all members of the team and implement negotiated decisions. This is very limited once a project has received funding and ethical approval which is why it is so important to engage with service users and carers at the planning stage. However, even during implementation there is capacity for change to make the study more meaningful and accessible to family carers (e.g. the way that respondents are approached, the wording of information sheets and letters of invitation, the precise outcome tools used, interpretation of the findings, dissemination ...). If family carers are to be involved there also needs to be flexibility in relation to the timing and location of meetings (to fit in with their caring responsibilities), and in the resources available to fund carer researchers on the team (this may need to re-imburse 'sitters' to allow carers to leave home, travel expenses and additional time).

Diversity. Whilst no one has exactly the same experiences and views of another person, a shared perspective is more likely to be found among people with shared experiences. It is therefore helpful to select one or more family carer researchers who share the experiences of the population being researched. So, for example, in a study of schizophrenia, family carers of people with a diagnosis of schizophrenia will bring the most useful perspective; a study of young women with eating disorders will benefit from the views of a carer of a young woman with eating disorder and so on. However diagnosis of the 'cared for' person is not the only variable of interest; people who provide care are a very diverse group so it is helpful if carers working on research teams come from a range of different backgrounds, cultures and experiences.

Accessibility. Whilst practical accessibility of research meetings is an important consideration for family carers (see flexibility above), it is equally important for service user and carer researchers to be able to 'access' the research process, so both verbal and written language must be accessible: free of technical terms, jargon and acronyms.

It is also evident that many family carers (and service users) have physical health problems and/or disabilities. In light of this, researchers need to consider the need to produce research and discussion materials in different formats (such as larger font size) and to ensure that meeting venues are accessible for those with visual, mobility or other

restrictions. Similarly, access to the tools of the trade for researchers, such as computers, printers, photocopiers and libraries needs to be organised.

2.4 The research priorities of family carers

There are two reasons for considering the research priorities of family carers. First, they have their own distinct perspective and experiences and this brings a particular view about where more research is needed² or where better dissemination of existing research is required (see Box 2). Second, carers all too often feel that they are the token family member on research that is led by professionals and focuses on service users. Their involvement is much more likely to be meaningful and effective if they have an active role in a project that addresses an area in which they have experience and interest.

Having said that, in the focus groups we conducted, carers stressed that whilst they were keen to be involved in research that directly concerned carers' needs and priorities, they were also interested in contributing to wider research agendas around improving mental health services providing the perspectives of carers would also be considered.

Box 2. A Study commissioned by Factor and Supporting Carers Better (Onwumere, 2008) used five different methods (postal survey, literature review, meetings with carer support groups, workshops at Factor conference) to identify the research priorities of carers of people with mental health problems (excluding dementia), aged 18-35.

The following areas were found to be of importance to carers:

- Improving carer functioning and well-being
- Developing carer focused and friendly services
- The interface between carers and services
- Illness causes, prevention and early identification
- Access and pathways to services, and responsiveness of services
- Improving quality of service provision
- Inpatient admissions (including alternatives to inpatient admissions)
- Optimal medications and side effects

² Some of the areas prioritised by carers are already supported by substantial evidence of which they were not aware. This suggests the need for better dissemination of research findings for carers.

- 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).

There was consistency in priorities expressed by carers across different sources of information and these differed from other stakeholders in the research enterprise.

2.5 Carers' rights

One reason for the paucity of research into family carers' experiences is the challenge of accessing them. This is occasionally due to them having busy lives and choosing not to be involved in research. It is, however, more often due to the fact that they are identified through 'patients' who may not recognise that they have anyone in a 'caring role' or may refuse permission for researchers to approach their named carer.

Carers have their own rights, their own experiences and their own stories to tell and it is generally not necessary either to identify them through service users, access them through health services or to gain permission from service users (or the service users' psychiatrist) to approach people who provide support.

2.6 Accessing 'carers'

All too often, researchers claim that the people they are studying do not have carers but most people do have someone they consider a friend or family member. The term 'carer' can lead to the exclusion of people who do not recognise themselves as carers, or whose loved ones consider the people they spend most time with to be friends rather than providing a caring function. It can, therefore be useful to change terminology to promote inclusiveness (see Box 3).

Box 3 Identifying carers of people using an assertive outreach service (Repper et al, 2000).

In this service evaluation, we wanted to explore the views of family members as well as service users however staff only identified very small numbers of carers and it looked as though we might have to abandon this part of the study. In one last attempt to identify family carers who might be able to give their perspective on the service, individual interviews were arranged with every member of staff to go through their case lists and talk about 'next of kin' or friends and family for each patient – but not using the term 'carer'. We found that instead of 2 carers identified for a team case load of 56, this approach led to the identification of 40 different people who received some form of informal support from family carers, friends and neighbours.

Identifying carers in studies of mental health inpatient care (Muir-Cochrane et al, in press)

In a study of the impact of locked and unlocked doors on mental health inpatient units, the researchers were keen to obtain the views of carers as well as service users and mental health staff. By simply talking about 'visitors' rather than carers, the terminology is immediately more inclusive and allowed service users to identify to the researchers their family and friends visiting them.

2.7 Building capacity amongst carer researchers

It is only possible to collaborate meaningfully in research with family carers if people with relevant interests and expertise are available. Too often, the lack of accessible local carer researchers results either in carers being excluded from research, or in any carer known by someone on the research team being tokenistically invited onto an established project advisory board. One carer quoted in Pinfold and Hammond (2006, p.8) makes a plea:

"Don't patronise them or just use them for political correctness. Make sure everyone involved is fully trained and briefed before they are asked to become involved. Don't waste their precious time. Listen to the quiet ones" .

There are various ways of identifying carer researchers to collaborate in research:

Building a local resource. Find out who has been involved in previous research. Build up a pool of family carers with interest and skills in research over time (see Box 4). Rather than selecting different family members every time a new study starts, it is helpful to keep a register of local projects which involve family carers, the people involved, their contact details, skills and experience.

Box 4. Recruiting carers to participate in a research advisory group in East London.

Researchers at City University London approached People Participation Leads in the local mental health Trust who were able to identify and approach carers that might be interested in getting involved. Researchers also contacted local Carer Support Groups and attended meetings to discuss the research projects underway in the area and to provide information about getting involved in research. Through these groups, carers themselves have suggested recruiting through the local media (newspaper and radio) and advertising in local shopping centres (supermarket notice boards).

Accessing an existing group. There now exist a number of groups which have been set up specifically to support 'patient and public' involvement in research. Members have access to research training and support and are available to collaborate in research studies in subject areas and methodologies that interest them (see Box 5). Even though such groups are increasing in number and membership, family carers are generally in a minority so their views, experiences and training needs are rarely attended to as distinct from service users. It is, however, important that the particular circumstances, experiences, training needs and issues around access for family carers are taken into account to maximise the contribution that they can make on these groups.

Carer support groups. Carer support groups, whether set up locally or part of a national network, are often attended by family carers who are interested in research but who lack the confidence in their own research skills to volunteer for research opportunities. Recruitment from such groups can be helped if researchers forge relationships with local carer groups: sharing findings, explaining research plans, consulting them about their priorities, and explaining the contribution that carers can make to research.

Professional researchers who are carers. There exist many family carers of people with mental health problems amongst professional groups and academic researchers. Similarly, many service users are themselves carers of other people with mental health problems. These people bring invaluable skills and experience and should be actively encouraged to

use their personal experience of caring to influence research. It is generally assumed that researchers are *either* academics, service users or carers, however in the ongoing bid to reduce discrimination and marginalisation, recognition of the multiple roles and identities that we all hold might be a powerful route towards breaking down 'us' and 'them' and respecting different perspectives and experiences.

If family carers are to be involved in all stages of research, and supported and trained to do so, then resources are required. Where effective groups have been established, it has been possible to fund a designated lead, pay for involvement in research planning as well as with ongoing projects, and to resource appropriate training. Now that service user and family carer collaboration is a requirement of most research funding bodies and ethical committees, there is a greater imperative for University Departments, research programmes and research networks to invest in such support. It is not, however, always possible for small organisations or departments and individual researchers to provide the necessary support themselves. They may, however find it helpful to contact local and national resources for advice (eg INVOLVE, or RETHINK) about ways of optimising family carer collaboration in their proposed research.

Box 5 Service User and Carer Involvement is increasingly supported through the development of local groups of people with interest and expertise in research skills. Most of these provide for a mixed group of service users and carers although some are specifically for family carers. Examples include:

MHRN FACTOR National carer researcher database. This list of carers interested in research provides details of their availability, skills and interests. The list is maintained by the Carer Lead at FACTOR, Geraldine Mason, who liaises between projects and carer researchers and provides information and support to both parties as required. MHRN Regional Hubs each have service user and carer groups. Members receive training and support and are available to work on relevant local research projects.

RETHINK has a peer review panel: 12 people with experience of either using services or as a family carer of someone who uses services who review all research projects submitted for support from Rethink and make suggestions to improve ethical accountability and collaborative methodologies. Once again, all members receive appropriate research training.

Various Universities have set up groups of service users and carers to develop strategies for increasing collaborative research. For example, Nottingham University has a service user and carer lead who chairs a partnership group which has developed strategies for involvement, agreed accessible payment policies, negotiated free access to University courses in research methods, and holds a database of people interested in providing service user and carer input. City University London has developed a group of 14 service users and carers who collaborate on all their mental health research programmes and projects. The group is facilitated by a senior researcher and role descriptions were produced alongside accessible payment policies, ground rules for meetings and guidance for researchers attending meetings. All service user and carer members have been awarded honorary lecturer status and have full access to university facilities including computers, libraries and seminars. Other research staff help to support the group and provide monthly capacity building sessions which focus on developing research knowledge and skills.

Collaboration for Leadership in Health Research and Care (CLAHRC) regional translational research programmes all have Patient and Public Involvement Leads who support and develop collaboration with service users and carers. For example the Peninsula CLAHRC enables and supports service users and carers to lead on the development of research projects and the Nottinghamshire, Derbyshire and Lincolnshire CLAHRC runs a service user and carer reference group to monitor ongoing involvement and provide a resource of trained and supported service user and carer researchers to collaborate on CLAHRC funded projects.

Various NHS Trusts have similarly developed partnership groups to develop collaborative research. For example Bradford Care Trust has set up Xplore Research Group to promote collaboration between service users, carers and staff in participatory action research; there is a service user and carer audit group and the Trust provides regular research training for mixed groups of staff, service users and carers.

2.8 Building Capability among Carer Researchers

If family carers are to become actively involved in research then they need sufficient understanding of the research process to feel confident, command respect and make a critical contribution. It is essential for people to bring at least some understanding of research - as well as their personal experience of caring - if they are to be seen as valuable members of the team. Indeed, adequate training is considered essential to maintain high standards of research (Townend and Braithwaite, 2002; Rose, 2003; Faulkner, 2004; Lockey et al 2004). Most of the training available to date has been provided on a project specific basis and has focussed on core skills as applied to the project requirements, see for example Box 6.

Box 6 Training provided for carers working as researchers on PICAP (Partnerships in Carer Assessments Project). Carers were members of advisory groups and employed in each of the 10 case study sites as interviewers. They collaborated in questionnaire design, analysis of data, constructing recommendations and dissemination of findings. (See Repper et al, 2008).

Day 1:	Ground rules, introductions, what carers bring to the research, doing constructivist research, introduction to research, different kinds of research, stages of the research process, role of researchers, reliable and valid research.
Day 2:	Aims of PICAP, research design and methods, involvement of carers, case studies, interviewing carers in PICAP, analysing data, dissemination, your role as carer researcher.
Day 3:	Qualitative research methods, qualitative research in PICAP, qualitative interviews, interviews with carers in PICAP, open ended questions, qualitative interview questions for PICAP, building PICAP questions for carers, agreeing the PICAP interview schedule.
Day 4:	Interviewing skills, active listening, and managing distress, some interviewing problems and how to avoid them, difference in interviewing styles, thinking about tape recorders, using the PICAP interview schedule.
Day 5:	Ethical issues and research governance, maintaining anonymity and confidentiality, providing information to participants, gaining informed consent, minimizing distress, organizing interviews and introducing PICAP, making arrangements to interview.
Day 6:	Working safely, working in other people's homes and neighbourhoods, dealing with complaints, concerns and difficult events. Practicalities: expenses and finances, access to support, useful contacts.

There are increasing generic training opportunities available for both service users and carers to prepare them for active involvement in local research projects (see Box 7). Of course, people who use services and family carers also have the same right as anyone else to access mainstream research education opportunities from introductory training through to post graduate research qualifications. If family carers are to make their rightful contribution to research then education providers need to make appropriate adjustments so that carers are enabled to attend the training (eg allowing flexibility to accommodate unexpected commitments and life events, drawing on available funds eg through carer grant to allow the family carer to continue their education.

Of course, it may well be appropriate for family carers to access mainstream research training - from certificate level courses through to post graduate research methods courses. At the University of Nottingham, service users and carers who provide support to health and social care training programmes can access post graduate research modules free of charge and at Sheffield Hallam University post graduate research course fees are waived for service users and carers.

Box 7. Examples of research training courses available for service users and carers.

Research Programme specific training for a selected group of 13 students who have experience of mental health services is being provided as part of an NIHR Programme Development Grant in partnership between University of Nottingham and University of Manchester. It has been set up to develop strong service user and carer collaboration, increasing capacity and confidence to fully engage in the programme grant. It is a 6 day course (one day per month) which will cover the following areas:

- What is research
- Understanding the research process
- Finding the right question
- Finding out what's known (searching)
- How good is what's known (appraisal)
- Ways to answer the question (1) – thoughts and feelings (qualitative)
- Ways to answer the question (2) – numbers (quantitative inc. health economics)
- Doing no harm to participants (ethics & governance).

The Academic Unit of Psychiatry at the University of Leeds held a series of 6 workshops funded by the ESRC) to provide research training and promote partnership research through joint education of unit staff as well as potential partners. Although family carers were under-represented in the group, sessions did include specific reference to carers' contribution. As a direct result of the workshops some participants have become involved in externally funded collaborative research projects at the Academic Unit. A service user and carer research group has been formed, which aims to develop further collaborative research and continue to build the research skills necessary for successful collaboration. Some workshop participants have become involved in research activities outside the unit. Evaluation of these workshops highlighted that training, although important, can only contribute partially collaborative research.

SUGAR (Service User Group Advising on Research) at City University London is a facilitated group of 14 service users and carers that meets monthly to discuss and collaborate with research staff and students on a range of mental health nursing research studies. In the second half of each meeting research staff deliver training sessions on various aspects of the research process. This ongoing programme of education has included an overview of the research process; identifying and designing research questions; ethics and research governance in the NHS; searching and critiquing research literature; writing funding applications; developing interview schedules; conducting research

interviews; and designing research questionnaires. SUGAR members and research staff have also jointly designed and conducted a reflexive stakeholder evaluation of the first year's work and presented findings and run workshops at international and national conferences. A paper for publication is in preparation.

2.9 Carer specific issues in training

Two studies have trained family carers specifically for a work on carer focussed research projects (Repper et al, 2004; Repper et al, 2008). During these training courses, specific needs that related to the experience of caring became apparent:

Meeting carers' emotional needs. Many carers have not had an opportunity to share their experiences and feelings about caring. When brought together with others who share often raw and painful experiences it can be hard to remain focussed on the business of the day. It is therefore helpful to devote some time at the beginning of each day to share recent events and experiences. It is also useful to set ground rules for speaking one at a time, listening to each other, not making value judgements, and maintaining confidentiality within the group.

Selection process. Just like everyone else, carer researchers who have a certain level of literacy, a basic understanding of what is meant by research, and the difference between research and service improvement, find research training more accessible. It may therefore be appropriate to develop a role description and person specification and conduct some kind of selection procedure when recruiting carer researchers.

Active listening skills. Many family carers find interviewing skills particularly challenging. They have volunteered to become involved in research so that they can use their experience to help others. They want to share their experiences, provide support and suggestions for how to cope. This seems anti-thetical to their role as interviewers who simply listen. At least one whole day needs to be set aside to role- play active listening skills (such as following up issues that interviewees mention, responding to comments to open up the discussion, acknowledging responses and encouraging respondents to give more detail). Participants need constant encouragement and feedback to help them to detach from their own experiences and remain focused on the respondent's account.

Coping with emotion. Family carers are frequently surprised at the level of emotion they experience when hearing someone else recount an experience with which they empathise

deeply. It is difficult to witness someone else's distress, particularly when you identify strongly with their feelings, and even more so when your role is not to offer solutions or suggestions, just to listen. Training needs to explore ways of behaving when the person being interviewed becomes distressed, and ways of managing their own emotions in an interview situation and afterwards. Researchers need to consider the support and supervision arrangements that can be provided to carer researchers to minimise the stressful impacts of research work.

Pro-active support for carer researchers. Since family carers have often coped and cared for many years, they may find it difficult to ask for help even when they need it. In both of these carer specific projects, carers opted for support and supervision on a pro-active basis ie whether they asked for or felt they needed it. Researcher staff also need to recognise that carer researchers may occasionally need to make contact at unscheduled times to discuss concerns and some flexibility is required to accommodate this.

Providing support for interviewees. Carer researchers are often very reluctant to interview other family carers and leave them without offering any support. In both of these projects, the training led to the development of lists of local resources where carers who were interviewed might be able to access the support they would find helpful. Carer interviewers felt more comfortable with the interview when they knew that they could discuss with them at the end of the interview. It is useful to discuss different models or approaches to the researcher role and clarify when it is appropriate, for example, for carer researchers to provide advice or direct carers to carer support or advice services once the research work is completed.

Disclosure. Training must address the issue of disclosure. The challenge lies in enabling interviewers to achieving a balance between disclosing enough information about themselves to facilitate the interviewee in telling their story, and disclosing too much: taking over or leading the interview. At a minimum, the carer researchers should introduce themselves as a family carer before the interview. During training, interviewees were encouraged to use non-verbal cues to convey agreement and familiarity, and brief comments ('I know what you mean', 'I've been there', 'It is awful when that happens...') to show empathy. However, no blanket rule can be made about how to answer direct questions asked of them (such as 'I'm terrified at times - are you?', 'Has your son ever been

sectioned?'). Some carers were reluctant to talk about the person they cared for as this compromised their privacy; others found it hard to know when to stop talking about their own situation. For this purpose, it is useful to address this in training, working in pairs, monitoring the amount and appropriateness of self disclosure and giving each other feedback.

2.10 Providing support to carer researchers

Although family carers may not be used to asking for support, if research is to be successful, they need to have access to academic, practical, emotional and financial support.

Academic support includes training in research skills and ongoing supervision or research related support for the duration of the project.

Practical support includes transport, ensuring that meetings are held at convenient times in accessible places, offering to fund for sitters to care for the person they might be leaving at home.

Emotional support includes regular meetings to discuss progress, challenges, successes; to problem solve, boost confidence, provide reassurance and debrief following difficult interviews/meetings. If carer researchers are to have contact with patients then support to complete Criminal Records Bureau checks and honorary contract forms may also be valued. These are complicated and often unfamiliar to people who have been out of paid work for some time.

Financial support includes realistic payment to researchers for the time they spend on the project. This often exceeds the hours planned as travelling to interviews may be lengthy, time taken to organise interviews, attend meetings, read through transcripts of interviews all adds up and must be taken into account when costing a project. Carer researchers will also need travel and subsistence expenses and financial cover for child or other care provision. Specialist advice may be necessary to help researchers find the most appropriate ways of receiving payment without jeopardising benefits, (for more detail consult various guidance on payment for researchers available at www.invonet.org).

2.11 Facilitating appropriate levels of involvement

Involve categorises patient and public involvement into either **Consultation** (where consumers are consulted but they have no share in decision making), **Collaboration** (which involves active partnership in the research process, and **Control** (where consumers design, undertake and disseminate the results of a project).

Consultation. It is increasingly recognised that involvement in the form of consultation can be a meaningless exercise in which carer researchers are invited to a professional/academic meeting in which the agenda is already set, questions might be asked of them, but there is no guarantee that their views will be taken into account. Although this is a starting point for involvement, it is all too often tokenistic and may achieve no more than a ticked box.

Collaboration. When the research team is open to questions from carers, prepared to listen to their suggestions and make adjustments, reconsider plans and adjust procedures in the light of carers' experiences, then involvement is more collaborative and more meaningful. Collaboration might be initiated by the research team, in which case this needs to take place as early as possible in the planning process. Or, in the case of true collaboration, researchers work with carers to generate a research question and proposal.

Carer-led research. There are few opportunities for family carers to lead research: funding is difficult to win without high level academic support, and preferred methodologies, likely to focus on process rather than outcome ("ethics before effectiveness" [Bracken and Thomas, 2000]) narratives and personal understanding, may not attract traditional funding. As capacity and capability increases, this situation should change (as is the case with user-led research). However the first stage is for carer researchers to lead particular aspects or parts of research projects. Thus they might design training materials, design a questionnaire, or determine how findings can be translated into recommendations (see Box 8).

Box 8. Carers might not lead the whole project but they can take a lead on specific aspects of a research project, for example:

In the ECHO study, (Expert Carers Helping Others) a training programme for carers was developed with carers and delivered by carers including additional coaching to help the carers develop intentions, plan and goals. This was found to reduce carer burden, anxiety and depression.

REACT - Relatives Education and Coping Toolkit

The aim of this study is to develop and evaluate a supported self management toolkit for relatives of

people experiencing first episode psychosis. Given this is an intervention to support relatives, it is vital that it meets the needs of relatives and addresses the difficulties they face. The best way to ensure this is to involve relatives as much as possible in the process. The research project team consists of a mix of clinical academics, clinicians, methodologists and a relative. Having a relative involved in the management team ensures that this perspective is heard at all stages and is key to meaningful carer involvement. The relative involved is active in a number of local and national organisations and has been an excellent source of information on political policies and agendas. She has provided a detailed "from the ground" perspective about the realities of the problems faced by relatives and the kind of support currently available. Four focus groups of relatives informed the content, format and support offered for the toolkit. The detailed writing of the toolkit was done in collaboration with a relative - which was particularly useful as she was also a teacher. We are currently piloting the toolkit in a small trial and are collecting extensive quantitative and qualitative feedback from the relatives using it. This trial is overseen by a Trial Steering Committee which also includes a relative. It is hoped that the end product will clearly reflect the constructive involvement of relatives.

In a collaborative evaluation of assertive outreach (Repper et al, 2004) carer researchers worked together to design an interview schedule for use with other carers. Their main concern and priority was the adequacy of support in a crisis and out of working hours, this meant that the focus of the interview differed markedly from the outcome measures used by professionals.

In the PICAP study (Partnerships in Carer Assessments Project, Repper et al, 2007) a large workshop was led by carer researchers to consider the findings of the research and develop a list of recommendations for managers, practitioners and for carers themselves.

2.12 The contribution of carer researchers throughout the research process

Family carers have experience of providing support for people in all kinds of distress over varying time scales and with differing caring roles. This experience may be helpful to guide research from early planning right through implementation to dissemination. For example:

Early planning (pre-protocol work). Inviting carers to early planning meetings raises awareness among the research team about the experience of 'living with' varying levels of disturbance, distress, unpredictability ... the impact this has on the lives of family members and close friends, upon relationships with these people – both positive and negative. This helps to shape the research question and the determine the scope of the study. It is not always practical to include the perspective of family carers in the research, but the decision to exclude them needs to be justified rather than merely an oversight.

Ethical considerations. One of the key reasons for actively promoting and supporting patient and public involvement in research lies in its potential to result in more ethical research. That is, more relevant and meaningful to the people it is trying to help, more sensitive to their needs and more accessible (Involve, 2009). The presence of family carers introduces a different perspective on every aspect of research, raising new questions: what impact does this issue have on family members and informal care givers; how can their views be incorporated, what is their experience of this, would they understand what this information sheet is saying?.

Designing information sheets. Removing jargon, abbreviations, wording that might seem insensitive.

Advising on procedures for accessing family carers. Seeking alternatives to recruitment through service users or statutory mental health services. For example recruiting family carers through local self help groups, advertisements, national groups like Rethink or Mind.

Designing interview schedules for use with carers. Ensuring that questions are clear, meaningful, relevant and reflect the priorities and interests of carers. Or participating in the selection of measurement tools from a range of standardised measures.

Undertaking interviews with other family carers or with staff. Although there appears to be little evidence that carer interviewers are more accessible to other carers, or that interviewees are more likely to speak to them freely, this is more likely to be due to lack of involvement than lack of impact.

Reminding the team about carer specific issues. For example the difficulties of speaking in private if living with the person they care about; the importance of offering separate interviews for different carers as they may have different roles and different opinions.

Data analysis. Involving carers in qualitative data analysis can ensure that interpretation is not conducted through a biased professional or managerial lens. Family carers may well bring a different interpretation to the text and it is important to test this through rigorous analytic procedures. For example, Allam et al (2000) recount the experience of analysing transcripts in a group with service users and carers. One man spoke of his practice of locking his wife in her room at night. Service users were horrified by the level of control he exerted, family carer researchers interpreted this as a measure of anxiety he felt about his wife harming herself during the night. This was a clear reminder that the research team had to stick closely to the words of the interviewee and avoid reacting emotionally .

Dissemination. It can be useful to consult carers about the most appropriate mechanisms to reach a family carer audience so that research has as wide an impact as possible. This will include writing a summary of the research suitable for a lay audience, writing papers in local

magazines, circulars and newsletters; presenting the results in various, research, service and voluntary sector settings both local and national.

Implementation. It is essential to consider ways in which the findings of research can be implemented and this may well be something in which carer researchers can play a significant role. For many carers, the main reason for getting involved in research is to try to improve the experience of other people, so if the findings lend themselves to the production of practical guidance or training materials then carer researchers could lead on these developments and make plans to roll these out.

2.13 ... and back to recruitment

When research projects come to an end, it can mark the end of employment, social structure, meaningful activity and purpose for those working on them. It is important to prepare for the end of the project and to help the service users and family carer researchers on the project to plan ahead. There may well be additional unpaid work available on the project : dissemination - writing for publication, presenting results. Or there may be a possibility of working on an extension to the project or working together to develop a new proposal. It might be helpful for researchers to leave with a formal record of the experience they have gained and training undertaken so that they can use it with their C.V. to pursue other similar work.

Carers with research experience might wish to contact the MHRN lead for carer research to register their skills and interest on the national database of carer researchers (see Section 2.6). Given the shortage of family carer researchers, it is most important that their skills are capitalised upon in the movement towards making carer involvement in research a routine expectation and activity.

3. Conclusion

The involvement of carers in research is not only necessary in terms of democracy and current mental health policy, it is also worthwhile. It has the potential to contribute to a 'culture' in mental health where carers are respected, included and valued as a key stakeholder within the mental health system. Through research the profile of carers can be raised by having more research focussed on carers, prioritised by carers, informed by carers,

as well as some being led by carers. This guidance is written to help to make this aspiration a practical possibility.

References

- Allam, S., Blythe, S., Newman, A. and Repper, J., (2004) Researching collaboratively with service users and carers. *Journal of Psychiatric and Mental Health Nursing*, 11, 365-373
- Arksey, H., O'Malley, L., Baldwin, S., Harris, J. et al (2002) Overview Report: Services to support Carers of People with Mental Health Problems. NHS Centre for Reviews and Dissemination, University of York.
- Bracken, P. And Thomas, P. (2000) Putting Ethics before Effectiveness. *Open Mind*, 102, 22
- Brooker, C. & Brabban, A. (2006) Effective training in psychosocial interventions for work with people with serious mental health problems. *The Mental Health Review*, 11, 2, 7-14.
- Chalmers, I. (1995) What do I want from health research and healthresearchers when I am a patient? *British Medical Journal*, 310, 1315-1318
- Entwhistle, V., Renfrew, M., Yearley, S. Et al (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. Joseph Rowntree Foundation, London. <http://www.jrf.org.uk/publications/ethics-survivor-research-guidelines-ethical-conduct-research-carried-out-mental-health>
- Forrest, S., Masters, H. & Milne, V. (2004) Evaluating the impact of training in psychosocial interventions: a stakeholder approach, part II. *Journal of Psychiatric and Mental Health Nursing*, 11, 194-201
- Hanley, B. (2005) User involvement in research: Building on Experience and Developing Standards. London: Joseph Rowntree Foundation www.jrf.org.uk/publications/user-involvement-research-building-experience-and-developing-standards
- Lockey, R., Sitzia, J., Gillingham, T., Millyard, J., Miller, C., Ahmed, S., Beales, A., Bennett, C., Parfoot, S., Sigrist, G. and Sigrist, J. (2004) Report Summary - Training for service user involvement in health and social care research: a study of training provision and participants' experiences. *Worthing, Worthing and Southlands Hospitals NHS Trust*. Accessed 13.02.2011 <http://invo.org.uk/pdfs/TRUE%20%20page%20summary.pdf>
- Minogue, V., Boness, J., Brown, A., Girdlestone, J. (2005) The impact of service user involvement in research. *Journal of Healthcare Quality Assurance*, 18 (2) 103-12
- Muir-Cochrane, E., van der Merwe, M., Nijman, H., Haglund, K., Simpson, A. & Bowers, L. (in press) An investigation into the acceptability of door locking to staff, patients and visitors on acute psychiatric wards

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

Repper J. (2008) Carers of people with mental health problems. Chapter in Brooker, C. and Repper, J. (Eds) Mental Health: From Policy to Practice Edinburgh: Bailliere Tindall

Repper, J., Nolan, M., Grant, G., Curran, M. and Enderby, P. (2008) Family Carers on the Margins: Experiences of Assessments of Carers of People with Mental Health Problems. DoH/SDO R&D Programme, Available at www.sdo.nihr.ac.uk/files/project/53-final-report.pdf

Repper, J. (2007) Carers as Researchers: Lessons from the Partnerships in Carer Assessment Project. Chapter in Nolan, M., Hanson, E., Grant, G., Keady, J. (Eds) User Participation in Health and Social Care, Open University Press.

Repper, J., Newman, A., Saul, C., Roberts, J., Brooker, C., Freeman, J. (2003) "*Going the extra mile....*" *Evaluation of the Lincolnshire Assertive Outreach Service*. SCHARR, University of Sheffield.

Simpson, A. & Benn, L. (2007) Scoping exercise to inform the development of a National Mental Health Carer Support Curriculum. London: City University/Together: Working for Wellbeing. Available at <http://www.citypsych.com/docs/Carersfinal.pdf>

Smith, S., Ross, F., Donovan, S., Manthorpe, J. et al (2008) Service user involvement in nursing, midwifery and health visiting research: A review of evidence and practice *International Journal of Nursing Studies*, 45 (2) Pages 298-315

Staley, K. (2009) Exploring Impact: Public involvement in NHS, public health and social care research. INVOLVE, Eastleigh.

Townend, M. & Braithwaite, T. (2002) Mental health research - the value of user involvement. *Journal of Mental Health*, **11**, 117