

rethink

Mental Health Research Network
Carers and Families Scoping Exercise

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Section One: Introduction

Public and patient involvement in research is increasingly recognised as a vital component for all studies (www.invo.org.uk). Mental health survivor researchers have documented user involvement roles across all aspects of the research process (Faulkner and Morris, 2002), and over the past 10 years there has been a growth in the number of dedicated departments within universities and the voluntary sector carrying out user-led / collaborative research. The growth of carer involvement in research has been far slower. A number of projects and forums have developed to address the carer perspective but there is no co-ordinated movement. For example a collaborative group of user and carer researchers have described their experiences of working together (Allam et al 2004), and there are a number of Carer Focused Monitoring projects adopting the UFM model developed (Rose, 2001), but little other published research adopting explicit carer partnerships is available in England. Few Randomised Control Trials (RCTs) have an explicit component addressing the carer perspective and the number of studies researching carer related topics across the mental health field is proportionately small. However, some research projects, including those run on the MHRN, do involve carers or carer organisations on steering committees.

The scoping study outlined in this report set out to explore potential roles for carers in the MHRN. The network is committed to supporting carer involvement in research, as set out in its principle aims (see below), but involvement thus far has proceeded without strategic guidance or development (see table one for outline of current activities). In order to progress carer involvement in the MHRN a study was undertaken to identify how carers can influence the work of the MHRN and get involved in specific projects. This report has been prepared based upon a series of recommendations from the consultation exercise and agreed action points with the MHRN.

The UK MHRN (mental health research network) has been set up with the following principle aims:

- To coordinate and facilitate the delivery of large-scale research projects that will inform policy and practice as it develops.
- To broaden the scope and capacity of research in mental health, including full involvement of service users and carers as well as frontline staff.
- To help identify the mental health research needs (particularly in health and social care)
- To develop research capacity through a range of initiatives at a local, regional and national level.

Table one: Current carer involvement in MHRN

Carer involvement in MHRN Hub committee structures (Autumn 2005)	No. of Hubs (out of 8)
Currently have carer representative on Hub Executive Committee	3
Current post vacant (as of the Autumn 2005), previous carer representation on Hub Executive Committee	2
No carer post on Hub Executive Committee	3
Carer representation on Hub steering / advisory committees	2
Other current involvement opportunities:	
Members of MHRN research writing groups	
Involved in individual Hub launch events and conferences	
Consumer forums in the Hubs bring together service users and carers to discuss research activities in the MHRN	
Identified good practice	
Hub chair meets with carer and user representatives prior to committee meeting to go through papers, clarify terms, identify points carers want to contribute in meetings to ensure these are heard. This also happens when carers are on local R&D or ethics committees.	
Networking with other agencies providing service user and carer research skills training.	

The role of carers in mental health across the life course of mental health problems from child and adolescents, working age adults and older persons, is the focus of increased government attention. For example, the National Service Framework for Mental Health (DOH, 1999) includes a standard for supporting carers, ensuring health and social services assess the needs of carers who provide regular and substantial care for people with severe mental illness, and provide care to meet carer's needs. In *Caring about Carers: a National Strategy for Carers* (1999), the government announced a package of provision for carers, including:

- Time spent caring entitling informal carers to a second pension
- Support for neighbourhood services, including carers' centres
- Considering the scope for extending help to informal carers to return to work
- Special funding for breaks for informal carers.

There is also guidance on developing services for mental health carers (DOH 2002) outlining how services should be:

- Positive and inclusive: carers should be involved in decision-making and recognised as partners and co-experts;
- Flexible and individualised, person centred and able to reflect the diversity of carers;
- Accessible and responsive, available at all times and able to offer a rapid response;
- Integrated and co-ordinated, carer services being embedded in mainstream services.

Alongside developments in policy there have been practical initiatives to empower carers, providing them with a louder 'voice', and research to assess carer priorities (Arksey et al 2002). Carer support services, carer forums, carer education projects, carer involvement leads in NHS Trusts and NIMHE/CSIP are all initiatives which are encouraging the active involvement of carers as a key stakeholder in mental health. The role of carers is changing, increasingly the 1.5 million mental health carers (ONS, 2002) are viewed as 'partners' in care alongside formal care providers in the statutory, voluntary and private health and social care sectors. However most studies emphasise where user and carer involvement are considered together, carer involvement is the least developed of the two activities. For example Rose et al (2002)

literature review of user and carer involvement in change management in mental health found only a small number of studies dealing only with carers and only a quarter of the literature made reference to carers. It is thus timely to consider the potential roles for carers in research, alongside those developing for service users, and begin the process of developing a strategy to support carer involvement across the MHRN.

Section Two: Methods

The scoping exercise has been led by Rethink in collaboration with Together, Making Space and www.mentalhealthcare.org.uk who promoted the consultation survey on carers involved in research. The project was carried out between June and December 2005 and involved several consultation stages:

- Scoping questionnaire to carers (web based and hard copy) – 176 responses from carers were received over 3 months;
- Stakeholder consultation including interviews and written e-mail questionnaire responses – see below;

Table two: Summary of stakeholder consultation exercise

Consultation group	Interviews	Written responses
Carers involved in research	7	1
Service users involved in MHRN	5	
MHRN Hub co-ordinators	8	
MHRN Hub Leads		4
MHRN Research writing group leads		4
MHRN Associate Director for User & Carer Involvement		1
Professional researchers	8	2
Carer involvements leads	5	
Total	33	12

- Follow-up web-based survey at www.mentalhealthcare.org.uk to carers with specific interest in research – 27 carer responses over 3 weeks;
- Compilation of innovative practice research work with carers:
 - Alzheimer's Society – Quality Research in Dementia Network www.qrd.alzheimers.org.uk
 - Mental health carers research network in South West
 - National Coordinating Centre for Service Delivery Organisations carer research programme www.sdo.lshtm.ac.uk
 - Resource for mental health carers www.mentalhealthcare.org.uk
- Draft report based upon scoping exercise data capture and consultation process submitted and considered by MHRN

The aim of the project was to establish how the MHRN can support carer involvement in its projects and activities, integrating carers as partners in the MHRN alongside mental health service users, academics and clinicians. We specifically sought views on:

- The role(s) for carers in research generally, including an exploration of carer enthusiasm for research in roles as consumer, participant and lead;
- Recommendations for how an organisation such as the MHRN could develop a programme to ensure the carer perspective is included in its work programmes alongside initiatives to develop user involvement in mental health research.

The scoping study has consulted widely though in the timescale and resources available it was not possible to carry out an extensive review. There will be research projects working directly with carers that we did not contact and carer groups who have carried out research themselves

that we did not reach. However, a range of stakeholders have contributed to the review, and consistent themes and recommendations emerge through the scoping process. The limitations of the exercise will be commented upon in the discussion, but throughout the exercise the team have acknowledged with participants that the scoping exercise is part of developing carer involvement in research, and is seen as one stage in this process rather than a distinct end point.

Throughout the scoping exercise a broad definition of research has been adopted. The team did struggle in several settings to communicate the aims of the MHRN and the scoping exercise to carer groups. The team were aware that involvement in research (committees, networks and as researchers) is not currently a priority for large numbers of mental health carers. We found that carers contacted for this project are interested in research, and particularly research findings, but most don't know how to get involved in MHRN. In addition, the team did not define the 'carer' role and the consultation exercises did not require carer participants to describe their support role so we do not have data on the range of carers consulted. However the promotion routes for the survey ensured we targeted a wide range of carers supporting adults of working age with mental health problems.

This report is the second summary document produced by the scoping exercise. Building upon a useful consultation session with the MHRN, recommendations from the study have been discussed and themed:

- Actions required from the MHRN
- Actions required for the wider academic community including researcher funding bodies and individual investigators.

The final summary has been circulated to a number of people involved in the study for final comment and approval.

Section three: Discussion

"Research has to be relevant to them – carers view: "not more research" "not more consultation". They want to see changes and have research carried out on topics that impact upon themselves" (Carer involvement lead)

"Hubs need to understand why lay groups come to research and they need to be clear how carer involvement will make a difference. Academics come to research with possibly different motivations, for example research as an academic exercise. Carers have to see the point of a project. They have less time because they are often trying to juggle several roles and responsibilities. When we did our research we could see the point. If research doesn't impact on people locally carers won't be interested unless they have an academic background themselves and are interested from that perspective" (Carer)

"At the moment carers are a bit of an afterthought and if someone has a service user involved in the research project then carers tend to be left out. Carer involvement needs to be given more priority" (MHRN Hub Lead)

"Carers will be some of the most concerned citizens about the future of mental health research. They have a stake in defining what research we should be doing. Need to identify opportunities for carers to get involved" (Service user)

"Carers have been fundamentally changed by the experience of caring and thus are often de-skilled, stigmatised and anxious about how they are perceived. Thus it is difficult for many to get involved in research activities from this position of dis-empowerment" (Academic)

Material collected from the surveys and interviews was drawn together into an initial report to identify key themes raised by the different stakeholder groups. The first key question we needed to address however was whether carers are interested in research and keen to become involved in the MHRN. The two surveys that were carried out for the consultation exercise identified that there is a small but enthusiastic group of carers interested in research activities. We heard from 176 carers in our general survey and 27 in our second targeted questionnaire. Although further work is required to establish level of interest in the types of activities supported by the MHRN and the mechanisms to support and sustain carer interests in research, the scoping study has identified that carers do want to be involved. Similarly other stakeholder groups are keen to work with carers in the MHRN as partners – though questions were raised on how to take this forward in practice.

The scoping exercise identified a number of areas that particularly interest carers in terms of research. When we asked carers "What advice would you give to ensure we attract carers and keep them interested?" The following actions were recommended (n=118):

- Dissemination - publicise results, make information available to carers, keep carers informed through newsletters, show them the value of being involved through effective feedback, provide a variety of ways to receive information (43%)
- Develop robust strategy for working with carers and ensure that those involved feel valued and listened to (16%)
- Offer regular support (10%)
- Provide networking and learning opportunities through conferences, seminars with expert speakers on informative topics (10%)
- Provide training (8%)

"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" (Carer)

"Keep it interesting, allow for times when people cannot attend for a while due to caring role. Be flexible. Help with financial costs, support for service user whilst carer busy." (Carer)

"Show them what has been advanced by being involved" (Carer)

A point emphasised by carers was to ensure that any involvement opportunities created in the MHRN were 'meaningful' leading to outcomes that were rated as important by carers. The barriers to carers becoming involved (in any activity) are re-iterated time and again in surveys, linked to the nature and responsibilities of being a 'mental health carer' (e.g. Pinfold and Corry 2003). A strong theme in the data was the problems that academics, carers involvement leads, hub co-ordinators experienced in identifying 'carers' to invite to events or to join committees. Carers are frequently a 'hidden' population, accessed through the service user rather than a stakeholder in their own right. The 'carer' label is well known to mean little to some individuals supporting people with mental health problems and the pressures of caring can take their toll leaving individuals with little capacity to engage in mental health research activities. In terms of identities, the scoping study also identified that there will be researchers working in mental health who are also mental health carers but are not professionally 'out' as such. Some researchers who are carers prefer to keep their carer experiences separate from the academic careers and would not want to be termed 'carer researchers'.

Overall, we captured a research commitment to carers but with most commentators admitting they did not know how to turn this commitment into practical actions to develop existing programmes or roles further. Collaborative carer research is still in the early stages of development and thus no conclusions can be made about the added benefits of carer-led / collaborative research studies. However, most feel that the user engagement research model would be one to aim for when developing carer research programmes, tracking how carers can influence (and own) each stage of the research cycle. There were of course contradictions in the data with different views expressed on ways forward for the MHRN in regard to working with carers. For example, a few carers said they didn't want involvement to only mean invitations to join committees, whilst others fed back the importance of the carer perspective on the ethics, R&D or hub committee. Some academics felt that carers needed research skills to get meaningfully involved in the MHRN, whilst others emphasised the skill base of carer experiences as the only essential criteria for participation.

Most research assessing organisational changes to incorporate user (and carer) involvement, emphasise the importance of addressing involvement at every level of the organisation including agenda setting, decision making and grass routes implementation e.g. Rose et al 2002, HASCAS, 2005. Stakeholders identified a number of key positions in the MHRN where carer involvement would be beneficial. Several of these are taken into the recommendation sections. The MHRN does not control research funding and thus calls for carers to be involved in prioritising research topics for research commissioning are directed to the mental health community. However within the MHRN structure, carer roles could be created at the following points ensuring carers as partners in care, as experts and as consumers are fully engaged across the network:

- Adoptions committee – appoint a carer with research expertise to take an active part in decisions about studies involving carers being adopted onto the network
- MHRN management group - Associate Director for User and Carer Involvement to use this report as the basis for future work on carer issues
- Specific carer development lead created to promote carer issues across the network, developing guidance and materials to support the hub coordinators
- All hubs to appoint a carer on their steering committee

A fundamental recommendation emerging from the study was the long term goal of contributing 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 directed towards carers, prioritised by carers, as well as some being led by carers.

The scoping study also raised a number of key questions that need to be addressed when developing a carers research strategy within the MHRN. The main questions raised are listed below accompanied by illustrative quotations. Further consultation will be required to position the MHRN in relation to these issues.

3.1 Considerations when planning carer involvement in MHRN

1. Carer involvement: which carers?

- Need to address representation issues both in terms of diversity of experience as carers and also how well equipped one individual will be to 'represent' the views of carers more generally if involvement is based on experiences as a carer alone (as opposed to a skills mix of research, caring experiences etc)
- Also need to consider what qualifications / skills are required for carers to become involved in the MHRN – research knowledge /expertise and experiences as a carer or solely carer experiences, previous roles on committees?
- The definition of a 'carer' was also raised as an important point requiring clarification – who is a mental health carer?

"Carers are not a homogeneous group, important to look at ways of engaging diverse groups of carers" (Carer involvement lead NIMHE)

"Black people are over represented in control aspects of mental health services and under represented in caring aspects. Hence, it is important to involve black carers in research for their experiences and views" (Carer)

"Just as many people come into research through having used services, so many researchers have experience of being carers. But it's my qualifications and publications, not my experience of caring, that testify to the quality of my research. Carer status should not override research qualifications in the design and conduct of research" (Academic)

2. Carer involvement: why?

- Clarity over why the involvement of carers in research is important
- Well defined roles / groups / networks for carers to be recruited into with clear remit, purpose, resources and support structures
- Clear vision of the expected outcomes to be achieved through carer involvement

"I am interested in research that I can apply in everyday caring" (Carer)

"For service users and carers – MHRN needs to find meaningful involvement – but this needs to evolve with clear and honest boundaries. Feeling that this 'meaningful' involvement needs to be more than recruitment to clinical trials" (Service user)

"Important that user and carer research projects are of a high standard to combat the criticism that they are not 'proper research' – problem when training is not high quality and too many people jump on band wagon– gives whole sector bad name" (Academic)

"There is still the general perception that we are a nuisance. Through carers involvement in research, important for all to understand the role of the carer. The reality that people must be aware of is the difficult situation that carers find themselves in" (Carer involvement lead)

3. Can you combine user and carer involvement roles?

- The consultation exercise provided strong indication that separate roles for user and carer involvement are required. Most of the stakeholders consulted were of this view.

"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' in the region." (Carer involvement lead NIMHE)

4. Can the MHRN build capacity to enable carer involvement in research?

- Need to be able to identify carers interested in research and understand what roles they are interested in (committee member, carer-researcher, monitoring role, member of research writing group)
- Need to be able to provide support and training to carers, or network with other organisations providing training courses
- Possibly need to adapt ways of working to accommodate needs of carers

"It takes a lot of time to involve users and carers effectively. It is important to co-ordinate activities so that not duplicating effort thus working with voluntary sector organisations and NIMHE as we are all drawing on the same pool of people" (Hub coordinator)

"It is important to train people so they have the skills and confidence to engage effectively in the MHRN. People need to feel they have a real and valid role – not just as a service user or carer". (Hub coordinator)

5. How will the MHRN promote carer involvement opportunities to carers?

- Increase awareness of the role of MHRN among carer groups and organisations
- Provide information about MHRN activities in different formats – web, leaflets, translations for BME communities
- Educate carers to frame expectations around involvement in research

"As for service users, find out what Hubs are up to already and learn/disseminate best practice if you can find it; if there is very little, draw up some role descriptions, identify barriers to involvement, develop good practice guidelines, disseminate, promote, audit them" (MHRN hub lead)

"Need to promote how research has worked and influenced service users' lives. Share this information to stimulate more carers to engage in research. Need to provide options for involvement all the time, and this requires education among staff as you must promote a culture of involvement with staff" (Carer involvement lead)

3.2 Benefits of involving carers in MHRN

The scoping study identified a number of benefits associated with carer involvement in research generally and the MHRN specifically. These are listed below themed by stakeholder group.

For research community:

- Encourage more research on carer / family related issues – an underdeveloped research area in mental health

- Providing a perspective that may be missed by researchers and using their carer experiences to improve research aims, questions, selected outcomes
- Service users involved in research will mostly be 'well' at that particular time, carers can be the only voice providing the experience of actively supporting someone who is acutely ill
- Make sure you are spending research monies on most important issues
- Carers promoting research locally and nationally ensuring there is a positive culture in regard to large multi-centre research studies
- Ensuring clinical trials pay due attention to the needs of carers and users throughout the research process
- Supporting new routes for dissemination of research findings

"An important voice not just as a route to the service user but perspectives in their own right" (Academic)

"Clinicians, academics look at lay members or carers and see them as: Unqualified; No real position. However as a lay advisor we take the role very seriously, often have more time to prepare and read papers, take position seriously and attend meetings on time do all preparatory work" (Carer)

Several carers provided reasons why they had joined the MHRN:

"Clinicians lose track, don't always hear from people very close to the service. You need people representing the views of people using the service – the service user or carer"

"Quite a lot of research put before the R&D panel isn't research but audit – feels that quality of studies can be poor even from experienced staff. Feels that HUB will encourage good quality research and need to have lay people scrutinising research to drive up quality in research".

"I can step back and look at the overall picture rather than the specific question. I can see how they can overcome problems so have something to contribute. We have coal face experience working with service users and the mental health system. Lot of academics and clinicians don't have that same experience"

For carers:

- To become more informed and thus provide family / friends with hope through new information that people with mental health problems can recover
- To raise the profile of carers within the mental health system by gaining a voice in the research community, promoting the expertise of carers
- To work using your expertise as a carer and gain new skills

"Carer led work is very rewarding. Been involved in different aspects of service development and the research project has been the most rewarding project because we saw as a result of the evaluation, the extension of the service locally" (Carer)

3.3 Barriers to carer involvement in MHRN

The scoping study also identified a number of barriers to carer involvement in research, considerations that are important when developing a carer involvement strategy. Again these are listed below in sections.

For carers:

- Carers fear their involvement won't make a genuine difference
- May require support to become involved: training; networking opportunities; travel costs reimbursed; accessible information

- Limited time to engage in involvement activities because of the pressure of caring and managing other responsibilities
- Emotional pressures of caring can make involvement in mental health research difficult and challenging
- Carers lack confidence to 'get involved' alongside clinical academics and researchers
- Roles in MHRN can be challenging and daunting
- Some carers need to be paid for their involvement – particularly when committing substantial amounts of time and skills alongside paid employees, but payment is rarely beyond travel expenses.

"If you've been involved before – you have confidence to turn up at events but will still need specific training to participate in MHRN. The academic world has its own language which can be difficult to understand" (Carer)

"It wasn't quite daunting but the first few meetings were different to what I usually deal with on other committees such as inpatients committee, clinical governance. I am on a lot of committees and steering groups and the MHRN one is different ... if you don't speak up items are passed without comment." (Carer)

"Carers are a disempowered group of people. They are reluctant to push themselves forward, main concern is for their relative. Carers feel they don't have the right to ask for more and this is reinforced by academics, clinicians and to a degree parts of the user movement who remain suspicious of carer" (Academic)

For MHRN:

- Carers are unaware of involvement opportunities in the MHRN
- Need to make involvement in MHRN worthwhile and relevant to carers
- Difficult to identify carers who would be interested in participating in MHRN activities
- Few dedicated resources to support carer involvement
- Resistance to carer involvement in research community – 'hearts and minds' on the value of carer involvement not won
- Effective carer involvement takes time and isn't easy to achieve
- Paying carers on benefits to become involved will present a challenge to MHRN and will require clear guidance on this issue
- Carers will be interested in research and evaluation studies with broader remit than the work of the MHRN – e.g. service audits. Clear communication of boundaries of MHRN interests essential to emphasise remit focused on clinical research.

"It is important to train people so they have the skills and confidence to engage effectively in the MHRN. People need to feel they have a real and valid role – not just as a service user or carer" (Hub coordinator)

For academic community:

- Lack of funding for protocol development work (in order to pay service users and carers to become involved)
- Lack of time available in their work plan to capacity build with users and carers, ensuring they engage with stakeholders effectively. Difficulty identifying relevant service users and carers to comment on their research idea
- Short deadlines on research funding calls limiting time available to consult effectively with stakeholder groups prior to submitting research proposals
- Heavy administrative burden attached to research, need to show evidence of involvement without process being overly bureaucratic or time –intensive
- Does carer involvement lead to better quality research being delivered? This case has not yet been made
- Limited guidance on best practice working with carers

"It is important to change hearts and minds locally among academic community – in terms of involvement of users and carers at the same time as identifying potential opportunities for involvement in MHRN structures". (Hub coordinator)

"Carer led research has got to be a good thing, a positive development. However it is not an easy thing to develop. Carers will need training and support to become 'researchers' understanding robust design and statistics. It's no good starting things off if the support is not in place to achieve long term goals" (Academic)

"Issue for academics – if you work with users and carers it is more complicated. They have gone down the route of working with users as there has been more emphasis on user involvement in research. The thought of doing anything with both groups which will ensure the process is more complicated is not well received. Carers add another dimension. Feels that academics are not skilled to carry out user and carer involvement and require training. Academics don't know how to involve users and carers effectively" (Carer)

"Need to promote how research has worked and influenced service users' lives. Share this information to stimulate more carers to engage in research. Need to provide options for involvement all the time, and this requires education among staff as you must promote a culture of involvement with staff" (Carer involvement lead)

"There are not many carers who will feel that research has any relevance for them. It is something other people do on behalf of their relative. We maybe think too narrowly of only empowering, building capacity and skills for a few people to get closely involved—but is this likely to happen? We should think of other complementary models—maybe employing consumer leads who can genuinely speak on behalf of carers... to go out to carers, to consult them on developing research questions/protocols and gathering ideas/views about specific projects. This might yield carers who will be interested in acting as consultants to particular projects for a limited time rather than necessarily a permanent task". (MHRN writing group lead)

3.4 Scoping study limitations

The study was carried out over a 6 month period with identified resources which did not enable the research team to consult as widely as would have been desirable. There will be key carer research projects, and their lead academics, we missed and carer organisations who could have made a greater contribution if time had allowed. We did not carry out a thorough literature search to identify published studies on caring and related issues of direct relevance to the carer. This would be beneficial in order to map the current carer research landscape.

Section four: Recommendations for MHRN

"Put simply - you have to make involvement worthwhile to carers" (Carer involvement lead)

"The MHRN can provide a supportive framework to encourage an expectation of carer involvement. It can facilitate liaison between local carer groups and organisations with MHRN Hubs so that researchers and carers have a common point of contact" (MHRN hub lead)

"If resources are limited, and this area is new, have a national role to take forward carer involvement. They can network with carer organisations and translate information for carers ... Need to raise awareness in carer organisations around how research is carried out, how decisions are made re-funding, ethics etc" (Service user)

"The carer is a valid stakeholder with frontline experience. Research proposals should include all relevant stakeholders with active listening and questioning process as basis for developing relevant high quality studies. Both users and carers require researchers to communicate projects in lay language which is useful discipline. User and carer involvement ensures that research groups are inclusive" (Hub coordinator)

Recommendation	MHRN response
Publication of a strategy for carer involvement in MHRN	This report is first step towards a MHRN carer strategy, to be followed up and developed over the next 2 years
Identify a senior carer lead in MHRN	In post – Associate Director for User and Carer Involvement in MHRN
Appoint a carer development officer to take the lead on developing carer involvement across the MHRN.	We plan to create a new post to take forward recommendations identified by the scoping exercise. We anticipate advertising this post April 2006.
Identify a budget for the carer development lead for specific activities to build capacity across the network to engage with carers	In concert with the new post outlined above, we will pursue a budget to provide appropriate management support, space, facilities and a development / working group to provide further support and advice.
Form a working group to provide support to the carer development officer, meeting twice a year. The group would include carers, academics and clinicians committed to promoting carer involvement in research	The carer development officer once in post would convene this group. The MHRN would provide resources to convene this group.
Carer development officer to build capacity for carer involvement: <ul style="list-style-type: none"> - Publish best practice guidelines for investigators working with carers including policy on paying carers - Publish guidance for hub co-ordinators who will promote carer involvement locally - Develop job descriptions for carer roles across the network e.g. role on hub executive committee - Work in partnership with other agencies to promote carer involvement in research 	The MHRN agrees these should be fundamental activities of the Carer Development Officer post to help ensure these activities are delivered.

<ul style="list-style-type: none"> - Identify and promote opportunities, including training opportunities, across MHRN for carer involvement - Identify carers willing to get involved in various aspects of the research process 	
<p>Hub coordinators to be responsible at a local level for building carer involvement.</p>	<p>MHRN will encourage and facilitate this activity by promotion via its various Committee meetings, including the MHRN Operational Steering Group and Hub Coordinator Meetings.</p>
<p>Support for carers to become involved in MHRN:</p> <ul style="list-style-type: none"> - Support to become committee members - Financial support to cover expenses - Facilitate and promote required training 	<p>MHRN will encourage its Hubs to support these activities in all ways possible, informed by the activities of the Carer Development Officer. The results of this scoping exercise and the lessons learned by the MHRN Service User Research Group, England (SURGE).</p>
<p>Adoptions process to require evidence of carer involvement in the development of a research proposal where appropriate (when the research involves carers)</p>	<p>MHRN will discuss an amendment to the current Adoptions Form. The question on carer involvement would be: 'Where the research involves carers: please outline carer involvement in the development and conduct of the study'</p>
<p>When a study is submitted to adoptions committee involving carers, an independent expert is called to sit on the committee to discuss the carer study</p>	<p>MHRN will aim to identify, within the next 3 months, an independent expert to consider carer projects within the Adoptions Committee. This information will be provided on the MHRN website.</p>
<p>Materials promoting the MHRN to include specific leaflets targeting service users and carers explaining the work of the MHRN and why their involvement is important. Need to show long term benefits of research linked to service user and carer motivations for becoming involved. Must also provide clear remit of MHRN to guard against carer frustration that the network can deliver beyond remit e.g. can not prioritise research topics, adopt studies on topics that have not been submitted.</p>	<p>This is part of the remit of the newly created MHRN Communications Manager post. It is hoped that this post will be recruited to by April 06 and this person will be encouraged to work with the Carer Development Officer and SURGE to provide meaningful information and appropriate materials on MHRN-adopted projects and MHRN activities.</p>
<p>Research dissemination resources accessible for carers</p>	<p>This is part of the remit of the newly created MHRN Communications Manager post. It is hoped that this post will be recruited to by April 06. The successful candidate will manage the provision of research dissemination resources accessible for MHRN stakeholders, including carers. One of the dissemination media will be via the MHRN website. With</p>

	potential for a discussion / feedback forum.
The recruitment process for paid employment within the MHRN should involve service user and carer representatives e.g. shortlisting candidates, on interview panel	MHRN agrees this is useful process to strive towards for the majority of MHRN posts, including the MHRN Communications Manager outlined above.

Future developments could include:

- Working group develops into a carer research writing group – if selected by the MHRN in open tender process.
- Carers and service users taking on a ‘monitoring’ role such as the one embedded in the Alzheimer’s QRD programme to audit effective involvement at various stages in a process that is beneficial to investigators and the MHRN alike
- Permanent carer post on adoptions committee when number of applications presenting a carers perspective increases

Section five: Recommendations for academic community

"Of course there is a role for carers in research. Important for carers to be involved in robust discussions with service users about various research activities. Carers want answers to key questions and carers also need to be asking some of the questions – setting the research agenda" (Service user)

"Important that user and carer research projects are of a high standard to combat the criticism that they are not 'proper research' – problem when training is not high quality and too many people jump on band wagon– gives whole sector bad name". (Academic)

"Research on carers is scarce and it will have greater validity if carers are involved. Carers should of course also be involved in setting research priorities. However, I see this as involvement in strategic planning, rather than research, not undertaken through MHRN but through the commissioners of research" (MHRN hub lead)

The implications for the academic community of working in partnership with carers are considerable. Engagement with carers in all stages of the research process will require researchers to devote a significant proportion of their time to providing training, supervision and support to carers. This in turn will involve extended project timetables and higher costs. Aspects of the research process that require further commitment from researchers and resource implications are listed below. In addition, a number of the recommendations are directed towards research funders to ensure carers are involved in setting the strategic research agenda.

- More carer involvement in setting research priorities is required and involvement in strategic planning, including setting priorities for research funding.
- Research including a carer perspective and research exploring carer issues directly are both under-developed areas. There are a number of academics carrying out 'carer' studies but these are scattered across universities and there is little capacity for co-ordinated developments with groups of experts forming writing groups, for example, within the MHRN at this time.
- Where studies involve a 'carer perspective' for example within an RCT when one module explores the impact of a treatment or service configuration on the carer, carers should be involved at all stages of the research process from developing the protocol, identifying core research questions and disseminating the findings.
- Involving carers and service users takes time and resources and involves commitment from investigators to develop partnerships and skills to facilitate positive experiences for all involved. This may require adapting the 'usual' way of working, for example changing timings of meetings, extending project time-line to include recruitment and training for carers, avoidance of research jargon and translating research terminology.
- More research skills workshops for service users and carers are required. To engage in aspects of the research process a basic understanding of the research economy and research methodologies are an advantage. A few courses exist (or have been run in the past) in universities or voluntary sector research bodies but more training initiatives for service users and carers are required to support wider involvement in research activities.
- Establish a national carers research network for people researching carer issues and carer researchers. The network would facilitate better collaborations, provide support

for individuals, and generate new research ideas / questions. Several organisations would benefit from such an initiative such as MHRN, NIMHE, voluntary organisations supporting carers, carer leads in NHS Trusts.

- Develop new routes for dissemination. For example develop a web site like www.mentalhealthcare.org.uk (covers one Institution's research), to provide accessible lay summaries of key UK and international research in mental health and promote this widely to service users, carers and people working in the field of mental health to support evidenced based practice. Secondly through best practice guidance encourage the use of creative ways of communicating with research participants through regular newsletters for example giving progress reports and summaries of departmental / university work.
- Promote the benefits of research to carers to encourage their involvement in the process. Carers can help recruitment rates to clinical trials as well as making the experience of being part of a trial a positive one through feedback to investigators.
- University departments to develop partnerships with health and social care organisations, encouraging creative work plans to build capacity among local consumers to undertake research studies. For example a university had teamed up with NIMHE and a junior researcher was acting as a mentor for a carer involvement officer who was undertaking some research as part of their job role.
- Carry out research on carers, and research with carers, in order to de-stigmatise the role of carers in mental health. Contribute to building a positive ethos of working with carers across health and social care settings.
- Encourage carer researchers to present research at conferences to raise the profile of carers and mental health issues of most importance to carers
- Research the benefits of consumer involvement in studies across health and social care fields and evidence the benefits of user-led research in mental health.

Section six: Acknowledgements and resources for carers

The Rethink research team would like to thank all of those who participated in the scoping review – carers, service users, carer involvement leads, academics and MHRN staff – and the organisations that supported us. We are grateful in particular to:

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Together (Phil Partridge)

Princess Royal Trust for Carers (Peter Tihanyi)

Alzheimer's Society (Dr. Susanne Sorenson)

Carers Research Network, South West (Ron Ritson)

Carers research information site www.mentalhealthcare.org (Caroline Moran, Kings College London, Institute of Psychiatry)

There are a number of initiatives to support carers which draw upon research. We outline a number of these below and provide contact details where more information can be obtained.

Supporting Carers Better Programme, www.scbnetwork.org from Together (formerly known as MACA)

The Meridan Programme – a carer education support programme from the University of Birmingham www.meridenfamilyprogramme.com

Partners in Care campaign – Royal College of Psychiatrists and Princess Royal Trust for Carers www.rcpsych.ac.uk/campaigns/pinc

Carer Education Support Programme from Rethink (www.rethink.org/cetp) and Carers web site: www.rethinkcarers.org

Carers research partnership – Robert Gordon University
<http://www.rgu.ac.uk/carers/general/page.cfm>

Carers UK training programme
www.carersuk.org/Policyandpractice/Training/Trainingcalendar

There are also initiatives which bring carers together who are interested in research. We list three below:

a) www.mentalhealthcare.org.uk, Institute of Psychiatry

The web site was set up in 2003 and is written specifically for carers of people with mental health problems, though in practice it is used by many stakeholder groups. The site has a dual

role – (1) dissemination tool of latest research findings from IOP and SLAM on studies concerned with schizophrenia / psychosis and bi-polar disorder; (2) provider of relevant information to carers on autism, eating disorders, schizophrenia / psychosis, bi-polar disorder, young people and mental health, local carer support groups, carer stories and a pharmacy inquiry service responding to non-urgent queries about medication.

b) Mental Health Carer Research Network, in the South West

Ron Ritson is in the process of setting up a mental health carer research network. The network is in the set up phase and supported by the local R&D committee. A summary description is provided on: <http://www.communicate.co.uk/wilts/carersresearch/> and reproduced below:

As the result of a Millenium Award from UnLtd a forum for carers is being formed to act as the focal point between the Avon and Wiltshire Mental Health Partnership Trust and its research partners, i.e. Bath University, Bristol University and the University of the West of England.

The new forum will be run for Carers by Carers and will enable them to take part in research and audit within the Avon and Wiltshire Mental Health Partnership Trust, not only as participants, but in the development and execution of projects.

Carers will be involved in the following ways:

- a. Becoming involved in the design of projects.
- b. Assisting in the running of projects.
- c. Being involved in data collection.
- d. Being involved in data analysis.
- e. Helping to interpret and disseminate results.

c) Quality Research in Dementia Network: Alzheimer's Society

The QRD programme is an active partnership between carers, people with dementia and the research community. The heart of Quality Research in Dementia is the QRD Advisory network: in which 150 carers, former carers and people with dementia are actively involved in setting the research agenda, awarding grants and assessing outcomes. For more information please visit www.qrd.alzheimers.org.uk

Carer research studies

It has been acknowledged that carer research is a small sub-section within the mental health research sector. However, there are a number of carer research programmes that we are aware of and these are listed below.

a) Carer research programme from NCCSDO

The National Coordinating Centre for Service Delivery and Organisation (NCCSDO) has a carer research programme. It has commissioned a number of studies, more information can be found at: www.sdo.lshtm.ac.uk/carers.htm

Professor Peter Huxley – Professionals sharing information with carers: examples of good practice. Final report and briefing paper at: www.sdo.lshtm.ac.uk/carers.htm#huxley

Professor Tom Burns – measuring outcomes for carers of people with mental health problems (final report not on web site)

Dr Hilary Arksey – services to support carers of people with mental health problems. The research identified the key services required to support carers of people with mental health problems. The reports from the project are listed on the NCCSDO web site: www.sdo.lshtm.ac.uk/carers.htm#arksey

Dr Julie Repper (University of Sheffield) - has carried out two studies working closely with carers. The first project was an evaluation of Lincolnshire Assertive Outreach Service with an essential component exploring the experiences of service users and carers receiving the service. The research was undertaken with 'Linc-Up', the Lincolnshire Partnership Trust user and carer reference group. Three service users and two carers undertook 4 days training in research skills and went on to design the interview schedules, conduct interviews, analyse transcripts, and disseminate research findings (Allam et al 2003a,b; Allam et al 2004).

The report 'Going the extra mile: evaluation of Lincolnshire assertive outreach service' (<http://www.nimhe-em.org.uk/upload/publication/bee82b04be048a405f5f.pdf>) made a number of recommendations in respect to working with user and carer researchers (from page 183). These are summarised below:

- Support should be available to user and carer researchers at every step of the journey, as people who have experience of mental health problems may find different aspects of the research process difficult.
- Ethics committee were suspicious of user and carer researchers and needed assurance about training, supervision and levels of risk.
- Where recruitment is through mental health teams user and carer researchers have to be prepared to justify their role and status to gain access to research participants
- Interviewers need to be well prepared prior to committing to the project and aware of the challenges, for example: travelling to and from unfamiliar places to interview sometimes in the evenings, recommends interviewing in pairs
- It is useful for interviewers to know someone will ring them afterwards to give them a chance to talk over concerns, worries and experience rather than leave it to people to opt in to phoning themselves. Proactive support is important.
- Training in research skills must include: active listening, reflection and exploring skills to probe appropriately during interviews; managing ones own emotions in interviews;

managing interviewees' emotions during interviews; responding to inappropriate behaviour or responses; one-to-one support with professional researcher within training so individuals can talk through concerns in confidence.

- The group found that working with user and carer researchers collaboratively was much more time consuming than expected (training, setting up interviews, carrying out interviews). The time commitment from users and carers was necessarily more than expected and thus had not been budgeted for sufficiently. Recommend that a realistic budget be set for user and carer researchers.

The second study working with carers as researchers is in progress. Funded by NCCSDO programme, the project entitled "Enabling Partnerships in Carer Assessments: the Way Forward" is working across 13 sites to explore the processes, experiences and consequences of the assessment of carers of people with mental health problems, and what helps and hinders partnerships between family carers and formal services. In each of the 13 sites carers are recruited to take part as carer researchers, receiving training and support to undertake interviews, analyse data and write up project findings. A brief summary of the project can be found at: http://www.sdo.lshtm.ac.uk/pdf/carers_53_scientific.pdf

b) Research publications

Young carers:

Saul Becker – University of Birmingham

Jo Aldridge – Loughborough University

Aldridge, J. and Becker, S. *Children Caring for Parents with Mental Illness: perspectives of young carers, parents and professionals*, The Policy Press, Bristol, 2003. (ISBN 1-86134-399-X)

Impact of caring:

George Szmukler (2001) *Mental illness - a handbook for carers*. Jessica Kingsley.

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