

THE UNIVERSITY *of York*  
Centre for Reviews and Dissemination

## York HS&DR Evidence Synthesis Centre

### Updated Meta-Review of Evidence on Support for Informal Carers Final Protocol

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## 1. Background

Policy and research interest in carers – those who provide support, on an unpaid basis, to sick, disabled or older people to enable them to live in their own homes – has grown in importance over the past 30 years. Since the first UK review of evidence on carers (Parker, 1985), the national and international body of research literature has grown substantially. It now covers data on, *inter alia*, the prevalence of care-giving; the impact and outcomes of caring for people with care-giving responsibilities; issues related to combining paid work and care; and the effectiveness of support and services for carers. Whilst some studies cover carers in general, others examine issues from the perspective of specific sub-groups of carers, for example: older carers; children and young people who provide care; carers of people with specific conditions. Likewise, studies adopt different designs ranging from randomised controlled trials to small-scale qualitative pieces of work.

Since 1995, the UK Government has introduced legislation and policy measures aimed specifically at carers, as well as setting up a cross-departmental Standing Commission on Carers. The revised 2008 national strategy for carers contained the Government's ten-year vision for carers for the then Government (HM Government, 2008). Since then, the 'next steps' document, has outlined a cross-departmental approach to carers policy, from identification to support, and which highlighted the need to develop the evidence base on supporting carers (HM Government, 2010). The document pointed out that while much is now known about the challenges that carers face and the impact that caring can have, much less is known about how to improve outcomes for carers.

In 2009, the Department of Health commissioned from the Social Policy Unit at the University of York a report for the Standing Commission on Carers, with the specific aim of informing their thinking about how best to improve outcome for carers, as well as identifying future research areas (Parker, Arksey and Harden, 2011).

The overall aim of that review was to provide the Department of Health with an overview of the evidence base relating to the outcomes and cost-effectiveness of support for unpaid carers of sick, disabled or older people. Specific objectives of the proposed study were:

- to undertake a scoping review of existing literature reviews, including systematic reviews, on support and interventions for carers
- to map out the extent, range and nature of the identified reviews on support and interventions for carers
- to summarise the main findings of the identified reviews
- to identify gaps and weaknesses in the evidence base.

The review encompassed carers of all ages (including children and young adults) supporting adults, including those making the transition from children's to adults' services, but did not cover people supporting adults with mental health problems.

The review followed a protocol with inclusion and exclusion criteria; search terms; search strategy; quality control tools; approach to data extraction and synthesis.

The following parameters for the review were used:

- include literature reviews published since 2000 to date and written in English only
- no geographical restriction, that is, include reviews covering both national and international research
- include published reviews only, that is, exclude research in progress, grey literature.

The overall conclusion of the meta-review was that the strongest evidence of effectiveness of any sort was in relation to education, training and information for carers. These types of interventions - particularly when active and targeted rather than passive and generic – appeared to increase carers' knowledge and abilities as carers. There was some suggestion that this might thereby also improve carers' mental health or their coping. However, we concluded that this latter possibility remained to be tested rigorously in research specifically designed to do so and which explored both effectiveness and costs.

Beyond this, we found little secure evidence about any of the interventions included in the reviews. This was **not** the same as saying that these interventions had no positive impact. Rather what we saw was poor quality primary research, often based on small numbers, testing interventions that had no theoretical 'backbone', with outcome measures that might have little relevance to the recipients of the interventions. The evidence on respite care was the key example of this. While qualitative evidence showed that respite care is often a lifeline for carers, the research that has evaluated it has often been too small to allow statistically significant effects to be identified, has been poorly designed, and has used outcome measures that in some cases were puzzling.

NIHR is keen to update the evidence in this area, given the recent Care Act and QOF responsibilities for the NHS to assess carers' own health needs. It was felt that a scoping review could usefully evaluate particular interventions and their cost-effectiveness, such as carer champions, respite care, resilience programmes and health checks. Given the existence of the earlier meta-review, updating this work would be an effective way of informing both the NHS and possible future research commissioning in relation to the needs of different types of carers and support interventions.

## 2. Methods

The methods will largely follow those of the original review (Parker, Arksey and Harding, 2011), updated, where necessary, to accommodate any change in electronic databases and indexing.

### 2.1 Search strategy

A range of health and social care resources will be searched to identify published reviews on support and interventions for carers. These will include:

- searches of appropriate electronic databases
- scrutinizing bibliographies of all relevant reviews for further relevant studies
- checking relevant internet sites
- searching for publications of experts in this area

Both the search strategies used in the original review and the databases used will be updated, where necessary, to accommodate change since 2009. Box 1 shows the databases used in the original meta-review.

A previously published strategy (Golder *et al.* 2008) to locate studies on respite care for carers of frail older people was used as a basis for developing the search strategies for the earlier meta-review. It contained relevant free-text terms and subject headings relating to carers, combined with terms for specific interventions. As the meta-review was concerned with any interventions or support for carers, the terms for specific interventions were omitted. This resulted in a more sensitive search strategy to retrieve any literature about carers. Where possible, a study design filter was added to the strategy to limit the search to reviews only for each database. A date limit of 2000 - August 2009 was applied and all searches were restricted to English language papers only. The strategy for the current updating review will be essentially the same, with a starting date of January 2009, to ensure full capture of publications in 2009.

The records from each electronic database will be downloaded and de-duplicated and entered into Endnote. We will carry out supplementary, targeted web searches to identify any published reports not retrieved by the database searches. Potentially relevant literature accessed via this and other sources, for example by contacting experts and manually searching bibliographies, will be recorded in the Endnote library.

The original review retrieved 11,009 through the main database searches after de-duplication. A further 19 references were accessed through other sources. Of these, 37 articles, reporting on 34 reviews, were included in the first stage of the meta-review. Twenty reviews, reported in 23 articles, met the quality appraisal criteria of four and above and

were thus assessed as of higher quality. The remaining 14 publications did not meet the quality threshold to be included in the full meta-review, but were included in the summary of the scope of the area.

**Box 1      Electronic databases searched in original meta-review**

The Cochrane Database of Systematic Reviews (CDSR) (via the Cochrane Library)  
(<http://www3.interscience.wiley.com/cgi-bin/mrwhome/106568753/HOME>)

Database of Abstracts of Reviews of Effects (DARE) (via The Cochrane Library)  
(<http://www3.interscience.wiley.com/cgi-bin/mrwhome/106568753/HOME>)

Health Technology Assessment Database (via The Cochrane Library)  
(<http://www3.interscience.wiley.com/cgi-bin/mrwhome/106568753/HOME>)

NHS Economic Evaluations Database (via The Cochrane Library)  
(<http://www3.interscience.wiley.com/cgi-bin/mrwhome/106568753/HOME>)

MEDLINE (OvidSP) (<http://ovidsp.ovid.com/>)

EMBASE (OvidSP) (<http://ovidsp.ovid.com/>)

PSYCINFO (Ovid SP) (<http://ovidsp.ovid.com/>)

Health Management and Information Consortium (HMIC) (Ovid SP) (<http://ovidsp.ovid.com/>)

CINAHL (EBSCO) (<http://www.ebscohost.com/>)

ASSIA (CSA Illumina) (<http://www.csa.com/>)

Social Services Abstracts (CSA Illumina) (<http://www.csa.com/>)

Social Science Citation Index (Web of Science) (<http://www.isinet.com/>)

Social Care Online (<http://www.scie-socialcareonline.org.uk/>)

A rapid re-run of the original search in MEDLINE (from August 2009) has identified 2819 records. On this basis, and assuming no major change in the relative presence or quality of reviews in the literature, we estimate that we may identify a further 15 to 20 reviews of the effectiveness of interventions that meet our quality criteria.

A brief examination of publications since 2009 suggests a continuing emphasis in reviews on carers' **needs**, about which we already know much, and much less on models of effective support.

## 2.2 Study selection

**Step 1:** Two members of the team will screen the titles and abstracts of all the identified references to determine relevance to the meta-review's focus of interest. Full papers and reports will be retrieved in all instances where the abstract or title indicate that it is broadly relevant. If abstracts are not available, and/or it is not possible to ascertain a review's potential relevance or value beforehand, the document will be obtained and a decision made on the basis of the full report.

**Step 2:** All potentially relevant reports will be appraised for eligibility for inclusion in the meta-review using an inclusion and exclusion checklist. Six criteria, outlined more fully in Box 2, will be applied, focusing on: population of interest; types of intervention; geographical coverage; language; period of interest; type of literature review.

**Step 3:** Two team members will independently assess the quality of all relevant literature reviews using a quality criteria tool used in the earlier meta-review. This was adapted from one used by Egan and colleagues (2008) in their systematic meta-review of psychosocial risk factors in home and community settings. This had itself been adapted for epidemiological reviews from two critical appraisal guides: the University of York's Centre for Reviews and Dissemination's DARE criteria for quality assessment of reviews and a systematic review tool created by Oxman and Guyatt (1991).

The set of criteria applied to relevant reviews embodies seven questions:

- Is there a well-defined question?
- Is there a defined search strategy?
- Are inclusion/exclusion criteria stated?
- Are study designs and number of studies clearly stated?
- Have the primary studies been quality assessed?
- Have the studies been appropriately synthesised?
- Has more than one person been involved at each stage of the review process?

The criteria will be scored as follows: yes=1; in part=0.5; no or not stated=0. High scoring reviews (i.e. those reviews that scored 4 and over) will go forward for full data extraction for the meta-review. Only brief summary information will be extracted from reviews of lower quality (i.e. those scoring less than 4).

**Box 2. Inclusion and exclusion criteria**

<i>Inclusion criteria</i>	<i>Exclusion criteria</i>
<p><b>Population of interest</b></p> <ul style="list-style-type: none"> <li>• Carers of all ages (including children and young adults) supporting any adults, including those with dementia and learning disabilities</li> <li>• Carers from any majority or minority group</li> </ul>	<ul style="list-style-type: none"> <li>• Parent carers of disabled children (n.b. review does cover transition from children's services to adult services)</li> </ul>
<p><b>Types of interventions</b></p> <ul style="list-style-type: none"> <li>• Primarily aimed at carers (rather than patients/care recipients)</li> <li>• Single, or multi-component</li> </ul>	<ul style="list-style-type: none"> <li>• Primarily aimed at patients/care recipients, but from which carers might benefit</li> <li>• Medical/pharmacological</li> </ul>
<p><b>Geographical coverage</b></p> <ul style="list-style-type: none"> <li>• Systematic reviews drawing on primary data from studies in any country, if the nature of the intervention could be transferable to the UK health and social care system</li> </ul>	<ul style="list-style-type: none"> <li>• Systematic reviews drawing on primary data from studies in any country, where the nature of the intervention could not be transferable to the UK health and social care system, because of substantially different funding issues or culture, for example</li> </ul>
<p><b>Language</b></p> <ul style="list-style-type: none"> <li>• Studies in the English language</li> </ul>	<ul style="list-style-type: none"> <li>• Studies not published in English</li> </ul>
<p><b>Period of interest</b></p> <ul style="list-style-type: none"> <li>• Systematic reviews published from January 2009 onwards</li> </ul>	<ul style="list-style-type: none"> <li>• Systematic reviews published prior to January 2009</li> </ul>
<p><b>Type of literature review</b></p> <ul style="list-style-type: none"> <li>• Published systematic literature reviews (addressing effectiveness, where carers are primary sample and primary outcomes for carers are reported)</li> <li>• Published meta-analysis (addressing effectiveness, where carers are primary sample and primary outcomes for carers are reported)</li> <li>• Cochrane Collaboration methodology</li> </ul>	<ul style="list-style-type: none"> <li>• Unsystematic literature reviews (unless covering areas where systematic review evidence is not available, and then reported separately as another form of evidence)</li> <li>• Report of single primary research studies</li> <li>• Grey literature</li> <li>• Research in progress</li> </ul>

The first review, as commissioned by the Department of Health, did not include the carers of adults with mental health problems. The main reason for this was the very different nature of the literature in this area.

The concept of 'carers' for adults with mental health problems, even when these are severe and enduring, is more difficult to define than in other areas, and in some parts of the literature remains contested. This difficulty is reflected in the nature of interventions evaluated; while these may be targeted at family members their intended outcome is usually improved mental health for the adult being supported. The literature can also encompass interventions for people with drug and alcohol dependencies, where there is the same issue that interventions may have an impact for family members (or 'carers') but this is not usually their primary purpose. We have discussed these challenges and complexities in reviewing this area elsewhere (see Parker et al, 2008; Beresford et al 2008).

However, the search strategies for the first review did not *exclude* interventions for carers of adults with mental health problems, so that we could indicate the likely size of the evidence base. No reviews focussed on carers in this area were actually identified.

NIHR has indicated that it will be acceptable to take the same approach in the updated review, again to allow us to indicate the likely current size of the evidence base.

### 2.3 Data extraction and synthesis

Data will be extracted into a spreadsheet to record a uniform set of information about each review included in the meta-review.

For high quality reviews (see above), this will include quality assessment scores and information about: the intervention(s) under review; target group(s); number, type and date range of primary studies included in the review; and sample sizes. Data will then be extracted, where present, in relation to seven potential outcomes for carers: physical health; mental health (e.g. depression, anxiety); burden and stress; coping; satisfaction; well-being or quality of life; ability and knowledge. Data will be described by differing socio-economic groups where this information is available.

As noted above, for the lower quality reviews basic information only about intervention(s), target carer group(s) and outcomes will be extracted, allowing us to present summary information about the growth and quality of the evidence base since 2009.

### 2.3.1 Synthesis

The reviews included in the earlier meta-review took two main approaches to reporting their findings. First, there were those that reported the findings of both qualitative and quantitative material using what we termed a 'qualitative' approach. In other words, they described what their primary studies found, but did not sum up or synthesise findings formally. Secondly, there were those that took a quantitative approach to quantitative findings, either by carrying out formal statistical meta-analysis, or by ascribing different weights to findings reported in primary studies of different quality or robustness. In either case, this quantitative approach gives more weight to RCTs than to non-randomised studies, and more weight to studies with control groups than to those without, and so on down the 'hierarchy' of research designs.

The distinction between these approaches was not perfect, and some of our included reviews had elements of both. However, given the different ways in which these reviews reported their findings, and ascribed weight to them, we decided to divide the reviews into groups that broadly fell into these two categories and to analyse them separately. Unless we find a substantial change in the ways in which reviews in this area are now being reported, we intend to take the same approach to the updating review.

## 3. Patient and Public Involvement

As outlined earlier, the primary research included in the reviews in the earlier work sometimes researched outcomes that were different from those that carers themselves might value. Over 25 years ago, the King's Fund (1988) identified a set of 'core needs' for carers:

- Information and advice about caring
- Assessment of review of their own needs and of those of the person they are supporting
- Financial support
- Training
- Help in the tasks of caring, including respite
- Emotional support

There is little in more recent literature to suggest that these core needs have changed substantially, although changes in women's labour market participation in the interim mean that support to remain in or take up paid work now feature both in the literature and in policy. However, it is clear that the ways in which these needs might be addressed (and the outcomes that addressing them might lead to) will vary substantially from person to person. It is also clear, that little intervention research actually addresses these core needs directly.

Because of this mismatch between the outcomes that research reports and what might be important to carers themselves, we propose a significant element of carer involvement in our updated review work. We will establish a small reference group of carers, drawn from one of SPRU's permanent consultation groups and from carers' representative organisations. This group will meet twice. At the first meeting, which will be soon after the searches are complete and material obtained, they will advise on carers' desired outcomes and the extent to which these are reflected in the literature. The second meeting will present the draft findings and seek the group's views on what has been found in and what is missing from the evaluative literature.

#### 4. Outputs

We will prepare a draft report of the findings of the updated meta-review of support and interventions for carers, in the form of an evidence briefing. The report will present data on: the areas of research covered; the carer sub-groups studied; what the reviews say about the effectiveness and cost-effectiveness of interventions for carers; gaps and weaknesses in the evidence base; and any issues to be considered in commissioning future research.

#### 5. Timetable

The proposed review will take 20 weeks.

- Weeks 1 to 4: searching and preliminary appraisal of range of material identified; set up carers' reference group.
- Weeks 5 to 8: finalise protocol; select material for preliminary inclusion, based on abstracts; download or otherwise obtain full copies of material; first meeting of carers' reference group to advise on carers' desired outcomes.
- Weeks 9 to 16: make final inclusion decisions; data extraction and synthesis.
- Weeks 17 to 20: draft final report; second meeting of carers' reference group to comment on draft.

## References

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