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## Including Family Carers: Adding Value and Impact to Research

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**School for  
Social Care Research**

**NHS**  
*National Institute for  
Health Research*

# **INCLUDING FAMILY CARERS**

**ADDING VALUE AND IMPACT TO RESEARCH**



**REPORT OF A SEMINAR HELD ON 21 FEBRUARY 2017  
AT THE LONDON SCHOOL OF ECONOMICS AND POLITICAL SCIENCE**

Independent Advisory Group on Carers  
NIHR School for Social Care Research

## The NIHR School for Social Care Research

The School for Social Care Research was set up by the National Institute for Health Research (NIHR) to develop and improve the evidence base for adult social care practice in England in 2009. It conducts and commissions high-quality research.

## Independent Advisory Group on Carers

The IAGC was established in 2016 as the successor to the Standing Commission on Carers (2007–2016), independent advisory organisations established by government to provide expert advice to ministers and to the Carers Strategy Cross Government Board in formulating the national carers strategy.

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# FOREWORD

As family carers we are not a homogeneous group but come in all shapes and sizes, and play an invaluable role in society. We have a variety of experiences, and expertise in the needs of the person or people we care for or have cared for as well as our own experiences of being carers. Across the diverse group of carers and caring situations, we each have our own individual voice which may differ from that of the person we care for.

Yet, in research studies our voices are sometimes excluded or only sought when the cared for person is unable to give their own views. The focus on services or the cared for person can sometimes ignore the experience and expertise carers bring to an issue. Often the symbiotic nature of the caring relationship is not recognised; so when the focus is on interventions for the cared for person the resulting impact on their carers is overlooked. There is no doubt that more research is needed on the role, needs and support for carers. But there is also no doubt that the voice of carers needs to be captured across all health and social care studies even when the focus is on the cared for person.

This report, from a workshop organised by the Independent Advisory Group on Carers and the NIHR School for Social Care Research, highlights the pivotal role carers play in the effectiveness of future health and social care-related research. Carers can be valuable partners, providing unique inputs into all stages of research design, from forming the research question to the methodology, analysis and in sharing the findings.

Our voice as carers needs to become an integral part of all health or social care-related research studies. There are actions that research funders, research teams, the health and social care sectors, and carers can take to make this happen. This report highlights some of these but it is important that actions follow. The first step is to recognise carers as a distinct, diverse and valuable group in research.

We welcome positive steps being taken to achieve the priorities set out in this report.

Jeanne Carlin and Margaret Dangoor  
NIHR SSCR User, Carer and Practitioner Reference Group



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**INCLUDING FAMILY  
CARERS**



## Introduction

A seminar on adding value and impact to research through the wider inclusion of family carers took place on 21 February 2017 at the London School of Economics and Political Science (LSE). It was funded jointly by the Department of Health and the National Institute for Health Research School for Social Care Research (NIHR SSCR), and organised by members of the Independent Advisory Group on Carers (IAGC) and the NIHR SSCR. This report provides an overview and reflections on the event.

The aims of the event were to showcase and explore the benefits and 'added value' of including family carers in health- and social care-related research, and to explore how such inclusion can contribute towards increasing the evidence base, maximising the impact of research in terms of the effectiveness and cost-effectiveness of support and interventions. The processes involved in broadening organisational and/or funding mandates to include family carers were also explored. This included discussion of the nature of support available to seminar delegates following the event itself to help them work to widen the involvement of carers in research, including advice from members of the IAGC and NIHR SSCR, and via networking opportunities between delegates.

The event was a 'by-invitation only' symposium and delegates were selected for their particular expertise as carers or representatives of relevant organisations, including those responsible for funding or delivering research programmes that are often relevant to carers' issues, and could include family carers. The number of delegates was deliberately limited to 30 to ensure meaningful engagement and

participation. Those who attended included: carers; leading carer researchers (from Kings College London, Bristol University, LSE, Sheffield University and the NIHR SSCR), and representatives from the following organisations:

- Association of Directors of Adult Social Services (ADASS)
- Age UK
- Carers Trust
- Carers UK
- Dementia UK
- Department of Health
- Economic and Social Research Council (ESRC)
- Greater Manchester CVS
- Health Education England
- Health Services & Delivery Research (HS&DR) Programme at the National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre
- Joint University Council Social Work Education Committee (JUC-SWEC)
- MENCAP
- MS Society
- NHS England
- National Institute for Health and Care Excellence (NICE)
- Office of the Chief Social Worker for Adults
- Parkinson's UK
- Public Health England
- Skills for Care

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### THE EVENT WAS ORGANISED AND FACILITATED BY

Dr Mary Larkin (IAGC)

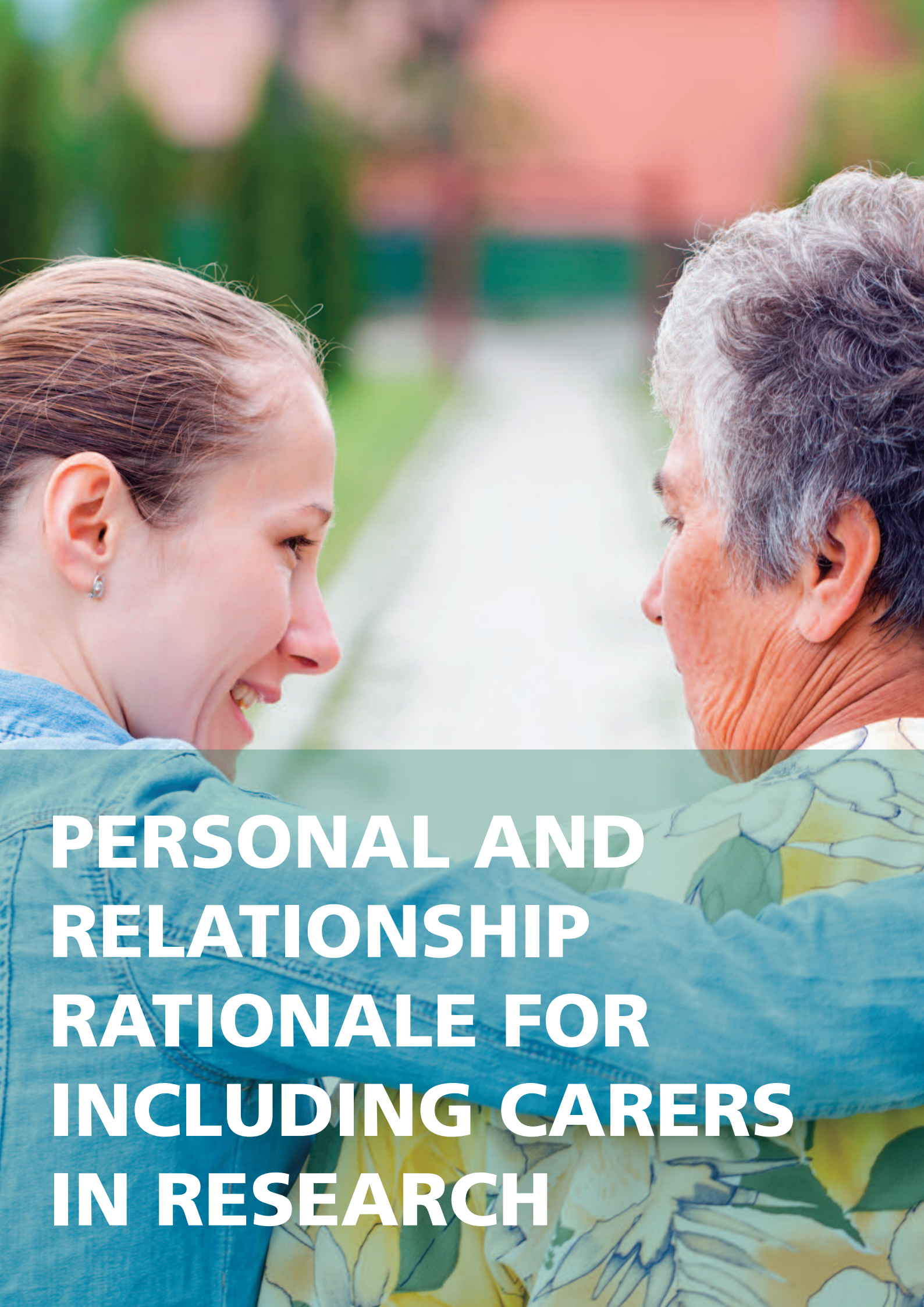
Professor Alisoun Milne (IAGC)

Dr Melanie Henwood (IAGC)

Professor David Croisdale-Appleby (Chair, IAGC)

Dr Michael Clark (NIHR SSCR)





**PERSONAL AND  
RELATIONSHIP  
RATIONALE FOR  
INCLUDING CARERS  
IN RESEARCH**

## The Rt Hon Norman Lamb MP

Presentation by the Liberal Democrat  
Spokesperson on Health and former Minister  
of State, Department of Health

The relationship between the carer and the cared-for is embedded in the shared life-course of both the carer and the cared for person. There are good relationships and bad relationships, constructive and destructive, and these will be amplified in caring situations.

Many carers have provided care for many hours a week, over many years. They know the person best and are experts in the situation, how the situation is developing, what seems to help and what seems to cause distress or detriment. Is this knowledge and information not essential to the wellbeing of the cared-for person? And, if not captured in research information, then important knowledge is being routinely ignored.

The duration and intensity of caring is increasing and is likely to continue to do so in the future because of the move to self-management and to more care being delivered at home. The latter is aided by technical developments such as telemedicine and telecare as part of the digital revolution. Therefore, carers, already central to the effective care of the cared-for person, are becoming increasingly involved in providing complex care and treatments etc. Indeed, as we move to compliance with a new treatment or intervention, we may be increasingly reliant on the cooperation and support of the carer, and on their capability to deliver such care.

The 'burden' on carers is increasing at an alarming rate. More and more carers find themselves as multi-generational, sequential and/or serial carers, caring for grandparents, parents, siblings and children. Diseases such as dementia often require years, even decades, of caring for someone with ever-increasing needs and often with increasingly irrational and sometimes violent incidents. Some caring situations, such as those of parents caring for children with learning disabilities, can extend over the majority of a

carer's lifespan. Thus, building the resilience and coping strategies of carers can be vital in enabling them to continue caring. How should research best address such issues?

We already know from research conducted amongst carers, that the activity of caring frequently has a direct and damaging impact on their health and well-being. But simply eliciting the views of carers in pre-designed research information-seeking is, in itself, not enough. We need to include carers in the triangulation of assessing the effectiveness of interventions, engaging them as part of evaluation methodology and seeking their input in all stages of research design, from its inception onwards. This is an essential move we want to see as 'normal' or standard research activity.

It is important too, that we assess the impact of interventions or treatment on the carer as well as on the cared-for person. The carer needs to be able to cope for interventions to be successful, so we need to ask – do interventions to support a person also benefit the carer, or are there dis-benefits to the carer to be identified and considered? Looking beyond this, what about situations where the benefit is to the carer but may make little objective difference to the person cared for? What are the trade-offs or tensions, and how should these be dealt with in future research?

We see research in a paradigm of looking for the potential benefit to the cared-for, but we should be seeking to consider, and where possible ensure, equality of opportunity both for the carer and the cared-for person.

I hope that the outcomes of today's innovative symposium will see researchers ensure the presence of carers in their research design considerations, and research funders insisting that this be a condition of providing funding. It is not so very long ago that the meaningful inclusion of service users became a mandatory feature of healthcare and social care research; let us ensure that today, we fire the starting gun to ensure the same becomes true for inclusion of carers.





**INCLUDING FAMILY  
CARERS:  
ECONOMIC  
CONSIDERATIONS**

# Professor Martin Knapp

Summary of a presentation by Martin Knapp, Professor of Social Policy, London School of Economics and Political Science, Director of the Personal Social Services Research Unit, LSE, and Director of the NIHR School for Social Care Research

Professor Knapp outlined the work of the NIHR School for Social Care Research. It has funded over 100 research projects to-date, some of which directly concern carers, and will add substantially to the evidence base.

Economic evidence is needed because resources are limited and decision-makers need to be informed about how to get the best out of available resources in terms of what is most effective, affordable, and cost-effective. If the core policy/practice question is: "Does this intervention work?" The economic question is: "Is it worth it?". So, an evaluation must define outcomes and costs, and there may be difficult trade-offs between these.

He drew attention to the evidence on projections of future demand/need for care, and supply of carers. A model developed at LSE has been used to explore different assumptions, which suggests the emergence of a growing gap between supply of, and demand for, family carers.

In looking at evidence on interventions Professor Knapp drew on a recent (forthcoming) review of international evidence undertaken at LSE. This identified four main types of intervention:

- Services aimed at the care-recipient
- Services aimed directly at the carer
- Work conditions
- Cash benefits.

Robust, quantifiable evidence to use in modelling could only be found in relation to carer employment status, suggesting that interventions around statutory care leave,

flexible working arrangements and formal care can all make a difference to improving employment outcomes for carers.

## The START Study

In looking at economic evidence, Professor Knapp used the example of the START (STrAtegies for RelaTives) intervention, a multi-centre Randomised Control Trial (RCT) involving 260 family carers\*. The intervention uses a manual-based coping strategy for family carers of people with dementia, providing an individual programme of eight sessions over 8–14 weeks delivered by psychology graduates. The programme teaches carers techniques for understanding and coping with the behaviour of the person they care for.

Outcomes at eight months:

- START improved carer mental health and health-related quality of life.
- Carers receiving usual support were four times more likely to have clinically significant depression than carers with START.
- The cost was off-set by reduced use of other services by carers.

Outcomes at 24 months showed:

- Carers with usual support were seven times more likely to have clinically significant depression.
- Carers with START had significantly better quality of life.

For the people with dementia there were no differences in health status or quality of life, but some delay to care home admission.

\* Knapp M, King D, Romeo R, Schehl B, Barber J, Griffin M, Rapaport P, Livingston D, Mummery C, Walker Z, How JL, Cooper C, Livingston G (2013) Cost effectiveness of a manual based coping strategy programme in promoting the mental health of family carers of people with dementia (the START (STrAtegies for RelaTives) study): a pragmatic randomised controlled trial, *British Medical Journal*, 347, f6342, 1–12.



START produces better outcomes; does not cost more; it is clearly cost-effective.


Further evaluation is being undertaken at five-year follow up and results will be available later in 2017.

#### Conclusion

In conclusion, Professor Knapp remarked that

it was essential to include economic evidence:

- Evidence on the economic consequences of 'carer interventions' is scarce.
- Ideally, every new evaluative study would include an economics component.
- Robust studies (e.g. RCTs etc.) are needed, but quicker, cheaper, yet still robust, studies also have a contribution to make.



# INCLUDING FAMILY CARERS: INDISPENSABLE IN DEMENTIA RESEARCH

# Professor Sube Banerjee

Summary of a presentation by Sube Banerjee, Professor of Dementia, Director of the Centre for Dementia Studies, and Associate Dean, University of Sussex

Professor Banerjee outlined the global incidence of dementia, and projections on the increase in numbers likely to be affected in future. He pointed out that the National Dementia Strategy had recognized that:

- Family carers are the most important resource available for people with dementia (and this is recognized in dementia strategies around the world);
- The availability of a carer is a vital determinant of positive outcomes for people with dementia; and
- Having a co-resident carer is a 20-fold protective factor on the risk of institutionalization.

At present, not enough is known about what works to support carers supporting people with dementia.

## Training healthcare professionals

Professor Banerjee described the 'Time for Dementia' programme, run by Health Education England, which focuses on the training of healthcare professionals, helping them to understand the impact of dementia on people and their family carers.

The programme involves the Brighton and Sussex Medical School, the Alzheimer's Society and the University of Surrey, to build an understanding in students of:

- What it is to be old and ill in society.
- What it is to have a long-term condition.
- The role of family and carers.
- Dementia.
- Compassion, empathy and understanding.

The Alzheimer's Society is managing a network of 300 families, and the medical student intakes of 2014, 2015 and 2016 undertake visits in pairs four times a year to families affected by dementia. The aim is to deliver the programme across all undergraduate healthcare in the region within three years.

The programme is being evaluated, looking at the impact both on students, and on people with dementia and their families. Outcomes so far indicate positive benefits.

## Supporting carers

Turning to consider interventions to support carers, Professor Banerjee also cited the START programme, and highlighted the implementation gap in getting such programmes taken up and adopted more widely.

Professor Banerjee also referred to a study to develop a measure of quality of life of carers of people with dementia (C-DEMQOL study).<sup>\*</sup> The voice of carers was an integral element of the study from design onwards, and included a carer as a co-applicant, and the establishment of a Lived Experience Advisory Panel (LEAP) which influenced both the direction and findings of the research.

\* [www.bsms.ac.uk/research/cds/research/quality-of-life-in-dementia.aspx](http://www.bsms.ac.uk/research/cds/research/quality-of-life-in-dementia.aspx)





**GROUP DISCUSSION:  
TOWARDS  
PRIORITISING  
CARERS**

## Group discussion

Informed by the three presentations, delegates were allocated to small groups and invited to consider three key questions:

- How can value be added by including carers in your field of research?
- What might be the opportunities to do so?
- What are the challenges/barriers and how do we overcome them?

The key points of discussion and reflection on each of these themes are captured below.

### How can value be added by including carers in your field of research?

The discussion groups were clear that there is value to be gained from appropriately including carers in health- and social care-related research. They stressed that the carer's perspective is different from that of the service user/patient, and is often very important to the lives of the dyad and to services and, hence, ought to be similarly important to research. Discussions indicated that in the right circumstances carers can bring a 'broader lens' to research than is currently often the case. Carers can bring their own distinctive perspectives and, in some circumstances, also act as a voice for the people they care for.

By contributing to research carers can:

- Help ensure research is relevant to the real worlds of many people, and resonates with their lived experiences of caring and dealing with care needs, disability and illness.
- Assist in ensuring research is robust by, for example, helping to make sure that it addresses the right questions and circumstances of people's lives, and help identify the right data to collect, especially that pertaining to outcomes.
- Support in helping to make the research practicable and deliverable by helping to plan, for example, data collection that fits best with people's lives. This may also help to make the delivery of research more efficient.

- Ensure research is relevant and thereby help it have impact on improving care, services and outcomes for people. Carers speaking about the findings and relevance of research can be an important additional voice in communicating important messages from research to relevant audiences, including practitioners, managers of services, commissioners and policy makers.
- There are good examples of carers being involved in all stages of research, and these can be adopted more widely. For example, the NIHR SSCR routinely includes carers in the running of the School and its research projects. Parkinson's UK also involves carers in the development of research projects and reviewing proposals.
- Members of the discussion groups also felt that involving carers in research can help to send an important public policy and societal message about the value of carers.
- People were very clear that involvement must be done in the right way, a point we will elaborate on in the next sections of this report.

### What might be the opportunities to do so?

Participants were asked to identify opportunities to include carers in research and considered that:

- The demographic changes society is going through, notably the ageing population



and more young people living longer with complex needs and the challenges these are likely to bring, present an opportunity to highlight the importance of carers, their value to society and the need to include them in research.

- People need to be creative about including carers and not assume they can contribute in the same ways or at the same time as others, but ensure suitable opportunities are made available. Use of technology, including video conferencing and online systems for contributing to surveys and documents, are good examples. Another creative idea may be to run an event for service users and enable carers to contribute to research at a parallel event.
- People can be involved in all stages of research, from the earliest stages of developing proposals, and there are lessons to be drawn together and shared to spread good practice. When carers are involved in reviewing research proposals and on research funding panels, they ought to be allowed to contribute to discussions about all the aspects of the research proposals that they feel comfortable discussing and knowledgeable about.
- There are networks of carers to work with and develop their capacity and skills to contribute to research. This may include building relationships between researchers and carer networks, and training about involvement in research for both groups. Longer term partnerships with carers are necessary and will be more beneficial than seeking one-off engagements with them.

In order to maximise the ability of carers to contribute to projects in the ways identified above, they need to be involved in the formulation of projects at an early stage. It is then that they can have the most impact in ensuring the questions are relevant and that methods will fit with the lives of carers and collect the most suitable data, especially in terms of outcomes.

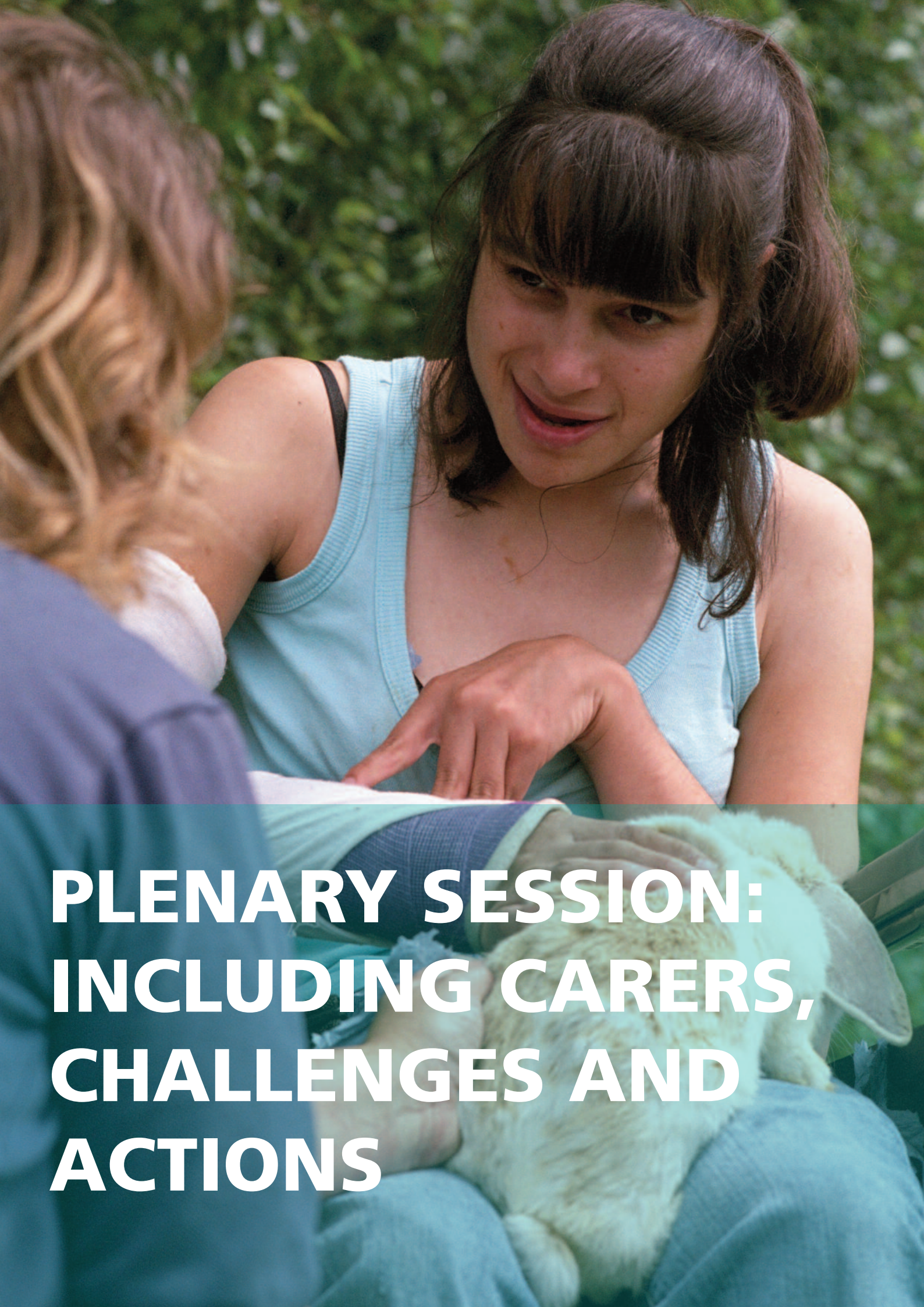
## What are the challenges/barriers and how do we overcome them?

Participants were also asked to identify what they saw as the main challenges and barriers to wider involvement of carers in research. They identified the following:

- People too often think of involving carers late in the process. Sometimes this may be merely an inappropriate 'tick box', tokenistic process of involvement.
- It should not be assumed that carers want specific things from being involved or expect particular treatment. Equally, it should not be assumed they will do it for free and the expectation should be that appropriate payment is available for their time and input. The main thing is to ask them, and to be respectful of them and what they want and expect. Longer-term partnerships with carers will make this easier.
- The diversity of carers and caring situations can be a challenge. It is not possible to develop a representative group of carers to be involved and they should not be seen in that role. They are there to offer their distinctive experiences as an additional perspective when considering the research project.
- There are groups of people who are more likely to be overlooked, notably former carers (those recently bereaved, or who have ceased to be carers because the person being cared for has moved to a care home). They should not be excluded, and, indeed, including people with recent caring experience but who now have more flexibility over their time can be beneficial. Longer-term partnerships with carers would help to identify these opportunities.
- There is a primary challenge to include those who do not identify themselves as a 'carer', but who nevertheless undertake caring for someone. Finding the right language and channels of communication will help to include this group of people.

- Third sector organisations are sometimes seen as a means of recruiting carers and there are risks that these groups can be taken for granted or treated as 'handmaidens' rather than engaged as full partners.
- Wider social expectations and stigma can mean that carers are not seen as a legitimate group in terms of research. There was a view expressed that research often mirrors societal unwillingness to face trade-offs or difficult decisions with regard to carers.
- There was a perception that in some quarters carer-related issues are seen as soft, 'fluffy' and not core concerns to health and social care practice or policy, and, hence, not to research. In reality, the issues are tangible, with measurable impacts on people's lives, and policy decisions.
- There were certain views expressed about research and methods that, in part, are real challenges to researchers and in part may represent lack of communication about approaches to research. For example, there was a view that including carers can make it harder to conduct randomised control trials, but this is not the case. In fact, involving carers can help to ensure that a trial addresses pertinent questions in its design, the outcome measures used, and the analysis of data. Another concern was that research is not very good at capturing things that are not specific interventions. Research can explore many types of questions. It can be harder to explore more complex or less tangible issues, but it is not impossible and progress has been made in a number of ways to address methodological challenges. One such is the use of the framework for evaluating complex interventions developed by the Medical Research Council.
- The concern was raised that it is difficult to obtain funding for longitudinal research about carers.
- Research systems can make it harder to include carers in research. For example, it is not easy to obtain the additional resources to undertake research in care homes and people's own homes compared with what might be available for research in hospitals.
- Carers may not fully understand the objectives of research and the uses of data, and may be fearful about why some data are being collected or that it may be shared inappropriately.
- For some there may be barriers in terms of tensions between payment for involvement in research and impact on receipt of welfare benefits. There are experiences and good practice to draw on here from involvement of patients/service users to help address these issues.
- It can be difficult to make alternative care arrangements to free up the time for carers to be involved. Similarly, involving working carers may be difficult because of the demands on their time (some of the ideas above on being creative about involvement may potentially overcome some of these challenges, such as with Skype, phone calls, emails etc.).
- There is a need to acknowledge that when the views of the carer and the 'cared-for' are entwined in a research project, it is important to separate views and experiences at all stages of the research programme and not assume they are always consistent.
- Involvement is not always an easy process and this needs to be recognised and managed when it is not going smoothly or as planned, and lessons need to be learnt where possible. The purpose of involving carers needs to be made clear throughout to set and manage appropriate expectations.
- There is a need to help carers to be involved. One example is avoiding the use of jargon. Another is explaining research processes that carers may not be familiar with; also, ensuring payments are made for time and travel and for any substitute care needed.





**PLENARY SESSION:  
INCLUDING CARERS,  
CHALLENGES AND  
ACTIONS**



# Plenary session summary

Reflecting on the discussions of the event, delegates prioritised the following:

## Adding value by including carers

- Ensuring research funding panels give adequate weighting to carers; funders should include the voice of carers and involvement of carers should be a full partnership and not a mere tick-box exercise.
- Involving carers throughout the research process and from as early a stage as possible i.e. when thinking about the research project design and identifying research questions.
- It should not be assumed that the carer is a derivative of the cared-for person or that views are shared and interests coincide.

## Challenges

- Accessing harder to reach groups, including carers who don't define or view themselves as such.
- Acknowledging and reflecting the variety and complexity of caring situations.
- Getting funders, especially health research funders, to prioritise carers' issues, and understand how issues could benefit from a carers' perspective and their inclusion.

## Actions needed

- Drawing on the lessons from 'PPI' (Patient and Public Involvement) to involve carers as a group with a specific role, remit and contribution and a clear 'set of voices' and perspectives.
- Recognising that carer involvement is complex and, whilst ultimately rewarding, can at times be challenging and, hence, needs appropriate time, resources and planning to make it work for everyone.
- Building an infrastructure and knowledge-base to enable more and better research partnerships with carers and resource their involvement properly.
- Providing support and training for carers to be involved, including appropriate financial support.
- Avoiding jargon and unhelpful assumptions to promote good involvement.





# CONCLUSIONS AND REFLECTIONS

## Conclusions and reflections

The objectives of this event, as stated in the introduction, were to look at the added value of including and involving family carers in health- and social care-related research. While there has been greater recognition of carers in social care research, and in service development too, it is apparent that this has been slower to gain traction in health-related research and health care matters. The seminar was therefore especially concerned to address this dimension.

### The value of including carers

Involving family carers, and valuing their role and contribution, is not only morally right but is pivotal to the future effectiveness of health-related research. Most people with long term health conditions live in the community and a growing number receive support from a relative. Until recently – where carers have been included in research – it has tended to be as proxies for the service user or patient. This not only risks inappropriate assumptions about proxy voices, but also fails to recognise that carer's views are valid in their own right and that they can add significantly to the depth, breadth and efficacy of research and its ultimate impact.

Expecting carers to 'represent' a service user is inappropriate. Many 'health care interventions' for patients can also affect carers and the patient/carer dyad and relationship. For a health-related service or intervention to be sustainable it almost certainly needs to have carer 'buy in' and support, especially if the patient lacks capacity or needs help to make use of the service. It is perhaps surprising that it has taken us so long to engage with the need to meaningfully include carers in health-related research.

Carers are a hugely valuable source of experience and expertise about the patient, themselves, the caring relationship and the delivery of effective health care to best fit their circumstances. They typically have a detailed knowledge about the health condition's trajectory and how it has affected the person's care needs, well-being and quality of life, as well as their own. Carers are a significant source of research evidence including: data on service effectiveness, health and quality of life; ability to undertake a range of activities; and on the lived experience, the difference an intervention has

made to their lives, their relative and to their relationship. Carers can help research to be better; to change the way it is undertaken, inform research questions, design and methods, analysis and reporting, and help ensure impact is captured in the round and in a meaningful way. It makes no sense not to make the best use of this rich experience and knowledge.

### Genuine involvement

One of the key messages that came out of the day was the importance of genuine involvement. For carer's perspectives and knowledge to benefit research, they need to be involved early: at the research design stage, and to be included at all subsequent stages. Their time and input needs to be adequately recognised, including financially, and they need to be treated as partners, as experts in their own lives and (often) the life of the person with the health condition. This is not only respectful but is about genuine involvement, not a token last minute tick-box exercise or afterthought. Longer-term research partnerships with carers would make all this more realistic.

### Learning from social care experience

Social care research has been working with carers for some time. It hasn't always done this well, and not always fully, but it has engaged with some of the challenges identified by participants, and lessons can be drawn to inform the health field. Gaining carers' views on how to best capture the impact of a service or intervention is one example, and incorporating tools and/or measures to evaluate carers' perspectives is another. Recognising that every carer, every relationship, every experience of a health



condition and of care needs is different is a third challenge that social care has acknowledged, if not fully addressed (yet!) and this is an issue that more health-related research now needs to routinely take serious account of too.

We heard at the event about at least two examples of well designed, robust health-related research that involved carers, and about interventions that benefited carers and the people they care for. Dementia is one of the key health challenges facing patients, carers and care services, and is a condition that has a profound impact on both individuals' lives as well as on relationships. It is probably no coincidence that this is one of the conditions that has begun to meaningfully involve carers, shifting from the proxy model to more sophisticated models of involvement and inclusion. Routinely gathering the views of users and carers about research proposals is one of the key ways in which funders, including some health-related funders, are taking carer involvement onboard.

There is a long way to go and carers often report feeling 'dumped on' or expected to respond to a researcher's questions without having been consulted about the study design or objectives. Good practice in carer inclusion and involvement needs to be collated and added to and then embedded in all stages of commissioning and conducting research. For this to happen it needs to be disseminated widely amongst funders of health-related research, health-related researchers and centres and among those who design, fund, commission or engage with research in the health care field.

There was clearly an appetite amongst participants at the event to learn from existing good practice and engage fully with

carers as research partners. Models from patient and public involvement initiatives were also seen as important to draw on.

Research methods can struggle to capture the complexity of 'research impact' and of users' and carers' lives and relationships, but capture it they must if we are to genuinely include carers in research. Work in this arena is growing but it needs investment. Other barriers can include the additional costs of involving carers in research, and there are some concerns about how to do 'involvement' properly, capture impact in a coherent and sufficiently 'gold standard' way, sensitively including those who do not view themselves as 'carers', and acquire organisational 'sign up' to multi-level carer involvement for longer-term research partnerships.

### Next steps

The event was infused with genuine enthusiasm, commitment, creativity, energy and a spirit of 'can do'. There was recognition that carers can add significantly to the effectiveness and cost effectiveness of research. Some participants were already doing work that involved carers and had examples to share.

There was wide acceptance that carers need to play a much bigger role in, and be valued by, health-related research. This is the beginning of an exciting and engaging journey for the health research community and we hope the event will be a catalyst in shifting thinking, engaging hearts and minds and (further) firing up participants to implement changes in their domain(s), and involve carers in current and future health research for all our benefit.

# The NIHR

**Since its establishment in 2006, the National Institute for Health Research (NIHR) has contributed significantly to the health and wealth of the nation and is now the most comprehensive research system in the world.**

The National Institute for Health Research (NIHR) is funded through the Department of Health to improve the health and wealth of the nation through research. It works with patients and the public to shape its research agenda, finds new ways of preventing, identifying and treating ill health, evaluates the effectiveness and impact of new healthcare treatments and ensures that the best possible evidence is available to inform decisions about health and social care. The NIHR provides world-class infrastructure in the NHS and attracts investment into the UK by supporting partnerships with life science companies, including small and medium enterprises, and charities, and builds capacity and leadership in the research workforce.

To find out more about the NIHR, and research commissioned through its various programmes and Schools, visit [www.nihr.ac.uk](http://www.nihr.ac.uk)

## NIHR SCHOOL FOR SOCIAL CARE RESEARCH

The NIHR School for Social Care Research was established in 2009 to commission world-class research to improve the evidence base for adult social care in England, and renewed in 2014. Since then, the School has commissioned 124 research studies – many of which look at the needs of, and/or support for, carers. Many of its studies engage with carers, and all have been reviewed by members of the School's User, Carer, Practitioner Reference Group.

To find out more visit the School's website at [www.sscr.nihr.ac.uk](http://www.sscr.nihr.ac.uk)

## NIHR DISSEMINATION CENTRE

The NIHR Dissemination Centre aims to put good research evidence at the heart of decision making in the NHS, public health and social care.

The Centre's work helps clinicians, commissioners and patients to make evidence-based decisions about which treatments and practices are most effective and provide the best use of resources.

Read more about the Centre's research Signals, Highlights and Themed Reviews at [www.dc.nihr.ac.uk](http://www.dc.nihr.ac.uk)

## NIHR INVOLVE

Involve was established in 1996 and is part of, and funded by, the NIHR to support active public involvement in NHS, public health and social care research. It is one of the few government-funded programmes of its kind in the world. Involve's Advisory Group includes a broad mix of individuals who use health and social care services, carers, people from voluntary organisations, and health service and social care practitioners, managers and researchers.

Read more about NIHR Involve at [www.invo.org.uk](http://www.invo.org.uk)





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