

School for Social Care Research

Annual Report
2009–2010

Improving the evidence base for
adult social care practice in England



The School for Social Care Research (SSCR) is a partnership between the London School of Economics and Political Science, King's College London and the Universities of Kent, Manchester and York, and is funded by the National Institute for Health Research (NIHR).

Acknowledgements

The School for Social Care Research is grateful for the support provided by a number of people in producing this report. We particularly thank Patsy Westcott, Jane Garton and Fiona Scorer for their efforts in producing and editing this report, and Sarah Moncrieff of Westminster European for designing, editing and producing this report.

OUR MISSION

Our mission is to improve social care practice for adults in England through commissioning and conducting research to:

- provide evidence of effective, pioneering and imaginative approaches
- enable people needing social care to lead satisfying, fulfilling lives, supported by accessible, easy-to-use, individually-tailored services
- underpin the development of social care practice through high-quality research evidence.

Directed by Professor Martin Knapp, the SSCR is a partnership between six leading academic centres, each with an excellent track record in social care research:

- Personal Social Services Research Unit at the London School of Economics and Political Science
- Social Care Workforce Research Unit at King's College London
- Personal Social Services Research Unit at the University of Kent
- Personal Social Services Research Unit at the University of Manchester
- Social Policy Research Unit at the University of York
- Tizard Centre at the University of Kent



SSCR Executive Group:

Back row l-r: Anji Mehta, Ann Netten, Jim Mansell, David Challis, Caroline Glendinning
Front row l-r: Gill Hastings, Martin Knapp, Jill Manthorpe

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The number of adults currently
using social care services

1.78 million

The number of people working in
adult social care

1.5 million

The number of people
providing unpaid care

5.2 million

The amount spent by councils
on social care for adults

£16.5 billion

The amount spent by older
people not eligible for public
support on their own care

£3.5 billion



*Professor Dame Sally C Davies,
Director General of Research
and Development for the
Department of Health*

"Developments in adult social care practice must be unpinning by world-class research evidence. The NIHR's School for Social Care Research, with its focus on social care practice is a unique centre of expertise. It will provide considerable benefit to the health and well-being of the population through the new knowledge gained."

FOREWORD

We established the NIHR School for Social Care Research in 2009 because we saw a real need to improve and expand the evidence base for social care practice to help improve the quality of life for both individuals and the wider population. Our investment in the School is an investment in the very fabric of society.

This excellent report sets out the School's focus and priorities. These were identified by those at the heart of social care practice, and include preventing and reducing the need for social care and support, choice and independence for those who use services, and the relationship between care and work. The School continues to work towards a better understanding of research needs and, in its look to the future in The Year Ahead (page 15), it hints at the important new challenges facing the social care community. Developing evidence-based solutions to these is of even greater importance as we enter a tighter fiscal environment and growing public expectations of social care that works.

Throughout the last year the School has clearly demonstrated its enthusiasm and energy in working towards improved adult social care, commissioning and undertaking research of considerable relevance. The School's current projects show some of the important work that is already underway. For example, evaluating the impact, outcomes and costs of using skilled staff to support people with complex needs who present challenging behaviours or who have severe and profound intellectual disabilities will, in future, ensure more effective and value for money care practices for those who are affected and need support.

The NIHR aims to ensure effective public participation in research. I am particularly pleased to see that the School is working closely with a number of SSCR Fellows, people who use services, carers and practitioners through its User, Carer, Practitioner Reference Group, key figures in social care through the School's Advisory Board, and other interested groups and individuals. This partnership working will help the School identify the right research questions, and to commission the studies needed to answer them.

This is an exceptionally interesting time for both social and health care in England, and the NIHR School for Social Care Research is uniquely well placed to contribute robust evidence to inform the changes of the coming years. I see the SSCR as being at the forefront of evidence-based discussion, through its innovative research programmes, its range of development and growth activities and its ability to draw patients and service users, their carers and social care experts into this highly important debate.

A handwritten signature in black ink, reading 'Sally C Davies'. The signature is fluid and cursive, with the first name 'Sally' being more prominent.

WELCOME

I am delighted to welcome you to the first *Annual Report* from the NIHR School for Social Care Research.


The School formally commenced in May 2009, following an invitation from the National Institute for Health Research to university groups across England to apply for membership. Six such groups were selected, and I was invited to act as the inaugural director – an invitation I was delighted to accept.

The mission of the School is to develop the evidence base for adult social care practice in England. Such an ambitious aspiration is imperative if we are to help increase the volume and improve the quality of research in the field. The need for a robust evidence base in social care has never been greater.

Our first year can best be summed up as one of infrastructure building. We have been busily consulting widely on research needs and priorities; exploring what has already been done in the field and what else is currently underway; commissioning reviews of research methods that will be helpful to people planning new studies; and setting up processes for commissioning, reviewing and quality – assuring all the School's research. Most importantly, we have commissioned studies on adult social care practice. Those studies are not just carried out within the six groups that constitute the School, but by many other groups across the country.

The School has a number of objectives, set for us by NIHR and taking us beyond just the conducting and commissioning of high quality research. We are also working to raise the profile of social care research within the NIHR and elsewhere. We will contribute to efforts by others to expand and improve research capacity. We are consulting widely about what needs to be researched with people who use services, their carers, practitioners and people who provide services and other stakeholders.

The task I have of directing the School has been made all the easier by a very engaged and expert Advisory Board (page 33) and an equally engaged and equally expert group of users, carers and practitioners who sit on our Reference Group (page 33). The NIHR has also been hugely influential in steering and encouraging the work of the School. I must also extend my huge gratitude to my academic and administrative colleagues on the School's Executive Group (page 29) for their hard work, expertise and good humour; to the School's Fellows for taking on commissioned work; and to many LSE colleagues.




*Professor Martin Knapp
SSCR Director*

MEET



**ADVISORY BOARD
MEMBER**

Christine Barton

I believe that people who use health and social care services have essential personal experience to bring to changing and developing practice, and that good research provides a solid knowledge base to work from. I am very pleased to have been able to bring these beliefs together through being a member of the School for Social Care Research's Advisory Group. I feel that my contributions have been listened to and acted on. Partnerships between people who use services and service providers can build secure and robust foundations for future development in practice, keeping the interests of people who use them at their heart.

Dr Christine Barton MBE has had a career as a teacher and lecturer and is now a trainer and equal opportunities consultant. She is quadriplegic and has personal experience of receiving social care. Christine is passionate about achieving rights and equality of opportunity for disabled people. She works both locally and nationally to improve choice and control for disadvantaged people. Locally she is a founder member of Sheffield Centre for Independent Living, a governor of the Sheffield LINK (Local Involvement Network), a lay member of a Biomedical Research Unit and a director of the Accessible Property Register Ltd. Nationally she is a member of the Long Term Neurological Conditions Advisory Group, a National Institute for Health Research Regional Funding Committee and a Lay Reviewer for research proposals.



**USER, CARER, PRACTITIONER
REFERENCE GROUP MEMBER**

Jeanne Carlin

My experience of social care is both personal, as a carer for my disabled daughter, and professional, as an independent disability consultant in children's services.

I am an advocate for my daughter, 27, who has multiple impairments and lives at home, as well as an active campaigner at both local and national levels. I am also a social worker and have managed disability services in Hull and the East Riding. For the past eight years I have worked at a national level – doing research, training, writing publications and acting as an advisor and consultant to various local authorities and third sector organisations – mainly in children's disability services.

Too often researchers find it hard to reach and include people who do not use language to communicate or use language differently. This adds to the exclusion of these individuals who are already marginalised within society. Researchers need to use a more diverse and imaginative range of methods so that the interests of all users of social care can be represented in research.

As a member of the reference group I bring to the discussion of research studies a reminder that people with impairments are a diverse group and that methodologies need to be creative and flexible to meet a range of communication methods.

AT A GLANCE: WHAT WE DID IN 2009/10

- We commissioned four research projects led by Executive Group members (see page 22)
- We received 36 outline proposals in our first open call – ten were short listed; five have been funded (see page 22)
- We commissioned 16 new methods reviews (page 24) and two scoping reviews (page 23)
- We welcomed 1 new Senior Fellow and 43 new Fellows (page 30).
- We developed more than 20 partnerships with individuals and organisations, including with Making Research Count, Research in Practice for Adults, the Social Care Institute for Excellence
- We held our first workshop on user-involvement in adult social care research
- We hosted our first annual conference
- 3 people who use services, 3 carers and 3 practitioners agreed to join our newly set-up User, Carer, Practitioner Reference Group (page 33)

£1.8 million

was committed to commissioned research projects (see page 10)

41 individuals and organisations submitted 121 topics

in response to our open call for research ideas by 30 September (see page 13)

29 peer reviews

were conducted by external reviewers



Winning Awards



We congratulate two members of the SSCR Advisory Board who were awarded CBEs in the New Year's Honours List:

[Julie Jones](#), Chief Executive of the Social Carer Institute of Excellence, for services to local government



[Imelda Redmond](#), Chief Executive of Carers UK, for services to disadvantaged people



In recognition of their achievements in social care research and the resulting impact on the nation's wellbeing Queen's Anniversary Prizes for Further and Higher Education were awarded to:

[LSE Health and Social Care](#) (LSEHSC), at the London School of Economics and Political Science, where Professor Martin Knapp of PSSRU is the Co-Director. LSEHSC was given the award for applying research to the advancement of global health and social care policy.

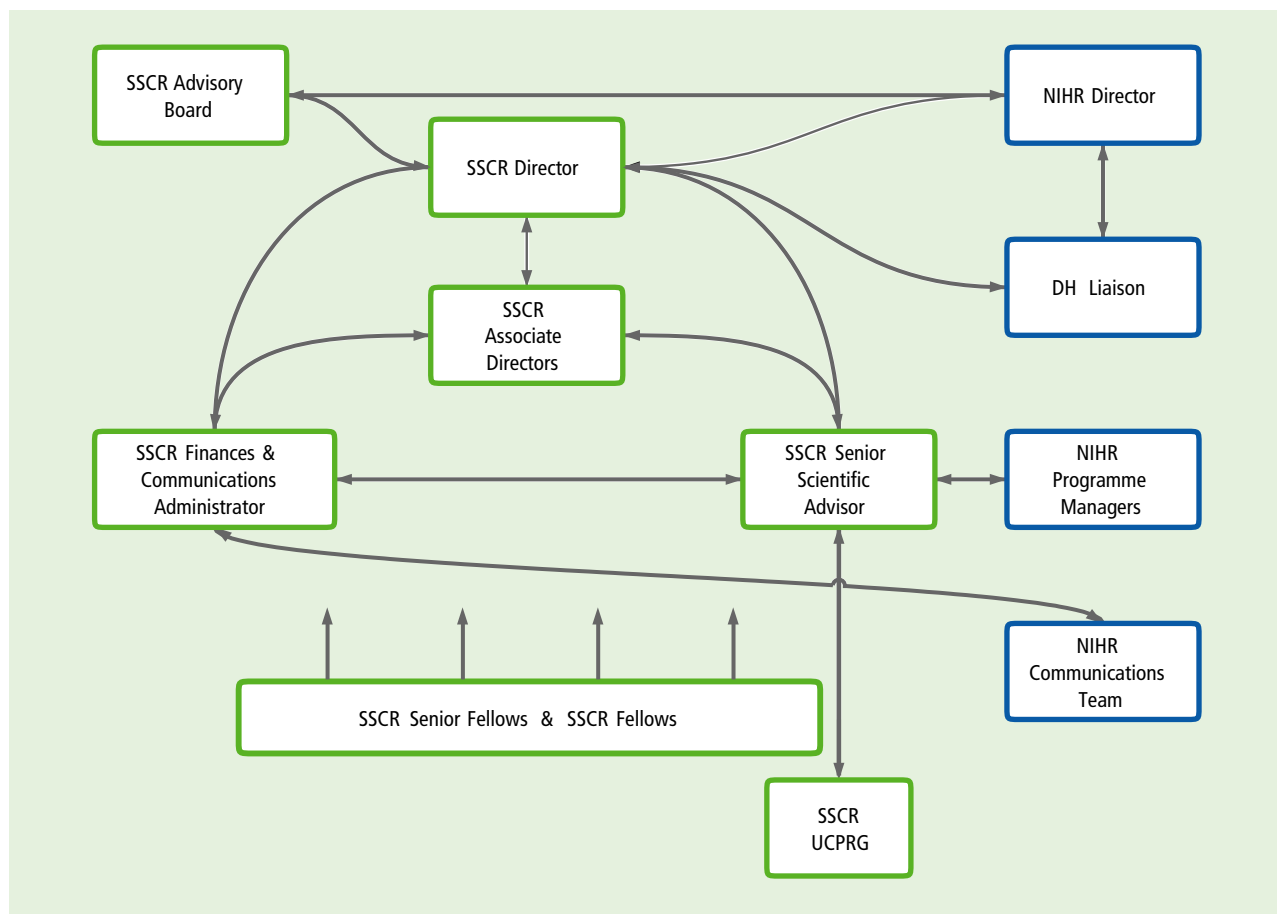
[Social Policy Research Unit](#) (SPRU), at the University of York, where Professor Caroline Glendinning is Research Director of the Adults, Older People and Carers Team. SPRU was given the award for over 35 years of research influencing social policy and practice.

WHO WE ARE AND WHAT WE DO

Established in 2009, the School for Social Care Research undertakes and commissions research to improve the quality of adult social care practice in England. Coordinated by an Executive Group and supported by a network of Research Fellows, an Advisory Board and a User, Carer, Practitioner Reference Group, we:

- commission and carry out high-quality research relevant to the lives of people needing social care
- provide a focus for social care research in the National Institute of Health Research (NIHR)
- encourage the development of social care research
- consult a wide range of stakeholders about research priorities
- develop a broad range of creative yet rigorous research methods
- improve awareness of the need for social care research
- publicise our findings in as many places as possible
- ensure that findings help to improve care and support.

SSCR structure



“As a long-term carer it's easy to feel isolated and that no one is addressing the real issues. It is therefore particularly rewarding to be involved as a member of the School for Social Care Advisory Board, where you are part of the decision-making process at the outset and can help to ensure that publicly-funded research will have a genuine influence on social care practice for the future.”

Conrad Hodgkinson,
SSCR Advisory Board Member

“The emergence of the School is one of the most welcome and impressive developments for research in the social care and social work fields for a long time. By engaging the best researchers from a range of disciplines, it holds firm promise of impact for good for both policies and service delivery.”

Professor Ian Shaw,
SSCR Advisory Board Member

Our people

Our Executive Group is led by Professor Martin Knapp. It coordinates the School's work, decides the research questions, monitors ongoing studies and assesses final reports. The Group includes the five Associate Directors (Professors David Challis, Caroline Glendinning, Jim Mansell, Jill Manthorpe and Ann Netten), the Senior Scientific Administrator (Dr Gill Hastings) and the Finances and Communications Administrator (Angela Mehta). The Executive is also responsible for making sure that the research findings promote real changes that make a positive difference to people who use social care.

Our Advisory Board, chaired by David Behan (Director General for Social Care, Local Government and Care Partnerships in the Department of Health), gives enthusiastic and expert input on matters ranging from our research programmes to our international links. See page 33 for a full list of Advisory Board members.

A network of senior fellows and fellows, which includes specialists in wider areas of disciplinary and methodological expertise relevant to social care and support, helps underpin our work and takes forward much of our research. See page 30 for a full list of fellows.

WORKING TOGETHER

To encourage research findings to be heard, seen and used by all those involved in adult social care, and to actively involve people who use social care, carers and practitioners in all aspects of the School's work, we have established a User, Carer, Practitioner Reference Group (UCPRG) coordinated by our Senior Scientific Administrator, Dr Gill Hastings.

The group advises us on research and related activities and helps to manage our relationship with key groups of service users, carers and practitioners.

Research is vital to validate and advance social care practice, but for this research to be relevant it is equally vital to engage service users throughout the research process. Our vision is to encourage research findings to be heard, seen and used by the full range of people involved in adult social care; and to champion the continuous and active participation of people who use social care, carers and practitioners in all aspects of research and the work of the SSCR.

This year we have helped the SSCR develop its research strategy by reviewing its research proposals, taking part in discussions on user-involvement in research and contributing to the School's research programme with ideas for new and innovative research.

SSCR User, Carer and Practitioner Reference Group

Jeanne Carlin, Angie Carmichael, Margaret Dangoor, Rashid Ebrahimkhan, Shamime Lakda, Dave Nwokedi, Jane Reast, Inam Shaikh, Heidi Wong

OUR RESEARCH THEMES AND PRIORITIES

We have identified five themes that focus on research that will help the SSCR in realising its aims. The aims of those five themes are:

- to prevent and reduce the need for social care and support
- to promote choice and independence
- to balance care and work
- to develop solutions to changing needs
- to provide evidence to help deliver integrated services

1. Preventing and reducing the need for social care and support

With demand for services rising, increasing costs and tighter budgets it is vital that we find ways to prevent or postpone people's needs for social care and support. We need to investigate whether there are arrangements, circumstances, processes or interventions that can help to avoid individuals reaching a situation where social care is needed; or that respond early in order to lessen unwanted longer-term exacerbation of 'problems' or needs; or that help individuals to re-integrate themselves into their family, community and societal roles. Assessing the impacts of such interventions is methodologically challenging and a variety of projects might be needed to build up an understanding of 'what works', how it is experienced and with what resource implications.

"How can we best prevent or reduce the development or exacerbation of circumstances that lead to the need for social care?"

2. Promoting choice and independence

People who use social care services should have choice and control over their lives. Personalisation works towards providing people who use social care services with choice and control over the shape their support takes. The success of personalisation lies in the achievement of a successful balance between choice, control and flexibility, on the one hand, and, on the other, security and safeguarding. We need to address areas of concern such as the balance of rights and risks in care and support; and the balance between flexibility and security. The roles of families, carers and formal support organisations in helping manage these balances will be of particular interest.

"How can we best empower and safeguard people who use social care services?"

"Good research is the cornerstone of innovation and development and the SSCR is leading the way to creating a coherent approach to Social Care Research that will provide the foundations for developing world class 21st Century Social Care Services. Demographic change and increasing expectations will require us to be as efficient as possible with our increasingly scarce resources and good quality research will help us all to understand which interventions and support services deliver the best outcomes."

Martin Green,
SSCR Advisory Board Member and
Chief Executive of the English
Community Care Association



"I feel excited by the potential of SSCR. There couldn't be a more timely and significant moment to be embarking on new programmes of work relevant to the future and funding of adult social care and support."

Dr Emma Stone,
Joseph Rowntree Foundation

3. Balancing care and work

The relationship between care and work is complex. We want to ensure that people who use social care and those who support them lead the fullest possible lives. We are focusing on the boundaries of formal and informal care work, including the employment of relatives and friends to provide support, and the employment outcomes for both social care users and those supporting them.

"How can we best equip and support people – practitioners, volunteers, informal carers – to provide optimum social care? How can we ensure that people who use services and their carers are enabled and supported in paid work and other types of meaningful activity?"

4. Developing solutions to changing needs

Social care is undergoing a period of unprecedented upheaval. Multiple simultaneous pressures are reshaping the commissioning and delivery of adult social care services. We want to answer questions such as how can service commissioning and delivery processes adapt to meet new demands for services that are both personalised and integrated? What are the impacts of decommissioning services as a result of these and longer-term trends? And how is decommissioning best managed to minimise negative consequences and make best use of resources?

"What interventions, commissioning and delivery arrangements best achieve social care outcomes?"

5. Providing evidence to help deliver integrated services

Social care does not exist in isolation. Historically, the resources allocated to individuals in adult social care have been a function of the costs of services they are assessed as needing. Personalisation has introduced new methods of allocating resources to individuals and is making levels of allocated resources more transparent. Evaluation is needed on the impacts, outcomes and cost-effectiveness of more flexible resource use involving social care, health care, housing, social security and other systems, both contemporaneously and over time. There is a need for research into the methods of allocating resources between groups of social care users and between localities, and the equity implications of different approaches to allocation.

"How can social care and other public resources best be deployed and combined to achieve social care outcomes?"



PUSHING THE BOUNDARIES OF RESEARCH

We are a leading funder of research into social care needs, the results of which will help drive new developments in social care policy and practice. Our aim in particular is to identify and fill gaps in evidence.

Making a positive difference

■ We are funding Professor Jim Mansell (SSCR Associate Director) at the University of Kent, to evaluate the impact of skilled staff support on a comprehensive range of outcomes and on costs for three important sub-groups of people with complex needs (people with severe and profound intellectual disabilities who present challenging behaviour, people with profound intellectual and multiple disabilities and people with intellectual disability and autistic spectrum disorder). It will enable people using services and their advocates to identify staff practices associated with good outcomes and to specify these in their care packages. It will enable people providing services to recruit, train and manage staff in order to promote these care practices and it will enable people commissioning, planning or regulating services to achieve better value for money by requiring effective staff practices.

■ Unpaid family members rather than professionals support most adults with an illness or disability and the need to support them is now well-recognised. Many new jobs in social care have been created to meet this need but at the moment their actual practice is an under-researched area. We are funding Professor Jill Manthorpe (SSCR Associate Director) and her team at King's College London to look at practice activities and models, and evaluate their effectiveness. This study will provide vital information, which will become more important as the number of carers is predicted to grow.

■ Too often services fail to cater for the interlinked requirements of people with complex and severe needs. Why? They need personalised, coordinated and specialised services from many different providers. Professor Caroline Glendinning (SSCR Associate Director), together with Kate Gridley and Jenni Brooks, at the University of York is carrying out research to identify evidence of good practice in service commissioning, organisation and front-line delivery for people with complex needs. The study will focus particularly on the role of social care in ensuring appropriate, coordinated services are available to support these individuals.

■ Local authorities cannot plan social care services for young, disabled adults unless they know how many will need support in the future. However, few authorities have this information, although over the last couple of years a way of predicting future need for services for people with learning disabilities has been

"The first year's work of the School demonstrates its confidence in taking a systematic and rigorous approach to securing evidence that can inform policy directions in this highly contested and politicised field."

Professor Janet Newman,
SSCR Advisory Board Member



"An important focus of my work is how people actually live their lives – not just how services perceive their needs or how staff or carers approach their work. What we are interested in is the impact services have on the lives of the people they serve".

Professor Jim Mansell,
University of Kent.

"If social care is to effectively address the social and health inequalities faced by disabled people, we need to begin thinking more strategically. We need to take prevention seriously. We need to get better at strategic planning. Our research should help."

Professor Eric Emerson,
Lancaster University

"For the ambitious policy outcomes in Putting People First to be achieved, it is important that a wide range of options is available to meet individuals' needs and help them achieve what they want in ways that suit them. Our research will help identify these."

Professor Ann Netten,
University of Kent

"I'm delighted that SSCR have chosen to fund work on adult safeguarding alongside projects focussing on the personalisation agenda, as I believe that these two issues are both of vital importance. I hope that my work, by starting with user and carer definitions of poor practice, will contribute to better understandings of how to deliver quality services which meet people's diverse needs."

Dr Rachel Fyson,
University of Nottingham

developed, which we want to extend to all young disabled adults. To this end we are funding Professor Eric Emerson of Lancaster University to collect information on a random sample of 500 people aged 14–16 years with special educational needs across ten local authorities to develop an open-access, web-based tool that authorities and other service providers can use to predict future need.

■ We have commissioned Professor Robert Jones and colleagues at the University of Nottingham to examine services for support at home for people with dementia and their carers, establishing evidence for what works, what is cost-effective and what is believed to be important in providing successful service support.

■ People experiencing psychosis often have less contact with family and friends than others. They may also find it difficult to hold down a job or find stable housing. Dr Martin Webber of King's College London is examining how social care workers can help these individuals access and use the power, prestige, wealth or abilities of people they may know – 'social capital' – to move forward in life. This research project will provide accessible and structured guidance about social capital interventions that is currently unavailable elsewhere. This study will be the first stage in what is hoped will be the longer-term development and evaluation of a social capital intervention for people with psychoses.

■ In an active response to the vision outlined in the Department of Health's *Putting People First*, Professor Ann Netten (SSCR Associate Director) at the University of Kent is conducting a scoping study to discover how to help councils and providers commission, develop and refine care and support in the context of personalised care. This research will inform what we hope will become a longer-term workstream providing up-to-date, robust and, above all, relevant, evidence about the challenges facing individuals and their carers, the personalised arrangements that can address these, and their likely impact and cost-effectiveness.

■ Individuals who lack the mental capacity to make important decisions often have to rely on others to support their choices and protect them from harm. There is a risk, however, that this can deprive them of their liberty. The Mental Capacity Act Deprivation of Liberty Safeguards (DoLS), which came into force in 2009, provide a framework to protect individuals' rights and to ensure that they are only deprived of their liberty when this is in their best interests. We are funding a team from the University of Bristol, led by Joan Langan, to find out what impact the safeguards are having on human rights and social care practice. The findings will be made widely available to the social care sector, including to voluntary sector organisations of and for individuals who may lack capacity, such as people with dementia, learning difficulties or mental health difficulties. An accessible version of the findings will also be produced.

■ We are also commissioning Dr Rachel Fyson at the University of Nottingham to investigate best frontline practice in safeguarding adults with learning disabilities.

Q&A In consultation...

FIRST PRINCIPLES

As the School was being set up we consulted a wide range of stakeholders who identified a number of priorities for our research, including:

To develop and use robust outcome measures

To understand 'process outcomes' – i.e. how individuals and their families access and experience support

To look at cost-effectiveness

To recognise cultural, ethnic, socioeconomic and other diversity

To chart and evaluate how social care services work with other support systems such as health, housing, education and the law

To understand the consequences of practice changes for the workforce

To make sure that our research is absolutely relevant we consulted a wide range of stakeholders. Here Dr Gill Hastings, Senior Scientific Administrator, explains the consultation process.

Q. What are the SSCR's research objectives?

A. We aim to produce new knowledge through high-quality research in order to inform the future development of social care practice. We do this through new empirical research and/or by reviewing and synthesising existing knowledge.

Q. How are you meeting these?

A. This report sets out what we have been doing so far, and will continue to do, including trying to understand key priorities and needs, commissioning world-class studies, and ensuring we have processes in place to ensure our findings reach those who can use them to improve practice.

Q. How does the SSCR decide which research to fund?

A. The School's Executive decides on the key research questions in consultation with many different stakeholders, our Advisory Board and our User, Carer, Practitioner Group. We then commission studies internally or externally depending on the requirements of the work (in each case after independent peer review). The results of our first consultation on research themes are available at http://www.lse.ac.uk/collections/NIHRSSCR/SSCR_consultation_report.pdf

Q. Why are you consulting others?

A. We want to identify priorities for topics, evidence gaps or 'grey areas', methods and processes, and how findings can be transferred into practice. We plan to do this throughout the School's five-year funding period.



Q. Who has the SSCR consulted?

A. We have approached many individuals and groups including:

- The SSCR Advisory Board
- The User, Carer, Practitioner Reference Group
- Commissioners and providers of services
- People who use services, carers, front-line professionals and other key individuals
- Researchers
- Social Care Institute for Excellence
- Making Research Count
- Research in Practice for Adults
- Joint University Council Social Work Education Committee
- Association of Directors of Adult Social Services

Q. How does the School approach these groups?

A. We have put out calls for ideas through:

- Caring Times
- Community Care
- Occupational Therapy News
- INVOLVE
- Journal for Care Services Management
- Eurohealth
- Shaping Our Lives

We seek to consult (and often to make presentations) at events such as the NIHR Regional Research Conferences; and we have held our own targeted meetings. We also have an online facility on our website for making suggestions; and a tear-off slip on our brochures.

Q. What is the best way to submit an idea?

A. Please use our online research suggestions form at www.lse.ac.uk/collections/NIHRSSCR/researchsuggestion.htm, email us at sscr@lse.ac.uk or call us on 020-7955 6528.



“At SCIE we were delighted with the announcement that a new School for Social Care Research was to be established. This signals a real commitment to developing the evidence base for social care. We have been particularly pleased with the willingness of the new School to engage with people who use research and believe this will lead to more timely and relevant research which can be used to inform both policy and practice improvement.”

Julie Jones, Social Care Institute for Excellence



THE YEAR AHEAD

New government, new expectations, new fiscal climate, but enduring challenges for social care: how to design care and support to meet needs and improve lives. SSCR is working to help meet this challenge by commissioning relevant, robust, informative studies.

Unanswered questions

Our wide-ranging consultation – begun before the School formally started – identified many research needs. Prevention, for example, is a major policy and practice emphasis, but there is only limited evidence on what works. We know little about the longer-term consequences of some of the interesting preventive arrangements now in place. How effectively does social care (broadly defined) assist in areas such as welfare rights, debt management, financial literacy and housing?

Many research questions are raised by the current emphasis on personalisation. How can ‘resource allocation’ mechanisms create the right incentives to improve resource use and impact? How can support planning and brokerage be organised to be fully effective, cost-effective and equitable? Social care markets are changing in response to personal budgets: how have commissioning arrangements altered? What about the empowerment of care home residents, a group often not included in discussions around personalisation?

There is much to be learned about unpaid carers and the role of social care in promoting work and other opportunities. What forms of social care practice work best in assessing and meeting carers’ needs? What support arrangements improve carers’ well-being?

Not much is known about social care ‘pathways’. How do individuals experience the move from an initial social care contact through different services and supports? What outcomes are achieved, and at what cost? Are there different experiences between, for example, people who are voluntary and involuntary users of care? It is the wish of most people to die at home: how can social care practice support such a choice?

What about people not eligible for local authority support? What social care needs do they have and how are these met? What happens when referral to a local authority does not lead to brokered support? How will social care be managed in a ‘colder’ economic climate? What are the implications for social care practice, for service providers and for users and carers? How will commissioner-provider relationships develop as budgets tighten?

Many people we consulted pointed to the lack of evidence on housing and care. What, for example, are the housing support needs of individuals with ‘low-level’ social care needs? What is the future of extra-care housing? Assistive technology is developing

rapidly, but public sector and other potential purchasers need better evidence to guide their decisions.

Methods and calls

We are committed to using the best methods to address these and other questions. We want to expand the methodological repertoire in social care research, and we will continue to commission methods reviews (see page 24). We will participate in a workshop in autumn 2010 to take stock of social care research, including looking at methods.

New calls for proposals will be designed to attract high-quality, robust, well-executed studies with considerable relevance to adult social care practice. Our User, Carer, Practitioner Reference Group (UCPRG) set us some challenges (see Box).

Good research can never be undertaken in isolation. Researchers must work closely with front-line practitioners, managers, policy-makers, people who use services, carers and volunteers. Therefore, as well as the School's UCPRG, all our projects have meaningful user, carer and practitioner involvement, for instance through (early) consultation and ongoing advisory processes.

Perceptions

Language, attitudes and behaviour are closely intertwined. People who use services can be viewed as dependent and generally portrayed negatively. Social care can be seen predominantly as care for older people. Social care workers are regularly pilloried in some sections of the media as uninformed, working in an 'evidence-free zone'. Social care is sometimes portrayed as a burden on the taxpayer. We can help change these perceptions by providing better evidence on the effects on individuals' lives, as well as on the wide-ranging contributions that social care makes to the activities and effectiveness of other systems such as the NHS.

We are putting considerable efforts into communications. This will include road-testing our findings to ensure they are usable, making the most of the professional press and other media, and working closely with knowledge transfer agencies such as SCIE, Making Research Count, and Research into Practice for Adults.

Raising profiles

As the work of SSCR builds up, so we aim to raise the profile of research within social care provider and commissioner communities, as well as the profile of social care within various research communities. We want managers and frontline practitioners to view research as potentially helpful to them, and we want practitioners, users and carers to tell us what topics need researching. To achieve these aims, the School's research must be high-quality, timely and communicated clearly. Our clichéd bottom line is that we need research to improve services to improve lives.

CHALLENGES SET BY THE UCPRG INCLUDE:

- ensure that research in social care covers all groups of people needing social care support, rather than concentrating on older people;
- avoid seeing carers as a single group but as a diverse group of individuals with different needs;
- encourage a range of research to reflect practice in the statutory, third and private sectors; and
- ensure that research addresses the changing nature of social care and the roles of individuals and organisations working in it.

MEET

USER, CARER, PRACTITIONER REFERENCE GROUP MEMBER

Angie Carmichael

My experience of social care is as a disabled person, family carer and as someone who has over 20 years experience as an independent consultant and researcher, working with disabled people and their organisations, to promote advocacy, rights, inclusive communities and self-directed support.

I sit on several equality and diversity executive bodies in the southwest and have written a number of published papers and research reports, and in 2001 coordinated a Joseph Rowntree Foundation funded user-led Best Value Review of Direct Payments and Support Services, in Wiltshire, having a particular interest in the co-production of user led research projects.

Previous to this, my background was in the media, making disability and current affairs programmes, for C4 and the BBC. These include the ground breaking 'Same Difference' magazine series broadcast on C4 in the 1980s and 90s, and documentaries in the People First strand covering issues of the abuse of people with learning disability in the care system, the disability movements campaign for anti-discrimination legislation the right to independent living and other key themes of importance to disabled people and those working with them.

I am currently working with Wiltshire Council as the independent Chair of the Adult Social Care Transformation Board and take a lead role working corporately with colleagues to implement the vision laid out in *Putting People First*.

For the past three years I have been a lay reviewer and referee for the Department of Health Social Care Workforce Research Initiative and I am very pleased to have been invited to join SSCR's UCPRG.

Professor Jill Manthorpe, SSCR Associate Director, on the User, Carer, Practitioner Reference Group

"We took the decision to include practitioners as well as users and carers in this group, not because they are identical but because the key audience for our work is practitioners and their managers. Much research claims to be potentially useful to practitioners and then wonders why they never get to see it or find its recommendations are unworkable. We have made a conscious decision to involve practitioners at all stages of the School's commissioning, decision-making, reviewing and debate, similar to the major contributions from users and carers. This innovation is designed to ensure that research projects think about practice from the very start of their study. We are hoping that individual projects will also build in early engagement from practitioners in the same way as they will involve users and carers. We are hugely grateful to all the members of the UCPRG who work for the benefit of the School."

REFLECTIONS

Social care has made great strides in recent years. There has been a positive shift in the way services are organised; in particular, people now have greater control over their care and support – indeed over their lives. There is a better understanding of needs, and a greater awareness of the social care resources that can meet them. There have been considerable efforts to develop services from all sides: national and local policy makers, senior and middle managers, provider agencies, social workers, other front-line staff, and carers. The research community has also played its part by generating new evidence.

We still face some challenges: people are living longer; people are living longer with long-term conditions; their aspirations and expectations are rising; yet resources (both public and personal) are becoming much tighter. Research evidence can provide policy-makers with a means of keeping one step ahead. Researchers need to be responding to these and future challenges. They should aim to provide robust high-quality evidence on the best, most cost-effective practices in social care, not just those already in place but those that could be introduced. Working alongside others in the field the School for Social Care Research has an opportunity to identify challenges facing social care practice and gaps in the evidence base, to conduct high-quality, robust evaluations examining the key questions, and to help in finding solutions for current and future challenges.

I congratulate SSCR for a productive first year, with many activities already underway for its second year. There are good projects beginning, with more innovative projects to be commissioned; some excellent methods and scoping reviews underway; good partnerships being formed and developed; a well-received annual conference; and welcome engagement with people who use services, carers, practitioners and others involved in social care.

The School started its first year in May 2009 with eight core members and an Advisory Board of 17 people, and finished in April 2010 with an additional 44 Fellows and Senior Fellows and 9 members in the User, Carer, Practitioner Reference Group.

I look forward to what next year brings both for SSCR and social care practice more generally.

David Behan
Chair, SSCR Advisory Board
Director General for Social Care, Local Government and Care Partnerships, Department of Health



*David Behan,
Chair, SSCR Advisory Board*

KEY STATISTICS

In 2008-09, local authorities in England helped 1.78 million people make use of social care services, including:

- 141,000 people with learning disabilities
- 335,000 people with mental health needs
- 81,300 people with sensory impairment
- 1.22 million older people
- 995,000 people with physical disability
- 335,000 carers

MEET

MEMBERS OF OUR USER, CARER, PRACTITIONER REFERENCE GROUP



Margaret Dangoor

My own experience of social care from the viewpoint of a carer (and a user/carer member of a number of working groups) is that much time is spent by statutory bodies designing and consulting on strategies for social care delivery and support and setting in place policies and procedures but the delivery of information and support and care so often fails or is not up to an acceptable standard. The resources for effective delivery are just not in place. There is a proportion of good practice but much room for improvement.

Although researchers may focus on a particular model of care delivery or seek the answers to questions within a narrow area of research, research projects need to be designed to encompass holistically the impact of any research findings on the wider social care environment. It is essential that professionals, users and carers participate actively and constructively in ensuring the validity and credibility of research findings, findings which may lead to a significant change in practice or service delivery.

From an NHS career background, I have been involved with the voluntary and community sector and user involvement opportunities for over 25 years. I feel privileged to be able to contribute to the work of the SSCR as a member of the UCPRG and believe that responsible, objective and informed involvement can make a real difference, particularly if group members are able to engage together, discuss issues and share their experiences.

“The great thing about the SSCR is that it is making research part of the culture for practitioners such as me. This will help define the real issues for things that we know are likely to happen, such as the need for services to reflect the needs of people living longer with complex conditions.”

Dave Nwokedi, Senior Practitioner

Dave Nwokedi

I have a wide range of experience in the field of social care services both in the voluntary sector and within statutory services. I started work in social care as a care assistant in learning disability day services on the south coast and also managed a hostel for homeless teenagers in south London. I took up social work training in 1992 and qualified in 1995. Since qualifying I have worked in a variety of statutory and voluntary settings with adults with learning disabilities and mental health needs and with Looked After disabled children.

My current position, as one of the first Consultant Lead Practitioners in adult services in London, has consolidated all of my past experience and has given me exciting opportunities to lead on good practice in the field of learning disabilities. I am committed to improving the lives of those I work for and challenging discrimination in all its forms and, in its broadest sense, to ensuring better services for vulnerable adults and children in the future.

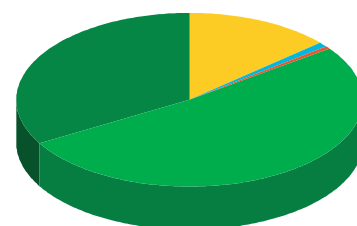
AT A GLANCE: WHAT WE WILL BE DOING IN 2010/11

- Our latest Call for Proposals was launched in June 2010, with another Call likely to follow later in the year. We hope to fund a number of research projects to start in January 2011.
- We will continue to conduct high-quality research.
- We will report on the responses thus far to our consultation for research ideas.
- We will publish reports from the methods and scoping reviews commissioned in our first year, and look at commissioning further reviews in areas where there is a research need.
- We will communicate interim findings from our early commissioned studies.
- We will continue to support and promote social care research in England.
- We hope to welcome a number of new Fellows.

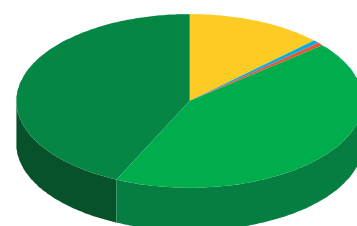
In addition:

- We are supporting the European Conference for Social Work and Social Care Research to be held 24–25 March 2011 in Oxford.
- We are looking for opportunities to disseminate and discuss our research findings and methods reviews in regional events in collaboration with Making Research Count. The first seminar is due to take place in London on 1 October 2010.
- And of course, we will continue to promote SSCR and its work in other ways, communicating and discussing new research findings as they emerge, and building on the partnerships we have developed.

SSCR Expenditure Overview 2010/2011



SSCR Expenditure Overview 2009 to 2014



MEET

MEMBERS OF OUR USER, CARER, PRACTITIONER REFERENCE GROUP



Rashid Ebrahimkhan

I have worked in health and social care in the public and private sectors for 35 years in educational and managerial capacities. For the last 18 years, I have been managing a private care home with nursing, and I am also a director of the company.

I have a degree in economics, diplomas in public & social administration and education. I am also a Registered Nurse (General and Psychiatry).

I became involved in SSCR as a result of participation in surveys and research conducted by King's College London on aspects of social care, and I was asked if I would like to be involved as a provider with experience of health and social care. I am particularly interested in the economics, organisation, policy making, personnel and staffing issues in health and social care.

I am also interested in action research as a professional manager in funding of health and social care in a changing demography. I believe that the current system of funding in England is unfair and there are disparities in funding within the UK.

The current tripartite funding system is cumbersome, bureaucratic and unfair. People with assets have to be self-funding or fully-funded, whilst retired people with similar backgrounds and previous occupational statuses who do not have any assets get full funding with a minimal contribution based on their pensions.

There are discrepancies in allocation of continuing care and the 96-page assessment process is cumbersome, lengthy and can be simplified, standardised and made fairer.

I would like in future to be at the forefront of the initiation and direction of research projects.

Heidi Wong

As a state registered Occupational Therapist I have worked across different health and social care settings with people of varying disabilities, to help them lead an independent life. Research with emphasis on service user engagement is important to validate and advance our practice. This crucial research evidence will help ensure the adult social care workforce are taught the right skills to support the 'Personalisation' agenda.

CURRENT PROJECTS

Care and support for people with complex and severe needs: innovations and practice – a scoping study

- To identify the key features of the service and support arrangements desired by different groups of adults and older people with severe and complex needs
- To provide evidence of initiatives to deliver support to people with complex and severe needs that have the desired features and the potential to constitute examples of 'good practice'. Examples may focus on some or all of the different levels of commissioning, operational organisation and front-line delivery.

Professor Caroline Glendinning,
University of York,
20 months, £249,869

Costs and outcomes of skilled support for adults with complex needs in supported accommodation

- To evaluate the impact of skilled staff support on the lives of people with complex needs. The focus is on people with severe and profound learning disabilities who have serious challenging behaviour and/or additional multiple disabilities, and/or autism.
- To describe the nature of the support required and its implications.

Professor Jim Mansell,
University of Kent,
18 months, £278,680

Connecting People: An exploratory study of how health and social care workers help people to develop and maintain relationships

- To examine how social care practitioners are helping people with mental health problems to access more social capital through discussions with and observations of social care workers in a range of NHS mental health services and voluntary sector services.
- To investigate how social care practitioners help people to develop new social relationships and to feel secure in these.
- To investigate how practitioners help people with mental health problems make use of the power, prestige, wealth or abilities of individuals they know to help them move on in their lives.

Dr Martin Webber,
King's College London,
24 months, £242,615

Estimating future demand for social care for younger disabled adults

- To predict future need for services for younger disabled people based on research carried out in ten local authorities. Information will be collected on a random sample of 500 children aged 14–16 who have special educational needs on: what planning has been undertaken for their transition to adult services; how likely they are to need adult social care services when they become adults; and the specific types of support they will need.

Professor Eric Emerson,
Lancaster University,
12 months, £99,350

Social care practice with carers: an investigation of practice models

- To consider practice activities and models, and their effectiveness as measured by the staff, commissioners and carers themselves using a concurrent mixed-methods design

Professor Jill Manthorpe,
King's College London,
12 months, £112,253

Professor Robert Jones,
University of Nottingham,
30 months, £244,298

Improving effective integrated home support for people with dementia and their carers – development of a service fidelity index

- To review the evidence on what works well, and is economic, in providing successful integrated support at home by service support teams for people with dementia and their carers
- To develop a 'template' of the key service components needed to provide such successful support for this user group
- To devise a measuring tool (fidelity index) to check how well service delivery matches up against the template and evaluate the tool through extensive field testing
- To disseminate the evidence base and measuring tool to support social care departments in the commissioning and auditing of dementia services.

Professor Ann Netten,
University of Kent,
18 months, £169,951

Personalisation of services — a scoping study

- To identify approaches and interventions that merit evaluation, providing a platform for formulating research questions and designing studies that will help to build the evidence base for what works in 'personalised' care. This will help councils and providers in commissioning, developing and refining effective and cost-effective care and support arrangements.

Joan Langan,
University of Bristol,
27 months, £249,953

Liberty, equality, capacity: the impact of the Deprivation of Liberty Safeguards on human rights and social care practice

- To generate knowledge concerning how the well-being of disempowered individuals can be safeguarded by adult social care practitioners and their autonomy promoted, in circumstances that may deprive them of their liberty.

Professor Eric Emerson,
Lancaster University,
5 months, £7,500

Prevention in the learning disability context – a scoping review

- To explore the issue of prevention in the learning disability context in relation to adult social care
- To ask what prevention would actually mean in a learning disability context (and in the context of adult social care services) and the impact of this on adult social care practice.

Dr Rachel Fyson,
University of Nottingham,
20 months, £156,991

Safeguarding and best practice in services for adults with learning disabilities

- To explore whether support staff share the same understandings of poor practice as people with learning disabilities using services
- To discover the extent to which support staff are able to acknowledge the impact of poor practice on service users
- To identify any barriers which exist in relation to frontline staff reporting poor practice and abuse to the appropriate authorities.

Professor John Carpenter,
Bristol University,
5 months, £7,500

Mental health in social care research – a scoping review

- To explore the issues in the mental health context in relation to adult social care.

SSCR METHODS REVIEWS

Chance-based designs

When there is little evidence about the relative effectiveness of two alternative approaches in social care, simple comparisons of the participants who happen to receive one approach with those who happen to receive the other are prone to bias arising from whatever social mechanism was responsible for these allocations. Chance-based designs (CBDs) address this problem by allocating participants between approaches at random, thus maximising internal validity, and are now the dominant research design in health care research. CBDs are much less widely used in social care research in the UK. This review explores the uses of CBDs and how social care research can utilise these.

Ian Russell, Bob Woods
*University of Swansea;
Bangor University*

Cost-effectiveness

There has always been a need to use resources efficiently. That need is especially stark today. Economists and others have developed various approaches to measure the relative efficiency of different practice arrangements, interventions or policies. A generic name for them is cost-effectiveness analysis. The review describes how this type of analysis is conducted: how it conceptualises and measures costs and effects (outcomes), and then combines evidence on them to measure comparative efficiency, while also taking into consideration the distributional (or equity) implications. The relevance of cost-effectiveness methods for social care is discussed. There are many unexploited opportunities to use cost-effectiveness evidence to support social care decision-making, but also pitfalls for the unwary.

Martin Knapp
*London School of
Economics and Political
Science*

End-of-life care research methods

The majority of end-of-life care research is based in health care settings and/or is led by health professionals or health based researchers. This review is informed by that work. It is a guide for researchers undertaking projects on end of life care when it is provided in residential and long term care settings, people's homes and community settings. These are locations where, alongside health care services, social care is involved in providing support to people who are dying. The aim of the review is to provide an overview of the range of research methods that have been commonly used in end of life care research, their relative advantages and disadvantages and a discussion of the particular ethical challenges and logistical issues that can arise when undertaking research in this area.

Claire Goodman, Katherine
Froggatt, Elspeth Mathie
*University of Hertfordshire;
Lancaster University;
University of Hertfordshire*

Large-scale datasets

This methods review aims to set out knowledge about current uses and applications of large data sets for research in social care. Using a targeted search strategy to identify recent published studies and current ongoing studies, focusing on social care and health research in the UK that used large data sets in their research design. The

Shereen Hussein
King's College London

Hazel Squires
University of Sheffield

review discusses examples of the use of different large data sets such as the Census, national surveys as well as social care related datasets. It focuses on the methods adopted to extract and use necessary data from different large data as well as a brief review of different quantitative and statistical methods adopted. The review discusses the challenges associated with using large data records; and illustrates various approaches adopted by researchers to extract, validate, refine and interpret results based on such data.

Modelling methods

This review aims to summarise key mathematical modelling methods, with a focus upon those methods currently applied within healthcare modelling, and to suggest previous and potential applications of these methods within the field of social care. This will include a summary of the model development process, including the use of problem structuring methods, literature reviewing, elicitation and uncertainty analysis. Specific modelling methods such as decision trees, Markov models and discrete event simulation will be described, with an outline of their strengths and limitations. Current approaches for quantifying outcomes within health economic evaluation will also be briefly discussed. The review will also aim to highlight any issues which may need to be considered when applying these modelling methods to social care.

Jim Mansell
University of Kent

Observational methods

This review focuses on observational research, primarily in services for people with learning disabilities. Observational research is particularly useful where people using services are unable to answer interviews or questionnaires about their experience, and where proxy respondents may not be sufficiently accurate sources of data. The review deals with the question of what to observe and how to define it so that the information gathered is valid and reliable. It deals with sampling (how often to observe and for how long) in order to obtain representative information. It considers the practical steps that have to be taken in order to make observations in services. Using examples from the research literature, it shows how to analyse and present observational data. Finally the review illustrates the use of observational data in assessing and improving the quality of services.

Ann Netten
University of Kent

Outcome measurement overview

In social care, as in other fields, there is increasing emphasis on 'outcomes', but what is meant by outcome inevitably varies depending on the context and scope of what is under consideration. The review considers the different 'types' of outcome and how these are related to one another; proposes outcome measures for social care; discusses challenges to measuring outcomes in practice; the implications of research designs for what is measured and potential drawbacks of different approaches; and considers the implications for measuring outcomes in social care in terms of practical issues to consider when designing a research study and gaps in knowledge.

Procedures and practices in research governance and ethics for adult social care research

This methods review describes the development of research governance arrangements in social care settings over the past decade and examines some of the consequences – both problems and opportunities – this creates for people who are interested in research within adult social care settings. This paper briefly defines ethics and governance and their application to social care research; looks at the context and history of research governance in social care; considers what is known about the current extent of research governance arrangements, and differences in approach; discusses key issues in respect of research governance; and considers the opportunities that research governance arrangements offer.

John Woolham
Coventry University

Qualitative methods overview

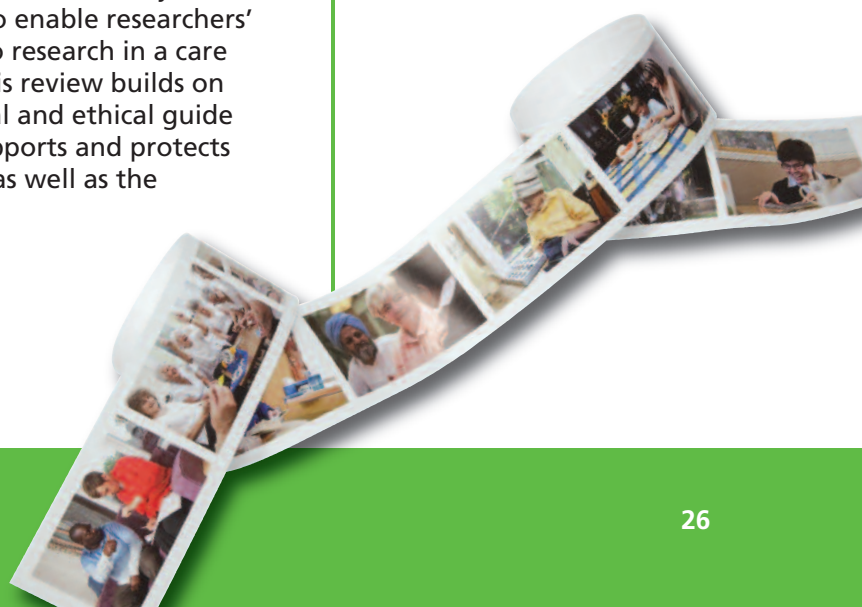
The social care evidence base reveals a distinct preference for qualitative methods and studies covering a broad range of social care topics can be identified. This review provides an introduction to the different ways in which qualitative research has been used in social care and some of the reasons why it has been successful in identifying under-researched areas, in documenting the experiences of people using services, carers, and practitioners, and in evaluating new types of service or intervention. Examples of completed research on a selection of topics are chosen to give an understanding of some of the differing underpinning approaches to qualitative research, including grounded theory, case studies, and ethnography. These are used to illustrate the advantages and disadvantages of the data collection methods used most frequently in qualitative research, including in-depth interviews, focus groups, and observation as well as issues such as sampling and data analysis. The review ends with a discussion on how qualitative social care research might be improved in terms of its quality and in terms of extending the repertoire of research methodologies on which it draws.

Jo Moriarty
King's College London

Research in care homes

This review is an evidence-based guide for researchers new to the field, focusing on three broad social research methodologies: Qualitative, (e.g. interviews and observations); quantitative (e.g. structured instruments and controlled trials); participative (e.g. action research). The review draws on illustrative examples from a range of larger and smaller scale studies and broadly follows the structure of the research process. It aims to enable researchers' understanding of the specific issues relating to research in a care home setting, at each stage of the process. This review builds on previous learning and provides both a practical and ethical guide to undertaking care homes research which supports and protects care homes, their staff, residents and visitors, as well as the research staff.

Rebekah Luff, Zara Ferreira
and Julienne Meyer
*University of Surrey;
City University;
City University*



Alys Young, Ros Hunt
University of Manchester

Research methods and d/Deaf people

This review specifically concerns research that is carried out with d/Deaf people. It addresses key background knowledge concerning the diversity of what it is to be deaf including the essentially contested nature of the term 'deaf' and its implications; how the special or additional considerations surrounding what it is to be deaf influence research design (including what happens when these are ignored); specific issues of innovative or adaptive research practice in research with d/Deaf people or in deaf contexts; ethical considerations in carrying out research with deaf people; criteria by which the validity of research concerning deaf people might be considered.

Nigel Charles
Plymouth University

Research methods and visual impairment

This methods review explores issues relevant to social care and visual impairment (VI) identifying the socio-demographic characteristics of the VI population; social care and related needs; services; measuring the impact of services; sampling VI people and service providers; practical steps in carrying out fieldwork with VI people; and organisations who can provide advice and guidance on carrying out VI research. Selected examples of academic and grey literature will be used to identify and discuss the problems, challenges and solutions to carrying out social care research in the visual impairment field. This will cover examples of good methodological practice, as well as the practical steps required when carrying out research with and about a population that is largely older and who might have other disabilities as well as visual ones.

Tom Vickers, Gary Craig and
Karl Atkin
Durham University;
Durham University;
University of York

Research with BME populations in social care

This review is an exploratory survey of the literature, addressing recent developments in research theory and practice with Black and Minority Ethnic (BME) populations in adult social care in England. The review identifies key issues in the field; current leading contributors to knowledge and practice; and useful resources. Whilst focusing primarily on the literature from social care in England, insights are also included from the broader health, social work and social policy literatures, and from several key studies outside England, where these offer relevant insights not evident in the English literature. The review also aims to provide an up-to-date bibliography for experienced researchers; to act as an accessible introduction for students and researchers in the early stages of their careers; and a starting point for further study.

Elizabeth Price
University of Hull

Sexualities in social care research

This review charts the development of sexualities research and provides an overview of associated methodological approaches and perspectives; particularly those that have a specific social care focus. The review includes a critical appraisal of the strengths and limitations of the various approaches, and addresses a range of methodological challenges associated with work of this nature

including the ethical context of research with vulnerable populations, the concept of 'insider status' and some of the problems associated with the use of uncritical definitions and measurements of sexual minorities and how these may be addressed in research that aims to be inclusive without running the risk of tokenism. The aim of the review is to enable researchers, particularly those working in the field of adult social care, to recognize and acknowledge the diversity of human experience in their own work.

Systematic reviews

This paper aims to set out an overview of systematic review methodology (setting questions, searching, assessing the quality of evidence and synthesis of findings), summarising limitations, strengths, and challenges to the authority of systematic reviews from within the health and social care research community. It highlights the uses of systematic reviews in social science and social care, and identifies ways in which reviews might be made more receptive to the needs of researchers, policymakers and other stakeholders. The paper introduces debates around the weighting of evidence, and the inclusion of qualitative studies. Topic selection, involvement of different stakeholders in review processes, and the proportionate use of this method are also discussed.

User-led research

This review explores terminology in this field, paying particular attention to the use of terms 'user-led', 'user-controlled', 'survivor' and 'emancipatory disability' research, examining their inter-relations and usage. It contextualises 'user-led' research, and looks at key characteristics associated with 'user-led' research and critiques that have developed around them. The review focuses on the implications for research methods of 'user-led' research; and the development of qualitative, quantitative and mixed method research in 'user-led' research in adult social care research. The review explores the impact of 'user-led' and involvement research; considers the implications of 'user-led' research for the conduct and boundaries of social care research; and makes recommendations for the future use and practice of 'user-led' research in social care.

Deborah Rutter
*Social Care Institute for
Excellence*

Peter Beresford, Suzy Croft
*Brunel University;
St John's Hospice, London*



Our Executive Group



MORE ABOUT US

[Professor Martin Knapp, Director; chair of Executive Group](#)

Professor of Social Policy at the London School of Economics and Political Science and Director of the Personal Social Services Research Unit (PSSRU)

Also Professor of Health Economics at King's College London, Institute of Psychiatry, and Director of the Centre for the Economics of Mental Health

Martin's research activities are primarily in the mental health, long-term care and social care fields. Particular areas of interest currently include prevention and promotion, dementia, autism, telecare and cost-effectiveness.

[Professor David Challis, Associate Director](#)

Professor of Community Care Research, and Director of the PSSRU at the University of Manchester

David's research includes studies of care coordination and assessment processes in older people's services, performance measurement in social care and old age mental health services.

[Professor Caroline Glendinning, Associate Director](#)

Research Director (Adults, Older People and Carers) in the Social Policy Research Unit, University of York

Over the years Caroline's research has focused on user experiences of social care, informal (family) care, partnerships between social care and health services, the governance of social care and comparative studies of social and long-term care in other countries.

[Professor Jill Manthorpe, Associate Director](#)

Professor of Social Work at King's College London, and Director of the Social Care Workforce Research Unit

Jill was a member of the IBSEN team, evaluating the pilot individual budgets pilots in England. Her research interests centre on workforce issues, older people and social care services, risk, adult safeguarding and mental health in later life.

[Professor Jim Mansell, Associate Director](#)

Professor of Learning Disability, and Director of the Tizard Centre, University of Kent

Jim's research includes studies of deinstitutionalisation and community living in the UK and internationally; the relationship between characteristics of residential services, quality of care and the quality of life of residents; and services for people with challenging behaviour.

Professor Ann Netten, Associate Director

Professor of Social Welfare, and Director of the PSSRU, University of Kent

Ann's research interests include developing theoretically based but pragmatic approaches to the measurement of costs, quality, outputs and outcome in social care, housing and care of older people and economic evaluation of social welfare interventions, including criminal justice.

Dr Gill Hastings, Senior Scientific Administrator

Gill is an experienced senior manager, with a background in health care and medical research science. She has previously developed and managed national patient safety, healthcare improvement and personal fellowship programmes.

Ms Anji Mehta, Finances and Communications Administrator

Dr Carol Lupton

RDD Social Care Lead, Department of Health

Clare Croft-White

SSCR Project Manager, Department of Health

Professor Karl Atkin, SSCR Fellow University of York

Co-author of methods review research with BME populations in social care

Professor Anthony Avery, SSCR Fellow University of Nottingham

Co-investigator on SSCR-funded project

Professor Peter Bartlett, SSCR Fellow University of Nottingham

Co-investigator on SSCR-funded project

Professor Jennifer Beecham, SSCR Fellow University of Kent

Co-investigator on SSCR-funded project

Dr Julie Beadle-Brown, SSCR Fellow University of Kent

Researcher on SSCR-funded project

Professor Peter Beresford, SSCR Fellow Brunel University

Co-author of methods review on user-led research in adult social care

Jenni Brooks, SSCR Fellow University of York

Researcher on SSCR-funded project

Lisa Callaghan, SSCR Fellow University of Kent

Researcher on SSCR-funded project



Department of Health/NIHR
liaison with SSCR

SSCR Senior Fellows and
Fellows

[Professor John Carpenter, SSCR Senior Fellow](#) Bristol University
Author of scoping review on mental health in social care;
co-investigator on SSCR-funded project

[Nigel Charles, SSCR Fellow](#) Plymouth University
Author of methods review on research with people with visual impairments

[Dr Michelle Cornes, SSCR Fellow](#) King's College London
Researcher on SSCR-funded project

[Professor Gary Craig, SSCR Fellow](#) Durham University
Co-author of methods review research with BME populations in social care

[Professor Eric Emerson, SSCR Fellow](#) Lancaster University
Author of scoping review on prevention in learning disability.
Principal Investigator on SSCR-funded project

[Zara Ferreira, SSCR Fellow](#) City University
Co-author of methods review on research in care homes

[Diane Fox, SSCR Fellow](#) University of Kent
Researcher on SSCR-funded project

[Dr Rachel Fyson, SSCR Fellow](#) University of Nottingham
Principal Investigator on SSCR-funded project

[Professor John Gladman, SSCR Fellow](#) University of Nottingham
Co-investigator on SSCR-funded project

[Professor Claire Goodman, SSCR Fellow](#) University of Hertfordshire
Author of methods review on end of life care

[Professor Chris Hatton, SSCR Fellow](#) Lancaster University
Co-investigator on SSCR-funded project

[Dr Shereen Hussein, SSCR Fellow](#) King's College London
Author of methods review on large-scale datasets

[Kate Gridley, SSCR Fellow](#) University of York
Researcher on SSCR-funded project

[Professor Robert Jones, SSCR Fellow](#) University of Nottingham
Principal Investigator on SSCR-funded project

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OUR PUBLICATIONS

Knapp M, Manthorpe J, Mehta A, Challis D, Glendinning C, Hastings G, Mansell J, Netten A (2010) Developing the evidence base for adult social care practice: The NIHR School for Social Care Research, *Journal of Care Services Management*, 4, 2, 167–179.

Knapp M, Mehta A (2010) Social Care: a new initiative in England to fill evidence gaps, *Eurohealth*, 15, 4, 12–14.
[<http://www2.lse.ac.uk/LSEHealthAndSocialCare/LSEHealth/pdf/eurohealth/VOL15No4/Knapp%20Vol15No4.pdf>].

Knapp M, Mehta A (2010) Research to support the improvement of adult social care practice in England: the NIHR School for Social Care Research, Research and Policy Update, *Research in Practice for Adults*, May 2010.

Manthorpe J (2009) Cool School for Care Research, *Professional Social Work*, September, pp.25.

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[http://www.lse.ac.uk/collections/NIHRSSCR/communications/NIHR_SSCR_Communications_strategy_6.pdf].

NIHR School for Social Care Research (2009) *Leaflet: School for Social Care Research*, London.

NIHR School for Social Care Research (2009) *Brochure: School for Social Care Research*, London.



OUR PRESENTATIONS

Martin Knapp, The NIHR School for Social Care Research, Natural History Museum, January 2009

David Challis, More R&D in primary and community care, jointly with the School for Primary Care Research, NIHR Regional Research Conference, East Midlands, 4 March 2009



Martin Knapp, The NIHR School for Social Care Research, ADASS Research Sub-Group, June 2009

Caroline Glendinning, More R&D in primary and community care, jointly with the School for Primary Care Research, NIHR Regional Research Conference, North East, 2 June 2009

Jill Manthorpe, More R&D in primary and community care, jointly with the School for Primary Care Research, NIHR Regional Research Conference, South West, 17 June 2009

David Challis, More R&D in primary and community care, jointly with the School for Primary Care Research, NIHR Regional Research Conference, West Midlands, 10 July 2009

David Challis, More R&D in primary and community care, jointly with the School for Primary Care Research, NIHR Regional Research Conference, North West, 16 October 2009

Caroline Glendinning, More R&D in primary and community care, jointly with the School for Primary Care Research, NIHR Regional Research Conference, Yorkshire and the Humber, 19 October 2009

Martin Knapp, More R&D in primary and community care, jointly with the School for Primary Care Research, NIHR Regional Research Conference, East of England, 6 November 2009

Ann Netten, More R&D in primary and community care, jointly with the School for Primary Care Research, NIHR Regional Research Conference, South East Coast, 23 November 2009

Jim Mansell, More R&D in primary and community care, jointly with the School for Primary Care Research, NIHR Regional Research Conference, South Central, 27 November 2009

Gill Hastings, The NIHR School for Social Care Research, Midlands Research Governance workshop, 28 January 2010

Martin Knapp, More R&D in primary and community care, jointly with the School for Primary Care Research, NIHR Regional Research Conference, London, 2 March 2010

Caroline Glendinning, Introducing SSCR, Social Services Research Group conference, University of Manchester, 9 March 2010

Caroline Glendinning, Services and support for adults and older people with complex and severe needs: a scoping study, Social Services Research Group conference, University of Manchester, 9 March 2010

Ann Netten and Lisa Callaghan, Personalisation: key issues and need for evidence, Workshop at the Social Services Research Group conference, University of Manchester, 9 March 2010

Peter Beresford, User-led research in adult social care, SSCR Annual Conference 2010, London School of Economics, 30 March 2010

Lisa Callaghan, Personalisation: what do we need to research?, SSCR Annual Conference 2010, London School of Economics, 30 March 2010

John Carpenter, Mental health: developing a new research agenda, SSCR Annual Conference 2010, London School of Economics, 30 March 2010

David Challis, State of the art of social care research, SSCR Annual Conference 2010, London School of Economics, 30 March 2010

Caroline Glendinning, Choice and change; conducting qualitative longitudinal research in adult social care, SSCR Annual Conference 2010, London School of Economics, 30 March 2010

Martin Green, Health and social care: building on a firm foundation, SSCR Annual Conference 2010, London School of Economics, 30 March 2010

Claire Goodman, End of life care research methods, SSCR Annual Conference 2010, London School of Economics, 30 March 2010

Martin Knapp, The NIHR School for Social Care Research: looking forward, SSCR Annual Conference 2010, London School of Economics, 30 March 2010

Jim Mansell, Skilled support for adults with complex needs in supported accommodation, SSCR Annual Conference 2010, London School of Economics, 30 March 2010

Jill Manthorpe, Carers: centre stage or in the wings?, SSCR Annual Conference 2010, London School of Economics, 30 March 2010

Denise Platt, Reflections: social care research, SSCR Annual Conference 2010, London School of Economics, 30 March 2010

Deborah Rutter, Ethical review in adult social care, SSCR Annual Conference 2010, London School of Economics, 30 March 2010

Martin Webber, Using ethnography to develop social care practice: supporting people recovering from psychosis to access social capital, SSCR Annual Conference 2010, London School of Economics, 30 March 2010

John Woolham, Challenges for governance and ethics in adult social care research, SSCR Annual Conference 2010, London School of Economics, 30 March 2010





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Research empowers people using services, their carers and the staff who support them to get the best out of the resources they have. It enables social care services to improve the current and future well-being of the people they support.

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