

NIHR School for Social Care Research

INITIAL CONSULTATION ON SSCR RESEARCH THEMES: ANALYSIS OF RESPONSES

Report commissioned from Ann Richardson
by the NIHR School for Social Care Research

June 2010



Improving the evidence base for
adult social care practice

The School for Social Care Research 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) <http://www.nihr.ac.uk/>.

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June 2010

NIHR School for Social Care Research (2010). *Initial Consultation on SSCR Research Themes: Analysis of Responses. Report commissioned from Ann Richardson by the NIHR School for Social Care Research*, London.

ISBN 978-0-85328-442-0

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INTRODUCTION

The School for Social Care Research (SSCR) was set up by the National Institute for Health Research (NIHR)¹ to develop the evidence base for adult social care practice in England by commissioning and conducting research. It was launched in May 2009, with a budget of £15 million over five years. Open to new ideas and suggestions, we actively sought to consult the practitioner communities, the wider public, users of social care services and carers about key social care practice issues SSCR should address through our research to inform our developing research agenda. This report sets out the responses from this exercise up to February 2010.

The principal means of consultation was on-line. We put out a general call for ideas on the SSCR website, with an invitation to anyone with an interest in social care to complete a short form suggesting topics for consideration. In all, 41 individuals and organisations submitted 121 topics through this process. In addition, we invited suggestions through a number of meetings, including the SSCR Advisory Board, the SSCR User, Carer, Practitioner Reference Group, a joint meeting between Making Research Count and directors and senior managers of adult social care services, and through emails directly to SSCR contacts, with a total of 32 ideas collected from these sources. We thank all those who have fed into our thinking by these means.

We must stress that the results from the process were dependent on the ability and willingness of particular individuals and groups to respond to the on-line consultation and, consequently, the results cannot be said to be 'representative' of the views of practitioners or the general public. Nonetheless, they do cover a wide range of people concerned with and about the future of social care. It should also be added that many of those proposing topics were undoubtedly unfamiliar with existing research in this area, so that some of the ideas proposed had been studied in some depth already. Some of the topics raised in the consultation were the concerns of an organisation or individual, without necessarily posing a researchable suggestion. All responses received in response to this initial on-line consultation are included in this analysis.

It is important to recognise that our consultation process will be ongoing, and we may revise this paper as new ideas emerge. We will also be looking to identify gaps not

¹ The National Institute for Health Research (www.nihr.ac.uk) provides a national framework for research on health and social care. As its website describes, its primary goal 'is to create a health research system in which the NHS supports outstanding individuals, working in world class facilities, conducting leading edge research focused on the needs of patients and the public. This will benefit patients, society, the NHS and all our stakeholders.'

covered by the consultation responses where evidence is urgently needed to support practice.

METHODS

Classification systems

In the course of our initial planning for establishing SSCR, we developed five research programmes, together with the core questions they address, and these have been set out on our website (<http://www.lse.ac.uk/collections/NHRSSCR/research/default.htm>). We knew that the boundaries would not be watertight, but that they would cover most areas of interest. These are:

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

Core question: 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

Core question: How can we best empower and safeguard people who use social care services?

3) Balancing care and work

Core questions: 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 social care and their carers are enabled and supported in paid work and other types of meaningful activity?

4) Developing solutions to changing needs

Core question: What interventions, commissioning and delivery arrangements best achieve social care outcomes?

5) Providing evidence to deliver integrated services

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

In addition to this classification by programme, we felt it would be useful to examine responses to the consultation according to two other dimensions. We were interested in the extent to which practice with different groups of social care service users was targeted by the suggestions. The most common classification of adult social care services divides these into i) older people, ii) people with mental health needs, iii) people with learning disabilities, iv) people with physical disabilities or sensory impairments and v) carers. It emerged that there were many submissions concerned with dementia care practice, and because the needs of this population are possibly different from those of other older people or of people with mental health needs, we decided to classify these separately.

In the process of examining and analysing the suggestions we note that our efforts to classify the submissions into the five research programmes listed above were hampered by the inevitable overlaps in classification systems of this kind. Some suggestions did not readily fit within any programme and are listed separately below.

FINDINGS

These suggestions were not elicited through any systematic methods and came from self-selecting individuals who responded to the invitation. They reflect a range of interests and perceived themes for SSCR to consider in future research commissioning.

Service user groups

The topics proposed via the online consultation were to some extent skewed by long lists of suggestions from organisations with a particular client or user group focus. Thus, while only a moderate number addressed the needs of older people (7 topics), an additional 16 concerned people with dementia (most of whom are older people). Other groups targeted included people with mental health needs (11), people with learning disabilities (8), people with physical disabilities or sensory impairments (5) and carers (5). An additional 11 topics concerned other groups, such as migrants, young people with disabilities in transition to adult services, and people with problems of substance abuse.

The research programmes

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

Many topics and suggestions addressed this first programme and there was no single theme. Some tackled *prevention* directly, with an interest in health promotion, the costs and benefits of preventive services, the value of preventive services from the viewpoint of users and practitioners, and a concern with 'low-level' preventive services, such as forms of telecare and other assistive technologies. One suggestion was for a general look at changing models of the family and caring, such as older spouses and family networks for gay and lesbian couples.

Several responses were concerned with *early intervention* for particular groups, for instance people with dementia, or via particular services, such as the impact of health care checks on the well-being of people with learning disabilities. One looked at the opposite end of the spectrum, with a concern for the *factors that influence service disengagement* among people with mental health needs. One suggestion was to look at the potential role of '*natural support systems*', such as postal workers or delivery drivers, who could keep a watching eye on 'vulnerable' people and report those in need to someone who could help.

Others were concerned with *predicting social care needs*, for instance in schools for young people with learning disabilities or identifying interventions or factors, such as resilience, that may contribute to prevention. A related group addressed *services which promote well-being or social inclusion*, such as involvement in the performing arts or life-long learning for people with mental health problems, in one case with an interest in staff training and development needs. One proposed an examination of means of supporting carers, particularly of very old people, including their cost-effectiveness. Another addressed how to ease the move of people with sensory impairments into independent living.

Some interest centred on *access to care*, in particular circumstances or for particular groups. For example, suggested topics included migrants' access to care, access to care at a time of crisis, access for people with learning disabilities, and the access to eye

health services for people from black and ethnic minority communities. Two contributions were concerned with the *nutrition* of older people.

Finally, one suggestion took a novel look at prevention, proposing that attention should be given to *how to increase child-bearing* as a long term approach to improving care for older people.

2) Promoting choice and independence

Many topics and suggestions fell under this programme, with considerable emphasis on the implications of the *personalisation agenda*. Some respondents proposed this as a general topic, in several cases with an emphasis on the nature and benefits of user involvement in their own care. But a number were concerned with more specific aspects, such as the support necessary to help service users to identify and access services for direct payments, the impact of personalisation on carers or the satisfaction of support workers in this process. One suggestion proposed attention to the contribution of occupational therapists and another suggested evaluation of the work of the London Adult Safeguarding Network in developing common policies and procedures. Finally, a literature review on the interface between empowerment and safeguarding was proposed, including international comparisons.

Some suggestions were addressed to the *needs of service users for emotional support* and general inclusion in the community. One focused on the development of friendships and sexual relationships for people with learning disabilities; another sought to address factors increasing isolation, such as bullying and hate crimes, for the same population. One focussed on the needs of people with sight loss for emotional support; another on the needs of people with dementia for psychosocial interventions, balancing independence and isolation; and another on the potential for increasing autonomy for people living in residential care.

A few other suggestions were concerned with *rights*. One suggestion concerned a rights-based approach in the NHS, another focused on criminal legislation pertaining to the neglect or abuse of vulnerable adults and argued that this should be addressed, and a third offered an examination of the nature of complaints services and barriers to their use. Other ideas were for an examination of *risk assessment systems for vulnerable adults* and one for study of the nature of *abuse in end of life care* and its relationship to costs.

3) Balancing care and work

The consultation did not elicit many suggestions under this third programme, covering care and work. Again, a few addressed the *personalisation agenda*, proposing research on the characteristics of personal assistants and the extent of turnover and changes in the care manager role. One was concerned with the ways in which staff conceptualised their role, given the need to empower service users. Another focused on decision-making by practitioners providing care, including the assessment of risk.

A few suggestions focused on the *match between the needs of service users and staff available*, in one case for care home residents and another with respect to referrals for occupational therapy. A few also raised *training issues*, for instance, using service users and carers to train practitioners or management attitudes to training workers for whom demand was low. One raised the issue of *professional leadership* in social care. Several

raised questions of the nature of the social care workforce, including management and training needs. One was concerned with how to mobilise volunteers, another was concerned with *helping people with learning disabilities to find employment*.

A number of responses concerned the *needs of carers*, including family members not living nearby and carers' relationships with practitioners.

4) Developing solutions to changing needs

Fewer responses were received for in the area of new approaches to meeting needs, but a number of ideas were offered. Studies of the *effectiveness of a variety of home-based services* were proposed, including the provision of meals, information prescriptions, occupational therapy services, vision rehabilitation services and telecare. It was also proposed that the standards of private services should be examined. Another suggestion was for a comparison between *assessments* made by staff and self-assessments.

Other suggested studies included the *impact of closed circuit monitoring* on inpatients in psychiatric wards and service development needs for *end-of-life care*. The cost-effectiveness of different forms of *intermediate care* was also proposed as a topic, as was the *effectiveness of family group conferencing* for young people with mental health needs.

A large number of suggestions focused specifically on *housing and social care*, particularly on the provision and effectiveness of extra care housing. It was suggested that research should examine the characteristics of tenants of such housing and the costs and benefits of different housing models in relation to resident outcomes. Particular attention was given to people with dementia, with a concern to explore the strengths and weaknesses of different models of funding care or mixing different groups of people. There was also interest in studying the housing options of people with learning disabilities. One suggestion was for a study of the accommodation/care needs continuum and the potential for flexible housing options.

5) Providing evidence to deliver integrated services

A number of the contributions addressed resource and intervention issues. Many of these were concerned with *joint working and the need for seamless services*, for instance between the NHS and adult services or with the voluntary sector. One proposed a study of good practice and training needs in the integration of health and social care for people with chronic/long-term conditions. Another suggestion was to examine the impact of joint (NHS and local government) appointments in public health. Related suggestions focused on *transitions*, both in general across the 'care pathway', such as hospital discharge, and specific situations, such as arrangements to assist young people to move into adult services.

Some suggestions proposed research to examine the *extent to which the use of one service saved resources on other services*, for instance, to see if housing adaptations reduced the need for supported care. One proposed a broad examination of the relative benefits and costs of community and residential care, with a particular focus on the impact on carers. Finally, there was interest in *integrating different government policies and funding streams*, including a suggestion to explore the savings to acute care from social care interventions and how best to reflect this in social care budgets.

6) Other responses and suggestions

A few of the ideas received did not readily fit into any of the above categories. Research on people *funding their own care* was proposed, including their numbers and the extent of their needs and preferences. It was suggested that *longitudinal studies of people using adult social care* should be undertaken, including their views and priorities. There was also interest in reflection on historical aspects of social care policy decisions, as well as a suggestion that a 21st century definition of '*social evils*' be developed, updating the 1940s work of Beveridge.

There was considerable interest in *methodological topics*. Some concerned learning from literature reviews. There was interest in understanding whether the results of rapid reviews were different from those from systematic reviews. It was proposed that the feasibility of creating a database of extracts of social care economic studies should be examined. One contribution noted that the US National Institute for Health had undertaken reviews of relevant research methods.

Some suggestions concerned the need for new tools or instruments for research or practice, such as an information tool to assist a 'whole system approach' to care delivery, a tool to assist occupational therapists working in social care, and a single assessment form for service users and carers. It was suggested that there was a need for instruments to measure particular high-profile policy goals, such as dignity, independence and well-being. Another suggestion was for developments in economic evaluations to ensure that they take into account a societal perspective.

A few other methodological issues were raised, such as ethical issues in conducting certain types of research and dissemination, and the problem of translating evidence drawn from research undertaken outside the UK. There was also concern to ensure that research had an impact on policy and practice, coupled with a concern to demonstrate that impact.

Finally, while most of the online suggestions focused on particular topics, the issues raised through other sources were often of a much more open nature, concerned with the *direction SSCR should take*. Several people argued that the SSCR should address issues of concern to users of social care. Several also stressed the importance of a focus on practice and practical issues (what works and why), rather than on policy or the development of theory. There was seen to be a need to understand change management, i.e. how best to transfer knowledge into practice. The SSCR was urged to link with other organisations, both those working directly in this area, such as the Social Care Institute for Excellence (SCIE), as well as others such as the Design Council (said to have an innovative approach to user involvement) and the Young Foundation (with an interest in social entrepreneurship and dissemination).

CONCLUDING DISCUSSION

Our consultation exercise was successful in eliciting a wide range of topics for research. These spanned, albeit unevenly, the five proposed programmes and, in a few cases, went beyond them. Some ideas were not easily classified and might have been added to a different programme, given the overlap between the programmes. In line with the aims of SSCR, most of the suggestions had a distinctly practical 'feel', with only limited interest in developing new theories of social care. Indeed, a number suggested the development of guidance or training tools following research in a particular area.

We can note, however, some missing voices. We did not hear much about the perspectives of social care providers in the independent sector and there was a more limited contribution from practitioners than we had hoped.

We need to emphasise that the suggestions included in this report were elicited from self-selecting individuals who responded to the invitation and did not emerge through any systematic method. No weighting has been given to particular suggestions and they cannot be interpreted as representative of all the views from those involved with adult social care, but they do reflect a range of interests and priorities for the individuals, groups and organisations that responded.

In SSCR we are certainly taking these suggestions into account in considering future research commissioning and we will additionally be looking to identify gaps not covered by the consultation responses. Our aim is to commission research in areas where we consider evidence is clearly needed now and in the future to support and develop adult social care practice.

We therefore continue to seek suggestions for research themes, and are actively seeking to enlarge the pool of ideas.

ACKNOWLEDGEMENT

This paper was prepared as part of the work of the Department of Health's NIHR School for Social Care Research. The views expressed in this publication are those of the authors and not necessarily those of the Department of Health, NIHR or NHS.