RESEARCH PRIORITIES IN ADULT SOCIAL CARE SCOPING REVIEW

Report to the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC)

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Acknowledgment

Background

The National Institute of Health Research School for Social Care Research (NIHR SSCR) was commissioned by the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) to review known research priorities in adult social care and map these to the NETSCC funding streams. The aim was to identify a list of research priorities that NETSCC could consider to commission further adult social care research projects and possible themed research calls.

There are few, large-scale examples of a structured priority-setting exercise in adult social care. One example is the James Lind Alliance (JLA) Priority Setting Partnership (PSP), which recently identify the "top 10" research priorities in Adult Social Work. Given the lack of such exercises in general in the sector – which of course have both advantages and disadvantages – the approach employed here is to use previous work that has taken various means to identify research priorities for the sector. These include reviews of evidence on a topic which have led to identified priorities (such as in guidance from the National Institute for Health and Care Excellence (NICE)) and consultation exercises. In this report we pull together previously identified research priorities in a format to help inform discussions about what research to commission.

Method

This review of research priorities focuses on adult social care, consistent with the remit of NIHR SSCR, and reflecting the administrative division of responsibilities between the Department for Health and Social Care (DHSC) (adult social care) and the Department for Education (social care of children and young people). However, the realities of social care and of research are not so neatly separated, and so some of the research priorities included here transcend this adult-young people divide.

The remit of NIHR SSCR also only covers England, and so this report similarly focuses on research priorities in England. NIHR SSCR's mission is to focus on practice rather than policy, and this consideration has also framed this work, although again we have recognised the difficulty of separating 'practice research' and 'policy research'.

The approach employed in this scoping review was to identify research priorities in social care reported in the NICE Social Care guidelines, NIHR SSCR-commissioned research projects and reviews, JLA PSPs and some other key reports. Details of the source documents are listed in the references section below.

Initially, a list of over 300 research questions was drawn from these sources. This preliminary list was reviewed and questions with known (and recent) research answers and those covering areas of on-going research were removed. Next, overlapping questions were combined, producing a list of 30 research priorities. Where possible, these were matched to NETSCC funding streams, as per the remit for this work. This composite list of research priorities was presented to two NIHR SSCR consultative groups: the User, Carer, Practitioner Reference Group (UCPRG) and the Advisory Board (AB).

The UCPRG brings together people with experience of adult social care from the perspectives of people who use services, carers of people receiving care, and/or working in the sector. The group was established in 2009, with its membership evolving over time; members of the UCPRG are very experienced in providing advice on adult social care research.

The NIHR SSCR AB has similarly been overseeing and advising the School's work for nine years. It is a broader group of people including representation from the UCPRG, representative organisations of social care providers and key professional groups, local authority-based Directors of social care, researchers and research funders, and national policy leads. Between the AB and UCPRG we were able to open our initial list of research priorities up to wider consultation. The feedback from both groups was incorporated into the final list of research priorities. The work was overseen by the NIHR SSCR Executive Group.

Research priorities

One of the main challenges in conducting this exercise was that the scope of identified research recommendations varied considerably. Some were focused on very specific questions or on particular groups or contexts, while others were much broader in focus. Some were recommendations about research methods.

To draw up a manageable list of priorities (shown in Table 1 below and in Appendix A), the following questions were excluded from the final list but are presented in the Appendices of this report to provide a comprehensive picture and in the hope that

bringing them all together may also be of help to some researchers and research funders:

- JLA social care-related priorities (Appendix B) were excluded on the basis that they are drawn from work focused on other specific topics, and have been known and in circulation for some time and the subject of other work to promote them.

- JLA Adult Social Work Top 10 research priorities and the Long list of uncertainties (Appendix C) were not included as there is a process of widely disseminating the outcomes of this work to

researchers, research funders, and others when it is finished.

- Questions about children and young people (Appendix D) were excluded for the reason discussed above about Government Department responsibilities.

- Questions about methods (Appendix E) were excluded as the focus of this work was on research priorities related to practice in line with the NIHR SSCR remit; consideration of these important questions should be managed through other avenues than this report.

Comments from NIHR SSCR consultative groups

Members of the NIHR SSCR AB and UCPRG were particularly keen to stress their support for this work. They welcomed the increased interest in social care research and the opportunity to input to research prioritisation work for adult social care. They stressed that this is a snapshot of research priorities that were identified at particular times.

In the meantime, the circumstances and practice of adult social care have continued to evolve and, consequently, further priorities are in the process of emerging. Some of the topics they see as emerging and developing areas of interest are touched upon in the priorities listed in Table 1 (e.g. prevention) but will need to be tracked over the short- to medium-term to ensure they are appropriately covered in further research prioritisation and commissioning work.

An example of an emerging topic identified by the consultees was that of self-funders of care (i.e. people who fund their own social care). They are mentioned in Table 1, but as we learn more about self-funders, and as policy develops (e.g. an expected Green Paper on funding social care for older people is expected later this year), new research priorities are likely to emerge.

Self-funders of care are significant players in the adult social care system for many reasons, including the fact that many may come to use state-funded social care once their own financial resources are depleted. NIHR SSCR has commissioned research on this topic and this should be considered in deciding the precise focus of any research call for work on self-funders of adult social care.

Another example of a developing area of practice that the consultees were keen to highlight is 'strengths-based' working. Although it overlaps with

some of the issues listed in Table 1 (e.g. working with communities), practice and research questions are still being formed. Hence, we see this as a topic where we again expect further, more focused research priorities to emerge over the next few years.

Working with communities and non-family carers was mentioned by the NIHR SSCR AB as important now, but still evolving in terms of being able to better identify the priority researchable questions. The area of intergenerational work in social care was discussed in the same vein.

The AB also stressed that changes in the wider welfare system, such as changes to benefits (e.g. universal credit), and in housing policy, are important topics now, but added that more recent developments in each can have consequences for social care that take some time to come in to focus as research priorities.

NETSCC funding streams

The main NETSCC funding streams most relevant to social care are:

- **The Health Services and Delivery Research** (HSDR) Programme funds research on the quality, accessibility and organisation of health and social care services. This includes evaluations of how the NHS and social care might improve delivery of services.

- **The Health Technology Assessment** (HTA) Programme funds research about the effectiveness and broader impact of treatments and tests for those who plan, provide or receive care. HTA research is undertaken where some evidence already exists to show that a technology (e.g. medications, psychological interventions, physical/technological aids) can be effective and this needs to be compared to the current standard interventions.

- **The Public Health Research** (PHR) Programme funds research to inform the delivery of non-NHS interventions. Specifically, its focus is to generate new knowledge, on the benefits, costs, acceptability and wider impacts of interventions intended to improve the health of the public and reduce inequalities.

In each of these cases, there is a historical legacy of terminology and focus that might not make them appear immediately focused on social care, but there is a commitment from NETSCC to move beyond this and consider the relevance of the research priorities identified here to each of these funding streams.

Research priorities identified

The 30 research priorities are presented in Table 1 with possible NETSCC research funding streams. This list of research priorities is also presented in Appendix A with additional detail, including comments on the topics (to clarify and contextualise some priorities and/or to identify where other research on that topic is on-going) and the original questions from which the combined questions were drawn. The list of research priorities is also provided in an accompanying Excel spreadsheet with further information, such as the sources of the original research questions, category classification by topics etc., so that the research priorities can be organised and searched as needed.

Each of the research priorities generated in this review could fit most naturally under the HSDR funding stream. Trying to match them all to one stream would, though, limit the opportunities to support adult social care research. Hence, we have sought to suggest alternative suitable funding streams for each research priority. We have managed this for all except one of the priorities in the list, which we could only see as appropriate to the one funding stream identified. The exact final wording of a question in a call for research proposals would obviously need to be agreed to shape its focus and remit for the specific funding stream.

A number of research recommendations incorporated in to the list of priorities presented here relate to **diversity and inequalities**, including the investigation of **user experience and long-term outcomes**. In some cases, a recommendation covered several settings or population groups (e.g. housing or support), while others did not specify a setting or population group. Therefore, the list of priorities presented here does not always specify the setting or population group as the issues were seen from the included recommendations to span areas of care and/or populations. However, if such specifications of population/setting are identified for specific research calls, that may ultimately determine which funding stream would fit best the questions.

The individual research priorities in the list may also need further refining for specific research calls in relation to the existing knowledge base and methodological issues. For example, some focus on effectiveness or cost-effectiveness, but further scoping work may be required to establish if descriptive research would be useful in the first instance. Also, there are studies that address some of the priorities but focus on particular groups/settings; these have been included in the list as the issues they cover are also likely to be relevant to other groups/settings.

Table 1. Research priorities identified with possible NETSCC research funding streams

The question numbers in column 1 are for reference and are not an indication of priority

Q no	Stream 1	Stream 2	Suggested combined priority research question
Q1	HSDR	PHR	Do different population subgroups receive or experience adult social care differently? If so, in what ways and with what consequences? How do organisations use this information to differentiate services and improve quality?
Q2	PHR	HSDR	Are approaches to community capacity-building (e.g. community assets, networks) to support better adult social care outcomes effective and cost-effective? What, if any, are the negative aspects of community attitudes (e.g. stigma) and their impact on use of social care?
Q3	HSDR	PHR	What is the effectiveness, cost-effectiveness and acceptability of advocacy as a means of supporting people in various circumstances? What is the current availability of advocacy to different groups and the impact of its loss or absence? Include people with a range of conditions and backgrounds, e.g. people who may lack capacity to make a decision.
Q4	HSDR	HTA	What are the components of an effective assessment of mental capacity to make a decision? Does a person's cultural background, ethnicity or religion influence the outcome of mental capacity assessments or best interests decision? What is the effectiveness and cost-effectiveness of mental capacity assessment tools in adult social care?
Q5	HSDR	HTA	What is the effectiveness and cost-effectiveness of targeted advance care planning interventions in adult social care?
Q6	HSDR	PHR	What are the characteristics and needs of self-funders of adult social care (including home care services and (extra-) care/nursing homes) and how could they be best supported to achieve the best outcomes for the cared-for person, family and the care system? What happens to those who, for whatever reason, choose to now self-fund care?
Q7	HSDR	PHR	What is the availability and what are the outcomes of financial advice in the context of planning or paying for adult social care? Include different groups of self-funders, e.g. sociodemographic groups, as well as various levels of needs and preferences.
Q8	HSDR	PHR	What is the effectiveness and cost-effectiveness of interventions (possibly including technology and social media) available to help (i) the lonely and (ii) the isolated who are in adult social care? What is the impact of different types of community support on the extent of loneliness or isolation in different groups?
Q9	HSDR	HTA	What are the most effective and cost-effective ways for adult social care commissioners/providers to deliver economic support and employment support? Include social forms, volunteering, apprenticeships, over long term, for various groups and levels of needs and preferences.
Q10	HSDR	HTA	What is the role and cost-effectiveness of extra-care housing (ECH)? Examine different models of housing and levels of support, for different groups, peer support, and whether or not technology is cost-effective in ECH.

Table 1. Research priorities identified with possible NETSCC research funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question
Q11	HSDR	HTA	What is the cost-effectiveness and the impact of different forms of housing and support on outcomes and care needs for different client groups (e.g. people with dementia, learning disabilities, mental health needs etc. and different socioeconomic groups)?
Q12	HSDR	HTA	Which types of housing and services assisting independent living are most effective and cost-effective in preventing a need for (further) care and the move into long-term care? How effective and cost-effective are they for different groups of people?
Q13	HSDR	HTA	What is the most effective and cost effective way of supporting people with various levels of needs, strengths and preferences in residential care or supported housing to live as independently as possible?
Q14	HSDR	HTA	What is the effectiveness of different models of support planning and brokerage in adult social care for different user groups? Why do these models (e.g. brokerage, personal budgets) work for some people and not for others?
Q15	HSDR	HTA	What is the effectiveness and cost-effectiveness of different home care packages for older people with a range of care and support needs (e.g. with dementia) and from different socioeconomic backgrounds?
Q16	HSDR	HTA	What are the most effective and cost-effective ways to support carers? What is the impact of informal support on the need for formal support and prevention of need? (Explanatory notes and specific questions are shown in Appendix A.)
Q17	HSDR	HTA	What increases and what decreases the pressures on carers, what interventions help, and how does this relate to the potential rewards of caring and maintaining a balance in life (e.g. employment)?
Q18	HSDR	HTA	What are the most effective and cost-effective ways to support young people in transition from children's and young people's services to adult social care? Examine different groups (e.g. young offenders, needs groups), include interfaces with other services (e.g. primary care involvement), and self-management.
Q19	HSDR	HTA	Which models of social care delivery are effective and cost effective for different groups (e.g. older people with social care needs and multiple long term conditions, people with severe and complex needs)? What is the impact of unmet needs, including from a public purse perspective?
Q20	HSDR	HTA	What is the impact of different kinds of social care on end-of-life care in various models of housing? What are the most effective and cost-effective ways of providing social care input to end-of-life care for older people, their family and carers? Include advance care planning, different groups, (e.g. people with learning disabilities) and different contexts (e.g. care homes, communities, home care).
Q21	HSDR	HTA	What interventions improve the experience of discharge from hospitals to social care support in the community or residential/care home setting, and are they cost-effective? Include various groups (e.g. people with dementia, mental health needs, complex needs), peer support, and training for professionals and carers.

Table 1. Research priorities identified with possible NETSCC research funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question
Q22	HSDR	HTA/ PHR	What are the most effective ways of supporting older people's independence? Include early interventions, self-management, housing, social contact, in different groups (e.g. older people with social care needs and multiple long term conditions). What happens if there are unmet needs, especially from a public purse perspective?
Q23	HTA	HSDR	What adult social care interventions/ approaches are effective and cost-effective in supporting people using intermediate care (for different groups, e.g. Black & Minority Ethnic [BAME] people, people with dementia)?
Q24	HSDR	HTA/ PHR	What is the effectiveness and cost-effectiveness of different ways of supporting identification, education and self-management of chronic health conditions and their social care needs in older people with learning disabilities?
Q25	HSDR	HTA	What is the effectiveness and acceptability of different strategies to enable positive risk taking of both users and professionals/services in adult social care? How can the principles of positive risk-taking be embedded in practice (for different groups and settings)?
Q26	HSDR	HTA/ PHR	What safeguarding practices are most effective in improving outcomes for vulnerable people (e.g. people with social care needs, people who may lack mental capacity to make a decision)?
Q27	HSDR	HTA	What is the effectiveness and cost-effectiveness of different models/degrees of person-centred support for people with learning disabilities and behaviour that is seen as challenging, and for their family members and carers? Include models of shared supported living, resource allocation models over people's lifespan, models of crisis response services.
Q28	HSDR		How can the views and experiences of people using social care be best utilised for improving services? Include various groups using adult social care, e.g. older people with multiple long-term conditions, care home residents and their families, people with learning disabilities.
Q29	HSDR	HTA	What staff skills, models of support/supervision and training deliver the best outcomes for people using different adult social care services and for different user groups? What are the most effective ways of improving the knowledge of social care staff?
Q30	HSDR	PHR	Focussing on the perspectives of adult social services, their users and carers, what approaches to integrated working with a range of public services (e.g. the NHS, housing, leisure, welfare, public health) are effective and cost-effective?

James Lind Alliance research priorities

We have included research priorities generated by the James Lind Alliance (JLA) in this report separately from the 30 generated priorities above. The JLA approach is a rigorous and inclusive process for setting research priorities and has been applied to several topics, principally from a health care perspective but sometimes also identifying questions relevant to adult social care. For each research area they consider, one of their outputs is a prioritised list of the "top 10" research questions. To date, the JLA has completed 61 Priority Setting Partnerships (PSPs) covering various topics. Fourteen of those PSPs had priorities relevant to adult social care and these are included in a separate table in this report (Appendix B), as they have been reported through the relevant JLA PSPs as considerations for research funding.

Recently, the JLA conducted a PSP focused on identifying unanswered questions (or uncertainties) in adult social work practice in England and agreed a set of research priorities from these, which were published in November 2018 (www.jla.nihr.ac.uk/priority-setting-partnerships/adult-social-work/top-10-priorities.htm accessed 14 June 2019). The "top 10" research priorities and the "long list of uncertainties" from this PSP work are included in Appendix C. The PSP set of priorities has been subject to a separate process of communication, including with NETSCC and other research funders, and so has not been included in the set of 30 priorities discussed in this report.

General principles and issues relevant to adult social care research

Several methodological and other issues were highlighted in our sources, such as in the NIHR SSCR Methods Reviews (MR), as important for generally considering when commissioning research on adult social care. We summarise them below to help inform any commissioning processes that NETSCC may undertake.

Quality of social care research

A number of sources concurred that methodological repertoire and rigour in social care research requires improvement (MR1; Scoping Review [SR] 5; Manthorpe and Moriarty, 2016). Several sources reinforced the view reported elsewhere, such as in the first Business Plan of the NIHR SSCR (2009), that social care research has a history of dominance of particular approaches (e.g. qualitative case studies). They commented that while there is a need to ensure that these strengths continue and evolve, of particular importance is extending the methodological repertoire in the sector. For this reason, NIHR SSCR has been commissioning methods reviews to encourage the use of, and support wider understanding of, a wider range of methods. In part this is a matter of research capacity in adult social care research to conduct these methods, an issue being considered in other work across NIHR.

Social care research capacity

Limited capacity in social care research has been emphasized previously, for example, in the first Business Plan of the NIHR SSCR (2009), and one of the newer aims of the NIHR SSCR is to contribute to the development of research capacity. This includes the point above about capacity to be able to use a broader range of research methods and designs (Manthorpe and Moriarty, 2016) but also covers nurturing capacity to undertake high-quality research generally in adult social care. Currently, the DHSC and NIHR are developing NIHR Incubators to support capacity building in a number of priority areas including adult social care (NIHR 2017). The Incubator for Social Care Research will help address the research capacity challenge in the field. The Incubator is being developed through the NIHR SSCR and the NIHR Academy and is expected to commence work in 2019.

Co-production and user input

It has been proposed that more research in adult social care needs to be co-produced, involving closer collaborations between all relevant stakeholders, e.g. people who use services, practitioners, commissioners, providers and researchers (NICE/TLAP 2018).

Although consultation and collaboration can be seen as incremental stages on the scale of public or user involvement in research, coproduction and user-controlled research have been argued to be more evolved approaches (SR5, INVOLVE 2012). Researchers should as a minimum ensure that people who use services, carers and those responsible for delivering care are appropriately and genuinely involved in all stages of the research process, and their views and experiences are gathered by acceptable, appropriate and effective methods. This

is in line with current practice across the NIHR (including the NIHR SSCR), as outlined in a recent NIHR Patients and the public newsletter (Hickey 2018), but it is an area where we might anticipate further evolution.

NIHR SSCR has continued to explore beyond this to support coproduction of research and is examining how to draw together lessons on this. While co-production of research has become more popular, there have also been arguments in favour of user-led or user-controlled research, especially for groups whose views are under-represented should lead research, e.g. people receiving social care, carers, older people, BAME people, people with mental health needs and people receiving disabled facilities grants (SR5). This remains a less developed area of research in general than involvement and co-production, and, hence, one open to more debate.

Diversity and inequalities

Many research gaps relate to questions of inequalities among different sociodemographic groups. Social care research should consider the implications of population diversity for the design, practice and validity of the research (MR9), as different population groups may have different social care needs, preferences, assets and experiences. Many of the client groups who are likely to need social care also have relative disadvantage in other aspects of society (NICE/TLAP 2018). For example, many people experience an increase in disadvantage and vulnerability as they age (Milne et al., 2014), while they are also susceptible to age discrimination, and older people are one of the groups most likely to need adult social care support. Groups identified as potentially facing more disadvantage and in need of further research about their use of adult social care are listed in Table 2.

Table 2. Groups identified as under-researched or under-represented in research leadership

Population groups	Black & Minority Ethnic (BAME) people
	Lesbian Gay Bisexual and Transgender (LGBT) people, especially older LGBT individuals
	Older people
	Residents of care homes
	Self-funders
	Older carers (i.e. over 65 years old)
	Carers in paid employment
	Hard to reach' carers (e.g. BAME, LGBT)
	Abused adults
	Young people in transition into adulthood and use of adult services
People with specific conditions	Dementia
	Learning disabilities
	Autism
	Cancer
	Sensory impairments
	Complex needs
	Other long-term conditions

Involving carers in research

It was estimated that there were 5 million adults providing unpaid care for older people in England in 2015 (Brimblecombe et al., 2018). As this number is likely to rise (and does not include other carers), it is evident that carers have a vital role in social care and should have opportunities to contribute to social care research. A recent review summarising carer-related research and knowledge suggested that the complexity of caring and caring relationships should be incorporated into future approaches, and the recommendations were consistent with the research priorities identified in this report (Henwood at al., 2018). The benefits and added value of including family members and carers in research have also been highlighted (Larkin et al., 2017). Genuine involvement and long-term partnerships with carers in research are thought to add significantly to its relevance, generalisability and impact. However, there are challenges to carer involvement, which include the difficulty of reflecting the variety and complexity of caring relationships and situations, helping carers potentially already pressed for time to be involved, accessing harder-to-reach groups and enabling funders to understand the benefits of including carers in research.

Engaging social care practitioners in research

Increasing the engagement of social care practitioners in research was also frequently suggested in work informing this scoping study. It was particularly thought to be helpful in ensuring that research is relevant to practice. Real partnerships between the research community and local authorities (and other stakeholders) should be developed, so that research can take place and have an impact on practice (Manthorpe and Moriarty, 2016). Whilst this is current practice in the NIHR SSCR, it is again an area that could develop significantly if more resources are committed to social care research and capacity-building.

It is not known how many social work practitioners are taking the professional doctorate route to a PhDs, nor which academics can offer this option of relating study to practice. A social care research network could help to monitor research activity and support an increase in research capacity (in terms of undertaking and using research) among practitioners. Opportunities could be created for social workers to enter teaching and research, and social care leaders could support and mentor potential research leaders as part of professional development (Manthorpe and Moriarty, 2016). These are issues that may be explored in the aforementioned research Incubator, but also could be supported through more commissioned research in adult social care.

Recruitment of participants into social care research

Recruitment of participants for social care studies raises specific issues. Accessing people who use social care services can be challenging (NICE/TLAP 2018). For example, people living in residential care settings can be difficult to recruit; identifying and gaining access to self-funders may require innovative methods (e.g. via social media). Recruiting people through social care providers and voluntary and community organisations depends on providers' willingness to facilitate research. New settings of interest to adult social care, such as interfaces with the criminal justice system and work in communities will require learning about new recruitment issues. NIHR SSCR is currently scoping the challenges in recruitment to social care studies. Additionally, the NIHR Clinical Research Network is beginning to support social care research and developing our evidence about recruitment.

Dissemination of research findings, knowledge exchange and developing pathways to impact

Social care practitioners and managers may not see how research could benefit their practice. Research findings need to be presented in ways that are accessible and relevant for the broad range of practitioners (NICE/TLAP 2018). This has been current practice in NIHR SSCR, which publishes accessible, four-page reports of its projects, focused on implications for practice. Means of developing knowledge exchange throughout the planning, conduct and reporting of research projects has been central to NIHR SSCR research.

Conclusions

The raised level of interest in adult social care and related research across NIHR and especially within NETSCC was keenly welcomed by those we consulted with in the course of this scoping work. They were very pleased to see pulled together for the first time the number and range of research priorities scoped here and the attempt to draw these together in a manageable list. It was recognised that the individual research priorities in the list will need refining in relation to specific research calls. The additional information for each priority set out in the accompanying Excel spreadsheet will provide context for each of the questions to help in doing this.

The research priorities presented here are a synthesis of known issues in what is a rapidly changing environment, in terms of how practice and policy are evolving, how societal and demographic developments are unfolding, and in consideration of the relevant research infrastructure and landscape.

It is hoped the research priorities presented here will form the focus for significant developments in social care research in the near future and a starting point for future reviews of research priorities as contexts develop.

Although welcoming this work, the groups we consulted with to produce this report were clear on the need to remain more vigilant about emerging research priorities in adult social care than research systems have been able to do so far.

References

National Institute for Health and Clinical Excellence (NICE) Social Care guidelines

Home care: delivering personal care and practical support to older people living in their own homes. NICE guideline 21. (2015).

Older people with social care needs and multiple long-term conditions. NICE guideline 22. (2015).

Transition between inpatient hospital settings and community or care home settings for adults with social care needs. NICE guideline 27. (2015).

Transition from children's to adults' services for young people using health or social care services. NICE guideline 43. (2016).

Transition between inpatient mental health settings and community or care home settings. NICE guideline 53. (2016).

Child abuse and neglect. NICE guideline 76. (2017).

Intermediate care including reablement. NICE guideline 74. (2017).

People's experience in adult social care services: improving the experience of care and support for people using adult social care services. NICE guideline 86. (2018).

Learning disabilities and behaviour that challenges: service design and delivery. NICE guideline 93. (2018).

Care and support of people growing older with learning disabilities. NICE guideline 96. (2018).

Decision making and mental capacity (in development).

NIHR SSCR Research findings

45 projects were available, 19 had research recommendations, though it should be noted that when reporting these studies the principle goal has been to report findings and recommendations to practice, and not research recommendations.

RF1 Care and support for people with complex and severe needs: Innovations and practice – a scoping study

RF2 Individualisation of services — a scoping study

RF6 Social care practice with carers: What social care support is provided to family carers? What support do family carers want?

RF10 Unpaid care and employment in England

RF12 Personalisation and carers: the role of carers in assessment, support planning and managing personal budgets

RF19 Are personal budgets always the best way of delivering personalised social care services to older people?

RF24 Acceptability of and satisfaction with social care among South Asian groups: a case study of Hampshire

RF25 Taking On and Taking Over: physically disabled young adults and their care and support arrangements

RF27 Factors that contribute to the levels of satisfaction with social care for physical disabilities amongst Chinese and African Caribbean service users

RF31 Relocation, portability and social care practice: investigating the barriers and solutions encountered by disabled people when moving across local authority areas for employment and education reasons

RF50 The economic consequences of community capacity-building projects

RF59 Health and wellbeing consequences of social isolation in old age: a scoping study

RF62 Meeting the information needs of self-funders

RF66 Predicting future unmet social care need and examining links with well-being

RF73 The everyday operation of models of social care provision within the extra care sector

RF77 Lesbian, gay, bisexual and transgender (LGBT) disabled men & women and social care support

RF80 Social care in prisons: a needs assessment and service requirements

RF87 Keeping control: Exploring mental health service user perspectives on targeted violence and hostility in the context of adult safeguarding

RF109 Independent financial advice about funding social care in later life – a project exploring evidence and practice

NIHR SSCR Methods reviews

MR1   Qualitative methods overview

MR2   LGBT sexualities in social care research

MR3   A brief guide to carrying out research about adult social care services for visually impaired people

MR4   Research governance and ethics for adult social care research: procedures, practices and challenges

MR5   The use of 'large-scale datasets' in UK social Care research

MR6   Overview of outcome measurement for adults using social care services and support

MR7   Mathematical modelling and its application to social care

MR8   Care homes

MR9   Research with d/Deaf people

MR10   Observational methods

MR11   Research with Black and Ethnic Minority people using social services

MR12   End-of-life care research methods

MR13   Systematic reviews in social care and social work research

MR14   Modelling social care complexity: the potential of System Dynamics

MR15   MRC guidance on developing and evaluating complex interventions: Application to research on palliative and end of life care

MR16   Quality of life: measures and meanings in social care research

MR17   Randomisation and chance-based designs in social care research

MR18   Practitioner research in social care: a review and recommendations

NIHR SSCR Scoping reviews

SR1   Prevention and social care for adults with learning disabilities

SR2   The role of the third sector in delivering social care

SR3   Economic evidence around employment support

SR4   The economic value of community capacity building

SR5   User-controlled research

SR6   New conversations between old players? the relationship between general practice and social care in an era of clinical commissioning

SR7   The impact of advocacy for people who use social care services

SR8   Care home managers

SR10   Residential school placements for children and young people with intellectual disabilities: their use and implications for adult care

SR11   People who fund their own social care

SR12   Housing and adult social care

SR13   Health and wellbeing consequences of social isolation and loneliness in old age

James Lind Alliance (JLA) Priority Setting Partnerships

61 PSPs were available, 14 had research questions relevant to social care:

JLA Autism 2016

JLA Dementia 2013

JLA Dementia (Canada) 2017

JLA Depression 2016

JLA Diabetes (type 2) 2017

JLA Frailty (Canada) 2017

JLA Intensive care 2014

JLA Kidney cancer (Canada) 2015

JLA Neurodevelopmental disorders (Canada) 2017

JLA Neuro-oncology 2015

JLA Palliative and end of life care 2015

JLA Patient safety in Primary Care 2017

JLA Pressure ulcers 2013

JLA Schizophrenia 2011

See Appendix B for the full list of JLA, social care-relevant research priorities.

JLA Adult Social Work Priority Setting Partnership

See Appendix C for the top 10 and the full long list of JLA adult social work research priorities.

Papers and reports

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Appendix A: Combined priority research questions by NETSCC funding streams

This table is also provided in an Excel spreadsheet, so that the priority questions can be organised in various ways, depending on the needs of NETSCC, or others. (The question numbers in column 1 are not an indication of priority.)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q1	HSDR	PHR	Do different population subgroups receive or experience adult social care differently? If so, in what ways and with what consequences? How do organisations use this information to differentiate services and improve quality?	One challenge with differentiating groups of service users is that some groups can become small, making recruitment difficult (but not impossible, e.g. see successful approaches used in NIHR SSCR studies on sexuality and experiences of social care). Overlap of groups of people may further add to the recruitment challenge.	What are the interventions for older people with different types of background and circumstances what is the impact on carers? What are the social care needs of subgroups of prisoners (female, with LD, with autism, with dementia) and how can those be met? How can the quality of care be improved for many client groups? E.g. people with dementia, or those needing palliative care What is the experience of social care support among lesbian, gay, bisexual and transgender (LGBT) disabled people from different and minority ethnic backgrounds?
Q2	PHR	HSDR	Are approaches to community capacity building (e.g. community assets, networks) to support better adult social care outcomes effective and cost-effective? What, if any, are the negative aspects of community attitudes (e.g. stigma) and their impact on use of social care?		What is the impact of community interventions to help community capacity building? (using quantitative measures of both capacity and benefits) What is the economic value of community capacity, including the impact on costs of public services? What is the relationship between community capacity and broader notions of (economic) value? (e.g. subjective well-being) The role of social networks and community capacity in supporting people (in relation to personalisation and more generally). What are the community attitudes to disability and ageing, to LGBT people, the concept of stigma? What is the impact of the 'benefit scroungers' rhetoric on service users?

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q3	HSDR	PHR	What is the effectiveness, cost-effectiveness and acceptability of advocacy as a means of supporting people in various circumstances?	There is some research on advocacy, e.g. on advocacy and costs, so a review of existing evidence may be needed before commissioning.	What is the effectiveness, cost effectiveness and acceptability of advocacy as a means of supporting people who may lack capacity to make a decision (on the presumption of capacity)?
			What is the current availability of advocacy to different groups and the impact of its loss or absence?		What is the impact of advocacy on the lives of users? Include people with a range of conditions and backgrounds
			Include people with a range of conditions and backgrounds, e.g. people who may lack capacity to make a decision.		Study the cost-benefit analysis of advocacy services, gathering information on costs and outcomes, including the experience of those receiving the service
Q4	HSDR	HTA	What are the components of an effective assessment of mental capacity to make a decision?	A definition of effective assessment would need to be developed. It is not clear what would be the best outcome, and associated measure, for this, so preliminary work would be needed to agree and define this.	Does a person's cultural background, ethnicity or religion influence the outcome of mental capacity assessments or best interests decisions and are these processes acceptable to service users and health and social care practitioners?
			Does a person's cultural background, ethnicity or religion influence the outcome of mental capacity assessments or best interests decision?		What is the accuracy and/ or effectiveness, cost effectiveness and acceptability of mental capacity assessment tools that are compliant with the Mental Capacity Act 2005?
			What is the effectiveness and cost-effectiveness of mental capacity assessment tools in adult social care?		What are the components of an effective assessment of mental capacity to make a decision (for example checklists, memory aids or standardised documentation)?
					What is the effectiveness and cost-effectiveness of using a checklist to support the best interests decision-making process?
Q5	HSDR	HTA	What is the effectiveness and cost-effectiveness of targeted advance care planning interventions in adult social care?	There is some relevant NIHR SSCR research on advanced care planning, but this question remains to be answered.	What is the effectiveness and cost-effectiveness of targeted advance care planning interventions?

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q6	HSDR	PHR	What are the characteristics and needs of self-funders of adult social care (including home care services and (extra-) care/nursing homes) and how could they be best supported to achieve the best outcomes for the cared-for person, family and the care system? What happens to those who, for whatever reason, choose to now self-fund care?	If needed, we can clarify why self-funders of care are a topic of interest given that the usual focus is on those receiving state-funded health/social care. There are some projects on self-funders by the NIHR SSCR and these should be looked at before specifying work in this area. It is probably the case that most self-funders will be for care of older people, but there will be some for other groups of people (such as young people transitioning to adult care and who then do not meet eligibility criteria, or adults below 65 who have needs that are not met by statutory care). Further consideration of the scope of research on this topic would be needed. Additionally, there is the question of what happens to those not eligible for statutory care and who cannot afford to or choose not to self fund. What information about the availability and use of advocacy is available for self-funders making a decision to move to a care home?	What are the unmet needs among people excluded from SC funding and what is the impact of its absence on their life experiences and life expectancy? E.g. self-funders, people with mild LD, those who used to use day centres How could self-funders be supported? What is the level of demand from self-funders for home care services and what are the factors that influence that? What are the main tasks carried out for self-funders and are these focussed less narrowly on personal care than for LA-funded recipients of care? What are the ages of self-funding service users and of those who opt to employ care workers directly? What are the numbers of self-funders in LA areas? What are the numbers of self-funders in care homes? Including people paying top up fees Investigate different types of self-funders, e.g. those with sufficient resources to be ineligible for funding, or those with few resources but insufficient needs to qualify for LA-funded home care

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q7	HSDR	PHR	What in the availability and what are the outcomes of financial advice in the context of planning or paying for adult social care? Include different groups of self-funders, e.g. sociodemographic groups, as well as various levels of needs and preferences.	There is some NIHR SSCR research on this topic that should be considered prior to decisions about commissioning work on this topic.	What are the outcomes and the usefulness of financial advice in the context of paying for care?
					What are the circumstances in which financial advice about paying for care costs is accessed? What do stakeholders experience as barriers to access?
					How does financial advice enables people to pay for care who might otherwise have depleted their capital and fallen back on LA funding?
					What is the relationship between financial planning/advice and cultural norms around familial provision of care, especially for BAME communities?
					How can people overcome behavioural barriers to thinking ahead about declining health in order to build on pre-existing relationships with financial advisers by encompassing advice on paying for care?
					What are the information needs of people from ethnic minorities who are not eligible for council-funded care? What is the ethnic make-up of the self-funding population?
					Examine price transparency for self-funders and people topping up their fees
					What/Are contracts in place for self-funders and people who top up fees, and do they contain clear and fair clauses about charges?
					What are the outcomes for self-funders who approach LAs for advice or information and are signposted elsewhere?

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q8	HSDR	PHR	What is the effectiveness and cost-effectiveness of interventions (possibly including technology and social media) available to help (i) the lonely and (ii) the isolated who are in adult social care? What is the impact of different types of community support on the extent of loneliness or isolation in different groups?	The 'different groups' could refer to different dimensions of diversity, age groups, or different categories of need.\n\nThis fits on with the broader evidence on loneliness/isolation but is focused on those receiving adult social care support.\n\nThere is some NIHR SSCR work on this topic.	What is the nature of interventions available to help the lonely/isolated and what is the impact of different types of community on the extent of loneliness/isolation in different groups?
					What is the effectiveness and cost effectiveness of personal technology and social media to help older people with learning disabilities to maintain relationships with friends and family, build social contacts and access volunteering, social and leisure activities?
					What are the longitudinal risk factors for becoming lonely/isolated?
					What is the use of health and SC by people who are lonely/isolated?
Q9	HSDR	HTA	What are the most effective and cost-effective ways for adult social care commissioners/providers to deliver economic support and employment support? Include social forms, volunteering, apprenticeships, over long term, for various groups and levels of needs and preferences.	This fits with the broader evidence on models of employment support (e.g. Individual Placement and Support) but is focused on groups receiving adult social care support.\n\nThere is some NIHR SSCR work in this area, notably on employment support for carers.	Is one economic support model cost-effective across more groups or is a single-disability approach more effective? Does employment support agencies being 'pan disability' or 'single disability' make a difference in realising outcomes for people? What is needed by those with more complex needs?
					How does economic support differ across the UK, in terms of intensity and training requirements and how do these affect cost outcomes?
					What are the key ingredients of economic support models?
					To what extent other services received have an impact on the outcomes of economic support and therefore its cost-effectiveness?
					What are the long-term costs and benefits of economic support?
					Analyse economic support across different models, e.g. compare IPS and supported employment

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q9 (cont.)	HSDR	HTA	What are the most effective and cost-effective ways for adult social care commissioners/ providers to deliver economic support and employment support? Include social forms, volunteering, apprenticeships, over long term, for various groups and levels of needs and preferences.	This fits with the broader evidence on models of employment support (e.g. Individual Placement and Support) but is focused on groups receiving adult social care support. There is some NIHR SSCR work in this area, notably on employment support for carers.	How can economic models be improved to obtain higher rates of getting people into employment? What happens to those who have received economic support but do not find a job? Do different groups (e.g. with MHP or LD) use personal budgets to buy ES? How do models such as social firms, volunteering or apprenticeships help people toward paid employment and the ways in which people are – or could be – using personal budgets to purchase employment support?
Q10	HSDR	HTA	What is the role and cost-effectiveness of extra-care housing (ECH)? Examine different models of housing and levels of support, for different groups, peer support, and whether or not technology is cost-effective in ECH.	This links to Q11 and there is a need to ensure related research clearly defines it focus. This Q is specific to ECH as a model, Q11 is more generic about models of accommodation. There is some relevant NIHR SSCR research to consider.	What is the role of extra-care housing for older people from black and ethnic minority communities and older single men? It is appropriate for fit people as well as those who are frail? What is the extent to which older people (or others) provide peer-to-peer support in extra care housing? What is the cost-effectiveness of different sizes, designs and models of organising and managing care in extra care housing? What are the user views of quality? What are the determinants of moving into or out of extra-care housing, where do people come from and where they go? Is extra care housing is a 'home for life' or are there circumstances when people move on? Who makes this decision? How to manage the expectations and aspirations of self-funders and public funded extra-care housing residents? Is extra-care housing an appropriate model of Housing with Care to support people with dementia?

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q10 (cont.)	HSDR	HTA			What is the role of technology enabled care in extra-care housing?
					How do managers support and promote an effective organisational culture in extra-care housing?
					What is the role of carers in sheltered housing or extra care housing in preventing the person cared for needing additional help? Which types of scheme enable carers to do this?
Q11	HSDR	HTA	What is the cost-effectiveness and the impact of different forms of housing and support on outcomes and care needs for different client groups (e.g. people with dementia, learning disabilities, mental health needs etc. and different socioeconomic groups)?	With this and other topics below, projects might be particularly alert to social care for people with learning disabilities and dementia.	What is the cost-effectiveness of housing related support and its impact on quality of life and care needs by client group? (e.g. people with dementia, LD, MHP)
Q12	HSDR	HTA	Which types of housing and services assisting independent living are most effective and cost-effective in preventing a need for (further) care and the move into long-term care? How effective and cost-effective are they for different groups of people?	There has been some work scoping the types of housing and related support by NIHR SSCR, which should be looked at before further studies in this area, but there may be a need for further reviews focused on this question and the issue of prevention before primary research.	What new forms of housing promote self-care and prevent moves into long-term care arrangements? (e.g.co-housing)
Q13	HSDR	HTA	What is the most effective and cost effective way of supporting people with various levels of needs, strengths and preferences in residential care or supported housing to live as independently as possible?	This potentially overlaps with the previous Qs on models of housing and especially the question of prevention (Q12).	What is the acceptability and feasibility of different house size/residency for people of different support needs?
					What is the effectiveness and cost effectiveness of different household's sizes on incidence and severity of behaviour that challenges and quality of life for people with different support needs?

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q14	HSDR	HTA	What is the effectiveness of different models of support planning and brokerage in adult social care for different user groups? Why do these models (e.g. brokerage, personal budgets) work for some people and not for others?		How can the bureaucracy involved in personal budgets be reduced? For users, carers and professionals.
					What is the role of carers in the PB process?
					Why do personal budgets (PB) work for some people and not for others?
					Alternative arrangements for those who might not want personal budgets? (e.g. older people)
					What is the effectiveness of different models of support planning and brokerage, apart from the options for management of PB?
					Use of direct payments by people with long term conditions to enable occupational engagement.
					New initiatives for services as a result of PBs for older people, for instance day activities and support
					The broader mechanisms for sustaining personalised care and support, including how best to support people using personal budgets
Q15	HSDR	HTA	What is the effectiveness and cost-effectiveness of different home care packages for older people with a range of care and support needs (e.g. with dementia) and from different socioeconomic backgrounds?	There is some NIHR SSCR research examining defining quality of home care that would be relevant here.	What is the most effective and cost-effective way to support people with dementia living at home?
					Identify innovative or effective practice on functional issues, such as accessing the toilet, strip-washing and access into a house, with a critique of any current guidance
					What is the effectiveness and cost effectiveness of different intensities of home care packages for older people with a range of care and support needs?

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q15 (cont.)	HSDR	HTA			What types of telecare are most effective and cost-effective, when provided to older people as part of a package of home care?
					What is the cost-effectiveness of systems for housing with care for different client groups?
					What are the relative merits of integrated or segregated social care facilities for people with dementia?
					How can housing reduce the need for social care for people with learning disabilities or people with mental health problems?
					Which types of low-level services intended to assist independent living are most cost-effective in preventing a need for care, and among which groups?
					What are the innovative solutions for keeping people at home, such as extra care housing or housing adaptations?
					What is the role of housing in helping people to remain in the community?
					Examine sheltered accommodation or retirement housing in terms of the ethnicity, gender and nature of the disabilities of the people catered for
					What is the effectiveness and cost effectiveness of care and support models (e.g. assistive technology) for older people with learning disabilities to enable them to live in the family home?
					What is the most effective and cost effective way of supporting older people with social care needs and multiple long term conditions in care homes to live as independently as possible?

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q16	HSDR	HTA	What are the most effective and cost-effective ways to support carers? What is the impact of informal support on the need for formal support and prevention of need?	These are broad questions, which could be redefined to focus it in a call. There is extensive research on carers but previous reviews stressed the need for more methodologically robust research, particularly for some types of interventions. Also, research focussing on particular groups or conditions may be relevant. There is relevant NIHR SSCR research on carers.	What types of services or approaches are effective in supporting family members, carers and staff to be resilient and able to provide care and support to people with a learning disability and behaviour that challenges?
					How to best support hard-to-reach carers and how to learn from good practice? E.g. from different cultural backgrounds
					What are the needs and cost of a replacement carer while a carer works? (e.g. of someone with DP)
					At what point is more cost-effective to provide additional services for the cared for person, rather than providing support to carers?
					What is the effectiveness, cost effectiveness and acceptability of training programmes (for example in the use of life story work) for families of older people with learning disabilities who have dementia or are at risk of developing it?
					Develop an economic model of the impact of supporting carers early on, enabling them to avoid burnout or family breakdown
					How to best support carers to enable them to lead their own lives?
					What is the effectiveness of the formal SC system in supporting carers?
					What support for carers is available in workplace?
					To what extent do family support services increase the capacity of informal support networks to the extent that the need for formal support is reduced? What are the characteristics of such interventions that are associated with greater reductions in the need for formal support? What are the social and economic costs and benefits associated with the widespread implementation of such programmes in England?

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q17	HSDR	HTA	What increases and what decreases the pressures on carers, what interventions help, and how does this relate to the potential rewards of caring and maintaining a balance in life (e.g. employment)?	There is already much work on the experiences of being a carer so this area should not simply be describing this again. There is relevant NIHR SSCR research, especially on employment support for carers to remain in employment.	How do the hours, intensity, nature of care, other responsibility of the carer, age of the carer and other factors contribute to the burden on carers?
					To what extent is unpaid care a chosen alternative to other forms of care? Does the provision of unpaid care results from unmet need for other preferred forms of care?
Q18	HSDR	HTA	What are the most effective and cost-effective ways to support young people in transition from children's and young people's services to adult social care? Examine different groups (e.g. young offenders, needs groups), include interfaces with other services (e.g. primary care involvement), and self-management.	There is research on transitions between young people's and adult service, e.g. in mental health, but this is specifically about social care transitions. There is one NIHR SSCR project on young people making a transition to manage their personal budgets as they move to adulthood.	What is the most effective way of supporting care leavers in transition from children's to adults' health services?
					What are the most effective ways for primary care services to be involved in planning and implementing transition, and following up young people after transfer (whether or not they meet criteria for adult services)?
					What is the most effective way of supporting young offenders in transition from children's to adults' health and social care services?
					What approaches to providing transition support for those who move from child to adult services are effective and/or cost effective?
					What are the consequences and the costs of young people with ongoing needs not making a transition into adult services, or being poorly supported through the process?
					What is the relationship between transition and subsequent self management?
					What is the most effective way of helping families to support young people who have been discharged from children's services (whether or not they meet criteria for adult services)?
					What is the most effective way to help carers and practitioners support young people's independence?

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q19	HSDR	HTA	Which models of social care delivery are effective and cost effective for different groups (e.g. older people with social care needs and multiple long term conditions, people with severe and complex needs)? What is the impact of unmet needs, including from a public purse perspective?	There is an ongoing James Lind Alliance Priority Setting Partnership looking at research priorities for the safe care of adults with complex needs.	Evaluate models of support for people with severe and complex needs, using comparison groups, and reporting of both costs and outcomes
					Which models of service delivery are effective and cost effective for older people with social care needs and multiple long term conditions?
					When social care needs are unmet, are savings on social care spending outweighed by spending on health and other services?
					What is the cost-effectiveness and impact on quality of life of other help, e.g. floating support, telecare, handyperson schemes and information and advice services? What are the views of users?
Q20	HSDR	HTA	What is the impact of different kinds of social care on end-of-life care in various models of housing? What are the most effective and cost-effective ways of providing social care input to end-of-life care for older people, their family and carers? Include advance care planning, different groups, (e.g. people with learning disabilities) and different contexts (e.g. care homes, communities, home care).	There is an absence of social care input at end of life, so it would be important to find out why first. This could also encompass evaluation of the impact of different models of housing on end-of-life care (such as extra care).	What is the effectiveness and cost effectiveness of advance care planning for end of life care for older people with learning disabilities, and their family members and carers?
					What is the effectiveness and cost effectiveness of end of life care for older people with learning disabilities?
					What are the costs and resource use associated with end of life care in SC settings? Explore cost differences between approaches to end of life care in a range of settings
					What models of housing with care are best suited to prevent an unwanted move at the end of life?
					What is the impact of different kinds of social care and support [on end-of-life care]?
					How can end-of-life care be supported in extra-care housing?

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q21	HSDR	HTA	What interventions improve the experience of discharge from hospitals to social care support in the community or residential/ care home setting, and are they cost-effective?	There is a current NIHR SSCR study on delays in discharge and links to social care and we ought to await its findings (early 2019) before defining research to be commissioned in this area.	What is the effect of specific interventions to support people with complex needs because of multiple diagnoses and resistance to treatment during transition between inpatient mental health settings and community or care home settings? (This includes people with physical or learning disabilities, people with personality disorder, people with complex psychosis, people with long-term severe mental illness and people on the autistic spectrum.)
			Include various groups (e.g. people with dementia, mental health needs, complex needs); peer support, and training for professionals and carers.	We believe there are other NIHR-funded projects and programmes relevant to this.	What is the effect of specific interventions to support people with dementia during transition between inpatient mental health settings and community or care home settings?
					How effective are home assessment interventions and approaches designed to improve hospital discharge outcomes?
					Is peer support that is provided during and after discharge from mental health inpatient settings effective and cost effective in reducing rates of readmission? Is there any particular benefit for black, Asian and minority ethnic communities?
					What is the effect of hospital discharge or transitions training for health and social care practitioners on achieving successful transfers from hospital to home or the community, including the effects on formal and informal carers, and on avoidable readmissions?
					What interventions are cost-effective in supporting people with mental health difficulties on discharge from general hospital inpatient settings?
Q22	HSDR	HTA/ PHR	What are the most effective ways of supporting older people's independence? Include early interventions, self-management, housing, social contact, in different groups (e.g. older people with social care needs and multiple long term conditions). What happens if there are unmet needs, especially from a public purse perspective?		What is the impact of different early intervention focused approaches to self management on outcomes for older people with social care needs and multiple long term conditions?
					What is the role of independence and resilience in enabling older people to manage difficulties with daily living, and the importance of suitable housing, social contact, involvement in activities and mobility in helping older people manage their care needs while maintaining good well-being?
					Which specific types of social care are best able to support good well-being among older people, while enabling people to maintain their independence? (focus on aids and adaptations)

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q23	HTA	HSDR	What adult social care interventions/ approaches are effective and cost-effective in supporting people using intermediate care (for different groups, e.g. BAME, dementia)?	There is a study at the University of York just finishing on reablement.	How effective and cost-effective are different approaches to supporting people from black and minority ethnic groups using intermediate care?
					Examine the Home from Hospital Service and the role of handyperson schemes in facilitating these
					What is the economic argument for the early provision of low-level interventions, to avoid more expensive subsequent interventions?
					What is the long-term effectiveness of occupational therapy, starting as a very early intervention, in keeping people independent and maintaining or improving their wellbeing?
					What factors determine the effectiveness of reablement services?
					Who benefits from what interventions (reacting to reablement)?
					How effective and cost-effective is introducing a single point of access to intermediate care?
					What is the optimal time between referral to and starting intermediate care in terms of effectiveness and cost effectiveness and in terms of people's experiences?
					How effective and cost-effective is intermediate care including reablement for supporting people living with dementia?
					How effective and cost-effective are repeated periods of reablement and reablement that last longer than 6 weeks?
					What is the cost-effectiveness of different reablement approaches, and what are the 'active ingredients'?
					How effective and cost-effective are different approaches, in terms of duration and intensity, to providing home-based intermediate care for adults?
					What is the role of carers in improving a person's functional abilities after rehabilitation?

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q24	HSDR	HTA/PHR	What is the effectiveness and cost-effectiveness of different ways of supporting identification, education and self-management of chronic health conditions and their social care needs in older people with learning disabilities?		What is the effectiveness and cost-effectiveness of different ways of identifying age related and other physical and mental health conditions, in older people with learning disabilities?
					What is the effectiveness and cost-effectiveness of education programmes to improve information and advice and to support self-management of chronic health conditions (for example obesity, diabetes and cardiovascular disease) for older people with learning disabilities and their family members and carers?
					What is the effectiveness and cost-effectiveness of telemonitoring for older people with learning disabilities in: • promoting understanding and improving management of chronic physical and mental health conditions? • supporting their ageing family carers to continue providing care?
Q25	HSDR	HTA	What is the effectiveness and acceptability of different strategies to enable positive risk taking of both users and professionals/services in adult social care? How can the principles of positive risk-taking be embedded in practice (for different groups and settings)?		What is the effectiveness and acceptability of different strategies to enable positive risk taking in care homes?
					How can the principles of positive risk-taking be embedded in practice?
					How can the understanding of the impact of risk management be improved?
					The skills, knowledge, competencies and attitudes to risk of health and social care staff – in particular commissioners.

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q26	HSDR	HTA/ PHR	What safeguarding practices are most effective in improving outcomes for vulnerable people (e.g. people with social care needs, people who may lack mental capacity to make a decision)?		How can people with SC needs be helped to safeguard themselves?
					Use of British and European laws to safeguard vulnerable people and the implications of the recent Supreme Court ruling on deprivation of liberty.
					What safeguarding practices are most effective in improving outcomes for people using services?
					Understand the balance between providing autonomy and risk-taking for people with issues concerning their mental capacity
					Investigate the experience of effective work with abusers (or alleged abusers) of vulnerable adults
					What are the best ways of responding to safeguarding alerts?
Q27	HSDR	HTA	What is the effectiveness and cost-effectiveness of different models/degrees of person-centred support for people with learning disabilities and behaviour that is seen as challenging, and for their family members and carers? Include models of shared supported living, resource allocation models over people's lifespan, models of crisis response services.	This could encompass more 'upstream' work in the form of early intervention and prevention. This could also take it in to the area of children and young people.	What is the effectiveness and cost-effectiveness of different resource allocation models of services over the lifespan for people with learning disabilities and behaviour that challenges?
					What are the barriers and facilitators to providing an effective and cost-effective crisis response service, with particular reference to different models for structuring delivery of this service?
					What models of delivering person-centred support are effective and cost effective for people with a learning disability and behaviour that challenges, and their family members and carers?
					What are the views and experiences of people with a learning disability and behaviour that challenges and their family members and carers, of different models of delivering person-centred support?
					What is the effectiveness and cost-effectiveness of models of shared, supported living, such as Shared Lives? What are the views and experiences of people sharing their home and people who live with them under programmes such as Shared Lives?

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q28	HSDR		How can the views and experiences of people using social care be best utilised for improving services? Include various groups using adult social care, e.g. older people with multiple long-term conditions, care home residents and their families, people with learning disabilities.		What is the lived experience of older people with social care needs and multiple long term conditions?
					How can residents of care homes be empowered to have a role in running them?
					What are the barriers and enablers to gathering, synthesising and applying data on the views and experiences of people who use services for the purposes of service improvement?
					How to create durable mechanisms for service improvement, which are sufficiently clear and flexible that they can be reproduced across organisations, sufficiently inclusive and collaborative that they can involve service users and their families and sufficiently robust to actually produce change
					What are the views and experiences of people who use adult social care services on assistive technologies?
Q29	HSDR	HTA	What staff skills, models of support/supervision and training deliver the best outcomes for people using different adult social care services and for different user groups? What are the most effective ways of improving the knowledge of social care staff?	Any commissioning in this area should be developed in consultation with the relevant Policy Research Unit for the social care workforce.	How to strengthen the skills of local authority managers responsible for managing contracting housing-related care?
					What skills and competencies deliver the best outcomes for people with behaviour that challenges including people in contact with, or who may have contact with, the criminal justice system in general and specialist services? What configuration of skills and professional competencies in general and specialist services can deliver the best outcomes for people with a learning disability and behaviour that challenges services?
					What are the types and levels of support offered to care home managers by different types of provider? What are their experiences of support?
					What methods of training are desired by staff?
					What is the impact and effectiveness of SC training on SC practice?

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q29 (cont.)	HSDR	HTA			Is the role of care home managers administrative or requires a SC or nursing qualification? To clarify the appropriate training and recruitment
					What are the effects of different approaches to home care training on outcomes for people who use home care services?
					What is the effectiveness of management arrangements and the effectiveness of different staffing models for housing with care?
					How effective and cost-effective, in terms of team structure and composition, are different approaches to providing home-based intermediate care for adults?
					How can the SC knowledge of housing staff working in choice-based lettings be improved?
					Examine leadership in SC organisations
					Do SC qualifications make a difference to the standard of care?
					How to provide the SC workforce with the skills to cope flexibly with very diverse groups, as well as with the constantly changing policy context?
					How to improve the initial education and CPD arrangements for unqualified lower paid social care workers?
					What is the level of understanding of care home owners concerning the challenges faced by care home managers?
					Who benefits from apprenticeships and how to best recruit for them?
					To improve understanding on the low level of SC staff retention, and the best practice for recruitment and retention and what are the perceived barriers to career progression

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q29 (cont.)	HSDR	HTA			What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions?
					What is the impact of the Social Care Registered Managers Support Programme, such as the My Home Life programme?
					What are the levels of stress, burnout and the general mental health of care home managers? Using validated scales
					Examine evidence from local authorities regarding their support to employers to be 'good' employers
Q30	HSDR	PHR	Focussing on the perspectives of adult social services, their users and carers, what approaches to integrated working with a range of public services (e.g. the NHS, housing, leisure, welfare, public health) are effective and cost-effective?	There is much work on integration but this is specifically asking about it and its impact form a social care perspective.	What are the effective components of an integrated regional challenging behaviour service across health and social care (including pooling budgets and other resources)? What are the barriers and facilitators to pooling budgets and other resources across regions?
					Could the paperwork be reduced by linking local and national systems for commissioning, inspection and monitoring?
					What is the impact of the Care Bill on integrated care?
					How can the cooperation be improved between the people working in SC and in housing, including on funding stream arrangements?
					What are the outcomes and cost-effectiveness regarding the role of housing in health and social care integration? E.g. where there was structural integration with the co-location of staff
					Relationship between general practice and social care within clinical commissioning

Appendix A: Combined priority research questions by NETSCC funding streams (continued)

Q no	Stream 1	Stream 2	Suggested combined priority research question	Commentary on combined priority research Q	Research question
Q30 (cont.)	HSDR	PHR			Examine the approach of different local authorities to partnership working, capturing the experiences of key players
					What is the impact of different arrangements for joint working on outcomes for both service users and the organisations involved?
					How can integration be supported between organisations coping with places of safety or the wellbeing of older people living on their own?
					What are the implications of the integration for the social model of care?
					Study successful examples of truly integrated commissioning and provision across health and social care work and understand why they work

Appendix B: JLA Research priorities related to social care

The number listed below for each priority refers to its place in that PSPs ranking of priorities; where no number is shown, the research questions were not ordered by priority. We have not sought to identify what, if any, research is underway for each topic, but know that some is. For example, a scoping review is underway for Q1 on Autism (effective ways to provide social care for people autistic adults, commissioned by Autistica). Also, Q9 on dementia (optimal time to move) is the subject of an NIHR SSCR commissioned project. Before commissioning any research on the following topics, a robust search would need to be done to identify whether or not it is still a research gap.

JLA research priority	Source reference
1 What are the most effective ways to support/provide social care for autistic adults?	JLA Autism
11 How can training for health and social care professionals be improved so that they are more able to recognise symptoms of autism/treat autistic people appropriately?	JLA Autism
7 What are the most effective ways of supporting carers of people with dementia living at home?	JLA Dementia
Is regular attendance at Day Care Centres with activities and social interaction effective for person with dementia for quality of life/outcomes/enabling person with dementia to stay at home for as long as possible for the person and their carers?	JLA Dementia
1 What are the most effective components of care that keep a person with dementia as independent as they can be at all stages of the disease in all care settings?	JLA Dementia
How health and social care services [for people with dementia] can best be coordinated and accessed including to improve speed of access to support, one point of contact rather than several agencies, improved communication between services.	JLA Dementia
How effective would better coordination and integration of health and social care services and other agencies be in meeting the needs of people with dementia and their carers?	JLA Dementia
17 What are the best ways to care for people from ethnic minority groups with dementia in all care settings?	JLA Dementia
2 How can the best ways to care for people with dementia, including results from research findings, be effectively disseminated and implemented into care practice?	JLA Dementia
16 What interventions/techniques/facilities/staff training are of most benefit in improving the quality of life for people with dementia and their carers in all settings and at all stages of the disease?	JLA Dementia
18 What are the most effective methods to improve the awareness and attitudes of all health and social care professionals towards people with dementia in all settings and improve their understanding of the challenges faced by carers and families?	JLA Dementia
9 When is the optimal time to move a person with dementia into a care home setting?	JLA Dementia

	JLA research priority	Source reference
12	Does high quality care from carer/care staff improve outcomes for people with dementia? What are effective ways to implement such high quality care in all settings, including care homes and hospitals? Including: Care that considers person-centred care, behavioural care interventions and kind, respectful and dignified caring. Effect on quality of life, behaviours that challenge, and progression of the disease.	JLA Dementia
9	How can the standard of care [for people with dementia in care homes] be improved?	JLA Dementia
5	After dementia is diagnosed, what would help persons with dementia and their friends, family and caregivers/care partners get the information, treatment, care and services they may need?	JLA Dementia (Canada)
17	What would help persons with dementia and/or their family, friends and caregivers/care partners plan and execute end of life decisions (including but not limited to medical assistance in dying)?	JLA Dementia (Canada)
11	What would improve care for persons with dementia in hospital settings, including emergency departments, inpatient units and rehabilitation facilities?	JLA Dementia (Canada)
18	What are the costs and benefits of alternative models of housing, including dementia villages and small group homes? Including costs and benefits to the individual, their family, and society.	JLA Dementia (Canada)
16	What are the costs and benefits of remaining at home in the community (with supports) compared to living in other settings such as long-term care and retirement homes? Including costs and benefits to the individual, their family, and society.	JLA Dementia (Canada)
14	What would help persons with dementia to maintain their independence and complete activities of daily living (including eating, bathing, dressing, taking medications, managing money and using the telephone) while remaining safe and minimizing risk (including financial)?	JLA Dementia (Canada)
8	What would ensure implementation and sustainability of best practices for dementia care within and across health care settings, including effective approaches to providing person-centred care?	JLA Dementia (Canada)
1	What can be done to support emotional wellbeing, including maintaining a sense of dignity, for persons with dementia?	JLA Dementia (Canada)
4	What services, supports and therapies for friend or family caregivers/care partners of persons with dementia would improve or maintain health, wellbeing and quality of life for persons with dementia and their friends or family caregivers/care partners?	JLA Dementia (Canada)
12	What would help persons with dementia and/or their friend or family caregivers/care partners recognize when the transition to a more supportive living environment should happen? What would make the transition process easier for persons with dementia and their friend or family caregivers/care partners?	JLA Dementia (Canada)
3	How can the health system build and sustain the capacity to meet the health and social care needs of persons with dementia and their friend or family caregivers/care partners?	JLA Dementia (Canada)
22	How can care, services and treatments for dementia be tailored to meet the needs of persons with dementia who are without family support?	JLA Dementia (Canada)

JLA research priority		Source reference
9	How can frailty measures be used by health care practitioners, older adults and family/caregivers to inform treatment and care decisions?	JLA Frailty (Canada)
21	What would help health care providers and persons with dementia and their friend or family caregivers/care partners to work together as a team in caring for persons with dementia?	JLA Dementia (Canada)
6	What dementia-related skills and knowledge should health and social care providers have? What are effective ways of providing them with these skills and this knowledge? How can the number of health and social care providers who have these skills and this knowledge be increased?	JLA Dementia (Canada)
19	What is the impact of staffing models and staff characteristics on the health and quality of life for persons with dementia living in long-term care homes?	JLA Dementia (Canada)
26	What is the effect of social isolation on depression?	JLA Depression
9	How can psychological or social support be best used to help people with or at risk of type 2 diabetes, and how should this be delivered to account for individual needs?	JLA Diabetes (type 2)
8	What are effective ways of supporting family/caregivers of older adults living with frailty to maintain their own health and wellbeing and/or that of older adults living with frailty?	JLA Frailty (Canada)
17	What would enable the creation of age-friendly communities that would better support older adults living with frailty?	JLA Frailty (Canada)
3	What is the impact of community- and home-based services, programs and resources in preventing and managing frailty (including slowing progression and/or minimizing the impact of frailty)?	JLA Frailty (Canada)
14	What would ensure that older adults living with frailty and their family/caregivers have access to appropriate community-based services (including care provided at home)?	JLA Frailty (Canada)
19	What would improve end of life care for older adults living with frailty and their family/caregivers?	JLA Frailty (Canada)
12	What would help older adults living with frailty to continue living safely in their own home or living environment of choice?	JLA Frailty (Canada)
4	What are the costs and benefits of alternative models of housing, including multigenerational or shared living, for older adults living with frailty?	JLA Frailty (Canada)
13	What would help older adults living with frailty to maintain their independence?	JLA Frailty (Canada)
1	How can health systems be organized to provide integrated/coordinated care that would better meet the health and social care needs of older adults living with frailty, and their family/caregivers?	JLA Frailty (Canada)

JLA research priority		Source reference
16	What would improve care, health and quality of life for older adults living with frailty living in long-term care homes?	JLA Frailty (Canada)
2	How can care, services and treatments be tailored to meet the needs of older adults living with frailty who are isolated and/or without family/caregiver support or advocates?	JLA Frailty (Canada)
7	What would help older adults living with frailty and their family/caregivers recognize when living at home is no longer viable?	JLA Frailty (Canada)
6	What frailty-related attitudes, skills and knowledge should health and social care providers have? What are effective ways of improving attitudes and providing skills and knowledge about frailty for health and social care providers?	JLA Frailty (Canada)
2	How can patients and their families be best supported as they start living at home again [after intensive care] (e.g, health and social care services, ICU support groups, long term follow-up)?	JLA Intensive care
6	How can psychological, emotional and social support be best given to patients [with cancer] and their families?	JLA Kidney cancer (Canada)
16	How can families and caregivers be more involved and supported to make informed decisions that address their needs, preferences and priorities?	JLA Neurodevelop-mental disorders (Canada)
2	How can system navigation be organized in a manner that enables coordinated services and supports across the lifespan for individuals with neurodevelopmental disorders and their families?	JLA Neurodevelop-mental disorders (Canada)
8	What is the effect of interventions to help carers cope with changes that occur in people with a brain or spinal cord tumour, compared with standard care?	JLA Neuro-oncology
3	What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients' preferences? Who should implement this and when?	JLA Palliative and end of life care
18	What are the benefits of, and best approaches to, providing palliative care in care homes, including symptom relief, emotional and spiritual support for patients, carers and families?	JLA Palliative and end of life care
4	What information and training do carers and families need to provide the best care for their loved one who is dying, including training for giving medicines at home?	JLA Palliative and end of life care
14	What is the best way to give palliative care to patients with dementia and their carers and families? This includes communicating about their diagnosis when they are being cared for at home or elsewhere?	JLA Palliative and end of life care
8	What are the benefits, and best ways, of providing care in the patient's home and how can home care be maintained as long as possible? Does good coordination of services affect this?	JLA Palliative and end of life care

JLA research priority		Source reference
11	How can people who live alone and do not have any friends or family nearby receive adequate palliative care, particularly if they wish to stay in their homes?	JLA Palliative and end of life care
1	What are the best ways of providing palliative care outside of working hours to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families	JLA Palliative and end of life care
24	What are the best care packages for patients, carers, family and staff which combine health care and social care and take individual prognosis into consideration?	JLA Palliative and end of life care
	What are the benefits of all health and social care staff having training in bereavement awareness and support? Is this possible?	JLA Palliative and end of life care
5	How can it be ensured that staff, including healthcare assistants, are adequately trained to deliver palliative care, no matter where the care is being delivered? Does increasing the number of staff increase the quality of care provided in all settings? To what extent does funding affect these issues?	JLA Palliative and end of life care
2	How can access to palliative care services be improved for everyone regardless of where they are in the UK?	JLA Palliative and end of life care
7	What are the core palliative care services that should be provided no matter what the patients' diagnoses are?	JLA Palliative and end of life care
9	What are the best ways to make sure there is continuity for patients at the end of life, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case coordinator improve this process?	JLA Palliative and end of life care
26	What are the best ways to support children and young people when someone close to them is dying or has died? This includes communicating with them about the diagnosis and dying process, enabling them to talk about their experience and providing bereavement support	JLA Palliative and end of life care
10	How can risks be mitigated to allow for safe complex care at home?	JLA Patient safety in Primary Care
3	Does the education of health and social care staff on prevention lead to a reduction in the incidence of pressure ulcers and, if so, which are the most effective education programmes (at organisational and health/social care level)?	JLA Pressure ulcers
5	What are the benefits of supported employment for people with schizophrenia in terms of quality of life, self-esteem, long-term employment prospects and illness outcomes?	JLA Schizophrenia

Appendix C: JLA priorities in adult social work

Top 10 research priorities in adult social work (in order of priority)
1   How is availability of funding impacting on (a) adult social workers' practice and (b) the decisions made?
2   What impact is the Care Act having on (a) adult social work practice and (b) the outcomes for people using services and their carers, particularly their well-being and safety?
3   How is 'wellbeing' understood and incorporated into adult social work practice? How can we assess whether adult social workers impact on the well-being of people using services?
4   How could communication between adult social workers and people using services be improved, especially with those people who have difficulty with communication (e.g. use of new media, better communication skills, working with other professionals)?
5   Has the Mental Capacity Act 2005 been embedded into practice and what are the impacts on people using services and their carers?
6   How are eligibility criteria applied to people with different types of needs and are the thresholds appropriate? What impact does this have on the care and support offered and / or early prevention?
7   What are the most effective ways for adult social workers to work with people who self-neglect?
8   Does regular contact with an adult social worker and / or a long-term professional relationship with an adult social worker improve outcomes for people using services?
9   How well do adult social workers support person-centred decisions and ensure holistic support? How well do they take into account a person's physical and mental health problems?
10   Does partnership working between adult social workers and other health and social care professionals result in better outcomes for people using services?

The following questions were also discussed and put in order of priority

11 What are the most effective ways for adult social workers to work with people with acquired brain injury? What knowledge and skills do adult social workers need to work with this group?

12 How can adult social workers work more effectively with people using services to involve them in decisions about their own care?

13 How can adult social workers use their professional judgement to produce flexible and creative care plans that (a) meet individual's needs, and (b) anticipate and respond to changes in people's circumstances?

14 How can adult social workers develop whole family approaches that enable all family members to be involved in decision-making? Which models work best (e.g. family group conferencing or open dialogue models)?

15 What are the most effective ways for adult social workers to work with individuals who are transitioning between child and adult services?

16 What model of management and supervision provides the best support for adult social workers and ensures quality control of their work?

17 What are the most effective ways for adult social workers to work with people with learning disabilities and their families?

18 What are the most effective approaches to building relationships with people using services and their families? What working conditions enable adult social workers to use such approaches?

19 What difference does it make if social workers are the first point of contact, rather than receiving referrals via a triage system?

20 Would the use of therapy-based skills (e.g. counselling) benefit adult social workers' practice?

21 How can the health and wellbeing of adult social workers best be maintained (e.g. through working conditions, support and supervision)?

JLA long list of unanswered research questions in adult social work (not ordered by priority)	Topic
How is availability of funding impacting on (a) adult social workers' practice and (b) the decisions made?	Current national context
What impact is the Care Act having on (a) adult social work practice and (b) the outcomes for people using services and their carers, particularly their wellbeing and safety?	Current national context
Has the Mental Capacity Act 2005 been embedded into practice and what are the impacts on people using services and their carers?	Current national context
What factors promote effective working partnerships between adult social workers and other organisations/professionals? What are the barriers and how can these be overcome?	Working with others
When adult social workers work with other professionals, how are their decisions influenced by other professional cultures and values?	Working with others
How do other organisations/professionals understand the role and responsibilities of adult social workers and how could this be improved?	Working with others
How can communication and information sharing between individual adult social workers and between agencies /organisations be improved?	Working with others
What is the unique contribution of adult social workers to decision-making? What is their unique contribution when working with other professionals to provide support to people using services and their carers?	Working with others
What is the role of adult social workers in safeguarding children and the role of children's social workers in adult safeguarding? How can they work together?	Working with others
Would adult social work practice be improved by social workers developing specialist knowledge (e.g. in working with people with complex needs or in a specific area of practice such as safeguarding)?	Knowledge and skills
Would the use of therapy-based skills (e.g. counselling) benefit adult social workers' practice?	Knowledge and skills
How could communication between adult social workers and people using services be improved, especially with those people who have difficulty with communication (e.g. use of new media, better communication skills, working with other professionals)?	Knowledge and skills
What are the most effective approaches to building relationships with people using services and their families? What working conditions enable adult social workers to use such approaches?	Knowledge and skills
How do adult social workers contribute to safeguarding adult reviews and how do the lessons learned influence practice?	Knowledge and skills
What model of management and supervision provides the best support for adult social workers and ensures quality control of their work?	Management

JLA long list of unanswered research questions in adult social work (not ordered by priority)	Topic
How can the health and wellbeing of adult social workers best be maintained (e.g. through working conditions, support and supervision)?	Management
What is the best way to allocate caseloads to maximise the benefits to people using services and carers, and minimise the stress for adult social workers?	Management
What are the advantages and disadvantages of an adult social worker being an independent professional versus being part of local authority services?	Management
On what basis do adult social workers make their decisions (including the law, evidence, accepted practice, social work theories)?	Decision-making
How well are asset and strength-based decision making working in practice when used by adult social workers? What factors promote or prevent their use?	Decision-making
Is safety and minimising risk prioritised over the preferences of people using services? What impact does this have on people using services, particularly in terms of their health and wellbeing?	Safeguarding
How effective are adult social workers in safeguarding vulnerable people? How could they better empower people using services and their carers to protect themselves?	Safeguarding
What has been the impact of 'Making Safeguarding Personal', particularly in the longer term, on adult social work practice?	Safeguarding
What are the most effective ways for adult social workers to intervene when adults are being abused, including cases of domestic violence?	Safeguarding
How can the quality and impact of social work be routinely assessed, particularly in ways that matter to people using services and their carers? How could this evidence be used to improve adult social work?	Professional accountability and development
How well do adult social workers support person-centred decisions and ensure holistic support? How well do they take into account a person's physical and mental health problems?	Outcomes for service users
Does regular contact with an adult social worker and / or a long-term professional relationship with an adult social worker improve outcomes for people using services?	Outcomes for service users
Does partnership working between adult social workers and other health and social care professionals result in better outcomes for people using services?	Outcomes for service users
How can adult social workers help to prevent, reduce and delay needs and what difference does this make to people using services and their carers in the long-term?	Outcomes for service users

JLA long list of unanswered research questions in adult social work (not ordered by priority)	Topic
How is 'wellbeing' understood and incorporated into adult social work practice? How can we assess whether adult social workers impact on the wellbeing of people using services?	Outcomes for service users
How are adult social workers working with communities to develop community-led and asset-based support? What difference does this make and what are the barriers to success?	Outcomes for service users
How can adult social workers work more effectively with people using services to involve them in decisions about their own care?	Outcomes for service users
How can adult social workers develop whole family approaches that enable all family members to be involved in decision-making? Which models work best (e.g. family group conferencing or open dialogue models)?	Outcomes for service users
How can adult social workers use their professional judgement to produce flexible and creative care plans that (a) meet individual's needs, and (b) anticipate and respond to changes in people's circumstances?	Outcomes for service users
What is the role of adult social workers in reviewing the suitability and quality of services provided as part of a care plan?	Outcomes for service users
What are the most effective ways for adult social workers to work with people with dementia and their families?	Social work interventions
What are the most effective ways for adult social workers to work with people with learning disabilities and their families?	Social work interventions
What are the most effective ways for adult social workers to work with people who self-neglect?	Social work interventions
What are the most effective ways for adult social workers to work with people who need long-term care and their carers, either living in care homes or with their families?	Social work interventions
What are the most effective ways for adult social workers to work with people with acquired brain injury? What knowledge and skills do adult social workers need to work with this group?	Social work interventions
What are the most effective ways for adult social workers to work with people with mental health problems, including personality disorders?	Social work interventions
What are the most effective ways for adult social workers to work with people with chaotic lifestyles (e.g. problematic gambling)?	Social work interventions
What difference do adult social workers make to people who are terminally ill and their families and how can they do this effectively?	Social work interventions
What are the most effective ways for adult social workers to help people using services who are socially isolated and / or lonely?	Social work interventions
What are the most effective ways for adult social workers to work with individuals who are transitioning between child and adult services?	Social work interventions

JLA long list of unanswered research questions in adult social work (not ordered by priority)	Topic
What are the most effective ways for adult social workers to help people using services during discharge from hospital?	Social work interventions
What are the most effective ways for adult social workers to work with older people with care and support needs?	Social work interventions
What are the best methods of making an assessment of care and support needs and risks? How well are current approaches working?	Assessment
How can assessments be more holistic and focused on improving wellbeing?	Assessment
How are eligibility criteria applied to people with different types of needs and are the thresholds appropriate? What impact does this have on the care and support offered and / or early prevention?	Assessment
How do adult social workers respond when service users have different political beliefs? How well do adult social workers support service users to take part in political processes like voting? (	Other
How could adult social workers influence the types of services being developed and commissioned?	Other
Do practice frameworks for adult social workers make any difference to the lives of service users?	Other
How should adult social workers engage with people's spiritual or faith belief?	Other
Are there differences in the professional practice of adult social workers with lived / worked experience of having a caring role, to those who haven't?	Other
Can adult social workers help to improve the wellbeing, mental and physical health of refugees?	Other
If adult social workers set their own budget levels, does this achieve innovation in services and good outcomes for people using services?	Other
What difference does it make if social workers are the first point of contact, rather than receiving referrals via a triage system?	Other
What is the impact of private sector care / support agencies on the relationship between adult social workers and people using services?	Other
Does the commissioning of adult social care from the private sector affect adult social work practice?	Other
How do changing definitions in gender, religion and race affect adult social work practice?	Other

Appendix D: Questions about children and young people (excluded from the final list in Table 1)

Because of the administrative separation of responsibilities for Adult Social Care (Department of Health and Social Care) and for the Social Care of Children and Young People (Department for Education). NIHR SSCR only researches adult social care. For this reason, we excluded from Table 1 (pages 4–6) research priorities we found to be about children and young people, but have included them in the report here for comprehensiveness and hope they are useful to some funders of research. Please note that this is not a definitive list of research priorities for the social care of children and young people, merely those we encountered in carrying out this work.

What are the experiences and conceptualisations of mental health related targeted violence and abuse of male service users and survivors?

What interventions are effective and cost effective in:

– Improving practitioners' recognition of children who are at risk of female genital mutilation (FGM) in the UK or overseas?

– improving recognition of co-occurring forms of abuse where relevant?

– preventing FGM in this group?"

What are the components of effective home visiting programmes for preventing child abuse and neglect in families of children and young people at risk of child abuse and neglect in the UK?

Are home visiting interventions effective and cost effective in improving parenting and preventing recurrence of child abuse and neglect in families in which abuse or neglect is occurring or has occurred?

What interventions are effective and cost effective in:

– improving practitioners' recognition of children who are at risk of or experiencing 'honour-based' violence and forced marriage?

– preventing 'honour-based' violence and forced marriage?"

What is best practice in co-production for safer supported housing, social housing and psychiatric wards through effective reporting of and responses to targeted violence and hostility against people with mental health problems?

What interventions are effective and cost effective when working with fathers and male carers to improve their parenting in families where children are being, or have been, abused or neglected?

What interventions are effective and cost effective when working with male foster carers and adoptive parents who are caring for children and young people who have been abused in the past?

What is the relative effectiveness and cost effectiveness of the KEEP intervention for foster carers of abused or neglected children compared to other interventions?

Are web-based parenting programmes effective and cost effective for improving parenting and preventing recurrence of child abuse and neglect in families where child abuse or neglect has occurred?

What is the role of peer support, advocacy and social work in navigating complex systems following incidents of targeted violence and abuse?

What peer support programmes are effective and cost effective in improving the wellbeing of children and young people who have been abused or neglected?

What are the wider socio-economic, environmental and political risk factors relating to targeted violence and hostility against people with mental health problems?

What is the effectiveness of interventions with people at risk or who have suffered abuse?

What is the extent of neglect and abuse in mental health services and on wards and its relationship to adult safeguarding?

What is the impact of social isolation on children, young people and families at risk of abuse and neglect in the UK? What interventions are effective and cost effective in a UK context in reducing social isolation and any associated child abuse and neglect?

What interventions, including family behaviour therapy, are effective and cost effective in improving parenting and preventing recurrence of neglect by parents or carers with substance misuse problems and whose children are on a child protection plan under the category of neglect in the UK?

What interventions are effective and cost effective in improving the wellbeing of children and young people who have experienced online-facilitated abuse, including grooming online?

What interventions, approaches and methodologies provided by social care and voluntary sector services are effective and cost effective in the UK to prevent the recurrence of child abuse and neglect, and to improve the wellbeing of children, young people and families?

What approaches to practice enable children (both boys and girls) who have been sexually abused to begin to tell practitioners about their experiences earlier, and in a way that does not contaminate the reliability of subsequent court proceedings?

What interventions are effective and cost effective in the UK to prevent abuse and neglect of children and young people in families at risk of, or showing early signs of, abuse and neglect?

What interventions are effective and cost effective in improving the wellbeing of young people aged 12 to 17 who have experienced abuse or neglect, including those who are now in temporary or permanent alternative care placements or living independently?

Appendix E: Questions about methods (excluded from final list in Table 1)

As questions about research methods are different to those research priorities about practice we have excluded them from the list in Table 1, but present them here in case they are helpful to researchers and research funders. Again, though, we would stress that this is not an exhaustive list of priorities about research methods in adult social care, only a list of those we found in doing this scoping work.

When conducting research for the purposes of service improvement, what research methods are acceptable, appropriate and effective in meaningfully gathering the views and experiences of people who use services?

Examine the scalability of economic models, including barriers to changes in scale and cost implications

How can the understanding of the outcomes arising from the use of PBs be improved? (with better methodologies and avoiding bias)

How do LAs measure the impacts on well-being in carrying out assessments, is this consistent and how does it impact on whether or not older people are regarded as having eligible needs?

Develop robust methods for comparative analysis of social care outcomes across providers in public, private and third sectors, including a comparative cost-benefit analysis

Examine the current methods of impact measurement used by third sector organisations to monitor their performance

How can the assessment of impact of services be improved? Use outcome measures of social-care related quality of life

Analyse the implications for third sector organisations of moves towards co-production and personalisation

What approaches have been shown to work in supporting the co-production of research for the purposes of service improvement with people who use services?