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| **Agenda item:** | **9** |
| **Attachment:** | **C** |

**HRA BOARD COVER SHEET**

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| **Date of Meeting:** | 24 September 2018 |
| **Title of Paper:** | **Supporting social care research** |
| **Purpose of Paper:** | To update the Board on progress in supporting social care research and discuss next steps |
| **Reason for Submission:** | For discussion and to propose next steps for Board consdieration |
| **Details:** | Proposed next steps are set out in section 4 |
| **Lead reviewer (if applicable):** | Juliet Tizzard |
| **Board review required?** | Yes / ~~No~~ |
| **Suitable for wider circulation?** | Yes / ~~No~~  |
| **Time required for item:** | 30 minutes |

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| --- | --- | --- |
| **Recommendation / Proposed Actions:** | **To approve** |  |
| **For information / to note** | **Yes** |
| **For discussion** | **Yes** |
| **Comments** |  |

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| **Name:** | Amanda Hunn |
| **Job Title:** | Joint Head of Policy |
| **Date:** | 24 September 2018 |

# Social care research – Background briefing paper and next steps

### Introduction

* 1. We presented a paper on social care research to the HRA Audit and Risk Committee on 1 November 2017. We agreed to lower the risk rating associated with social care research and also to further debate social care research in more detail. Subsequently we held a Round Table Event for Social Care Research experts on 30 July 2018 to further scope the issues and priorities.
	2. This paper summarises where we’ve got to in our thinking and proposes next steps on taking the HRA approach to social care forward. The background to this issue, including our current arrangements for reviewing social care research, is at Annex A.

### Round table discussion

* 1. We held a round table discussion with social care research experts on 30 July chaired by Jonathan Montgomery. Participants included representatives from the Social Care Research Ethics Committee (SCREC), Research in Practice, ADASS, and NIHR School for Social Care, UKRI/ESCRC and academia. The aim of the round table was to consider how we work together to provide better support to social care researchers and the appropriate level of oversight of social studies. The discussions on the day were really valuable and helped to move our thinking on about how to improve the quality of social care research.
	2. In summary, participants confirmed our assumptions around the lack of research capacity in social care. The group went further and suggested that there is lack of a research culture in this area. The importance of evidence is not ingrained in those commissioning services and consequently the importance of research is not always recognised.
	3. Participants drew our attention specifically to problems around local research governance. In many cases, LAs do not have adequate resources to provide local research governance staff and processes, and even where they do exist there is no little consistency in process and expertise. A strong case was made for the HRA to support the development of local research governance in Local Authority settings. At the end of the day, participants identified the most important actions to take to improve social care research. These have been incorporated into the next steps section below.

### Next Steps

* 1. Building on the information we have collected so far, combined with intelligence and recommendations made at the Round Table event, we have developed a series of next steps which we have divide into two sections. The first table shows those simple next steps that we plan to take forward. The second table sets out some further recommendations for consideration by the Board.

#### Table 1 - Actions we plan to take forward

|  | **Recommendation** | **Actions** | **Benefits** | **Risks** |
| --- | --- | --- | --- | --- |
| **1** | Increase social care expertise in ethics review  | Supplement existing membership of London Camberwell and Coventry & Warwickshire RECs with new members with social care research expertise and/or replace members with natural turnover  | Would show a commitment to social care research and an intention to understand social care research in context. | No risks, recruitment can be carried out as membership turnover requires. |
| **2** | Ensure social care studies seen by appropriate RECs and expertise well-used (SCREC is underused) | Change the HRA booking system triage process so that the social research topic takes priority over Mental Capacity Act requirement in allocation of the study so that the SCREC is filled first | Better use of social care expertise and fewer meetings cancelled. | The risks are low as the SCREC is flagged to look at applications under the MCA. |
| **3** | Ensure our own information and guidance refers to social care | Review the HRA website and other material to ensure appropriate references made to social care research including case studies where appropriate. | Making the website more accessible to the social care community thus contributing to research culture and capacity. | No risks per se but will require resource. |
| **4** | Ensure that HRA training materials refer to social care research and include relevant case studies where applicable. | Develop new training material with both health and social care in mind where it is applicable. Invite ESCRC to join the external learning group. | Demonstrates that we take social care research seriously and will help to develop research culture and capacity | No risks |

#### Table 2 - Recommendations for consideration by the Board

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Recommendation** | **Actions** | **Benefits** | **Risks** |
| **5** | Increase social care research expertise at Board level  | Consider appointing a representative of the social care research community to the Board as a NED  | Shows commitment to social care research. | Social care research is a small proportion of overall business. |
| **6** | Work with other interested parties to support: - research culture - research capacity and- the importance of an evidence base  | Invite the following organisations to work collaboratively as part of a forum:- NIHR School of Social Care- SCIE- Research in Practice in Adults- UKRI/ESRC- DHSC- DE- Social Work England. | Support a research culture and encourage a wider recognition of the importance of research in social care.HRA will be seen as an authoritative body in leading this collaboration. | We have no authority to implement any of these objectives but with the backing of DHSC we may be able to lead and encourage strategic collaboration. |
| **7** | Consider the existing remit of the HRA for ethical review of social care research | Conduct an options appraisal of the HRA remit of ethical review of social care research | Provide more consistent protection of participants and support for researchers  | Risk of not being able to meet demand if remit is extended |
| **8** | Consider how the HRA can best support local research governance undertaken by LAs under existing arrangements | Establish a unified consistent process for research governance across LAs – perhaps encourage a federated approach whereby groups of LAs can work together on a single process.Provide simple and concise standards for local research governance by LAs | Encouraging some consistency across the country and providing some assessment of the quality of research particularly where it has not been subject to ethical review by the HRA.  | Some LAs will not have the resources to undertake any research governance, hence the suggestion to take a federated approach.   |

### Conclusion

* 1. Whilst we are mindful of the narrower remit for the ethical review of social care research and the calls for us to do more in this area, we are keen protecting participants and support social care research without introducing unnecessary bureaucracy. Clearly social care research does not include a great deal of interventional or experimental methodology where there is a serious risk of harm or of being deprived of ‘normal care’. However we know that our services in health research in terms of both ethical review and assessment have a clear role in promoting high quality research across the board. Any changes to our remit for both ethical review and assessment will likely require further consideration and discussion.
	2. Given the lack of a research culture in social care combined with a low level of capacity and resource, we feel that there is a need to support the social care community in recognising the importance of research in generating an evidence base and supporting researchers to do good quality research. Some of this can be done quite easily by making small changes to our website, eLearning material and other materials. However, other work will require collaboration with others in the social care community a range of other organisations.

# Annex A: Background

### Ethical review of social care research by the HRA

* 1. In April 2015, we took over responsibility for ethical review of the social care research studies previously reviewed by SCIE. Alongside the Social Care Research Ethics Committee (SCREC), there are now two other NHS RECs flagged to review social care research:

London – Camberwell St Giles

West Midlands – Coventry and Warwickshire

* 1. The three RECs reviewed 55 studies over the last year – a reduction from previous years. With around 5000 health studies going through HRA Approval each year, social care research represents 1% of our activity. Although there is much less social care research going on than there is health research, one reason for the low volume of studies is the narrower remit that we apply to social care research. We currently provide ethical review of:

social care studies funded by Department of Health and Social Care including research funded by the Policy Research Programme, NIHR and NHS Digital.

social care studies which fall under the Mental Capacity Act 2005.

social care studies that involve sites in England and another UK country.

own account research undertaken by councils where the CI or the sponsor feel that there are substantial ethical issues.

studies of integrated services (health and social care) where there is no clinical intervention.

studies taking place in NHS settings with NHS patients where the approach uses social science or qualitative methods and does not involve a change in treatment or clinical practice

intergenerational studies in social care where both adults and children or families are participants

adult social care research involving changes in or withdrawing of standard care.

other social care studies where there are ethical concerns but the study is outside the remit of NHS RECs.

* 1. We could expand the categories of social care studies that go through our RECS as our legal remit is wider. However, we are not empowered to provide ethical review of:

social care research involving children (this falls under DE)

social care research involving self-funded service users in the independent sector.

* 1. The narrower remit for ethical review of social care research (which we retained when we took over the SCREC) means that we don’t usually review unfunded research unless it involves the Mental Capacity Act. Whilst there is limited use of interventional methodology in social care research, other methods can expose participants to different types of risks and we cannot be sure that the research is reviewed elsewhere either from an ethical perspective or for a research governance purpose.
	2. A further reason for the low number of social care studies coming to us for ethical review is that the NIHR funding round has a five year cycle which runs to March 2019. Most of the funding was initiated in the 2nd year of the cycle (15/16) and no new funding is made available in the last two years of the cycle hence no new NIHR funded studies are coming to the SCREC now. As NIHR is the main funder of social care research, this impacts significantly on the flow of applications.

### Ethical review outside of the HRA

* 1. We are not able to accurately assess how many social care research studies are ethically reviewed outside of the HRA, though the possible pathways are:

review by a University Research Ethics Committee

review by a local authority ethics committee

no ethical review at all.

#### *University RECs*

* 1. Universities are likely to account for a large proportion of social care research, including both funded and unfunded social care research together with unfunded student research. So, it is likely that most ethical review of social care research that does not fall within our remit is conducted by University Research Ethics Committees. We know from our work with universities and from our listening events that the quality of ethical review undertaken by universities is variable.

#### *Local authorities*

* 1. We know that local authorities are conducting less research directly themselves. LAs have seriously cut back on their R&D spend in last 10 -15 years. In the past LAs often employed dedicated Research Managers and researchers to conduct their own research; many of these roles no longer exist.
	2. Whilst Directors of Adult Social Services in each LA are technically responsible for social care research, the day to day responsibility is allocated to a multitude of roles – often individuals with other roles to fulfil. This would suggest that research governance conducted by LAs is likely to be variable and could be lacking in robustness in some places, given their lack of resources.
	3. Studies which involve four or more LAs are reviewed by ADASS, who endorsed only 14 studies in 2017. ADASS charge for their services but it is not clear that the service they provide meets the normal requirements of research governance.

### Research governance in social care research

* 1. We do not currently provide an assessment service for social care research. Currently the responsibility for local research governance falls to Local Authorities. Beyond ethical review, research governance in social care is not consistently applied. Individual universities and some LAs apply some research governance. However, LAs have little resource to devote to research governance in their gate keeping role.

#### *Care homes and self-funders*

* 1. There are over 18,000 care homes in England providing homes and care for over 386,000 people. Research involving care homes is thought to be on the increase with a growing interest from researchers in both social care and health.
	2. Stakeholders have reported issues with obtaining research governance approval for research in care homes in England. Research governance for care homes is extremely variable and to some extent reflects the different service provision.
	3. Service users with places in an independent care home funded by the local authority or the NHS are covered by the latter’s research governance system. However those service users who are self-funded in an independent care home may not be covered by a research governance process and fall outside of the HRA remit legal remit. Similar issues around research governance apply with self-funders in other settings, such as in domiciliary care where users employ their own carers with a personal budget.