

Commissioning of Social Care Research Recommendations: Scoping Review Prepared for the National Institute for Health and Care Excellence (NICE) Research Support Unit (RSU)

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The views expressed in this report are those of the authors and not necessarily those of the National Institute for Health and Care Excellence or the NICE Research Support Unit.

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1 EXECUTIVE SUMMARY

KEY POINTS AND RECOMMENDATIONS

- Relative to health research, available budgets for social care research tend to be much smaller.
- With the exception of the NIHR School for Social Care Research (SSCR), no funding organisation solely, or primarily, funds social care research.
- Except for NIHR SSCR and Health and Care Research Wales, funding organisations do not manage their budgets so that social care research funding can be separately identified, nor do they have social care-specific calls or processes.
- Interviews conducted for this study suggest that formal research recommendations are not systematically consulted to inform funding priorities.
- Formal research recommendations may, however, be consulted in scoping studies, once topic areas have already been identified as priorities.
- Many funding organisations are not just research funders, but have multiple strategic objectives to balance.
- The organisations interviewed for our study were open to accommodating NICE research recommendations within their funding programmes provided they fitted with their strategic priorities.
- Interviewees said they thought NICE was generally seen as “about health” suggesting that NICE needs to promote itself as being active in social care research.
- Social care funding organisations do not generally have formal processes for engaging with external organisations such as NICE, necessitating that NICE adopts a responsive approach.
- The NIHR School for Social Care Research and the Economic and Social Care Research Council have relatively large budgets, flexibility in what they fund and do not have to balance research funding priorities with other organisational priorities.
- NIHR health-related funding programmes may be particularly relevant for research recommendations around the health/ social care interface.
- Other, often charitable, organisations may be most relevant where NICE research recommendations relate to specialist topic areas.
- NICE may need to be flexible in the research designs and methodologies it proposes, given smaller available research budgets, as well as more limited capacity in the sector generally and in some types of research methodologies in particular (e.g. quasi-experimental research, economic evaluations).
- NICE should consider the potential funding sources for research recommendations as an integral part of developing social care guidance.

1.1 Aims of this report

NICE seeks to develop a strategic approach to help ensure that research recommendations, produced as part of its social care guidance, are funded and lead to commissioned research projects. This report aims to inform the development of such an approach.

1.2 The 'landscape' for social care research funding

Compared to health research, much less funding is available for social care research. The National Institute for Health Research (NIHR) has an overall budget of £1 billion (approximately 1 per cent of overall NHS spending). In comparison, funding for the NIHR School of Social Care Research (NIHR SSCR), a major funder in this area, is £15 million over 5 years, from May 2014-April 2019 (with an earlier round of funding, covering May 2009-April 2014). The infrastructure for distributing social care research funding is also less developed. The infrastructure for funding children's social care research is particularly fragmented and the research that is funded, generally very small scale.

There is no clear agreement on where the boundaries of social care research lie and, for this reason, few funders attempt to identify how much of their research budgets are spent specifically on social care research. The Economic and Social Research Council (ESRC), for example, identify research spending by academic discipline.

There are many areas of unaddressed research need in social care. NICE social care research recommendations are, therefore, entering a crowded market of unaddressed research gaps while, at the same time, researcher capacity for addressing these needs is relatively limited. NIHR SSCR note that, while the quality of proposals submitted to them has improved in recent years, in part due to a range of initiatives and support introduced by the NIHR SCCR, there continues to be limited capacity in the sector to undertake high quality research, especially in specialist areas and some methodological specialisms (e.g. economics, quasi-experimental research).

1.3 How funding priorities are set

Priority setting for social care research funding tends to be flexible and responsive, rather than highly structured or routinised. Most funders have an advisory group and undertake consultation exercises, often at irregular intervals, with these generally used to identify broad areas of priority rather than specific research topics and questions. Many funders have open calls, accepting high quality proposals for research on topics outside of identified priority areas.

There are some examples of more structured priority-setting exercises (e.g. the Alzheimer's Society and James Lind Alliance priority setting partnership for identifying and prioritising service user priorities in dementia research). However, this type of formal priority-setting exercise tends to identify high-level priorities and, while they may help to guide the direction of research funding, their breadth means that the link between these priorities and the funding of specific research projects is not always clear. Such formal consultations can also be time-consuming.

NIHR SSCR and the ESRC fund research as their primary and main activity. However, other funders, such as Government departments and charitable organisations, have competing objectives. These include addressing political and policy priorities in the case of Government departments, or lobbying and organisational positioning in the case of charitable organisations. These other priorities influence the research topics and questions that are funded.

Organisations that we consulted were generally unable to describe any experience of using formal research recommendations to inform their funding priorities. However, some said they might consult them when scoping a specific topic. Others, with experience of funding health research, had previously consulted sources such as the NICE-hosted Database of Uncertainties about the Effects of Treatments (UK DUETs¹), Cochrane reviews and other high quality systematic reviews to inform their research calls. However, these organisations nonetheless lacked practical experience of commissioning research on the basis of these recommendations, reporting a lack of response from researchers.

1.4 Key social care research funders

NIHR SSCR and the ESRC are two of the largest and most comprehensive funders of social care research. These organisations have relatively (for the sector) large budgets and flexible commissioning processes and are able to respond to well-developed research recommendations where these exist. They also have links into, and knowledge of, many smaller funders.

NIHR SSCR provides funding for adult social care research and has a broad view of the sector. However, NIHR SSCR is currently only funded until 2019 so is currently unable to commission projects that would complete after this date. NICE should remain in contact with NIHR SSCR to monitor developments here.

¹ <https://www.nice.org.uk/about/what-we-do/evidence-services/database-of-uncertainties-about-the-effects-of-treatments-uk-duets>

Where NIHR SSCR and ESRC include priorities identified by NICE in their research calls, they cannot ring-fence funding for these purposes; whether such projects are funded in practice will depend on receiving proposals of suitable quality.

NIHR funding programmes for health research such as Health Technology Assessment (HTA) or the Health Services and Delivery Research (HS&DR) may be particularly relevant for research that sits on the boundary between health and social care.

1.5 Other social care research funding bodies

Other funding bodies tend to have narrower remits than NIHR SSCR, ESRC and NIHR. These may be relatively broad (e.g. social well-being) or more specific (e.g. a particular health condition or specific social problem). Within this, some organisations may have a stable remit, while others may shift their areas of focus over time, for example, in response to the policy environment. Some organisations primarily fund health research, but may also fund social care research where this is relevant to their area of interest. Few are likely to consider themselves explicitly as social care research funders.

Government departments generally focus on the development and evaluation of service delivery models in external research programmes and the ad hoc research needs of policy teams in internal research programmes.

Charitable funders may commission research with organisational and political or lobbying objectives in mind, and many may prefer to focus on action-based projects or projects with direct and immediate benefits to their constituents. However, there may be opportunities for NICE research recommendations to influence the research funded by these organisations where they coincide with, or fit, organisations' existing priorities. Occasionally, the research funding function is more 'arms-length' from other parts of the organisation, allowing for greater breadth in the types of research funded.

Research funders in some topic areas have more infrastructure than others. For example, end of life care has The UK End of Life Care Research Interest Group, currently chaired by Marie Curie. Ageing research is also well covered and represented by a network group, the UK Age Research Forum. The infrastructure in other areas, particularly in children's social care, is more fragmented.

We recommend that, while developing its research recommendations, NICE simultaneously identify who the most relevant potential research funders are likely to be. This is not likely to be onerous as there are likely to be very few - often only one or two - in any specific topic area. It is also probable that such organisations will already be known to NICE through its evidence gathering.

Given the wide range of social care topics that may be covered by NICE research recommendations and the wide range of sometimes small, specialist organisations that could potentially support research in these areas, it is not possible, within this report, to provide a comprehensive mapping of all such organisations. However, a selection of larger and more prominent funding organisations is detailed in Chapter 4 of this report.

1.6 Strategies for engagement

In the interviews we conducted with representatives of a range of funding organisations, we encountered much goodwill and willingness to accommodate NICE social care research recommendations. However, blanket communications about research recommendations are unlikely to be effective in most cases. Most of the organisations that fund social care research will not fund social care research solely, nor will they cover all areas of social care. Few will recognise themselves as social care research funders and for any individual organisation, the vast majority of NICE research recommendations are likely to be irrelevant. Respondents commented that, for these reasons, NICE social care research recommendations were unlikely to be routinely consulted and general communications about NICE's social care recommendations would be overlooked. The exception to this is the NIHR SSCR.

The advice to NICE from those we interviewed was to engage directly with individual funders, particularly those who may have a special interest in the specific area to which the research recommendation pertains, and also to do this as early as possible so that there is time to explore the 'fit' of recommendations to the organisation's own objectives and existing programmes.

1.7 Formulating research recommendations

Some of those we interviewed commented that if NICE research recommendations were too narrow and prescriptive it could be difficult to incorporate them into their organisational priorities or thematic programmes. Others felt less constrained and were willing to fund projects based directly on NICE research recommendations, however specific. This may be in the context of open calls. However, on the other hand, there was concern that if recommendations were too broad and general, then they were unlikely to add value.

It was also thought that NICE may need to be flexible concerning the research methodologies they recommend for addressing specific research questions. This is because of the significant and numerous methodological challenges involved in conducting social care research and the fact that, partly as a result of this, the capacity of the research sector to deliver high quality research is limited, particularly research that uses certain

methodologies (e.g. economics, quasi-experimental research) or in smaller and more specialised areas of social care research. It was noted that in some areas, the only available evidence may be low quality or based exclusively on small-scale qualitative evidence, or it may be published in grey literature and carried out by not-for-profit organisations rather than by academics or specialist researchers. NICE may need to decide whether to adapt its guideline methodology to include these different types of evidence in a realist-type review as well as consider how far it is likely to be able to prompt higher quality or more extensive research in these areas given the likely the significant methodological challenges that are often involved.

2 INTRODUCTION

2.1 Aims

NICE has a process, working with the NIHR, to help ensure that its clinical, health and public health recommendations for research are commissioned as research projects. In parallel, NICE seeks to develop a strategic approach for ensuring that research recommendations, produced as part of its social care guidance, also lead to commissioned research projects. This report aims to inform development of such an approach.

2.2 Methods

The methods used in this study were:

- Consultation of online and other public sources to identify relevant information about organisations that fund social care research; and
- Interviews with representatives from a selection of these organisations.

Selection of organisations

It was not possible within the scope of this study to comprehensively map all potential funders of social care research. Rather, we purposively selected research funders for mapping and, from these, then selected a smaller set of organisations to approach for personal interviews, focusing on England and Wales and on larger research funders. We acknowledge that, in prioritising larger funders, a significant number of smaller research funders (especially those that fund children's research) are not included. Within our sample, however, we did aim to cover funders of different types (e.g. research councils, public bodies, government departments, charitable foundations, advocacy organisations etc.), with different sources of funding and governance structures, and with different remits and areas of social care interest. We also interviewed two academic bodies working closely with research funders, including children's social care research and a relevant professional body.

We used a variety of methods to identify interviewees through the research offices of our respective universities, research funder directories, online searching and via our personal knowledge and networks.

Interviews

We selected a small number of organisations to approach for interview based on information identified through publicly available and other sources accessible to us, with a view to gaining perspectives from a wide range of research funding organisations. We also

identified two organisations (a professional organisation and an academic body) that work closely with social care research funders. For each organisation with responsibility for commissioning research that we contacted, senior individuals were identified for interview. A small number of organisations declined to take part in the review on the grounds that they did not engage actively in the commissioning of research or in the shaping of research priorities.

Discussion-based qualitative interviews of between 20 and 40 minutes' duration were conducted with the identified interviewees (n = 12). A brief topic guide (included in Appendix 1) was used to elicit information about the interviewee's organisation, their approach to commissioning social care research and experience of using research recommendations, as well as general insights and considerations for NICE in developing their strategic approach.

Findings from the qualitative interviews are reported in Chapter 1 (Executive Summary) and Chapter 3 (Key Findings) of this report. It is made clear where points relate to specific organisations or types of organisation. Where possible and appropriate, some information was also elicited to augment the organisational summaries (reported in Chapter 4 of the report). However, it was not possible or appropriate, within the scope of an interview with a single senior individual, to systematically or comprehensively collect a range of pre-defined factual information to augment what was available publicly. Nor was it within the scope of this study to undertake extended research with each organisation for these purposes.

Interviews were conducted face-to-face, where this was possible, while others were conducted by telephone. Written notes were taken consecutively and key findings were summarised and typed up immediately following each interview. Some follow up by email correspondence was entered into where required (e.g. information that the respondent agreed to forward following the interview). Respondents from the following organisations were represented:

- Two Government departments;
- One non-departmental public body;
- Two Government sponsored (funding organisation/ research council);
- Four charitable organisations;
- One professional body; and
- Two academic organisations.

Findings from these interviews are set out in Chapter 3 of this report. These are structured under a series of headings, reflecting NICE's requirements set out in the brief for this work. These are:

- The current landscape for the funding of social care research

- How organisations establish their research funding priorities
- Key groups and networks associated with social care funding (and contact details)
- Experience of using, and views on, social care research recommendations
- Other strategic considerations and next steps
- Contacts and further discussions.

Organisational summaries

Chapter 4 of this report provides organisational summaries for a wider range of organisations to assist NICE in identifying potential external funding streams for NICE social care research recommendations. These draw primarily upon a range of publicly available sources and, where relevant, are augmented by the interviews with representatives from funding organisations and the pre-existing knowledge of the report's authors.

3 KEY FINDINGS

3.1 The current landscape for the funding of social care research

Overview

The sector that funds social care research oversees considerably smaller sums of money than those available for health research. NIHR has an overall budget of £1 billion (approximately 1 per cent of overall NHS spending). However, for the purposes of broad comparison, the funding for NIHR SSCR (established in May 2009) is £15 million over five years, from May 2014-April 2019 (with an earlier round of funding, covering May 2009-April 2014). The school covers adult social care only, practice (rather than policy) and covers England only. To put this in further context, there are two other 'schools' funded by NIHR. One for primary care has a budget of £30 million over five years, plus additional funding for capacity development, fellowships etc., and one for public health which has a budget of £20 million over five years.

Health research also has a stronger overarching infrastructure of major funders (notably NIHR and the Medical Research Council, MRC) and funding representative organisations (notably the Association of Medical Research Charities, AMRC), which, combined, give more strategic direction, lobbying and fund raising power to health research. This also provides for diversity amongst smaller funders allowing, especially charitable, organisations to specialise in different health conditions (e.g. cancer, heart disease) and/or aspect of health research (e.g. the Human Tissue Authority, basic science, translational research). Social care research does not benefit from having such a well-developed infrastructure and is consequently more disparate and fragmented. Organisations funding social care research include:

- Government departments, directly commissioning research for policy needs and outward-facing research funding programmes
- Government-sponsored bodies and research councils
- Charitable organisations, charitable foundations and advocacy groups.

These different organisations vary considerably in their size and in their aims, objectives and remits and the types of research evidence they produce (e.g. academic peer reviewed articles versus unpublished grey literature reports). They also vary in how much of their activity and budgets are devoted to research, both to research in general and to social care-related research in particular. In the vast majority of cases, organisations were not able to distinguish how much of their budgets were spent on social care research, because their budgets were not structured in this way and because of difficulties in defining what counts as social care research. Some funders we interviewed spoke of explicitly trying to expand

the amount of research they fund on issues concerning the interface between health and social care, integration or joint working between health and social care services. Other organisations primarily fund health research but do not exclude social care. Still others may fund research around a condition (e.g. Alzheimer’s Society) or a particular social issue (e.g. Joseph Rowntree Foundation on poverty). To the degree that organisations fund social care research, they also vary in the sort of research they fund, ranging across policy-driven research, programme evaluations, academic ‘blue sky’ research and more applied and translational research.

The landscape of children’s social care research funding is even more complex than adult social care. Children’s health conditions are more numerous, with relatively small number of children in each disease category. This makes undertaking research more challenging. As noted by Dame Sally Davis in her report ‘Children Deserve Better: Prevention Pays’², children’s health and social care generally lacks a robust evidence-base and, even compared to adult social care research, is critically underfunded. Because, in this report we necessarily focus on the major funders of social care research, it is important to note that many smaller charitable organisations may fund the only relevant evidence on a specific children’s social care issue.

Social care research producers versus social care research funders in children’s social care research

In this report we mainly focus on organisations that facilitate open competitive research funding schemes or otherwise provide funding to researchers to carry out research studies. There are however many organisations that are major or niche producers of social care research, particularly in children’s social care. Barnardo’s, for example, has an internal research department that funds a programme of children’s social care research³. Likewise, the National Society for the Prevention of Cruelty to Children (NSPCC) funds an internal research department and programme of work on child safeguarding⁴. The Kings Fund, similarly, produces research on a range of health and social care topics with a specific stream of social care research⁵. Smaller charities also commission specific pieces of research (e.g. an analysis of return on investment of children’s wheelchair provision⁶). The types of research produced by such organisations frequently provide the main, or only, evidence on some issues. Furthermore, some research is unfunded. For example, many of the systematic

²https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/255237/2901304_CMO_complete_low_res_accessible.pdf

³http://www.barnardos.org.uk/what_we_do/policy_research_unit/research_and_publications.htm

⁴<http://www.nspcc.org.uk/preventing-abuse/research-and-resources/>

⁵<http://www.kingsfund.org.uk/topics/social-care>

⁶http://www.whizz-kidz.org.uk/uploads/general/Healthcare_professionals/Social_Return_on_Investment_for_Whizz-Kidz_services.pdf

reviews in the Campbell and Cochrane libraries have been produced at no cost by volunteers. It is unclear whether these sources of ‘research capacity’ are able to engage with NICE’s social care research recommendations, but in some specialist areas they may be of importance.

3.2 How organisations establish their research funding priorities

Evidence-based methods for research prioritisation

Research priority setting is a relatively new concept in social care, and is complicated by the interface with health care and the multiple stakeholders involved. Consequently, flexible and less structured approaches are commonly adopted. However, more formal exercises are sometimes undertaken and there is an emerging methods literature on research priority setting that applies to both health and social care research prioritisation. For example, the James Lind Alliance has produced a research prioritisation methods manual that has been used in a UK health and social care context⁷. Cochrane has an Agenda and Priority Setting Methods Group and lists relevant methods literature on its website⁸. The US Department of Health and Human Services Agency for Healthcare Research and Quality has also developed the Prioritisation Criteria Methodology for Future Research Needs Proposals within the Effective Health Care Program: PiCMe-Prioritization Criteria Methods⁹. There is also a recent systematic review on health research priority setting methods in selected high income countries¹⁰.

There are, however, few published examples of formal priority setting exercises in social care. One recent example, covering palliative and end of life care, was initiated by Marie Curie in 2013 and took 18 months to complete¹¹. In this example, James Lind Alliance research prioritisation methods were used to include around 30 organisations and groups, resulting in a ‘top 10 of unanswered research questions’ including questions relevant to social care such as ‘*What are the benefits, and best ways, of providing care in the patient’s home, how can home care be maintained as long as possible and does good coordination of services affect this?*’ It is not yet clear, however, how these 10 questions will translate into specific funded research projects.

⁷ http://www.lindalliance.org/pdfs/Methods_page/JLA_Priority_Setting_approaches_V2_Nov_09.pdf

⁸ <http://capsmg.cochrane.org/>

⁹ Andrews J (ed) AHRQ Methods for Effective Health Care, Agency for Healthcare Research and Quality (US); 2013 Jan. Report No.: 12(13)-EHC152-EF, Rockville (MD). Accessed from <http://www.ncbi.nlm.nih.gov/books/NBK49468/>

¹⁰ Bryant J, Sanson-Fisher R, Walsh J, Stewart J (2014) Health research priority setting in selected high income countries: a narrative review of methods used and recommendations for future practice, Cost Effectiveness and Resource Allocation, 12:23. Accessed at <http://www.ncbi.nlm.nih.gov/pubmed/25873787>.

¹¹ The Palliative and end of life care Priority Setting Partnership, January 2015 http://www.palliativecarepssp.org.uk/wp-content/uploads/2015/01/PeolcPSP_Final_Report.pdf

Horizon scanning

Organisations generally have some form of advisory group as well as a process (or processes) for wider consultation and environment/ horizon ‘scanning’ in order to inform their funding priorities. NICE may be represented in these processes, although at present this seems to be generally from a health perspective. Different funding organisations will bring different considerations to this process, consult different stakeholders and review different sources of information. Research recommendations, from whatever source, did not feature strongly in these processes for the organisations we spoke to. One or two respondents did refer to identifying NICE and other relevant research recommendations as part of scoping a commissioning brief, but only after they had already specified a topic area of interest. One primarily health-related research funder, was unique amongst the organisations we spoke with, in that they regularly consulted Cochrane reviews and NICE research recommendations to identify research gaps.

Government departments

Government departments, because they are amongst the largest funders of social care research (the Department for Education, DfE, for example, spend an annual £8 million on research into children’s social care), have the potential to take an objective and considered overview on research needs and are able to establish large, systematic and comprehensive programmes of funding. It was, however, recognised that Government’s external research programmes commonly focus on evaluating new and innovative approaches to service delivery rather than addressing specific evidence gaps or undertaking more academic or ‘blue sky’ research. For example, the Department of Health runs the Innovation, Excellence and Strategic Development Fund (IESD) grant programme, worth £6.9 million in 2012, in which voluntary sector organisations are invited to submit proposals that test and develop innovative approaches to health and care¹².

Similarly, the DfE runs the Children’s Social Care Innovation Programme, which has been set up to provide tailored and substantial support – £30 million in 2014/15 and a much larger amount in 2015/16 - to pilot and test innovative approaches to supporting children requiring care from social care services¹³ with Professor Judy Sebba, at the Rees Centre, Oxford (judy.sebba@education.ox.ac.uk) heading up the Research Evaluation Framework for this programme. ‘Inward-facing’ Government research, focused on the needs of policy teams, is necessarily driven by political priorities and can be reactive. While our interviewees from Government departments did not rule out being able to accommodate a NICE identified priority within their programmes and evaluations, these do not seem to provide ‘a natural fit’ for NICE social care research recommendations.

¹² <https://www.gov.uk/government/publications/iesd-voluntary-sector-funding-for-health-and-care-projects>

¹³ <https://www.gov.uk/government/publications/childrens-services-innovation-programme>

Charitable, advocacy and lobbying organisations

Charitable organisations and those that have a lobbying or advocacy role will have broader objectives that extend beyond the funding of research. In addition to addressing research evidence gaps, their priorities will also be guided by wider strategic, lobbying, political and organisational objectives, and by judgments about where they can make most difference, to policy and/or to practice. Such organisations may also aim to ‘find a niche’ by addressing areas that are not well addressed by other similar organisations. Some may also deliver social care services and support (either commissioned or self-organising), using a mixture of paid workers and volunteers.

Larger charitable foundations have greater independence in the priorities they set and may consider themselves to have an important role in ‘leading the agenda’. Given that social care is an area that has considerable gaps in evidence, there is wide scope for organisations in this sector to select somewhat different priorities for the research that they choose to support and they may not be incentivised to ‘pick up and run with’ research priorities generated elsewhere. JRF, for example, after a long period of funding research around the theme of ‘ageing society’, which included social care research funding, has shifted its focus for the next period (three years or so) to look at the direct effects of poverty on pay and conditions in the social care workforce and on embedding learning from previous research into their own housing-based services.

Charitable and lobbying organisations are also likely to want to pursue research thematically or through programmes of linked projects in order to establish a ‘critical mass’ of relevant research in an area of lobbying interest rather than to fund disparate or single small studies. However, organisations we consulted did vary in their approach. Some said that they would consider funding specific projects where they could influence policy or practice and improve outcomes in their area of interest, while others described being willing to fund research priorities and questions identified as important through rigorous processes, including Cochrane reviews, high quality systematic reviews and NICE research recommendations.

Some charitable organisations may also be more geared to supporting pilot initiatives, innovative practice and programmes of action and only, as part of this, fund, albeit sometimes significant, evaluations. We identified a wide range of research funding that is spent in this way, exploring new approaches and service delivery models, and mirroring the large ‘innovation-focused’ Government research programmes discussed in the previous section. For example, the Big Lottery (technically, a non-departmental public body) has a £7 million evaluation programme, being conducted over a 10-year period, for their *A Better Start* early years intervention programme¹⁴. Organisations may also be providing this type of evaluation funding as part of wider consortia and, themselves, have limited engagement

¹⁴ <https://www.biglotteryfund.org.uk/betterstart>

with evaluators. One charitable organisation, for example, said it rarely funded social care research and had no such funding in its current programme. However, we later identified academics being funded by a consortium of funders, including this organisation, to conduct an evaluation on a children's social care programme. In children's social care research, smaller organisations are adapting to the new commissioning environment in England by competing for contracts to deliver government-funded services, which require evaluation as part of the contract (e.g. Whizz-Kidz delivers wheelchair services and life skills programmes under this model, and has commissioned social return on investment research, which has been used by the Government in England).

It is not inconceivable that NICE social care research recommendations could be addressed within such evaluations, especially where there is early engagement. However, these would need to fit comfortably within the programme evaluation activity, which may only be possible in exceptional cases. Evaluation research also, commonly, needs to be more flexible and pragmatic than the research NICE might generally wish to promote, with research programmes sometimes having to be re-designed at the last minute as initiatives change and evolve or where things on the ground don't work out as planned. Many organisations also described spending part of their research budgets on evaluating their own services. Other large organisations involved in children's social care research such as the NSPCC and Barnardo's are major commissioners of social care support and services for children and families, which are monitored by the Care Quality Commission as well as evaluated internally.

Government-sponsored research funding organisations/research councils

Organisations for whom research funding is the core activity have a range of processes for setting themes for research calls. These are generally based on a two-stage process. Firstly, there is wide consultation to inform broader thematic priorities and then, once there is agreement about the areas to focus on, more in-depth analysis is undertaken into specific topics. Identifying formal research recommendations is most likely to be undertaken at this more detailed stage. The organisations we spoke to believed that NICE recommended research priorities could be included in their future research calls. Although funding for these could not be ring-fenced, these could be set, in an appropriate way, within a wider set of thematic priorities and open research calls.

Funding of research centres

Some organisations fund or part-fund specialist research centres and, in this way, effectively delegate some of their priority setting for research funding. Such centres are discussed in more detail in the next chapter.

Consultation with users and unpaid carers

Direct consultation with service users and carers forms part of most organisations' priority-setting activity. This may be done in various ways. For example, some organisations have carried out consultations with the public or particular groups of service-users. Others have standing user and carer advisory or reference groups. Two organisations have undertaken systematic survey, consultation and priority setting exercises in partnership with the James Lind Alliance (discussed above); these are Marie Curie¹⁵ and the Alzheimer's Society¹⁶. These priority-setting processes tend to set broad areas of priority rather than identify specific research questions or narrow areas of enquiry. The organisation INVOLVE¹⁷ and its Welsh counterpart INVOLVING PEOPLE¹⁸ also play a key role in facilitating public involvement in all aspects of health and social care research, and aim to contribute to the process by which research is identified, prioritised, designed, conducted and disseminated. In the children's sector, Together for Short Lives¹⁹ and the Association for Paediatric Palliative Care Medicine²⁰ facilitate a joint research board that has prioritisation of research as part of its remit (currently chaired by Professor Bluebond-Langner, bluebond@ucl.ac.uk). Some groups (e.g. children and young people) are, however, rarely directly consulted to identify research priorities of importance to them and their families.

3.3 Groups and networks associated with social care funding

There are a number of research groups and networks relevant to social care research. These take various forms, reflecting the diversity of the sector, and generally include membership-based networks designed to coordinate efforts between research funders, research-active professional associations, 'what works centres' and jointly funded research funding bodies (set up to attract outside funding and conduct research). In this section, we identify some of the key groups relevant to adult social care research.

In the children's sector, the focus tends, instead, to be on individual named researchers or teams who commonly include social care issues as part of a wider children's research remit. These build their own relationships and coalitions, with specific organisations and other like-minded researchers. Children's research networks are few. Those that exist are unfunded and mainly self-organising and commonly have no virtual presence, such as the Disabled Children's Research Network whose remit is to develop the future disabled children's research agenda.

¹⁵ <http://www.palliativecarepsp.org.uk/>

¹⁶ http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1804

¹⁷ <http://www.invo.org.uk/>

¹⁸ <http://www.wales.nhs.uk/sites3/home.cfm?orgid=1023>

¹⁹ <http://www.togetherforshortlives.org.uk/>

²⁰ <http://www.appm.org.uk/>

Membership-based networks

There are a number of membership-based networks of research funders covering social care research. Key amongst these are:

- The UK end of life care Research Interest Group (UK eolcRIG)
- The National Cancer Research Institute (NCRI), and
- The UK Age Research Forum (UK ARF).

Each of these includes a wide range of relevant research funding organisations. Some of the networks have a wide brief (e.g. ageing research), while others are more specialised (e.g. cancer research). More detail on these three networks is provided below.

UK end of life care Research Interest Group (UK eolcRIG): Key contact: Dr. Sabine Best, Head of Research at Marie Curie, 89 Albert Embankment, London SE1 7TP, Tel. 020 7091 4144, sabine.best@mariecurie.org.uk, <http://www.ncri.org.uk/initiatives/eolc>.

The UK eolcRIG is a group of research funding bodies and affiliated organisations with an interest in end of life care, which operate one or more competitive, peer-reviewed funding streams for research into end of life care. Members include:

- Age UK
- Alzheimer's Society
- British Heart Foundation
- British Lung Foundation
- Chief Scientist Office
- Department of Health
- Dimpleby Cancer Care
- ESRC
- Marie Curie
- MS Society
- NIHR
- National Institute for Social Care and Health Research (Wales)
- Parkinson's UK
- Stroke Association
- Target Ovarian Cancer
- Lung Cancer Foundation
- Wellcome Trust

The UK eolcRIG was initiated by the National Cancer Research Institute in 2011, but has been open to non-cancer funders from the start. Marie Curie organises the annual meeting and the group has an independent chair, Professor Jane Seymour (University of

Nottingham). The UK eolcRIG's aims are to bring supportive, palliative and end of life care for all diseases and conditions into the mainstream of health and social care research, raising the awareness of both funders and researchers to the needs and opportunities for research in the field.

National Cancer Research Institute (NCRI): Coordinator: Jodi Baxter, email.

Jodi.baxter@ncri.org.uk / Director: Karen Kennedy, email. karen.kennedy@ncri.org.uk

<http://www.ncri.org.uk/about-us/members>

The NCRI is comprised of 22 partner organisations, either Government-based or charity organisations, each of which spends at least £1 million per year in funding competitive, peer-reviewed cancer research projects. Members include:

- Association of the British Pharmaceutical Industry
- Bioscience for the Future
- Breakthrough Cancer
- Breast Cancer Campaign
- Cancer Research UK
- Chief Scientist Office
- Children with Cancer
- Department of Health
- ESRC
- Health and Social Care Public Health Agency (Northern Ireland)
- Leukaemia and Lymphoma Research
- Ludwig Cancer Research
- MacMillan Cancer Support
- Marie Curie
- Medical Research Council
- National Institute for Social Care and Health Research (Wales)
- Prostate Cancer UK
- Roy Castle Cancer Foundation
- Tenovus
- Wellcome Trust.
- Worldwide Cancer Research
- Yorkshire Cancer Research

The NCRI aims to coordinate members' research activities, avoid duplication and maximise the impact of research for cancer patients and the public. Member organisations are primarily funders of health research but not exclusively so, with the current strategic aims of the NCRI including prevention and inequity linked to social deprivation, gender and ethnicity. The NCRI's core activities include an annual conference, running clinical studies

groups and maintenance and analysis of the NCRI Cancer Research Database. The partnership routinely works with external organisations including cancer charities whose spend on research does not meet the NCRI threshold, organisations working in diseases other than cancer which have an overlapping research interest, trade associations, individual companies, regulatory bodies and patient groups.

UK Age Research Forum (UK ARF): Coordinator: Alistair Scott, email. alistair.scott@ukarf.org.uk <http://www.ukarf.org.uk/our-members.aspx>

UKARF is an alliance of organisations and government departments that fund research relevant to older people and ageing. Members include:

- Action On Hearing Loss
- Age UK
- Alzheimer's Research UK
- Alzheimer's Society
- Arthritis Research UK
- Arts and Humanities Research Council (AHRC)
- Association of Medical Research Charities (AMRC)
- Biotechnology and Biological Sciences Research Council (BBSRC)
- British Heart Foundation (BHF)
- Centre for Ageing Research and Development in Ireland (CARDI)
- Chief Scientist Office, Scotland (CSO)
- Department for Business, Innovation, and Skills (BIS)
- Department for Work and Pensions
- Department of Health (DH)
- Economic and Social Research Council (ESRC)
- Engineering and Physical Sciences Research Council (EPSRC)
- HSC Research and Development Division, Public Health Agency, Northern Ireland
- Joseph Rowntree Foundation
- Medical Research Council (MRC)
- National Institute for Social Care and Health Research (NISCHR)
- Research into Ageing
- Technology Strategy Board
- The Atlantic Philanthropies
- The Nuffield Foundation
- The Stroke Association
- Thomas Pocklington Trust
- Wellcome Trust

The main purpose of the alliance is to facilitate networking, to provide an opportunity for exchange of information and to assist different ageing research funders to see their issues in a wider context. It maintains a regularly updated website, produces a regular newsletter, issues email alerts and holds twice-yearly meetings.

What Works Centres

There are currently nine 'What Works Centres'. These are a network of designated centres, with a range of new centres established over the last couple of years, joined with the pre-existing NICE and Educational Endowment Foundation. The centres vary in how they are structured, and include charities, university centres and arms-length bodies. Three of these are of relevance to social care research. These are:

The Centre for Ageing Better is funded with £50 million from The Big Lottery Fund. Contact: Anna Dixon, Chief Executive Officer (from 1 September 2015). Email: ceo@agebetter.org.uk (<http://www.centreforageingbetter.com/>)

A **What Work's Centre for Well-Being** is funded with £3.5 million over three years by ESRC and Public Health England (PHE), with in-kind support from 17 partner organisations. Contact: Paul Litchfield, Chair. Email. paul.litchfield@bt.com or Nancy Hey, Lead for Hub. Email: nancy.hey@whatworkswellbeing.org (<http://whatworkswellbeing.org/>)

The **Early Intervention Foundation** is funded with £3.5m of Government Funding over 2 years. Contact: Leon Feinstein, Director of Evidence. Email: leon.feinstein@eif.org.uk (<http://www.eif.org.uk/>).

These centres focus on gathering, assessing and sharing evidence. They are also responsible for identifying research and capability gaps and will work with partners to help fill these. The Centre for Ageing also grant-funds research directly.

Jointly funded Research Funding bodies

The National Prevention Research Initiative: Contact: Gavin Malloch, Programme Manager, Medical Research Council, 20 Park Crescent, London W1B 1AL. Tel. 020 7670 5244. Email: Gavin.Malloch@headoffice.mrc.ac.uk (<http://www.mrc.ac.uk/research/initiatives/national-prevention-research-initiative-npri/>)

The National Prevention Research Initiative (NPRI) is a national initiative made up of Government departments, research councils and major medical charities, working together to encourage and support research into chronic disease prevention. Its core aim is to develop and implement successful, cost-effective interventions that reduce people's risk of developing major diseases by influencing their health behaviours. Primarily focused on health education and public health, their research portfolio also covers aspects of social care. The NPRI funding partners have just completed their fourth phase of funding. NPRI

Phase 4 provided a commitment of £10 million over five years. The MRC manages the initiative on behalf of its 16 funding partners, which are:

- Alzheimer’s Research Trust
- Alzheimer’s Society
- Biotechnology and Biological Sciences Research Council
- British Heart Foundation
- Cancer Research UK
- Chief Scientist Office, Scottish Government Health Directorate
- Department of Health
- Diabetes UK
- Economic and Social Research Council
- Engineering and Physical Sciences Research Council
- Health and Social Care Research Division, Public Health Agency, Northern Ireland
- Medical Research Council
- Stroke Association
- Wellcome Trust
- Welsh Government
- World Cancer Research Fund

3.4 Experience of using, and views on, social care recommendations

All organisations we spoke with described undertaking some form of horizon scanning, which could include scanning for research and evidence gaps. Only in some cases was this described as formally or systematically undertaken, with specific sources of information about gaps in the evidence base, such as NICE research recommendations, high quality systematic reviews or the Cochrane library, consulted. None of the organisations we spoke to in the course of writing this report had direct experience of funding research based on specific research recommendations. However, one organisation has a representative of the Cochrane Collaboration on its advisory committee and had, on occasion, also directed applicants in their open research funding call to consider addressing research recommendations held on the NICE-hosted Database of Uncertainties about the Effects of Treatments (UK DUETs²¹). However, they reported never having received such an application. Exceptionally, a representative from one organisation we spoke to did not know how NICE research recommendations were generated and assumed they were equivalent to the ‘more research needed’ type of recommendations that are commonly included in the concluding sections of research reports.

²¹ <https://www.nice.org.uk/about/what-we-do/evidence-services/database-of-uncertainties-about-the-effects-of-treatments-uk-duets>

No specific views were expressed about how NICE research recommendations should be framed, other than about their level of specificity. Government funders stated, for example, that, although they felt that research priorities could potentially be informed by NICE's identification of specific gaps, they would not have the flexibility to fund specific projects, where the research question and methods are tightly defined. Other informants, particularly those from charitable and lobbying organisations, also described being unlikely to want to just 'pick up and run' with a highly specific research recommendation. Rather they saw NICE's research recommendations as being part of a wider picture of evidence about research priorities in their area of interest. Others, however, saw the specificity of research recommendations as a potential strength, arguing that the recommendations represented a research project "on a plate", with all the hard work of identifying and refining the research question and undertaking the literature review completed in advance for the researchers. It was also noted that too general recommendations might not pass the 'so what' test or add value, since broad research gaps are widely understood amongst those working in, or with, specific areas of social care research.

3.5 Other strategic considerations and next steps

Our discussions with informants also highlighted a number of challenges for NICE in effectively communicating their social care research funding recommendations as well as challenges to do with capacity in the social care research sector to respond to recommendations.

Distinguishing social care from health research recommendations

While NICE may have an interest in promoting research recommendations that address not only social care issues but also issues around the social care/ health interface, it may need to think about how it situates communications about social care research recommendations within current communications about health research recommendations. One respondent noted that people think of NICE as "about health". NICE will need to consider how they promote themselves to possible funders of social care research as active, not just in health, but also in social care.

Targeting recommendations

Given the diversity of funders of social care research and their different areas of interest and activity, there is likely to be a need for NICE to think about how to target their recommendations. Few organisations, with the exception of NIHR SSCR, have a blanket interest in NICE's social care research recommendations. In fact, many organisations may not even think of themselves as carrying out research that is social care specific and, amongst those that do consider themselves to be carrying out social care research, there

may be variation in what these funders think constitutes social care research. ESRC, for example, have funded research that could be described as social care research but which is likely to be marginal in terms of likely areas of engagement for NICE; for example, research about migrants or linguistic research looking at the language employed to discuss dying and death. Because of difficulties in identifying the boundaries between social care and other categories of research, ESRC do not attempt to identify the 'social care research' that they fund but, instead, monitor research funding by academic discipline. Other organisations may focus on research into a particular condition, such as dementia, or a particular social issue, such as poverty. These organisations are likely to keep up with the evidence base around their topic but are unlikely to have an interest in wider social care-specific sources of information. Targeting NICE recommendations for children's research is also likely to be especially complex due to the particularly fragmented and diverse nature of children's research funding. For these different organisations, the relevance of a specific NICE research recommendation may need to be brought to their attention.

The fact that a NICE research recommendation might only exceptionally be of relevance consequently means that blanket forms of communication about social care recommendations are unlikely, in most cases, to be effective. Indeed, there was some discussion amongst our respondents of NICE sending "too many emails." NICE may need to think further about how to target their communications about social care recommendations so that they reach the attention of those bodies with a specific interest in funding research on the particular topics covered.

NICE may also need to consider the methodologies and approaches it recommends, adapting these to reflect capacity to engage with them, in the sector and in specific specialist areas. For example, NICE has committed to producing guidelines on the 'Transition from children's to adult services for young people using health or social care services'. This is a particularly long-standing and complex issue that sits at the interface between health, social care, education and employment and the not for profit sector (e.g. hospice care). It is an issue that affects a relatively small number of children and young people with a range of different diagnoses and conditions. They are represented by a myriad of condition-specific support groups as well as umbrella groups such as the Council for Disabled Children and Together for Short Lives. Another layer of organisations such as Whizz-Kidz also provide specialist mobility equipment and life skills training through transition into adulthood. Additional key stakeholders include the young people themselves (who may or may not have capacity to be involved in decision making) and their parents and carers. There are few (if any) trials of interventions and service models and much of the current literature includes qualitative research or grey literature produced by not for profit organisations. Given this complexity, NICE would need to decide whether to adapt its approach to include smaller grounded studies and different types of research evidence.

Demonstrating relevance and impact

Two respondents also commented that there was little information provided by NICE about if and whether previous research recommendations had been commissioned and, if so, who had used the findings and what impact this has had. This could lead to what one informant described as a potential 'credibility gap'. Others stated that the work of NICE had many strengths which needed to be better promoted, including the rigour with which the existing evidence on a topic is surveyed, and argued that NICE needed to be 'more centre stage'. It may be especially important to demonstrate relevance and impact of research recommendations in social care since there are many evidence gaps and many competing priorities for research investment.

Sector capacity

Some concern was expressed about the lack of research capacity in the sector, with one informant saying that there may not be sufficient researchers able to deliver the quantity of high-calibre research in adult social care that NICE might consider to be needed. The NIHR SSCR, for example, reports seeing an improvement in applications over recent years with fewer very weak applications. Most applications are now assessed as being in a 'middling' range in terms of quality. However, despite NIHR SSCR introducing initiatives to help to address these issues, there are persistent methodological weaknesses including in quasi-experimental methods and in economic approaches.

In children's social care, the large number of diagnostic conditions and social care issues for a relatively small population means that research capacity or understanding of the issues is even more specialist and thinly spread. There is also a critical lack of active children's researchers in the UK who have the skills to undertake child-centred social care research and evaluation (e.g. by including children as research partners or data collectors). This type of research is also more expensive and more time consuming and funders sometimes question the value for money of such studies.

The need for on-going informal contact with key funders and key producers of research

Informants from the largest funding bodies stressed the need for on-going contact, in the form of occasional meetings, as a means of sharing information about emerging and future plans and priorities. Face to face informal discussion, it was felt, could enable funding organisations to better understand why and how these recommendations were identified. In specialist areas and in many areas of children's social care research, relevant smaller funders (or producers) of research may need to be included in these discussions.

Larger funders are also likely to provide links into other relevant organisations by, for example, regularly being represented at the meetings of wider formal networks and groups. There may also be opportunities for NICE to attend and/or present to existing groups and

networks. There are fewer formal networks in children's social care research. One informant thought that there may be an appetite for a one-off 'by invitation' seminar or workshop to allow exchange between research funders and other organisations such as NICE about research priorities and to discuss gaps in the evidence base for children's social care.

4 A SUMMARY INDEX OF KEY ORGANISATIONS FUNDING SOCIAL CARE RESEARCH

Chapter 4 provides a summary list of key social care research funders. The information presented for each organisation in this section is drawn from publicly available sources. This limits what is included to publicly available statistics and description of formal structures and processes. For the nine organisations with which we conducted interviews, some further factual information is included in Chapter 4 where available. Within the scope of this study, it was not possible to interview representatives of all the organisations included in this section but it is likely that the findings detailed in earlier chapters, including on how best to engage, apply equally to these organisations.

GOVERNMENT

4.1 Department of Health: Policy Research Programme (PRP)

Description

The Department of Health funds research in health and social care through two main routes:

- The DH Policy Research Programme (PRP)
- The National Institute for Health Research (NIHR).

PRP is a national research funding programme within the DH Research and Development Directorate. Research and Development Directorate commissions and manages a large number of research grants and projects within the PRP, in addition to managing the Policy Research Units. PRP research is commissioned by open competitive tender within the DH Research Governance Framework. The PRP commissions high quality, research-based evidence relevant to the full policy remit of the DH. In addition to individual projects, the PRP funds and co-funds multi-study research initiatives and long-term programmes of research in university-based units. PRP funds 12 policy research units (PRUs). The following carry out significant amounts of social care research:

- The **Policy Innovation Research Unit (PIRU)** brings together leading health and social care expertise and focuses on evaluation methods, particularly of pilots to improve evidence-based policy-making and its implementation across the NHS, social care and public health. PIRU includes researchers from the London School of Hygiene & Tropical Medicine (LSHTM), the Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science (LSE), and the Health and Care Infrastructure

Research and Innovation Centre (HaCIRIC) at Imperial College London Business School plus RAND Europe and the Nuffield Trust.

- The **Economics of Social and Health Care Research Unit (ESHCRU)** undertakes policy-relevant research, based on economics and using quantitative methods. ESHCRU includes researchers from the Centre for Health Economics, University of York, PSSRU at both LSE and the University of Kent. ESHCRU's programme of research addresses three aspects of social and health care systems:
 - How services can be financed in a fair and efficient way
 - The best ways of organising care and support systems
 - How it can be measured whether services provided are high quality and make the best use of public funds
- The **Quality and Outcomes of Person-centred Care Policy Research Unit (QORU)** was funded in 2011 for 7 years with an aim to improve the quality of health and social care of people with long-term conditions (LTCs), developing and using high quality evidence about need, quality and outcomes of person-centred care. QORU research considers how individuals are affected by organisations, services and other forms of support, and how those organisations and systems can and should account for needs and outcomes of individuals. QORU includes researchers from PSSRU at the University of Kent and LSE and the University of Oxford.
- **Social Care Workforce Research Unit (SCWRU)** is based at King's College London and has been conducting research into issues relating to the social care workforce in England since 2002.
- **Children's Policy Research Unit (CPRU)** provides evidence for policy and practice for the health and wellbeing of children, young people and families.

Financial information

The DH spent £984.6 million on Research and Development in 2012-13. Of this, £29.7 million were provided to PRP (£954.9 million to NIHR).

Priority-setting for research funding and support

The research priorities for funding and support are negotiated regularly between the research units and DH. Moreover, DH established Research Commissioning Board which brings together key stakeholders such as DH, Monitor, NHS England, CQC to regularly discuss research priorities for DH. Different units also cooperate with other Government funders, academia, charities, public and industry in setting their research priorities.

4.2 Department for Education

Key contacts: Richard White, Children's Services Analysis & Research team/ Catherine North, Senior Research Officer, Strategic Analysis and Research

Contact details: 0207 340 8083, [Richard.white@education.gsi.gov.uk/](mailto:Richard.white@education.gsi.gov.uk)
Catherine.north@education.gsi.gov.uk.

Description of organisation

The Department for Education social research aims to provide high-quality evidence to inform policy development and delivery. DfE has the following principles behind its research strategy:

- to promote the importance of robust quantitative evidence, in combination with other methods, to increase understanding of 'what works' in education and children's services;
- to identify evidence gaps and promote discussion of these with the research community, practitioners and other stakeholders;
- to initiate collaboration with the research community, practitioners and other stakeholders to research these issues;
- to support work that helps understand and tackle the barriers to evidence based practice, including how to make evidence accessible to practitioners.

The department published a number of documents with detailed descriptions of research priorities in a number of areas (e.g. 'Early education and childcare'²²; 'Children in care'²³; 'Social work and child protection'²⁴; 'Special educational needs and disability'²⁵). These documents provide a coherent strategic context for the research community, sector bodies and practitioners as well as the department, to plan and prioritise research. The department commissions research, informed by the published priority questions.

Moreover, the following research centres were under contract with DfE and are now finishing the work DfE commissioned:

- the [Childhood Wellbeing Research Centre \(CWRC\)](#) provided evidence on children's wellbeing and life chances, including safeguarding, families, and the relationship between wellbeing and educational outcomes

²² <https://www.gov.uk/government/publications/early-education-and-childcare-research-priorities-and-questions>

²³ <https://www.gov.uk/government/publications/children-in-care-research-priorities-and-questions>

²⁴ <https://www.gov.uk/government/publications/social-work-and-child-protection-research-priorities-and-questions>

²⁵ <https://www.gov.uk/government/publications/special-educational-needs-and-disability-research-priorities-and-questions>

- the [Centre for Analysis of Youth Transitions \(CAYT\)](#) provided evidence on young people's transitions through education and wider adolescence into the labour market and adulthood
- the [Centre for Understanding Behaviour Change \(CUBeC\)](#) provided evidence on drivers of behaviour and 'what works' to help people make better choices for themselves.

DfE publishes calls for expression of interests and invitations to tender for new research projects online.

Financial information

The department spent £12.4 million on research and development costs in 2013/2014. Key research strands included International Evidence, Study of Early Education and Development (SEED), Longitudinal Study of Young People in England (LSYPE2) and approximately 40 other research projects.

Priority-setting for research funding and support

DfE prioritises research effort or bids in the light of the evidence questions and gaps outlined in published research priorities in specific areas. These priorities are based on academic evidence principles and the department's research strategy is inspired by Ben Goldacre's vision set out in 'Building Evidence into Education' (2013) as well as Roger Plant's recommendations for data systems in DfE.

NON-DEPARTMENTAL PUBLIC BODY

4.3 The Big Lottery Fund

Key contact: Ambreen Shah, Deputy Director

Contact details: ambreen.shah@biglotteryfund.org.uk

Description of organisation

The Big Lottery Fund was created by the National Lottery Act 2006. The Minister for the Cabinet Office issues policy directions which the Fund must take into account when distributing funds; these apply generally to all UK funds and specifically to England. The administrations in Scotland, Wales and Northern Ireland issue policy directions relating to the funds distributed in those countries.

The Fund is governed by a Board with members appointed by the Minister for the Cabinet Office. The Board sets the Fund's strategic framework. Each country has a committee

responsible for the funding programmes in their country; the Board has also appointed a committee for UK-wide funding.

Committees make grant decisions, or agree the delegated arrangements for making them, within these programmes. In 2014 the Fund employed 980 full-time equivalent employees.

The Fund's money goes to community groups and projects that improve health, education and the environment. The Fund works on a belief that people should be in the lead in improving their lives and communities.

The BLF funds programmes and research in the following areas:

- Health and well-being, including:
 - clinical care and prevention programmes
 - overall health programmes
 - palliative care projects include medical and wider support systems
 - mental health programmes
- Children, young people and families
- Communities and places: Helping communities become stronger
- Education, learning and skills
- Environment
- International projects: many focus on millennium development goals
- Making the most of funding: sharing best practice and maximising the impact of grant making
- Older people, including:
 - health and social care
 - independent living
 - poverty and social exclusion
 - employment and education
 - active citizenship
- Social investment.

Open calls are published on the Fund's website and details on how to apply for funding for a particular call are available [online](#).

Financial information

Fund's total income in financial year ending 31st March 2014 was £756,640,000 and its total expenditure during the same period of time was £970,506,000.

Structure of funding activity

BLF is responsible for distributing over £650 million each year and it also distributes non-Lottery funding on behalf of public bodies such as the Department for Education and the Office for Civil Society. The Fund gives grants from £300 to over £500,000 to organisations ranging from small local groups to major national charities. In 2014, over 90% of funds went directly to the voluntary and community sector, and 88 % of awards went to projects valued at £10,000 or less. In 2012 over 77% of all grants were made through its Awards for All small grants programme, however, this only accounted for 10% of the total funding.

Priority-setting for research funding and support

The Fund applies community-based approach to funding and places people in the lead at every stage of the funding cycle, both in the programmes the Fund develops and the projects funded.

GOVERNMENT SPONSORED FUNDING ORGANISATIONS

4.4 The National Institute for Health Research (NIHR)

Description of organisation

The NIHR was set up in 2006 with an aim to improve the health and wealth of the nation through research. NIHR funds a range of programmes addressing a broad range of health and social care priorities to produce evidence that enables professionals, policy makers and patients to make informed decisions and provide the means to turn new interventions into better care. The following research programmes operate within NIHR:

- Research for Patient Benefit (RfPB) funds NHS research. The projects funded are for regionally derived applied research in health services and social care
- Systematic Reviews (SR)
- Programme Development Grants (PDG) are available to strengthen the basis for a full Programme Grant application when applications need preparatory work
- Efficacy and Mechanism Evaluation (EME) grants are designed to secure the progress of new technologies and interventions through early clinical trials and onto larger, later clinical trials

- Health Services and Delivery Research (HS&DR) produces evidence on the quality, accessibility and organisation of health services
- Health Technology Assessment (HTA) is undertaken where some evidence already exists to show that a technology can be effective and this needs to be compared with current NHS methods
- Invention for Innovation (i4i) supports collaborative projects that cultivate new techniques or technologies in areas of clinical need
- Programme Grants for Applied Research (PGfAR) funds major programmes of research that are a priority for the NHS
- Public Health Research (PHR) evaluates public health interventions.

NIHR's [research programmes](#) fund research using a wide range of study designs, including but not only, evidence synthesis, pilot and feasibility studies, randomised controlled trials and both quantitative and qualitative research. NIHR also funds Research Design Service which provides advice, guidance and practical support to help researchers prepare a funding application that is of sufficient quality to gain a recommendation for funding from the NIHR funding committee.

Financial information

In 2012-13 DH provided £954.9 million to NIHR. This funding was utilised in four areas:

- £618.7 million – Infrastructure to provide the support and facilities the NHS needs to deliver first class research
- £209 million – Research Programmes to provide evidence to support decision making by professionals, policy makers, patients, and the public
- £100.2 million – Development of a research capability and talent in clinical and applied health and social care research
- £26.5 million – Systems to simplify and streamline the approvals and procedures underpinning research.

Around 60% of the NIHR budget provides the infrastructure and systems in the NHS to support research, 30% is spent on directly commissioned research programmes, including projects and programmes within the NHS.

Structure of funding activity

NIHR's [calls](#) are issued for:

- Commissioned research to address specific topic areas.
- Researcher-led projects to questions proposed directly by researchers in all areas of health and social care research.

- Themed calls to meet an identified health challenge or government priority. These topics are diverse and have included dementia, primary care interventions and long-term conditions in children and young people.

Calls/Competitions, funding amounts and periods

Research programme									
	EME	HS&DR	HTA	i4i	PGfAR	PDG	PHR	RfPB	SR
Calls and competitions (number of opportunities to apply per year)									
Researcher-led	3	3	3	2	2	2	3*	3	1*
Commissioned	3	3	3	2	n/a	n/a	3*	n/a	n/a
Themed calls	Frequency and participating programmes as advertised								
Funding amounts and periods									
Funding limit	No limit	No limit	No limit	No limit	No limit**	£100k	No limit	£350k	£400k
Period of funding	No fixed period	No fixed period	No fixed period	Up to 3 years	No fixed period	1-18 months	No fixed period	Up to 3 years	Up to 3 years

*subject to change

**Period and level of funding depends on nature of proposed work - funding above £2.5 million will be unusual

Priority-setting for research funding and support

NIHR collaborate with many sectors including DH (see PRP section, above, for more information about DH Research Commissioning board), other Government funders, academia, charities, public and industry in setting their research priorities. Moreover, NIHR cooperates with The [Health Research Authority](#) (HRA) in establishing research priorities. HRA was established in December 2011 and is responsible for protecting and promoting the interests of patients and the public in health research and for streamlining the regulation of research. In partnership with patients and the public, HRA is developing a Public Involvement Strategy which will inform how to ensure patients' and public input into its work. In January 2015, the HRA became responsible for publishing policy and guidance on principles of good practice in the management and conduct of health and social care research in England.

4.5 NIHR: Evaluation, Trials and Studies (NETS)

Description of organisation

The NIHR, Evaluation, Trials and Studies (NETS) programmes fund independent research for health and social care decision-makers. These programmes are a key part of a portfolio of work managed by the [NIHR Evaluation, Trials and Studies Coordinating Centre](#) (NETSCC), based at the University of Southampton.

NETS programmes comprise five distinct but interconnected evaluation research programmes:

- [Efficacy and Mechanism Evaluation](#) (EME)
- [Health Services and Delivery Research](#) (HSDR)
- [Health Technology Assessment](#) (HTA)
- [Public Health Research](#) (PHR)
- [Systematic Reviews](#)

Other key activities that NETSCC leads on, or manages, on behalf of the NIHR, are:

- [NIHR themed calls](#)
- [NIHR Trials Overview](#)
- [NIHR Journals Library](#)
- [Adding value in Research Framework](#)
- [James Lind Alliance \(JLA\) Priority Setting Partnerships \(PSPs\)](#)

Structure of funding activity

The structure of funding is complex, with each of the five programmes funded by different organisations. For example, The EME Programme is funded by the Medical Research Council and the NIHR, with contributions from the Chief Scientific Officer in Scotland and NISCHR in Wales and the HSC R&D, Public Health Agency in Northern Ireland.

NETS [website](#) contains a list of currently open calls for proposals, both researcher-led (this is an ongoing funding with three cut-off dates per year for outline applications) and commissioned calls (there are three rounds of commissioned calls per year). NETS also issues cross-programme [themed calls](#) on an ad hoc basis.

Priority-setting for research funding and support

NETS priority for research funding is identified using a '[needs-led, science-added](#)' approach - a set of principles intended to ensure that the research is of the highest possible value to decision-makers, and that it provides real benefits to patients, the NHS and public health.²⁶

NETS works with a wide range of stakeholders, such as NICE and the National Screening Committee (NSC), to identify gaps in knowledge. Systematic reviews are also used to reveal areas where evidence is lacking. Having identified gaps in knowledge, NETS develops 'commissioning briefs' to guide research proposals. These briefs are generally developed and reviewed with external experts. Possible topics for research are reviewed by advisory groups of external experts and public members to assess the need for the proposed research. Research proposals that have come in through researcher-led workstreams and in response to themed calls go through a similar prioritisation process.

4.6 NIHR: Health Technology Assessment Programme (HTA)

Description

The HTA Programme is the largest of the NIHR programmes to fund independent research when evidence exists to show that technology can be effective. The purpose of an HTA study is to establish clinical- and cost-effectiveness for the NHS in comparison with the current best alternative(s). A study may also investigate uncertainty around a technology's place in the existing care pathway. "Technologies" in this context means any method used to promote health; prevent and treat disease; and improve rehabilitation or long-term care. They are not confined to new drugs and include any intervention used in the treatment, prevention or diagnosis of disease (e.g. procedures, drugs, devices, diagnostic tests, settings of care, screening programmes). The technology doesn't necessarily need to exist in current NHS practice, but a study would need to show that it could. Funded research serves a variety of key stakeholders including: decision-makers in local government, policy-makers ([including NICE](#)), researchers, NHS health professionals, other NIHR stakeholders, and the general public. Studies are funded via a number of routes including [commissioned](#) and [researcher-led](#) workstreams.

²⁶ Additional information from Prof. Tom Walley explaining the priority-setting process for HTA can be found here [http://www.nets.nihr.ac.uk/programmes/hta/our-people/a-word-from-the-director?utm_source=Funding+programmes+mailing+list&utm_campaign=5356277600-HTA Bulletin February 2015 20 2015&utm_medium=email&utm_term=0_0ff7d16771-5356277600-153623441](http://www.nets.nihr.ac.uk/programmes/hta/our-people/a-word-from-the-director?utm_source=Funding+programmes+mailing+list&utm_campaign=5356277600-HTA+Bulletin+February+2015+20+2015&utm_medium=email&utm_term=0_0ff7d16771-5356277600-153623441)

Priority-setting for research funding and support

The HTA commissions research proposals that address specific topics or themes, as identified by the HTA [boards and panels](#). HTA works with a range of individuals including academics, practitioners, policy makers and the public. There are three rounds a year (opening March, July and October) containing up to 20 separate call topics.

4.7 NIHR School for Social Care Research (NIHR SSCR)

Key contact: Michael Clark, Research Programme Manager, NIHR SSCR

Contact details: 07734483518/ m.c.clark@lse.ac.uk

Description of organisation

In 2009 NIHR established the School for Social Care Research (NIHR SSCR) to develop the evidence base specifically for adult social care in England. In early 2014, following a competitive process, the School was provided with a further five years of funding from May 2014. NIHR SSCR is a partnership between the London School of Economics and Political Science (LSE) and the Universities of Bristol, Kent, Manchester and York.

NIHR SSCR's mission 'is to develop the evidence base for adult social care practice by commissioning and conducting world-class research'. Some key features of this are the following:

- NIHR SSCR only cover adults, not children and young people;
- NIHR SSCR don't cover social care policy, only practice (DH commissioned Policy Research Units cover policy);
- NIHR SSCR only covers practice in England.

NIHR SSCR research aims to cover:

- A range of client groups and needs (e.g. older people, physical disabilities, mental health, carers etc.)
- A range of care contexts (e.g. communities, care homes, homes, hospices etc.)
- A range of practice and policy-into-practice issues (e.g. safeguarding, prevention etc.).

NIHR SSCR's Business Plan identified nine broad themes for the School's research programme: prevention, personalisation, partnership, plurality, protection, productivity, workforce, carers, and research methods. These were intended to provide an overview of the areas encompassing the majority of their proposed work but were not intended to be restrictive, and are not mutually exclusive. Over the course of the first year of Phase II, the School has, because of the breadth of coverage for adult social care and consequent

difficulty in restricting its research programme by specific themes, developed and amended these categories to respond to specific needs.

NIHR SSCR is the only part of NIHR that has an explicit focus on social care research, however, as NIHR is large and complex, each constituent part operates differently in terms of how it considers social care applications. There is no simple demarcating line between health and social care and other parts of NIHR would commission research that is relevant to social care, for example, health issues in care homes or other social care settings, research concerned with issues of integration, covering clients' needs that also concern social care (such as learning disabilities or dementia), or covering public health issues that overlap with social care concerns.

Financial information

NIHR SSCR has a budget of £15m for a 5 year contract from May 2014. Eighty-eight per cent of its budget is allocated to research - about two-thirds to the Core Member universities (LSE, Kent, Manchester, York & Bristol), with the remainder allocated through open competition to external applicants.

Structure of funding activity

Internal research projects are developed by the NIHR SSCR's Core Members. For this, outline proposals are submitted for discussion by the School's Executive Group. Following initial approval, full proposals are developed, peer-reviewed, revised as needed and suitable projects are then commissioned. The School's internal research budget allows for flexibility in responding to external priorities.

NIHR SSCR awards funding to external research through open competition. Proposals received under specific research calls are peer-reviewed and considered by a commissioning panel. In 2014, NIHR SSCR issued a call for research proposals, received 42 applications and commissioned six projects for a total of £1.7 million. Their second call for applications closed in May 2015; a budget of £2.4m is available for projects under this call. This is expected to be NIHR SSCR's last external call in the current contract period until 2019. Any subsequent calls for external research will depend on whether a further five-year contract is awarded to the NIHR SSCR and upon the processes NIHR SSCR would work to in that new phase.

Priority-setting for research funding and support

In setting priorities for commissioning research, initial Core Member (internal) projects have developed from the expertise of each Core Member university and its staff. For external projects, NIHR SSCR's Executive Group agree topics for calls for external research proposals. In both cases, the areas in which to fund studies are determined after consultation with both the School's Advisory Board (with extensive membership from stakeholders in adult

social care) and its User, Carer, Practitioner Reference Group, as well as through wider discussions with external stakeholders. Projects are then agreed upon and, following the required commissioning processes, funding is awarded to suitable projects.

NIHR SSCR seeks input from (among others):

- Central government
- Local government
- Researchers
- Users and carers
- Professionals
- Members of the public
- Previous research evidence recommending research topics
- Recommendations from its own commissioned scoping reviews
- Practice guidelines

4.8 The National Institute for Social Care and Health Research (NISCHR) – Relunched as Health and Care Research Wales June 2015

Description of organisation

The National Institute for Social Care and Health Research (NISCHR) is the Welsh Government body that develops, in consultation with partners, strategy and policy for research in the NHS and social care in Wales. An advisory board provides governance and an operational steering group oversees day to day issues. NISCHR delivers its strategy and policies through commissioning services, running research schemes and initiatives, and through strategic investment and partnership working with other funding bodies and industry. The key strands of NISCHR's approach are supporting excellence, building capacity and infrastructure, and streamlining research processes in line with a review undertaken by the Academy of Medical Sciences: A New Pathway for the Regulation and Governance of Research (2011).

Financial information

NISCHR budget is £43m. Just about a half of the budget is directly allocated to NHS Wales via a range of funding streams, services or initiatives.

Structure of funding activity

NISCHR Schemes have been set up "to support capacity building in health and social care research" and include the following:

- NISCHR Health Research Award & NISCHR Social Care Research Award

- NISCHR PhD Health Studentship Award (HS) & NISCHR PhD Social Care Studentship Award (SCS)
- NISCHR Health Fellowship Award (HF) & NISCHR Social Care Fellowship Award (SCF):
- INVENT: to support the “development of technologies that have the potential to benefit patients and service users”. Funds of up to £30,000 are provided to support innovation within the NHS and Local Authority Social Services Departments in Wales.
- Research for Patient and Public Benefit Programme is primarily an NHS focused research programme but can include the interface with social care.

Calls are related to programmes and the guidance for researchers is available [online](#). Webinars are held to support researchers in the application process.

In terms of Social Care the NISCHR works in collaboration with partners such as Bangor, Cardiff, Swansea, Glyndŵr, Newport, and Cardiff Metropolitan Universities, and the University of South Wales. For this purpose the All-Wales Academic Social Care Research Collaboration (ASCC) was set up. This has resulted in three projects falling under the social care aspect:

- Skills and capacity development in social care and social work research (Bangor University, Glyndŵr University, Wales Council for Voluntary Action (WCVA))
- WISERD e-learning initiative (WISERD, Cardiff University, Glamorgan and Cardiff Metropolitan universities; Social Services Improvement Agency (SSIA), the Research in Practice Wales College Network (RIP))
- Research and practice in social care and social work: ‘Making Research Count’.

NISCHR Centres and Units

NISCHR has recently recommissioned, through competitive tender, key strategic Centres and Units of research excellence in Wales to further build research capacity in specific areas. The competition brief had an explicit focus on the integration of social care research into all activity.

NISCHR has invested in Secure Anonymised Information Linkage (SAIL) Databank (<http://www.saildatabank.com/>) The main aim of SAIL is to realise the potential of electronically held, person based, routinely-collected, anonymised information (Big Data). Social care information from a variety of organisations is being built into the databank for research purposes.

NISCHR has invested in clinical trials units and a health economics support service that includes expertise in managing trials in social care contexts and in the health economics of social care (Bangor University).

Priority-setting for research funding and support

NISCHR consults practitioners, research communities and third sector organisations in setting its research priorities. Grant applications are screened by a priority setting panel of lay members.

4.9 The Economic and Social Research Council (ESRC)

Key contacts: Naomi Beaumont, Research Division

Contact details: 01793 413044. Email: naomi.beaumont@esrc.ac.uk

Description of organisation

The ESRC is the largest organisation funding research on economic and social issues in the UK. The ESRC is a non-departmental public body, established by Royal Charter in 1965. It receives the majority of its funding through the Department for Business, Innovation and Skills (BIS).

The ESRC has a Council made up of members from business, civil society and the public sector, as well as representatives from the academic community. The Council consists of a structure of committees working alongside a Peer Review College and grant assessment groups and panels. The Council delegates day-to-day responsibility for the allocation of funds, management of current research investments, and development of policy and strategy to a senior management team including the Council's Chair, the Chief Executive, Directors and Deputy Directors.

The ESRC's primary activity is distributing and managing research grants to academics in universities and other institutes throughout the UK. Besides funding research, the ESRC focuses on:

- Continuous provision of training and development for the social science community
- Building strategic partnerships with academia, the public and private sectors, and civil society
- Taking the strategic lead in driving the expansion of the UK's data infrastructure and supporting cutting-edge methodological developments
- Fostering international collaboration
- Raising public awareness of social science
- Engaging the public in social science research.

At any one time the ESRC is supporting over 4,000 researchers and postgraduate students in academic institutions and independent research institutes.

Financial information

ESRC's total budget for 2014/15 is £213 million.

Structure of funding activity

A wide range of themed, ad-hoc programmes and calls, with grants often administered with partners or through centres funded by ESRC. Funding varies, depending on the programme. Many of these appear to involve international partnerships and collaborations.

The Centres and Large Grants competition provides funding of between £2 million and £10 million. The next Centres and Large Grants call will be announced at the end of 2015, with the ESRC reviewing its strategic priorities for this competition.

Research Grants provide funding, ranging from £200,000 to £2 million. These are researcher led with considerable flexibility around topic area. The ESRC, however, maintains a commitment to funding longer, larger awards for social science. They do not therefore issue small research grants and under new arrangements from July 2015, the lower threshold will rise to £350,000 and the upper threshold will be reduced to £1 million at Full Economic Costs.

It also distributes a wide range of doctoral and post-doctoral funding, with applications directed through universities and other eligible institutions. It also funds seminars and seminar series, a Research Leaders Scheme and knowledge exchange activities.

Priority-setting for research funding and support

ESRC funds a wide range of research in social care and social care/ health under priority areas set out in their [Strategic Plan](#). The Plan sets the principles for how the ESRC will work over the period of the plan, setting out a commitment to areas where it is deemed it can add the most value and where it can collaborate with a range of partners to maximise the value of their investments. The plan complements and builds upon the more immediate priorities set out in the ESRC's annual [Delivery Plan](#). These are the result of wide consultation with partners and the social science community broadly.

The research ESRC commissions cuts across different discipline areas (for which funding totals are provided), including economics, social policy and social work. It conducts an annual review of progress and has identified a number of new areas in which it is currently intending to fund new research, which include 'Innovations in Health and Social Care'²⁷.

²⁷ <http://www.esrc.ac.uk/about-esrc/mission-strategy-priorities/refining-priorities/index.aspx>

CHARITABLE

4.10 The Joseph Rowntree Foundation (JRF)

Description of organisation

The Joseph Rowntree Foundation (JRF) and Joseph Rowntree Housing Trust (JRHT) exist to investigate the root causes of poverty and disadvantage, understand the experience of people and places in poverty, and to identify and develop solutions. JRF uses the evidence and practical experience of developing housing and care services to influence policy, practice and public debate.

The expectation is that Trustees (6-12 Trustees) will serve for a minimum of five years and normally for no more than ten years (15 for the Chair and Deputy Chair).

Trustees are jointly appointed to JRF and JRHT; they meet separately as Trustees of each organisation to deal with the different issues that arise.

The stewardship sub-committees that report to the Trustees are:

- Audit Committee
- Finance and Resources Committee, and its Investment Sub-committee
- Remuneration Committee
- Nominations Committee

Ageing society is one of the three strands in JRF research, which aims to respond positively to the opportunities and challenges of an ageing society and includes the following areas:

- [A Better Life](#)
- [Care Homes: Risk and Relationships](#)
- [Dementia without walls](#)
- [Generations, work and poverty](#)
- [Housing with care for older people](#)
- [Living standards and poverty in later life](#)
- [Neighbourhood approaches to loneliness](#)
- [Risk, trust and relationships](#)
- [Unheard voices: power and purposeful participation](#)

JRF's strategic plan for 2015-2017, however, envisions limited funding of social care research in the next 3-5 years. The organisation will focus more on embedding learning about best practice in their own housing-based services, and will carry out research into the impact of low pay and working conditions on outcomes such as poverty and mental health (excluding social care interventions to tackle these) in the social care workforce.

JRF also funds research on child poverty.

Financial information

From 31st December 2009 to the 31st December 2013 JRF's income increased from £8,198,000 to £8,747,000. In 2010, income dropped to £6,918,000, a low from which the organisation gradually recovered over three years. The JRF exhibits higher spending than income over consecutive years. From 2009 to 2013, annual spending increased by £793,000 from £9,239,000 to £10,032,000, respectively.

Structure of funding activity

JRF only accept proposals in response to a specific call. Detailed guidelines and background information for those wishing to respond to a call for proposal are online (<http://www.jrf.org.uk/funding>).

Grant commitments in 2013 were: £5,674, 000: see details in the table below:

	2012	2013
Poverty	£1,356,000	£1,948,000
Place	£735,000	£1,106,000
Ageing society	£1,537,000	£1,134,000
Bradford project	£158,000	£11,000
Cross-theme work	£130,000	£160,000
Other funding streams	£1,312,000	£1,315,000
Total	£5,339,000	£5,674,000

Priority-setting for research funding and support

JRF works across the political spectrum and with partners in all sectors. They engage with different policy, practice and research networks. JRF's Directors propose to Trustees programmes that meet JRF's priorities and they must be in line with the strategic plan. JRF funds its research through grant-making based on the above criteria, the Director of Policy & Research has overall responsibility for commissioning research.

4.11 The Nuffield Foundation

Key contact: Sharon Witherspoon, Director.

Contact details: 020 7631 0566 / 020 7618 9605. PA: Ms Alexandra Cornish. Email: acornish@nuffieldfoundation.org)

Description of organisation

The Nuffield Foundation is a charitable trust established in 1943 by William Morris, Lord Nuffield. Today, The Foundation works to improve social well-being by funding research and innovation in education and social policy. It also works to increase research capacity, both in science and social science.

The Foundation employs 33 staff. A senior management team, comprising the Director, Finance Director, Director of Education and Director of Social Research and Policy is responsible for the management of the Foundation and for advising Trustees on strategic and operational matters. Trustees are responsible for grant-making decisions at meetings, although these may be delegated according to agreed procedures.

Nuffield trust has four grants programmes that are open to applications. Their main grant programs include: children and families, civil law, and education. Additionally, Open Door programme is for proposals that lie outside these areas, but that meet Trustees' wider interests. Nuffield considers research projects, practical experimental projects and development projects, but all must have the potential to influence policy or practice in the short or medium term. Through the [Open Door](#) programme, it has funded social policy projects in such areas as the [economics of ageing](#).

Grants are mainly for research (usually carried out in universities or independent research institutes) but are also made for practical developments or innovation (often in voluntary sector organisations).

Financial information

Nuffield's income comes from interest on investments, it does not fundraise or receive funding from the Government. The Main Fund includes Lord Nuffield's original endowment and there is also an Auxiliary Fund, together with a number of subsequent gifts including the Ada Newitt bequest and the Albert Leslie Stewart Bequest.

Accounts for 2013:

- Income £17,232,000
- Spending £30,875,000

Structure of funding activity

In 2013 total amount awarded in grants was £3.8 million, £0.7 million to Open Door programs, £1 million to children and families programs, £1.8 to education and £0.3 million to law and society strand.

Guidelines for applicants including information on acceptable methodology and topics are provided [online](#). Most of the projects funded last for less than four years, but occasionally it funds projects of longer durations. Applicants are asked to provide an outline of the application first and, if the outline is short-listed, to proceed to a full application. In 2013 the Foundation received 378 initial applications and awarded 30 grants.

Priority-setting for research funding and support

Nuffield's projects must relate to the Foundation's main programme areas. The [Open Door Programme](#) is for proposals of exceptional merit for research projects or practical innovations that lie outside Foundation's main programme areas, but that meet Trustees' wider interests. These must have some bearing on its charitable objective to "improve social well-being". All grants made under Foundation's major grant programmes are peer reviewed by independent referees. Final decisions on these applications are made by Trustees. Details of available funding and the application process for each programme are published on Nuffield's website.

4.12 Marie Curie

Key contact: Dr. Sabine Best, Head of Research

Contact details: 020 7091 4144. Email: sabine.best@mariecurie.org.uk

Description of organisation

Marie Curie is a charity set up in 1950s. It offers expert care, guidance and support to help terminally ill people. Marie Curie opened their own research facility in 1962 and the charity funds palliative and end of life care research for people with all terminal conditions. It aims to create an evidence-driven, evidence-generating culture through the development of research capacity. Marie Curie is investing in programmes of research at their long-term [research centres](#). Marie Curie has taken forward a number of funding activities, both independently and in partnership with other organisations, its research centres work closely with its hospices in developing a portfolio of peer-reviewed research projects and programmes.

Financial information

Accounts for 2014:

- Income £154,805,000
- Spending £164,920,000

Structure of funding activity

Marie Curie has £1 million available in 2015 for research addressing palliative and end of life care needs of people with dementia, heart disease or stroke. In both 2012 and 2013, Marie Curie grants made up more than 50% of the research in palliative and end of life care related to cancer.

Calls are arranged around themes, e.g. for 2015 Marie Curie is considering applications in the following research themes: Communication around terminal illness, prognosis and dying; Bereavement; Symptom control. Detailed guidelines for applicants are available [online](#).

Research project grants are awarded in open competition to the Marie Curie Cancer Care Research Programme and there is an ongoing portfolio of projects funded through the Dimbleby Marie Curie Cancer Care Research Fund.

The aim of the joint Dimbleby Marie Curie Research Fund is to invest in research areas that are currently poorly funded nationally. The following criteria must be fulfilled for research to be funded by the joint fund:

- The research method may be quantitative, qualitative or mixed
- There must be a demonstrable need for research in this area
- It must not replicate existing or past research within the UK
- It must represent value for money
- Research projects should run for a maximum of two years unless it can be demonstrated that a longer period is necessary to achieve the optimum outcome(s)

In addition, the research outcomes should:

- Enhance existing knowledge and practice
- Have a positive impact on patients, families and carers
- Be widely applicable across the UK

Priority-setting for research funding and support

Marie Curie Cancer Care Research Committee comprised a number of experts who aid the selection process for the Marie Curie Cancer Care Research Programme. Marie Curie also consults patients, carers and families and they also take part in research.

4.13 The Wellcome Trust

Description of organisation

The Wellcome Trust is a charitable foundation set up in 1880, the Trust is dedicated to improving health and championing science, funding research and influencing health policy across the globe. Their [Strategic Plan](#) 2010-2020 provides a detailed framework for how the Trust intends to evolve their support.

Their funding focuses on:

- Supporting outstanding researchers
- Accelerating the application of research
- Exploring medicine in historical and cultural contexts.

Wellcome Trust focuses their work on tackling 5 challenges:

- Maximising the health benefits of genetics and genomics
- Understanding the brain
- Combating infectious disease
- Investigating development, ageing and chronic disease
- Connecting environment, nutrition and health.

The Trust employs over 500 staff, and Board of Governors has ultimate responsibility for what The Trust does.

Financial information

Accounts for 30 September 2014:

- Income £337,962,640
- Spending £869,843,888

Structure of funding activity

Wellcome Trust provides more than £700 million a year to support research in science, the humanities and the social sciences, education, public engagement and the application of research to medicine. In 2014 it awarded 1044 grants in 43 countries. The Trust offers a wide variety of funding schemes to support individual researchers and teams.

Funding areas include:

- Biomedical science (Investigating health and disease in humans and animals)
- Innovations (Helping the development of innovative, early-stage projects with potential medical applications)

- Medical Humanities (Supporting research at the interface of medicine, health-related sciences and the wider humanities)
- Society and Ethics (Supporting research that explores the social and ethical aspects of health and biomedical science)
- Engaging Science (Imaginative and experimental projects that bring biology and medicine to new audiences).

Details regarding calls, eligibility and deadlines are available [online](#).

Priority-setting for research funding and support

The Trust works with expert advisory groups and the international research community to explore new research areas and to develop targeted funding initiatives. They consult with governments, international organisations as well as communities to bring new perspectives, analysis and interpretation to their identified five challenges for research.

4.14 The Health Foundation

Description of organisation

The Health Foundation is an independent charity working to improve the quality of health care in the UK. It operates in Scotland, Northern Ireland and Malawi, employing 71 individuals. It supports people working in health care practice and policy to make lasting improvements to health services. The Health Foundation carry out research and in-depth policy analysis, run improvement programmes to put ideas into practice in the NHS, support and develop leaders and share evidence to encourage wider change. In 2013 they funded a range of research and evaluation projects, exploring in depth how quality improvement interventions are implemented in practice, usually within providers of care (mainly hospitals).

The board of governors oversees the work of the Health Foundation. Meeting quarterly, the board is responsible for setting the overall strategic direction of the Health Foundation, as well as discharging our statutory responsibilities as a registered charity and company limited by guarantee.

Research is central to the work of the Health Foundation, and the Board of Governors approves research strategy. Their research covers a broad approach of original research, formative and summative evaluations, systematic reviews and evidence scans to explore what works to improve the quality of care.

Financial information

Accounts for 31 December 2013:

- Income £14,405,000
- Spending £32,068,000

Each year The Health Foundation give grants in the region of £18m to fund health care research, fellowships and improvement projects across the UK.

Structure of funding activity

The Foundation sets out specific entitlement criteria for each programme at its launch. These criteria for open calls vary from programme to programme and are made available on their website. Applications are then assessed against these criteria and awards made taking into account funds available and the quality of applications. The period for which grants are awarded depends upon the programme but typically are of between one and four years' duration. Grants are monitored regularly and appropriate progress reports are required from recipients.

Examples of recent and current calls include:

- Innovating for Improvement: £1.5m for up to 20 teams to test and develop innovative ideas and approaches to improving health care delivery in the UK (call will re-open in July 2015)
- Shine 2014 supported 20 teams with funding of up to £75,000 each to run and test innovative ideas to stimulate improvements in the quality of health care.

Priority-setting for research funding and support

In setting out their research and funding priorities The Health Foundation works with individuals and organisations across the health system – from clinicians and managers through to the charity sector, patient representative organisations, academics, national bodies and policy makers.

4.15 Age UK

Description of organisation

Age UK is a registered charity in the UK, formed in 2010 out of the previously separate charities Help the Aged and Age Concern.

Charitable objects:

- Preventing or relieving the poverty of older people
- Advancing education
- Preventing or relieving sickness, disease or suffering in older people (whether emotional, mental or physical)

- Promoting equality and diversity
- Promoting the human rights of older people in accordance with the universal declaration of human rights
- Assisting older people in need by reason of ill-health, disability, financial hardship, social exclusion or other disadvantage
- Other charitable purposes for the benefit of older people as the trustees from time to time decide.

These objects are achieved by providing grants to individuals and organisations, providing buildings, providing advice and information, sponsoring research, and functioning as an umbrella or resource body. Apart from funding research it also disseminates age related information, provides services and training.

Age UK is a national body with 1,934 employees and 34,277 volunteers. It incorporates a network of 170 local Age UKs in England. There are also partnerships' with Age Cymru, Age NI, Age Scotland and Age International. There are currently 10 Senior Directors and a board of 9 Trustees. This format is replicated for local Age UK organisations. Age UK also has seven subsidiaries: Age UK Trading Limited, Age UK Services Limited, Age UK Enterprises Limited, HelpAge International UK, Aid-Call Limited, Charity Flowers Limited and intune Group Limited.

Financial information

Income: £166,629,000 (up from £160,665,000 in 2010)

Expenditure: £159,656,000 (down from £159, 896,000 in 2010).

Structure of funding activity

The Research into Ageing Fund (RiAF) is a fund set up and managed by Age UK to support age-related research. It funds eligible individual and organisations, based on an annual grant competition, covering PhD Studentships, Research Fellowships, Senior Research Fellowships, Clinical Research Fellowships (in conjunction with the British Geriatrics Society), Research project grants and New Investigator awards. Although, in principle, it covers social care research, most current funding appears to cover clinical and health research.

The value of a PhD Studentship in 2012 was, over the 3 years of study, £74,250 outside London and £77,250 in London. For Research Fellowships and Senior Research Fellowships, the maximum value for 2012 was £235,000 over three years.

In the case of Senior Fellowships, the host institution must commit to meeting 50% of the cost. For Clinical Fellowships the maximum value in 2012 was £285,000 over three years. New Investigator awards were last made in 2009 and the maximum value was £50,000 for up to three years.

The emphasis is on applied and translational research that will or is likely to lead to interventions within 5 years of the end of the research project. They also fund research in areas of health and wellbeing that affect large numbers of older people but are under-researched, and endeavour to build capacity in ageing research in the UK.

Age UK funds research on a joint basis with other partners. In the past, Age UK has entered funding partnerships with Action on Hearing Loss (PhD Studentships), University College London, King's College London, University of Leicester and Medical Research Council Harwell as well as the British Geriatrics Society (Clinical Research Fellowships).

They awarded 11 new research grants in 2012, the majority of which were PhD studentships.

	2012	2010	2009	2008
Fellowships	3	3	2	1
PhD studentships	8	10	4 (joint) + 2	5
Research projects			2 (applications received in 2008)	1
New Investigator award			1	1
Total	11	13	11	8
Total value	£985,122 excl. British Geriatrics Society contribution to one fellowship	£971,857 excl. British Geriatrics Society contribution to one fellowship	£956,457 excl. Action on Hearing Loss contribution (50%) to the joint PhD Studentships	£707,403

Priority-setting for research funding and support

Age UK has a number of funding routes, and is part of a range of networks, for informing its research priorities, including:

- advice from the Research Advisory Council, consisting of 23 experts as well as from three members of the British Geriatrics Society
- local partnerships with 24 local volunteer committees, which engage through focus or discussion groups with researchers from local academic institutions, and also help researchers to access the local older population
- membership of the UK Age Research Forum, which is a strategic partnership between government, research councils and charities
- ministerial Advisory Group on Dementia Research (MAGDR) involving DH/NIHR, research councils, other charities, the pharmaceutical sector and a former carer of someone living with dementia
- national partnerships with the British Geriatrics Society, the British Society of Gerontology, the British Society for Research on Ageing and the British Council on Ageing.

4.16 Alzheimer's Society

Description of organisation

Alzheimer's Society is a registered charity in the UK (charity number: 296645) as well as a registered company limited by guarantee (registration number: 2115499) focusing on Alzheimer's disease and related dementias. The charity operates throughout England and Wales, as well as in Guernsey, the Isle of Man and Northern Ireland. Alzheimer's Society has provided funding for research since 1990. It has 1,529 employees and 6,874 volunteers.

Charitable objectives:

- Relieve and treat and promote the relief and treatment of those suffering from Alzheimer's disease and related disorders and to provide support both for such persons and their families
- Promote, support and carry out research into the care and possible cures whether partial or completed, and the possible prevention of Alzheimer's and related disorders.

The society achieves these objective by:

- Making grants to individuals and organisations
- Providing services and advice
- Sponsoring and undertaking research.

Financial information

Income: £84,437,000 (up from £58,907,000 in 2010)

- 38% from contracts
- 37% from donations
- 18% by legacies
- 6% by trading & other
- 1% through investment.

Expenditure: £74,699,000 (up from £57,299,000 in 2010)

- 5.3% on advancing research - This (just over £3m in 2010) constitutes a sizeable fraction of the £14m (2010) of charitable funding spent on dementia research each year. Additionally, around £36m (2010) comes from Government funding.
- 63% on meeting needs
- 3.7% on sharing information
- 8.8% inspiring change
- 1.5% on trading costs of subsidiaries
- 0.4% on governance
- 16.5% on fundraising.

Structure of funding activity

The Alzheimer's Society's research spending is split between research into dementia care and into biomedical research, under the slogan, 'care for today and cure for tomorrow'. Social care or social care/ health research is funded under their 'care, services and public health research funding stream'. This is broad, and covers research, review and evidence synthesis focused on:

- identifying or modifying risk factors
- the burden of dementia at an individual or population level
- psychological, social or assistive technology interventions
- quality of life of those affected by dementia
- models of service delivery in primary care, care homes and hospitals
- end of life care.

It will also consider any other dementia-related, UK-based research that would fall within the usual remit of the Arts & Humanities Research Council (AHRC) or the ESRC.

The Society only funds research projects at UK-based Universities, NHS sites or other recognised higher research institutions. Applicants may apply for direct research costs up to £400,000 over 36 months to support their research. It also offers a range of fellowships - Junior Fellowships (up to £225,000), Senior Fellowships (up to £400,000) and Clinician and

Healthcare Training Fellowships (up to £225,000), as well as PhD studentships (up to £85,000, through applications from prospective supervisors). Dissemination grants of up to £50,000 are available to enable improved communication of findings to enable transmission of research findings into practice.

The organisation has a research team, consisting of 11 members who are responsible for research programme coordination, liaison, research network management and communication of research. Internally, the team support fundraising and media work.

Priority-setting for research funding and support

Alzheimer's Society's setting of priorities for funding research is closely linked with its wider lobbying, advocacy and national agenda-setting activities. It takes a broad-based approach, with its priorities being actively informed by policy-makers, practitioners, researchers and service-users. In particular, it has high involvement from 'experts by experience' and practitioners and others with direct experience of dementia. For example, the Alzheimer's Society established a priority-setting partnership with James Lind Alliance, which, in 2012, surveyed over 1500 people with dementia, their carers, health and social care practitioners and relevant organisations about research priorities. The work established ten priorities which continue to inform the Alzheimer's Society's own work and their work with other research funders. These priorities cover maintaining independence, influencing care practice, early diagnosis, pharmacological and non-pharmacological interventions, best practice in hospital care, ensuring adequate hydration and nutrition, supporting carers, end of life care, transition into a care home and dementia friendly environments.

Also, the Research Network was set up in 1999, and consists of 250 volunteer carers, former carers or people with dementia who 'inform research priorities, guide funding decisions and ensure that research has the maximum possible impact on dementia care'. They have wide involvement in all aspects of the research process. However, every two years, Research Network volunteers are specifically asked to highlight areas of dementia research that they consider to be particularly urgent, relevant or neglected.

Alzheimer's Society also looks for leadership from research applicants in identifying and articulating research priorities. It is also very active in policy, advocacy and lobbying, which inform its priorities for research funding and it may commission work from known experts and researchers in relevant fields.

4.17 Esmée Fairbairn Foundation

Description of organisation

Esmée Fairbairn Foundation was established in 1961 and today it is one of the largest independent grant-making foundations in the UK. The Foundation is a charity registered in England and Wales, number 200051. The Foundation has 28 members of staff.

The Foundation's funding priorities are in five areas:

- [Children and Young People](#): Early years development; The rights of vulnerable children and young people; Addressing root causes of low educational attainment and challenging behaviour; Civic and political participation for young people under-represented in decision-making.
- [Social Change](#): Participation – marginalised and excluded individuals and groups; Place – revitalising community life; Injustice – systemic change around injustice and inequality
- Arts
- [Environment](#)
- [Food](#).

Across all areas the foundation aims to unlock and enable potential, back the unorthodox and unfashionable, build collective networks and catalyse system change.

Financial information

2014 accounts:

- Income £8,948,000
- Spending £39,370,000

Structure of funding activity

Esmée Fairbairn Foundation makes grants of £30 - £35 million annually towards a wide range of work within the arts, education and learning, the environment and social change. It also operates a Finance Fund which invests in organisations that aim to deliver both a financial return and a social benefit. The Foundation offers three types of support: grants, [social investments](#) and [Grants Plus](#) support. Their detailed funding Strategy for 2015 to 2019 is available [online](#). There are no application deadlines and no restrictions on reapplying. An Executive Committee takes decisions on grants up to £60,000. An Applications Committee, comprising Trustee and Executive members, takes decisions on grants up to £150,000. All decisions on grants over £150,000 go to the Trustee Board. There is a separate Finance Fund Panel for social investments. Those in excess of £1 million are referred by the Finance Fund Panel to the Trustee Board.

Breakdown of funding activity in 2013

Main Fund	Value (£)	%	Number of grants
<i>Arts</i>	11,184,696	36	88
<i>Education and Learning</i>	3,784,459	12	35
<i>Environment</i>	4,390,484	14	36
<i>Social Change</i>	11,819,237	38	144
<i>Total</i>	31,178,876		
Other	Value	%	Number
<i>Food</i>	2,173,418	29	22
<i>Finance Fund</i>	4,373,082	58	22
<i>TASK</i>	916,800	12	114
<i>Grants Plus</i>	90,209	1	0
<i>Other total</i>	38,732,385		

Priority-setting for research funding and support

Esmée Fairbairn Foundation’s funding strategy has been developed with Trustees, staff, stakeholders and grantees and informed it by external research and analysis. The organisation currently has no programme that includes funding for social care.

Appendix: Topic Guide for Interviews

Experience of drawing on 'recommendations for research':

- Has body previously made call/funded research on basis of 'recommendations for research' or identified research gaps? If so, based on what recommendations for research?
- How successful was this and why? What went well, less well?
- Generally, what attention is paid by the body to recommendations for research and from what sources?
- What are the strengths and weaknesses of such recommendations for research/ identified research gaps in their experience?
- How available are 'recommendations for research'? Are they consistent and high-quality in their experience (general experience and social care in particular)?

Structure of calls/ programmes:

- Why structured in this way? What are the main choices body has taken in establishing calls/ programme in way they have?

Support to applicants:

- What challenges faced in calling for funding applications (e.g. quality of proposals, particular methodological expertise, etc)?
- What support is offered to applicants, both at proposal stage and throughout project?
- Example(s) of recent calls/ programmes?
- How topic selected and why? How successful? How many applications attracted? Quality of applications? Barriers? What worked well and less well?

Interest in working with NICE:

- What interest would funder have in using NICE recommendations for research (social care) to influence topics funded? Why/ why not?
- Would they like to input into them, before they are published (see below for how they would like to engage with NICE in practice)?

Helping to understand research gaps:

- What would be the best approaches/ means for NICE to communicate with funding body, e.g. if NICE want to gain funding body's views on reasons for specific evidence gaps?

Best way of communicating re: recommendations for research:

- What would be the best means of communicating with funding body about NICE's recommendations for research (methods of communication, optimum timing, push or pull approach, involvement in advisory panels/ networks etc.)?

How recommendations are formulated:

- Are recommendations for research (as currently formulated) helpful for funders?
- If yes, in what way?
- If not, how could they be improved? (e.g. size and scope, specificity, level of detail etc.)?

Existing engagement with improving reach and quality of social care research and wider networks

- What is the funding body already doing/ who is it working with to improve capacity for research into social care and/or social care/health interface?
- What wider networks is it involved with and what is the purpose of these?
- How might NICE engage in this work/ these networks?