

from the Research Design Service East Midlands

## Research for Patient Benefit East Midlands Advisory Panel Update

### An introduction to the new Chair

I am Professor Neil Coulson and on the 1st August 2017 I took up the position of Research for Patient Benefit Programme (RfPB) Regional Advisory Panel Chair – East Midlands. I am delighted to have been appointed to this role and over the next few years I am very much looking forward to working with colleagues across the region to help advance and support patient-focused research. Before outlining (briefly) my objectives for the programme in the East Midlands I thought it might be useful to briefly tell you about my background and research interests.

I am a Professor of Health Psychology in the School of Medicine at the University of Nottingham. I am both a Chartered Psychologist (British Psychological Society) and a Registered Health Psychologist (Health and Care Professions Council). I completed my MA (Hons) Psychology at the University of St. Andrews followed by my MSc Health Promotion & Health Education at the University of Edinburgh and then my PhD Health Psychology at the University of Exeter.

My research passion is concerned with the role of the Internet and social media in supporting those affected by long-term conditions. In today's connected world the opportunity to participate, collaborate and interact online has never been greater and so one key theme within my programme of research is how peers can support each other through digital platforms (e.g. asynchronous discussion forums).

Over the past few years I have also been a member of various NIHR funding panels including the Doctoral Research Fellowships panel as well as the Programme Grant for Applied Research panel where I have been serving as a methodologist – health psychology/behavioural science. Prior to my appointment as Chair of the RfPB Advisory Panel for the East Midlands, I was an ordinary member of the panel for 4 years.



### New opportunities

One question I have been asked by colleagues since taking up this role is: "So what are your objectives going forward?". This is a good question and there are a number of important objectives I am would like to work towards during my tenure as Chair.

Firstly, I would like to encourage more high-quality research funding applications from across the breadth of the East Midlands region. Across this region we have some excellent teams and individuals and I would like to see greater representation from all with an interest in promoting patient benefit through research.

Secondly, I would like to encourage applications drawing upon a greater array of research designs and methods. Across all three funding tiers within the RfPB programme, there is potential for a range of designs and methods to be proposed (e.g. qualitative, observational). To illustrate this, I would draw your attention to the Tier 3 funding stream within RfPB and the many exciting projects that have recently been funded (see RfPB website for a recent review of Tier 3 funding). Indeed, within the East Midlands we have had some excellent applications using innovative methods and designs and I would like to encourage more of this!

### My advice

The key to success, in my opinion, is to develop a sound proposal with the right team and appropriately evidenced methodological expertise that has integrated the patient perspective throughout and which employs an appropriate research design to answer an important question and with a clear view of how this can be taken forward to ultimately benefit patients.

Please speak to the RDS and discuss your ideas and proposals. I cannot emphasise enough how important this is and applications which have done so fully and properly are stronger!

Good luck and I very much look forward to reading your proposals.

**Professor Neil Coulson**

[www.nottingham.ac.uk/medicine/people.neil.coulson](http://www.nottingham.ac.uk/medicine/people.neil.coulson)

# Applying for NIHR Social Care Research Funding

The following article illustrates points raised by Dr Mike Clark, Research Programme Manager at the NIHR School for Social Care Research in a recent talk ([www.rds-sc.nihr.ac.uk/videos](http://www.rds-sc.nihr.ac.uk/videos))

## Background: Adult Social Care in England

Social Care is hard to define as it represents a diverse range of needs, clients, care settings and care providers. Social care is very different from Health Care provided by the NHS as access is not universal but dependent upon a mix of means-tested state funded services and self-funded support, whereas the NHS provides care, free at the point of use. Social Care operates through a national policy framework devolved down to Local Authorities for them to implement. Theoretically, there could be as many as 152 different social care systems operating across Local Authority areas in England. Differences in how Health Care and Social Care are managed and administered are significant, consequently researchers cannot assume that approaches used in healthcare research will automatically work in Social care research.

In 2010, the Adult Social Care sector had capacity of c.474,400 institutional beds, compared with average overnight beds in English NHS hospitals of 137,000 demonstrating the significant capacity and scale of the social care sector. The social care sector is increasingly caring for people with a range of co-morbidities and higher levels of dependency. Funding pressures are significant, (between 2009/10 – 2014/15 spending on social care for older people fell by 9% in real terms). These pressures yield important research questions: How is the sector coping? What are the implications for people who used to get state funding and will now find that they are no longer eligible? Which services are being lost in the community and what are the consequences for the sector and individuals concerned?

## Adult Social Care research and the NIHR

The heterogeneity within the Social Care sector, means researchers need to think carefully about:

- how they frame their research questions who to include in their studies
- The challenges of working with multiple agencies
- different funding and organisational systems
- recognising the limited research experience within the sector.

Research is often smaller scale, addressing specific issues in a given locality, with significantly fewer multi-disciplinary, multi-institutional large scale research projects; There are opportunities for social care research to overlap with health care, for example in dementia, mental health, and patient pathways and in these areas researchers in the social care sector have been successful. There are no NHS support costs available for social care research, limited help available to recruit participants or research partners, and a challenge to fund intervention costs.

As well as these practical issues, it can be difficult for social care researchers to demonstrate impact and patient benefit, which are key criteria of NIHR funding, due to the diverse and devolved nature of the sector and the range of systems and approaches adopted by Local Authorities. Social Care researchers have in the past aligned their research with public health, stressing the areas of overlapping and shared interest as well as potential benefit for the NHS (i.e. reduction in-patient admissions, delayed transfers of care) as a means of securing NIHR funding.

## Funding Priorities

Previously social care funding focused on a) research relevant to social care interests (i.e. balance of care in old age mental health services, medical care and care homes, dementia care) and b) infrastructure to support social care research (i.e. ENRICH and care homes, Join Dementia Research, Involve). There have also been a number of successful fellowship applications relating to social care research.

There is however, increasing interest and support for social care research '*in its own right*' within the NIHR. In previous research calls it was not always obvious how social care research fitted with the scope of the programme, and there was a lack of consistency in presentation and visibility of this information.

Some pertinent research questions which currently face the sector:

- How effective are current models of care? How are new responsibilities (e.g. well-being) and new areas (e.g. self-funders) being addressed? What are the new social care models?
- How to innovate in times of austerity?
- How to provide an evidence base to help organisations adapt?

What is key is that social care researchers are well-prepared to make the most of these funding opportunities and are submitting high quality applications.

## The NIHR School for Social Care Research (SSCR) funding

In addition to NIHR funding the SSCR also directly funds research. Its mission is to

'develop the evidence base for adult social care practice in England by commissioning and conducting world-class research'

The SSCR is interested in a number of new themes and future challenges including:

- Prevention – developing a local prevention evaluation framework;
- Offenders – Social care in prisons; needs assessment and service requirements;

- New Workforce – Exploring the role of workplace personal assistants for physically disabled people;
- Self-funders – Meeting the information needs of self-funders;
- Future demands – Investigating ‘optimal time’. Multiple perspectives on the timing of moving people with dementia into a care home;
- Predicting future unmet social care need and examining links with well-being; and
- Future challenges and opportunities – collaborative programme examining future of adult social care and responses to challenges.

The SSCR is also interested in developing research methods which are applied to social care research and have commissioned a number of methods papers on various approaches including quality of life measures, modelling social care complexity, use of large scale datasets, and structured observational research.

For general enquiries contact:

✉ [rds.em@nihr.ac.uk](mailto:rds.em@nihr.ac.uk)

☎ 0116 252 3276 Leicester

(covering Leicestershire, Northamptonshire and Rutland)

☎ 0115 970 9310 Nottingham

(covering Nottinghamshire, Derbyshire and Lincolnshire)

## Research Design Service – Public contributors group

Nationally the Research design service (RDS) is now in partnership with INVOLVE. One of the joint aims is to unify the language used in support to researchers, so that researchers use the same public involvement language in their NIHR research applications.

Amongst various public involvement initiatives within the East Midlands the RDS has established a Public Contributors Group. These are people with a wide diversity of backgrounds and experiences who may be living with particular health conditions or caring for those that do. Essentially they are non-scientific, and contribute a lay persons’ perspective to research plans and proposals. The RDS helps to train and equip the members to comment on the relevance of *your* planned research using *their* personal experience and knowledge. The range of tasks that group members help with include: Public involvement workshops with researchers, the scientific panel, the lay review service, and different kinds of public engagement work including conference talks and seminars for national RDS training.

## As a researcher what can the public contributors group do for me?

- Provide feedback on the quality of the plain English summary in your research proposal and comment on it’s readability and clarity.
- Consider the feasibility and acceptability of any interventions /tests that you will be asking your research subjects to participate in
- Help with dissemination of the results through their contacts/ networks and consider the impacts generated on clinical work and processes e.g. developing new guidelines etc.
- Look closely at the all-important public involvement plans for your study. As this is their over arching role in the RDS they may be able to comment on training plans and costs involved and have ideas for improving the quality of involvement to strengthen the application.

Ruth is currently a member of the group which the RDS is planning to expand.

## What have you been involved in?

**(Ruth)** My main role is reviewing scientific health research. Within a research summary there has to be what is called a ‘Plain English Summary’ which should contain no medical jargon and be easy for a lay person to understand. I also help see that the practical and emotional issues of patients and carers are addressed when they are being asked to take part in a research trial.

If you would like more information visit the website: <http://www.rds-eastmidlands.nihr.ac.uk/public-involvement> or contact Raksha, [rp185@leicester.ac.uk](mailto:rp185@leicester.ac.uk)



**The NIHR Research Design Service for the East Midlands provides free support to researchers undertaking health related research. A team of research advisors is able to help with developing and submitting research protocols to national peer-reviewed funding streams.**

To subscribe to our newsletter visit:

<http://www.rds-eastmidlands.nihr.ac.uk/#Signup>

# NOTICEBOARD

## Changes to consent for children in clinical trials from May 2018

A change in the **EU Directive 95/46/EC General Data Protection Regulation (GDPR)** affects consent conditions for use of data from children within clinical trials where the data is considered identifiable personal data.

Currently, trials may use an opt-out strategy for parents (negative assent). When the new directive comes into force in May 2018, positive parent assent will be needed to process the data.

Researchers who think their study protocols may be affected should contact their sponsors for more information and advice.

<http://www.eugdpr.org/key-changes.html>

## NIHR signs up to WHO initiative on trial registration

NIHR is the latest research funder to sign up to an international joint statement, developed by the **World Health Organization (WHO)**, pledging to ensure clinical trials will be both registered and their results released.

The pledge, is in line with NIHR's existing policy on **Adding Value in Research**, and will mean that all fully funded studies will be required to register in a publicly accessible database and make sure all results are disclosed in a timely way.

<http://www.who.int/ictrp/results/jointstatement/en/>

## The Health Foundation – communicating your research toolkit

This toolkit is for researchers to help increase influence and impact in health and health care. It is divided into 4 sections:

- Section 1: Planning for impact
- Section 2: Communicating your research results
- Section 3: Extending influence and widening impact
- Section 4: Glossary of terms

[http://www.health.org.uk/collection/communications-health-research-toolkit?utm\\_source=charityemail&utm\\_medium=email&utm\\_campaign=July-2017&pubid=healthfoundation&description=July-2017&dm\\_i=4Y2%2C52TPS%2C6IJB LM%2CJG0FS%2C1](http://www.health.org.uk/collection/communications-health-research-toolkit?utm_source=charityemail&utm_medium=email&utm_campaign=July-2017&pubid=healthfoundation&description=July-2017&dm_i=4Y2%2C52TPS%2C6IJB LM%2CJG0FS%2C1)

## Newly published Clinical Research Nursing Strategy shows research nurses as 'visible leaders'

A strategy setting out the direction of travel for Clinical Research Nurses has been released by the National Institute for Health Research (NIHR) Clinical Research Network (CRN).

The strategy, sets out the next set of strategic goals for 2017-2020.

NIHR funded clinical research nurses (CRNs), midwives and specialist community public health nurses all have a vital role in the delivery of

quality clinical research care. The CRN strategy will ensure the CRN workforce meet the expectations of patients in the NHS and are seen as visible leaders.

For the summary and report:

<https://www.nihr.ac.uk/our-faculty/clinical-research-staff/clinical-research-nurses/>

## NIHR commissioned report from RAND - Future of Health

RAND Europe was commissioned by the National Institute for Health Research (NIHR) to gather and synthesise stakeholder views on the future of health and healthcare in England in 20 to 30 years' time. The aim of the work was to gain an understanding of a wide range of stakeholders' views on the differences and trends affecting the future of health and healthcare as well as of the key drivers of change, in order to inform strategic discussions about the future priorities of the NIHR - and the health and social care research communities more widely. This work is based on an online survey of a range of stakeholders in health and social care in the United Kingdom (UK), including policy experts, academics, professional bodies, advocacy organisations and patient representatives.

Sections 4 and 5 are the most pertinent for researchers

- Perceived priority areas for health research
- Perceived priorities for supporting future health research and impact

<http://www.rds-eastmidlands.nihr.ac.uk/news>

## NIHR RfPB Programme Guidance on Applying for Feasibility Studies

The NIHR Research for Patient Benefit (RfPB) programme issued **updated guidance on applying for feasibility studies in July 2017**. This guidance is essential reading for anyone considering applying to the RfPB Programme for funding for feasibility or pilot studies. The following is covered within the guidance:

- Definition of feasibility vs pilot studies
- Feasibility and pilot studies: which NIHR programme should I apply to?
- RfPB policy on funding feasibility and pilot studies
- Guidance on applying to RfPB for a feasibility or pilot study, including:
  - Outline of the proposed follow on full trial
  - Key parameters which the feasibility study intends to clarify or estimate
  - Progression criteria for a full trial

[https://www.nihr.ac.uk/funding-and-support/documents/funding-for-research-studies/research-programmes/RfPB/Guidance%20Documents/Guidance\\_on\\_feasibility\\_studies.pdf](https://www.nihr.ac.uk/funding-and-support/documents/funding-for-research-studies/research-programmes/RfPB/Guidance%20Documents/Guidance_on_feasibility_studies.pdf)