

# Research Design Service South East (RDS SE)

Newsletter 12 Spring 2022

Director's foreword

RDS SE news

RDS SE supporting  
local researchers

PPIE news

Equality, Diversity and  
Inclusion in Research

News updates

**National Institute for Health and Care Research**  
NIHR has changed its name to emphasise its enduring commitment to social care research. The acronym 'NIHR' remains unchanged.

**Key RDS SE Strategic aims**

- Support researchers developing funding proposals to help increase quality and volume of applications to NIHR and other funders
- Strengthen links with stakeholders, partners and NIHR
- Continue to embed public involvement and EDI in all activities
- Continue to develop a highly skilled workforce.



## RDS making an impact across South East

**For NIHR, research impact is about making a meaningful difference to people's lives through the research they fund and support. Commitment to maximising the impact of funding is one of five NIHR operating principles.**

So, it is only right that our 2022 [Annual Stakeholder event](#) on 18th May will update you and us on this topic. Three highly engaging speakers will provide an overview of current debates around impact, the newly developed Impact Toolkit, and Research Clinics as a practical effort to ensure impact in our locality.

The past two years have been full of change for all and as Covid-19 endured and mutated, researchers across the NHS, Social Care and Public Health continued to face huge challenges. RDS SE continues to evolve and develop as a valuable source of support for researchers of all kinds and levels of experience and – importantly – in new areas.

Evolving RDS priority areas include social care, public health and industry-driven research, equality, diversity and inclusion (EDI) and impact (along with well-established priorities like PPIE).

Inside we feature highlights of the past year supporting research across Kent Surrey and Sussex, and the many ways we have made an impact across our region.

Do fill in our [online form](#) if you would like RDS SE Support. We look forward to our next year of working with you.

# Foreword

## Professor Jörg Huber, Director RDS SE

Dear Friends and Supporters,

Two years of successful remote working, due to the pandemic, has created a 'new normal', with only occasional face-to-face meetings. It is unlikely that we will go back to the 'old ways', as cost and time saved on travelling are considerable. Busy clinicians and practitioners greatly appreciate the ease of meeting online, accessing wider specialist expertise and 'mock' interviews.

That said, our national RDS Grant Writing Retreat for Social Care Researchers took place in Kendal, Cumbria where fifteen research teams worked together, including two from Sussex and Kent plus two RDS SE advisers. A forthcoming national staff away day and a regional get-together will be a welcome chance to reconnect with colleagues in person.

We can look back on a successful year. Despite Covid, we are busier than ever, having expanded support for social care, public health and industry-driven research. We have supported researchers on their journey to winning significant funding in all these areas.



As Chair of our National Operational Group, I enjoy working with colleagues to coordinate and deliver our programme of national RDS priorities, designed to strengthen our service and increase our reach to researchers who may have felt perhaps the NIHR was 'not for them'. Working with the RfPB Programme Managers, targeted efforts are under way to increase and improve

submissions to Research for Patient Benefit and Research for Social Care funding.

We held successful events in 2021 including in May our Stakeholder Event on Equality, Diversity and Inclusion, and in October a national RDS Research for Social Care funding event with over 100 attendees, reflecting our local expertise in this area. We held several popular 'researcher journey' seminars and you can watch these and other event [videos on our website](#).

We welcome several new staff (below) to our team, who continue their outstanding work to develop our offer to clients across the region. I hope to see many of you on 18 May at our Stakeholder event, 'Make Impact Work'.

With best wishes  
Jörg

## Want to develop a high-quality funding proposal? RDS SE can help!

**RDS SE advisers give FREE guidance on all aspects of research design and funding applications. Contact us as soon as possible for [support](#).**

Resources to help your research journey:

- [RDS SE Public Involvement Fund](#) – help with embedding patient and public involvement
- RDS SE Presubmission Review Panel – valuable feedback on your proposal. Contact your RDS Adviser for details.
- [RDS SE Fellowships Guide](#) – our go-to guide to applying for an NIHR Fellowship

- [RDS National Blog](#) – 'From the RDS desk' covers a different research design or methodology topic each month. RDS SE is a regular contributor.

[RDS SE events](#) support every stage of your research career and the grant development process.

- NIHR Funding Workshops
- Project Development Sessions
- Research Application Writing Workshops
- Research Career Journey Events
- Fellowships Workshops
- Mock Interviews

See our [events page](#) and [Twitter](#) feed for details of what's coming up.

Find out more about how RDS SE can help, on our [website](#).

## Welcome to new RDS SE staff



Kate Gee  
RDS SE Programme Manager



Funmi Vaughn  
RDS SE Strategic Lead,  
Patient and Public  
Involvement & Engagement



Amanda Bates  
RDS SE Senior Adviser,  
Patient and Public  
Involvement & Engagement



Karen Stenner  
RDS SE Research Adviser



Diane Fox  
RDS SE Social Care Research  
Adviser



Barbora Silarova  
RDS SE Social Care Research  
Adviser



Philippa Jevons  
RDS SE Data Information  
Officer

# Research success stories

## RDS SE supporting Early Career Researchers: a path to NIHR Advanced Fellowship

**We are delighted to have been working with Dr Carys Banks who was awarded a prestigious NIHR Advanced Fellowship in July 2021.**

Carys, an Early Career Researcher (ECR) at the School of Health Sciences at the University of Surrey, has an anthropology background. Her research focuses on social care for people with learning disabilities. She was awarded the 2016 Radcliffe Brown/Sutasoma Award from the Royal Anthropological Institute (RAI) for her doctoral research. This is *'a starred award and given to students of exceptional quality in recognition of doctoral research that is of potentially outstanding quality and likely to make an important contribution to social anthropology'*.

Carys came to us early in 2020 after being introduced to the RDS by her colleague Dr Marianne Coleman. Marianne received RDS SE support several times, including for her successful 'Fight for Sight' post-doctoral Fellowship.

In our initial discussions, Carys was exploring a number of options for her new research proposal. Its focus was investigating loneliness in people living in care settings with learning disabilities. In April 2020, she began working on an application to NIHR for an Advanced Fellowship.

Dr Manavi Maharshi in our RDS SE Surrey team was assigned as Carys' Lead Research Adviser. During 2020, several RDS SE Advisers joined Manavi to support Carys in developing her submission. RDS SE Advisers have the skills and expertise to support researchers in our region with all aspects of applying for Fellowships.



Applications require evidence of a high-quality research proposal, with meaningful and comprehensive Patient and Public Involvement (PPI). There must be demonstrable potential to become a future research leader, with an ambitious training plan to support this.

Carys sent her application to the RDS SE pre-submission panel, for review by RDS colleagues and lay members prior to submission to NIHR in January 2021.

We were delighted to hear in May that Carys had succeeded at stage one of the NIHR review process and her application was to be sent for peer review. RDS SE are experienced in holding mock interviews for personal awards, such as fellowships. Drawing on this expertise and our network of contacts, we set up a mock session for Carys in early July – shortly before her formal NIHR interview took place.

In late July 2021, Carys heard the great news that she had been awarded her Advanced Fellowship, in the same week as her first baby was born!

Carys said of her RDS SE Advisers, *'I wanted to say a huge thank you, you have gone above and beyond to support me in getting this application to the standard it's at and submitted on time, I am immensely grateful. This has been a real team effort and any success that may come from this will definitely also be down everyone who has contributed. I feel very fortunate to be a research fellow within such a supportive institution.'*

Our web pages have more information about NIHR fellowships and how RDS SE can help [support your research career](#).

# Research success stories

## Adapting the Easy-Read Adult Social Care Outcomes Toolkit (ASCOT-ER)

NIHR funding to help older users report their care experiences

**The Research for Social Care (RfSC) call is an annual competition run by NIHR's Research for Patient Benefit (RfPB) programme. It funds research to increase social care service effectiveness, provide value for money and benefit users and carers.**



In 2021, RDS SE supported a successful RfSC application submitted by the University of Kent's Centre for Health Services Studies (CHSS) and Personal Social Services Research Unit (PSSRU). The research team will co-produce an adapted version of the ASCOT (Adult Social Care Outcomes Toolkit) with older people and carers.

ASCOT captures people's experiences as social care users or unpaid (family/friend) carers, and measures impact on social care-related quality of life (SCRQoL). It informs indicators within the national Adult Social Care Outcomes Framework (ASCOF) in England, and many other countries use it. Social care users complete ASCOT quality of life questionnaires themselves, but the oldest and those with cognitive decline may find it difficult and need additional support. These groups are under-represented in national surveys.

Principal Investigator Ann-Marie Towers, Reader at CHSS, received RfSC funding of £219,997 to lead this two-year study from April 2022 with co-investigators Stacey Rand and James Caiels (PSSRU). The team will work with older users and carers to co-produce an adapted version of ASCOT for this age group.

They will test iterations of the new version in interviews with people who struggle to self-complete conventional surveys. One carer in the co-production group commented, "We need proper evidence from the very people who are receiving care. Thank you very much for giving us an opportunity to have a voice."

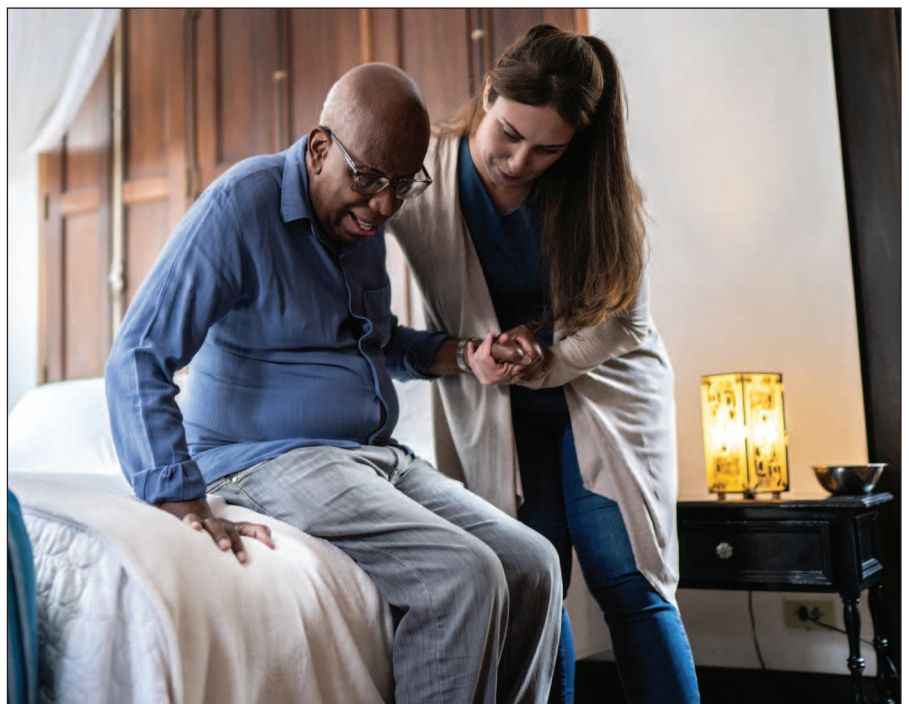
The study will use easy to read adaptations with simplified text and pictures. These can help people to continue to share their views and inform care providers, policy makers and researchers about how they feel. A [previous study](#) adopted a similar approach to produce a version of ASCOT for adults in England with intellectual and developmental disabilities.

Ann-Marie and her team are very excited to be undertaking this important work, 'ASCOT is ultimately a quality of life tool and the best way to find out about someone's quality of life is to ask them.

*Many older adults using social care have difficulty with conventional questionnaires. We are always looking for ways to improve our methods and help people using social care to share their own views.'*

RDS SE supported the application, peer reviewing the first draft proposal and providing valuable feedback to the research team. Lead RDS SE Adviser Dr Ferhana Hashem, Reader in Health Services Research, University of Kent said, 'It's been good to see another RfSC project supported through RDS SE, and great that it was successful in securing funding for this meaningful project. Our expertise in social care continues to grow, and we recently welcomed new social care specialist advisers to the Kent RDS team'.

*'We are seeing more applications for the RfSC funding stream coming through at Kent. It reflects NIHR's commitment to funding high quality research to improve and develop the evidence base around this sector.'*



# Research success stories

## Increasing access to Cognitive Behavioural Therapy (CBT) for psychosis patients

(GiVE3) Randomised controlled trial evaluating brief, targeted CBT for distressing voices delivered by assistant psychologists

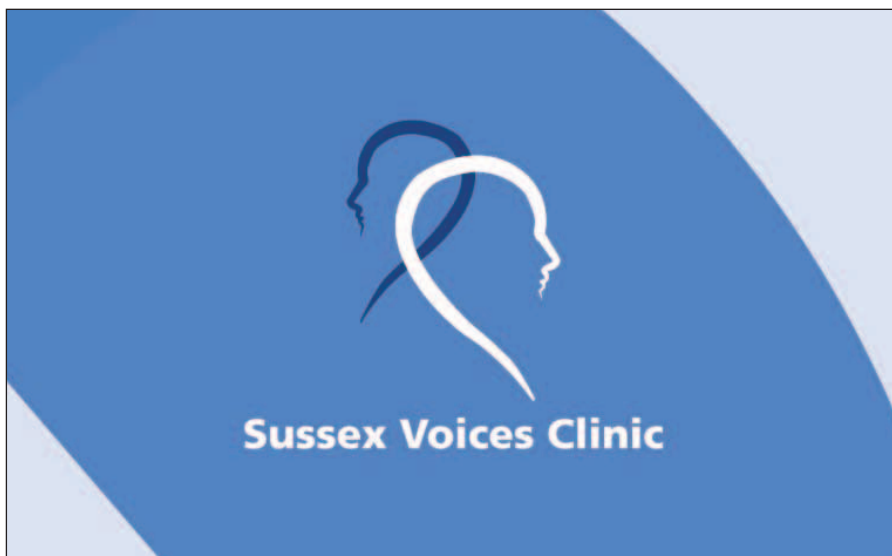
RDS SE is here to help researchers at all stages of their career. We have been working with Professor Mark Hayward, clinical psychology researcher and R&D Director of Sussex Partnership NHS Foundation Trust, since 2008.



In September 2020, Mark and his research team came to the end of an 18-month study exploring the feasibility of running a large trial to evaluate a novel intervention they had developed to support people distressed by hearing voices. The [feasibility study](#) was a success. Mark now wanted to apply for NIHR Research for Patient Benefit (RfPB) programme funding to conduct the larger clinical trial to establish whether the intervention was clinically effective and/or cost effective.

The novel intervention is a “guided, self-help cognitive behavioural therapy (CBT) intervention for distressing voices” (GiVE) which targets the psychosis symptoms of distressing voices. Uniquely, this intervention is designed to be delivered by briefly trained therapists (assistant psychologists) rather than highly trained therapists (e.g., clinical psychologists).

If found to be clinically and cost-effective, a wider range of NHS therapists would be able to deliver GiVE across secondary mental health care services. The impact of this would be to increase timely access to cognitive behavioural therapy for psychosis (CBTp) for those who need it.



### How did RDS help?

RDS SE had already supported Mark and his team to secure funding for the GiVE2 feasibility study. Dr Claire Rosten then became a member of the Trial Steering Committee providing post-award support.

In preparation for submitting to RfPB for the larger clinical trial (GiVE3), Mark met Dr Ellen Donovan to discuss the challenge of how to make a compelling case for altering the GiVE3 RCT design from the one used in the feasibility study. Mark prepared a draft RfPB application and due to the rapid nature of being ‘fast tracked’, a small group of RDS Advisers (clinical trialists, statisticians and health economists) were quickly convened to conduct a critical review. They helped identify areas that could be strengthened, including thinking ahead to future implementation and training needs if GiVE were scaled up and rolled out across the NHS. RDS Advisers also provided advice on recruitment, Equality, Diversity & Inclusion (EDI) and Patient & Public Involvement (PPI).

Ellen said ‘Mark and his team had previous experience in designing clinical trials, but we were able to look at it with a fresh view and provide our objectivity. We were able to identify areas in the application that could be enhanced and made clearer. We hoped that these changes would enable the RfPB review panel to understand the study and design more easily.’

Mark and the team were awarded £346,014 for the trial which runs from April 2022 to October 2024. He commented: ‘During development and writing of the application, the RDS SE Advisers helpfully acted as a ‘critical friend’. They invited me to question the appropriateness of the proposed design, and to consider alternatives. This helped me to step back and consider how others may view my ideas. The consultations helped me to feel more confident that the proposed study design would facilitate the addressing of the research question.’

# Patient and Public Involvement & Engagement

## Reaching Out

Working with our NIHR partners the Clinical Research Network Kent Surrey Sussex and the Applied Research Collaboration Kent Surrey Sussex (CRNKSS and ARCKSS), and following the disproportionate impact of Covid-19, we have been forging links with organisations from ethnic minority groups.

We have tried to move away from the usual short term, 'transactional' relationship between researcher and community, towards developing an ongoing trusting relationship. With funding from the NIHR Centre for Engagement and Dissemination's 'Reaching Out' programme, we brought together researchers, professionals and people from ethnic minority groups across the region to discuss experiences, challenges and benefits of being involved in research and how we can work together going forward.

This project was a chance to capture what needs to change at local and national level; to ensure an ongoing partnership between NIHR and the public – NIHR partners see this as the foundation for greater representation and involvement in research – and ensuring that research activity reflects everybody's needs. We intend to co-produce the partnership's way forward, and define its purpose and activities.

Written by a public member of the established ethnic minorities group with the Reaching Out Steering Group, the [resulting report](#) is available on the NIHR website.



## New RDS SE Strategic PPI Lead



### Funmi Vaughn

A researcher with a background in Public Health and Social Care, Funmi has extensive experience within the NHS and local authorities,

with roles including Community Engagement and Public Involvement.

She wants the PPI experience to be, 'accessible, normal, everyday and rewarding – the public need to feel they are a part of research and confident to inform it'.

## That Co-production Podcast!

*"That Co-production Podcast is a really valuable resource. We would love there to be many more episodes!"*

Head of Co-production Collective, UCL

Last year we launched our successful series 'That Co-production Podcast!' Viewed over 1,000 times and in 29 countries, the podcasts are a useful and accessible resource for those interested in co-production in research. The [podcasts](#) are also available on Spotify, SoundCloud and Anchor.

RDS SE public contributors Julie Wright and Kati Turner shared their reflections in a [blog](#) about the podcasts.



## Embracing co-production principles

The RDS SE PPIE team seeks to aspire to [NIHR co-production principles](#). Our pioneering work has led to and greater involvement of public reviewers [in our work and governance](#). All projects, presentations and CPD events are now co-produced with our public members. This helps develop skills and increases participation in the wider RDS SE events programme.

Two public members attend every team meeting for 18 months, joined by a different 'floating member' at each one. This helps familiarise new members with the team and our work. Rotating the Chair at each team meeting gives everyone a chance to develop chairing skills.

A buddying system gives new RDS SE lay members support from other public members in the early days. Regular reflective sessions help us capture the impact of working co-productively, record how far we are modelling co-production principles – and how we might improve.

## Improving our PPIE

Our Public Involvement Fund (PIF) supports researchers to include the public in the development of the NIHR research proposals. Moving to an [online](#) PIF application process has reduced turnaround time and embedded an approach which gives lay reviewers feedback on the outcome from their comments. The changes are captured in a [blog](#).

Our [Plain English Summary review service](#) is available as a valuable resource for those researchers who are having difficulties finding public members.

# Patient and Public Involvement & Engagement

## Celebrating young people making a difference in health research

**Kent Surrey and Sussex Young People's Advisory Group (YPAG KSS) advise researchers across the region on projects which will involve children and young people. Here, the Group reflect on the benefits they can bring to research, and their YPAG experience.**

"We all know that it's important to involve young people in research that will have an impact on us. We have a right to be involved, and we can play a vital role in improving the quality of research and its relevance. We would like to encourage other young people to get involved, and encourage more researchers to work with groups like us!

### Who are we?

The Kent Surrey and Sussex Young People's Advisory Group in Health Research (YPAG KSS) was formed in 2017. We are a group of children and young people aged 8 to 18, with adult volunteer facilitators, who meet every two months to advise researchers on their projects. Many of us have experienced problems with our own health, which give us particular insights. Since March 2020, due to COVID, we not been able to meet face to face, but we have continued to hold lively, well-attended meetings on Zoom.

In March 2022, YPAG KSS celebrated our fourth Anniversary. We took this opportunity to reflect on all our work and how we have benefited from being part of the group.

### What do young people bring to the table?

Quite simply, we can look at research from the perspective of the people it is aimed at – the young people who are going to be partners in the research!



We have advised health and social care researchers from across Kent, Surrey, Sussex and beyond, helped them with grant and Research Ethics Committee applications, and to design relevant research which young people want to take part in. We have also joined the [GenerationR Alliance](#) and helped them design a [toolkit](#) for others wishing to start up a new YPAG.

At YPAG meetings, researchers present their projects to us and we give direct, honest feedback. This helps them to refine and improve their research proposals, ideas and instruments. For example, after a YPAG meeting, one researcher we worked with completely redrafted their recruitment materials. These new versions were submitted as part of their ethics application. They also used YPAG feedback to design a new guide for foster carers who will support children to complete the questionnaires.

For some researchers, advice from YPAG has helped them develop a successful application for competitive funding. For others, YPAG has helped make sure their research is asking the right questions, those of relevance to young people.

### Why do we get involved?

We all want to help and to make a difference. We want to improve care for ourselves and for the young people of the future. But we also really appreciate the chance to be *heard* – not just talked to or talked about! It's really nice to get your opinion out, because when you're a child you don't often get that chance.

It's good when you see a project and it's obvious that the research team have forgotten it's for children and they've approached it from a very clinical, or a very adult, point of view. In those cases, it's good to take them back a peg or two and let them know 'you've forgotten who your target audience are here.' And they go 'oh yeah!'

For some of us, involvement in YPAG could also help with career options. Some of our group are interested in research and a career in the medical world, and being part of YPAG gives an interesting insight. Finally, the group is an opportunity to meet and interact with new people. This was particularly welcome during the lockdown period when some of us had forgotten the world outside, and it was a welcome reminder of normality!

To sum up, young people have an important voice in research and getting involved can be an interesting and rewarding experience. Our group, and others like it, improve the relevance and quality of research and enable young people to make a difference, learn new skills and meet new people."

## Want to learn more?

If you are a researcher interested in getting the views of young people:

- contact [ypagkss@nihr.ac.uk](mailto:ypagkss@nihr.ac.uk), if you are based in Kent, Surrey or Sussex
- take a look at the NIHR [guidance](#) on involving children and young people
- contact your local Research Design Service for their advice and support

If you are a young person interested in getting involved in research:

- if you live in Kent, Surrey or Sussex, ask about joining the YPAG by emailing [ypagkss@nihr.ac.uk](mailto:ypagkss@nihr.ac.uk) or find your local YPAG here: <https://generationr.org.uk/meet-the-team/>
- Read NIHR's [Public Information Pack](#).

# Equality, Diversity and Inclusion in Research

## Is research really for everyone?

Since the onset of Covid-19, it feels safe to say that there is a heightened awareness of the inequalities in health and social care research. People historically marginalised from mainstream services still face multiple barriers to accessing and engaging in research.

NIHR has made a strong [commitment](#) to support Equality Diversity & Inclusion (EDI) across the health and social care research system. For instance, researchers applying to NIHR must show how they address EDI issues. As RDS Advisers, promoting EDI to local researchers has been an interesting and educational journey.

Our 2021 RDS SE Stakeholder Event with guest speaker [Dr Esther Mukuka](#) (NIHR Head of EDI), focused on illustrating EDI in research, its challenges, and how we might overcome these. She outlined future NIHR ambitions, and explained the difference between the concepts of diversity and inclusion. Based on Dr Mukuka's words, diversity centres on recognising differences and acknowledging the benefits of multiple perspectives in research, including decision-making, design, delivery and infrastructure. Similarly, inclusion is where everyone's differences are valued, and used to enable everyone to participate and thrive.



We've noticed that the definition and scope of EDI is often misunderstood and limited to only considering ethnicity and gender. In reality, EDI is about involving so many more groups; LGBTQ+ communities, people with learning disabilities, people with educational disadvantage, people living in rural communities, etc. It is also about avoiding potential language barriers and digital exclusion. Please see the [INCLUDE project list](#) for more examples.

Familiarity is growing around the phrase 'EDI in research' but achieving it seems to be a challenging craft. One solution doesn't fit all, but we've found guidance and tools for researchers to critique how inclusive their study really is. An example is the [INCLUDE project](#) guidance, the helpful summary on how to improve inclusion and the list of 'under-served' groups.

The National RDS EDI Working Group have developed an [Equality Diversity and Inclusion \(EDI\) Toolkit](#) to lead users through a range of pertinent questions for designing studies (see below). Detailed guidance and case studies are due later this year.

We felt that an expert voice was needed to bring the wealth of new EDI guidance to life so we organised a series of EDI sessions for RDS Advisers. Speakers were invited to share their experiences of breaking down barriers and improving diversity and inclusion. The sessions gave researchers and advisers a safe space to discuss issues and raise questions about different aspects of EDI.

Our first session in January 2021 featured '[creating inclusive care homes](#)' by Berkeley Wilde and '[Trans Ageing and care project](#)' by Paul Willis. Key messages were the importance of making it clear who the research is for and being more

overt in participation invitations. Adding rainbow and trans flags to participant facing materials, using positive and inclusive LGBTQ+ images, and respecting gender-neutral terms are effective ways to promote inclusivity. Peer recruitment or interviewing, and early working with local community groups, are key for engaging marginalised groups.

Our successful series continued with the impact of Covid-19 on ethnic minority communities, including people with disabilities in research, and a second LGBTQ+ research discussion (see [Video Resource 9](#) on RDS SE website). Later sessions covered improving access to research for people with intellectual disabilities, stroke, or transient ischaemic attack (see [Video Resource 10](#)).

So, when you look at the design of a research study, ask yourself "is this [research for everyone](#)"? If not, why not? A good approach is to try and make your research inclusive for the most vulnerable group, which in turn will help open up your research for all.

Your [local RDS team](#) is here to support you to develop inclusive studies. [Get in touch](#) and we can help you plan research which is mindful of the different values, cultures and needs of your future participants.

By Dr Anna-Marie Jones & Dr Manavi T Maharshi, NIHR RDS SE edited from December 2021 National RDS Blog.

### RDS EDI Toolkit

Our national [Equality Diversity and Inclusion \(EDI\) Toolkit](#) was developed to support researchers to better understand how to embed EDI in research design and to meet the [NIHR's EDI requirements](#).

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Access live links for this issue and our previous RDS SE newsletters on our website: [www.rds-se.nihr.ac.uk/outreach-and-events/newsletter-ebulletin-blogs](http://www.rds-se.nihr.ac.uk/outreach-and-events/newsletter-ebulletin-blogs)

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