

Research Design Service South East (RDS SE)

Newsletter 11 Spring 2021

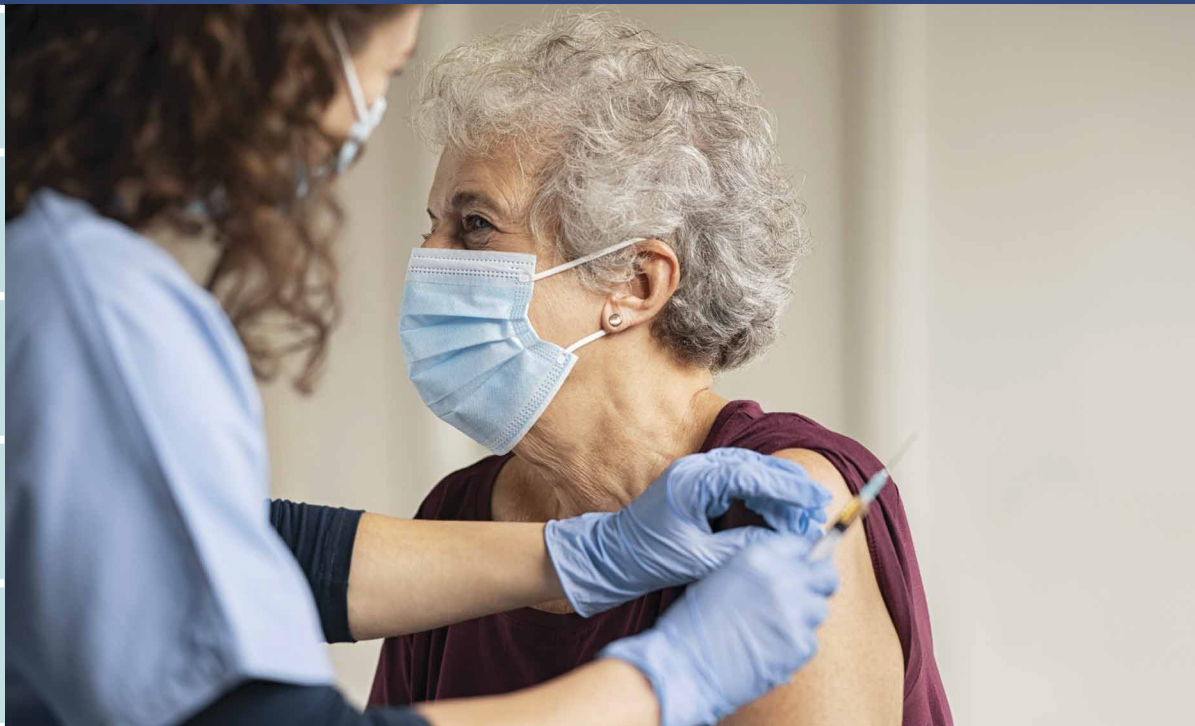
Director's message

RDS SE supporting
local researchers

PPI news

One year of COVID
research

RDS SE in lockdown



RDS SE: Moving forward

Our mission:

The provision of free, confidential, high-quality advice and support to individuals and teams to develop applied health and social care research proposals.

As we go forward we will continue to deliver expert support for researchers across Kent, Surrey and Sussex, regardless of uncertainties around the pandemic.

We continue to operate a full online service, using digital channels to communicate and collaborate with clients.

A year like no other

Unforeseen, shocking and – that much-touted word – unprecedented; 2020/21 will be unforgettable. Throughout the pandemic NHS and Social Care colleagues faced a barrage of challenges – from accessing PPE, workforce shortages and rising COVID admissions – to personal separation, illness and loss.

The pandemic brought positive changes too though. Critically, it made crystal clear to everyone the urgent need for, and value of, high quality research and the vital role it plays. The public signed up in droves to vaccine and treatment trials. Researchers mobilised and responded to calls for research to understand, treat and mitigate against COVID 19.

RDS SE continued its invaluable research design support service throughout. We found new ways to work together and connect with stakeholders, despite the challenge of operating wholly online, away from the collaborative environment. We worked with researchers applying to NIHR Rapid Response and other COVID calls. Some feature inside.

We delivered an expanded online [events programme](#). Freed from travel, record numbers attended our workshops. Social Care researchers joined webinars and our NIHR Research for Social Care Call (RfSC) workshop. We built a bank of [video resources](#) for those unable to join 'live' (also available via NIHR TV).

Many individuals attending our virtual weekly 'Project Development Sessions' (to discuss ideas with RDS SE Advisers) submitted research proposals. Book a slot [here](#).

As the vaccination programme rolls on, research has moved centre stage for all to see. We look forward to building on this momentum with you next year.

Foreword

Professor Jörg Huber, Director RDS SE and Deputy Chair National RDS Strategy Group

Dear Colleagues and Friends

Providing a quick RDS SE Director's update is surprisingly easy; we are still here despite COVID, and perhaps even better at reaching out and engaging with you! While it was a tough year for many, our staff kept activities going at the high level achieved in 2019/20. I am proud that in spring 2020 our whole team managed to adjust at speed to the challenges of moving all activities online (see page 8). Similarly, we are very pleased that those registering to use RDS services are willing to engage with a rapidly changing landscape. They have dealt with very tight funding deadlines and disruption through studies being paused then restarted. During COVID we continue to work closely with ARC, CRN, AHSN and CTU colleagues across Kent, Surrey and Sussex to support researchers adjusting to this new reality.

Nationally, we have developed a coordinated programme of RDS priorities to address strategically important issues. These range from social care research to workforce development and knowledge exchange. RDS SE is focusing on overcoming barriers and helping researchers to engage and apply for NIHR funding. Ferhana Hashem, Bernadette Egan and I are taking this forward, working to connect with less research-active organisations, and adopting a collaborative approach between the NIHR Research for Patient Benefit (RfPB) Office and RDS regions. This will include a summer 2021 RfPB event jointly hosted with RDS South Central.

I hope to see you at our Annual Stakeholder event on 28 April. [Professor Kamlesh Khunti](#) will talk on recent research on COVID-19 in ethnic minorities, and new NIHR Head of



Equality, Diversity and Inclusion Dr Esther Mukuka will discuss her vision for the role.

We thank you all and look forward to continued joint working to help boost the south east as a vibrant hub for high quality applied health, public health and social care research.

With best wishes,
Jörg

What can RDS SE do for you?

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
- Presubmission Review Panels
- 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](#)

Now booking:

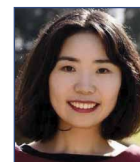
[NIHR Research programmes workshop](#)
10am-1pm, Wed 21 April

[NIHR Fellowships Event](#)
10am-1pm, Wed 30 June

RDS SE welcomes New staff members



Amanda Roberts
RDS SE Data
Information Officer



Wenjing Zhang
RDS SE Social Care
Research Adviser

New co-applicants



**Professor
Simon
Skene**



**Professor
Shereen
Hussein**

New collaborators



**Professor
Chrissie
Rogers**



**Professor
Julien
Forder**



**Professor
Julie Beadle-
Brown**

Research success stories

Developing and delivering targeted COVID-19 health interventions to Black, Asian and Minority Ethnic (BAME) communities living in the UK – The COBHAM study

There is widespread concern that the COVID-19 pandemic disproportionately affects Black and South Asian communities, and death rates are higher among Black and Asian than in White ethnic groups. In May, the Intensive Care National Audit and Research Centre (ICNARC) reported that Black and Asian patients were over-represented among those critically ill with confirmed COVID-19.

Professor Aftab Ala at the Royal Surrey County Hospital NHS Foundation Trust successfully applied to the UKRI-NIHR COVID-19 rolling call for funding for a project aimed at reducing COVID-19 risk and protecting these communities.

The COBHAM study aimed to design and deliver culturally specific targeted digital health messages around the pandemic. The multidisciplinary team would co-produce culturally relevant outputs including short films and key guidance documents. They would deliver them across Black, South Asian and Minority Ethnic groups, through trusted communication channels, such as community and faith leaders, community groups and health professionals.

The project should benefit Black and South Asian communities through messages on behaviours that reduce COVID-19 transmission, including social distancing, infection control and vaccine uptake. It should also benefit the NHS by helping to reduce the number of people from BAME communities contracting the virus. The resources will be available for use by policy makers including NHS England and Public Health England.

RDS SE was involved from the outset, discussing with Professor Ala what might be required for a successful UKRI-NIHR/ COVID-19 application, which differed from the usual NIHR application process. We offered advice on PPI, study design and team composition, specifically the need for public health expertise. We emphasised that the project must be feasible in a 12-month period, with tangible outcomes and impact.

Professor Ala revised his plans by targeting the wider community and not just patients. He was very appreciative of RDS SE input: *'Huge thanks for your significant support with the NIHR-UKRI bid to the high-profile ethnicity and COVID-19 call. Your enormous efforts in guiding me as CI were instrumental in getting the multicentre group, proposal and PPI together for the successful bid.'*

'We were delighted to accept the £371,000 award and look forward to actively developing our relationships with RDS for our Trust and KSS'

RDS SE Research Adviser Dr Bernadette Egan said: *'It was a pleasure to support Professor Ala and the team for a very worthwhile project. We were delighted the application was successful. The work builds on their successful RfPB project where they established strong links with community and faith leaders. The outputs have the potential for significant impact for BAME communities nationally in addressing challenges associated with COVID-19.'*



Research success stories

Development of a Haemophilia Physiotherapy Intervention for optimum musculoskeletal health in children (DOLPHIN II)

Affecting males, haemophilia is a rare, inherited disorder where blood does not clot normally, causing bleeding into joints and muscles. This leads to disabling joint damage and pain, muscle weakness and reduced mobility. Physiotherapist and experienced researcher Dr David Stephensen at East Kent Hospitals University NHS Foundation Trust has worked closely with RDS SE over several years.



He leads DolPHIN II, a randomised controlled trial investigating the impact of exercise on the health of boys with haemophilia. In a previous study funded by NIHR Research for Patient Benefit Programme (RfPB), David led a team of researchers in designing an exercise programme for boys with haemophilia, co-produced by children, families and healthcare professionals.

DOLPHIN II aims to determine whether the 12-week programme increases muscle strength, and if it has an impact on walking, games and other activities, as well as bleeding frequency. The study is managed by health care professionals and researchers experienced in this area. Boys with haemophilia are allocated randomly into one of two groups of 66: one group completes the 12-week exercise routine to strengthen leg muscles.

The other group does not perform the exercises. Throughout the study the boys are monitored for muscle strength, how far they can walk in six-minutes and the time taken to ascend and descend 12 steps. They will also wear physical activity trackers. The boys' level of satisfaction with their health is also recorded.

After receiving support for the first DOLPHIN study, which showed that progression to a definitive trial was feasible, David returned to RDS SE with his DOLPHIN II funding application to NIHR RfPB. We offered help with PPI, health economics and statistics. He received funding of over £343,000 for the three-year trial until September 2023.

David said: 'The RDS team supports you throughout the application process to help you hone a proposal into something fundable. It's very helpful when their experienced advisers and methodologists look with fresh eyes at your proposal.'

For DOLPHIN II, NIHR RfPB fast-tracked us straight to Stage 2 which was a new experience. RDS help, along with feedback from their pre-submission panel, meant I could fine-tune the application before submitting in November 2019. I was delighted to receive funding for the Trust to sponsor this important study.

'Being able to enjoy games and activities with friends really matters to boys with haemophilia. The trial will see how the programme affects participation and discover the role of exercise in preventing and treating joint damage. The sample size was challenging as there was limited information to draw on and this is a rare population. We used the feasibility study data and previous work to provide estimates of variability for the primary outcome, and draw on expert opinion and existing research regarding what would be a clinically meaningful difference. Over the three years we will see whether it can improve these boys' long-term health'.



Research success stories

Testing feasibility and acceptability of case-finding and subsequent comprehensive geriatric assessment intervention for older people with HIV with frailty

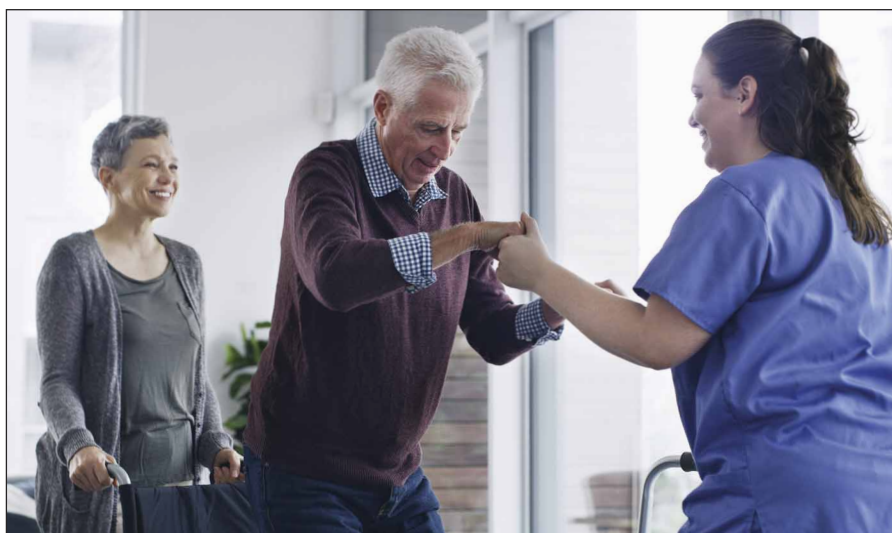
More people aged over 50 are now living with HIV, partly due to antiretroviral treatment.



Compared to HIV negative people, this group has complex additional needs, with increased risk of comorbidities like cardiovascular disease, osteoporosis and frailty. Having HIV with frailty increases risk of death seven-fold compared with having neither.

Dr Jaime Vera, Senior Lecturer in HIV Medicine and Honorary Consultant Physician BSMS/BSUH wanted to respond to the NIHR Themed Call *Improving the outcomes of health and social care for frail people and their carers* through the Research for Patient Benefit Programme. Research Adviser Anna-Marie Jones met with Jaime in September 2018 and worked with him in developing his application over the next two years.

Jaime wanted to investigate the feasibility of introducing The Silver Clinic – a new proactive screening and management approach for frailty in older people with HIV – into routine care. The approach is based on the Comprehensive Geriatric Assessment. The study will also examine the feasibility of testing this new intervention's effectiveness in a randomised control trial.



Eighty-four older people with HIV and frailty will be recruited when they present for routine HIV and health checks. They will be randomised to either have standard care from HIV experts and GPs, or the new intervention from HIV and elderly care experts. The team will explore whether older people with HIV can be recruited to the study and if they are happy with the new frailty test and assessment. They will also explore whether Silver Clinic makes a difference to patient health and wellbeing. These findings will help support the design of larger trial if feasibility outcomes are favourable.

Anna-Marie said: *'I worked with Jaime on this important project for almost 2 years. With each iteration of the draft, I could really see the application moving forward. The challenge was to help Jaime make a solid case demonstrating how this project could make a difference to older people living with HIV, and a necessary step change to the HIV care pathway. One way was to draw out how The Silver Clinic could reduce hospital admissions.'*

By November 2019, Jaime's funding application went before the RDS SE Pre-Submission Panel where a team of advisers with a mix of specialist expertise conducted an in-depth review. Their suggestions to strengthen the bid included adding a qualitative component to gain insight into participant experiences during the study. It was clear that there were significant potential cost-savings to be made, so the RDS also recommended adding a Health Economist to the study team.

Jaime said: *'RDS SE supported our bid with helpful recommendations and constructive feedback on every aspect of the proposal. This support was crucial in securing a grant of £249,889 for a two-year project. We look forward to continued working with the RDS on other bids.'*

One year of COVID research

NIHR partner perspectives

A new Government report '[the future of UK clinical research delivery](#)' describes clinical research as the 'backbone of healthcare innovation'. It is how we improve prevention, detection, diagnosis and treatment of disease.

Delivering that research depends on healthcare professionals from all backgrounds, working hand-in-hand with research participants, families and carers. NIHR has helped drive the pace of UK COVID-19 research. (See more on the [NIHR's response to COVID-19](#)).

NIHR partners RDS SE and [CRN KSS](#) work across Kent, Surrey and Sussex to support high quality health and social care research.

The 10 Research Design Services advise at the earliest stages, on all aspects of designing a potentially fundable research project. The 15 Clinical Research Networks work with the NHS and other partners to coordinate and support the set-up and delivery of research.

Here we look at work undertaken in both organisations to support the huge COVID-19 research effort.

RDS SE quickly switched to a wholly online 'from home' delivered service. Demand for RDS SE support remained high throughout the pandemic. We provided RDS support to 36 COVID studies over the past year.

Topics ranged from impact on the care workforce to patient recovery outcomes. Studies that received funding quickly got under way; others await funders' decisions.



Professor Aftab Ala's project to reduce COVID transmission rates in ethnic minority communities features on p3. These and many other research ideas contributed to the enormous effort to change the course of the pandemic and highlighted the importance of health and social care research.

CRN KSS faced different challenges. At the start of the pandemic NIHR paused the set-up of any new or ongoing studies at NHS and social care sites, with the exception of Urgent Public Health (UPH) COVID-19 research. UPH studies were set-up and delivered at pace across the region and made a huge contribution to quickly finding treatments and vaccines.

Research achieved great successes over the year. The Randomised Evaluation of COVID-19 Therapy (RECOVERY) trial, delivered at 11 NHS trusts across the region, identified dexamethasone as the first drug to improve survival rates in certain coronavirus patients.

The trial also shows tocilizumab, an anti-inflammatory arthritis treatment, reduces deaths and hospital stays – with benefits additional to those from dexamethasone.

The Randomized, Embedded, Multifactorial, Adaptive Platform trial for Community-Acquired Pneumonia (REMAP-CAP) trial also showed that tocilizumab along with sarilumab (both are immune modulators called IL-6 receptor antagonists) have significant impact on patient survival. This trial also found that convalescent plasma was not effective in seriously ill patients.

Nationally, over 925,000 people, including more than 22,000 from across Kent, Surrey and Sussex have taken part in NIHR UPH studies. COVID-19 vaccine trials have also taken place within our region. The NHS COVID-19 Vaccine Research Registry gave volunteers direct access to research opportunities, with over 38,000 people across Kent, Surrey and Sussex signing up so far.

Research has never had such a high profile with the public, decision-makers and NHS colleagues. We have all seen research in action. Treatment advancements can be directly linked to results of trials happening in our NHS organisations. We should be proud of the hard work and dedication shown by everyone involved in delivering vital research across Kent, Surrey and Sussex.

Public involvement and engagement

That Co-production Podcast!

Throughout March and April, we are launching our six-part 'That Co-production Podcast!' series, delivered in partnership with the NIHR Centre for Engagement and Dissemination. The aim is to make co-production accessible. Not everyone has access to – or the desire to read – an academic journal.

In each episode, we have an informal discussion with people from across and beyond the South East region, on their work and/or a co-production theme.

Our first guest was Jeremy Taylor OBE, NIHR Director for Public Voice and Director of the NIHR Centre for Engagement and Dissemination.



Upcoming episodes include Oli Williams, Research Fellow at THIS Institute (The Healthcare Improvement Studies Institute, University of Cambridge), discussing the difference between patient and public involvement and co-production and Nadia Brookes outlining co-production plans at the NIHR Applied Research Collaboration Kent, Surrey and Sussex (ARC KSS).

You can see the full line-up of [episodes](#) and view the podcasts on our website. They are also available on [Spotify](#) and [Soundcloud](#).

For further information contact Gary: g.hickey@brighton.ac.uk



Embedding patient and public involvement

We have been working hard over the past year within the RDS SE PPI team to embed PPI in our own practices and activities, using the [UK Standards for Public Involvement](#) as a guide. We look forward to building on what has been a really informative and beneficial process:

- **Working together** – our lay members had a core role in updating the [Public Involvement Fund \(PIF\)](#) and together we made a shift from feedback only from lay members to involvement in the full process, including checking feedback and assessing re-applications.
- **Impact** – lay members critiqued our researcher feedback form, designed to measure the impact of the researcher's PPI activities following a PIF award.
- **Communications** – In Mar 2020, lay members formally joined our online team meetings, which greatly enhanced communications across the whole PPI team and we got to know each other better. This has also

allowed shared decision making involving our lay members in the Governance of our work.

- **Inclusive opportunities** – different opportunities are available, which are designed to be accessible to all. As part of this, current lay members are now 'buddying' new lay members, which alongside support by RDS Advisers provides **Support and Learning**.

For more information contact Julie: J.A.Hedayioglou@kent.ac.uk



Reaching out

We know that some communities are under-served by research – both in terms of issues researched, and involvement and participation. We are one of five RDSs working in partnership with the NIHR Centre for Engagement and Dissemination to influence NIHR to:

- i further embrace and invest in relationships with communities in shaping and delivering research,
- ii review and adapt its funding and contracting systems, policies and processes to enable this.

In the South East we will be working with colleagues from various minority ethnic communities and with colleagues at the Clinical Research Network and Applied Research Collaboration, to co-produce a local online event (May/June 2021). The aim is to identify barriers and opportunities and how NIHR can best enable and support community partnerships which shape health and care research.

For further information contact Gary: g.hickey@brighton.ac.uk

RDS SE in lockdown

A year of home working

Working exclusively from home is a new experience. We feel lucky to be able to do our jobs effectively online, despite challenges. Everybody's lockdown is unique, but common themes emerge below:

A room with a view

It was rather a relief to abandon the office last March. Tension in the population was high and none of us knew much about coronavirus transmission. I am fortunate to have space at home and set up overlooking the front gardens. Watching the natural world move through the seasons has been a lovely antidote to staring at a screen. Juggling remote caring of family with work has been hard, but removing travel issues improved contact with colleagues, which is good.

Ellen Donovan, Surrey Site Lead and Senior Adviser

Home schooling

The first lockdown was difficult as my youngest boy was only four. My husband did a lot of home schooling but we often juggled. Workwise it was easier to contact colleagues at short notice. Lockdown has

enhanced cross-site team working. Last year we worked really well as an involved team (Academic Leads, Co-applicants and collaborators) and successfully reapplied for the RDS contract.
Ferhana Hashem, Academic Site Lead, Kent

Online PPI not 'second best'

None of us would have chosen to move completely to online working but our PPI work has adapted – and sometimes flourished. Our team meetings are now accessible to all through technology (we recognise that digital exclusion is a real issue). We have reached out to various ethnic minority groups and begun to form partnerships. Before, much time would go into finding accessible venues and travelling. We managed to record seven podcasts from the comfort of our homes! (see p7). Online may not replace face-to-face, but it need not mean second best.
Gary Hickey, PPI Strategic Lead

A new work 'normal'

I think lockdown will continue to change how we work. Working more flexibly is great both for employer and employee, and connections across our region have definitely improved as we have become more familiar with online working.

I am very happy the kids are back at school – as are they! Juggling was difficult on days I was alone with them on 'school/work days'. Pets have benefited most from the experience! Badger, our dog, has never been happier or enjoyed so many walks!
Emma Doohan, RDS SE Programme Manager

A room for two

My husband and I spent lockdown in one shared room – difficult when one or both have Zoom meetings! More positively, it has been great to access high-quality webinars in social care and other fields, upskilling and expanding my networks in ways not available before!

Wenjng Zhang, Research Adviser

Lone lockdown

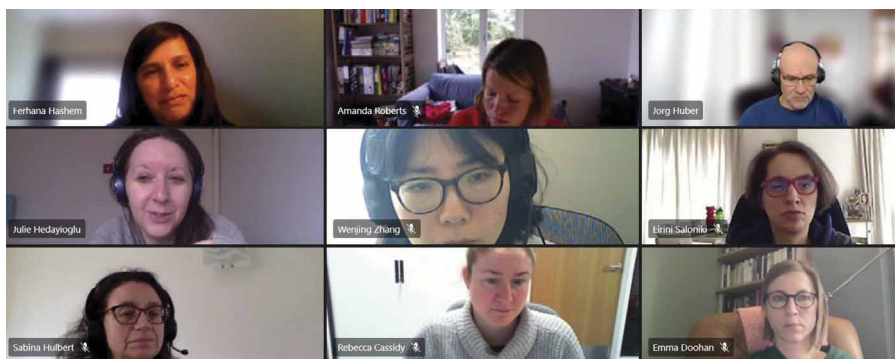
I was shielding initially and I felt isolated but now I enjoy the flexibility and being able to work without interruption. Work relationships deepened and colleagues became friends. Zoom kept me sane, though sometimes I talk to the TV. A weekly quiz, daily walks and Friday 'virtual pub' drop-ins all help. I last saw my 90-year-old mum in January 2020. Some crave foreign holidays – I just want to go to Cumbria and see her.

Helen McGregor, RDS SE Comms Officer

Teenage kicks

The challenge with teenagers is their tendency to play FIFA or Call of Duty or on one computer while 'listening' to the teacher on another. Academic progress may be limited but they are well and reasonably happy. The downside of pressure to achieve is the negative effect on family mental health – including the dog, who was most upset by a recent teenage meltdown! Four hours plus of online meetings in a day is challenging, but I have had more creative interaction with people than before.

Lindsay Forbes, Research Adviser



Keep up-to-date with RDS and NIHR news!

Subscribe to RDS SE monthly e-bulletin for news of our regional and national events, plus training and fellowship opportunities, NIHR calls and more!

Read the [RDS blog](#) for tips and hints from the RDS experts across the country

 Follow RDS SE: @NIHR_RDSSE **General RDS SE enquiries email:** rds.se@nihr.ac.uk