

## Research Design Service South East

Newsletter 8 • Spring 2018

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Our current and incoming Directors give their perspectives on the RDS SE's achievements, reflecting on past success and an exciting future.

We highlight how RDS SE advisers helped researchers to enhance and develop their ideas into funded research.

The RDS SE can advise on all aspects of your application and research design.

Contact us at [rds.se@nihr.ac.uk](mailto:rds.se@nihr.ac.uk) or via our website.

# New contract for RDS SE: great news for our region's researchers

**A new five year contract with renewed funding from the NIHR will enable the NIHR Research Design Services (RDSs), to continue their valuable support for health and social care researchers. Set up in 2008, the RDS has helped secure funding for thousands of research projects, as well as individual career development awards.**

RDS SE is part of the network of ten RDS services in England, which play a key role in NIHR's success. We help with all aspects of research design and methodology and cover the whole south east region, operating from the Universities of Kent, Surrey and Brighton.

The funding, from 1 October 2018, will allow our expert advisers to continue offering free and confidential advice, drawing on a unique breadth of experience and a proven track record in improving funding applications.

RDS SE Director David Wilkinson said: 'The renewal of our contract is really great news and allows us to continue our essential work supporting health and social care researchers at all levels in our region'.

Whilst some improvements to our service are planned, on the whole it will be 'business as usual', with advisers across the SE continuing to provide free advice to health and social care researchers.

## RDS National Grant Development and Writing Retreat



**10-12 September 2018**  
**School of Psychology**  
**University of Kent, Canterbury**

RDS offers a unique opportunity for busy professionals to attend a three-day residential Grant Development & Writing Retreat to rapidly progress their research proposal. Open to teams of two or three people (at least one must be a health or social care professional working in England).

This year, successful applicants will be offered a **free** place at the retreat including food and accommodation\*.

Applications are now being received for places at the retreat. Please contact your RDS SE adviser for more details of how to apply.

Closing date for applications is midday on 6 June 2018.

Full details on the NIHR website:  
[www.nihr.ac.uk/about-us/how-we-are-managed/our-structure/research/research-design-service/grant-development-and-writing-retreat.htm](http://www.nihr.ac.uk/about-us/how-we-are-managed/our-structure/research/research-design-service/grant-development-and-writing-retreat.htm)

\*excludes travel to/from Canterbury

# Forewords

## Professor David Wilkinson Director, RDS SE (2014-2018), University of Kent

It gives pleasure to see highlighted in this newsletter some of the world-leading health and social care research that occurs across Kent, Surrey and Sussex.

Despite economic pressures, grant awards continue to be won, fruitful research collaborations continue to develop, and improvements to the research infrastructure, most recently via the commissioning of a new medical school in Kent, continue to be announced.

RDS SE forms an important part of this infrastructure, maintaining a presence across the region and comprising advisers who have expertise from many academic disciplines and who share an ambition to help make a difference to health and social care outcomes beyond the achievements of their own research.

Since my appointment as RDS SE director in 2014, I have sought to ensure that we remain an approachable but candid advisory service. Our core purpose remains the same; to provide free methodological advice for individuals submitting grant applications to the NIHR and allied bodies. We work on a diverse range of funding proposals but do tend to see common qualities in those that are successful.

Over the last 4 years, I have witnessed many new funding announcements and priorities, and attended many meetings with academic and clinical stakeholders – some extremely valuable, some less so – but the elements of a good grant application remain largely unchanged. Come talk to us!



## Professor Jörg Huber Director, RDS SE (from 1 October 2018), University of Brighton RDS SE III – new RDS SE contract to start in October 2018

We are very pleased to announce that NIHR have awarded us a new contract, starting in October 2018. While the new contract will build on what has been achieved during RDS SE II since 2013, we will also see significant changes: new co-applicants and collaborators will join us to deliver and enhance the service, widening our expertise and the opportunities this creates to reach out and engage with health and social care practitioners.

In addition to our existing work in the fields of medical and health research, public health – and above all social care – research, will become central as we, like all other RDSs, have been asked by NIHR to support research in these areas in the South East coastal region, more commonly referred to as the Kent, Surrey and Sussex region.

Our academic colleagues in the region will still play a very important role and linking them and practitioners will be part of our role.

We will communicate these changes in full to all of those interested in developing high quality research proposals, at our launch event in October. For now I would like to just also say a big thank you to our outgoing Director Professor David Wilkinson and all those who helped develop RDS SE over the recent years. Watch our website, e-bulletin and social media channels for further news.

With best wishes to our partners and colleagues, past, present and future in the Kent, Surrey and Sussex region



# SE researcher success stories

## PPI input was 'Invaluable' to project – Optimum 'Hospice at Home' Services for End of Life Care

**Hospice at home (H@H) services aim to bring the quality of hospice care into the home and provide patients with choices around where they receive end of life care.**

The evidence for H@H services is mixed and services vary widely in how and where they operate. Evaluations of the services often show positive patient benefits such as increased choice and (preferred) death at home. Not all demonstrate the same outcomes though, so lack of clarity and consistency makes it difficult to share good practice and develop services effectively.

The OPEL Hospice@Home project funded by the NIHR Health Services and Delivery Research Programme, is addressing this evidence gap. It is a multi-site evaluation of different models of H@H care, with a central question: 'What are the features of H@H models that work, for whom, and under what circumstances?'

OPEL will capture an in-depth picture of structure, process and outcomes to inform national policy, to enable commissioners to provide optimum H@H services by:

- assessing the impact of H@H models on patient and carer outcomes,
- investigating each model for resource and patient care cost implications,
- exploring patient, family carer, provider and commissioner experience of different models,
- identifying enablers and barriers to embedding H@H models as part of service delivery.



Chief Investigator and Consultant in Palliative Care Claire Butler previously used the RDS SE service at Kent when applying to NIHR Research for Patient Benefit (RfPB) programme, to evaluate a local H@H service. The project was funded and she was quick to return to us for help with this new, larger and wider-reaching proposal.

RDS input was key, particularly when it came to PPI. Claire's team successfully applied for an RDS SE PPI grant to set up a user advisory group. This included bereaved carers, hospice volunteers and the public. The group commented on many aspects of the developing application including data collection tools and methods – particularly challenging for this patient/carer group. They were also involved with the plain English summary and gave feedback on the research question and outcome measures.

"We found the PPI grant invaluable to facilitate the PPI meetings and this input enhanced every aspect of developing the project, as well as advocating for patient and carer needs and preferences."



# SE researcher success stories

## Surrey addictions researcher receives RDS support 'in SPADes'

**Dr Christos Kouimtsidis is a Consultant in Addiction Psychiatry at Surrey and Borders Partnership NHS Foundation Trust and Honorary Senior Research Fellow with University College, London. He Chairs the Mental Health Clinical Academic Group (MH CAG) of Surrey Health Partners.**

The RDS Surrey team provided a package of support to Christos when he successfully applied for NIHR funding from the Research for Patient Benefit (RfPB) programme, receiving £234,099 for a feasibility study to test an intervention for structured preparation before detoxification in alcohol dependence (the SPADe trial).

Previous research indicates that trying to help patients stop using alcohol too quickly, often does not help them to stay off it for the rest of their lives. It may also be harmful to go through numerous detoxes and could inhibit future attempts to stop drinking. For the best chance of achieving long-term abstinence, it is important that patients have treatment before detox.

This funded study tests pre-detoxification in the form of a structured group programme of themed sessions aimed at helping participants regain control over their drinking. Sessions include 'understanding your drinking', 'reducing alcohol to safer levels', and 'relapse prevention strategies'. Alcohol-dependent patients attending NHS alcohol community services will be randomised to receive either the detox preparation group programme, or usual care. A future larger trial is planned.

Christos' application went before the RDS SE pre-submission panel and PPI feedback from lay reviewers and RDS SE PPI team was pivotal in finding an appropriate balance between scientific detail and plain English to enhance understanding and engagement of service users.



Christos said the support that he received from the Surrey RDS team was 'immensely empowering'. Professor Heather Gage provided not just health economics and methodological expertise, but also great emotional support throughout the process. RDS Surrey Academic Lead Dr Bernadette Egan's extensive knowledge of NIHR processes and friendly, approachable manner all contributed to his positive RDS experience.

RDS SE is the first port of support that Christos recommends to new researchers. This is based on both his personal experience of the service, and support from Bernadette Egan at MH CAG meetings – which has played a huge role in the group's successful development and achievements.



# SE researcher success stories

## RDS supports Sumita's study to improve care for patients with advanced cirrhosis

**Ascites, the most common complication of advanced liver cirrhosis, is a build-up of fluid causing pain, breathlessness and other problems. If it stops responding to treatment (refractory ascites) then the average patient life expectancy is six months or less. Patients attend hospital for drainage every 10-14 days. But repeatedly inserting temporary abdominal drains can cause pain and potential problems including infection and bowel perforation.**

Dr Sumita Verma, a consultant in Hepatology at Brighton and Sussex University Hospital Trust wanted to improve care for patients with refractory ascites. She had found palliative long-term abdominal drains effective in a small group of patients and using them seemed to reduce the need for hospital drainage.



Sumita wanted to find out if long-term drains would improve symptom management and help develop a more integrated palliative care programme for patients. She came to the RDS SE in Brighton with her idea. David Crook led the RDS support for Chief Investigator Sumita and her team, with substantive input from Statistician Anna-Marie Jones and Duncan Barron and Heather Gage, respective leads for Patient and Public Involvement (PPI) and Health Economics.

The RDS team helped her design a feasibility randomised controlled trial comparing long-term abdominal drains with current care (temporary drains) in patients with advanced cirrhosis and untreatable ascites. Individuals were allocated randomly to either the control arm (usual care), or the study arm (hospital insertion of long-term abdominal drains with home drainage from a carer or community nurse).

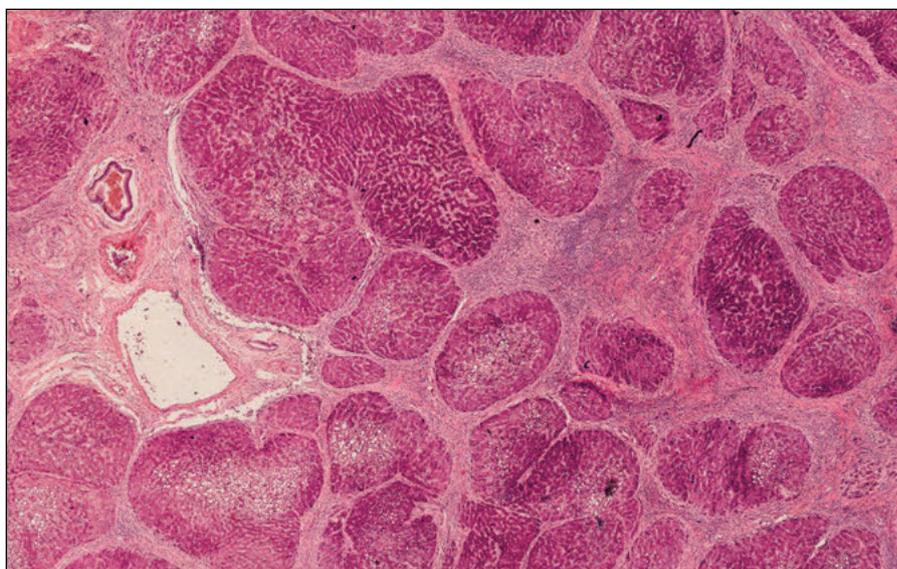
Feedback from participants and staff, and questionnaires about symptoms, tolerability, resource implications and impact on carers will show if long-term drains improve quality of life, are less costly and reduce hospitalisation.

Sumita's team really appreciated the range of RDS support with practical issues including recruitment, sample size calculation and dissemination plans. The application benefited from an RDS SE PPI grant as well as feedback from the RDS SE pre-submission panel.

Duncan Barron also helped to set up discussion groups and make contact with co-applicants who were service users. These discussions highlighted quality of life and hospitalisation as important patient outcomes. They felt the study would enhance end of life care and reduce stigma associated with advanced liver disease. Most felt that the drains would put them in control and empower them.

Sumita was delighted when NIHR awarded a Research for Patient Benefit grant of £249,953.

'I was very fortunate to have had the help of RDS SE. They were pivotal in refining the research question and methodology that undoubtedly contributed to the bid's success. The NIHR appreciated the importance of this study and we received a year's funded extension so it will now run for three years'.



# RDS SE: working in partnership to improve research

RDS SE has been working with partners including the NIHR Clinical Research Network, Kent, Surrey and Sussex (CRN KSS) and INVOLVE to increase public involvement and encourage co-production in health and social care research.

## Empowering children and young people to contribute to health research:

Introducing the new Young People's Advisory Group for Kent, Surrey & Sussex (YPAG KSS)



The south east now has its own YPAG (Young People's Advisory Group) – an exciting forum for children and young people to get involved in health research affecting them and their future wellbeing.

This feature, based on an account by RDS SE lay panel member Victoria Hamer, celebrates the success of Kent Surrey and Sussex YPAG which grew out of a highly successful patient and public involvement (PPI) collaboration across the region.

RDS SE worked in partnership with INVOLVE and the NIHR Clinical Research Network (CRN KSS) to establish YPAG, which has gone from strength to strength since its November launch at the Royal Alexandra Children's Hospital, Brighton.

The launch event attracted young people, parents/carers as well as Consultants in Paediatrics and Paediatric Dentistry, a Clinical Researcher and a Paediatric Research Nurse.

RDS SE PPI lead and group facilitator Duncan Barron gave a talk on 'Empowering Children and Young People to contribute to Research'.

The group meets on a Saturday every other month at the Royal Alex. It is open to young people aged 8-18 who want to help make research better. Consultant Paediatrician Professor Paul Seddon, a leading figure in the group's evolution, secured funding for the first year from children's charity Rockinghorse. This allows the young people to receive vouchers as a thank you for attending and covers refreshment costs.

The friendly, supportive environment, with icebreakers and games encourages the young people to think and contribute creatively, supported by researchers and clinicians, who really value this unique input. With a shiny writing space on each table, ideas come fast and furious!

*"It was fantastic, I liked talking about the things you can do to help children with asthma" (Faye, 8)*

*"It was good to say my views, I am definitely coming again" (Christian, 9)*

*"I am eager to listen to the thoughts and ideas of the other young people... as well as voice my own opinions" (Alexis, 15)*

*"The subjects were very good choices and were made interesting through the use of games and group discussions." (Marwan, 9 and Mustafa, 11)*

YPAG is not just for young people. Our region has a parallel parents and carers' group (PAC) that can provide their own and different perspectives on the research proposals being presented. They hear the same presentations but in a separate room.

Everyone benefits from learning new skills, working together and making friends at YPAG. At the launch the young people, facilitated by Duncan Barron, used Mind-Mapping to generate their own rules, including that some of the group wanted to help facilitate sessions themselves.

## The YPAG experience

Teenagers Vindya and Sofia joined the third YPAG meeting in March. Below are brief snippets of larger accounts each wrote about the day.

*"...I immediately felt comfortable in the friendly and welcoming environment. We discussed how video games could help or be adapted to accommodate disabled people such as those with cerebral palsy. Our groups came up with some ideas such as using virtual reality, head and eye sensors and adapted controllers for disabled people. Some games may be upsetting for some children. It was amazing to see really young children coming up with great ideas as well and their opinions were valued and respected"* Vindhya, 17

*"...we had an opportunity to find out about 'diabulimia' – an eating disorder where people with diabetes don't take enough insulin so they can lose weight. We discussed how to help Dr Peter Christian encourage young people to take part in his survey, which can potentially be a first step in diagnosing this serious condition. We took it very seriously and came up with great ways to help in this project."* Zofia, 18



## YPAG research discussions

Three presentations to YPAG's second meeting generated so much discussion that it was agreed to limit future sessions to two topics per meeting. Among research ideas presented so far are:

- Consultant Paediatrician Professor Paul Seddon's pilot study around treating acute asthma in 2-12 year olds with HiFlo oxygen. Did the group think the study worth doing? Could they help design posters and information?
- Specialist Speech and Language Therapist Katherine Buckeridge on 'developing an information-sharing tool for children with complex communication needs using parent's experiences'
- Extended Scope Physiotherapist Viccie Smith on preventing osteoporosis. She was keen to find out if boys would be interested, even though mainly girls are affected.
- Dr Peter Christian on Diabulimia in young people with diabetes. In their own session, parents and carers could ask questions about potentially sensitive issues.

## Like to attend YPAG?

**Next meeting:** 19 May 2018

**Location:** Royal Alexandra Hospital, Brighton

**Contact:** ypagkss@nihr.ac.uk  
or Duncan Barron: d.barron@brighton.co.uk

YPAG KSS is a collaboration between Kent, Surrey and Sussex NHS Trusts & Universities, INVOLVE, NIHR RDSSE and NIHR CRN KSS and our lay panel membership.

Thanks to Rockinghorse and INVOLVE for their support



INVOLVE

### Stop press!

YPAG KSS has been officially invited to be part of the national group of YPAGs and will soon have dedicated space on the Generation R website <http://generationr.org.uk>

*"I was surprised how much feedback I got, particularly from the children who don't have constraints on their thinking. They give a different perspective and can be much more creative"* (Researcher)

*"Hattie did not stop talking about the meeting and asking endless questions about research. We are both really excited to be part of the team"* (Ruth, Mum)



# Ask Dr Claire

Dr Claire is a Research Adviser for the Research Design Service. She answers questions about designing and submitting research proposals. If you would like to ask Claire a question write to her at [rds.se@nihr.ac.uk](mailto:rds.se@nihr.ac.uk)

Dear Claire,

I am a bit confused about what the Research Design Service actually is and what it does. A colleague mentioned that the RDS helps people with their research, but how is it different to other bits of the NIHR?

Yours sincerely,

Fergus

## Dear Fergus

It can be hard getting to grips with who does what in an organisation like the NIHR, and there are so many acronyms to remember! However, if you're a health or social care researcher, or would like to be one, then 'RDS' is one acronym well worth knowing.

There are 10 RDS services across England all employing expert advisers dedicated to providing support for researchers. We're a collection of triallists, statisticians, health economists, qualitative methodologists, psychologists, epidemiologists, patient and public involvement leads, grant writers (amongst other things). But we all share a common goal. We want to help you design your research and get it funded.

So what are the defining characteristics of the RDS? It's helpful to know about our unique selling points – or USPs (another acronym!).

- First, we have experience with literally hundreds of funding applications from a wide range of funders. We've seen what works and what doesn't. We've worked on bids that have been funded first time around and some that have been funded fifth time around. We've worked on a huge variety of research topics. We know our remit as advisers and our strengths as researchers and methodologists in our own right. Perhaps most importantly, we occupy a unique position of being committed to an application's success, but not part of the research team and, therefore, not too close to the research idea.

- Peer review is our second USP. All RDSs offer some form of formal peer review. One way this can happen is in the form of a regular meeting where advisers across the region get together to review funding applications in detail in a way that mirrors as closely as possible, the assessment process of the NIHR research programmes. This trial run gives researchers an invaluable opportunity to address any potential weaknesses identified in their application before submission. It also allows them to make the (sometimes vital), decision not to submit just yet.
- Thirdly comes lay review. We give researchers the opportunity to have their applications reviewed by service users who offer their insight and expertise by experience. It reflects the NIHR's assessment procedure, which can involve lay review of applications and scrutiny by lay members of NIHR funding panels. It also allows researchers to hear directly from service users.
- I don't in any way believe that consultation with an RDS will necessarily mean a successful application. However, this does bring us to a fourth USP: we provide our service to researchers confidentially and free of charge.

So hopefully, that has cleared up the confusion a bit. So if you are preparing an application to any national, peer-reviewed health or social care research funder, you really need to come and talk to us at the RDS!

*Dr Claire*

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

Subscribe to RDS SE mailing list to receive our monthly e-bulletin and annual newsletter.

Our bulletin brings researchers up to date with regional and national events, training opportunities, funding calls and more. [www.rds-se.nihr.ac.uk/join-our-mailing-list](http://www.rds-se.nihr.ac.uk/join-our-mailing-list)

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