NIHR | Applied Research Collaboration Kent, Surrey and Sussex

Annual Report

April 2021 - March 2022

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Kent, Surrey and Sussex

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Message from our Chair

It's no secret that, in the past, relatively little health and social care research was carried out in Kent, Surrey and Sussex. Already, in less than three years, our Applied Research Collaboration (ARC) has started to change that. It's clear that there was lots of untapped interest and enthusiasm among staff working in the NHS, third sector organisations and social care to get involved in research, many examples of which you can read about in this report.

What has been particularly impressive and exciting has been the wide diversity of people who have responded to the new opportunities the ARC has been able to offer. Areas of interest have extended from clinical care in hospitals to the role of the arts in improving people's well-being, from better ways for people with long-term physical illnesses to manage their health, to a better understanding of how young people with psychological problems might be helped more effectively.

The ARC has a major role to play in assisting and supporting the work of Integrated Care Boards in their quest to transform the way we meet the health and social care needs that people, across the three counties, face. Better evidence of how best to organise care - centred on patients' needs - is urgently needed if the NHS, local government and third sector organisations are going to succeed in the daunting challenges they face. That includes improving the way our most precious resource, our staff, are treated.

Under Professor Stephen Peckham's leadership, the ARC has achieved much in the first couple of years, laying the foundations for what promises to be an increasingly productive enterprise over the coming years.

Professor Sir Nick Black MD, FRCS, FRCEPEd
Chair, ARC KSS Board

Foreword

It may be hard to imagine what life was like before the Applied Research Collaboration Kent, Surrey and Sussex (ARC KSS) came into existence. Yet, it's only been two and half years since we were set up. The ARC KSS was the missing piece of the research infrastructure, here in the southeast.

And, while it may be a little premature to determine the full impact we have made in our region and within our communities, I am confident that this report will give you a glimpse of some of the excellent work that our team in ARC KSS, working with our health and care partners, universities and the public, have been doing and is still underway, thanks to the funding from the National Institute for Health and Care Research (NIHR) and our many co-funders.

I have been continually impressed by the range of work and willingness of researchers, practitioners and public partners to deliver high-quality and timely research within our region. Together, we have been able to develop new ways of working to: develop research ideas; co-design and co-develop outputs; and help to share research findings. This is clearly evident in the projects we funded at the start of the pandemic - which you can read about below.

Through the work of our Academy, we have been able to recruit, nurture, support and mentor our PhD students. And, this year alone, we have also been able to support more than 20 individuals to either develop their research careers in their own clinical or academic setting, or develop their own personal research skills.

However, it's thanks to the continued support of our host Sussex Partnership NHS Foundation Trust and our partners and collaborators, including: Kent, Surrey and Sussex Academic Health Science Network; Clinical Research Network Kent, Surrey and Sussex; Research Design Service South East; Higher Education Institutions; healthcare providers; local authorities; the care and voluntary sector; as well as our public members; that we have been able to put ourselves on the map as a recognised leader of applied health and care research in the region and beyond.

I'd like thank all those who have contributed to the work of the ARC. It's because of their commitment and continued support that ARC KSS is as successful as it is today.

Professor Stephen Peckham
Director of NIHR ARC KSS

Introduction

The National Institute for Health and Care Research (NIHR) has invested £135 million in Applied Research Collaborations (ARCs) to support health and care research that responds to and meets the needs of local populations and local health and care systems.

The NIHR Applied Research Collaboration Kent, Surrey and Sussex (ARC KSS) is one of 15 ARCs across England.

The ARC KSS was awarded five-year funding, from October 2019 to September 2024, to deliver agreed objectives across specific health and care themes in collaboration with higher education institutes, the health and care system, together with communities and the public.

Our funding

We are funded by the NIHR to develop support and capacity for research across eight key themes.

Many NHS Trusts, health and social care providers, third sector organisations, emergency services and higher education institutes have also committed to co-funding the ARC KSS to support applied health and care research and implementation, within the communities we serve.

We are also the ARC National Lead for Social Care. This means we are committed to delivering national impact in social care through strategic direction, driving collaborative work across NIHR ARCs in England, and maximising efficiency and impact for the benefit of patients and the public, health and care services and broader economic gain.

Our themes

Social Care

Starting Well: Children's Mental Health

Primary and Community Health Services

Living Well with Dementia

Co-production

Public Health

Digital Innovation

Economics of Health and Social Care

Governance

The NIHR ARC KSS Board is accountable to the host organisation, Sussex Partnership NHS Foundation Trust and through them to the National Institute for Health and Care Research and the Department of Health and Social Care.

Our Board

Meets 3 times a year in public

Maintains **strong engagement** with Integrated Care Boards in the region

Has 3 public members.

Find out more about the roles of our: Executive Group; Theme Lead Forum; Implementation Strategy Group; Research Capacity Group (ORCA); and Public Involvement Network here.

The Board provides oversight and governance of the NIHR ARC KSS, by guiding the overall vision and making sure that the work carried our addresses the specific health and social care issues in the region with tangible outcomes.

Chaired by Professor Sir Nick Black, the Board members include: higher education institutions; integrated care boards; Academic Health Science Network; Clinical Research Network; primary care networks; public health; local authorities; the NHS; and public advisors.

18
HEALTH & CARE ORGANISATIONS

7 HIGHER EDUCATION INSTITUTIONS

2 MEDICAL SCHOOLS

Are members of our governance structure.

Our Governance arrangement continues to strengthen with the introduction of the Programme Management Office (PMO) and Project Management Framework (PMF) to provide structure to the management and accountability of the wide range of ARC KSS projects.

Our partners & collaborators

Kent Surrey Sussex Academic Health Science Network

The Kent, Surrey and Sussex Academic Health Science Network (KSS AHSN) and ARC KSS work closely together to ensure that our research is relevant and implementable and collaborates with industry partners.

The views and thoughts of those accessing or delivering health and social care services are also placed at the heart of our research, to make sure their voices are heard, as well as addressing the needs of our population, including seldom heard individuals and groups.

Establishing communities of experience

The use of co-production is a core part of our work. That's why we work with 36 Communities of Experience groups to bring people together including: health and care providers; commissioners; clinicians and members of the public, to help us to develop shared priorities and solve problems through research and innovation within and across our themes.

Working alongside the KSS AHSN, we are able to further galvanize support for the scale and spread of research.

For example: Dementia and Alcohol; Student Mental Health; and Homecare (domiciliary care sector).

We work collaboratively with our member organisations to deliver applied health and care research that can be implemented to improve the delivery of health and social care services in the region.

"We seek granularity on what matters to people who use and deliver health and social care services."

Des Holden, ARC KSS Implementation Lead and Chief Executive Officer KSS AHSN

Implementation Panel

The engagement of health and care commissioners and providers took place in 2021/2022, with the aim of setting up an ARC KSS Implementation Panel to assist in prioritising implementation of research evidence and to monitor impact. The first meeting is scheduled for Autumn 2022.

This year, we leveraged funding for two research assistants to support the implementation and impact of projects.

Read our Implementation Strategy.

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Funding research

Since 2019, we have funded or supported 127 projects across Kent, Surrey and Sussex.

Throughout 2021/2022, we were able to directly fund additional projects due to successful grant and co-funding from our member organisations.

This year, we secured almost £1.2 million in co-funding, bringing the total, since 2019, to nearly £3 million.

Combined with our core funding, we were able to commission projects under a second open call - Towards Changing Practice - in addition to a second round of Future Leaders Award.

We have also funded three new cross-theme projects, including:

- A community-based mental health intervention for young people living in coastal communities.
- A dementia digital monitoring app.
- The development of a data governance, methods, and training resource to support ARC-wide data analysis of routinely collected health and social care data.

People leaving hospital

In collaboration with NHS England and Kent, Surrey and Sussex Academic Health Science Network, we are delivering the NHS Insights Prioritisation Programme (2021/2023).

This funds the Discharge to Assess (D2A) Programme that aims to support local health and social care systems to support people to leave hospital, when safe and appropriate to do so, and continue their care and assessment out of hospital.

We have secured almost £5.4 million in external funding, since 2019.

Building research capacity in children and young people's mental health

We were awarded the NIHR ARC Mental Health Capacity Infrastructure funding to build the capacity of researchers, in clinical practice, looking at creative solutions to support children and young people's mental health and wellbeing and developing models to enable their involvement in research.

ARC KSS Academy

Our Academy has been working with other organisations to maximise opportunities for individuals to develop their research career through fellowships, supporting researchers to apply for NIHR opportunities and through funded PhD scholarships.

The ARC KSS mentorship programme provides individuals with a bespoke programme of support, including an academic and/ or health or social care professional mentor.

Our Academic Career Development Strategy sets out our plans to build and grow a sustainable research environment and workforce with expertise within practice, as well as the academic field.

Last year, we launched a Learning and Development Tool for researchers.

In July 2021, we held a virtual Research Week, specifically designed to bring people together from across academia, health and social care.

"Our aim is to develop, empower, support and grow a sustainable applied research workforce."
Professor Sally Kendall, MBE ARC KSS Research Capacity Lead

[Read blog]

We also appointed a one-year Darzi Fellow to understand how to build and grow research careers and awareness in the NHS, social care and other providers organisations.

Dr Diana Ramsey, occupational therapist at Sussex Partnership NHS Foundation Trust, stepped out of her clinical role in 2021 to embark on a year-long Fellowship with ARC KSS.

Mentorship

34 trained **mentors**

36 matched **mentees**.

including: academics, health professionals, nurses and doctors

Our PhD students

34 PhD Students now appointed across all our themes, with the first cohort finishing in September.

Read blog

As part of his ARC KSS funded PhD, Patrick Nyikavaranda, a second-year doctoral researcher, based in the Primary Care and Public Health Department at Brighton and Sussex Medical School, has been researching and gathering evidence around some of the challenges migrant females encounter when accessing primary care support and what may help them access support.

Patrick co-authored a report, Ethnic inequalities in involuntary admission under the Mental Health Act: an exploration of mediation effects of clinical care prior to their first admission (The British Journal of Psychiatry, October 2022)

Gill Eaglestone is an ARC KSS PhD Student from University of Greenwich.

In this interview, Gill explains what led her to undertake a research project that looks at assessing the cost-effectiveness of non-pharmacological community interventions for persons living with dementia, using a modelling simulation approach.

Read interview

University co-funding has enabled 10 PhD students to start projects in 2021/22, focusing on under-researched areas, such as public health, and develop a cross-theme cohort of new supervisors.

Damla Harmanci is an ARC KSS PhD student for the public health theme studying at Brighton and Sussex Medical School.
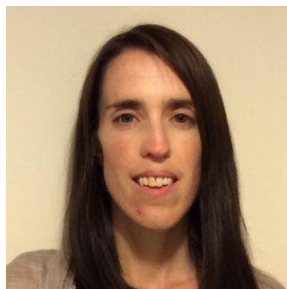
In this interview, Damla explains how she got into research and what led her to undertake a research project that investigates the associations between mental health, sexual health and substance use for adolescents and young adults to inform service provision in Kent, Surrey and Sussex.

Read interview

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Our researchers

Supported learning

Our Individual Development Awards (IDAs) - Springboard Awards and Investment in Future Leaders Awards - support individuals to develop their applied health and care research skills and enable them to have the dedicated time to conduct any of the activities that will create change and make an impact in their local areas.

14 Future Leaders are now supported to develop their research career in a clinical or academic setting as first-time project lead.

Alys Mathers is a Highley Specialist Speech and Language Therapist at East Kent Hospitals University NHS Foundation Trust. She received a Springboard Award for her project: Working together in mainstream primary schools: a scoping review of the roles and relationships of Speech and Language Therapists and teaching staff.

Seven individuals are now supported by Springboard Awards to develop personal research skills; of which, one has made a successful application to the NIHR Pre-doctoral Clinical Academic Programme, and another has gone on to the Integrated Clinical Academic Programme (ICAP).

Dr Anna Cox, from the University of Surrey, received a Future Leaders Award, to explore the acceptability, use and perceived impact of the Together Project resources, co-produced to support the delivery of good maternity care for people with learning disabilities.

Luke Hodgson is an intensive Care and Respiratory Consultant at University Hospitals Sussex NHS Foundation Trust.

Luke's Future Leaders Award looked at how smartwatch technology could support people following a hip fracture. Luke recently used the outcomes from this project to support his submission to NIHR Research for Patient Benefit scheme.

[Read interview]

[Read story]

[Read blog]

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Public and Community Involvement and Engagement

Meaningful public and community involvement and engagement (PCIE) is a central part of the research that we do.

We work in partnership with members of the public to develop our vision and aims for ARC KSS and make sure that public involvement continues to be embedded throughout our organisation.

Public Involvement Network

Our Public Involvement Network (PIN) is the ARC KSS PCIE governance group.

Over the last year, the PIN has progressed from the development of relationships and defining of its values and role, to a supportive network of colleagues who report back on theme and project activities, input into strategy review groups, provide information for impact and reporting, as well as acting as community connectors.

> "It is important to us that the people who are the focus of our research in health and care have a say in how that research is identified, designed and carried out."
>
> **Pippa Shaw, ARC KSS PCIE Lead**

Our public members

We have built up a pool of public members that are, included, supported and offered opportunities to get involved and are paid for their time.

13 public contributors

11 theme public advisors

3 Board public advisors

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Public and Community Involvement and Engagement

A public member's perspective

Michelle Gardener, joined the ARC KSS as a Board Public Advisor in April 2020. In her blog, Michelle explains why she joined, where she feels her involvement has already made a difference, and what she's hoping to achieve.

Read blog

Karin Webb a former carer for her mother who had vascular dementia and is a Public Advisor for the Living well with Dementia theme describes why she decided to join the ARC KSS and what this role means for her.

Watch interview

Michele Powponne is a Public Member at the ARC KSS and a creative writing facilitator and Lead Governor at Surrey and Borders Partnership NHS Foundations Trust Mental Health Trust. In this interview, she explains the work she has been doing.

Read interview

Public members have supported NIHR Applied Research Collaboration Kent, Surrey and Sussex's (ARC KSS) commissioned projects, focused in diverse groups that are often underrepresented in research, including: people with learning disabilities; unaccompanied asylum-seeking children; care home residents; young people leaving care; and older adults from the Nepalese and Hindi communities.

They have been involved in:

- Three prioritisation processes, including the National Social Care Panel.
- Being part of funding application review panels.
- Communities of Experience, to offer a public perspective.

Public and Community Involvement and Engagement

Equality, Diversity and Inclusion

To make sure that our research is appropriate, respectful and meaningful, we engage with a wide and diverse population representative of our region. This includes people of different ages, ethnic backgrounds, with lived, professional experience and from different geographical locations.

We are currently in the process of involving and engaging with underrepresented groups - such as patients with early onset dementia and LGBTQ+ communities - to fill in any gaps.

Resources

Our co-produced Public and Community Involvement and Engagement (PCIE); How to Guide was launched to help our researchers understand the value of engaging with and involving members of the public in their work and how best they can do this.

Our ARC KSS Public and Community Involvement and Engagement Strategy was published as our commitment in delivering meaningful PCIE in our work.

Working with our partners

Our continued work with our NIHR partners in the region, helps us to increase diversity in our research.

The *Reaching Out Project*, made up of a collaboration of NIHR partners in the south east of England, has helped build relationships with organisations from ethnic groups, community groups, and researchers from Kent, Surrey and Sussex.

We held an event in June 2021, funded by the NIHR Centre for Engagement and Dissemination, to explore the barriers to ethnic minority group involvement in research.

This was followed by *The Reaching Out: Building relationships to increase research Impact report*, written by a member of an ethnic minorities group, along with members of the steering group, it sets out the findings of the event and recommends next steps for the implementation of a forum.

"This guide is a useful tool that will enable the research community to fully understand the work of ARC and how to get support for their upcoming research projects."

Jason Grant
ARC KSS Board Public Advisor

Co-production

The co-production team has developed an evolutionary co-production research programme that helps support our core themes: Living with Dementia; Starting Well: Children's Mental Health; Primary and Community Health Services; and Social Care, to bring about positive changes to our local health services.

"Our goal is to co-produce research and implement change in equal partnership with people living in the region, service providers, commissioners, and researchers."
Nadia Brookes,
ARC KSS Co-Production Theme Lead

[**Read blog**]

Co-production explained

We created a leaflet for services and research teams to use as a way of introducing the key ideas behind co-production to members of the public who may be new to working in this way.

[**Download leaflet**]

We asked a variety of stakeholders what they thought would be helpful in terms of promoting co-production within the region. The most frequent suggestion was a short guide in what co-production really means and how to differentiate it from patient and public involvement.

As a result, we produced a guide which is intended as an introduction to co-production from its conceptualization in research and service delivery.

[**Download guide**]

Co-production case studies: A retrospective review of case studies carried out within ARC KSS

We undertook a comprehensive programme of work forward to explore co-production approaches across several ARC KSS projects.

This guide presents studies utilizing aspects of co-design or co-production to share learning and support the reader's own co-production journey.

[**Download review**]

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Research, implementation & impact

Co-producing culturally sensitive COVID-19 resources: the ARC Kent, Surrey and Sussex story

Read the blog >

#ARCimpacts

Co-producing COVID-19 Resources with ethnic minorities

Early in the pandemic there was growing research evidence that showed how ethnic minorities in the UK were experiencing a disproportionate impact from COVID-19, in particular, older adults from the Asian populations.

Public health information was not hitting the spot and lacked cultural nuance. So, we focused our research on two south Asian communities.

The study we funded was all about building relationships with Hindi and Nepalese communities. We worked in partnership to co-produce health information that offered, simple and relevant information about Coronavirus for Hindi and Nepalese speaking communities.

The leaflets were co-designed and co-produced by a team of researchers at the Brighton and Sussex Medical School (BSMS) with the help of community members from Kent, Surrey and Sussex. This approach included the proposal, design and the co-production and health information on the resources. It allowed the research team to listen and get a real understanding of the issues, what information should be included in the leaflets, and how the communities wanted to receive the information.

The research team ran a community of practice event with community groups, public health colleagues, and health care practitioners across the region - to share the process and launch the co-produced leaflets.

The leaflets, produced in Hindi and Nepali, were produced in digital and printed format and included advice and information on COVID-19 including, symptoms and how it spreads. They were then shared throughout the region but also gained interested throughout the UK and abroad.

"[The] leaflet is clear and comprehensive, cannot wait to share among our communities."
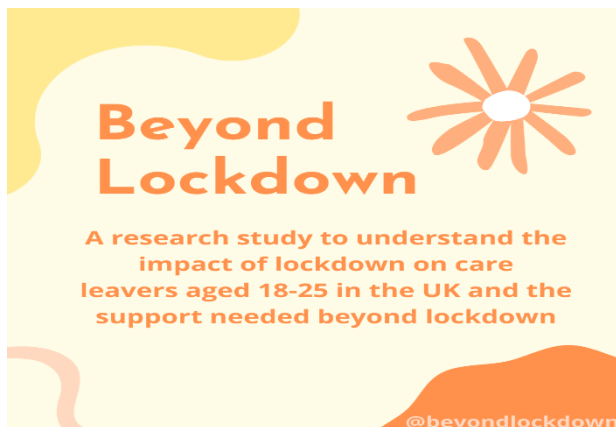**Community Lead, Nepalese**

Download resources

The report, *COVID-19 health information needs of older adults from ethnic minority groups in the UK: qualitative study,* was published in British Medical Journal (June 2022).

Research, implementation & impact

Supporting care leavers to move on after lockdown

Leaving home is a challenge for everyone, but young people leaving care often do so without the help of a family, or the support networks most of us take for granted. Nationally, over 10,000 young people each year transition from 'being in care' to being a 'care leaver'. For many, this can often be a time of high anxiety.

During the first lockdown, we funded researchers, at the University of Sussex and the Creative Research Collective, to conduct rapid research into the impact of lockdown on care leavers and their support needs as lockdown eased.

The project included a national, online survey that told us how 70% of care leavers' mental health had been affected by lockdown, 55% had talked about being lonely, and a quarter told us they didn't feel safe in the housing they were in.

We bought together groups of care leavers to work with us producing co-designed artwork, videos and messages for other care leavers and for those working with care leavers, suggesting how they could be supported.

We held together two communities of practice that brought together care leavers, local authorities, Department for Education, NHS England, care leaving services across Kent, Surrey and Sussex, voluntary and community sector and academia, to discuss the impact of COVID-19 on care leavers' wellbeing.

At the first event, care leavers were able to talk about their experiences and share their videos and stakeholders were asked to pledge their support.

The second event, focused on the progress on the 35 pledges made in Kent, Surrey and Sussex to support care leavers. This included the National Advisor for Care Leavers to the Department for Education, Mark Riddell, who championed some of the progress that had been made and fed it back up to government.

The care leavers were then invited to attend the National Benchmarking Forum for Care leavers where they presented their messages to other care leavers across the UK and across 120 local authorities to further develop message that can be taken out across the whole of the UK.

[Download resources]

"It was great to be part of the event and hear care leavers tell their story. We also heard some fantastic pledges being made across Kent, Surrey and Sussex and I am keen to see where they are in a few months. My pledge is to take key messages back to the government."

Mark Riddell MBE, National Advisor for Care Leavers to Department for Education

Research, implementation & impact

## Helping clinicians deliver better services for people with dementia

During the COVID-19 pandemic, memory assessment services, which are responsible for assessing and diagnosing dementia, had to find ways to deliver services for patients in ways that did not need to be face to face.

We funded a study which aimed to understand patient, carer and clinician satisfaction with and experience of receiving or undertaking memory assessment, during the pandemic.

Following the study, the team of researchers at Sussex Partnership NHS Foundation Trust and Brighton and Sussex Medical School published and shared a Remote Memory Assessment (RMAS) toolkit, at an online event held in December 2021, for clinicians responsible for assessing and diagnosing patients.

The event was attended by around 100 people including: clinicians, commissioners and charity representatives from Kent, Surrey and Sussex and across England, and more than 120 people signed up to receive the toolkit and further information.

The toolkit consists of three resources: a guide for clinicians; an information leaflet for patients; and a patient video.
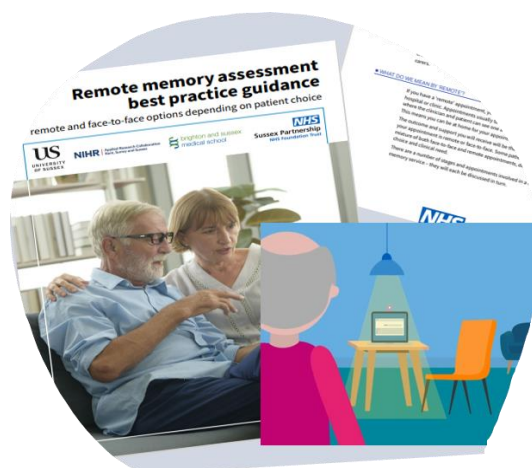
Funded by the University of Sussex Higher Education Innovation fund, the toolkit was co-designed and co-produced by clinicians, researchers and people with lived experience of dementia (including carers).

The clinicians and commissioners who downloaded the toolkit and responded to our survey found it useful and beneficial by:

- increasing confidence in delivering their service;
- leading to adaptations or changes in parts of their service;
- supporting conversations about remote memory assessments with clinicians and commissioners; and
- enabling patient choice in their memory assessment service.

Download toolkit

Research, implementation & impact

Impact of COVID-19 on care home workers, residents and their families

The first wave of the COVID-19 pandemic represented a major challenge for staff working in adult social care settings.

Together with, the Higher Education Fund at the University of Sussex and the National Institute for Health and Care Research (NIHR) Clinical Research Network (CRN), we funded a project led by a team of researchers from Brighton and Sussex Medical School (BSMS) to look at the barriers faced by staff in residential and domiciliary care.

The research showed how care staff, not only had difficulty getting guidance and advice on infection control, but there was also limited or no testing in place and inconsistent or conflicting information between health and care setting, which led to unclear responsibilities.

We were able to share our findings and key messages with our colleagues in Kent, Surrey and Sussex, as well as Public Health England.

[Download report]

Zoom or Room: Effectiveness and guidance for in-person versus online intervention sessions

At the beginning of the pandemic, interventions in health, education and social care moved online almost overnight and, in some cases altogether. Many mental health services accessed by children and their parents.
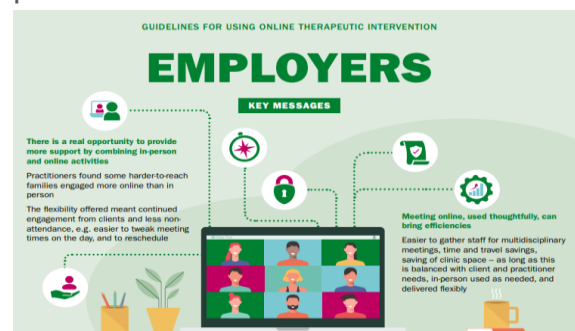
Led by a team of experts at the University of Sussex, we funded a study that looked at the quality and experience of online interventions compared to in-person therapy.

This was followed by the launch of a set of guidelines to help practitioners provide better support to parents and children accessing mental health services online.

The guidelines include: advice on planning, ground rules and strategies for practitioners; points on support, information governance & policy guidance; what clients need to consider when accessing online services; and guidance on working online with groups of people.

[Download guidelines, videos and leaflets]

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Research, implementation & impact

The impact the pandemic on people with dementia and their carers

The COVID-19 pandemic and subsequent local, regional and national lockdowns led to significant disruption to health and social care services. Along with many other vulnerable groups, people with dementia and their carers saw a reduction in the services and support they normally receive.

We funded a study led by researchers from Brighton and Sussex Medical School (BSMS) and Sussex Partnership NHS Foundation Trust to find out the impact the pandemic had on people living with dementia in the region.

The findings of the research are aimed at anyone involved in supporting people with dementia and sit within the Time For Dementia study, which is looking at student and family outcomes from a wider dementia education programme for undergraduate healthcare students being delivered across Kent, Surrey and Sussex.

The findings from the study have been published in to research papers: British Medical Journal and PLOS ONE.

Download key findings

National Priority Programme in Social Care and Social Work

NIHR Applied Research Collaboration Kent Surrey and Sussex (ARC KSS) leads the National Priority Programme for Adult Social Care and Social Work, a collaboration between nine ARC partners, to support and stimulate the implementation of evaluated service change.

Following a prioritisation exercise, five projects, plus a national evaluation of public involvement, have been commissioned across the next two years, including: digital technology and community resources to support and improve wellbeing and inter-partner violence and abuse.

Read priority-setting report

The work also includes the capacity development of social care, including the national strategy for public and community involvement, engagement and participation.

Research, implementation & impact

Regional Social Care

Our report, *Identifying the Priorities for Adult Social Care research* sets out the foundations for the research projects we are looking to set up within the social care theme and wider Applied Research Collaboration Kent, Surrey and Sussex.

Download report

Primary and Community Health Services

Download report

Primary and community care services in England have faced years of chronic under-resourcing and were under strain prior to the COVID-19 pandemic. As a service, in the front line of patient care, primary care is under immense pressure to manage the needs of a growing and ageing population.

We recognise the need for contextualised understanding of the best ways to support patients and their families and carers within this changing landscape. We, therefore, conducted a community priority-setting exercise to capture the views of members of the public on the areas of need within primary and community health services working with public advisors as collaborators.

We intend to use these insights to guide future research, to strengthen funding bids, and encourage further collaboration to improve primary and community health services.

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