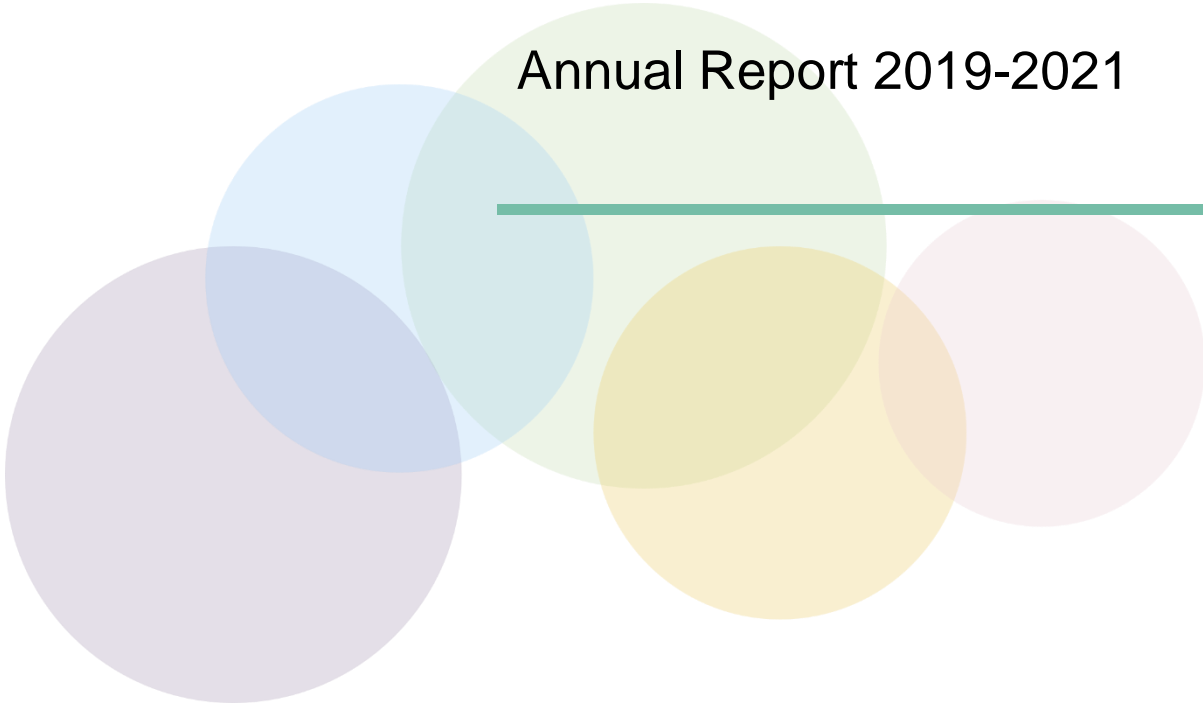




Norfolk and Suffolk
Primary and Community Care
Research Office

Norfolk and Suffolk Primary and Community Care Research Office

Annual Report 2019-2021



Foreword

Good research is essential to health and social care and this has never been more apparent than this year, helping to save lives and increasingly to manage the long term effects of COVID-19. UK research is integral to the global fight to bring the pandemic under control through treatment and development of vaccines.

Norfolk and Suffolk health systems are high performing areas for research and this has served us well during this most challenging year; with studies halted, new COVID research developed and delivered at a pace never imagined, all alongside the necessary deployment of the team to help support the CCG's pandemic response. Research performance has been strong with grants achieved and patient involvement high resulting in the CCG reaching the top of the national league tables for 2020/2021.

This year we undertook significantly more development of research studies with our academic partners and facilitated strong virtual input from our public panel (PPIRes), critical to developing strong research applications, together with essential work undertaken with research teams to rapidly set up new priority studies and adapt existing studies to operate in a COVID safe manner. Despite these challenges, local and national research infrastructure has been shown at its best with integrated working across health organisations, GP teams, networks, and academic partners. All working as one to support the research portfolio. This would not be possible without the enthusiasm and selflessness of the public and volunteers that have supported and taken part in research.

We would like to thank our partners in West Suffolk and Ipswich and East Suffolk CCG (Lisa Nobes and Dr Imaad Khalid), Norfolk Community Health and Care (Dr Venu Harilal and Lynne Fanning) and East Coast Community Health Care (Susie Capon and Ali Jennings) for sharing our passion for research, and all our General Practices for continuing to support research over the years and throughout this pandemic.

The team is moving into a new era, Dr Mark Lim, Director of Clinical Services and Clinical Transformation will appoint a new Associate Director of Research to lead the delivery of CCG Research and Evidence Strategy and the new UK strategy *Best Research for Best Health* (June 2021). This Annual Report is a testament to the hard work, expertise and passion of the research team, the primary and community delivery teams (led by Kate McCloskey, Jo Watts, Deborah Dean and Jenny Johnson), GP teams across Norfolk and Suffolk, CRN Eastern teams (led by Dr Helen Macdonald, Dr Martin Batty, and Karen Tibbenham), and the many academic partners at UEA. It has been a great privilege to lead the research team since 2007, and I pay tribute to my senior managers Clare Symms, and Dr Judy Henwood, and their teams, who have never faltered over many years in their drive to deliver research excellence.

I would like to thank the Norfolk and Waveney CCG Governing Body, the Chief Officer, Melanie Craig, the Executive Team, and all those leaders that played their part in the many predecessor organisations, for having the vision to retain a research unit within a commissioning organisation. This continuous support has made the difference from things being good to things being great.

There has never been a better time to get involved in Research.

Dr Tracy Shalom, Associate Director of Research, June 2021

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1. Introduction

This report has been compiled to highlight the work of the Norfolk and Suffolk Primary and Community Research Office (Research Office) over a two-year period from April 2019 to March 2021, covering the period prior to and during the COVID-19 pandemic. The report both captures the impact of the pandemic on the work of the Research Office and the local research community, but also highlights the huge contribution research has made, both locally and further afield on our understanding of, treatment and prevention of COVID-19.

The Research Office has continued to provide the CCG research infrastructure that supports research development, management, delivery and dissemination across Norfolk and Suffolk commissioning, primary care sites and community care within Norfolk Community Health and Care NHS Trust (NCH&C) and East Coast Community Healthcare CIC (ECCH).

Norfolk and Suffolk have a long-standing reputation of being high-performing research areas, with engaged clinicians, and this continued throughout the pandemic as can be seen throughout this report. This is supported by close collaborations between the Research Office, academic partners, CCGs, Trusts, NHS professionals, practices and the National Institute for Health Research (NIHR) Clinical Research Network (CRN) Eastern.

Clinical research is vital for providing the evidence needed to deliver high quality and cost-effective healthcare services, and to improve outcomes for patients both locally and nationally. It is through research that we are able to develop and test new treatments and approaches to healthcare, and better understand existing conditions. Research studies are taking place all the time across all settings in the NHS - in hospitals and Trusts; in Primary Care settings such as General Practices and pharmacies; in the community; and increasingly within social care.

The importance of clinical research has never been more apparent than now, where it has been central in helping to combat the COVID-19 pandemic. The ways in which research has played a vital role during the pandemic include:

- Identifying symptoms, and developing tests to allow for diagnosis
- Mapping the spread of the virus in relation to population movement and behaviour
- Working to understand the impacts of the virus/pandemic on both physical and mental health
- Developing treatments and finding effective vaccines.

Researchers and clinicians have worked tirelessly to design, deliver and publish clinical research studies at pace, so that the evidence produced can be used to directly inform treatment and policy responses. This would not be possible if it was not for patients and members of the public themselves volunteering to participate. Indeed, the COVID-19 pandemic has greatly boosted the profile of research, with a huge number of individuals signing up to take part in research studies and vaccine trials during the past 18 months.

This annual report covers the work of the Research Office over two financial years, 2019/20 and 2020/21; from research development through to delivery and dissemination. It highlights in Section 4 the huge achievements that were made locally in relation to COVID-19 research and looks forward to how research will continue to meet the coming challenges in 2021/22 and beyond.

Key Achievements 2019-2021

Supported UK priority research in Norfolk and Waveney that led to the first effective treatments for COVID-19

Over 100 Norfolk and Waveney practices recruited over 8000 participants to NIHR Portfolio studies in 2020/21, making Norfolk and Waveney the top recruiting CCG in the country

Supported One Norwich and Dr Engamba, at UEA Medical Practice to gain a CRN Eastern Green Shoots Award, to support UEA Medical Practice to become more research active and pilot opportunities for working at scale across the PCN

Worked with UEA on design and development of the successful funding application to the NIHR Public Health Research project for BabyBreathe which was awarded £1.5M funding in 2019 and started in Oct 2020.

Six NHS Norfolk and Waveney CCG hosted research grants recommended for funding in 2019-21, totalling over £5m

Together with four NIHR grants already supported by the CCG during 2019-21, the total is over £7.8m

Achieved £419,063 Research Capability Funding (RCF) over the 2019/20 and 2020/21 financial years

113 discrete grant applications supported over two years and 76 funded studies reviewed for local roll out

Supported Patient and Public Involvement in the development of 43 research projects, recruiting and supporting volunteers and researchers

Hosted two UEA Undergraduate Placement Students from September 2020 to June 2021

In collaboration with Cambridge & Peterborough CCG Research Office, undertook a three month project for the NIHR Clinical Research Network looking at ways to support adult social care research

Development of a 5 year Research and Evidence Strategy for Norfolk and Waveney.
Supporting development of an equivalent strategy in Suffolk

Evaluation of COVID Protect and MSK-FCP completed. Work ongoing on the Cancer Alliance Transformation Programme Evaluation and the EAHSN commissioned Teledermatology Evaluation

2. 2019-2023 CCG Research Strategy

Norfolk and Waveney CCG is committed to promoting research and ensuring commissioning decisions are based on best available evidence. During 2019, the research team worked with the then five CCG Clinical Executive Committees and Governing Bodies to develop a 5 year Research and Evidence Strategy.

The 2019-2023 CCG Research and Evidence Strategy⁴, was endorsed by the Joint Strategic Committee in December 2019 and focused on six key areas - Best Research for Best Health, Reduction of Inequalities, World Class Prevention and Care for Major Health Problems, Supporting People to Age Well, Supporting the Transformation of Services and Development of an Integrated Care System) (See Figure 1). The strategy aims to ensure that the CCG continues to develop a strong research and evidence culture that is - flexible and sustainable; able to focus on health and service priorities, supporting the use of best evidence to inform better investment / disinvestment decisions and the commissioning and transformation of services; and to support improved quality of care and service change and improve outcomes of our population and patients.

The Strategy for Research and Evidence was used to inform the research elements of the Norfolk and Waveney CCG Commissioning Strategy in August 2019, the Norfolk and Waveney 5 Year Operational Plan in January 2020 and the 2020/21 Annual Operational Plan in February 2020. This Annual Report highlights the areas that have continued to roll out during the pandemic. Some areas have necessarily been paused to accommodate the redeployment of staff and the need to focus efforts on COVID Research - both delivery of nationally important Urgent Public Health (UPH) studies at pace as well as the accelerated development and delivery programmes that are required to test vaccines and develop grant proposals with UEA partners.

The Research and Evidence Strategy remains relevant in relation to the 10 year NHS Plan and we will refresh the CCG Research and Evidence Strategy during 2021/22 taking account of CCG priorities, the new opportunities and challenges resulting from the pandemic and the new UK research Vision published March 2021 - [Saving and Improving Lives: The Future of UK Clinical Research Delivery](#). This sets out a UK-wide programme of work designed to:

- Ensure the restoration of clinical research activity that was underway pre-COVID
- Maximise opportunities to build back a better and more resilient clinical research system
- Deliver on the commitment to make the UK the leading global hub for life sciences

The UK Government published "[Best Research for Best Health: The Next Chapter](#)" in June 2021, making a commitment to continuing their long-term investments, to deliver world-class research outputs and benefits to people today and into the future.

⁴https://drive.google.com/file/d/1al_NdhfaUCO5n8FvXwVmzWBNvzSwoL15/view

Underpinning the CCG Research and Evidence Vision

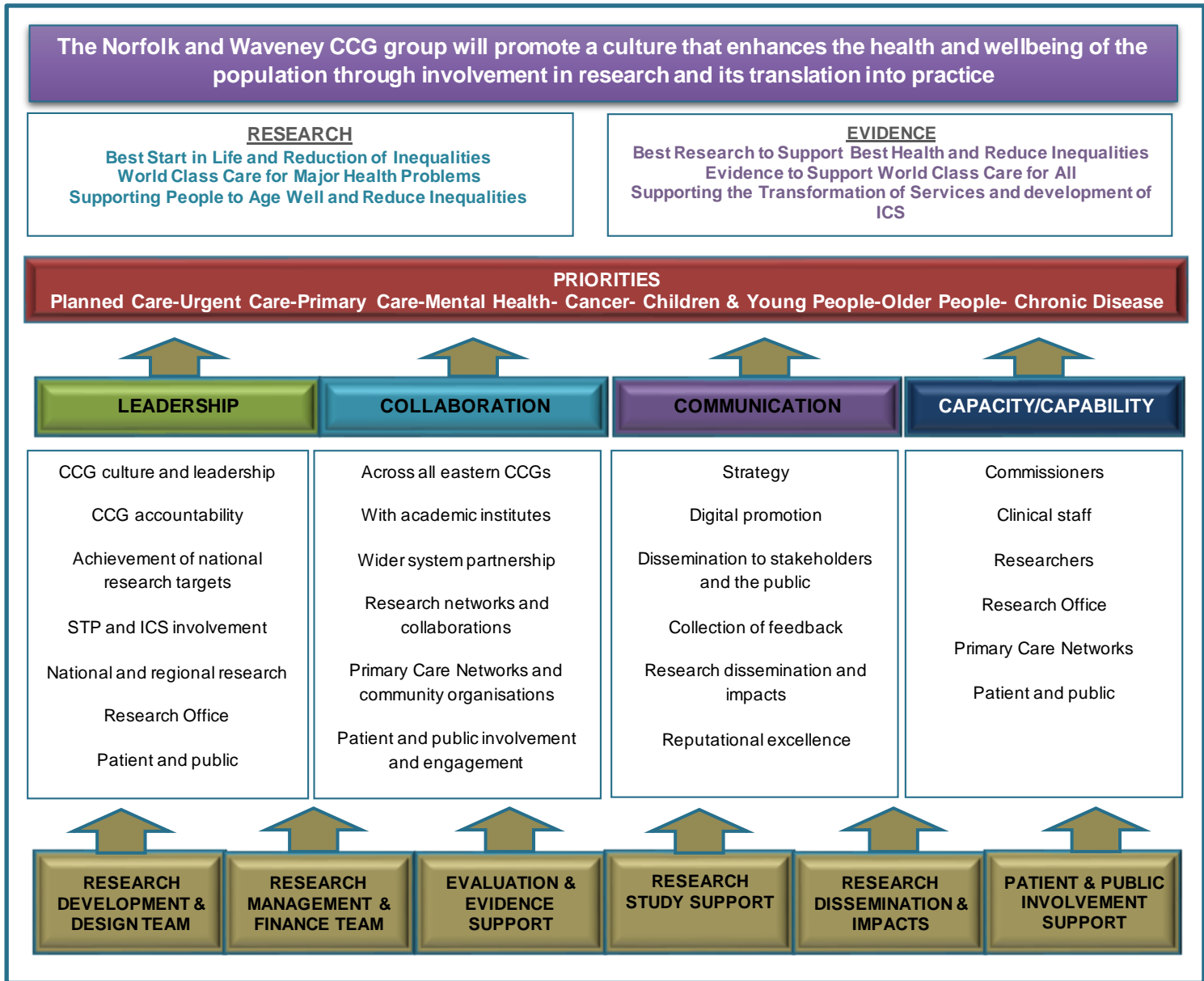


Figure 1 – Plan on a Page - 2019-2023 CCG Research and Evidence Strategy

3. Suffolk Research Strategy

In the context of the emerging Integrated Care System (ICS) in Suffolk, the new white paper and the above recently published national research strategies, the Research Office, through our SLA arrangement is working with Lisa Nobes, Director of Nursing and Dr Imaad Khalid to develop a **2021-2026 Research Strategy** for Suffolk and North Essex CCGs to support research across the area. The Research Office is helping to organise and support a series of three virtual **Strategy Workshops** in Autumn 2021 to develop this work with stakeholders across the Suffolk and Essex system. This event will help review the current picture across the region for research and to articulate how this needs to move forward to build on the work already going on across the patch. The ambition is to:

- Shape the direction of research across our system and the emerging ICS

- Promote and support strong NHS, Social Care, Public Health and Academic collaborations
- Offer increased opportunities for involvement to patients and clinicians
- Increase coordinated leadership and facilitation of research
- Enhance service provision and patient outcome

4. Covid Research across Norfolk and Waveney Integrated Care System

The COVID pandemic has highlighted the huge importance of clinical research in supporting the health of our population. As a result of the research undertaken in the past year, together with the hard work of research teams and those volunteering to take part in trials, we now have effective vaccines against, and treatments for COVID-19, as well as a greater understanding of the transmission, symptoms and impact of COVID-19 on our lives. It has been estimated that evidence generated as a result of the [RECOVERY Trial](#), which was one of the first trials undertaken on COVID-19, and the first to find an effective treatment for patients hospitalised with COVID-19, [has saved more than 22,000 lives in the UK](#) and more than 1 million lives globally (presentation by Louise Woods, Director of Science, Research and Evidence at the Department of Health and Social Care (DHSC) and Co-Lead NIHR at the NHS R&D Forum Reflect and Connect Conference, May 2021).

NIHR Urgent Public Health (UPH) Studies

COVID-19 urgent public health research was prioritised to gather the necessary clinical and epidemiological evidence to inform national policy and enable new diagnostic tests, treatments and vaccines to be developed and tested for COVID-19

Researchers and clinicians have worked tirelessly to design, deliver and publish clinical research studies at pace, so that the evidence produced can be used to directly inform treatment and policy during the pandemic. The [PRINCIPLE Trial](#), the first trial looking at treatment for patients in the community (see Case Study 1), recruited its first participant less than a month after the trial concept was conceived.

Research throughout the pandemic has accelerated the use of innovative research designs such as platform trials. Platform trials were first used in cancer to test different therapeutic options within a single trial design to rapidly evaluate efficacy. In this way treatments can be quickly ruled in or out, enabling effective medications to be fast tracked into clinical care and avoiding unnecessary side effects of ineffective medications. Both RECOVERY and PRINCIPLE use a platform design.

The learning from COVID-19 research will be adapted as a holding methodology to enable rapid investigation of any future pandemics.

The drive to find an effective vaccine for COVID-19 has also resulted in vaccine trials being delivered at pace. The [Novavax Vaccine study](#) (Case Study 2) is the largest COVID-19 vaccine trial undertaken in the UK, recruiting over 15,000 participants from 35 research UK sites, including NNUH, in just over two months.

Case Study 1

PRINCIPLE - Platform Randomised trial of INterventions against COVID-19 In older peoPLE

PRINCIPLE is a nationwide clinical study from the University of Oxford to find COVID-19 treatments for recovery at home, recruiting participants through self-referral via the study website or through GP practices. Patients aged ≥ 50 -64 years with onset of symptoms of possible COVID-19 in the community (continuous cough and/or high temperature) within 7 days are eligible for inclusion.

The trial has a primary care focus on therapeutic interventions to prevent hospitalisation, to target those who may be very ill and to help patients get well quicker. The trial has enabled evidence to be put into practice within days.

Interim analysis on use of Budesonide indicated a 3-day median benefit in self-reported recovery for patients with COVID-19, as well as patients feeling better whilst recovering and having a more sustained recovery – leading to a [Central Alerting System](#) (CAS) alert being published.

PRINCIPLE also provided the evidence behind the NHS [CAS alert](#) – highlighting that Antimicrobials (azithromycin and doxycycline) are not beneficial in the management of COVID-19 (SARS-CoV-2) positive patients in Primary Care

The PRINCIPLE Study findings as reported in the Research Office COVID-19 Bulletins are listed in Appendix 1.



Case Study 2

NOVAVAX Vaccine Study - A trial to evaluate SARS-CoV-2 Recombinant Nanoparticle vaccine

The Novavax study is the largest COVID-19 vaccine trial undertaken in the UK, which recruited over 15,000 participants from 35 research UK sites in just over two months.

Potential participants were identified from the NHS COVID-19 vaccine research registry (which may be converted to a general registry once the need for vaccine trials has ended). NNUH recruited their target of 500 participants to the study whilst the other two sites in CRN Eastern, Colchester General Hospital and Wansford Surgery, Cambridgeshire recruited 168 and 105 participants, respectively.

The study consists of a screening period, study vaccination days (Days 0 and 21) and follow-up outpatient study visits on Day 35 and at 3, 6, and 12 months after last study vaccination.

The Research Office supported:

- weekly Novavax Study Delivery Group virtual meetings to discuss trial set up and progress
- discussions on the option to engage GPs as Participant Identification Centres for the trial
- management of queries from practices on coding; feeding back issues to the study team (e.g. ensuring notification to GPs of enrolment; notification of unblinding status etc)
- escalating issues nationally (inability to code vaccine on GP records as not licensed medication)

In January 2021 it was reported in the study's first interim analysis that the vaccine demonstrates 89.3% efficacy. See Appendix 1 for findings disseminated through the Research Office COVID-19 Bulletins.

The emergence of the COVID-19 pandemic in early 2020 led the NHS to suspend many routine clinical services and the NIHR (National Institute for Health Research) shifted focus to prepare for the Government's research response. Subsequently, decisions were taken in March 2020 by many research sponsors, funders, investigators and study sites to pause non-COVID-19 research, and by the NIHR Clinical Research Network (CRN) to pause set up of new sites or studies, to focus on nationally prioritised COVID-19 studies.

In May 2020, as some of the pressures on services started to ease, and Sponsors had begun to adapt their studies to adhere to COVID-19 guidelines, the Restart Framework was published by the NIHR to guide the restart of studies which were paused as a result of COVID-19. This framework provided a basis for prioritisation based on urgency or recognition that some studies provide access to potentially life preserving or life-extending treatment not otherwise available to the patient. The Restart Framework was subsequently updated and transitioned in April 2021 into managing the [research recovery process](#). More information on the Research Office's activity in relation to the Restart Framework can be found in Section 7.2 below.

5. Research Development and Evaluation Team

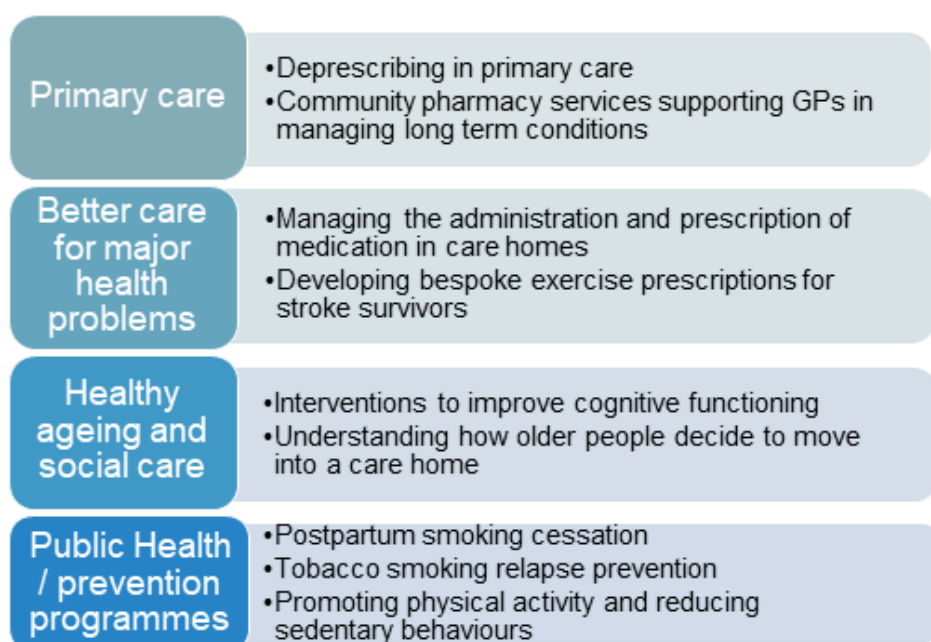
5.1. Research to underpin evidence-base commissioning

Grant application development

The Research Development and Evaluation Team works in partnership with academic, healthcare and other partners to drive the development of nationally competitive research applications, usually to the National Institute for Health Research (NIHR) that have relevance to the population of Norfolk and Waveney.

2019/2020 grant development:

The development of 47 discrete grant applications were supported during this financial year in the broad areas shown in the figure below. Eleven grant applications to NIHR were submitted with NHS South Norfolk CCG as host, on behalf of all the Norfolk and Waveney CCGs, in order to maximise the potential Research Capability Funding (RCF) that can be attracted into the system (see Section 11.2 below).



Within this year, three proposals submitted as stage 1 were invited for stage 2 submission. One Public Health Research (PHR) application, BabyBreathe, was submitted in August 2019 and recommended for funding. The application was submitted with NHS South Norfolk CCG as contractor/host. Following the merger of the 5 CCGs, NHS Norfolk and Waveney became the contractor and this successful grant application will attract Research Capability Funding (RCF - currently £0.28 per £1 of research funds) from 2021/22. The project started in October 2020 following a number of adaptations to ensure the study was COVID safe, and will test whether a package of support delivered via the Health Visitor Service can help prevent a woman's return to smoking after having given up during her pregnancy (see Case Study 11, Section 7.2). Members of the Research Office sit on both the Steering and Management Groups to oversee the conduct of the project.

BabyBreathe

- BabyBreathe Trial (A randomised controlled trial of a complex intervention to prevent return to smoking postpartum)
- 01/10/2020 - 31/12/2023; £1,498,227.27
- NIHR Public Health Research Programme
- Professor Caitlin Notley, UEA

2020/2021 grant development:

During the 2020/21 financial year, the topics covered in the grant applications developed in partnership with UEA fell into these broad categories, with some examples:

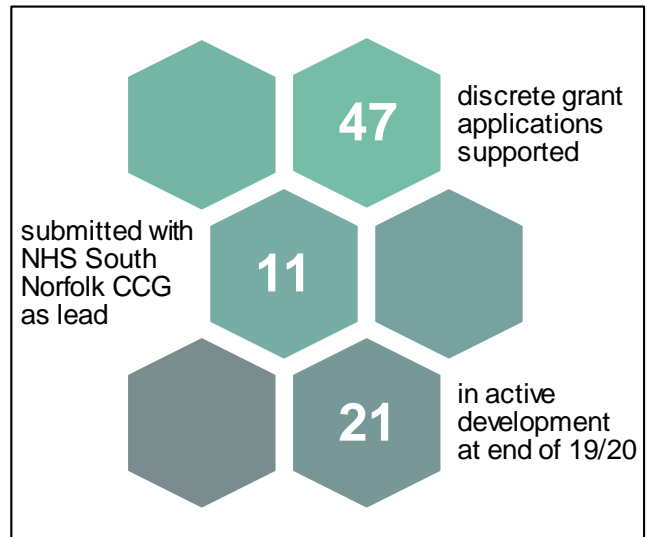
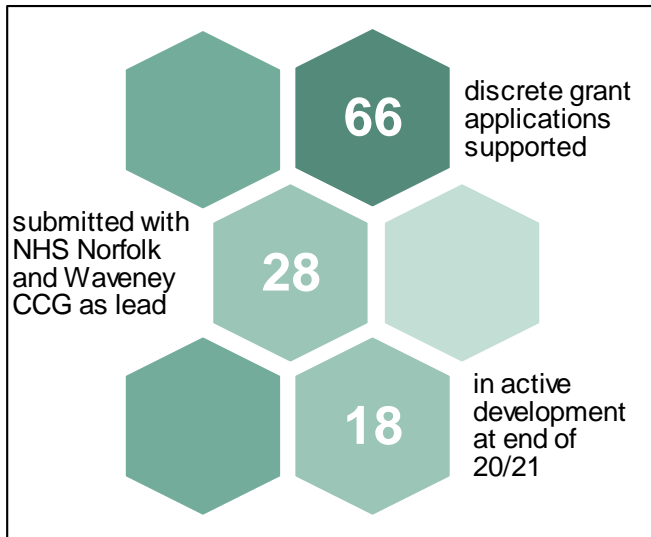
COVID-19 specific calls	<ul style="list-style-type: none"> •Medicines management •Secondary impacts of the pandemic •Wellbeing of healthcare staff •Mental resilience; health-seeking behaviour
Dementia and ageing	<ul style="list-style-type: none"> •Sleep management for people with dementia •Approaches to sustain older people in coastal communities • Prevention of hospital-associated deconditioning
Primary care	<ul style="list-style-type: none"> •Medicines management and optimisation •Managing chronic pain •Support for carers of those with long-term conditions
Public Health interventions	<ul style="list-style-type: none"> •Uptake of influenza vaccination uptake in carers •Improving cardio-metabolic health in deprived areas •e-cigarettes to prevent smoking relapse

COVID-19 presented extra challenges for research development as our academic partners answered the call for specific research projects addressing priorities identified early in the pandemic. During 2020/21 we worked with our academic and NHS partners on 66 individual research projects; 28 of these were submitted to NIHR with NHS Norfolk and Waveney CCG as the contractor. We worked intensively during the initial stages of the COVID pandemic to support research applications to the NIHR COVID-19 Urgent Public Health call – and more recently the Recovery and Learning calls that have been issued. In the 2020/21 financial year, the number of grant applications submitted with Norfolk and Waveney CCG as contractor (and therefore if funded, attracting RCF) was greater than the previous two financial years together:

Financial year	Number of CCG-led applications
2018/19	9
2019/20	11
2020/21	28

During 2020/2021, six Stage 1 applications were invited to submit to Stage 2 and since March 2020 we have had four grants recommended for funding, all of which will attract RCF.

Moreover, another funded grant application has been transferred to NHS Norfolk and Waveney as contractor when the lead applicant moved from the University of Oxford to UEA. This will also attract RCF to the CCG.



Grants funded or recommended for funding in 2020/2021

<p>Learning from CHIPPS - moving to policy</p>	<ul style="list-style-type: none"> • Following on from the CHIPPS PGfAR (2015-2020), this invited application will develop policy guidance for implementing the Independent Pharmacist Prescriber initiative in care homes and other settings • 01/04/2021 - 31/03/2022 (12 months) • Turning Research into Practice (TRiP); £150,000 • Professor David Wright, UEA
<p>Improving the quality and experience of care for patients prescribed medicines with a risk of dependence or withdrawal</p>	<ul style="list-style-type: none"> • Working with the patients and healthcare professionals the research will identify changes that can be made to ensure patients have the best possible experience in stopping medications appropriately • 01/02/2021 - 31/07/2022 (18 months) • Research for Patient Benefit; £172,870 • Dr Jennifer Seddon, University of Bedfordshire
<p>HIP HELPER</p>	<ul style="list-style-type: none"> • A feasibility study to improve patient recovery following hip fracture through caregiver support • 01/09/2020 - 30/06/2022 • Research for Patient Benefit; £249,996 • Dr Toby Smith, UEA (transferred from Oxford)
<p>Recommended for funding - start date likely Feb 2022; still at contracting stage</p>	<ul style="list-style-type: none"> • A programme to develop a decision support tool to optimise sleep management for those living with dementia • 60 months • Programme Grant for Applied Research; £2,325,484 • Professor Chris Fox, UEA
<p>Recommended for funding - start date likely Autumn 2021; still at contracting stage</p>	<ul style="list-style-type: none"> • Development and testing of a fatigue risk management system in the Ambulance Service • 30 months • Health Services and Delivery Research; £640,779 • Professor Kristy Sanderson, UEA

5.2. Developing people

Early Researcher Bursary Scheme

The 3-tier Early Researcher Bursary Scheme is available to all NHS-based staff⁵ who want to make their first forays into research. Funds awarded are usually up to £6,000 for Tier 2 and up to £12,000 for Tier 3. The funds are used to backfill the recipient's clinical or other NHS time, and sometimes to buy in some academic support.

Tier 2 bursaries are usually taken up by those who want to develop nascent research skills and take on some supervised independent work. For the bursary detailed below (Case Study 3), we were able to build on our relationships with researchers at UEA to provide a very talented physiotherapist with the opportunity to work directly with academic supervision.

Case Study 3

Tier 2 Bursary – with placement at UEA

A physiotherapist within the Early Supported Discharge (ESD) Stroke Team at NCH&C was been awarded a specially designed Tier 2 bursary to allow her to work alongside an experienced academic at UEA, one day a week for 39 weeks. The bursary pays for the recipient's time to be back-filled so that the service is unaffected.

During the period covered by the bursary, the recipient worked with her academic mentor to develop the skills needed to complete a systematic review, data extraction and analysis of the literature on lower limb recovery for stroke patients. The secondment added variety and diversity to her primary role.

The work completed as a result of this bursary will result in a publication and a research grant application, in collaboration with her academic mentor.

Recipient reflection: “... this has added variety and diversity to my job. The bursary has allowed me dedicated bought out time and clinical backfill which has been critical to completing the review.

I have been able to develop my skills in completing comprehensive literature searches, data extraction and analysis. Findings from the systematic review will help aid my own clinical practice, improve clinical effectiveness and consequently have a positive impact on the stroke team and patient's outcomes. I have recently presented my findings to the clinical team which has been motivational. In the near future, I would like to take this to the next stage in developing a research protocol. With new skills acquired I hope to continue to be involved in research in the future.”

Mentor reflection: “From an academic's perspective it is really rewarding to mentor and support clinical colleagues to develop their research skills. I am seconded to a half time post in an NHS Trust as well as my academic post and am really keen to support a future generation of clinical academics.”

Bursary total value: £6,000

⁵ In those organisations with whom the Research Office hold an SLA, namely Suffolk CCGs, NCH&C and ECCH as well as Norfolk and Waveney CCG and Primary Care colleagues in Norfolk and Suffolk

The Tier 3 bursaries are intended for those who want to take on a piece of more independent research, illustrated in Case Study 4.

Case Study 4

Tier 3 Bursary

During 2019/20, a Designated Nurse for Safeguarding Children for the Suffolk CCGs had one day per week backfill supported by a Tier 3 bursary from the Research Office, complemented by some funding to provide academic support for the bursary recipient.

The work of clinical staff involved in the safeguarding of children can be extremely stressful, with staff experiencing burnout. The recipient set out to evaluate a pilot programme of mindfulness practice training sessions delivered over 6 weeks to colleagues. She also worked with her academic mentor at UEA to get formal guidance in the conduct of the evaluation and the analysis of the data.

This small scale evaluation showed that the course decreased perceived stress levels for the participant, a reduction in emotional exhaustion and a reduction in cynicism with work for participants, suggesting a likely positive impact in their ability to cope with the emotional stress of their work.

The work has also contributed in part to research development in the area of NHS staff stress and resilience.

An evidence briefing based on the report can be found at <https://bit.ly/3cgoQFc>

Bursary total value: £11,741

The benefit of the bursary support in leading to further research is illustrated in Case Study 5, which describes how Dr John Havard, has continued to develop his new “Flume Catheter” following the work we initially supported by a Bursary from the Research Office.

Case Study 5

The Flume Catheter

In 2013, Dr John Havard from Saxmundham Health Centre was the recipient of a bursary from the Research Office, which he used in support of the development of a new type of in-dwelling urinary catheter, called the Flume Catheter (more information about which is available [here](#)).

Following a long and detailed process of product development, licensing applications and building research collaborations, this new catheter design is soon to start its “first in human” testing. Led by Professor Marcus Drake at the University of Bristol, John Havard and other collaborators have been awarded £149,864 for a Tier 3 Research for Patient Benefit (RfPB) project from the National Institute for Health Research (NIHR). The research is due to start in May 2021, and 65 patients will take part.

This is the first new urinary catheter since 1937, and is intended to reduce considerably the leakage and discomfort that many who have to live with an indwelling catheter experience. More details of the research project are available [here](#).

The Research Office is delighted to have been a part of the early development of this potentially significant improvement in treatment for some of our most vulnerable patient groups.

Undergraduate Placement Students

Between 01 September 2020 and 30 June 2021, the Research Office offered two placement opportunities to undergraduates from UEA who were on 4-year degree programmes with a placement year. Funding for these posts was 50% from the Applied Research Collaboration for the East of England (ARC EoE) Capacity Building Committee and 50% from Research Office/CCG funding. We hosted one student undertaking a degree in Psychology and one undertaking a degree in Economics and Finance.

Initial plans for these placements were made before the pandemic, with the intention that the students would rotate through different teams within the CCG to understand the work of healthcare commissioning and the roles that research, evidence and evaluation can play in supporting the work of the CCG. However, by the time the students were in place, all staff were working from home and the students were set up to do the same – having only met one member of the team the day they collected their IT equipment.

Despite the challenges posed by the pressures of the pandemic and the changed working arrangements, both students settled well, and have supported the whole Research Office (and where possible, teams outside the Research Office) in a variety of tasks, developing skills in: preparing concise literature summaries; qualitative and quantitative data analysis; costing grant applications; case studies for special projects support; presentation preparation and delivery; report writing and evaluation reports.

“I have thoroughly enjoyed my experience of working with the Research Development team; it has been extremely supportive, rewarding and educational. I have learnt a great deal about the various types of NIHR Grants that are hosted by the CCG as well as the importance of the evaluations they deliver ...”

Placement Student 1

“Working for NHS Norfolk and Waveney CCG has vastly improved my skills-set; I have thoroughly enjoyed analysing ... data and producing qualitative reports”

Placement Student 2

5.3. Evaluations

Where funding was available the Research Development and Evaluation Team have been involved in designing and carrying out evaluations during 2019/21 and 2020/21, as detailed below.

Musculoskeletal First Contact Practitioner (MSK-FCP) Service Evaluation: Completed

- The evaluation was designed and carried out to assess the impact of the MSK-FCP Service on healthcare use and on patient and primary care experience.
- The final report was delivered in July 2019 and presented at the STP Planned Care Board in August 2019. It was subsequently shared with NHS England to be used to develop a case study.
- The report can be found at <https://bit.ly/MSK-FCP>

Evaluation of COVID Protect: Completed

- An initiative to support protect the most vulnerable in our population was set up by the CCG during the early days of the pandemic, by ensuring that access to health and social care, support with shopping and medications could be provided, and that people were protected from going out.
- For those who were unable to access online portals, a call handling centre was set up.
- The aim was to reduce the incidence of COVID-19 in the most vulnerable.
- Initial analyses suggested that there was a strong effect of the intervention - COVID-19 infection rates were low in the vulnerable groups and reduced in those who engaged in the programme.
- It was not possible to demonstrate a direct correlation between the intervention and the reduced incidence of COVID -19.
- Internal report delivered on October 2020

Cancer Alliance Transformation Programme (CATP) Evaluation: Ongoing

- The Cancer Transformation Team has commissioned the Research and Evaluation Team to assess the impact of the East of England Cancer Alliance Transformation Programme (CATP) across the Norfolk and Waveney Health and Care Partnership.
- The evaluation is currently collecting data on the impact of the Programme on the lung, prostate, colorectal, breast and upper gastrointestinal cancer pathways at the three Acute Trusts in Norfolk and Waveney.
- We will also assess the impact of the new Serious Non-Specific Symptoms pathway, the Rapid Diagnostic Service, screening and earlier diagnosis programmes of work.
- The evaluation uses both quantitative and qualitative data to determine the impact of the Programme on patient and staff experience and clinical outcomes.

Teledermatology Evaluation: Ongoing

- The Eastern Academic Health Science Network (EAHSN) supports innovation within the NHS and commissioned the Team to evaluate the provision of a primary care based Teledermatology service within Norwich Primary Care Network.
- The service provides GP staff with access to a remote dermatology consultant for cases where there is uncertainty about the need for a referral to secondary care.
- The evaluation is assessing the impact of the service on referrals, the accuracy of the remote consultant and the potential impact of rolling out the service across Norfolk and Waveney primary care.

We award some of our RCF to our academic partners, to support grant development (see Section 11.2). As a condition of the award, we ask that they also develop a plain English evidence briefing in two formats (4 pages and a one-page summary flyer) that can be useful to commissioners. These are posted on the Research Office website and are publicly accessible. Examples of those received in 2019/20 and 2020/21 (from RCF awards made in previous years) are detailed below:

RCF-supported evidence briefings (available on the Research Office website)

- Support needs of informal carers and implications for improving carer support
- Identifying and discriminating between mild cognitive impairment, dementia, delirium and combinations: delivery of the most suitable care for patients
- Hospital-Associated Deconditioning (HAD)
- Post-Stroke Fatigue Guided Exercise Self-help: a brief evidence review
- Community-based support for smoking relapse prevention
- Supporting people living with multimorbidity
- Intergenerational Practice
- Is person-centred social prescribing in older adults with frailty and/or dementia effective and cost-effective?
- Managing potentially inappropriate medication
- Reasons for discontinuing oral anticoagulation therapy to treat atrial fibrillation.
- Management of sleep for people living with dementia or mild cognitive impairment and sleep disturbance
- Can we safely increase HbA1c targets for older people with diabetes?
- Supporting more effective health service responses to adult survivors of childhood sexual abuse: the role of self-assessment tools

6. Public and Patient Involvement in Research

Involvement of patients and the public in the development and delivery of research is critically important ensuring research quality and relevance. People who are affected by research have a right to have a say in what, and how, publicly funded research is undertaken, and the importance of PPI in the research process was highlighted in the government vision for research in the NHS - [Saving and Improving Lives: The Future of UK Clinical Research Delivery](#)

“No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well.”

Professor Dame Sally Davies, Chief Medical Officer (2011-2019)
 Founder of the National Institute for Health Research (2006)
 (Forward in [Staley, 2009](#)⁶)

6.1. Public and Patient Involvement in Research (PPIRes)

PPIRes was set up in 2004 to support Patient and Public Involvement (PPI) in the development and delivery of research. PPIRes supports volunteers and research teams of UEA health and social researchers and NHS clinicians to:

- develop research ideas
- design research with patients and carers at the heart
- represent patients and carers on research steering/management group and advisory groups on funded studies
- support dissemination of results and outputs

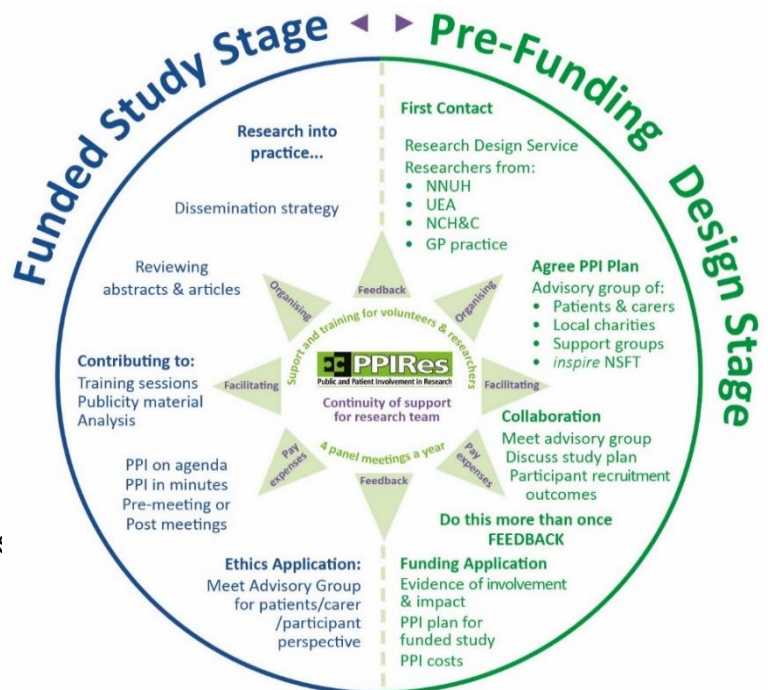


Figure 2 - Patient and Public Involvement across all stages of the research lifecycle

With changes in organisational structures, research requirements and policy, and funding arrangements, the PPIRes remit has variably encompassed research across Norfolk and Suffolk and across different sectors of healthcare. However, the core purpose of PPIRes, to

⁶<https://www.invo.org.uk/posttypepublication/exploring-impact-public-involvement-in-nhs-public-health-and-social-care-research/>

support patient and public involvement in the development and delivery of research, continues to remain at the heart of what PPIRes does.

PPIRes has 50 volunteers, a number of whom have been with the project since the beginning. Over the past two years PPIRes has been involved in the whole circle of research from development through to dissemination (see Figure 2 above). Below are four case studies describing PPIRes volunteers' involvement, the support given to research teams and our work with UEA to strengthen PPI in the Faculty of Medicine and Health.

During the COVID pandemic PPIRes has continued to support PPI activity in developing research ideas through to involvement in funded studies. Many volunteers continued their work with researchers, and we would like to take this opportunity to thank them for their continued support, interest and work.

“At a time when everything we knew and trusted seemed to be turned upside down PPIRes was a constant that provided support, interest and continuity.

Meetings for ongoing research projects were organised via Zoom or Teams, those without this technology were included by phone and with hard copy notes.

We were involved in new studies or adaptations to ongoing studies to address the COVID pandemic so that PPI was as strong as ever.

Support for PPIRes members continued with online Panel Meetings and regular telephone calls and emails.

Thank you, Jacqueline and PPIRes for being an anchor in the storm.”

Jennie Griffiths - PPIRes Volunteer

This is a summary of PPIRes activity during 2019/21:

Involvement in the development of 43 projects:
Recruiting and supporting volunteers for 43 discussion group meetings (facilitated by PPIRes)

Presented at
South Norfolk Stakeholder Engagement Panel
North Norfolk Panel
Great Yarmouth & Waverney PPG Forum
RDS NIHR Fellowship Event

8 PPIRes Panel meetings
PPIRes supported 36 volunteers on steering, management and advisory groups across 7 funded studies

Represented primary care on:
ARC Inclusive Involvement in Research for Practice-Led Health and Social Care
Clinical Research Network Eastern PPIE steering group
RD Forum Service User and Carer Working Group

PPIRes Involvement in COVID Research

Despite the accelerated timelines for undertaking Urgent Public Health Research during the COVID pandemic, patient and public involvement remained vitally important to ensure that the public voice was not lost in the drive to find effective treatment and vaccines for COVID. PPIRes had to adapt to working in 'lockdown' and to respond to research requests in an expedited manner to meet the demands of the research calls. One such request, at the start of the pandemic was for a review of a funding application for the Norwich Testing Initiative. This is detailed in Case Study 6 below.

Case Study 6

Norwich Testing Initiative: COVID-19 testing resources for universities

In March 2020, during the height of Covid-19, PPIRes volunteers were asked to review a funding application and answer a set of questions to gather their perspectives on the Norwich Testing Initiative. This required a rapid turn-around over the Easter bank holiday weekend.

Pre-COVID we would have posted out all the documents in advance of face to face discussion group meetings with the researchers and volunteers. During this time we had to work differently, inviting the panel members to comment via email, text or on the telephone.

Despite the short turn around, nine volunteers replied to the request for feedback and their comments and suggestions were incorporated into the research design.

"PPIRes provided fantastic input to the initial design of the Norwich Testing Initiative which went on to deliver over 20,000 C-19 PCR tests and identify over 250 cases of asymptomatic infection. Service user perspectives were key in ensuring good communication and ethical approaches to the initiative."

Mark Hitchcock, Managing Director at UEA Health and Social Care Partners

The Norwich Testing Initiative was delivered by the Earlham Institute, the University of East Anglia (UEA), the Norfolk and Norwich University Hospitals, the John Innes Centre, the Quadram Institute and The Sainsbury Laboratory - all based on Norwich Research Park.

<https://www.earlham.ac.uk/norwich-testing-initiative-covid19-testing-resources-universities>

PPIRes involvement in a Stage 2 National Institute for Health Research (NIHR) funding application

PPI involvement in developing an NIHR funding application can range from months to years depending of the length and complexity of the study. Our involvement in the following case study (Case Study 7) demonstrates how we need to adapt our ways of working with patient, carers and partners to ensure we have worthwhile and ethical involvement, to strengthen the research idea and delivery plan.

Case Study 7

EASE: A multi-centre, international, randomised, double-blind, placebo-controlled trial to establish the effect(s) of administration of sertraline (50 mg once daily) in people with a recent stroke and post-stroke emotionalism.

Having emotionalism means you cry or laugh, without warning, when it is inappropriate, and you cannot stop or control it.

PPIRes has supported the EASE research team to recruit patients, carers and partners who have experience of post stroke emotionalism, determining the best way to involve this group of patients in the study.

The research team are committed to feeding back the changes that have been made to the funding application as a result of their involvement. If the study is funded they will invite this group to join the Lived Experience Advisory Forum (LEAF) to work with the research team over the course of the study (three years).

PPIRes has also supported the PPI co applicant and the PPI arm in Australia.

"It has been a pleasure to work with Jacqueline and the team at PPIRes support and involvement. Their input has been crucial as we build this next important phase of post-stroke emotionalism clinical trial research."

Niall M Broomfield, Head of Department of Clinical Psychology and Psychological Therapies (CPPT), UEA

"I've been fortunate enough to have been able to make a significant contribution to this research, but I've only been able to do this because of PPIRes and specifically Jacqueline. Jacqueline has made a huge difference to this study and my role in contributing to research"

Jeremy Dearling PPI Co-applicant

PPIRes involvement in a five year NIHR Programme grant

PPIRes has been working with the INHALE research team since 2016 to support and develop the PPI plan. This involved recruiting five patient/carers representatives with an interest or experience of critical and adopting two PPI representatives already involved in the study to form the PPI panel. They have contributed to many aspects of the study including working on ethics applications, all patient facing materials, qualitative analysis of interviews with clinicians, leading on a survey to the PPI group and wider researcher team on the impact of PPI on the study and finally dissemination activities, one of which is described below in Case Study 8.

Case Study 8

INHALE: Potential of molecular diagnostics for Hospital-Acquired and Ventilator-Associated Pneumonia in UK critical care ([INHALE](#))



After discussions on how dissemination could be done creatively an opportunity came to contribute to the [Rise of the Resistance Festival](#). One of the members, Amander Wellings suggested she could work with the group to write a poem about INHALE and antimicrobial resistance. Using words and phrases suggested by the group she composed a poem and filmed it for the festival. The video can be viewed [here](#). Another member, Jennie Griffiths, wrote a letter to her grandchildren explaining the work she had been doing with the INHALE research team over the last 5 years and asked them to draw some pictures about the study to add to the poem.

"For the past four years I have been one of seven PPIRes members involved with INHALE. When the pandemic struck it seemed that the study would have to be paused but the INHALE research team were able to quickly design a sub study to address the problem of secondary pneumonia in COVID patients. It has been a real privilege to be part of such essential and groundbreaking research and to continue to be included and valued at times of such change and pressure."

Jennie Griffiths PPI Panel member

UEA Patient, Carer and Public Involvement in Teaching and Research

During 2018/19 discussions with UEA identified that there was potential to strengthen collaboration on PPI work across health and academic organisations in research and teaching. This is described in the Case Study 9 below:

Case Study 9

UEA & PPIRes PPI Stakeholder Event and Task and Finish Group

To explore what might be possible a stakeholder event was organised in March 2019. We brought together 35 stakeholders from across UEA Schools, local trusts, Quadram Institute, CRN Eastern, local charities, PPIRes volunteers and UEA volunteers.

We discussed the following questions:

1. What PPI models are currently being supported?
2. What are the possibilities for PPI collaborations across the system?
3. What would a good PPI system look like?
4. What recommendations do we want to make?

As a result of the event it was agreed that a task and finish group made up of representation from the UEA Service User Group, PPIRes, academic and administrative staff from UEA would explore how to develop a unified and coordinated gateway to PPI. Over six meetings the group considered the following questions:

- What best-practice, policy and resources currently exist to support the delivery of PPI?
- What policies and resources are needed to ensure PPI is nationally excellent?
- How might these be delivered so that PPI develops in a coherent and sustainable way?

The group held two Staff Insight Workshops to identify areas of strength and barriers to excellent PPI.

As a result, a set of recommendations were agreed including:

Policy and procedures to be standardised and made prominent

PPI leads to oversee the development, consolidation, and implementation of PPI support and resources

Payment and reciprocity

Staff and service users expressed the need for service user payment parity across teaching and research

Service user database

Develop to makes this more diverse and representative of the general population, both to embed community viewpoints in teaching and also to serve the needs of research PPI.

This work has led to UEA establishing a Citizen Academy to support research across both teaching and research.

6.2. Patient and Public Involvement in CCG Held Research Grants

Appendix 2 highlights how the public and patients have been involved in some of the research grants held by the CCG (see Section 7.3), and without exception, all projects have benefitted from the involvement of patients and the public in the development, delivery and dissemination of their projects – exemplified by the quote below included in the annual submission to NIHR on grant outputs:

What difference do you think patient and public involvement in your research has made to your research?

“Gives us confidence in the relevance of the project to those it ultimately seeks to support (informal carers of patients with breathlessness) and ensures appropriate recruitment materials and study outputs (planned website content) for those carers.”

LAB2 ResearchFish Submission 2021

7. Research Management Team

The Research Office has a small team supporting NHS Research Management in Primary Care across the Eastern region, NCH&C and ECCH, working with partners to ensure that research is undertaken in line with all governance and legal requirements; encouraging high quality research undertaken in line with local and national health needs and commissioning priorities; providing expert advice to support research and minimise risks to participants, patients, staff and organisations; developing and maintaining robust systems for contract oversight and delivery, and facilitating study delivery in line with national guidance, timelines and targets. The Research Office also supports NCH&C with completion of the quarterly Performance in Initiating and Delivering Clinical Research (PID), a reporting requirement on recruitment to clinical trials for NHS providers.

7.1. Study review and assessment

We work in partnership with the [Cambridgeshire and Peterborough Primary & Community Care Research Office](#) and CRN Eastern to provide a central point of coordination management for research across the CRN Eastern region for primary care NIHR Portfolio Studies.

NIHR CRN Portfolio Studies are those which are deemed of national importance to the NHS.

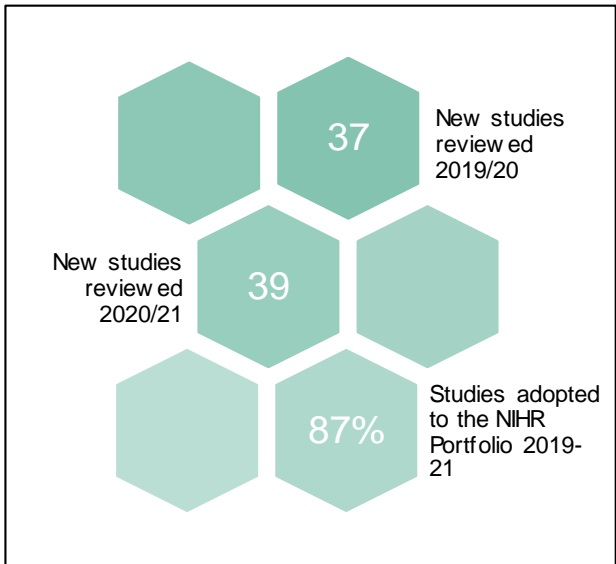
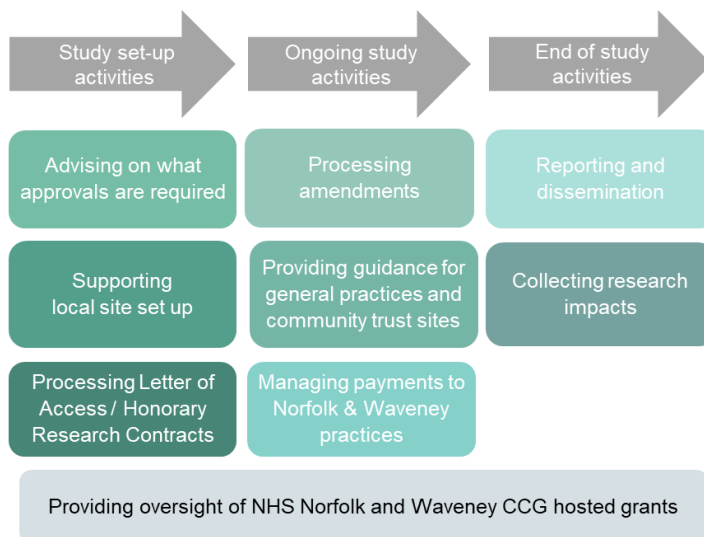


Figure 3 - Overview of study support activities undertaken by the Team

We also work closely with the Research Teams at NCH&C and ECCH to advise on local requirements, support the management and set up of research, and confirm, on their behalf, capacity and capability to undertake research studies.

Figure 3 on the previous page outlines the activities we undertake to support study set up, to support ongoing studies and to report on study findings (see Section 9.1) or collect research impacts (see Section 9.3), and Figure 4 (Case Study 10) gives an illustration of the activity undertaken by the office during study set-up.

Case Study 10 below shows the timelines between initial approach to NCH&C by the study sponsor and the recruitment of NCH&C's first participant to BASIL+.

Case Study 10

Behavioural Activation for Social IsoLation (BASIL+)

BASIL+ is an Urgent Public Health randomised control trial to test the clinical effectiveness of a psychological intervention, Behavioural Activation (BA) to reduce and prevent depression and loneliness amongst older adults with long-term physical health conditions who are isolated as a result of the COVID-19 pandemic. A trained 'Basil Support Worker' works together with the participant to develop a collaborative treatment plan to reinstate or introduce behaviours that connect people to sources of positive reinforcement. The trial aims to recruit 590 participants nationally

NCH&C is the only site in Eastern to be selected as a site for BASIL+ and is aiming to recruit 50 participants locally with the support of Millwood Surgery and Watton Medical Practice acting as Participant Identification Centres (PICs). The Research Office has supported the set up of the study by reviewing local requirements, costs, contracts and confirming the study.

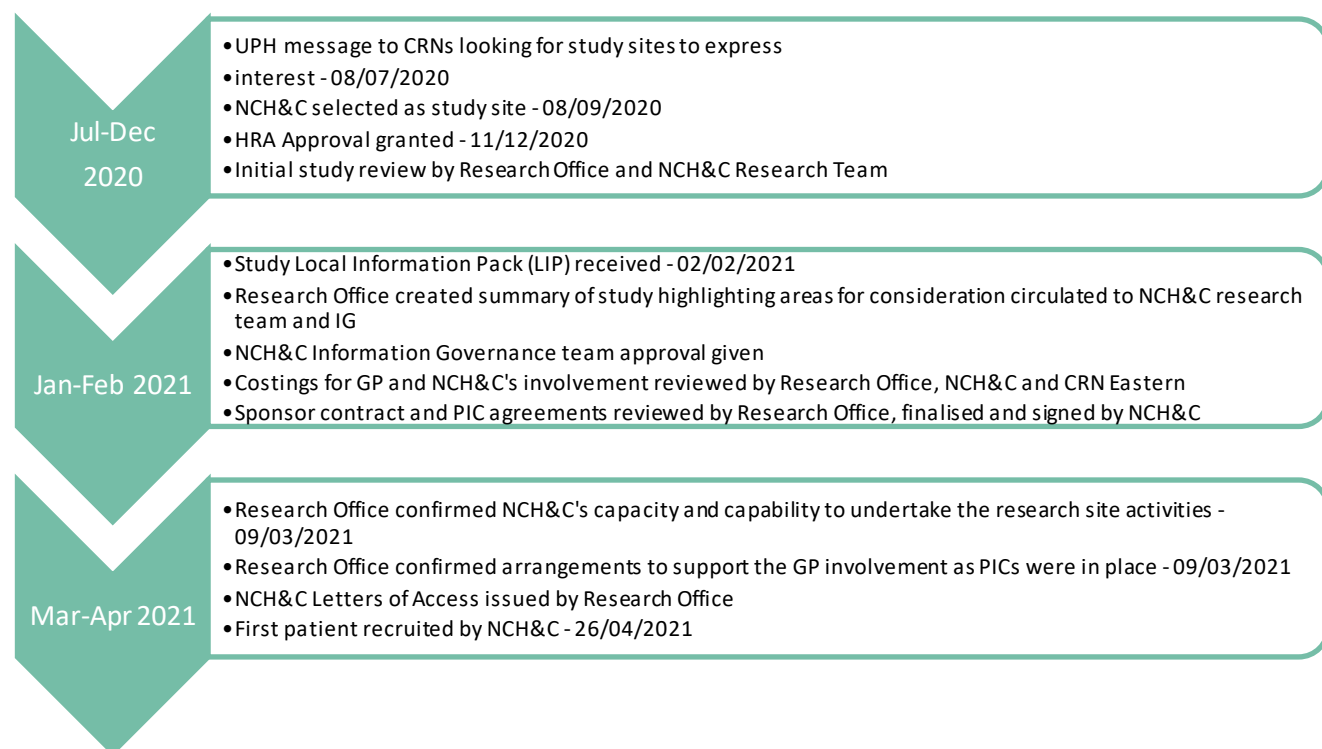


Figure 4 - Overview of Office Activity in relation to the set-up of BASIL+

A total of 76 Norfolk and Suffolk primary and community care studies were reviewed during 2019-21, with similar numbers reviewed in each year. 87% of these studies were portfolio studies; with non-portfolio studies usually being local student led studies.

Details of studies which were active across Norfolk and Waveney primary care sites, NCH&C and ECCH during 2019-2021 can be found on the Research Office website.

7.2. Restart and Recovery

The Research Office developed a study risk assessment form in line with NIHR's Restart Framework (see Section 4) to assess studies paused due to COVID-19. This was used to support NCH&C to identify and manage the restart of their paused research. The Research Office prepared information and guidance on the Restart Framework, which was shared with General Practices across the region to aid them in the restart of paused studies and published on our website. Studies were, and continue to be adapted so that they could or

Case Study 11



Babybreathe is a UK wide randomised controlled trial (RCT) to test a package of support, produced by working with women, their partners and NHS staff to help women who have stopped smoking before or during pregnancy to stay smoke free.

BabyBreathe Intervention Components comprise:

- a leaflet for women, partners, friends or family
- access to the BabyBreathe website and app
- text message and/or app notification support messages
- a free BabyBreathe box with journal, photo frame, tea bags etc.



This NIHR funded research programme (almost £1.5 million) is led by Professor Caitlin Notley at UEA who worked with the Research Development team to develop the study and apply for NIHR funding. The trial was recommended for funding in March 2020 with the CCG as the lead contractor.

The trial start was postponed to 1 October 2020 because of the pandemic, which allowed the research team to take the opportunity to modify the trial to meet COVID-19 restrictions and the changes to care provision. These adaptations include:

- All face to face visits with Health Visitors were moved to remote consultations as a result of COVID-19, the trial has therefore been adapted to work with a remote HV service.
- The face to face consent visit by the researcher has moved to an electronic consent model, with telephone or online/virtual meetings arranged to ensure participants have the opportunity to ask any questions about the study.
- 6 month and 12 month follow up data will be collected remotely, by telephone, post, or virtual visit from a researcher, depending on local restrictions.
- As Carbon Monoxide (CO) monitoring is now being undertaken using individual use CO monitors to be posted to the women in the study.
- Participants are not able to see a health visitor before birth as part of usual care, so this will proceed in the current standard way.

can restart in a COVID-secure way – this included supporting questionnaire/online survey studies, amending study protocols so that consent can be gained remotely, sourcing appropriate PPE for the research delivery teams, and following infection control advice.

As we move into 2021/22, COVID-19 research continues to be important, but is now balanced against the recovery of other important research studies. We are working alongside CRN Eastern to support new primary and community studies coming to the region, and continue to support any remaining paused studies to restart. Please see the Babybreathe Case Study (Case Study 11 above) as an example of the changes made.

7.3. Management of Grants

During 2019-21 the Research Office held seven NIHR grants on behalf of NHS Norfolk and Waveney CCG, undertaking contract negotiation, and overseeing their delivery and financial management. Figure 5 below details the different stages undertaken for management of hosted grants.

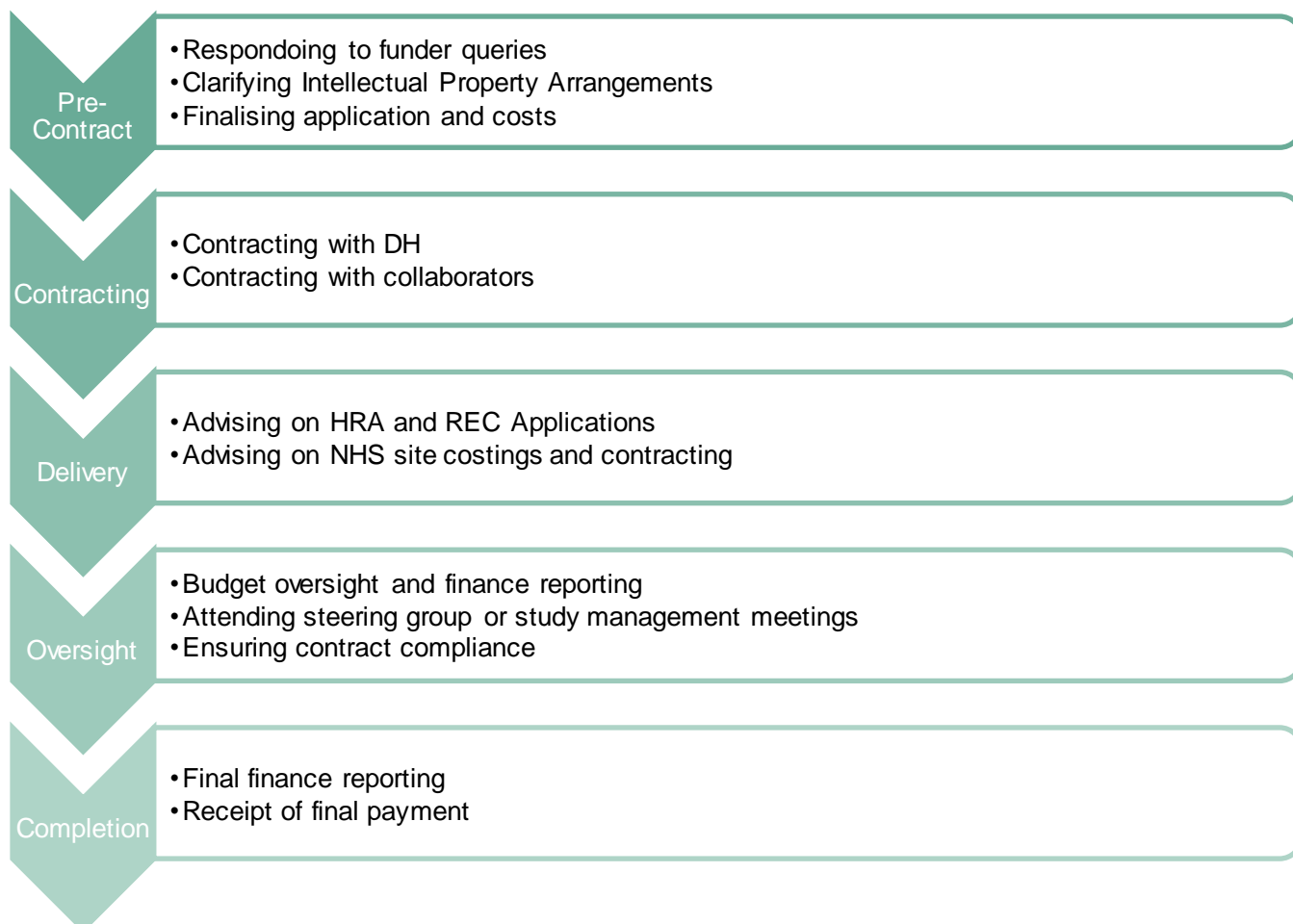


Figure 5 - Overview of NHR Research Grant Management Processes

Oversight is achieved through working closely with the study teams, research offices at collaborating organisations and attending management and steering group meetings.

In addition to the three projects detailed in Section 5.1 above, which were awarded funding and commenced during the last two years (HIP HELPER, Babybreathe and Improving the

quality and experience of care for patients prescribed medicines with a risk of dependence or withdrawal) the a further four projects were ongoing as detailed below

CHIPPS	<ul style="list-style-type: none"> •Care Homes Independent Prescribing Service: Development and delivery of a cluster randomised controlled trial to determine both its effectiveness and cost-effectiveness •01/05/2015 -31/10/2020 •Programme Grants for Applied Research £1.99m
LAB-2	<ul style="list-style-type: none"> •Development, refinement, and acceptability of an educational intervention for informal carers of patients with breathlessness in advanced disease (Learning about Breathlessness Study 2: LaB2) •01/08/2018-15/05/2020 •Research for Patient Benefit £150k
PEP-TALK	<ul style="list-style-type: none"> •A behaviour change physiotherapy intervention to increase physical activity following hip and knee replacement: a pragmatic randomised controlled trial. •01/08/2018 - 21/12/2021 •Research for Patient Benefit £350k
Quit Sense	<ul style="list-style-type: none"> •Feasibility randomised controlled trial of a smoking cessation smartphone app that delivers 'context aware' behavioural support in real time •01/06/2019 - 31/01/2022 •Public Health Research £356k

Outputs, including publications or presentations at meetings or conferences and impacts, of NHS Norfolk and Waveney CCG hosted studies are collected annually by NIHR through an online system called ResearchFish, for 5 years post study completion. Two key outputs from the CHIPPS study and the LAB2 study, both of which finished this year are highlighted in the table below, with Appendix 3 giving a more detailed list of outputs from CCG held grants.

Study	Output Type	Details	Weblink
CHIPPS	Publication	Lane K. et al. Everyone needs to understand each other's systems: Stakeholder views on the acceptability and viability of a Pharmacist Independent Prescriber role in care homes for older people in the UK. Health & social care in the community. 28(5), 1479-148, 9 2020	http://europepmc.org/abstract/MED/32124516
LAB2	Website	The key output of the LaB2 study is the evidence-based website "Supporting Someone with Breathlessness": https://supporting-breathlessness.org.uk/ Those wishing to adapt material from the website can do so under licence. This has enabled adaption of material for a wider range of users internationally e.g. licences issued to Australia (L01) and New Zealand (L02) to date (March 2021)	LaB2's "Supporting Someone with Breathlessness" website https://supporting-breathlessness.org.uk/

7.4. Delivering Research in Adult Social Care

While the Health and Social Care Act 2012 positioned research as a core function of NHS organisations, the role of research in Adult Social Care settings is less clearly defined, and knowledge of the regulatory environment is somewhat limited. In order to support its expansion into the social care environment the CRN Co-ordinating Centre funded six pilots to look at different aspects of working in adult social care, which Local Clinical Research Networks were able to bid for.

In collaboration with the Research Office in Cambridge and Peterborough CCG, and on behalf of CRN Eastern, the Research Office submitted a bid to look at how best the NIHR Clinical Research Network can support adult social care research and what the key issues and barriers are for delivering research in this setting from a governance perspective, with funding being awarded in November 2019



This project was completed by staff from the Research Management Team between November 2019 and March 2020, together with the Research Office at NHS Cambridge and Peterborough CCG, with further amendments being made to the report in March 2021.

Key findings of Social Care Report

In general, there was limited familiarity with the UK Policy Framework for Health and Social Care Research and the CRN amongst adult social care providers and there appeared to be a lack of clarity as to what form of ethical review was required.

There is, largely, no national approval process in social care, meaning researchers need to develop relationships with and secure buy-in from the relevant services for research to happen.

The overall context was that social care gatekeepers have busy roles and little capacity for agreeing and supporting research; subsequently, research procedures and activities need to be designed in a way that is proportionate, building on existing systems and with CRN support.

The key findings from the interviews and review were prepared as a report, accompanied by a series of resources ('factsheets') that were developed to address some of the key considerations/gaps in understanding raised in the report. These are currently with CRN for a final review.

28 interviews (face-to-face and telephone) were conducted with a wide range of relevant stakeholders including: social care researchers, local authority commissioners and social workers, staff from care homes, hospices and learning disability services, and staff from CCGs

These interviews covered the research already happening and systems already in place in Social Care settings, the main challenges to conducting research in these settings, and potential solutions to meet these challenges.

Alongside this, a scoping review was carried out to identify and analyse existing guidance/resources relating to the regulatory set-up of Adult Social Care research. The report will be made available once it has been finalised by the NIHR.

The Research Office will be involved in further work, building on this report, being undertaken by CRN Eastern throughout 2021-22 to support placement and delivery of research within adult social care.

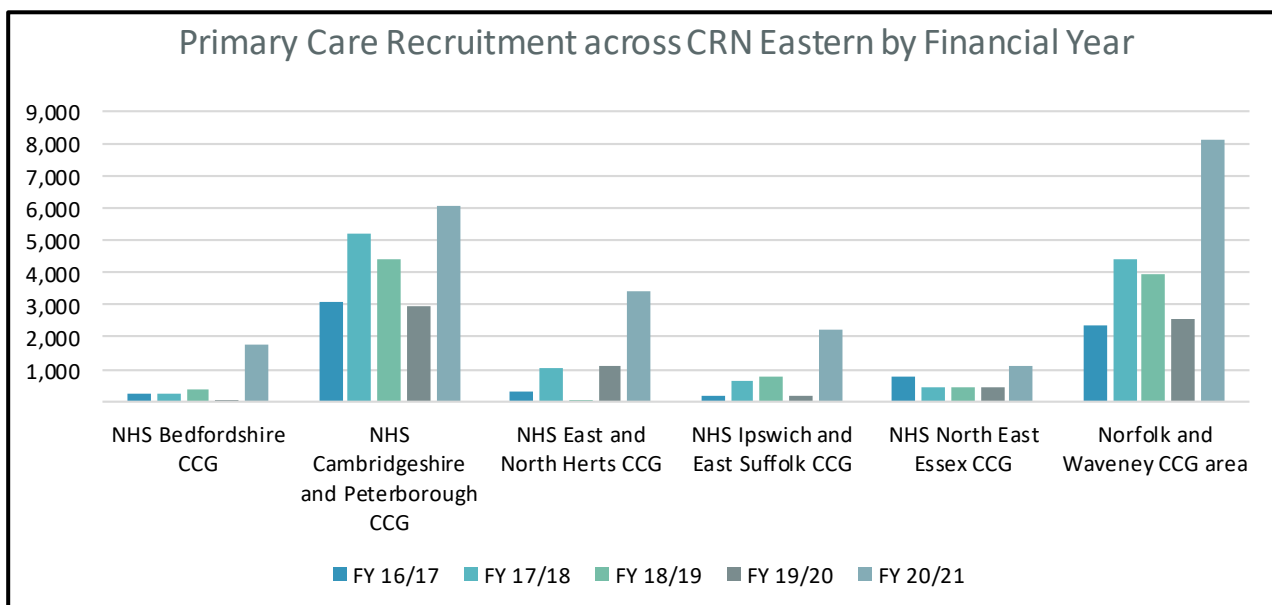
7.5. Supporting NCH&C and ECCH Research Teams

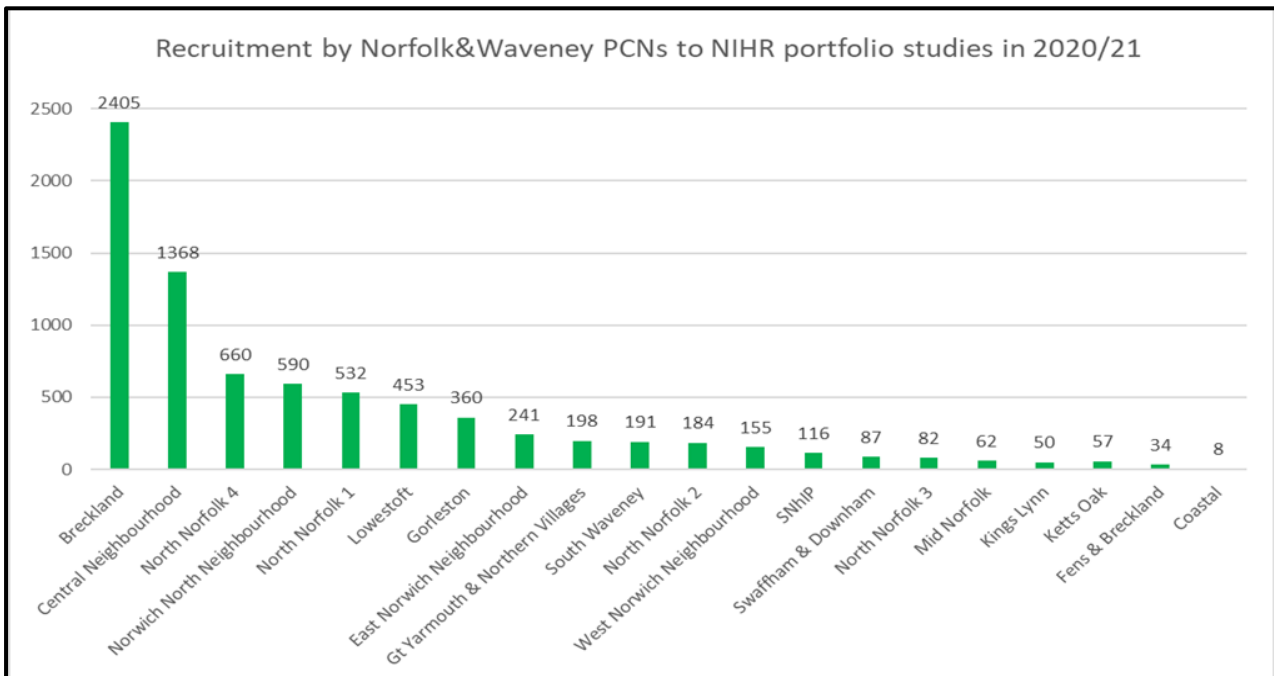
The Research Management Team have provided guidance and support to new starters at NCH&C and ECCH. 2020/21 saw a change in research management and leadership at NCH&C with Joanna Watts taking up the post of Community Research Manager in March 2020 and Lynne Fanning taking up the post of Head of Clinical Education and Research shortly in July 2020. Two new research nurses, Rachel Hollings and Rachel Stebbings joined the Primary Care Research Delivery Team at NCH&C and Cherry White joined ECCH’s research team as a Research Nurse supporting both community and primary care studies.

8. Research Delivery

8.1. Recruitment to NIHR Portfolio Studies

In 2020/21 Norfolk & Waveney practices recruited over 8000 participants to NIHR Portfolio studies, far exceeding the preceding years’ recruitment of 2552 and the highest number of recruited study participants of any CCG in England (followed by NHS Cambridgeshire and Peterborough CCG, with 6000 recruits). The graphs below and the top of the next page show recruitment by the CRN Eastern region CCGs over the last five years and the recruitment by Norfolk and Waveney Primary Care Networks (PCN) in 2020/21.

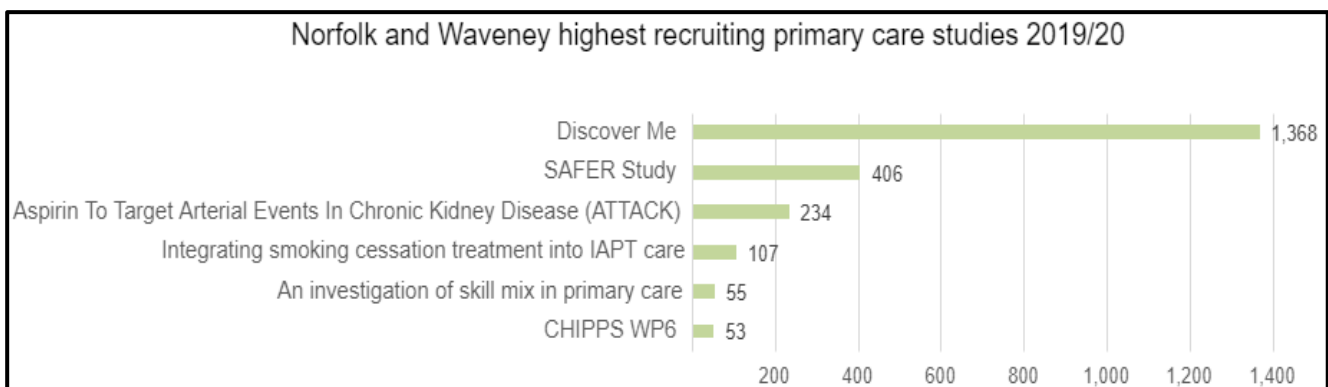


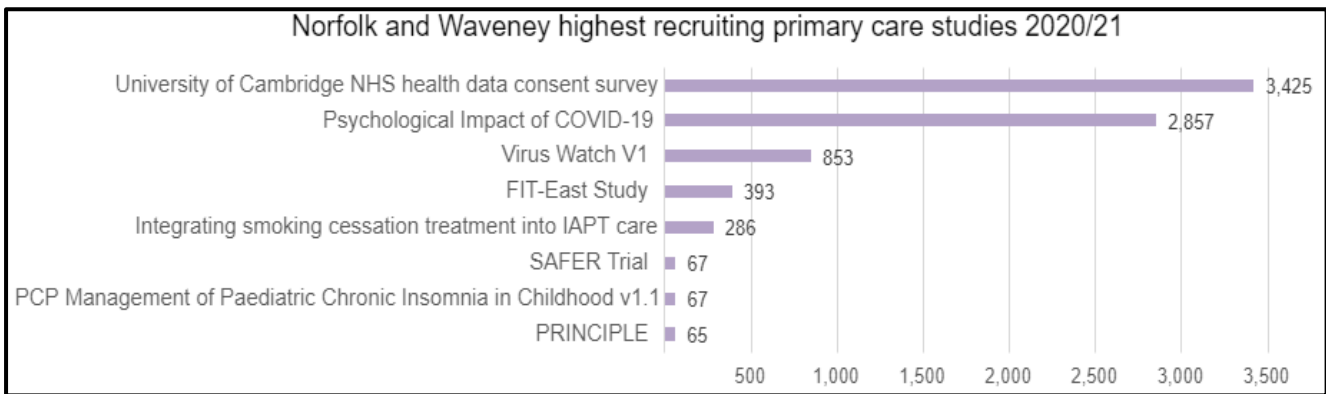


Approximately 50 General Practices in Norfolk and Waveney hold single site Research (RSI) contracts with CRN Eastern (see Section 8.3), with Breckland Alliance holding a cluster RSI contract with CRN Eastern across their three practices (see Case Study 14, Section 8.3).

Over 100 Norfolk and Waveney practices recruited to portfolio studies during 2020/21 compared to 70 practices the year before, which is a remarkable achievement given the massive changes practices have had to undertake due to COVID, and is testament to the enthusiasm and hard work of practices and the research delivery team in supporting their involvement. 930 Norfolk and Waveney patients took part in UPH COVID-19 Studies 2020/21 through their General Practice, with a further 7,732 recruited through our acute Trusts; 318 at NCH&C and 132 at NSFT.

The studies which recruited the most participants across Norfolk and Waveney primary care sites during 2019/20 and 2020/21 are shown below.





More information on the 2020/21 two highest primary care recruiting studies, CLIMB, the University of Cambridge Data Consent Survey, and the Psychological Impacts of COVID-19 can be found in Case Studies 12 and 13

Case Study 12:

University of Cambridge NHS health data consent survey (CLIMB)

Overview of study

- Survey study to establish patient and public views on the sharing of identifiable health data for clinical purposes, and anonymous health data for research purposes.
- Findings from the study are to be used to enable better procedures for sharing and accessing data for clinical and research use.
- Study is now closed, having received over survey 29,000 survey responses.

Primary Care site involvement

- Practices assisted in the study by sending text messages to their patients, and by sharing promotional material in practices and via social media.
- The Research Delivery Team created 'The Climb Race', with a monthly leader-board and chocolate-based incentives, to encourage recruitment and friendly competition between practices.
- 3,425 Primary Care participants across 39 Practices were recruited between April and September 2020, making Norfolk and Waveney CCG the second highest recruiting Trust / CCG nationally.
- St Stephens Gate Medical Partnership in Norwich ranked 4th nationally across recruiting GP practices in terms of the number of participants recruited (303).

Case Study 13

Psychological Impact of COVID-19 Pandemic and Experience: An International Survey.

Overview of study

- International online survey to monitor and explore the psychological impact of the COVID-19 pandemic (and accompanying restrictions) on wellbeing, about which little is currently known.
- Participants invited to complete the survey include members of the general public, health professionals and those with pre-existing mental health conditions in order to identify groups who may be experiencing more extreme impacts.

NCH&C and Primary Care Involvement

- The Research Delivery Team used a wide variety of recruitment techniques to encourage uptake of this study – for example - sharing information about on Twitter and in GP newsletters, sending formal Expression of Interest Forms to practices, contacting practices by phone, and supplying posters and flyers.
- Some members of the research delivery team also attended the mass vaccination site in Norfolk with iPads in order to recruit potential participants.
- 2,857 participants were recruited from Primary Care in Norfolk and Waveney, making Norfolk and Waveney CCG the top recruiting Trust/CCG in Eastern, and third nationally. A further 449 participants were recruited from NCH&C Community Care sites.

NCH&C recruited 828 participants to portfolio studies in 2020/21, including 318 recruited to Urgent Public Health Studies. When compared with other Community Trusts, NCH&C ranks third nationally in terms of the number of participants recruited to Portfolio studies during 2020/21. As Community Trusts vary in terms of the number of sites they have open to studies, a figure that has adjusted for the number of open recruiting sites is also included. By this measure, NCH&C ranks second nationally.

The Research Office supports NCH&C with compiling their Research Annual Reports and further information on NCH&C's research activity can be found in the 2019/20 and 2020/21 reports published on their website.

8.2. Feedback on Patient Experience

Each year, CRN Eastern collects patient feedback on the experience of participating in research via the Participant in Research Experience Survey (PRES). The information collected helps us to understand patient experience and make improvements to how research is delivered.



"I've found the staff to be very professional, passionate and thorough. I've felt my contribution is valuable."

Feedback from participants in three primary care studies was collected in 2019/20 whilst the 2020/21 survey focused on the patient experience of COVID research, particularly with respect to involvement in COVID vaccination trials.

Overall 2020/21 participant feedback across the CRN Eastern region was very positive, with 91% of participants saying they felt the researchers valued their taking part in the research, 97% saying they had been treated with courtesy and

respect and 94% saying they would take part in another research study. 74% of 2019/20 respondents agreed they had a good experience of taking part in a research study.

Following the results of the [PRES 2020/21 report](#), CRN Eastern has created two recruitment enhancement tools based on the feedback from research participants.

8.3. Research Site Initiative (RSI) Scheme

The RSI scheme is an annual scheme run by CRN Eastern which offers practices funding in return for undertaking NIHR portfolio studies. 39 and 42 Norfolk and Waveney practices took part in the RSI scheme on a Single Site contract in 2019/20 and 2020/21, respectively. In addition, there was one cluster of three practices in 2019/20 involved in the scheme in Norfolk and Waveney and two clusters involved in 2020/21 with two and three practices in each. Appendix 4 lists the practices involved the scheme by Primary Care Network (PCN) location.

The vast majority of research activity in Norfolk and Waveney takes place within RSI practices, with Norfolk and Waveney consistently having a high proportion of research engaged practices. When viewed nationally, CRN Eastern has the highest number of General Practices recruiting into NIHR Portfolio studies (75.1% in 20/21 compared to a national average of 50.5%).

Research Site Initiative (RSI) Scheme

Offers practices infrastructure funding from the CRN in return for recruitment to Portfolio studies.

Primary Care Cluster

A group of general practices that have formed a partnership to work together and share resources.

Case Study 14

Breckland Alliance

The Breckland Alliance was shortlisted for the 2019 Nursing Times Awards in the Clinical Research Nursing category. The team was nominated for their success in collaborating to deliver research opportunities to patients across their three GP surgeries. Karen Norcott, an experienced research nurse, coordinated the research activity across all the practices: Grove Surgery, School Lane Surgery and Watton Medical Practice.

Aims of the Breckland Alliance Research Team

- To establish a cluster model across practices
- To maximise recruitment across the practices
- To get the practice teams on board
- To make themselves attractive to industry and academic teams
- To work closely with CRN Eastern to deliver portfolio research

Key Achievements

- Breckland accepted their first commercial study within short timeframe
- Study teams actively request to work with the Breckland Alliance
- Opportunities for patients to participate in many more research studies
- Staff development and progression, including job satisfaction
- An innovative and inspirational way of working
- More income generated to support research and enhance patient services

Case Study 14 above illustrates research success of the Breckland Alliance Cluster who were shortlisted for the 2019 Nursing Times Awards.

8.4. Green Shoots Award

The Greenshoots (GS) scheme, offered by CRN Eastern aims to grow the region’s research capability and recruitment activity, providing 24 months funding for clinicians in the form of PA or sessional time to develop capability and expertise to deliver NIHR Portfolio Research.

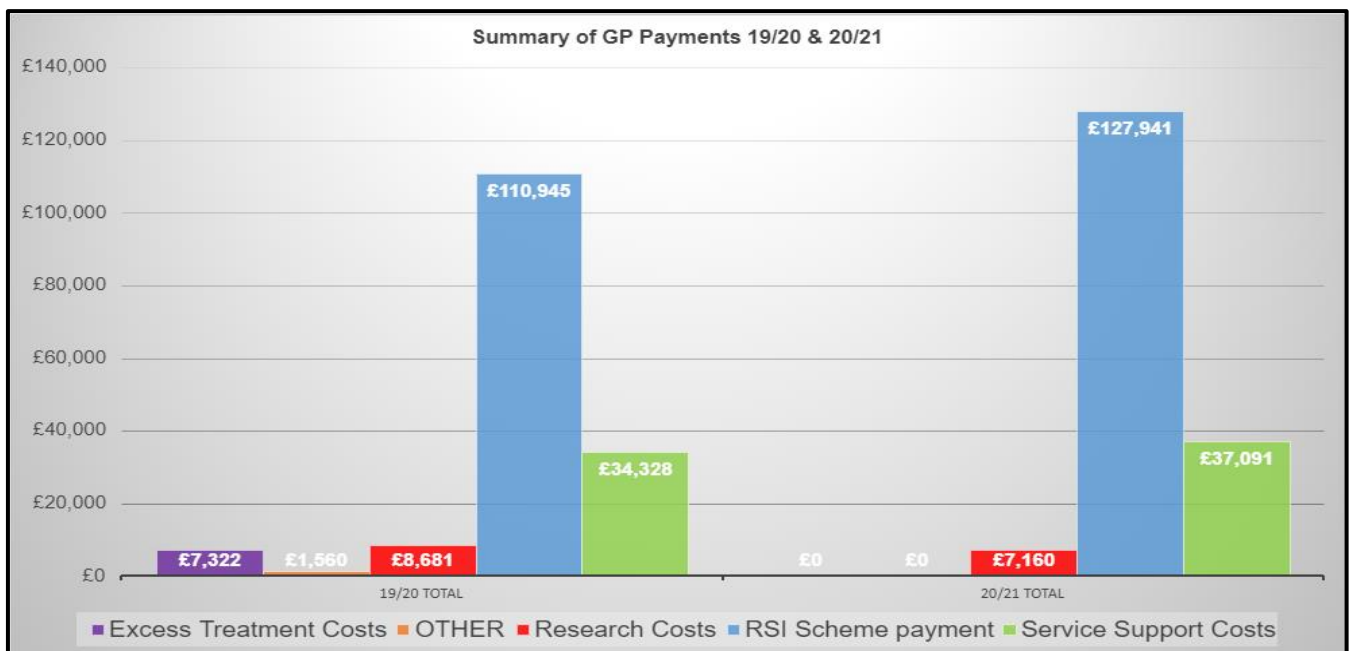
In a joint application early in 2019, between the Research Office, the Primary Care Research Delivery Team, Dr Engamba and Research Leads from One Norwich we were successful in obtaining Green Shoots Funding to support Dr Engamba to support research within the UEA Medical Practice and to work within the One Norwich region to pilot how we might deliver research work across a PCN area.

0.5 PA funding was awarded on the 1st of April 2020 (01/04/2020), for 24 months. Despite the pandemic, as a result of this work One Norwich have instigated a virtual research notice board and are now running a regular bi-monthly virtual forum for all interested practices within the PCN through which new research studies are discussed as well as opportunities for working at scale across the PCN area. This work is being led by the CRN Norfolk and Waveney delivery team and the Research Office with Dr Engamba and One Norwich. Dr Engamba is also engaging with less research experienced practices within the PCN with a view to growing the activity across the PCN.

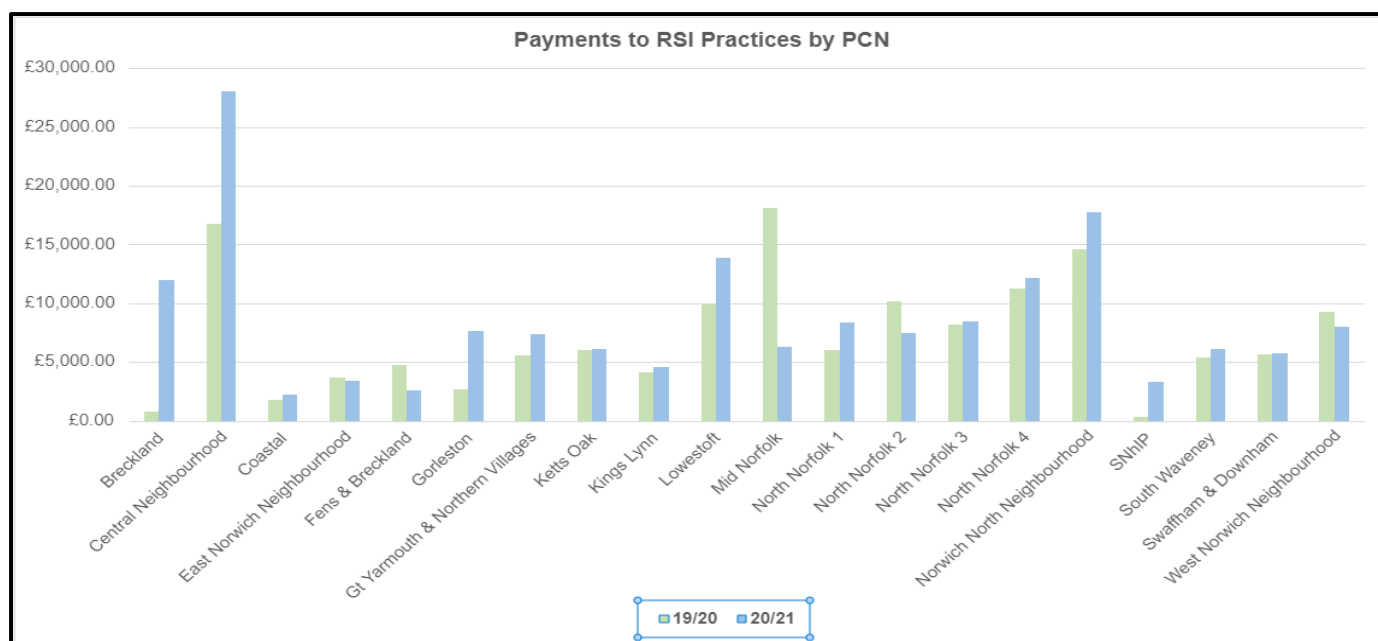
Regular meetings are held to oversee the project and review progress and action planning.

8.5. General Practice Payments

The Research Office continues to co-ordinate payments to practices in Norfolk and Waveney on behalf of the CRN. The team collate research activity and payments due each quarter for payment through NNUH (as host organisation for CRN Eastern), prepare practice



statements and manage any queries. The graphs show the payments to practices by cost type and the distribution of payments across the PCNs.



Research Costs - the costs of the research itself that end when the research ends. They relate to activities that are being undertaken to answer the research questions.

Excess Treatment Costs (ETCs) are the costs that arise as a result of the difference between the cost of standard treatment and the cost of treatment within a research study. The NHS is responsible for these costs which are funded through normal commissioning arrangements for commissioning patient care. The costs would continue to be incurred if the patient care service in question continued to be provided after the research study had stopped.

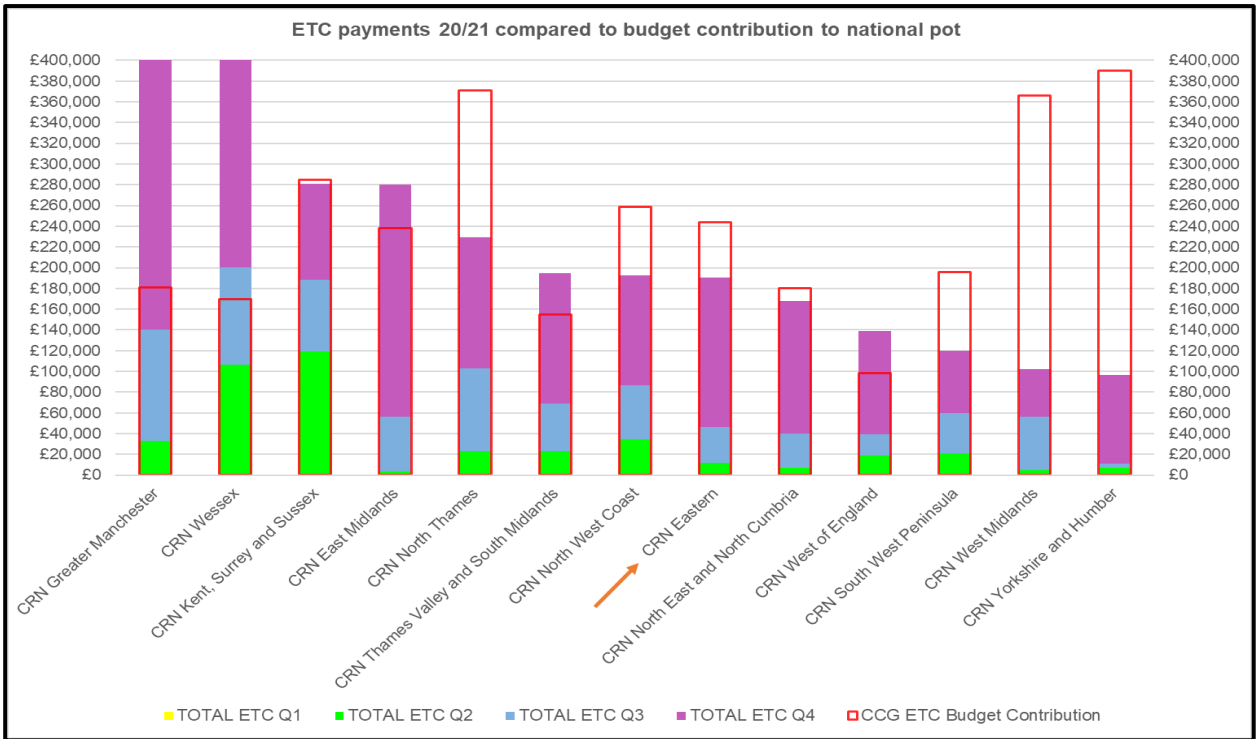
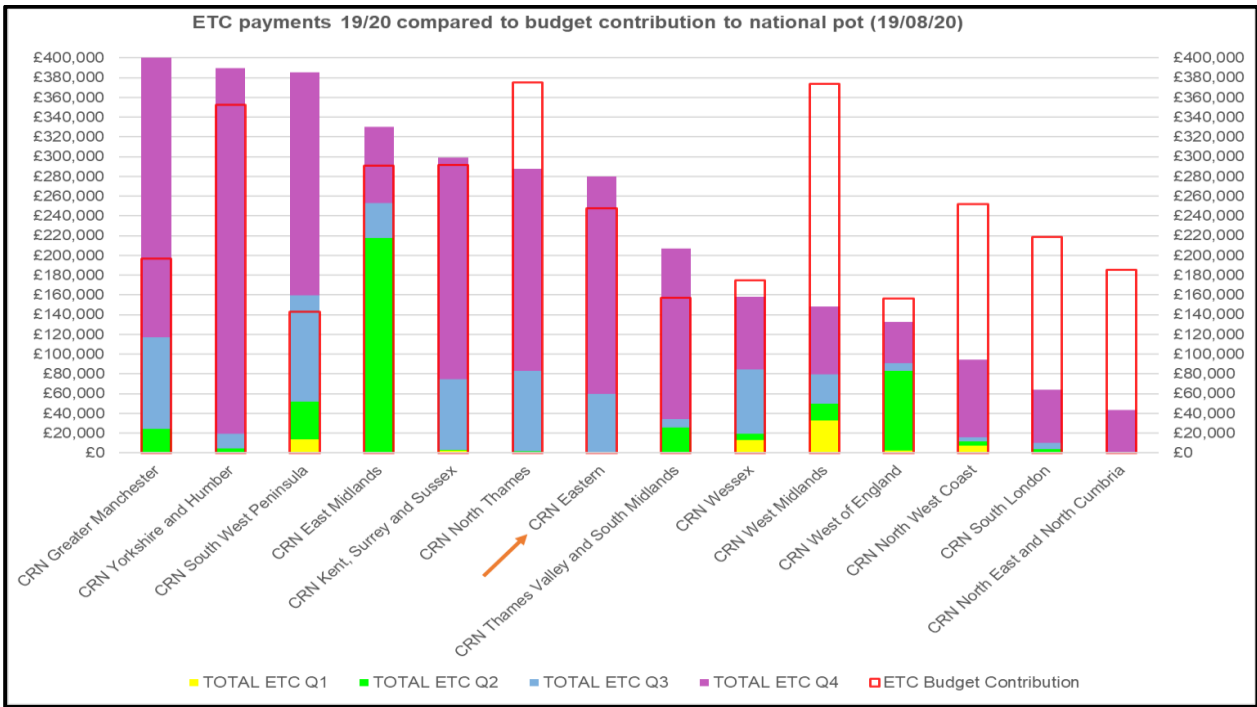
NHS Support Costs - the additional patient care costs associated with the research, which would end once the R&D study in question had stopped, even if the patient care involved continued to be provided.

8.6. Excess Treatment Costs in Research

Excess Treatment Costs (ETCs) are the costs of care provision within a research study over and above the cost of normal care and are the responsibility of commissioners. In 2018 a national system came into effect whereby CCG contributions are top-sliced and pooled nationally to support studies incurring ETCs. Payments are made through the national system quarterly to Trusts and Practices on a per participant recruited basis, with Trusts subject to a threshold under which they have to absorb any costs.

The following graphs show the distribution of ETC pay outs per CRN compared to budget contributions (red box) for 2019/20 and 2020/21. As this is a national scheme all CCG contributions are pooled, however the graphs give an indication as to what proportion of CCG monies spent come back into region to support research activity locally (if the coloured bar exceeds the red box – as can be seen for the Eastern region in 2019/20 - more money

has come into region than has gone out, if the coloured bar is smaller than the red box - as in 2020/21 in CRN: Eastern - then more has gone out of region than has come in).



9. Dissemination and Impacts

9.1. Research Office Communication and Dissemination Activity

Reporting the outcomes of research projects and programmes in a variety of ways ensures that information is disseminated in many formats that are of relevance to different groups of people and are of use in the design, commissioning and delivery of health and social care services. Researchers, sponsors and funders all have a duty to disseminate findings from research, both contributing to the evidence base and keeping information flowing to those who gave their time to support their research and to be recruited into studies.

We collaborate with national and local bodies (e.g. ARC EoE and Eastern Academic Health Science Network (EAHSN)) to ensure research findings, relevant to patients and the NHS are disseminated and to encourage translation into practice.

Bulletins

While communication and dissemination activities have continued to take place throughout 2020, this has primarily focused on sharing information relating to COVID-19 studies to promote awareness of these during the pandemic. This has included details of ongoing trials and activity through to interim results and findings from research. From the very start of the pandemic, the Research Office produced weekly updates on COVID-19 study activity and shared these with both the Norfolk, Suffolk and North East Essex ICCs and the Communications Team for wider dissemination. As the pace of research slightly eased towards the end of the year, this has since been reduced to bi-weekly updates and has been expanded to incorporate a wider range of research related information. Appendix 1 gives examples of news stories disseminated via Covid Bulletins throughout 2020/21.

Update on COVID-19 research in Norfolk and Waveney – 18/03/2021

More than one million people have now taken part across more than 180 COVID-19 research studies across the UK, including nearly 9000 participants in Norfolk and Waveney.

This week the NIHR launched their [ResearchVsCovid campaign](#) to highlight the significance of NIHR-supported COVID-19 research achievements in the past year and thank everyone who has been part of COVID-19 research. All Trusts and a large number of practices in Norfolk and Waveney have been involved in Urgent Public Health COVID-19 research leading identification of new vaccines and better treatments to combat COVID-19. The campaign may be extended for another week.

We would like to say a [big thank you](#) to everyone who has been part of COVID-19 research over the last year. If you wish to join in, please [share your own thank you message](#) via your social media with the hashtag [#ResearchVsCovid](#)

COVID-19 Research findings and updates:

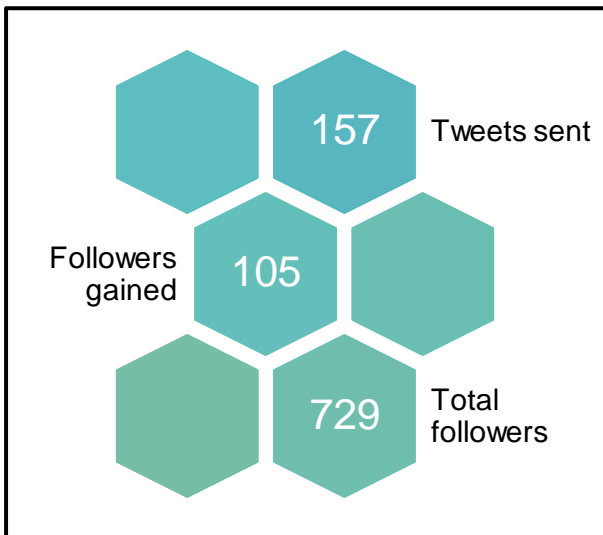
PRINCIPLE study - the most recent findings from the azithromycin treatment arm of the trial, published in [The Lancet](#) showed no justification for the routine use of azithromycin for reducing time to recovery or risk of hospitalisation for people with suspected COVID-19 in the community. Researchers conclude that *these findings have important antibiotic stewardship implications during this pandemic, as inappropriate use of antibiotics leads to increased antimicrobial resistance, and there is evidence that azithromycin use increased during the pandemic in the UK.* The trial is currently evaluating inhaled budesonide (a commonly used inhaled corticosteroid) and colchicine (a commonly-used anti-inflammatory). PRINCIPLE is recruiting participants through their [website](#) and also through GP practices across the UK and is also open to those who have received a COVID-19 vaccine.

NIHR second themed review on 'Long Covid' - building upon the [first themed review](#) published in October 2020, the second review considered over 300 papers and academic opinion pieces from around the world, and provides a unique, evidence-based perspective. The review finds that there is a considerable variation in the range of symptoms that have been considered Long Covid by researchers. Used as an umbrella term, Long Covid may cover conditions which may have different causes. You can access the full review [here](#).

Twitter Review

The Research Office Twitter account, @NHS_NSResearch, continues to be a useful tool, supporting engagement with multiple NHS, funding, academic and patient organisations and increasing the visibility of the Research Office locally and nationally. In addition, it provides another communication channel by which we can promote opportunities to take part in research and disseminate research related news. From March 2020, the Research Office Twitter account has also been used to actively promote COVID-19 research.

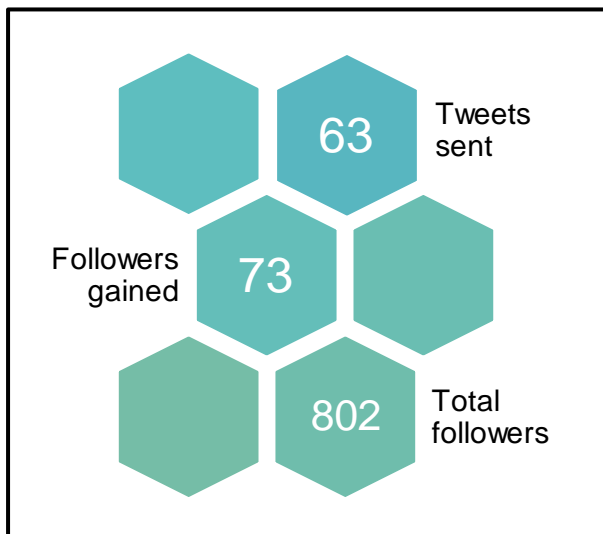
April 2019 – March 2020



Our top Tweet was sent in October 2019 and was seen 10,479 times by other Twitter users. The Tweet was promoting recruitment for the NIHR-funded GLAD study, the largest ever study of anxiety and depression.

The month with the highest overall number of impressions (28,508) and engagements (751) was May 2019, following attendance at the National NHS R&D Forum conference.

April 2020 – March 2021



Our top Tweet was sent in April 2020 and seen 5,384 times by other Twitter users. The Tweet shared a resource with advice on how to manage breathlessness at home during the COVID-19 outbreak.

The month with the highest overall number of impressions (17,476) and engagements (1,026) was April 2020, with members of the Research Office taking part in the #Red4Research campaign and wearing red in a show of support for COVID-19 research.

Website

The [Research Office website](#) was updated throughout 2019-21 to provide advice for researchers and signpost to further resources and guidance.

Research output from managed studies

The outputs, including publications or presentations at meetings or conferences and impacts of NHS Norfolk and Waveney CCG hosted studies are listed in Appendix 3.

9.2. Events and Forums

International Clinical Trials Day (ICTD)

To mark ICTD the Research Office hosted a 'Be Part of Research' session in May 2019 with a presentation by Prof Eneida Mioshi, Chair of Dementia Care from the UEA entitled 'The Dementia Hub: an innovative approach to Dementia Care'.

ICTD was also promoted by 11 GP practices and two RSI clusters (see Section 8.2) in Norfolk and Suffolk.



GP Forums



The second CRN Eastern annual GP Forum in Newmarket on 25th September 2019 brought together GPs and research community from across Eastern and further afield to showcase and celebrate achievements in Primary Care in our region and to learn about new studies from lead academic and clinical researchers.



There were opportunities for delegates to network and attend workshops including: Principal Investigator training, Research meeting Population Needs, and Patient and Public Involvement.



The Norfolk and Waveney local GP Forum was held at Park Farm Hotel in Hethersett on Wednesday 20 November 2019. Representatives from over 25 practices heard presentations by the Tasmin S5 study team (an Oxford/ Cambridge collaboration), The BICS study team (University of Aberdeen) The ME/CFS study team (London School of Hygiene and Tropical Medicine), The Brio team (UEA) and the Safer team (Cambridge).

In 2020/21 the majority of Norfolk and Waveney RSI practices (see Section 8.3) attended either of the two CRN Eastern GP Forums held virtually to learn about vaccine study updates, the Royal College of GP Research and Surveillance Centre studies, and findings from the Barrett's oEsophagus Trial 3 (BEST3) and PRINCIPLE Trial. There was also a panel discussion on guidance for primary care research, with a panel member from the Research Management Team.

As part of the Green Shoots award which was awarded to Dr Serge Engamba in 2020 (see Section 8.4) a virtual GP Forum within One Norwich has been set up to share and disseminate information about research within the One Norwich PCN. This is run bi-monthly and started early in 2021. The focus is to encourage and share good practice between the research active and non-research active practices and to discuss working at scale across the PCN area.

9.3. Impacts

The Research Office routinely collects in-depth information regarding the impacts and benefits of research for services, staff and patients. Prior to the pandemic, a short impact survey was distributed to practices to capture their experiences of participating in the IQuit in Practice study, a clinical trial testing the effectiveness of a tailored text and web-based intervention for smoking cessation. This study took place across the entire Eastern region, including in several practices across Suffolk and North-East Essex. Case Study 15 provides a summary of the survey responses received from practices. More detailed summaries of our research impact work are available on the [Research Office website](#).

Case Study 15

Evaluating the Impacts of IQuit in Practice

Overview of study

- University of Cambridge randomised control trial to assess the feasibility and effectiveness of a 90-day web and text based service to support smoking cessation in primary care.

Practice involvement

- 57 practices across Eastern involved with more than 14,000 participants recruited.
- Practices involved in the identification of eligible patients, inviting and gaining consent from participants, and collecting both baseline and follow-up data.

Survey feedback from practices - impacts for service and staff

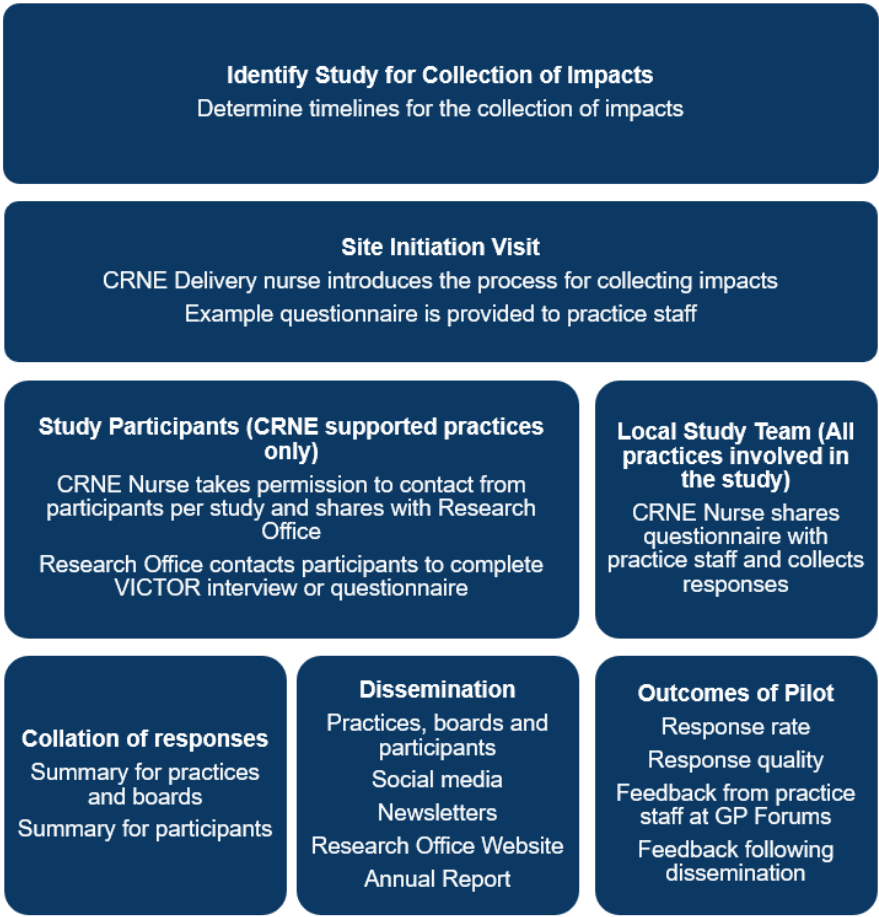
- Staff took enjoyment from prospect of improving patient's health.
- Increased engagement with patients.
- Improved knowledge of disease to share with patients.
- Presented challenges in terms of time implications (training, administration), but improved staff's time management and administrative skills.

Survey feedback from practices - impacts for patients

- Smokers have become non-smokers.
- Allowed for patients to be monitored and supported for longer than in usual care.
- Increased patient's awareness of cessation services.
- Increased patient's access to a smoking advisor.

"To offer this study alongside normal intervention has motivated some patients to quit, as they have more services on hand to help."

"It's very relevant to our work in the Doctor's surgery and enhances the work we already do for our patients"



In January 2020 members of the Research Management Team and the CRNE Eastern Norfolk and Waveney Primary Care Delivery Team adapted the [VICTOR \(Visible Impact of Research\) Tool](#) for collecting impacts in a more in depth manner, with a view to piloting in Primary Care. This work was put on hold at the start of the COVID-19 pandemic due to reduced staff capacity, and also to avoid placing additional pressure on practices which were working to respond and adapt to the many new challenges that have come with the pandemic. We intend to restart this work during 2021/22 and are specifically hoping to undertake more

detailed evaluation to capture the impact that being involved in studies has had not only on services as a whole, but also on individual patients.

NCH&C have used the VICTOR tool to collect impacts for WIELD 2 (see Case Study 16). The Research Office summarised the BIG CACTUS impacts feedback from NCH&C's Speech and Language Therapy Team, which can be viewed on the [Research Office website](#). The [study's findings](#) were also highlighted in the Research Office's Summer 2019

STROKE

The University of Sheffield

Big CACTUS

The findings of a study of self managed computer therapy to help word finding for people with aphasia

Big CACTUS is a pragmatic randomised controlled trial (RCT) was funded by NIHR to compare outcomes for people with persistent aphasia using computerised speech and language therapy at home with those having usual care (standard speech and language therapy provision or general daily communication activity), or attention control (daily completion of puzzle book activities). 278 participants with aphasia and 177 carers from across UK participated

The study found that people with aphasia improved their word finding ability with the addition of a low cost computer therapy and these improvements lasted at least 6 months after the therapy. The findings are summarised in a published **Booklet** and a Video which can be viewed on the [Big CACTUS study webpage](#).

NCH&C Involvement

- Assisted with the identification of participants
- Took part in screening and obtaining consent
- Followed the computer exercises for individuals and demonstrated the programme
- Conducted assessments at participants' homes

Service benefits

- Reduced support needed for research by primary care
- Successfully assessed Aphasia & Stroke consequences
- Ability to streamline processes
- Increased cost effectiveness

Dissemination Bulletin.

Case Study 16

Using a picture booklet as a reasonable adjustment to improve epilepsy management for people with learning disabilities (WIELD 2)

Overview of study

- Mixed-methods intervention study, evaluating the use of a picture booklet – ‘Getting on with Epilepsy’ – as a tool for improving epilepsy management for people with learning difficulties, accompanied by interviews with carers and staff.

NCH&C staff involvement

- Attended training for intervention
- Identified relevant patients (n=5 + 1 carer) and obtained consent
- Nurses/doctors involved in patient’s care used the booklet with the patient in a 30-min audio and video recorded consultation.

Key impacts for patients

- Reinforced medication times and identified risks to patients
- Supported appropriate information sharing between clinic and home
- Allowed patients to relate to and understand their epilepsy/seizures and share that information with others close to them.
- For one patient who was a parent, the book could be used to support information sharing/ storytelling with their child.

Key impacts for service

- Resource has been incorporated in clinical setting and has informed updated policy guidelines.
- Epilepsy nurses who did not have a background in learning disability have learned to communicate at a more effective level; resource also shared with community LD nurses.
- Broader understanding of research, how this can be inclusive and support positive outcomes, and increased willingness to engage further.

10. Redeployment of Team to Support Norfolk and Waveney CCG’s COVID-19 Pandemic Response

In support the NWCCG response to the COVID-19 pandemic members of the Research Office were redeployed to the Incident Coordination Centre (ICC); the Care Provider Incident Room (CPIR); the Prescription Ordering Direct Service (POD) and Covid Protect.

10.1. Incident Coordination Centre (ICC)

A number of staff from the Research Office undertook shifts in the ICC to support the Norfolk and Waveney Pandemic response. Staff at all levels covered ICC shifts as both managers and loggists, and Clare Symms, Senior Manager - Research and Finance agreed to undertake the ICC Operational Lead role alongside her research role from end May 2020 to end October 2020. This role included:

- Production of twice weekly Situation Reports for Norfolk and Waveney

- Overseeing and managing the ICC inbox and guide
 - Troubleshooting and resolving issues as they arose and dealing with queries from Managers and Loggists
 - Developing and rolling out online training for new managers and loggists
 - Supporting the ICC runners
 - Analysis of activity
-

“Working in the ICC provided a unique opportunity to get a better understanding of the work of the CCG and to get to know, and work with individuals across the entirety of the organisation.

Although ICC was certainly challenging at times, testing my problem solving, organisational and decision making skills; working in the ICC gave me a sense that I was really helping to support the pandemic response, which was particularly important for me early on in the pandemic when much research activity had been paused.”

Clare Symms

10.2. The Care Provider Incident Room

The CPIR was set up in June 2020 to act as a central conduit for all Covid-19 queries and questions relating to Care Providers in Norfolk and Waveney. Emily Frost, Research and Evaluation Officer (Cancer Alliance) from the Research Development Team took on the role of the CPIR Coordinator role and was involved in managing the operating of the CPIR from June 2020 to October 2020. The role involved:

- Maintaining an accurate electronic log of all queries taken within the CPIR;
 - Tracking the progress of outstanding actions on behalf of the CPIR;
 - Escalating any element which is high impact, significant or needs raising for a wider resolution to the CPIR Operational Lead;
 - Keeping up to date with processes and procedures as set out in the CPIR guide.
-

“I enjoyed the fast pace and intensity of the role, which challenged me to become more confident about working independently in a decision-making role.

I also appreciated the opportunity to support the CCG and contribute to its response to the Covid - 19 pandemic, gaining valuable experience of working in an incident room.”

Emily Frost

10.3. Prescription Ordering Direct Service (POD)

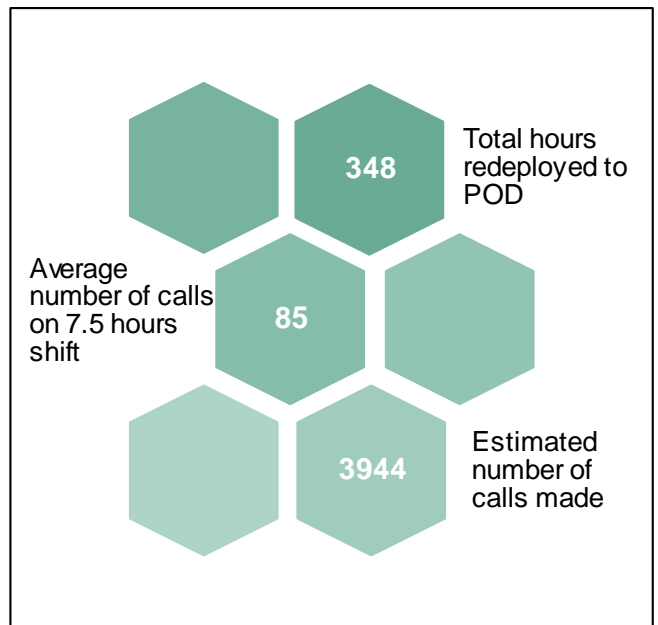
The NWCCG POD service, enabling patients to order their repeat prescription over the phone, had to rapidly increase capacity during the pandemic. Marie Fearn, Finance Officer from the Research Management Team volunteered to be redeployed to the POD team based in Beccles.

“It was an opportunity to work in an area that I would never have normally considered but it gave me valuable experience of dealing directly with patients.

I found the work to be both interesting and extremely challenging at times, but these were far outweighed by the calls with patients where I came away feeling that I had been able to make a real difference.

Many of the patients I spoke to were either elderly or vulnerable and for some I was the only person they had spoken to in weeks and working in POD enabled me to appreciate the real impact lockdown had on so many people.”

Marie Fearn

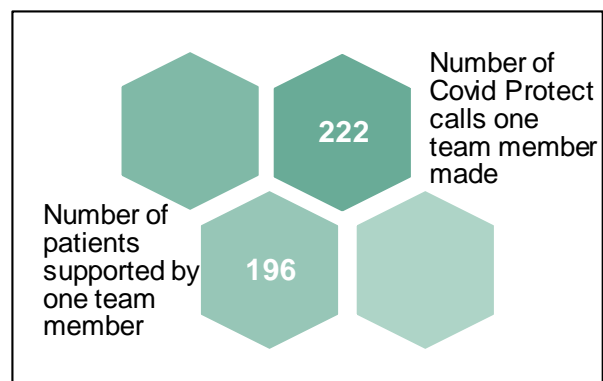


10.4. Covid Protect

Covid Protect aimed to proactively support people identified as highly vulnerable to COVID-19. The project was a huge success in supporting many of the most vulnerable people in our community. NWCCG contacted about 40,000 people, of whom 14,000 provided online updates for themselves and the Virtual Support Team was pivotal in reaching out to about 9,000 patients without access to the internet, many of whom were at the very highest risk in relation to Covid-19. From April to August 2020 a number of the Research Office undertook calls as part of the Virtual Support Team. The Research Office also undertook an evaluation of Covid Protect (see section 5.3).

“Having spent most of my research and NHS career based in a laboratory or office, it was particularly rewarding to have direct contact with and support patients through Covid Protect, and this was especially poignant during the first wave of the pandemic.”

Helen Sutherland



11. Financial sustainability

11.1. Research Office Income

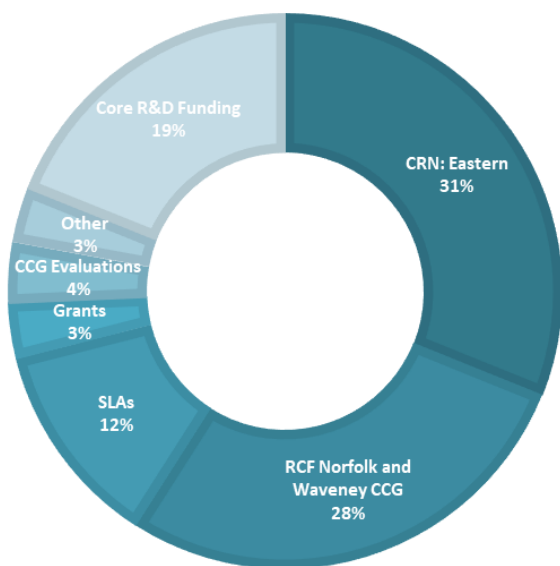
Income for the Office comes from a variety of sources. Agreements are in place for all funded activities, including:

- CRN Partnership Agreement (funding of 3.34 WTE posts, plus some ad hoc monies (e.g. to undertake the social care report – see section 7.4)

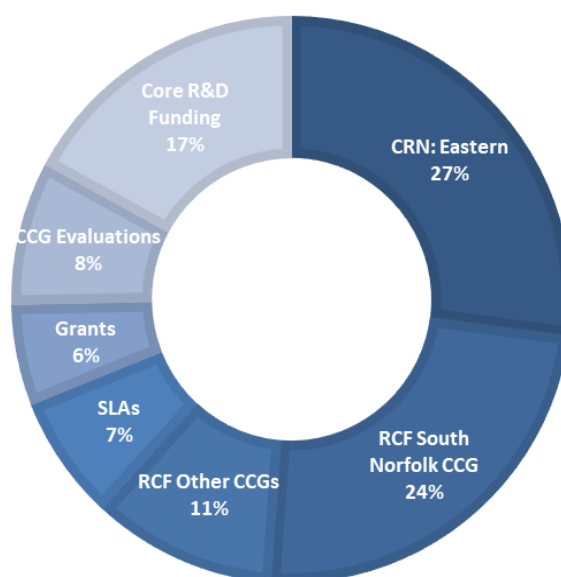
- NIHR Research Capability Funding (RCF) – see Section 11.2 below
- Grant funding including NIHR grants plus four PPIRes Project agreements
- Service Level Agreements with:
 - Norfolk Community Health and Care NHS Trust
 - East Coast Community Healthcare CIC
 - NHS Ipswich and East Suffolk CCG and NHS West Suffolk CCG
 - University of East Anglia (PPIRes activity only)
- CCG funding for specific service evaluations

The charts below show the split of the income sources.

MAIN INCOME SOURCES 2020/21



MAIN INCOME SOURCES 2019/20

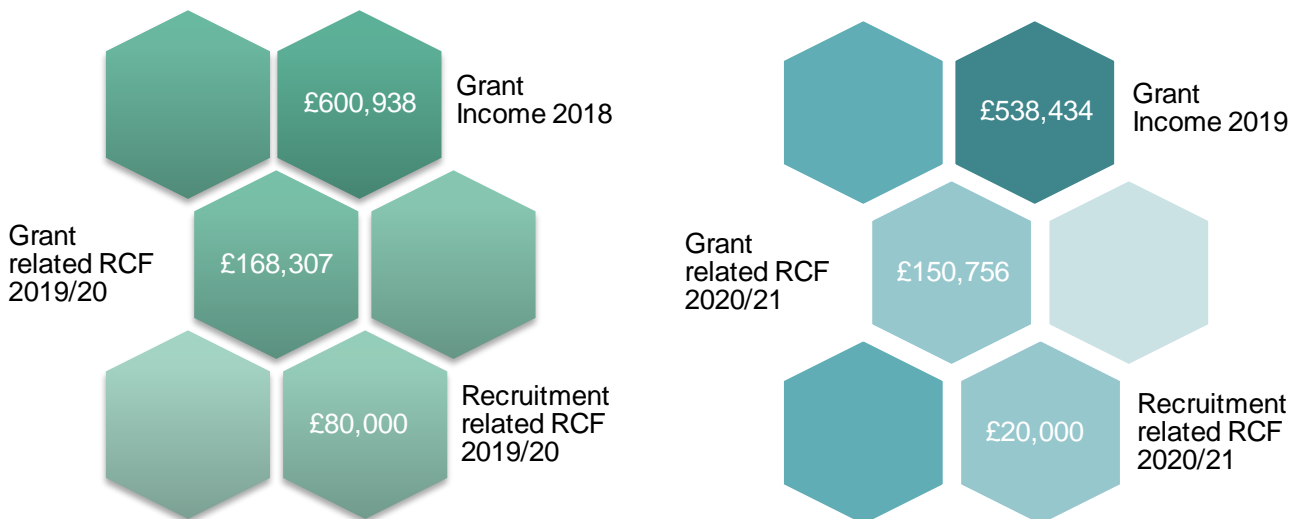


11.2. Research Capability Funding (RCF)

Research Capability Funding (RCF) is awarded to research active NHS organisations. RCF can be earned in two ways: either by an organisation being the contractor on NIHR funded research grants (which NHS South Norfolk CCG was on behalf of the Norfolk and Waveney CCGs until 31 March 2020) or by GP practices in a CCG recruiting 500 patients into NIHR Portfolio adopted studies.

For 2019/20 the Norfolk and Waveney CCGs received a total of £248,307. This comprised £168,307 of grant-related RCF received by NHS South Norfolk CCG, and the receipt of £20,000 recruitment-related RCF by each of the other four Norfolk and Waveney CCGs.

For 2020/2021, the RCF received was £150,756 of grant-related and £20,000 of recruitment-related RCF that NHS Norwich CCG had earned by recruiting more than 500 patients through primary care.



Each year, some RCF is used to support our academic partners in developing new research grant applications in areas of importance to the healthcare system. The funds are intended to fund the time of a Research Associate to develop the literature review that is the background for any grant application. Thus, the funds also support the retention of talented Research Associates who might otherwise leave the academic sphere, as most are on rolling short-term contracts.

Funds were awarded to UEA academics and for the first time, to an academic at the University of Suffolk (UoS). The broad areas of research development for which awards were made in 2019/20 and 2020/21 were:



12. National and Local Influence

12.1. National and Local Influence

Strategic engagement with relevant stakeholders and partners both locally and nationally is maintained through members of the senior team holding positions on local, regional and national groups. This work enables the team to maintain and local initiatives and continue to drive the development and delivery of research for the benefit of our patients.



12.2. UEA Health and Social Care Partners

This partnership is chaired by Professor Dylan Edwards, (UEA Pro-Vice Chancellor, Faculty of Medicine and Health Sciences) and led by Mark Hitchcock (Managing Director). It brings together NHS, social care and academic partners to enhance health and care research and innovation for Norfolk, Suffolk and North Essex.

This partnership champions the needs of its combined workforce and the local population it serves, aiming to bring better outcomes for both service users and the health and care professionals.

UEA Health and Social Care Partners (UEAHSCP) have combined resources to attract investment, and deliver the following ambitions:

- Radically increasing the level of research and innovation in the region’s health and care sector
- Shared and improved research infrastructure and inter-organisation clinical data access and analysis
- Mass engagement with both service users and healthcare professionals to improve their experience and identify areas for innovation
- Development of a truly mature innovation culture across partners that creates projects which achieve direct impact on service user care and
- Lead thinking on workforce development and innovation of healthcare professions

Supporting Mental Health of Children in Care

- LANTERN: This research group led by Dr Simon Hammond UEA and Honorary Professor at NSFT and Dr Jon Wilson , Director of Research, NSFT has CCG representation and focusses 3 priorities
- Better evidencing practice innovations
- Promoting Positive mental Health and mental health support
- Supporting better on line lives

Medicine Optimisation

- The group has identified three priorities for research to support the health and wellbeing of people in East Anglia - personalised medicine; use of prescribed opioids and deprescribing
- Representatives on group include Research Office, Norfolk & Waveney CCG GP Prescriber Lead and CSU Prescribers

Frailty

- Research to explore and understand frailty better and how using routine NHS data, health and social care service innovation and interventions may benefit people with frailty and their carers.

Partnership findings are already having transformative effects on regional, national and international conversations on health and social care. The collaborative research groups are the driving force behind delivering real change to service users in our region. The CCG has representatives on the Groups shown below:

During the pandemic, UEAHSCP partnership turned its focus to delivering practical support to partners and associates across the region and took the lead on the following projects:

- Producing 10,000 visors and thousands of litres of hand sanitiser
- Developing 3D printing ventilator parts
- Comfort bands for mask wearers for front line staff
- Disseminated public messages and call outs
- Sourced fit testing solution for front line organisation
- Provision of expert advice on medical ethics to COVID 19 data analysis
- Provided accommodation and car parking to essential workers.

NWCCG MEMBERSHIP

FRAILITY

Julian Brown

LANTERN - LOOKED AFTER CHILDREN'S MENTAL HEALTH

Anita Bagge
Victoria Stanley
Zoe Lewis

MEDICINES OPTIMISATION

Françoise Price
Judy Henwood
Michael Dennis

NUTRITION

Anna Johnson
Judy Henwood

PARENTAL & CHILDHOOD OBESITY EARLY PREVENTION

Claire Angell
Linda Hunter
Tracy Mclean

WORKFORCE SUSTAINABILITY

Evelyn Kelly



Over 2020/21 the partnership has focussed its efforts on young people's Mental Health, Healthy Ageing and Living with Long Term Conditions. The partnership continues to support its 16 research groups. Dr Mark Lim Interim Executive Director for Clinical Services and Clinical transformation represents Norfolk and Waveney CCG on the UEAHSCP Executive Board and Dr Tracy Shalom Associate Director of Research sits on the UEAHSCP Management Board.

12.3. CRN Partnership Group

Working with stakeholders through the CRN Partnership Group, CRN Eastern manages and distributes around £20 million per year to research active organisations in our region.

CRN Eastern is part of the NIHR and is the clinical research delivery arm of the NHS, set up to support research across all 16 Trusts, primary care organisations and any other qualified providers of NHS services. CRN: Eastern oversees the distribution of over £20m to

regional health organisation to support delivery of portfolio research.

Dr Helen Macdonald is the Chief Operating Officer for CRN Eastern and Dr Jeremy Turner and Dr Jesus Perez provide the clinical leadership.



The focus is to ensure that studies are carried out efficiently and support the Government's Strategy for UK Life Sciences by improving the environment for clinical research (including commercial research) in the NHS.

In 2019/20 and 2020/21 CRN Eastern provided £350K funding to the Research Office to support primary and community care research. A further £6 million approximately is given to Norfolk, Suffolk and North East Essex Trusts to deliver research. £2 million is spent on primary care across the eastern region.

Norfolk and Waveney CCG is part of the CRN Eastern Partnership group (represented by the Associate Director of Research) alongside representation from Cambridge and Peterborough CCG and all NHS trusts in the region.

During 2019 to 2021, Norfolk and Waveney CCG:

- Contributed to the development of the funding models being used by CRN Eastern to distribute research monies.
- Presented at the CRN cluster meeting on research management in primary care, measuring research impacts and understanding the new excess treatment costs model
- Chaired the Norfolk Research Vaccine Delivery Hub
- Took part in the Green Shoots Initiative (Section 8.4)
- Led a piece of work on research in Social Care (Section 7.4)

13. Looking Forward

As we move into 21/22, with the focus shifting from a pandemic response into business as usual and towards a Norfolk and Waveney Integrated Care System, we are looking to build on the ambitions delivered in our Strategy for Research and Evidence, and on the research successes and collaborations that have been delivered during the COVID-19 pandemic. Our core aims for 21/22 are:

Strategic	Drive the ambition to embed clinical research within the core function of the CCG and ICS for the benefit of staff, patients and the public, prioritising areas for integrated working
	Work with national, regional and local partners to influence policy and practice and to develop research capacity and capability in people and organisations.
	Robust business planning to support funding applications to CRN Eastern; NIHR and other relevant stakeholders.
	Work with UEA to integrate PPI at all stages of research so that research reflects the needs and priorities of our population.
	Work with communications to develop a communication plan and promote and disseminate research and evidence throughout the CCG and ICS.
Research Development and Evaluation	Work with NHS and HEI partners to develop and deliver research that addresses key priority areas for the CCG and ICS.
	Develop and maintain systems for development of CCG hosted Research Grants
	Deliver business case for the Evidence and Evaluation Hub to support the commissioning of best value effective patient care for our population
	Support commissioners to embed evaluations within routine service developments to ensure initiatives benefit our population and provide evidence of what works and what does not work
	Work with SLA, academic partners and other relevant stakeholders to develop research capacity and capability in people and organisations.
Research Management Finance and PPI	Collaborate with Primary Care Networks (PCNs), Public Health, and social care to ensure research follows patient need, particularly those in deprived communities.
	With CRN Eastern and our SLA partners, pilot mechanisms for collection of research impacts from patients and staff involved in research.
	Continue work with CRN Eastern to expand research into social care maximising opportunities for participation.
	Develop and maintain systems for overview and management of hosted studies
	With CRN Eastern and NCH&C maximise research delivery in primary and community care.
	Find ways to incorporate PPI in our communications and wider research related activities.

UK Research has played a central role in the management and treatment of COVID. The UK government has just published “Best Research For Best Health” research strategy 2021 which articulates a renewed vision to make the UK a global leader in research and the economic benefits that it brings and recognises the speed of change that has been necessitated by COVID. We will be reviewing our Norfolk and Waveney Research and Evidence strategy to ensure it reflects this UK direction.

Thank you for your interest in research activity across the Norfolk and Suffolk Health systems, if you would like to know more, please visit our website at <https://nspccro.nihr.ac.uk/> or follow us on Twitter @NHS_NSResearch.

Glossary of Terms

AHSN / EAHSN – Academic Health Science Network / Eastern AHSN – organisations whereby the NHS and universities can work with industry, with the goal of improving patient and population health outcomes by translating research into practice.

ARC EoE – Applied Research Collaboration East of England - brings together health and social care professionals, researchers, and the communities they serve, to ensure future research meets a wide range of health and social care needs.

CRN Eastern – NIHR Clinical Research Network for the Eastern region, providing researchers with practical support they need to make clinical studies happen across the NHS– supporting the set up and delivery of studies through the funding of some Research Office management and delivery team staff costs and payment of research support costs. CRN Eastern replaced the previous research networks in the East of England on 1 April 2014.

CLAHRC / CLAHRC EoE – Collaborations for Leadership in Applied Health Research and Care / CLAHRC East of England bring together a collaboration of the local providers of NHS services and NHS commissioners, universities, other relevant local organisations and the relevant AHSN.

CPIR - Care Provider Incident Room

CPRD – Clinical Practice Research Datalink. A not-for-profit research service, jointly funded by the NHS NIHR and the Medicines and Healthcare products Regulatory Agency (MHRA), which collects and manages a large dataset of anonymised healthcare records from UK GP practices for use in public health research.

DHSC – Department of Health and Social Care

ECCH – East Coast Community Healthcare CIC

EDGE – Web-based database used for the management and monitoring of research studies by R&D Offices and the CRN.

ETC – The costs that arise as a result of the difference between the cost of standard treatment and the cost of treatment within a research study in non-commercial research projects.

GCP – Good Clinical Practice - an international ethical and scientific quality standard for designing, conducting, recording, and reporting trials that involve the participation of human subjects.

GDPR – EU General Data Protection Regulation

HEI – Higher Education Institute

HRA – The Health Research Authority was established in December 2011 to protect and promote the interests of patients and the public in health research, and to streamline the

regulation of research. In 2015/16 HRA Approval was introduced to centralize the process of approval of research in the NHS.

ICC - Incident Coordination Centre

National Portfolio – Studies on the national portfolio are those which are deemed of national importance to the NHS. They can be non-commercial (project needs to be awarded a grant through a funding body which is open to national competition and applications are peer-reviewed) or commercial (need to have a valid research question with a possible future benefit for patients as its objective). Portfolio studies receive CRN support not available to non-portfolio studies such as access to CRN Research Nurses and support funding.

NCH&C – Norfolk Community Health and Care NHS Trust

NIHR – National Institute for Health Research – organisation which is aiming to maintain a health research system in which the NHS supports leading edge health research, focused on the needs of patients and the public.

NUHFT – Norfolk and Norwich University Hospitals NHS Foundation Trust

PPIRes – Public and Patient Involvement in Research – a patient group run by the office which provides researchers with the facility to access patient and public involvement.

Primary Care Network (PCN) - GP practices are working together with community, mental health, social care, pharmacy, hospital and voluntary services in their local areas in groups of practices known as primary care networks (PCNs)

Principal Investigator (PI) - An individual responsible for the conduct of the research at a research site. There should be one PI for each research site.

RCF – Research Capability Funding – DHSC funds allocated to research-active NHS organisations to maintain capability and capacity for research. Funding is awarded in proportion to the total amount of other NIHR income received by that organisation (grant-related RCF), or on recruitment of more than 500 participants to NIHR research in the previous reporting year (1st October- 30th September; recruitment-related RCF). Organisations receive either grant-related or recruitment-related RCF, not both.

RSI – Research Site Initiative Scheme – CRN scheme whereby practices receive funding to support research infrastructure and delivery on portfolio studies. The scheme is run annually, and funding is tied to performance.

UEA – University of East Anglia

UEA HSCP – UEA Health and Social Care Partnership - the partnership is a group of organisations who want to work together to improve health and social care for our region, including academics, health and social care professionals, service user representatives and associates.

Appendix 1: Research Office COVID-19 Bulletins

THE SIREN Study

Date of Bulletin	Study Findings
21/01/2021	<p>The first report from this vital study to monitor post-COVID-infection immunity highlights that past COVID-19 infection provides some immunity for at least 5 months, but people may still carry and transmit the virus. Between June and November, researchers detected 44 potential reinfections out of 6,614 participants (healthcare workers across 102 NHS Trusts) who had tested positive for antibodies. This represents an 83% rate of protection from reinfection. PHE cautions that although those with antibodies have some protection from becoming ill with COVID-19 themselves, early evidence from the next stage of the study suggests that some of these individuals carry high levels of virus and could continue to transmit the virus to others. Read the press release from PHE here.</p> <p>https://www.gov.uk/government/news/past-covid-19-infection-provides-some-immunity-but-people-may-still-carry-and-transmit-virus</p>

The PRINCIPLE Trial study

Date of Bulletin	Study Findings
25/01/2021	<p>The PRINCIPLE study interim data analysis found no benefit of the commonly used antibiotics, Azithromycin and Doxycycline, on reduction of recovery time for patients in the community. Azithromycin and doxycycline were investigated as separate treatments in the PRINCIPLE trial to see if they help people with early stage COVID-19 to recover more quickly at home or prevent the need for hospital admission. Both drugs are being used by some doctors in the hope of treating COVID-19 in the early stages of the disease. Following interim analyses of data from both the azithromycin and doxycycline arms of the study, the independent Trial Steering Committee concluded that there is no beneficial effect in patients aged over 50 who are treated with either antibiotic at home in the early stages of COVID-19. Read more here. The trial is currently evaluating inhaled budesonide (a commonly used inhaled corticosteroid) vs usual care.</p>
18/03/2021	<p>The most recent findings from the azithromycin treatment arm of the trial, published in The Lancet showed no justification for the routine use of azithromycin for reducing time to recovery or risk of hospitalisation for people with suspected COVID-19 in the community. Researchers conclude that 'these findings have important antibiotic stewardship implications during this pandemic, as inappropriate use of antibiotics leads to increased antimicrobial resistance, and there is evidence that azithromycin use increased during the pandemic in the UK'. The trial is currently evaluating inhaled budesonide (a commonly used inhaled corticosteroid) and colchicine (a commonly used anti-inflammatory). PRINCIPLE is recruiting participants through their website and through GP practices across the UK and is also open to those who have received a COVID-19 vaccine.</p>

08/04/2021	Favipiravir will be investigated within the PRINCIPLE trial as another possible treatment for COVID-19 in people recovering at home and in other non-hospital settings. Favipiravir is an antiviral drug that has been licenced in Japan since 2014 to treat influenza. It works by inhibiting a viral enzyme called RNA polymerase, preventing viral replication within human cells. This viral enzyme is common to several viruses, including SARS-CoV-2, which causes COVID-19. The drug has shown positive results against SARS-CoV-2 in laboratory and animal studies, with small pilot studies in humans demonstrating some benefit in reducing symptoms and the duration of illness.
12/04/2021	The PRINCIPLE Trial reports that inhaled budesonide, a common, inexpensive drug used for treatment of asthma shortens recovery times in COVID-19 patients aged over 50 who are treated at home and in other community settings. The results of the interim analysis of data from 1,779 participants showed the estimated median time to self-reported recovery for inhaled budesonide was 3.011 days shorter compared to usual care. 32% of those taking inhaled budesonide, compared to 22% in the usual care group, recovered within the first 14 days since being randomised into the trial and subsequently have remained well until 28 days. Participants in the budesonide group also reported greater wellbeing after two weeks. A pre-print of the research paper is available here . The drug is the first COVID-19 treatment for use in the UK within a community setting and is now available on a case-by-case basis.

The Virus Watch

Date of Bulletin	Study Findings
01/04/2021	The Virus Watch further findings published on the Virus Watch website include information on changes in attitude to vaccine uptake. 86% of people who said they were hesitant or unlikely to agree to have a vaccine when interviewed in December 2020 have now had one or intend to have one (as of February 2021). The findings also show that those in "overcrowded households" had twice the risk of SARS-CoV-2 infection compared to "under-occupied" (e.g. more rooms than occupiers) households.

The RECOVERY Trial

Date of Bulletin	Study Findings
11/01/2021	The latest results from the RECOVERY trial showed that Tocilizumab, an anti-inflammatory rheumatoid arthritis treatment, reduces deaths in patients hospitalised with COVID-19, reduces the length of hospital admission, and the risk of patients requiring mechanical ventilation. Read more here . The RECOVERY is the second NIHR-supported study to demonstrate the effectiveness of tocilizumab as a treatment for COVID-19 patients, after results from the REMAP-CAP study last month showed that tocilizumab and a second similar drug called sarilumab have a significant impact on survival and can reduce the relative risk of death for critically ill patients in intensive care.

NOVAVAX Vaccine study

Date of Bulletin	Study Findings
29/01/2021	Novavax vaccine proves to be 89.3% effective . As you would have heard from the media news, the Novavax vaccine COVID-19 trial interim analysis showed positive results for the vaccine to be 89.3% effective at preventing COVID-19, including effectiveness against the new variants. The Novavax study is the largest COVID-19 vaccine trial undertaken in the UK, which recruited over 15,000 participants from 35

	research UK sites in just over two months. Huge thanks go to staff at the Norfolk and Norwich, East Suffolk and North Essex NHS Foundation Trusts and all other teams in the Eastern region (including Primary Care teams) in supporting the trial locally and their contribution to the success of getting the fourth vaccine to be hopefully soon approved by the regulators.
04/02/2021	NOVAVAX Confirms High Levels of Efficacy Against Original and Variant COVID-19 Strains in United Kingdom and South Africa Trials Figures from the final data analysis for the Novavax NVX-CoV2373 vaccine trial showed 96.4% efficacy against the original virus strain and 86.3% against the B.1.1.7/501Y.V1 variant. The primary efficacy endpoint demonstrated an overall vaccine efficacy of 89.7%. 106 COVID cases were observed, with 10 in the vaccine group and 96 in the placebo group. NVX-CoV2373 was effective against severe disease: five severe cases were observed in the study, and all occurred in the placebo group. Four of the five severe cases were attributed to the B.1.1.7/501Y.V1 variant. Fourteen days after dose 1, vaccine efficacy was 83.4%.

REMAP-CAP clinical trial

Date of Bulletin	Study Findings
07/01/2021	Results from the REMAP-CAP clinical trial show the drugs tocilizumab and sarilumab reduced the risk of death by 24% for clinically ill patients and time spent in intensive care by up to 10 days. Updated guidance has been issued by the government and the NHS to trusts across the UK, encouraging them to use tocilizumab in treatment of COVID-19 patients who are admitted to intensive care units. Read the press release from the DHSC here .

National COVID-19 Infection Survey

Date of Bulletin	Study Findings
26/04/2021	The latest findings from the National COVID-19 Infection Survey, as reported on the national media headlines, show that a single dose of either the Oxford-AstraZeneca or Pfizer-BioNTech vaccines leads to a substantial drop in the spread of COVID-19. A study of test results taken from more than 370,000 participants showed that in the three weeks after the first dose of either vaccine, rates of new infections had fallen by 65%. Symptomatic infections were down by 74% while infections without symptoms decreased 57%. A second study compared how antibody levels changed after one dose of either vaccine, or two doses of the Pfizer-BioNTech vaccine. Among all groups who had not contracted the virus, a single vaccine dose boosted levels of protection, although fewer antibodies were present in those over 60. However, older people had a significant boost in their antibody levels on receipt of a second jab of the Pfizer BioNTech vaccine, which led to high levels of protection for all groups. Read more here and you can access the pre-print papers for the two studies here .

Other findings

Date of Bulletin	Study Findings
24/02/2021	Single dose of Pfizer BioNTech vaccine reduces asymptomatic infections and potential for SARS-CoV-2 transmission - preliminary findings from Addenbrooke's Hospital in Cambridge suggests that a single dose of the Pfizer BioNTech vaccine can reduce by 75% the number of asymptomatic SARS-CoV2 infections. This implies that the vaccine could significantly reduce the risk of transmission of the virus from people who are asymptomatic, as well as protecting others from getting ill.

01/03/2021	'A silent epidemic of grief': a survey of bereavement care provision in the UK and Ireland during the COVID-19 pandemic published in BMJ Open. The first major study of pandemic-related changes in bereavement care, from the University of Cambridge, has found that the switch to remote working has helped some services to reach out, but many feel they do not have capacity to meet people's needs.
05/03/2021	Coping with remote consultations to reduce the risk of Covid-19. The Rapid COVID-19 Intelligence to Improve Primary Care Response (RAPCI) study has found that the rapid shift to remote GP consulting was successful and maintained a focus on vulnerable patients during the pandemic. Concerns were raised by GPs, however, that remote consulting may have risks and would need adjusting after the pandemic. See press release and the RAPCI Study infographic. The paper: 'The implementation of remote consulting in UK primary care following the COVID-19 pandemic: a mixed methods longitudinal study' by Mairead Murphy et al. Published in British Journal of General Practice.

Appendix 2: Patient and Public Involvement in Norfolk and Waveney CCG hosted NIHR Grants

Study	Details of involvement	Factors that contributed to the success of PPI	The challenges of involving patients and the public	What difference do you think patient and public involvement in your research has made to your research?
CADDY (Completed)	<ul style="list-style-type: none"> • Prioritising the research question(s), • Developing the application for funding, • Design of the research, • Management of the research, • Analysing and interpreting the data generated by the research • Writing up of the research • Implementing research findings or recommendations, • Disseminating of research findings • Other - PPI advisory group (PPIAG) 	<ul style="list-style-type: none"> • Involving people throughout the research cycle, • Effective building of relationships and trust, • Close and effective collaborative ways of working, • Good information, training and support, • Building on existing relationships, • Sufficient resources to support effective involvement, • Enthusiasm and commitment of all involved 	No challenges	<p>PPI is under-developed in epidemiologic research, and many volunteers and researchers are unsure as to the nature and value that this interaction will bring in the absence of a 'recruitment', or 'participant experience' aspect to the research. Nevertheless, CADDY has benefited enormously from this interaction, often in unexpected ways owing the diversity of the personal and professional expertise that was brought into the study through the PPI group. As PPI members are independent of the research team, they provide a level of oversight to an ongoing research study that may not otherwise be present depending on the specific requirements for composition of the study steering committee. There have been some challenges, particularly around PPI members feeling initially nervous about contributing to discussions regarding work that is mainly statistical in nature, and at the outset in some PPIAG members not understanding that we are largely unable to alter the nature of the data available to us or the experience of the participants of the wider CFAS II study. However, these challenges were overcome, and as the public become more aware of 'big data' research and PPI groups participate more often in epidemiological studies we believe that the value of PPI in epidemiology will be better understood.</p>

Study	Details of involvement	Factors that contributed to the success of PPI	The challenges of involving patients and the public	What difference do you think patient and public involvement in your research has made to your research?
Lab2 (Completed)	<ul style="list-style-type: none"> • Prioritising the research question(s), • Developing the application for funding, • Design of the research, • Management of the research, • Undertaking the research, • Analysing and interpreting the data generated by the research 	<ul style="list-style-type: none"> • Involving people throughout the research cycle, • Effective building of relationships and trust, • Close and effective collaborative ways of working, • Good information, training and support, • Building on existing relationships, • Sufficient resources to support effective involvement, • Enthusiasm and commitment of all involved 	Nature of condition can affect ability to be involved	Gives us confidence in the relevance of the project to those it ultimately seeks to support (informal carers of patients with breathlessness) and ensures appropriate recruitment materials and study outputs (planned website content) for those carers.

Study	Details of involvement	Factors that contributed to the success of PPI	The challenges of involving patients and the public	What difference do you think patient and public involvement in your research has made to your research?
CHIPPS (Completed)	<ul style="list-style-type: none"> • Prioritising the research question(s), • Developing the application for funding, • Design of the research, • Management of the research, • Undertaking the research, • Analysing and interpreting the data generated by the research, • Writing up of the research, • Dissemination of research findings • Implementing research findings or recommendations 	<ul style="list-style-type: none"> • Involving people throughout the research cycle, • Effective building of relationships and trust, • Close and effective collaborative ways of working, • Good information, training and support, • Building on existing relationships, • Sufficient resources to support effective involvement, • Enthusiasm and commitment of all involved 	<p>Finding the 'right' people to involve, Concerns about how 'representative' views are</p>	<p>It has made us focus on the patient and their perspective e.g. we have just reviewed our plans for process evaluation and dissemination with our PPI members and identified firstly that we hadn't considered the patient and carer voice sufficiently within our process evaluation plans / logic model and secondly that there are lots of opportunities for the PPI members to make our dissemination / implementation process more effective.</p>

Study	Details of involvement	Factors that contributed to the success of PPI	The challenges of involving patients and the public	What difference do you think patient and public involvement in your research has made to your research?
QUITSENSE (Ongoing)	<ul style="list-style-type: none"> • Prioritising the research question(s), • Developing the application for funding, • Design of the research, • Undertaking the research, • Disseminating of research findings • Other - Input and advice on app development and appearance, study and app logo choice, recruitment approach 	<ul style="list-style-type: none"> • Involving people throughout the research cycle, • Effective building of relationships and trust, • Close and effective collaborative ways of working, • Building on existing relationships, • Enough resources to support effective involvement, • Enthusiasm and commitment of all involved 	Maintaining relationships and continuity over time	<p>PPI input has been very valuable so far on this project. Prior to submission of the grant application, a PPI panel of four members of the public provided very useful steerage on what a feasibility trial should provide in terms of 'answers' (for example this included adding in a firmer research question around estimating the impact of the app). This helped reassure the team that we were on the right lines with producing meaningful questions, provided useful suggestions that helped improve the proposed project and helped established relationships for continued partnership. Since funding was acquired we have had several PPI meetings and additional feedback from the panel on research team generated queries, questions and enquiries. Additional value to the project has been in input and advice on app development and appearance, study and app logo choice and particularly recruitment approach (adverts images, advert wording etc.) and the participant journey. We hope to continue to work together positively to ensure the project is grounded, is delivered appropriately and provides valuable insight.</p>

Study	Details of involvement	Factors that contributed to the success of PPI	The challenges of involving patients and the public	What difference do you think patient and public involvement in your research has made to your research?
PEP-TALK (Ongoing)	<ul style="list-style-type: none"> • Prioritising the research question(s), • Developing the application for funding, • Design of the research, • Management of the Research 	<ul style="list-style-type: none"> • Involving people throughout the research cycle, • Effective building of relationships and trust, • Close and effective collaborative ways of working, • Good information, training and support, • Building on existing relationships, • Sufficient resources to support effective involvement, • Enthusiasm and commitment of all involved 	Concerns about how 'representative' views are	It has provided a vital, patient-link to the design and conduct of the trial (to-date). Their role in patient-facing document review and approaches to assist in recruitment and data collection have been particularly valuable to-date. We are excited on how this will develop as the project progresses.
BabyBreathe (Ongoing)	<ul style="list-style-type: none"> • Prioritising the research question(s), • Developing the application for funding, • Design of the research, • Management of the research 	<ul style="list-style-type: none"> • Involving people throughout the research cycle, • Effective building of relationships and trust • Close and effective collaborative ways of working, • Good information, training and support, • Building on existing relationships, • Sufficient resources to support effective involvement, • Enthusiasm and commitment of all involved 	<ul style="list-style-type: none"> • Maintaining relationships and continuity over time, • Nature of condition can affect ability to be involved, • Small number of people or appropriate people are difficult to engage, • Finding the 'right' people to involve 	Essential throughout

Appendix 3: Outputs from NHS Norfolk and Waveney CCG hosted NIHR Grants

Ongoing Studies

Feasibility randomised controlled trial of a smoking cessation smartphone app that delivers 'context aware' behavioural support in real time

Prof Felix Naughton, University of East Anglia

Study Details

Start Date	01/06/2019	Funding Stream	NIHR Research For Patient Benefit
End Date	31/05/2021 (extended to 31/01//2022)	Funding	£356,131

Publications

Publication Type	Details	URL
Journal Article	Naughton F, Brown C, High J, et al Randomised controlled trial of a just-in-time adaptive intervention (JITAI) smoking cessation smartphone app: the Quit Sense feasibility trial protocol BMJ Open 2021;11:e048204. doi: 10.1136/bmjopen-2020-048204	https://bmjopen.bmj.com/content/11/4/e048204

Engagement Activity

Dissemination	Results of Activity	URL
University of Bristol invited talk	Departmental seminar for a part psychology and part computer science audience - Presentation focused on how smartphone sensing can be used to tailor smoking cessation support and other Just-In-Time Adaptive Interventions (JITAI), drawing largely on Quit Sense and introducing the feasibility trial.	

Dissemination	Results of Activity	URL
Invited plenary talk at Sangath Addiction conference in Goa	Invited plenary talk at an Addiction and Gender based violence conference organised by the NGO Sangath, based in Goa, India. The talk had a significant focus on Quit Sense and the trial and generated interest and drew many questions, and contributed to a meeting the next day discussing an mHealth project that Naughton (PI) is involved in.	https://www.eventbrite.com/e/symposium-on-innovating-care-for-addictions-and-gender-based-violence-registration-83540867985#
Invited talk at Manchester Metropolitan University on ultra tailored interventions	Talk at departmental seminar at Manchester Metropolitan University, within computer sciences but also including psychology academics. Focus of talk was on ultra tailored interventions and used Quit Sense (and trial) as an example of how such approaches could be used to tailor behaviour change interventions.	
Poster presentation at Norwich Science Festival	Poster presentation of Quit Sense and feasibility trial as part of a stand on smoking cessation at the Norwich Science Festival 2019. Lots of discussions with members of the public on our ongoing projects including Quit Sense.	https://norwichsciencefestival.co.uk/
Presentation at the Norwich Institute for Health Ageing symposium	Online presentation as part of larger symposium focused on outlining the trial, including novelty of the design and intervention and progress to date. A brief Q and A after the online presentation.	https://healthyageingnorwich.com/2020/11/18/norwich-institute-of-healthy-ageing-symposium/
Poster presentation at the Centre for Behaviour Change annual conference	Poster presentation outlining trial protocol as part of an online conference - included a brief pre-recorded talk that was available on the conference platform and an online Q and A session.	https://www.ucl.ac.uk/behaviour-change/events/cbc-online-conference-2020

Software / Technical

Details	Description	Type	Url
QUIT Sense App	Quit Sense app was refined and optimised as part of the early stages of this project. The app provides context aware smoking cessation support when smokers are likely to be experiencing cravings to smoke as a result of triggers from their moment to moment environment. Released on Google Play store as a research/invite only app currently.	Software	https://play.google.com/store/apps/details?id=uk.ac.cam.quitsense&hl=en_GB

A behaviour change physiotherapy intervention to increase physical activity following hip and knee replacement: a pragmatic randomised controlled trial (PEP-TALK)

Dr Toby Smith, University of East Anglia

Study Details

Start Date	01/08/2018	Funding Stream	NIHR Research for Patient Benefit
End Date	21/12/2021	Funding	£350k

Publications

Publication Type	Details	URL	Reference
Journal Article	Smith TO, Parsons S, Fordham B on behalf of the PEP-TALK Trial Collaborators, et al. Behaviour change physiotherapy intervention to increase physical activity following hip and knee replacement (PEP-TALK): study protocol for a pragmatic randomised controlled trial. BMJ Open 2020;10:e035014. doi: 10.1136/bmjopen-2019-035014	http://europepmc.org/abstract/MED/32690503	PMC7371148

BabyBreathe Trial (A randomised controlled trial of a complex intervention to prevent return to smoking postpartum)

Dr Caitlin Notley, University of East Anglia

Study Details

Start Date	01/10/2020	Funding Stream	NIHR Public Health Research Programme
End Date	31/12/2023	Funding	£1.5m

Influence on Policy

Type of Influence	Influence	Impact
Influenced training of practitioners or researchers	ASH smoking in pregnancy factsheet	Improvements in public well-being: quality of life or morbidity or survival, Improved educational and skill level of workforce, Effective solutions to societal problems
Participation in a national consultation	SPECTRUM smokefree 2030 consultation meetings	No impact yet

Engagement Activity

Dissemination	Results of Activity	Impact
Protocol for a randomized controlled trial of an intervention to prevent return to smoking postpartum	Society for Research on Nicotine and Tobacco (Virtual conference) oral talk and panel Q&A session	
BabyBreathe trial: A randomised controlled trial of a complex intervention to prevent return to smoking postpartum	Conference presentation at the Norwich Cancer Research Network annual symposium	
Incentives and relapse prevention	Presentation to APPG on Smoking and Health and APPG on Baby Loss joint meeting: Getting back on track: delivering a smokefree start for every child	

Completed Studies

Care Homes Independent Pharmacist Prescribing Service (CHIPPS): Development and delivery of a cluster randomised controlled trial to determine both its effectiveness and cost-effectiveness

Prof David Wright, University of East Anglia

Study Details

Start Date	01/05/2015	Funding Stream	NIHR Programme Grants for Applied Research
End Date	30/04/2020 (extended to 2/11/2021)	Funding	£1,985,354

Publications

Publication Type	Details	URL	Reference
Journal Article / Conference Proceeding Abstract	Bond CM. et al. GP views on the potential role for pharmacist independent prescribers within care homes: Care Homes Independent Pharmacist Prescribing Study (CHIPPS): 'There has to be something in it for me'. Int J Pharm Prac. 2016 24 (S2), 6	http://onlinelibrary.wiley.com/doi/10.1111/ijpp.2016.24.issue-S2/issuetoc	
Conference Proceeding Abstract	Wright D. et al. Development of a training plan for pharmacists to assume responsibility for medicines management in care homes: Results from a rapid review of the literature. Int J Pharm Prac. 2016 24 (S3), 60-61	http://onlinelibrary.wiley.com/doi/10.1111/ijpp.2016.24.issue-S3/issuetoc	
Conference Proceeding Abstract	Millar A. et al. Development of a core outcome set (COS) for studies relating to prescribing in care homes: The Care Homes Independent Pharmacist Prescriber Study (CHIPPS). Int J Pharm Prac. 2016 24 (S3), 17	http://onlinelibrary.wiley.com/doi/10.1111/ijpp.2016.24.issue-S3/issuetoc	

Publication Type	Details	URL	Reference
Journal Article	Millar A. et al 2017. Development of a core outcome set (COS) for studies relating to prescribing in care homes: The Care Homes Independent Pharmacist Prescriber Study (CHIPPS). <i>Trials</i> 2017; 18(1), 175	http://europepmc.org/abstract/MED/28403876	PMID: 28403876 PMCID: 5389003
Journal Article	Inch J. et al. The Care Home Independent Prescribing Pharmacist Study (CHIPPS)-a non-randomised feasibility study of independent pharmacist prescribing in care homes. <i>Pilot and feasibility studies</i> . 2019 5, 89	http://europepmc.org/abstract/MED/31338204	PMC625047
Journal Article	Wright DJ. Et al. Systematic review and narrative synthesis of pharmacist provided medicines optimisation services in care homes for older people to inform the development of a generic training or accreditation process. <i>The International journal of pharmacy practice</i> . 28(3), 207-209, 6. 2020	http://europepmc.org/abstract/MED/31713918	PMC7317947
Journal Article	Bond CM. et al. Protocol for a cluster randomised controlled trial to determine the effectiveness and cost-effectiveness of independent pharmacist prescribing in care homes: the CHIPPS study. <i>Trials</i> . 21(1), 103, 1 2020.	http://europepmc.org/abstract/MED/31964398	PMC6975047
Journal Article	Bond CM et al. Protocol for the process evaluation of a cluster randomised controlled trial to determine the effectiveness and cost-effectiveness of independent pharmacist prescribing in care home: the CHIPPS study. <i>Trials</i> . 21(1), 439, 5 2020	http://europepmc.org/abstract/MED/32471514	PMC7257128

Publication Type	Details	URL	Reference
Journal Article	Lane K. et al. Everyone needs to understand each other's systems: Stakeholder views on the acceptability and viability of a Pharmacist Independent Prescriber role in care homes for older people in the UK. Health & social care in the community. 28(5), 1479-148, 9 2020	http://europepmc.org/abstract/MED/32124516	PMC7496840

Influence on Policy

Type of Influence	Influence	Impact
Influenced training of practitioners or researchers	Competency Framework use in national training scheme for care home pharmacists (2018, UK wide)	The evidence based framework and methodology we developed within CHIPPS work package four was used to inform the training plan for 240 FTE care home pharmacist and pharmacy technician posts which have been released across England in 2018

Engagement Activity

Dissemination	Results of Activity	Impact
Key note speaker at Primary Care Pharmacist Association (Care Homes) symposium 2018	45 minute lecturer on CHIPPS and feasibility study outcomes	
Research lecture to Royal Pharmaceutical Society National Conference 2017	Lecture on Care Homes Independent Pharmacist Prescribing Study (CHIPPS): Early Experiences	
Key note lecture at Primary Care Pharmacy Association (Care Homes) conference 2017	30 minute lecture on early phases of CHIPPS work	
British Society of Gerontology small events grant funded: Event title: Can research make a difference in your care home? 2018	CHIPPS Provided a breakout workshop which involved learning about the role of the pharmacist in care homes. considering the process of medication review and supporting people with dysphagia	

Development, refinement, and acceptability of an educational intervention for informal carers of patients with breathlessness in advanced disease (Learning about Breathlessness Study 2: LaB2)

Morag Farquhar, University of East Anglia

Study Details

Start Date	01/08/2018	Funding Stream	NIHR Research For Patient Benefit
End Date	01/12/2019 (extended to 3/8/2021)	Funding	£149,622

Publications

Publication Type	Details	URL	Reference
* Conference Proceeding Abstract	Barnes S, Ewing G, Farquhar M. What carers of people living with breathlessness want to learn about 'what to expect in the future' (HUKNC 2019 abstract). BMJ Supportive & Palliative Care 2019. 9(4).	https://spcare.bmj.com/content/9/Suppl_4/A39.3	
* Conference Proceeding Abstract	Barnes S, Ewing G, Farquhar M. What carers of people living with breathlessness want to learn about 'what to expect in the future' (Marie Curie 2019 abstract). BMJ Supportive & Palliative Care 2019. 9(3).	https://spcare.bmj.com/content/bmjspcare/9/Suppl_3/A8.3.full.pdf	
* Conference Proceeding Abstract	Development and piloting an educational intervention for informal carers of patients with breathlessness in advanced disease (EAPC Abstract 2020). Palliat Med 2020;34(S1):125.	https://journals.sagepub.com/doi/full/10.1177/0269216320958098	

Influence on Policy

Type of Influence	Influence	Impact
Influenced training of practitioners or researchers	Evidence from LaB programme: <ul style="list-style-type: none"> informed revision of pulmonary rehabilitation provision at Royal Brompton & Harefield NHS Foundation Trust to better meet the needs of carers was used by British Lung Foundation when reviewing their information for carers 	Not known
	Prepared clinician guidance on supporting informal carers during COVID-19 (Farquhar, Ewing & Grande) - used by RCGP, BTS, Pennine Acute Hospitals NHS Trust, UEA etc. Co-produced COVID-19 resource to support people living with pre-existing breathlessness in managing their breathlessness at home during the outbreak, with colleagues from national NIHR ARC Palliative & End of Life Care group	Not known
	LaB2's "Supporting Someone with Breathlessness" website used as an educational tool for UEA physiotherapy students	Not known
Citation in other policy documents	Link to Lab2 "Supporting someone with Breathlessness" website added to: <ul style="list-style-type: none"> Queens' Nursing Institute (QNI) Coronavirus Information Centre Respiratory Futures website Royal College of General Practitioners' website British Lung Foundation website Primary Care Respiratory Society website International Primary Care Respiratory Group (IPCRG) website as a practitioner and a Carer / Public Resource 	Not known

Further Funding

Funding Body	Details
Online Acceptance and Commitment Therapy for family carers of people with dementia: A feasibility study of a new mode of delivery (iACT4CARERS)	Research grant (including intramural programme) – NIHR – 2 year - £232,622

Intellectual Property

Name	Details	Protection	URL
LaB2's "Supporting Someone with Breathlessness" website	The key output of the LaB2 study is the evidence-based website "Supporting Someone with Breathlessness": https://supporting-breathlessness.org.uk/ . Those wishing to adapt material from the website can do so under licence.	Trade Mark	https://supporting-breathlessness.org.uk/

Engagement Activity

Dissemination	Results of Activity	Impact	URL
Presentation at Dyspnea 2018 (Prof Johnson)	SNAP tool and LaB programme cited in oral presentation given by Professor Miriam Johnson (Professor Johnson requested SNAP and LaB slides) at: Dyspnea 2018, Canada:		https://www.mcgill.ca/dyspnea2018/welcome-dyspnea-2018-montreal
Presentation at Palliative Care Doctors Education Meeting (Norfolk) 2018	Farquhar M "Improving care and support for patients and carers living with advanced disease' Palliative Care Doctors Education Meeting, Norfolk & Norwich University Hospitals and Priscilla Bacon Lodge Hospice, Norwich - Bob Champion Building, Norwich Research Park [oral presentation] Nov 2018		
LaB2 in British Lung Foundation King's Lynn Breathe Easy newsletter 2018	Newsletter piece introducing the LaB2 study to carers and patients with breathlessness who are group members.		
LaB2 at NNUHFT Respiratory Seminar 2018	Farquhar M, Barnes S, Ewing G. "Learning about Breathlessness Study programme". NNUHFT Respiratory Team seminar [oral presentation]. 12/12/18		
LaB and SNAP in Norfolk Palliative Care Doctors Educational Meeting - Nov 2018	Nov 2018 - Farquhar M "Improving care and support for patients and carers living with advanced disease' Palliative Care Doctors Education Meeting, Norfolk & Norwich University Hospitals and Priscilla Bacon Lodge Hospice, Norwich - Bob Champion Building, Norwich Research Park [oral presentation] - included LaB and SNAP		
LaB2 presentation at University of East Anglia's School of Health Sciences Festival	LaB2 presentation at University of East Anglia's School of Health Sciences Festival - Q&A session afterwards		

Dissemination	Results of Activity	Impact	URL
LaB2 at NIHR Charities Consortium for Hospice and Community Research Conference	NIHR Charities Consortium for Hospice and Community Research Conference 6th June 2019 Poster Presentation: "What do informal carers of people living with breathlessness in advanced disease need to learn about "Knowing what to expect in the future"?" Q&A afterwards		https://apmonline.org/apm-events/the-annual-nihr-and-charities-consortium-for-hospice-community-research-conference-2019-thursday-6th-june-2019-london/
LaB2 at RCN International Research Conference 2019	Royal College of Nursing (RCN) International Nursing Research Conference 2019 (oral presentation - filmed) "What do informal carers of people living with breathlessness in advanced disease want to learn about "Knowing what to expect in the future"?"		https://www.rcn.org.uk/professional-development/research-and-innovation/research-events/rcn-2019-research-conference
LaB2 presentation at University of East Anglia's Research Exchange Meeting - 4th March 2020	LaB2 presentation at University of East Anglia's Research Exchange Meeting led to questions and discussions and interest in when the Supporting Someone with Breathlessness will be launched (as those present knew of others they would like to share it with)		
Short piece on LaB2 Study in British Lung Foundation's King's Lynn Breathe Easy Support Group newsletter	Short piece on LaB2 Study in British Lung Foundation's King's Lynn Breathe Easy Support Group newsletter, January 2020. Paved way for recruitment activities for LaB2 Study (Task 3)		https://www.blf.org.uk/support-in-your-area/breathe-easy-kings-lynn-support-group
LaB programme highlighted in Primary Care Respiratory Society (PCRS-UK)'s "Spotlight" (Dec 2019) - online newsletter	LaB programme included in profile in Primary Care Respiratory Society (PCRS-UK)'s "Spotlight" (Dec 2019): https://www.pcrs-uk.org/spotlight-snap-team-uea		https://www.pcrs-uk.org/spotlight-snap-team-uea
LaB2 at PCRS-UK Conference 2019	Awarded the plenary oral slot at the Primary Care Respiratory Society (PCRS-UK) 2019 conference for our LaB2 Study abstract as it was awarded Best Scientific Abstract award (peer-reviewed). Question and answer session followed. PCRS-UK offered to promote LaB2's website for carers ("Supporting Someone with Breathlessness" once launched)		https://www.pcrs-uk.org/2019-winning-abstract

Dissemination	Results of Activity	Impact	URL
LaB2 presentation at University of East Anglia's Qualitative Research Methods seminar - 20th March 2019	LaB2 presentation at University of East Anglia's Qualitative Research Methods seminar - 20th March 2019. As it is methods-driven (rather than topic-driven), this seminar series goes beyond our usual health sciences academic audience at UEA and extends to other Schools and Faculties within UEA that use qualitative methods e.g. social work, humanities, etc. Question and discussion session that followed led to a request to run a related dedicated cross-UEA 2-hour workshop		
LaB2 presentation at Association of Respiratory Nurse Specialists conference (ARNS 2020)	Oral presentation of peer-reviewed abstract: Co-development of a web-based educational intervention for informal carers of patients with breathlessness in advanced disease. One of three top scoring abstracts at ARNS 2020. Generated Q&A discussion		https://arns.co.uk/2020-arns-annual-conference/
LaB2 at EAPC 2020	Poster presentation of: Farquhar M, Barnes S, Ewing G. Development and piloting an educational intervention for informal carers of patients with breathlessness in advanced disease (EAPC Abstract 2020). Palliat Med 2020;34(S1):125		https://eapcresearchcongress2020.eu/
LaB2's "Supporting Someone with Breathlessness" website presented to Hospice UK Project ECHO event (27th May 2020)	201 organisations/individuals attended the online event with a further 44 views of the recording (data correct at 17th June 2020 - email from Kate Fleming, Hospice UK)		
LaB2 presented at UEA's 3MT Researcher Competition			
LaB2 presentation at National Cancer Research Institute conference (NCRI 2020)			

Award Recognition

Type	Reason for Recognition	Impact	Url
Invited talk to the Life of Breath Project, University of Bristol, 18th January 2019.	Farquhar M. Improving care and support for people living with breathlessness. Talk comprised of four sections, one of which related to the LwB, SNAP and LaB programmes.	Discussion around clinical implications	https://lifeofbreath.org/
Chair of funding panel 2019	Dr Morag Farquhar invited to act as Chair of funding panel - Health Research Board (Ireland) Investigator-Led Projects 2019 (Dublin, June 2019)	Event yet to occur	https://www.hrb.ie/funding/funding-schemes/all-funding-schemes/grant/investigator-led-projects/
Invited oral presentation 16th Annual British Thoracic Oncology Group (BTOG) Conference 2018, Dublin, 24th-26th January 2018	Farquhar M. Developing an educational intervention for carers of patients with lung cancer: the Learning about Breathlessness Study. [related video interview: https://www.vjoncology.com/]	Interest from Roy Castle Lung Foundation and Macmillan Cancer Support	https://www.vjoncology.com
LaB2 Keynote speaker at BTS Summer Meeting 2019	Dr Morag Farquhar personally invited to give an oral presentation on "Enabling informal carers to support patients with COPD" at the British Thoracic Society (BTS) Summer Meeting 2019 in Manchester - this will focus on the Learning about Breathlessness research programme.	Event will occur 13/14 June 2019	https://www.brit-thoracic.org.uk/bts-learning-hub/bts-summer-and-winter-meetings/summer-meeting-2019/
LaB Keynote speaker at Life of Breath seminar 2019	Farquhar M. Improving care and support for people living with breathlessness. Talk comprised of four sections, one of which related to the LaB research programme.	unknown	https://lifeofbreath.org/
Panel chair Health Research Board (Ireland)	Panel chair Health Research Board (Ireland Investigator-Led Projects (Dublin, 2019)	Invited to chair Health Research Charities Ireland/Health Research	https://www.hrb.ie/funding/funding-schemes/all-funding-schemes/grant/hrcihrb-joint-

Type	Reason for Recognition	Impact	Url
Investigator-Led Projects (Dublin, 2019)		Board (HRCI/HRB) Joint Funding Scheme 2020 (Dublin, June 2020)	funding-scheme-2020-previously-mrcg-hrb/
Chair of funding panel - HRB NCTCP 2020	Chair of funding panel for Health Research Board (HRB) Ireland 2020's National Clinical Trials Coordination Programme (NCTCP) 2020	Unknown	https://www.hrb.ie/funding/funding-schemes/all-funding-schemes/grant/national-clinical-trials-coordination-programme-2020/
Invited to join NHS England's "National Breathlessness Workstream" (from Oct 2020)	Invited to join as work has had a significant impact in helping better understand breathlessness and its management	Highlighted the importance of including the needs of patients' informal carers in the workstream	
Invited to join European Respiratory Society guideline taskforce on breathlessness management in advanced lung disease (COPD & ILD)	Invited to join for expertise in patient and carer experience of breathlessness and (non-pharmacological) interventions to support them.	In progress	

Other outputs	Details	Benefit to Patients
UEA HSC Associate Director for Research (Research Environment) (2018+)	Internal appointment as Associate Director for Research (Research Environment) for the School of Health Sciences, University of East Anglia from September 2018 (3 year role)	Ensuring a positive research environment, facilitating the quality and quantity of research outputs from the School of Health Sciences, University of East Anglia, and the impact that can bring to society/economy.
LaB research programme "meticulous programme of work" Currow et al 2018	LaB research programme described as a "meticulous programme of work" in Currow et al 2018: Currow DC, Johnson MJ, Ekström M. Ensuring caregivers are part of palliative care service delivery. Palliat Support Care. 2018 Oct;16(5):639-640. doi: 10.1017/S1478951517001262. Epub 2018 Jan 24.	unknown

Dementia undetected or undiagnosed in primary care: the prevalence causes and consequences (CADDY)

Clare Aldus / George Savva, University of East Anglia

Study Details

Start Date	01/01/2016	Funding Stream	NIHR Health Service and Delivery
End Date	31/03/2018	Funding	£353,923

Publications

Publication Type	Details	Url
Other	The Prevalence, Causes and Consequences of Undiagnosed Dementia in England: A Record Linkage Study of the Cognitive Function and Ageing Study II (2017)	
Conference Proceeding Abstract	Dementia undetected or undiagnosed in primary care: the prevalence, causes and consequences (2017)	
Other	The prevalence, causes and consequences of dementia undetected or undiagnosed in primary care (2017)	
Other	What predicts missed diagnosis among people with dementia (2017)	
Conference Proceeding Abstract	Dementia undetected or undiagnosed in primary care: The CFAS II Dementia Diagnosis Study (CADDY) (2018)	
Conference Proceeding Abstract	What can epidemiology tell us about dementia? (2019)	
Conference Proceeding Abstract	The prevalence and correlates of undiagnosed dementia (2018)	
Journal Article	Ashton J. Public and patient involvement in research on ageing and dementia. Journal of Public Mental Health 2020; 3	http://dx.doi.org/10.1108/jpmh-06-2020-0064

Engagement Activity

Dissemination	Results of Activity	Impact	URL
Local PPI board meeting 2016: The role of patient and public involvement in epidemiologic* studies: insights from three on going projects in dementia epidemiology (CADDY, ZED and ABCD)	The aim was a two-way dialogue between researchers and a local PPI group, explaining the purpose of epidemiologic studies, the role of PPI in epidemiologic research and how PPI has specifically informed three ongoing studies at UEA. We also heard what the PPI group would expect or need in terms of training to fully participate and feedback from the studies. As an outcome we have agreed to prepare an article for the benefit of the PPI and research community summarising our discussion.		
The prevalence, causes and consequences of undiagnosed dementia - workshop and panel discussion 2017	Key experts presented the findings from four recent research studies into dementia diagnosis and facilitated a workshop and panel discussion. This event provided a forum for Healthcare Commissioners, Policy Makers, Patient Representatives, Primary and Secondary Care Practitioners, Research Commissioners and others working towards timely dementia diagnosis to get together for face-to-face discussion on current perspectives, experiences and key challenges in dementia diagnosis policy and practice in England.		
Public Lecture 2017, University of East Anglia, Norwich, UK	Undiagnosed dementia: prevalence, causes and consequences		
Talk - Contemporary Populations and dementia, what have we learnt and where are we going?	Talk in Tazmania June 13 2019 to Alzheimers Disease Forum		
Online webinar	Dementia Care Research Centres & Dementia Training Australia (part of the Government's Australia Dementia Research Institute), advertised as View of dementia from a public health and population perspective.		
Presentation to dementia interest group	Presentation to disseminate CADDY to a dementia interest group comprising patients, public, academics, clinicians. Presentation virtual with interactive discussions. Participants from as far away as South America.		

Goal-setting in care planning for people with multimorbidity: feasibility study and intervention refinement

Prof Nick Steel, University of East Anglia

Study Details

Start Date	01/11/2016	Funding Stream	NIHR Research For Patient Benefit
End Date	31/07/2018	Funding	£241,721

Publications

Publication Type	Details	URL
Journal Article	Salter C. et al. Setting goals with patients living with multimorbidity: qualitative analysis of general practice consultations. British Journal of General Practice. 3 June 2019, bjgp19X704129	https://doi.org/10.3399/bjgp19X704129
Journal Article	Ford JA, Lenaghan E, Salter C, et al Can goal-setting for patients with multimorbidity improve outcomes in primary care? Cluster randomised feasibility trial BMJ Open 2019;9:e025332. doi: 10.1136/bmjopen-2018-025332	https://bmjopen.bmj.com/content/9/6/e025332.full
Journal Article	Murdoch J. The "unknown territory" of goal-setting: Negotiating a novel interactional activity within primary care doctor-patient consultations for patients with multiple chronic conditions. Social science & medicine (1982), 2020; 256	http://europepmc.org/abstract/MED/32473530
Journal Article	Shiner A. Goal-setting with patients with multi-morbidity Finding a way to achieve 'what really matters'. InnovAiT: Education and inspiration for general practice 2020; 3	http://dx.doi.org/10.1177/1755738019891190

Further Funding

Funding Body	Details
NIHR Collaboration for Leadership in Applied Health Research & Care (CLAHRC)	Research grant (including intramural programme) - 1 year; £51,194
Development of an e-learning resource for GPs - Goal setting with patients living with multimorbidity	Research grant (including intramural programme) - NIHR CLAHRC East of England – 1 year - £48,541

Engagement Activity

Dissemination	Results of Activity
GoalPlan study results dissemination meeting 2018	29 attendees at dissemination meeting held at UEA on 08/11/18, presented results of GoalPlan and one other primary care based study with academic colleagues, patient stakeholders, GPs and members of the public.
Society for Academic Primary Care regional meeting Oral Presentation January 2018	10 minute presentation of ongoing research to Society for Academic Primary Care regional meeting.
The Commonwealth Fund Harkness Fellowships in Health Care Policy and Practice 20th anniversary event, Surrey, 20-22 July 2018 (panel presentation: Nick Steel)	Expert panel presentation
1. International Conference on Communication in Healthcare, Porto, 1-4 September 2018: i. Workshop presentation (C Salter); ii. Poster presentation (N Steel)	Workshop and poster presentation at International Conference on Communication in Health Care
Centre for Inter-professional Practice Conference, University of East Anglia, Norwich, 7 September 2018: Oral presentation (C Salter)	Conference presentation
University of East Anglia Faculty of Medicine & Health Lecture Series, Oral	Seminar presentation

Dissemination	Results of Activity
Presentation 28 September 2018 (C Salter)	
Royal College of General Practitioners Annual Primary Care Conference, Glasgow, 4-6 October 2018: i. Oral presentation (N Steel); ii. Poster presentation (N Steel)	Oral presentation and poster presentation, both of which generated a lot of interest, discussion and enquiries from the audience. The poster was awarded 'Best in Category: research'. Contact was made with RCGP Clinical Innovation and Research Centre representatives and discussions are ongoing regarding collaboration on an e-learning training package relating to the research intervention.
British Geriatric Society Autumn Meeting, London, 16-18 November 2018: Abstract Presentation (N Steel)	Abstract presentation
GP goal setting training: How to set goals with patients living with multimorbidity	3-module online training course on FutureLearn platform with integrated experiential learning between modules 2 and 3. Learning hours: 1 hour per module + approximately 6 hours of experiential learning; total = 9 hours Launch date: September 2019 The course is regularly available on the FutureLearn learning platform at: https://www.futurelearn.com/courses/gp-goal-setting-training/ . The course has run 6 times on FutureLearn, starting in July 2019, Sept 2020, May 2020, July 2020, Sept 2020, Nov 2020. All course runs have had at least 10 GPs attending and actively engaged by commenting on the course, with a 100% satisfaction response (a smiley face 'sentiment rating') in 5 of 6 runs. Feedback comments on the course online chat include: 'well rounded team: advice should be superb. Complements counselling and coaching skills.' And 'great teachers' and many other positive comments.

Other Outputs

Other outputs	Details	Benefit to Patients
The study team developed an open access online training course for GPs and other clinicians, based on the study findings. The first run of this course with enhanced facilitation from educators and researchers will be available at https://www.futurelearn.com/ 1st - 31st July 2019.	During three interactive sessions, and using examples from real-life consultations, GPs will get the chance to investigate the theory and practice of goal-setting in primary care, be supported as they try the techniques, and evaluate their readiness to be a goal-setting GP.	

Appendix 4: RSI Practices 2019-21

Norfolk & Waveney

Practice Name (Single Site RSI)	PCN	19/20	20/21
Alexandra & Crestview Surgeries	Lowestoft	✓	✓
Andaman Surgery	Lowestoft	✓	✓
Beccles Medical Centre	South Waveney	✓	✓
Bridge Road Surgery	Lowestoft	✓	✓
Bridge Street Surgery	Swaffham & Downham	✓	✓
Castle Partnership	Central Neighbourhood	✓	✓
Cromer Group Practice	North Norfolk 4	x	✓
Drayton and St Faiths Medical Practice	North Norfolk 3	x	✓
East Norfolk Medical Partnership	Gt Yarmouth & Northern Villages	✓	✓
Elmham Surgery	Mid Norfolk	✓	✓
Fakenham Medical Practice	North Norfolk 1	✓	✓
Feltwell Surgery	Fens & Breckland	✓	✓
Great Massingham Surgery	Coastal	✓	✓
Hingham Surgery	Ketts Oak	✓	✓
Hoveton & Wroxham Medical Centre	North Norfolk 4	✓	✓
Humbleyard Practice	Ketts Oak	✓	✓
Lakenham Surgery	Central Neighbourhood	✓	✓
Lawson Road Surgery	Norwich North Neighbourhood	✓	✓
Lionwood Medical Practice	East Norwich Neighbourhood	✓	✓
Long Stratton Medical Group	SNHIP	x	✓
Longshore Surgery	South Waveney	x	✓
Ludham and Stalham Green Surgeries	North Norfolk 2	✓	✓
Magdalen Medical Practice	Norwich North Neighbourhood	✓	✓
Manor Farm Medical Centre	Swaffham & Downham	✓	✓

Practice Name (Single Site RSI)	PCN	19/20	20/21
Mattishall & Lenwade Surgeries	Mid Norfolk	✓	✓
The Millwood Partnership	Gorleston	✓	x
Mundesley Medical Centre	North Norfolk 2	✓	✓
Oak Street Medical Practice	Norwich North Neighbourhood	✓	✓
Orchard Surgery	Mid Norfolk	✓	✓
Prospect Medical Practice	Norwich North Neighbourhood	✓	✓
Reepham and Aylsham Medical Practice	North Norfolk 3	✓	✓
Rosedale Surgery	Lowestoft	✓	✓
Roundwell Medical Centre	West Norwich Neighbourhood	✓	✓
Sheringham Medical Practice	North Norfolk 1	✓	✓
Southgates and Wootton Surgeries	Kings Lynn	✓	✓
St Stephens Gate Medical Practice	Central Neighbourhood	✓	✓
Staithe Surgery	North Norfolk 4	✓	✓
The Market Surgery	North Norfolk 3	✓	✓
Trinity & Bowthorpe Medical Practice	West Norwich Neighbourhood	✓	✓
UEA Medical Centre	Central Neighbourhood	x	✓
VIDA Healthcare	Kings Lynn	✓	✓
Wells Health Centre	North Norfolk 1	✓	✓
Wensum Valley	West Norwich Neighbourhood	✓	x
West Pottergate Surgery	Central Neighbourhood	✓	✓

Practice Name (RSI Cluster)	Cluster	19/20	20/21
Grove Surgery	Breckland	✓	✓
School Lane Surgery	Breckland	✓	✓
Watton Medical Practice	Breckland	✓	✓
Beaches Medical Centre	Gorleston	x	✓
The Millwood Partnership	Gorleston	x	✓