NIHR | National Institute for Health Research

NIHR APPLIED RESEARCH COLLABORATIONS (ARCs)

Annual Report
(1 April 2021 to 31 March 2022)

3. Overview of Activities (no more than 1500 words)

Please provide an overview of the activities of your NIHR ARC for the period 01 April 2021 to 31 March 2022, addressing the following areas:

- **Progress against short, medium and/or long-term objectives as detailed in your approved full application; please state each objective and outline the progress made towards achieving it; Please indicate whether these objectives are complete, on track or delayed.**
- **Progress with leadership, governance and management arrangements for your NIHR ARC;**
- **Any changes to the approved strategy for your NIHR ARC;**
- **Any significant developments in implementing the strategy;**

Please note that the overview of activities (and other sections of the Annual Report) should reflect activities which fall within the remit of the NIHR ARC funding scheme.

Strategy development – the pandemic and beyond

This period spans periods of high incidence of COVID 19, of significant restriction of activities to protect the NHS and public health, and the beginnings of the recovery phase for services. PenARC has responded to the direct encouragement from NIHR to flex activities to respond to needs of services and service users throughout this period. In doing so we have continued to deliver against our core long-term objectives – delivery of high-quality research, seeking to improve health outcomes through using evidence, building capacity amongst staff to use and generate evidence and generating wealth – as evidenced throughout this report and all on track.

We have made full use of NIHR permission to redeploy staff from paused and slowed studies to enable us to deliver against these needs. As stated in our last annual report, we are immensely proud of the contribution of our staff, both in continuing wherever possible to adapt and maintain existing programmes of work, and in responding directly to the Covid 19-related needs of the services.

The recovery phase has posed new questions and challenges. We have moved to reinstate progress on existing original research studies. We are also now confronted by new questions from service partners who seek to address issues of backlogs, particularly in elective services, and severe shortages of staff. Changes to ways of working also offer some new opportunities which we seek to exploit – in particular, far more widespread use of technology in every aspect of service delivery and capacity building.

The scale of the challenge facing services is immense and could easily overwhelm our ability to respond. We have substantially strengthened joint working with partners, particularly ARC West, our two partner AHSNs and the CRN, in an attempt to increase the effectiveness of this response. The “Beneficial Changes Network” helped to cement the partnership through joint work relating to the use of remote consultation which will result in the production of a toolkit for use by services contemplating moving outpatient services to greater use of this approach (ORCER). The overall aim is to produce evidence that enables providers/commissioners to decide in what circumstances and for whom remote consultation is most likely to be effective and where on the contrary it is likely

to reduce patient satisfaction or exacerbate inequalities. PenARC, SW AHSN and CRN leadership now meet regularly to share specific initiatives and to discuss joint approaches to capacity building. This has led to joint working on some key areas (such as child mental health) and joint posts between AHSN and ARC. PenARC staff contributed to a recent meeting between SWAHSN and key leads from NHSE and to drafting proposals for increased SWAHSN funding which resulted from this meeting.

We continue to build on experience during the pandemic in transferring many activities from in person to virtual. We were particularly impressed that our PPIE staff found ways to help public collaborators who had never previously used digital media to engage effectively and maintain our collaborative approach, in fact opening new possibilities of meaningful involvement for many people. The bulk of our capacity building activities, including *Making Sense of Evidence* and *Health and Police Service Modelling Associates* have primarily transferred to remote delivery. We are returning to some in person delivery but are using this learning to produce blended programmes for the future, enabling greater access and spread of opportunities.

Progress against Short and Medium-term aims

*NB. Progress against all aims is **on track**.*

Aim 1: Engage organisations commissioning and providing NHS services, clinicians, and members of the public in identifying and prioritising information needs and translate these into clearly delineated questions amenable to research.

Aim 6: Ensure effective links across the landscape of health and social care providers and commissioners, including local authorities.

Although the pandemic posed challenges to links with the 27 organisations in the ARC collaborative, we continue to build on previous successful delivery of joint working. As discussed earlier, we are increasingly coordinating contacts with services with the SW AHSN and CRN. We have overlapping aims but distinct areas of expertise and coordination helps to avoid duplication and increases efficiency.

ICSs (3 within this region) are increasingly central to service development - the Chief Executives have joined our Management Board and we are working with key staff to align our work to their evidence-needs. Examples of joint work include:

- Modelling to study the interface between hospital discharge, intermediate care and long-term care with Somerset ICS
- Modelling patient flows in Somerset for the management of acute stroke to develop efficient approaches to service configuration, diagnostics and mobile stroke unit(s)
- Jointly with CRN and AHSN, developing a strategic approach with Devon ICS regarding research, evaluation of innovation and utilization of evidence.
  Initiatives include:
    - Mapping of child and adolescent mental health research and capacity against need
    - Co-production of an AHRC bid to develop an ICS Community Asset research hub between universities, VCSE, public health departments, citizen community asset builders, and PCNs in three diverse areas of coastal and rural deprivation.
    - Supporting evaluation of the Community Mental Health Framework transformation

Co-developing research with public collaborators ensures relevance to their needs and recent examples include:

- NIHR-funded, PenARC supported, research addressing continence needs of children with disabilities. https://pubmed.ncbi.nlm.nih.gov/34866570/

- Resources for people with dementia and their carers, including *My Life, My Goals*, a self-help resource for people with dementia, and the *Living with Dementia Toolkit*, an online resource for people with dementia.

Aim 2: Lead and contribute to programmes of work in areas of national priority

PenARC themes reflect many areas of national priority – Complex Care, Mental Health, Dementia and Public Health (see section 4). We lead a national collaboration to address "Children's Health and Maternity" (section 13) and the "National Leadership Area" of Operational Research, (section12).

PenARC also plays a leading role in the "Aging, Frailty and Dementia Collaboration", including leading the PPIE work for the collaboration. PenARC staff contribute to other national priority areas, including particularly "Inequalities" and "Prevention", sitting on programme management groups, leading PPIE provision to the former, and contributing to adopted projects.

Aim 3: To undertake research and improvement work to address identified priorities, where appropriate gaining external funding.

NIHR PenARC "human infrastructure" enables us to identify and address key questions with partners, frequently seeking external funding. Over this period staff attracted a further £5.7m in external grant funding as either PIs or Co-Is.

Examples include:

- Kailo: Systemic prevention of poor adolescent mental health and promotion of social connection and wellbeing ***UKPRP £5,300,000***
- Intergenerational practices and learning in health and social care: exploring the evidence from the perspective of older people ***NIHR ESPG £99,849***
- Green Social Prescribing: Preventing and Tackling Mental Ill Health through Green Social Prescribing Project Evaluation for DEFRA ***HMT Shared Outcomes Fund £887,413***
- DREAM: Digital and remote enhancements for the assessment and management of older people living with frailty ***NIHR PDG £ 149,463***
- Torbay Children in Care ***Torbay Medical Research Fund £237,850***
- Hope: Health Outcomes for young People throughout Education ***NIHR PGfAR £1,445,777***

Aim 4: With partners, including the AHSN, mobilise evidence to achieve service improvement and conduct research into effective methods for doing so.

Aim 7: Gain the maximum impact from pre-existing PenCLAHRC projects.

Aiming to achieve impact on services, and drawing widely applicable lessons, is a core objective. Close partnership with public collaborators and those who deliver services throughout the research process, from defining questions to disseminating results, helps to build in "implementability".

We continue to build on PenCLAHRC initiated projects e.g. previous modelling of acute stroke services forms the basis for a national investigation of drivers of effective delivery of thrombolysis at a hospital level as well as a new local model to improve access.

PenCHORD, the PenARC operational research modelling group drives a programme of service improvement work, including related to the pandemic such as the redesign of dialysis services in Southeast England to modify infection risk. The HSMA programme, detailed elsewhere, combines capacity building and developing solutions to problems facing organisations.

A core activity within the CH&M Programme has been planning research on implementation crossing the adopted programmes and we are currently seeking to extend this to include a project led from within PenARC within the Ageing and Dementia programme.

Aim 5: Build receptivity in the health workforce to research and innovation.

We offer a range of opportunities for staff in partner organisations and public collaborators to develop skills in the use and generation of evidence. These range from short courses such as "Making Sense of Evidence" (MSE) to "clinics" where they can discuss methodological issues. The MSE programme is of particular importance in helping develop skills, and allowing identification of potentially important research questions. In addition, we offer longer-term secondments such as the HSMA programme and our new Mental Health Research Associate and Internship programmes (jointly with CRN). Alumni form an important group in partner organisations with whom we work on future projects.

4. Progress Made in Each Research & Cross-cutting Themes (no more than 500 words per theme)

Please set out clearly, in bulleted points, the progress made against the objectives (*short/medium term*) within each research and cross-cutting theme, addressing the following areas (*where appropriate*):

- **Details of progress against specific objectives detailed in your approved full application, highlighting any significant achievements; provide 1-2 indicative examples of how progress has been made, and not an exhaustive list; please indicate whether these objectives are complete, on track or delayed.**
- **Details of any significant challenges faced (and proposed solution(s)) in delivering the work programme during 2021/2022**
- **Progress with leadership of the theme, including any changes or challenges faced; please include the name of the theme lead. If there has been a change in theme lead please submit the CV for the new theme lead;**
- **Details of the progress of the theme's strategy, including any changes *e.g.* discontinuation of originally planned work or new areas of research;**
- **Major grant awards received as a consequence of NIHR ARC funding;**
- **Highlights of research activities supported by the NIHR ARC award during the reporting period;**
- **Highlights of implementation research activities supported by the NIHR ARC award during the reporting period;**
- **Initiation of new research or implementation projects, or new areas of activity;**
- **Examples of effective translation of research findings into improved outcomes for patients, or significant progress along the translational research pathway, as a result of the NIHR ARC funding; and**
- **Examples of the creation and development of intellectual assets (*i.e.* patents, etc.) through the work of the research theme.**

Theme Title	Theme Progress
Mental Health **Short and Medium-term** **1.** Maximise impact from current research by effective dissemination and promotion of adoption. **2.** Develop and evaluate interventions to reduce the risk of mental health problems and manage established conditions. **3.** With AHSN partners, develop and evaluate care pathways and organisational systems to deliver evidence-based interventions. **4.** Develop robust, evidence-based measures of patient experience and outcomes. **5.** Build the capacity of staff in mental health to generate and use research evidence.	**Lead: Prof Dickens** **Progress against objectives / strategy** We continue to deliver against our long term aims of producing research and evidence-based service improvement. Our strategic relies on building shared understanding of priorities, working closely with patient groups and peer researchers, and with leaders in providers and new Integrated Care Systems and the AHSN. **Progress against short and medium-term aims**

Long-term **6.** Producing widely applicable clinical, public health and organisational research evidence **7.** With partners, adopt, contextualise and spread evidence-based service improvement.	*1. Maximise impact from current research by effective dissemination and promotion of adoption.* ***And*** *3. With AHSN partners, develop and evaluate care pathways and organisational systems to deliver evidence-based interventions.* ***On-track*** These aims overlap, both often being delivered in partnership with SWAHSN. Highlights include: • The **Integrated Psychological Medicine Service (IPMS)** is a key initiative in partnership with a local acute trust. This has been rolled out in clinical services including: Diabetes, Long Covid, Renal and Pain services and is being evaluated by conducting an ethnography of change, to examine factors that influence how IPMS is adopted. The project slowed during the pandemic but is now being reinvigorated. • **PARTNERS 3** This study builds on previous PARTNERS research and aims to optimise key components of the community mental health policy, implementing the PARTNERS intervention for people with severe and enduring mental illness. *2. Develop and evaluate interventions to reduce the risk of mental health problems and manage established conditions.* ***On-track*** We are working on a large range of interventions related to both prevention and treatment, many externally funded. Highlights include: • Particularly exciting is the Kailo Project (UKPRP c£5.3M) which will evaluate a new approach aiming to use an evidence-informed framework to support local partnerships to co-design strategies which address the underlying drivers of adolescent mental health. • Our Community Mental Health Framework Pilot evaluation (NHSE/CCG funded) continues. Lived experience, embedded researchers have identified the key themes which

	determine success, including: managing patient flow for system sustainability; the change in use of language to support culture change; the value of cross organisational leadership work to promote system integration. • ATTEND This NIHR-funded study aims to establish feasibility of implementation and delivery of a mindfulness-based approach for adolescent non-responders and their carers to first-line treatments of depression. *4. Develop robust, evidence-based measures of patient experience and outcomes.* ***On-track*** A key aspect of our study design is the development of outcome measures that reflect the views of people with lived experience as well as of clinicians and policy makers. For instance, working with Devon Partnership Trust, we have established CAMHS-RISE**,** a partnership with CAMHS-experienced young people to help us better understand what matters to young service users, informing research questions and measurement of outcomes.
Dementia **Short and Medium-term** **1.** Maximising impact from existing research by effective dissemination and implementation. **2.** Better understanding of the needs of people affected by dementia, and developing interventions to improve care and support. **3.** Better understanding of population risk factors for dementia and using this evidence to develop risk-reduction interventions. **Long-term** **4.** Co-producing widely-applicable evidence within and across clinical care, social care, public health, and organisational practice. **5.** Working with Partners across geographies and sectors to adopt, contextualise, spread, and sustain evidence-based service improvement. **6.** Building capacity among people who work with or are affected by dementia to understand, participate in, and contribute to research.	**Lead: Prof Clare** **Progress of the strategy** We partner with people who are affected by dementia, or who work with them, to deliver our long term aims, producing widely applicable evidence, promoting service improvement and building capacity. **Progress against short- and medium-term objectives** *1. Maximising impact from existing research.* ***On-track*** e.g. "GREAT-into-Practice" built on evidence from the NIHR HTA-funded GREAT trial to develop a foundation for implementing cognitive rehabilitation in community-based services. *2. Better understanding needs, and developing interventions.* ***On-track***

	A series of studies, many with external funding, address this aim. These include: • IDEAL-2 which examined the impact of the pandemic conducted its final round of data collection, and provided new evidence about the needs of people with dementia. • ENLIVEN gathered evidence about preferences for and access to outdoor nature-based activity as a precursor to supporting business innovation. • D-PACT is developing and testing a person-centred approach to post-diagnosis support in general practice for people with dementia. testing the intervention. • The WHELD COVID-19 study developed digital support materials which are being tested in 149 care homes. • EXCHANGE co-designed and ran Making Sense of Evidence workshops with care home managers, and interviewed care staff to identify research priorities. *3. Better understanding population risk factors, and developing interventions.* ***On-track, some delays*** While continuing to deliver against this objective, in the pandemic our public and service collaborators encouraged us to focus primarily on aims 1 and 2. We contributed to intervention development in the UCL-led APPLE-tree project and have co-led a PhD studentship which validated measures in the UK older population and examined the role of subjective ageing. **Highlights of research activity** We drew on existing work to provide evidence about the experiences of people with dementia and carers during the pandemic. IDEAL-INCLUDE evidence was cited in several policy documents and the IDEAL study provided novel evidence about trajectories of quality of life and the psychological processes involved in adapting to a dementia diagnosis. Baseline data from WHELD identified a 55% increase in antipsychotic prescribing for residents with dementia during the pandemic, leading to

	development of further interventions to facilitate appropriate prescribing. **Highlights of implementation research activity, including translation of findings into improved outcomes** GREAT-iP demonstrated that when implemented in community-based health services the benefits of cognitive rehabilitation are equal to those observed under trial conditions. The intervention is included in the WHO Package of Rehabilitation Interventions for Dementia. The WHELD programme has been delivered to 309 care homes, benefitting approximately 9,000 residents and 7,000 staff. IDEAL used a theatre production, 'The World Turned Upside Down', to explore communication in dementia care and promote public awareness. ENLIVEN has developed a network of businesses who meet to promote accessibility for people living with dementia. Intellectual assets GREAT-iP co-produced My Life, My Goals, a self-help resource for people with dementia, now translated into several languages. IDEAL-INCLUDE co-produced the Living with Dementia Toolkit, an online resource for people with dementia. **Major awards** RecoverED. NIHR PGfAR £2.5m. WHELD-into-Practice. NIHR Priority Area. £465,000
Complex Care **Short and medium-term** **1.** Further develop engagement with people with complex needs and their families, and health and social care systems. **2.** Review, develop and evaluate interventions (individual and systemic) aimed at improving the care and outcomes for people with complex needs. **3.** Work with partners, particularly the AHSN, to effectively utilise evidence to enable service improvements. **Long-term** **4.** Improve health outcomes for people with complex needs through patient-focused research and evidence-based service improvement. **5.** Develop coherent and overarching theory to support co-production of intervention and service configurations which improve outcomes for people with complex care needs.	**Lead: Prof Byng** **Progress of the strategy** We are **on track** with our long-term aims, conducting patient-focused research and service improvement and working towards the development of coherent and over-arching theory to support co-production of interventions and service improvement to improve outcomes for people with complex care needs. We have continued our successful strategy of engaging with local initiatives and building collaborative research which has local impact and national relevance. The establishment of a Health Foundation funded development of a unit to import, adapt and spread innovation for those

	living with frailty is increasing our ability to work more proactively at locality level. **Progress against short- and medium-term objectives** **<u>Short and medium-term</u>** ***1.*** *Engagement with people with complex needs and their families, and health and social care systems.* ***On-track*** As detailed in section 6, PenARC has always invested heavily in PPIE, making a particular effort to ensure that we include people with complex needs and their carers. Every study within this theme includes working with public collaborators and they are co-applicants on many external grants. ***2.*** *Review, develop and evaluate interventions (individual and systemic) aimed at improving the care and outcomes for people with complex needs.* ***On-track*** A series of studies with support from further external funding address this aim. Highlights of research activities include: • **ICON**. (https://arc-swp.nihr.ac.uk/research/projects/improving-continence/) Families whose children have disabilities identified continence as a key problem impairing their ability to participate and this NIHR-funded study is evaluating interventions. • **DREAM**. (https://arc-swp.nihr.ac.uk/research/projects/dream/) This NIHR-funded study, in collaboration with Cornwall Partnership Trust is developing and evaluating a remote-based, comprehensive geriatric assessment, aiming to improve management of older people living with frailty. • **CASTLE Sleep-E**. NIHR-funded study to improve management of sleep and learning in children with epilepsy. • **Peer Connect.** Torbay Medical Charity-funded, feasibility randomised controlled trial of a targeted peer coaching service for outpatients with

	chronic pain, Rheumatoid arthritis and MS. • **Remote by Default 2: The 'New Normal'?** NIHR-funded study which aims to inform high-quality, safe and equitable care in UK general practice in the context of policies which require phone, video or e-consultation by default. ***3.*** *Work with partners, particularly the AHSN, to effectively utilise evidence to enable service improvements.* ***On-track*** Highlights of implementation research and service improvement include: • **FLEXI** : In partnership with the AHSN, we are implementing the Falls Management Exercise programme (FaME) – based on previous work demonstrating efficacy - in Devon, and Manchester. • **Building a Brighter Future** (with co-funding from Torbay Medical Research Fund) is developing and evaluating community-hospital pathways for individuals with frailty and orthopaedic problems with the aim of focusing on future needs while addressing workload challenges. • **Healthy Parent Carers:** This programme is a peer-led group-based health promotion intervention for parent carers of disabled children, co-designed with parent-carers, and is now being implemented in partnership with national charities.
Public Health **Short and Medium-term** **1.** Maximise impact from current research by effective dissemination, adoption and implementation. **2.** Develop and evaluate public health interventions addressing environmental, social and individual determinants of health. **3.** Establish the SW Public Health Research Action Group (PHRAG) to: a) Actively engage partners in Public Health, Local Authorities, Education, Police, Social Services, the NHS and Third Sector. b) Identify uncertainties in public health, Local Authorities, Education, Police, Social Services, the NHS and Third Sector. c) Share experiences in implementing public health interventions	**Lead: Prof Wyatt** **Progress of the strategy** Our over-arching aim - to work closely with Public Health, local authority colleagues, SWAHSN and CRN, to co-produce research and implementation activities and to develop capacity – remains on track, demonstrated by projects discussed here and elsewhere. Many PH projects are conducted jointly with other themes, particularly the Mental Health and Methods Themes. **Progress against short- and medium-term objectives**

d) Be a link to NIHR DC enhanced dissemination, Phinder, and work in other ARCs. **4.** Work with the SW AHSN and other partners to facilitate local contextualisation and implementation of interventions and modes of service organisation identified as effective. **Long-term** **5.** Co-produce high quality research; collaborate in the enactment of change which impacts positively on public health within an ecological framework; and develop capacity to generate and use evidence.	*1. Maximise the impact of existing research and work with local partners to appropriately contextualise interventions developed elsewhere*. **And** *4. Work with the SWAHSN and other partners to facilitate local contextualisation and implementation of interventions and modes of service organisation identified as effective.* ***On-track*** These overlapping aims drive our collaboration with partners, identifying key issues where primary or secondary research can help to inform service delivery. Highlights include: • Improving health of young people is an agreed regional priority. We are developing a relational approach to health-promoting secondary schools and piloting the approach in areas of high economic deprivation to understand feasibility, acceptability and impact. Highlights include: School engagement and learning, PPIE Summer Schools and Teacher-led interventions on social/emotional behaviour • PH and provider organisations in the region are keen to explore the use of social prescribing to improve wellbeing. Our team has attracted grant funding from multiple sources (NIHR, UKRI, MRC, and local NHS organisations) to develop the evidence base to underpin the use of this approach amongst people with mental health problems, with dementia, for promotion of wellbeing and for frequent users of the health service. Project highlights include: CHOICES and Nature on Prescription 3. *Increase engagement with local PH practitioners through development of the* ***PHRAG***. ***Substance On-track though format changed*** We had envisaged a new, **named** organisation as the vehicle for engagement with groups listed. The launch was delayed by the pandemic although close engagement continued. The development of the ICSs with active interaction between linked PH groups and our close working with CRN/SWAHSN has enabled us to effectively achieve these

	ends. This success is for instance demonstrated by our provision of academic leadership for Devon County Council and Plymouth Local Authority proposals to become Health Determinants Research Collaborations (awaiting 2nd round outcome), our Police Service Modelling Associates Programme and school-based research programmes (above) *2. Develop and evaluate public health interventions addressing environmental, social, and individual determinants of health.* ***On-track*** We are undertaking research projects to achieve this aim. Highlights include: • There is interest (particularly Kernow CCG) in harnessing the skills of older people to build more cohesive communities to promote wellbeing. With NIHR funding we are reviewing existing evidence before working with those involved in delivering and receiving such programmes to delineate key research questions which we will then seek to answer. • Deprivation is a significant risk for depression and mental health difficulties. It is recognised that conventional approaches often fail these communities. As part of the national, cross-ARC Inequalities programme, we are building on PenCLAHRC research to further develop and evaluate DeStress, a primary care-led approach to depression in the most deprived communities.
Methods for Research and Improvement – Cross-cutting **Short and Medium-term** **1.** Provide the methodological expertise for the ARC across the key disciplines: a. PPI; b. Health economics; c. Epidemiology; d. Statistics; e. Trails and evaluation methods; f. Qualitative methods;	**Lead: Prof Logan** **Progress against objectives / strategy** This cross-cutting theme provides the methodological expertise to underpin the work across all other themes and helps bridge the care-research divide by building analytic and critical thinking capacity within the public, practitioners and managers,

g. Information science; h. Evidence and synthesis; i. Operational Research; j. Implementation science. **2.** Develop synergies across this range of disciplines to effectively contribute to research and service improvement. **3.** Contribute to building capacity in the local health economy to generate and use methodological evidence. **Long-term** **4.** The overall aim is to contribute to the ARC programme of patient and public health focused applied health research, evidence-based service improvement, wealth creation, and capacity building. A specific endeavour is to help bridge the care-research divide by building analytic and critical thinking capacity within the public, practitioners and managers, ensuring more productive engagement in both research and improvement.	ensuring more productive engagement in both research and improvement. The success against objectives (research, service improvement, wealth creation and capacity building) in these other themes demonstrates that we are on track with this long term aim. **Progress against short and medium term aims** *1. Provide the methodological expertise for the ARC across the key disciplines; **And** 2. Develop synergies across this range of disciplines to effectively contribute to research and service improvement.* PenARC staff have expertise across all key areas of methodology needed in our work and our processes ensure that methodological experts are involved early in the process of developing projects to maintain quality. We are committed to cross-fertilisation and encourage a team approach between disciplines. For example, our programme of work aiming to improve the management of acute stroke services brings together our PPIE team, OR modellers, Qualitative researchers, Epidemiologists and Implementation scientists as well as content experts to ensure that the results are thoroughly grounded in understanding the real world of clinicians and those who experience strokes. *3. Contribute to building capacity in the local health economy to generate and use methodological evidence.* We have a strong commitment to spreading skills across the local health and social care sector and more recently are taking a national role as well with the opening of our HSMA programme beyond the region. Methodology staff offer “clinics”, where partners can consult about methodological problems (e.g. “Search and Review” or “PPIE clinics”); we run “Making Sense of Evidence” workshops, including training tutors to cascade across organisations; and multiple internship/secondment opportunities discussed elsewhere. In addition, we offer opportunities for staff from partner organisations to develop skills while working on joint projects.

	Highlights of research and implementation The pandemic stimulated numerous projects where we assisted NHS organisations to manage services effectively by sophisticated use of data. These (spanning this and previous reporting period) included: • Developing a generic open-source simulation model of COVID-19 vaccination delivery • Forecasting COVID 19-related demands on bed, staff and equipment. • Modelling ambulance transport needs related to dialysis and to acute call outs. Our programme of work around Stroke services encompasses modelling to inform distribution of thrombolysis and thrombectomy units, both at national and regional levels and the SAMueL project which has developed methods employing AI to interrogate national audit data as the basis for designing approaches to be used in hospitals to improve outcomes. We are developing a theme around "Researchers-in-residence". A longstanding project in a local trust has addressed a number of service problems by bringing together clinicians, policy-makers, service users and researchers to mobilise evidence to underpin real-time solutions. We have now located an embedded researcher in CoLaB, a multi-agency wellbeing hub, as part of a creative approach to providing mental health services for homeless people.

5. Impact on Healthcare Provision and Public Health (no more than 500 words)

Please provide descriptions of impacts on healthcare provision or benefits to patients' outcomes arising from work undertaken by the NIHR ARC (where appropriate). You should provide examples of actual impacts that the NIHR ARC's research and implementation activities have had on health services, health policy, or public health detailing how research findings have led to changes in the way services are delivered to patients, both locally and further afield. Please consider the following impact example types that NIHR ARCs could provide:

- **Influencing policy, clinical guidelines or service improvement;**
- **Changes in service delivery, including service reconfiguration or service redesign, patient or care pathways, or patient safety**
- **Improved patient/public/ service user outcomes, social or clinical outcomes; and/or**

- **Economic impact, net health benefits, improvements to efficiencies in health and care system/NHS, boost to industry**

Impact is referenced throughout the report and AVEs. From many possible examples, these were chosen to illustrate the breadth of impact.

Social prescribing

There is substantial interest amongst local service partners, and nationally, in the role that social prescribing can play in promoting wellbeing and reducing service use. Our programme aims to assess the evidence for what works and to make it easily usable for services.

DEFRA (Department for Environment, Food and Rural Affairs)-funded work involved describing current provision and clarifying what works in nature-based therapeutic programmes for diagnosed mental health conditions and informed subsequent DEFRA/NIHR funding calls. We worked closely with local Health and Social Care Partnerships and policy makers (e.g., Defra, DHSC, NHSE, MHCLG) to evaluate the £5.5 million investment in seven 'test and learn' sites targeting seriously COVID-19-hit communities in England, reporting emerging findings to shape efforts to embed green social prescribing into practice.

We led a National Academy for Social Prescribing (NASP) academic partnership on social prescribing to produce accessible and useful evidence. With partners including NHSE and NHS Improvement we produced seven evidence briefings (e.g., the economic impact of social prescribing and the accessibility of schemes to people from Black, Asian and ethnically diverse population groups), presenting findings to policy makers, VCSE sector leaders and the All Party Parliamentary Group for Health and the Natural Environment. Our economic briefing helped make the case for NHSE to continue investing in the NHS Link Worker programme.

ExCHANGE

There is a large private sector-owned care homes industry in the region and a relatively large population of older people. The ExCHANGE Collaboration is a partnership with the SWAHSN, Devon Care Homes Collaborative (250 independent care providers committed to improving residents' lives through continual improvement) and funders (Alzheimer's Society, Dunhill Medical Trust). Working with residents, carers and staff, we aim to develop the capacity of people living and working in care homes to engage with and use research; mobilise knowledge by improving communication between stakeholders and collaborators; and identify important problems in care home practice that we can address through collaborative research and implementation.

The Collaboration has brought about widespread change in local care homes, including the introduction of "research champions", and has directly contributed to the growth of the NIHR's ENRICH (Enabling Care in Research Homes) programme (previously underdeveloped in the Southwest). It has also delivered an adapted version of our "Making Sense of Evidence" workshops to a range of stakeholder groups. Social Care Wales is interested in using our workshop model and we are in discussions with them about its delivery there.

Health Service Modelling Associates

Amongst numerous products from our HSMA programme was a "Vaccination Clinic Model" (based on generic Free and Open Source), produced in response to the pandemic, which minimises resource use and opportunities for infection. The model allows users to test approaches, predicting queue lengths and the risks of breaching capacity. It was used in primary care in North Devon to underpin vaccine rollout. The model is now being used elsewhere in the region.

6. Public and Community Involvement, Engagement and Participation (PCIEP) (no more than 1000 words)

6.1 Please give a brief summary of progress in implementing your PCIEP strategy.

In particular, please describe any work you are doing to embed the UK Standards for Public Involvement in your Facility. For example, any plans for addressing:

a) Diversity and inclusion;
b) Public involvement in governance; and
c) Capturing and reporting on impact as a result of your PCIEP strategy.

6.2 Please highlight any significant challenges or barriers experienced, and identify any areas where you would like further support or information.

A central PenARC principle is that public collaborators are partners in research on equal footing with other partners. Our work is guided by our strategy Patient & Public Involvement & Engagement - PenARC (nihr.ac.uk) and the NIHR Standards for public involvement.

Aim 1: To build on and develop the involvement and engagement legacy of PenCLAHRC
Within PenCLAHRC we developed a culture of meaningful public involvement in every aspect of our work, underpinned by appropriate resourcing. We have continued this approach, including providing: a dedicated administrator who helps public collaborators with practical requirements to access research meetings, training based on expressed needs by public collaborators and researchers, payment to public collaborators for their time and partnership with the Peninsula Public Engagement Group (PenPEG). PPI expenditure in 21/22 was £176,789.

Aim 2: To run a programme of involvement that is experienced as engaging and creative, which facilitates the excellent research that can be achieved with meaningful public collaboration
Online meetings have enabled us to reach a wide geographical area and people with diverse backgrounds. We use online tools to make these engaging, for example Miro Boards, Mentimeter, music and images. For some meetings we post tea/coffee/biscuits and a printed agenda to attendees in advance. We have organised social events, for example an online Christmas party with a quiz.

A regular newsletter, produced with and for public collaborators called 'Connect' brings together the personal and research-focused aspects of our PPIE work.

Our team and PenPEG members have offered 21 ideas cafes and 34 advice clinics to researchers, and run 5 joint journal clubs for public collaborators and researchers.

In this financial year we have processed c.750 payments to 125 public collaborators.

Aim 3: To reach a diverse group of public collaborators through proactive, varied and creative involvement and engagement activities, formed through working together
Our public collaborators are diverse in age, gender, education and occupation. Kristin Liabo has worked with refugees to co-produce research, which successfully gained funding to start in May 2022. Refugees' central role in the co-creation process was essential in designing this community-based study.

We actively seek opportunities for widening contacts. Examples include:

- Contributing to a local church event, part of a national initiative to build bridges between the Christian church and science.
- In the DREAM study with older patients, an in-person advisory group has been established in addition to one that meets online. People without internet access and/or

language barriers meet with someone in their community who subsequently briefs the research team about the group's views.
- We are working with a food bank and their users in Torbay, with a team member taking an embedded approach, including participating in their user-led wild water swimming group.

In our work with minoritized populations we have met with community leaders and third sector colleagues to consider how we build and maintain relationships, create mutual understanding, and engage diverse communities in research meaningfully. Key partners are the public collaborators already involved in PenARC's work. PPIE Team members have completed Diversity, Inclusion, Cohesion and Equality (DICE) training led by BeCohCo.

Aim 4: To integrate public involvement at the heart of PenARC to support early and ongoing involvement in research
Monthly PPI cafes for researchers to meet with PenPEG members to discuss research ideas are fostering early involvement. Advice "clinics" focus on how to work meaningfully with public collaborators and embed the NIHR involvement standards in their work. They are in huge demand.

Aim 5: To research and evaluate involvement so that we can improve practices and capture involvement impact
Members of PenPEG and the PPIE team co-designed a survey of PenARC involvement, focused on communication, experiences of involvement, and values. This was distributed to all public collaborators involved in PenARC in 2021 (n=125), the response rate was 62% (N=78). Findings from the survey were shared at an online event in January 2022, attended by 44 people.

We have reviewed feedback on involvement meetings for the past year. This, and the survey event, did not surface any concerns but prompted discussions on what we mean by feedback (from who and on what), and we will develop this further.

We produced an infographic on what 'good' looks like in PPIE Patient & Public Involvement & Engagement - PenARC (nihr.ac.uk) The BMedSci student on placement with the team in 2020-21 analysed impact of PPIE. Her report received a 1st, now being prepared for publication. A report in *The Scientist* https://www.the-scientist.com/careers/how-to-bring-the-public-into-the-scientific-process-69776 profiled Kate Boddy and Malcolm Turner.

Aim 6: To enable and support researchers, health and social care service providers and members of the public to build their capacity for collaborative work
PPIE Team member Naomi Morley leads involvement in two National Priorities: Ageing and Child Health & Maternity. She has used the 'community of practice' model to bring project leaders and public collaborators together and work towards a common goal of creating and sharing learning of meaningful involvement and overcoming barriers. The groups have addressed digital exclusion, creative ways to involve persons living with dementia, working on sensitive topics, and creating a safe space.

PenPEG member Angela King and Naomi Morley updated our PPIE teaching resources for MSc students. PenPEG member Lynn Tatnell and Kristin Liabo delivered PPIE training to allied health professionals at the South West Clinical School in Cornwall.

Significant challenges or barriers experienced in the last year, and areas where we would like further support or information
The PPIE team capacity was significantly impacted by Covid-19 through school closures and staff and family sickness.

Further support would be welcomed on how to work with communities when a research application is rejected and innovative plans for collaborative work are put on hold or side lined by new funding calls. There is a tension between the impact-driven agenda of the research community and the need to develop meaningful and reciprocal relationships with under-served communities. Similarly, writing about relationships in a report can feel like we are instrumentalising these relationships to our own gain. Advice on how to do this sensitively would be welcomed.

7. Academic Career Development (formerly Training) (no more than 1000 words)

7.1 Progress. Please provide progress against the academic career development plans outlined in your approved application, addressing any feedback provided by the review panel. Please include any additional objectives for the coming year.

a) **Regarding research capacity building;**
b) **Regarding NIHR Academy members.**

(a) The online Making Sense of Evidence Programme (MSE) delivered 18 workshops, a masterclass and a seminar to 234 delegates, including GPs, public health specialists, consultants, nurses, therapists and healthcare assistants. Two workshops comprised newly developed sessions for Care Home staff as part of ExCHANGE.

The current (4th) round of the Health Service Modelling Associates (HSMA) Programme was opened to anyone working in health, social care or policing anywhere in England. We had 300 registrations of interest and accepted 80 HSMAs working across 18 projects, many focused on using modelling and machine learning methods to tackle backlogs in health and social care. We recruited 11 "trainee mentors" for the programme, comprising modelling and data science academics, practitioners and HSMA alumni from across the country. Trainee mentors access the same training but provide project mentorship in the second phase. We have recently secured funding to run the fifth (beginning October 2022) and sixth rounds of HSMA at a national scale for 200 HSMAs and 40 projects.

(b) Each of our five themes has a linked PhD student and two as part of our TriARC network, all of whom have completed the upgrade from MPhil to PhD. Two reciprocal studentships funded by ARC Y&H and NT, with supervisors from PenARC, have also commenced their studies. Students have published their work and presented at conferences, with one (Taylor) being awarded the President's prize at the British Geriatrics Society Conference.

Alongside ARC West and Health Education England Southwest in 2021, we awarded 8 ICA internships, pre-doctoral and post-doctoral bridging awards. We meet awardees quarterly to monitor progress and support next steps including PCAF, DCAF or ACAF applications. The 2022 round is open, and we hosted a webinar to launch the awards on 29/3/22, attended by 39 delegates from backgrounds including dietetics, healthcare science, midwifery, nursing, pharmacy, physiotherapy, psychology, radiography, and speech and language therapy. We meet quarterly with the AHP, healthcare science, pharmacy, and nursing leads from HEE SW to develop and monitor our regional ICA programme. A SW strategic research workforce development capacity and capability task and finish group, supported by the HEE SW Senior Leads Team, has been established to identify the research development needs for our health, social care, and scientific workforce.

7.2 Deviations. Please describe any deviations or barriers to meeting your academic caree development objectives, and provide details of how these are being addressed.

a) **Regarding research capacity building;**
b) **Regarding NIHR Academy members.**

(a) All our capacity building programmes (MSE, HSMA and methodology clinics) remained online during the reporting period. Face to face sessions are being re-introduced in line with government and university guidance during 2022.

(b) Two Academy members have had university supported COVID extensions to their PhDs and two have moved to part time study due to changes in personal circumstances.

7.3 Impact. Please describe what has worked well and provide examples of impact. Examples of academic career development impact may include (but are not limited to):

- **Training courses/teaching that have been particularly successful that could be shared with other parts of the Infrastructure;**
- **Preparatory fellowships/funding that have led to successful applications for personal/career development funding;**
- **NIHR Academy members leveraging additional research funding.**

Our ACD Lead (Goodwin) and Academy Members meet as a group 6-monthly and are in regular contact. In 2021, they had an off campus awayday discussing post-doctoral fellowship opportunitites and an academic writing workshop, using Lego Serious Play © to facilitate discussions and thinking.

Supporting Fellowship applications: Our ACD lead and ARC staff have supported the development of applications for NIHR Fellowships across the NIHR Academy programme including internships, pre-doctoral, Development and Skills Enhancement (DSE), post-doctoral bridging and advanced fellowships. Successes include Advanced fellowships (Atkins, Bailey and Masoli), Pre-doctoral clinical academic fellowship (Tansley), pre-doctoral fellowship (Wilkinson), post-doctoral bridging awards (Collings and Lyndon) and SPCR post-doctoral fellowships (Hall and Cockcroft). Support includes advising on proposals and running mock fellowship interview panels.

Two Academy Members have been awarded additional research funding (From the Violence, Abuse and Mental Health Network (Allen) and the NIHR/Autistica Social Care Action fund (Featherstone).

7.4 Collaborations. Please give details of ongoing or planned collaborative academic career development and research capacity building activities with other parts of the NIHR infrastructure, wider NIHR and other partners.

We run 3-monthly collaborative workshops with ARC West for the successful regional NIHR ICA Internship and bridging fellowship Academy Members, providing mentoring and support to prepare for fellowship applications and allowing the Academy Members to present their research.

In collaboration with our TriARC partner from ARC NT and Y&H we have developed a Economic Evaluation workshop for the health and social care community.

For our Academy members we encourage and support applications to the IVSA and SPARC awards. In 2022, (Taylor) was awarded an NIHR SPARC award in conjunction with ARC Greater Manchester to develop her learning around diverse and inclusive PPIE.

Goodwin (ACD Lead) represents ARCs on the NIHR Academic Career Development Forum steering group. She is planning a re-establishment of regular ARC Leads meetings to share practice and learning opportunities.

7.5 Equality, Diversity & Inclusion. Please outline how you are supporting equity of opportunities through capacity building and training offered.

Recruitment of Academy Members is conducted with at least one male and female panel member,

and panel members complete equality and diversity and recruitment and selection training.

We offer flexible working arrangements for our Academy Members with the option for office, home-based or hybrid studying. Part-time studying is fully supported around the needs of individuals, including equipment. Local Academy member events are planned around the needs identified by members themselves. Academy members are based across the region, and we work with them to plan venues, accessibility and timings for face-to-face events ensuring inclusiveness in terms of travel times, caring responsibilities, and health needs.

7.6 Sharing best practice. Please provide a short paragraph summarising your academic career development and research capacity building activity over the past year that can be circulated to all other academic career development leads. Please include any highlights, novel or innovative approaches to academic career development.

Our training aims to both develop the researchers of the future and increase capacity within the health economy to use and generate evidence. We have well-supported PhD students and an active programme in the ARC and partner organisations to provide staff with research training and to help them work towards post-doctoral fellowships. Academy Members have the opportunity to work with others in the TriARC collaboration and are encouraged to make the most of opportunities in the NIHR Academy.

We offer a range of opportunities for staff and PPIE group members to develop their skills from regular methodology "clinics", to short courses such as MSE, to longer secondments such as the HSMA programme. These activities are both valuable in themselves but also provide the basis for long term relationships to help drive impact.

7.7 Expenditure on training. Please specify 202/21 NIHR spend on academic career development. For ARCs, please include any official co-funded expenditure.

Please provide the overall amount of expenditure on academic career development for this reporting period. This should include:

- **Cohort costs for networking/training/events for multiple NIHR Academy members;**
- **Salary and support costs for NIHR Academy members (can include items such as travel, training, equipment, consumables and PCIEP costs); and**
- **Costs for wider academic career development and development.**

The salary and support costs for NIHR Academy Members during the period totalled £110,527. A further £10,588 was spent on wider academic career development.

A total of £108,259 was spent on networking/training/events, of which £105,147 (over 97%) was leveraged as co-funding from our Health Service and Police Service Modelling Associates (HSMA and PSMA) programmes.

8. Links with NIHR Infrastructure (no more than 500 words)

It is a contractual requirement/expected for NIHR ARCs to use reasonable endeavours to work with, collaborate and generate synergies with other elements of the NIHR Infrastructure [*e.g.* with Biomedical Research Centres (BRCs), Clinical Research Facilities (CRFs), MedTech and In Vitro Diagnostic Co-operatives (MICs), Health Protection Research Units (HPRUs), Translational Research Partnerships (TRPs), NIHR BioResource, MRC/NIHR Phenome Centre, Experimental Cancer Medicine Centres (ECMCs), Clinical Research Networks (CRNs), the Translational Research Collaborations (TRCs), and the Patient Safety Translational Research Centres (PSTRCs) and NIHR Innovation Observatory.

Please provide specific examples of the work undertaken in collaboration with other NIHR funded infrastructure involved in the research, and their role/contribution.

Bringing together ARCs offers the opportunity for wider impact than can be achieved in one area alone. There has been considerable strengthening of cross-ARC activities over the last two years, in part facilitated by the development of the national priority themes. PenARC leads the Children's Health and Maternity (CH&M) national priority area (Section 13) which has adopted four projects, including one each in collaboration with the Inequalities and Prevention Themes, all including multiple ARCs. PenARC is also a member of the consortia leading for Ageing and Dementia, Inequalities, Health Promotion and Prevention themes and our staff lead or are co-apps on projects within the Multimorbidity, Inequalities, and Ageing and Dementia themes. All ARCs came together to coordinate our response to the request from NHSE to evaluate key questions posed from the Better Care Network, including jointly funding a senior project manager to ensure that we avoided duplication and provided helpful responses.

PenARC leads nationally on Operational Research Modelling (Section 12) and has been extremely active in engaging with other ARCs, NHS organisations and academics during the pandemic to help coordinate modelling activity related to Covid-19 demands and now the recovery process.

The TriARC partnership, jointly with Yorkshire and Humber and North Thames ARCs, includes joint projects and four jointly supervised PhD studentships in areas of ageing and frailty and child mental health. In addition, this has helped to boost collaboration around methodology, particularly related to PPIE and implementation science.

We have ongoing strong links with other elements of NIHR infrastructure, including:

- **NIHR Clinical Research Network (CRN) South West Peninsula.** As discussed elsewhere, over this period we have worked closely with the CRN and SWAHSN to better coordinate our interactions with the regional NHS and SC. Our aim is to ensure that each organization is able to direct partners to the appropriate source of expertise. In addition, we are coordinating our capacity building activities, avoiding duplication and publicizing each other's offerings across our networks. We have recently used the opportunity afforded by the MHRI (Section 14) to launch a joint "Internship" scheme with the CRN, designed to attract staff from within health and social care who are considering a career in research. This will offer exposure to research, training tailored to individual needs and mentorship to support Fellowship applications for appropriate candidates.
- **NIHR Research Design Service (RDS) South West.** We have worked closely with the RDS to ensure coordination of support for grant applications, combining ARC stakeholder engagement and RDS's system of peer review and support.
- **NIHR Exeter Clinical Research Facility.** We have developed shared standard operating procedures, joint training, and collaboration between methodologists
- **Peninsula Clinical Trials Unit (PenCTU) and Exeter Clinical Trials Unit.** We work closely with both local CTUs and share staff, methodological expertise and standard operating procedures.
- **NIHR Policy Research Unit in Cancer Awareness, Screening and Early Diagnosis.** We (Ukoumunne, Pitt, Hamilton) work with the PRU, with a particular focus on producing tools to facilitate early diagnosis of cancer within primary care

9. Links with Industry (no more than 500 words)

Please describe your NIHR ARC engagement with industry. Please ensure that this section refers to your progress against your plans for links with industry as outlined in your approved application. Please provide a small number of key examples to highlight progress (a full list is required in the F&A report).

In completing this section please consider the following areas, where relevant to your specific activities:

- **NIHR ARC's progress against its strategy for engaging with industry, describing any significant successes or any challenges faced during the financial year 2021/2022.**

We are on track against our targets in this area. As described elsewhere, we have significantly strengthened our collaboration with the SWAHSN and CRN which is key to this area. In particular, working with them and the developing ICSs, and industry partners, we are boosting local capacity in data analytics, facilitated by funding from HEE for our HSMA programme. Our active joint capacity building programme seeks to develop the capacity of practitioners to engage in research as local investigators including engaging in industry related research, especially clinical trials, something identified as a barrier to local engagement in commercial research.

Based on a model developed in Manchester, these partners are establishing an "Innovation pipeline". The aims include early identification of potential innovation relevant to problems facing the local health economy, a single point of access through any of the partners to route people to the appropriate partner, and straightforward access to resources to facilitate evaluation of innovations and their adoption into the system.

- **Any strategic plans for increasing engagement with industry that are not outlined in your application.**

We continue to develop an effective approach to providing PPIE input for industry partners who wish to conduct clinical trials. Our MRC-funded 'Widening patient engagement in orphan drug trials' now involves a collaboration with a European-wide pharmaceutical company (Galapagos) to support patient contribution to the design of clinical trials for rare diseases (currently working with people diagnosed with idiopathic pulmonary fibrosis (IPF)).

- **Key examples of working with Small and Medium Enterprises (SMEs), related to the list requested in the Finance & Activity Report).**

Our key partnerships with SMEs relate to the care home and child and youth sectors (see below). Our recent Social Care Research capacity building bid involved the wider care sector and is under stage 2 review.

- **Details of:**
  - **Any new strategic partnerships between your NIHR ARC and industry during the financial year 2021/2022 related to the list requested in the Finance & Activity Report;**
  - **The progress of ongoing strategic partnerships between your NIHR ARC and industry during the financial year 2021/2022.**

NOTE: ***For the purposes of this report a strategic partnership/collaboration with industry is where there is a long term relationship with an industry partner, with evidence of mutual benefit (i.e. not just single collaborative projects). Examples could include being a preferred partner for industry, completing a series of studies with an industry partner etc.***

We have been working with Dartington Service Design Lab, Redthread (youth work charity) and Shift (service design agency) on KAILO, a project to develop, test and scale an evidence-informed framework to support local partnerships to co-design strategies that address the underlying drivers of poor adolescent mental health.

We worked with a range of partners e.g., Living Options Devon, Teignbridge Community and Voluntary Service, Torbay Community Development Trust, One North Devon, Sunrise, Wellbeing Exeter, on a researcher-in-residence project to map social prescribing projects in Devon, support their evaluation and share learning with sites to aid quality improvement.

We continue to work closely with Classic Care Homes (Devon) Ltd on projects to understand stakeholders' perspectives on implementing deprescribing in care homes (STOPPING) and develop and test a creative model of engaging care home practitioners and other stakeholders in research. (ExCHANGE).

We worked with Dartington Service Design Lab, Research in Practice and the Centre for Youth Impact to support 129 Youth Endowment Fund grantee organisations to understand the impact of COVID-19 on young people at risk of being drawn into violent crime and share learning about the most effective approaches to engaging with vulnerable young people during the pandemic.

Within the NIHR-funded Remote by Default project investigating digital and remote care in general practice, we worked with the Design Service in collaboration with Plymouth 'Deep End' practices to analyse practice websites and develop design options for how they could be changed and intercom system updated.

We continue to work in partnership with Network Canvass as part of the C2: Connecting Communities project, using their software to generate relational maps in low-income neighbourhoods to show the services and spaces where people connect.

- **Brief details of key examples of studies active in financial year 2021/2022, as follows:**
  - **Contract commercial studies;**
  - **Industry collaborative research studies; or**
  - **Other academic commercial research including Investigator-led industry funded clinical research.**

We are not currently involved in formal studies.

- **Please provide the number and key examples (including name of funder/grant scheme) of any partnerships or studies with industry which have led to further industry, public or charity research funding, including as part of consortia.**
  - **For each example please highlight whether the product is commercially available or not;**
  - **How many of the projects are in collaboration with industry compared to how many are not.**

We have no current industry studies which have led to further funding

- **Please provide brief details of key examples of agreements signed with industry including:**
  - **Non-Disclosure Agreements;**
  - **Model Trial Agreements, including mICRA and mCTA.**

None

10. Co-Funding (no more than 500 words)

A fundamental requirement of the NIHR ARC funding scheme is the demonstration of additional funding contributions from member organisations in the collaboration. Co-funding (financial or other contribution) to support research and/or implementation activity from health and care member organisations (*e.g.* NHS organisations, local authorities, public health and care organisations) to a minimum of 25% of the level that NIHR provides for the designated and funded NIHR ARCs for the first year of the award and additional co-funding (financial or other contribution) from the University member organisation(s) for the duration of the contract. NIHR ARCs will be further expected to confirm annual commitments for co-funding (financial or other contribution), from health and care member organisations, for each subsequent year over the contracted period.

Please provide (where appropriate):

- **A narrative on key activities supported by the co-funding received in the reporting period allocated for;**
    - **i) research and;**
    - **ii) implementation;**
- **A narrative on key achievements arising from the co-funding received in the reporting period, clearly indicating the Specific Theme type it sits within and whether the achievement relates to applied health research and/or implementation; and**
- **Information on any new partners and co-funding commitments.**

The narrow definition of sources of co-funding (only from "members of our collaboration") substantially underestimates the external funding we attract to underpin PenARC activities. We have a national as well as local remit to attract funding from NHS and SC organisations beyond our region, from charities and the private sector. Our strategy is responsive to the needs of decision makers and projects often cross ***Themes*** and include elements of both implementation and research.

The following are some key projects supported by co-funding from collaboration members, though often also attracting other funding.

AHSN Partnership

The SWAHSN is a close partner and supports multiple joint projects, all primarily **implementation** (total value - £315,725).

Highlights include:

- **PenMHRI** (section 14) – design and delivery of the programme and commitment to a joint *Applied Mental Health Research & Service Improvement Lead* role ***(Mental Health Theme)***
- Design and delivery of the Health Services Modelling Associates Programme (HSMA) This programme enables Associates to develop skills in the use of OR modelling while solving problems for their organisations. The programme now has national reach and future funding (£333k) has been provided by Health Education England (***Methods for Research and Improvement Theme)***
- **ORCER**. Design of a toolkit to promote the use of remote consultation in secondary care in ways that increase effectiveness without leading to inequity (***Complex Care and Methods for Research and Implementation)***
- NHS Insights Prioritisation Programme (NIPP) –Evaluation to enable scale-up Community Assessment & Treatment Units (**CATUs**) in Cornwall and the Isles of Scilly's rural and coastal communities (***Complex Care and Methods for Research and Implementation)***

Torbay NHS Trust

- **Researcher in Residence Programme** (Primarily Implementation). This programme is now in its fourth year. Embedded researchers work with staff and service users to address complex issues related to service delivery. The current project concerns how multiple service innovations within the locality can contribute to providing coherent, person-centred care for people with long-term conditions (***Complex Care and Methods for Research and Improvement).***
- **PARC** - Peninsula Adult Social Care Research Collaborative (Primarily Research). This project aims to embed research teams into Social Care provider teams with the aim of improving outcomes (***Methods for Research and Improvement*).**

University Hospitals Plymouth NHS Trust

- **ProGroup** (Research). This study aims to establish group based treatment in Tier 3 weight management and then to evaluate efficacy and cost-effectiveness. The project devised with clinical partners has been awarded NIHR funding (***Complex Care***).

Somerset CCG

- **Community Mental Health Framework Pilot Evaluation** (Research and Implementation). This project seeks to evaluate 3 (Somerset is one of the three) of the 12 pilot sites across England testing potential models of delivery of community mental health services. The project uses rapid feedback to support site development, but the evaluation will also have an element of research, producing widely applicable knowledge (***Mental Health***).

Devon ICS (formerly STP)

- **DESSPERS** - The implementation and impact of social prescribing across Devon (Research and Implementation). This project sought to map and evaluate these services across Devon and contribute to rapid service improvement (***Mental Health and Complex Care).***

11. Collaborative work with Academic Health Science Network (AHSN) (no more than 500 words)

- **Please specify in what way the NIHR ARC is supporting the evaluations of AHSN priority programmes (local evaluations, high priority service innovations, such as digital innovations).**
- **Please provide details on any relevant research and implementation programmes co-produced/ongoing with the AHSN(s). In order to assess the relevance of these projects, you might want to consider the following points:**
    - **the project(s) value proposition, how the research addresses regional/local needs, the strength of evidence underpinning the project(s), the outcomes/outputs as well as the potential impact.**

Partnership with the South West Academic Health Science Network (SWAHSN) is key to our programme, bolstering our ability to facilitate service improvement with regional partners. This partnership is strengthened by cross-organisational involvement in governance arrangements, with Stuart Logan sitting on the SWAHSN Board and Jon Siddall (SWAHSN CEO) on the PenARC Management Board. Increasingly this has become a 3-way partnership, involving the CRN in our “Regional Programme for Adopting Innovation” (modelled on the Greater Manchester ARC and AHSN pilot).

We are coordinating a process of engagement and collaboration with the 3 regional ICSs, attempting to respond to their needs for capacity building, adoption of large studies, evaluation of local innovation and evaluation of implementation of imported evidence-based innovation.

SWAHSN links with our work on improvement and implementation, particularly in areas such as: mental health in Children and Young People (CYP), innovation in care homes, remote working, and health inequalities. In response to the Beneficial Changes Network we established a partnership with SWAHSN, AHSN West and ARC West to better understand effective use of remote working and produce a toolkit for services wishing to increase their use of this technology. The ORCER: Optimising remote consultation in elective recovery project is currently being piloted and will be made available across the NHS.

We seek to coordinate capacity building across organisations. An area of joint focus is in developing capacity through the effective use of data to underpin service delivery and improvement. The SWAHSN, PenARC and the Association of Healthcare Analysts support the Regional Information Analysts Network, bringing NHS business intelligence analysts together.

The HSMA programme was established initially using funding from SWAHSN and continues to be supported by their staff.

Projects in partnership with SWAHSN include:

- Collaboration across multiple projects to develop the evidence base for social prescribing **(Complex Care, Mental Health and Public Health Themes)**, including:
    a. Linking people to social prescription in primary care
    b. Defra Green Social Prescribing Evaluation
    c. Developing the evidence regarding the role of Social prescribing for Children and Young People
    d. Establishing a "researcher in residence" within Cornwall Council, linked to both the CCG and Public Health departments

- A programme of research developing and implementing best practice interventions for care homes, including: DACHA, CHIK-P, ExCHANGE and Care Home Conversations. **(Complex Care, Dementia Themes)**.

- The development of an Integrated Psychological Medicine Service within Royal Devon University Healthcare NHS Foundation Trust.

- A programme of research using Operational Research modelling to improve the effectiveness of acute stroke services, including the SAMueL – Stroke Audit Machine Learning project.

- As described in section 14, the SWAHSN is a full partner in our new Mental Health Research Initiative, in part because the areas of focus reflect AHSN priority areas in CYP mental health and addressing of inequalities in service provision.

- From application, to project prioritisation, we have collaborated to develop our National Insights Prioritisation Programme (NIPP) funded project: An Evaluation to enable scale-up of Community Assessment & Treatment Units (CATUs) in Cornwall and the Isles of Scilly's rural and coastal communities project.

12. NIHR ARC National Lead Area (no more than 300 words)

Please provide a brief summary of progress on the activities related to the NIHR ARC National Leadership Area.

- **Please provide a high-level summary of the key activities that have advanced and supported evidence generation and implementation beyond the NIHR ARC's local region.**
- **Highlight whether the leadership area work informed the identified NIHR ARC national priorities or any other national work programme specifying the mechanisms and stakeholders involved.**
- **Please describe how the NIHR ARC National Lead work has catalysed collaborative approaches with other NIHR ARCs and other NIHR-funded research infrastructure; and**
- **Highlight how the research supported by this initiative is taking place in areas of the country where the relevant disease burden and needs are greatest.**

PenCHORD, the operational research (OR) group within PenARC, has contributed substantially to developing capacity nationally.

The Health Service Modelling Associates (HSMA) programme, initially offered to PenARC partners was opened to organisations including the police service in 20220. The programme offers 1 year, I day/week secondments to develop skills in OR while addressing problems facing their host organisation. We have now acquired funding from Health Education England enabling

the programme to take participants for the next intake from the whole NHS. We have integrated tutors from across the UK to enable widespread use of course materials and approaches for capacity building.

The first cross-ARC OR meeting, scheduled in early 2020, was abandoned due to the pandemic. Instead in response to NHS need we established and now host the "National Covid-19 Operational Research Network (N-CORN)", with monthly meetings and an MS Teams resource base, bringing together OR researchers and NHS policy makers. Topics have included Covid demand and population analysis, end of life care modelling, vaccination roll-out simulations, workforce models and research to address elective backlogs. N-CORN has spawned a number of collaborations, successful grant applications and publications. It has provided a basis for health and care staff, such as those within the Demand and Capacity team at NHSE&I, to communicate needs and link with researchers.

PenCHORD has also led a range of collaborative research initiatives including work on national stroke modelling as well as a Health Data Research UK funded partnership with Bristol and Bath universities working on developing models for hospital efficiency and improving the interface between acute and community care.

Staff have led development of a comprehensive competency framework for health service analysts in the national Association of Professional Healthcare Analysts (Pitt is research liaison director of AphA).

13. National Priority Areas (no more than 1000 words)

Please list all the projects that underpin the NIHR ARC National Priority Area (NPA) that you are leading on using the table below. The purpose of the table is to provide a high-level introduction to each of the selected projects for the NPA so please use the minimum wording as possible.

ESMI-III: The Effectiveness and Implementation of Maternal Mental Health Services

- ***Consortia ARC(s)***
  - ARC South London (PI), Co-Is ARC North West Coast, ARC South West Peninsula
- ***Objectives:***
  - *Site mapping and Programme Theory Development (Phase 1)*
    - ***Status – Complete***
    - ***High-level activities***
      - NHS England and site document review
      - Stakeholder engagement
      - Findings analysed, report in progress
  - *Organisational Case Studies at 3-4 sites (Phase 2)*
    - ***Status – On track***
    - ***High-level activities***
      - Ethics application complete
      - Data collection (interviews; survey and collection of outcome data) await ethical approval

- ***Outcome measures/Impact***

Understand variation in service delivery models. Inform further development, scale-up and sustainability of maternal mental health services nationally

- **Further engagement plans for key stakeholders/partners and PCIEP;**
  - New advisory group specific to trauma related to childbirth and loss

- **ARC engagement with the wider NIHR and other Infrastructure schemes:**
  - Three ARCs collaborating

- **What supra-regional and/or national level structures facilitate the implementation;**

- Implementation led by NHS England, with whom the research team are working closely.

- **What contribution has the National Priority Area work made on the system/patient need(s) so far.**
  - This mapping exercise has identified key components of maternal health services and areas of variation in service delivery models.

BRUSH (optimising toothBrushing pRogrammes in nUrseries and ScHools)

- ***Consortia ARC(s)***
  - ARC Yorkshire and Humber (PI), qualitative data sites - ARC Greater Manchester, ARC South West Peninsula, ARC North East and North Cumbria
- ***Objectives:***
  - *Stocktake of toothbrushing programmes*
    - ***Status – On track***
    - ***High-level activities***
      - Ethics approval obtained
      - Data collection in process
  - *Qualitative interviews with key stakeholders in four areas of England*
    - ***Status - On track***
    - ***High-level activities***
      - Ethics approval obtained
      - Agreement from 4 collaborating sites
  - *Design and development of implementation toolkit*
    - ***Status - On track***
    - ***High-level activities***
      - Co-design of toolkit with children, parents and teachers ongoing
      - Involvement of national policymakers

- ***Outcome measures/Impact***

Documenting variation in toothbrushing programmes
Understanding determinants of implementation
Toolkit to support further implementation.

- **Further engagement plans for key stakeholders/partners and PCIEP;**
  - 2 PPI representatives in governance of project
  - Child and parent PPI groups established
  - Nursery engagement work for children on oral health.

- **ARC engagement with the wider NIHR;**
  - Collaboration of four ARCs.

- **What supra-regional and/or national level structures facilitate the implementation:**
  - Support and engagement from the national Child Oral Health Improvement Board, Chief Dental Officer and NHS E&I.

- **What contribution has the National Priority Area work made on the system/patient need(s) so far.**
  - A stocktake is underway to understand variation in implementation of toothbrushing programmes.

ADaPT: Assessment and delivery of PTSD treatments (for care-experienced young people)

- ***Consortia ARC(s)*** PI ARC North Thames and ARC West, Co-I ARC East of England, ARC North East and North Cumbria, ARC Wessex, ARC Yorkshire and Humber

- ***Objectives:***
  - *To identify the sector-, service- and professional-level barriers and facilitators of delivering tf-CBT to CEYP.*
  - *To add to the existing literature on tf-CBT, including providing further evidence for its effectiveness.*
  - *Assess acceptability of treatment to young people and services*
    - ***Status – all on track***
    - ***High-level activities:***
      - Recruitment of sites completed
      - Ethics review in process
      - Young person and professional advisory groups being established

● ***Outcome measures/Impact***
Assessment of:
- barriers and facilitators/acceptability;
- effectiveness and cost-benefits to health and social care system.

○ **Further engagement plans for key stakeholders/partners and PCIEP;**
- Recruiting to a care-experienced advisory panel and to a professional panel

○ **ARC engagement with the wider NIHR;**
- Discussions with multiple ARCs about infrastructure schemes for developing video resources for mental health professionals to increase the use of NICE recommended treatments for PTSD.

○ **What supra-regional and/or national level structures facilitate implementation;**
- Working with multiple ARCs and NHS trusts nationwide to facilitate local implementation. Clinical Research Network promoting the research to trusts and encourage participation.

○ **What contribution has the National Priority Area work made on the system/patient need(s) so far.**
- N/A – project in initial stages

Evaluating models of health-based Independent Domestic Violence Advisor (IDVA) provision in maternity services (RIVA project - mateRnIty Violence Advisors)

● ***Consortia ARC(s)***
- ARC South London (PI), Co-Is - ARC South West Peninsula, ARC North East and North Cumbria, ARC West, ARC Yorkshire and Humber

● ***Objectives:***
- *Mapping exercise of English NHS Trusts to identify and describe models of Independent Domestic Violence Advisors (IDVA) provision in maternity services*
  - ***Status - Complete***
  - ***High-level activities that contribute to achieving the objective***
    - Survey of Trusts with maternity services in England
    - Map the prevalence, diversity, and common characteristics of IDVA models
- *World Café event to learn how to support implementation and improvement of IDVA models in maternity services*
  - ***Status - On track***
  - ***High-level activities***
    - Ethics approval received
    - World Café planned with stakeholders
- *Case studies examining implementation of IDVA models in three Trusts*
  - ***Status - On track***
  - ***High-level activities***
    - Ethics application submitted
    - Site recruitment completed
    - Data collection will commence after ethical approval

● ***Expected/Realised Outcome measures/Impact***
Evaluating impact of increasing staff awareness of DVA on referrals to DVA risk management conferences, and increasing timely referral and access to DVA services.

○ **Further engagement plans for key stakeholders/partners and PCIEP;**
- PPI advisory group meet twice-yearly
- World café event: Online stakeholder workshop

○ **Whether this project has increased the ARC engagement with the wider NIHR;**
- A collaboration of five ARCs are delivering the project.

○ **What are the supra-regional and/or national level structures that facilitate the implementation process for the selected interventions;**
- A national domestic abuse agency (Safelives) tis providing additional implementation support to study sites.

○ **What contribution has the National Priority Area work made on the system/patient need(s) so far.**
- Carried out the first national mapping exercise of IDVA interventions in English NHS Trusts.

14. Mental Health Initiative (no more than 450 words)

Please describe any developments or updates on the NIHR ARC's progress:

- **in meeting the aims of the Mental Health Funding Initiative (up to 150 words);**
- **towards meeting its objectives, as described in the final proposal (up 300 words)**

We aim to increase the capacity and capability of the system to conduct Mental Health research in populations and geographies who are underserved or with unmet need. PenARC consulted with partners and agreed to focus on children and young people (CYP) and people with MH problems whose needs exceed the capacity of primary care but don't meet criteria for secondary care services.

Success will depend on collaborative relationships in local health and social care systems, including the 3rd sector, and meaningful PPIE. Key team members are in post and are establishing relationships at policy level in the ICSs, NHS and LAs and with those delivering and accessing services on the ground.

Services face significant challenges and we are designing collaboration opportunities which ensure that the programme offers tangible benefits to partners, making active partnerships with people with lived experience, clinicians across primary and secondary care groups and the voluntary sector.

Objective 1: To work with MH services and people with lived experience to identify and prioritise key evidence gaps.	To maximise the possibility of research impact we seek t partner with those who use services, who deliver them an who plan them. We are collaborating with policy makers in th ICSs and services, and service providers in primary an secondary care, social care, public health and voluntar sector. We have devoted substantial resources to developin active partnerships with service users, including thos traditionally ignored, working for instance with schools t connect with young people with experiences of CAMHS through foodbanks with people experiencing deprivation, a well as existing service-user groups.
Objective 2: To produce high quality MH research to serve populations with the highest needs	Our research programme is developing and projects include, inter alia: evaluation of a community-based intervention to improve access to mental health support; support for a CYP led research initiative to characterise and address research questions identified by CAMHS-experienced CYP; support to Torbay Public Health needs assessment for CYP self-harm; systematic review of brief interventions for homeless people with mental health difficulties and substance abuse as the basis for intervention development.
Objective 3: To increase the skills and capacity of staff within local services, the voluntary sector and universities to generate and use evidence.	Our capacity building programme (with SWAHSN, CRN an local partners) includes: • Internships (joint CRN) which aim to develop 'futur research leaders', providing training and a path t future fellowships; • Mental Health Associates, part-time secondmer programme to enable people working in services or 3 sector to develop expertise in conducting and usin research to address challenges in their work. "Mentoring" for service staff already doin research/evaluation, connecting them to expertise to improv research quality and develop skills.

Objective 4: To work with partners to facilitate service improvement based on research evidence.	We focus on problems facing services and public collaborators where evidence may lead to potential solutions and seek to ensure partners have a clear vision of how evidence can help them change services. Partnership with the SWAHSN, including a joint post, brings added expertise in service improvement.
Objective 5: To improve MH outcomes within our region	Though too early to have evidence of effects on MH outcomes but this remains a key aim.

Details of Added Value Example

1. Title of the AVE

Title of AVE (insert below) *[A short title using plain active language that summarises the impact (not the research finding)]*
Improving the experience of care for people living with dementia in hospital
Is this a new AVE? (insert '**Yes/No**' below)
YES
Is this an update of a previously submitted AVE?(insert '**Yes/No**' below)
NO
If this is an updated AVE, please provide the title and year of submission of the linked AVE (insert below)
NA

2. Concise impact Statement (maximum 100 words)

Briefly summarise, in plain English the impact of the research - what has changed, for whom, (and how, and to what extent) and why did this matter?
We developed a set of practical evidence-based 'pointers for service change' to help organisations better deliver person-centred care for people with dementia. Approximately two-thirds of hospital admissions are older adults and almost half of these are likely to have some form of dementia. People with dementia are not only at an increased risk of adverse outcomes once admitted, but the unfamiliar environment and routinised practices of acute care can heighten their confusion and agitation, further impacting the ability to optimise their care. It is well established that a person-centred care approach helps alleviate distress but how to embed this in the acute-care setting remains a challenge.

3. Background and impact information

Please provide a short paragraph in each box - around 250 words

Background summary
Describe briefly the key research insights or findings that led to the impact in this AVE, including why the research is important (*e.g*. overall prevalence of condition, and cost to society and/or NHS and social care) and the hoe long the research has taken to get this point (insert below).

There are over 55 million people worldwide with dementia and this is projected to double in the next 30 years. In the UK, one in four hospital beds are occupied with someone with dementia and the last 5 years has seen an increase of 35% of unplanned hospital admissions for people with dementia. People with dementia are more likely to spend longer in hospital once they are admitted and have higher rates of readmission once they are discharged. The unfamiliar environment and routinised practices of the wards and acute care is particularly challenging for people living with dementia. The absence of family and familiar surroundings, on top of the physical issue leading to the admission, heightens anxieties, confusion and distress. Challenges in communication can impact effective pain medication, hydration, nutrition and all aspects of physical and emotional care. Whilst these challenges have long been recognised, it remains an ongoing issue, and has been further impacted by the COVID-19 pandemic.

It is well established that a person-centred care approach helps alleviate some of the unfamiliar stress from being in the acute care environment. In this research we developed a set of evidence-based and actionable pointers for service change to help organisations and staff implement and deliver person centred care across the whole hospital environment.

The idea for the research came from conversations with carers and members of the Alzheimer's Society Research Network volunteers in 2016. They identified improving hospital care as being one of their top priorities. With their help, we sought funding to look at the evidence of how best to improve care for people with dementia in the hospital setting. We received NIHR HSDR funding in 2017 and completed our research at the end of 2019, which included development of a booklet and poster of the DEMENTIA CARE pointers for service change for use in hospitals. In 2022 the research and the DEMENTIA CARE pointers for service change were cited in the British Geriatric Society position statement on person centred care for people with dementia in hospitals.

Impact information

What change happened/is going to happen as a result of the research?

- Please provide details of the change which resulted from the research activities (*e.g.*, changes in policies, guidelines or practice, quality improvement, service redesign or ways of working,improved health outcomes, costs and/savings, *etc*).
- Outline briefly how your research has led to the change described, adding any (qualitative or quantitative) evidence you have to show these activities have led to change (insert below).

It is early days to demonstrate impact at the hospital level in terms of the DEMENTIA CARE pointers being included as policy or guidelines. However, an invitation to join the British Geriatric Society discussions around how to better embed person centred care for people living with dementia into hospitals, and the inclusion of our reviews and pointers in the Position Statement published Jan 2022, is a step towards this goal. We currently have a 'future horizons' article being considered by the peer-reviewed journal *Age & Ageing*, documenting the pointers in more details and highlighting the fact that they are underpinned by evidence, and developed through extensive consultation with stakeholders.

One of our key stakeholders Deborah Cheeseman (Consultant nurse for older people at the Royal Devon University Healthcare NHS Foundation Trust) is, as a result of her involvement in this project and its findings, undertaking her own research into the evidence base for how to better identify delirium for older adults in acute care. We will be working with Deborah on this and intend to seek further opportunities for capacity development.

Why does this change matter?
Please provide details on who has benefited/been affected (*e.g*. individuals, specific user/affected groups) from the change, and how, and to what extent (*e.g*. local, regional, and/or nationally) (insert below).

The NHS Long Term Plan (2019) committed the NHS in England to improving the care provided to people with dementia and their carers in hospitals and at home. The Prime Minister's Challenge on Dementia 2020 was clear and unequivocal: aiming to make England the best country in the world for dementia care.

The DEMENTIA CARE pointers for service change highlight institutional and environment practices and processes that warrant consideration for those aiming to improve the experience of care in hospital for people living with dementia, their carers and the staff providing care. It is evident that implementing these changes could improve the hospital experience for every patient, but they are likely to bring most benefit to those in need of reassurance, comfort and understanding.

What was NIHR's contribution to the change?
Outline the NIHR ARC's role and contribution towards the change (insert below).

Providing infrastructure support to enable lead applicants to explore research uncertainties with carers and family members, develop and build on relationships with relevant stakeholders, prepare the funding application and deliver the project.

Where impact is in the early stages yet to be fully realised, describe how the research findings will be taken forward to facilitate impact in the future (*e.g*. knowledge mobilisation, patient and public involvement, capacity building or engagement activities) (insert below).

It is early days to demonstrate impact at the hospital level in terms of the DEMENTIA CARE pointers being included as policy or guidelines. However, an invitation to join the British Geriatric Society discussions around how to better embed person centred care for people living with dementia into hospitals, and the inclusion of our reviews and pointers in the Position Statement published Jan 2022, is a step towards this goal. We currently have a 'future horizons' article being considered by the peer-reviewed journal *Age & Ageing*, documenting the pointers in more details and highlighting the fact that they are

underpinned by evidence, and developed through extensive consultation with stakeholders.

We have also worked with the Policy@Exeter Unit in the last year to produce a 'Policy Brief' about 'Improving hospital care for people with dementia', and this is currently hosted on the Exeter University (link is available in section 8)

We have a designated page on the PenARC website called 'Caring about Care' which describes the project in both scientific and lay terms and provides links to the many and varied outputs from the project, including a briefing paper, blogs and peer reviewed research papers.

4. Engagement with wider stakeholders

Outline the role/contribution of other stakeholders/partners (*e.g.* other research funders, research teams, health and social care providers, voluntary and community sector, universities, NHS, public involvement groups, commissioners, policymakers, industry, ICS, etc) towards bringing about the change(s) (insert below).

The idea for the Caring about Care project came from a meeting with Alzheimer's Society Research Network volunteers, researchers, health practitioners. At the meeting we discussed what was needed most to improve things for people with dementia. How to improve the experience of care for people with dementia was seen as one of the most pressing issues, particularly by former carers at the meeting who had experience of hospital care. This formed the foundation for this study. We took this idea, and with the input of the same former carers and Alzheimer's Society Research Network volunteers, applied for funding to undertake the three systematic reviews to help us understand the experience of care for people with dementia in hospital and how care can be improved.

An Expert Advisory Group (EAG) worked with us on the reviews. The group comprised former carers who were members of the Alzheimer's Society Research Network, healthcare practitioners (geriatric consultant and nurse specialists), care home staff, age concern staff and researchers with methodological and dementia expertise. We also had an Admiral nurse and a representative from Age UK and Hospiscare.

5. Collaboration/involvement of other NIHR infrastructure or programmes

Please specifically identify other NIHR funded infrastructure or research programmes and/teams, involved in the research, and their role/contribution (insert below).

The research underpinning the development of the DEMENTIA CARE pointers for change was funded through an NIHR HSDR grant (16/52/52) and supported by PenARC staff.

6. Dissemination and communication beyond academia/research setting

Please provide details, and examples of how you have communicated the outcomes of your research **outside** the academic or research setting. This may include materials/resources for patients, public, clinicians, health and care professionals, policy makers or other stakeholders, and include alternate formats, style and approaches (*e.g.* workshops, networks, press releases, social media, briefings, infographics, videos, animations, etc).

We have shared our research findings and draft DEMENTIA CARE 'Pointers for Service Change' resource with i) the National Dementia Action Alliance Taskforce, ii) the South West Mental Clinical Network 'Dementia Improvement Group' and iii) more locally, the Royal Devon University Healthcare NHS Foundation Trust 'Care Matters Meeting'. At all three meetings, it was clear that the findings resonated well with stakeholder group experiences and the discussions helped shape and consolidate our DEMENTIA CARE pointers for service change resource.

Having been invited to present the DEMENTIA CARE pointers at the British Geriatric Meeting, we have since been in discussion with them about how to take the findings of the research and the pointers further. In the first instance, the research findings have been included as evidence in the *Position Statement* put forward by the British Geriatric Society Dementia Special Interest Group for the delivery of person-centred care for people with dementia in hospitals. On the back of this, we were also invited to write a commentary about the challenges of delivering person centred care and to highlight the pointers further.

We have also employed several dissemination strategies:

- We worked with the Policy@Exeter Unit to produce a 'Policy Brief' about improving hospital care for people with dementia, and this is currently hosted on the Exeter University (link is available in section 8)
- We have written a briefing paper hosted on the PenARC website (link in section 8)
- We created a visual summary of the findings to be used as a poster and a booklet for easy access for hospital staff, and shared with stakeholders involved in the project
- We have a designated page on the PenARC website called 'Caring about Care' which describes the project in both scientific and lay terms and provides links to the various outputs from the project
- We have written blogs and used social media such as twitter to routinely disseminate messages showcasing the project findings

7. Next steps

Please highlight any follow-on funding, collaboration or further research plans. Where applicable, provide further details (including name of organisation, relevant stakeholders/groups, or company - including type of industry, where relevant - research funder details, nature of further research, future plans (insert below).
Are there any factors that might prevent or reduce efforts to achieve or further maximise your impact?
The pandemic has slowed wide scale dissemination of the booklet – many of the recommendations became impossible to implement due to COVID-19 restrictions. As these restrictions reduce we will seek further dissemination. We hope that the publication of a Research Horizons paper, showcasing the DEMENTIA CARE pointers for service change, within the journal *Age & Ageing* will continue to keep the research findings current as the NHS emerges from the pandemic.

8. Evidence and References (if applicable)

Provide a list of the most significant evidence (key sources and/or references) underpinning this example (titles and hyperlinks where applicable) (insert below). Evidence may include: policy documents, reports, datasets, news articles, videos, news reports, testimonials, quotes, weblinks, awards, reviews. ***For publications, please include the link to the Digital Object Identifier (DOI).***
Cited in: **Position Statement: Person-centred acute hospital care for people with dementia,** British Geriatric Society Dementia and Related Disorders SIG, January 2022 • https://www.bgs.org.uk/resources/bgs-position-statement-person-centred-acute-hospital-care-for-people-with-dementia Outputs – A5 booklet • https://drive.google.com/file/d/1-dK85cK-jR71r7ouQ6oPEK510fVp51Tw/view Outputs – briefing paper • https://drive.google.com/file/d/1O48YrH7fFx9LqhO2FrSOR_-hJqorUx43/view Outputs – Exeter University policy brief • https://www.exeter.ac.uk/media/universityofexeter/research/policy/briefs/R_Abbot_M_Rogers_Improving_dementia_care_in_hospitals.pdf Outputs – Invitations to present:

- Foundation meeting on Dementia for members of the public, Torbay & South Devon NHS Foundation Trust, Devon, May 2020 (but cancelled due to Covid-19)
- Dementia Steering Group, Torbay & South Devon NHS Foundation Trust, January 2020

Outputs – peer reviewed articles:

- Abbott RA, Cheeseman D, Hemsley A, Thompson Coon J. Can person-centred care for people living with dementia be delivered in the acute care setting? Age Ageing. 2021 Jun 28;50(4):1077-1080. doi: 10.1093/ageing/afab065.
- Lourida I, Gwernan-Jones R, Abbott R, Rogers M, Green C, Ball S, Hemsley A, Cheeseman D, Clare L, Moore D, Hussey C, Coxon G, Llewellyn DJ, Naldrett T, Thompson Coon J. Activity interventions to improve the experience of care in hospital for people living with dementia: a systematic review. BMC Geriatr. 2020 Apr 10;20(1):131. doi: 10.1186/s12877-020-01534-7
- Gwernan-Jones R, Abbott R, Lourida I, Rogers M, Green C, Ball S, Hemsley A, Cheeseman D, Clare L, Moore DA, Hussey C, Coxon G, Llewellyn DJ, Naldrett T, Thompson Coon J. The experiences of hospital staff who provide care for people living with dementia: A systematic review and synthesis of qualitative studies. Int J Older People Nurs. 2020 Dec;15(4):e12325. doi: 10.1111/opn.12325.
- Gwernan-Jones R, Lourida I, Abbott RA, Rogers M, Green C, Ball S, Hemsley A, Cheeseman D, Clare L, Moore D, Burton J, Lawrence S, Rogers M, Hussey C, Coxon G, Llewellyn DJ, Naldrett T, Thompson Coon J. Understanding and improving experiences of care in hospital for people living with dementia, their carers and staff: three systematic reviews. Southampton (UK): NIHR Journals Library; 2020 Nov. DOI: 10.3310/hsdr08430

Outputs – presentations:

- Improving the Experience of Care for People with Dementia in Hospital: Synthesis of Qualitative & Quantitative Evidence, British Geriatric Spring Meeting, April 2019
- Improving the experience of care for people with dementia in hospital: Synthesis of qualitative and quantitative evidence, development of a logic model and co-production of plans for practice change, Alzheimer's Society Conference, May 2019
- Improving the Experience of Care for People Living with Dementia in Hospital: Synthesis of Qualitative & Quantitative Evidence, Alzheimer's Association International Conference, July 2019
- Improving the experience of care for people with dementia in hospital: Synthesis of qualitative and quantitative evidence, development of a concept model and co-production of plans for practice change, Health Services Research UK Conferences, July 2019

Outputs: BLOGS

- Our reflections on the British Geriatric Society Spring Meeting 2019 where we presented early findings from the project – Tri yn mynd ar antur yn y gwanwyn
- Our reflections on the Alzheimer's Society Meeting where we presented early findings from the project in May 2019 – Cricket bats and conversations
- Sharing thoughts on our early findings and asking for feedback – What matters to you matters to us

9. Health category/ field of research

Please indicate 'YES' to **all** that apply.

UKCRC Health Category	**Please indicate 'YES' where applicable**	**NIHR priority Areas / Fields of Research**	**Please indicate 'YES' where applicable**
Blood		Artificial Intelligence	
Cancer and Neoplasms		Equality, Diversity, & Inclusion	
Cardiovascular		Patient & Public Involvement (PPI)	
Congenital Disorders		Prevention agenda	
Ear		Health information technology/ digital transformation	
Eye		Levelling up (research following burden of patient need)	
Infection		Innovative clinical trials	
Inflammatory and Immune System		Research addressing health inequalities	
Injuries and Accidents		Healthy ageing	
Mental Health		Multiple long-term conditions	
Metabolic and Endocrine		Med-tech	
Musculoskeletal		Covid-19	
Neurological		Public health	
Oral and Gastrointestinal		Obesity/ healthy weight	
Renal and Urogenital		Dementia	YES
Reproductive Health and Childbirth		Diabetes	
Respiratory		Antimicrobial resistance	
Skin		Social care	
Stroke			
Generic Health Relevance			
Disputed Aetiology and Other			

NIHR ARC - Added Value Example (AVE) Guidance and Form

1. Title of the AVE

Title of AVE (insert below) *[A short title using plain active language that summarises the impact (not the research finding)]*
Co-production of resources to support well-being for people living with dementia and their carers
Is this a new AVE? (insert '**Yes/No**' below)
No
Is this an update of a previously submitted AVE?(insert '**Yes/No**' below)
Yes
If this is an updated AVE, please provide the title and year of submission of the linked AVE (insert below)
Supporting people with dementia and their carers during the pandemic

2. Concise impact Statement (maximum 100 words)

Briefly summarise, in plain English the impact of the research - what has changed, for whom, (and how, and to what extent) and why did this matter?
This work was originally carried out in response to an obvious need for a source of support at a time when people with dementia felt abandoned during the pandemic. The powerfully positive reception we received for the Living with Dementia toolkit https://livingwithdementiatoolkit.org.uk/ has to led to it evolving into a resource that will outlast the pandemic. It was co-produced with members of the IDEAL programme involvement group and additional members drawn from previous co-production initiatives and based on evidence from our research programmes. The toolkit offers practical, evidence-based approaches for people with dementia and their carers which can help them to improve their well-being and enjoy a good quality of life.

3. Background and impact information

Please provide a short paragraph in each box - around 250 words

Background summary

Describe briefly the key research insights or findings that led to the impact in this AVE, including why the research is important (*e.g*. overall prevalence of condition, and cost to society and/or NHS and social care) and the hoe long the research has taken to get this point (insert below).
A significant number of people are affected by dementia, either directly or because they are caring for someone living with the condition. It is well recognized that living with dementia can negatively impact quality of life and can adversely affect the lives of carers. Our region has a population which is significant older than the average for the UK, so achieving a better quality of life for those affected is a key objective for local services. The IDEAL research programme is exploring what makes it possible for people living with dementia, and the family members or friends who support them, to experience well-being and enjoy a good quality of life. Researchers and members of the general public have different understandings of what the concept of living well actually means. Findings suggest that the factors related to the likelihood of living well with dementia include capital, assets, and resources; specific challenges; access to and use of services; and the degree of adaptation achieved by the person and family. The key to the research is ensuring that the perspective of people living with dementia and those who care for them is central. The programme aims to build on this research to identify approaches that can improve the lives of people affected by dementia. Starting in 2014, this is a long term, continuing research programme which has attracted support from the ESRC, NIHR, Alzheimer's Society and PenARC.
Impact information
What change happened/is going to happen as a result of the research? ● Please provide details of the change which resulted from the research activities (*e.g.*, changes in policies, guidelines or practice, quality improvement, service redesign or ways of working,improved health outcomes, costs and/savings, *etc*). ● Outline briefly how your research has led to the change described, adding any (qualitative or quantitative) evidence you have to show these activities have led to change (insert below).
During the initial stages of the pandemic the research team talked with people with dementia and carers to find out about their experiences and needs. The team produced advice leaflets for people with dementia and carers and developed the linked INCLUDE study to interview all IDEAL participants about their experiences during the pandemic. The team shared the resulting evidence with colleagues from DHSC, NHS-E, NHS-I, PHE and Alzheimer's Society, and informed several policy reports. The research team built on evidence from IDEAL and INCLUDE to develop three initiatives that could offer practical benefits for people living with dementia and carers: the Living with Dementia Toolkit, the theatre production 'The World Turned Upside Down', and the song 'Brave New World'. Originally envisaged as a source of support at a time when people with dementia felt abandoned during the pandemic, the Living with Dementia toolkit has evolved into a resource that will outlast the pandemic. It was co-produced with members of the IDEAL programme involvement group and additional members drawn from previous co-production initiatives. Organised around key themes emerging from

IDEAL, the toolkit is intended to offer hope, ideas, and inspiration. The Toolkit was launched in November 2021 and has been extremely widely distributed (e.g. from Coventry https://www.coventry.gov.uk/directory-record/57861/living-with-dementia-toolkit to New Zealand https://www.findglocal.com/NZ/Wellington/241804265841471/Rehabilitation-Teaching-%26-Research-Unit). It forms part of Alzheimer's Society's support package via helplines and frontline staff.

Why does this change matter?
Please provide details on who has benefited/been affected (*e.g*. individuals, specific user/affected groups) from the change, and how, and to what extent (*e.g*. local, regional, and/or nationally) (insert below).

A message that the team has heard repeatedly from people living with dementia is that they need a sense of hope, but formal services do not offer them any hope. These materials offer practical tips, based on good evidence, for people with dementia and those who care for them to help them make the most of their lives.

It isn't possible to directly measure the impact of these resources but the response from people with dementia, their carers and those who work with them has been overwhelmingly positive. The resources have been widely distributed across England through networks including the charities, the national ARC network and the national AHSN network. They are equally relevant in other parts of the UK (e.g. they have been translated into Welsh) and in the rest of the world.

Fiona Carragher, Chief Policy and Research Officer at Alzheimer's Society said: "It's great to see the publication of this practical guidance for people with dementia led by the Exeter team that also leads one of Alzheimer's Society's Centre of Excellence in care research. From all the calls we receive to our Dementia Connect support line, we know loneliness is a real issue for people affected by dementia, and strict lockdown measures due to the coronavirus pandemic have exacerbated this by shutting people with dementia and their carers away from loved ones and other forms of support. We're expanding our services in response to this need, and this new guidance will form part of our support to ensure people affected by dementia don't feel forgotten and alone."

What was NIHR's contribution to the change?
Outline the NIHR ARC's role and contribution towards the change (insert below).

The research team which produced this programme of work is led by Prof Claire, PenARC Dementia Theme Lead.

The appointment of Dr Charlwoord, Research Translation and Impact Manager for the programme, has been instrumental in the widespread distribution of the materials and, in particular, for helping the development of novel methods to reach a wider audience, including through working with artists who have produced both a theatre production 'The World Turned Upside Down' and song 'Brave New World', (written and performed by Paul Hitchmough and Tommy Dunne BEM, both of whom are living with dementia).

Our network of PenARC partners, including NHS organisations, local authorities and charities, helped us to spread the materials across the region.

Where impact is in the early stages yet to be fully realised, describe how the research findings will be taken forward to facilitate impact in the future (*e.g*. knowledge mobilisation, patient and public involvement, capacity building or engagement activities) (insert below).

The team has completed its final, post-pandemic round of data collection. Alongside providing new scientific evidence and contributing to knowledge about the experience of living with dementia, the team is continuing to co-produce and enhance resources to support people with dementia and carers. The co-production group continues to enhance the content, focusing on diversity and inclusion.

4. Engagement with wider stakeholders

Outline the role/contribution of other stakeholders/partners (*e.g.* other research funders, research teams, health and social care providers, voluntary and community sector, universities, NHS, public involvement groups, commissioners, policymakers, industry, ICS, etc) towards bringing about the change(s) (insert below).
The ALWAYS network (Action on Living Well: Asking You) are people with dementia and carers of people with dementia who advise on different aspects of the project based on their personal experience, skills and expertise. The network, recruited through their links with Innovations in Dementia and Alzheimer's Society, is at present around 12 people. https://www.idealproject.org.uk/takingpart/involvement/ . Their involve continues to be central to future development of this work. This work has received funding from multiple sources including NIHR, ESRC, and Alzheimer's Society who have also collaborated actively in the distribution of materials. Widespread distribution was also supported by numerous NHS organisations, local authorities, SWAHSN and the national AHSN network.

5. Collaboration/involvement of other NIHR infrastructure or programmes

Please specifically identify other NIHR funded infrastructure or research programmes and/teams, involved in the research, and their role/contribution (insert below).
The research that underpinned the toolkit was supported by both NIHR grants and by NIHR PenARC. Widespread distribution was supported through the national ARC network.

6. Dissemination and communication beyond academia/research setting

Please provide details, and examples of how you have communicated the outcomes of your research **outside** the academic or research setting.This may include materials/resources for patients, public, clinicians, health and care professionals, policy makers or other stakeholders, and include alternate formats, style and approaches (*e.g.* workshops, networks, press releases, social media, briefings, infographics, videos, animations, etc).

As discussed in previous sections, dissemination of this work (in both downloadable and print formats) was promoted across networks including NHS organisations, local authorities and charities to ensure wide availability to people with dementia and their carers.

During the pandemic, challenges for carers intensified as services offering respite closed and formal support dwindled. Under these circumstances, it was sometimes harder to communicate effectively. The theatre production 'The World Turned Upside Down' focused on communication, exploring scenarios where interaction is difficult. People with dementia and carers worked with the actors and director to ensure a realistic portrayal. Audiences were invited to suggest alternative ways of managing situations, enabling the actors to explore how this affected communication between the person with dementia and the carer. Audiences for the three performances in January 2022 included family and professional carers, students, and the general public. The production will form the subject of a forthcoming documentary film.

7. Next steps

Please highlight any follow-on funding, collaboration or further research plans. Where applicable, provide further details (including name of organisation, relevant stakeholders/groups, or company - including type of industry, where relevant - research funder details, nature of further research, future plans (insert below).
This is a continuing research programme. We will seek further funding to develop the research and to ensure that the evidence can be translated into benefits for people living with dementia.
Are there any factors that might prevent or reduce efforts to achieve or further maximise your impact?

8. Evidence and References (if applicable)

Provide a list of the most significant evidence (key sources and/or references) underpinning this example (titles and hyperlinks where applicable) (insert below). Evidence may include: policy documents, reports, datasets, news articles, videos, news reports, testimonials, quotes, weblinks, awards, reviews. ***For publications, please include the link to the Digital Object Identifier (DOI).***

Video endorsement from Pro Alistair Burns, National Clinical Director for Dementia: https://youtu.be/HVAHYbY1CqI

Quinn, C., Pickett, J.A., Litherland, R., Morris, R.G., Martyr, A., & Clare, L. (2022). Living well with dementia: what is possible and how to promote it. *International Journal of Geriatric Psychiatry*, *37*, e5627. doi: 10.1002/gps.5627 (open access) click here to read an accessible summary

Living with Dementia toolkit https://livingwithdementiatoolkit.org.uk/

Theatre production 'The World Turned Upside Down'

Song 'Brave New World'.

9. Health category/ field of research

Please indicate 'YES' to **all** that apply.

UKCRC Health Category	Please indicate 'YES' where applicable	NIHR priority Areas / Fields of Research	Please indicate 'YES' where applicable
Blood		Artificial Intelligence	
Cancer and Neoplasms		Equality, Diversity, & Inclusion	
Cardiovascular		Patient & Public Involvement (PPI)	YES
Congenital Disorders		Prevention agenda	
Ear		Health information technology/ digital transformation	
Eye		Levelling up (research following burden of patient need)	
Infection		Innovative clinical trials	
Inflammatory and Immune System		Research addressing health inequalities	
Injuries and Accidents		Healthy ageing	
Mental Health	YES	Multiple long-term conditions	
Metabolic and Endocrine		Med-tech	
Musculoskeletal		Covid-19	YES
Neurological		Public health	
Oral and Gastrointestinal		Obesity/ healthy weight	

Renal and Urogenital		Dementia	YES
Reproductive Health and Childbirth		Diabetes	
Respiratory		Antimicrobial resistance	
Skin		Social care	
Stroke			
Generic Health Relevance			
Disputed Aetiology and Other			

NIHR ARC - Added Value Example (AVE) Guidance and Form

1. Title of the AVE

Title of AVE (insert below) *[A short title using plain active language that summarises the impact (not the research finding)]*
Creating the conditions for living, dying and grieving well; death as a social process rather than a medicalised event
Is this a new AVE? (insert '**Yes/No**' below)
No
Is this an update of a previously submitted AVE?(insert '**Yes/No**' below)
No
If this is an updated AVE, please provide the title and year of submission of the linked AVE (insert below)

2. Concise impact Statement (maximum 100 words)

Briefly summarise, in plain English the impact of the research - what has changed, for whom, (and how, and to what extent) and why did this matter?
There is a lack of palliative care in the UK and a sense that as a society we are failing to understand how best to live, die and grieve well. These problems are worse for the poorer members of society. This research has helped to open discussions with the public, with people working in palliative care and with researchers from multiple disciplines. It has already led to hospices sharing challenges and new ways of working and working with the researchers and the community groups to reflect on how we can work together to better support dying and grieving well.

3. Background and impact information

Please provide a short paragraph in each box - around 250 words

Background summary
Describe briefly the key research insights or findings that led to the impact in this AVE, including why the research is important (*e.g*. overall prevalence of condition, and cost to society and/or NHS and social care) and the hoe long the research has taken to get this point (insert below).

The Lancet commissioned a policy report on the 'Value of Death' to re-value death and dying as a social process and look at the barriers to supporting living, dying and grieving well. A GW4 award in 2018 brought possible commissioners (health care practitioners, faith leaders, academics and lay people from the Global North and South) together to reflect on death and dying and articulate the nature of the problem the Commission would respond to. A significant aspect of the Commission which Wyatt contributed extensively to was how to create the conditions in communities facing significant inequalities to support living and dying well. A Wellcome Centre Fellowship was awarded to Lorraine Hansford to explore poverty and caring at the end of life. This research has highlighted the social determinants of death and their impact on caring and grieving. This research has led to an NIHR network award (Hansford, Creanor, Wyatt) to create a South West network of practitioners, carers and academics to generate research ideas and create a culture of engaged end of life research across the South West. The network includes all the hospices in the SW, the CTU, the Wellcome Centre for Cultures and Environments of Health, PenARC and Public Health consultants. The Lancet Commission was launched in February 2022 and has received wide-spread media coverage https://commissiononthevalueofdeath.wordpress.com/

Impact information

What change happened/is going to happen as a result of the research?

- Please provide details of the change which resulted from the research activities (*e.g.*, changes in policies, guidelines or practice, quality improvement, service redesign or ways of working,improved health outcomes, costs and/savings, *etc*).
- Outline briefly how your research has led to the change described, adding any (qualitative or quantitative) evidence you have to show these activities have led to change (insert below).

The Lancet report on re-balancing death and dying was commissioned in response to the widening inequities in access to palliative care across the globe. Whilst many people are over-treated in hospitals, still more remain undertreated, dying of preventable conditions and without access to basic pain relief, with people experiencing disadvantage and powerlessness suffering the most from the imbalance in care. The Commission sets out five principles for a new vision of how death and dying could be: (i) addressing the social determinants of death, dying and grieving; (ii) widespread understanding and acceptance of death as a relational and spiritual process rather than a physiological event; (iii) to create the conditions for networks of care to support people; (iv) for conversations and stories about everyday death, dying and grieving to become commonplace; and (v) recognising that death has value. Examples of transforming systems from Kerala and C2 informed the Commission and research is underway with hospices, palliative care physicians and service users and carers across the South West to explore how meaningful engagement with communities can take place. Patients and carers have spoken about 'feeling abandoned' during the pandemic, a situation made worse by the increased complexity of people's health when they present to a hospice (before the pandemic people were expected to live for, on average, 60 days; now it is 17 days).

Why does this change matter?

Please provide details on who has benefited/been affected (*e.g*. individuals, specific user/affected groups) from the change, and how, and to what extent (*e.g*. local, regional, and/or nationally) (insert below).

The South West Peninsula (Cornwall, Devon, Dorset) has the highest proportion of over 65's (24.2%), highest projected population growth (15.1%), and lowest proportion living in conurbations. The Chief Medical Officer identified coastal populations as having the worst health outcomes in England. The Peninsula is the only rural population in England with greater economic deprivation than urban areas. Despite innovation among communities to support those with health and social care needs, there has not been research to evaluate palliative care interventions or understand what communities and health and social care

practitioners need to better support dying and grieving well. Moreover, Devon Clinical Commissioning Group has made end-of-life care a priority within its Integrated Care System. This is intended to address local data that reports hospital as both the least preferred (44%) and most common (48%) place of death, with home (66%) and hospice (27%) the most preferred. Within its Joint Strategic Needs Assessment, end-of life has been recognised as one of three programmes underpinning the Integrated Care Model (ICM) theme of the Sustainability and Transformation Plan (STP).

What was NIHR's contribution to the change?
Outline the NIHR ARC's role and contribution towards the change (insert below).

Wyatt, PenARC Public Health Theme Lead helped to lead this work. She was supported to gain an NIHR network award to continue to achieve lasting impact in the region. Other NIHR groups are working together to further develop the research coming from this initiative.

Where impact is in the early stages yet to be fully realised, describe how the research findings will be taken forward to facilitate impact in the future (*e.g*. knowledge mobilisation, patient and public involvement, capacity building or engagement activities) (insert below).

Overtreatment at the end of life is part of the broader challenge of overuse of medical services, defined as the provision of services likely to produce more harm than good. Whilst overtreatment is increasing in some countries, others face a lack of basic resources such as access to adequate pain relief. The Commission highlights that health systems cannot deliver the scale of change that is needed, nor can they afford to carry on simply doing more of the same, and therefore that new ways of partnership working with communities (and particularly with populations experiencing the greatest inequalities') are needed. The work we are doing has a two fold impact: using creative techniques such as the Academy of Medical Sciences Departure Lounge props, we are hosting conversations in areas of high economic disadvantage about death and dying; we are also listening to hospice staff and bereaved carers about the challenges of delivering and accessing services at this time.

4. Engagement with wider stakeholders

Outline the role/contribution of other stakeholders/partners (*e.g.* other research funders, research teams, health and social care providers, voluntary and community sector, universities, NHS, public involvement groups, commissioners, policymakers, industry, ICS, etc) towards bringing about the change(s) (insert below).

This research involves all seven hospices across the SW, voluntary sector organisations, community development trusts and carers. It also includes the CRN, CTU and RDS. The CRN, CTU and RDS are hosting training events highlighting clinical research opportunities for participation; the hospices are sharing current challenges and new ways of working in response to Covid and working with the researchers and the community groups to reflect on how they can work together to better support dying and grieving well. A series of public engagement events have been held across the SW and a local story telling group has been commissioned to create an online resource of people's narratives.

5. Collaboration/involvement of other NIHR infrastructure or programmes

Please specifically identify other NIHR funded infrastructure or research programmes and/teams, involved in the research, and their role/contribution (insert below).
Exeter CTU part of the NIHR end of life care network bid; SW CRN and SW RDS are collaborators on the bid and supporting through capacity building in research methods and engaging communities. (please see above)

6. Dissemination and communication beyond academia/research setting

Please provide details, and examples of how you have communicated the outcomes of your research **outside** the academic or research setting. This may include materials/resources for patients, public, clinicians, health and care professionals, policy makers or other stakeholders, and include alternate formats, style and approaches (*e.g.* workshops, networks, press releases, social media, briefings, infographics, videos, animations, etc).
In 2019 the Academy of Medical Sciences launched the Departure Lounge – an installation in a disused shop in Lewisham to provoke conversations about death and dying. We were lucky enough to secure one of 40 Departure Lounge packs to re-create the installation in appropriate settings. Lorraine has created five departure lounges to date, in community settings across the SW. The conversations generated are feeding into focus groups and interviews with people experiencing poverty and/ or living in rural isolation across the SW. We have commissioned a local story telling group, Filament, to work with six people who are part of the community conversations to co-create their experiences as a series of stories which can be shared as a digital resource.

7. Next steps

Please highlight any follow-on funding, collaboration or further research plans. Where applicable, provide further details (including name of organisation, relevant stakeholders/groups, or company - including type of industry, where relevant - research funder details, nature of further research, future plans (insert below).
The initial funding in 2016 from the GWR initiator fund (£19,800) led to the Lancet Commission and a Wellcome Centre (through Wellcome Trust) funded fellowship. Ongoing collaborations have secured funding for a SW Palliative care research network (£100,000) which will put us in a good position to apply for funding in October 2022 when NIHR puts out a commissioned call in end of life care research. Ongoing collaborations include researchers from Kings College, St Christopher's, Hull Medical School and WHO research team in Laos. We are also exploring how we can work with housing associations to better support people at the end of life and those caring for them
Are there any factors that might prevent or reduce efforts to achieve or further maximise your impact?

The current massive challenges facing the NHS will inevitably hamper service engagement but we believe that the discussions already begun have substantial potential for future impact.

8. Evidence and References (if applicable)

Provide a list of the most significant evidence (key sources and/or references) underpinning this example (titles and hyperlinks where applicable) (insert below).
Evidence may include: policy documents, reports, datasets, news articles, videos, news reports, testimonials, quotes, weblinks, awards, reviews.

For publications, please include the link to the Digital Object Identifier (DOI).

Report of the *Lancet* Commission on the Value of Death: bringing death back into life Libby Sallnow, Richard Smith, Sam H Ahmedzai, Afsan Bhadelia, Charlotte Chamberlain, Yali Cong, and others *The Lancet*, Vol. 399, No. 10327 Published: January 31, 2022
https://commissiononthevalueofdeath.wordpress.com/

Lorraine Hansford, Felicity Thomas & Katrina Wyatt (2022) Poverty, choice and dying in the UK: a call to examine whether public health approaches to palliative care address the needs of low-income communities, Mortality, DOI: 10.1080/13576275.2022.2044299

9. Health category/ field of research

Please indicate 'YES' to **all** that apply.

UKCRC Health Category	Please indicate 'YES' where applicable	NIHR priority Areas / Fields of Research	Please indicate 'YES' where applicable
Blood		Artificial Intelligence	
Cancer and Neoplasms		Equality, Diversity, & Inclusion	
Cardiovascular		Patient & Public Involvement (PPI)	
Congenital Disorders		Prevention agenda	
Ear		Health information technology/ digital transformation	
Eye		Levelling up (research following burden of patient need)	

Infection		Innovative clinical trials	
Inflammatory and Immune System		Research addressing health inequalities	YES
Injuries and Accidents		Healthy ageing	
Mental Health		Multiple long-term conditions	
Metabolic and Endocrine		Med-tech	
Musculoskeletal		Covid-19	YES
Neurological		Public health	YES
Oral and Gastrointestinal		Obesity/ healthy weight	
Renal and Urogenital		Dementia	
Reproductive Health and Childbirth		Diabetes	
Respiratory		Antimicrobial resistance	
Skin		Social care	YES
Stroke			
Generic Health Relevance	YES		
Disputed Aetiology and Other			

NIHR ARC - Added Value Example (AVE) Guidance and Form

1. Title of the AVE

Title of AVE (insert below) *[A short title using plain active language that summarises the impact (not the research finding)]*
Health Service Modelling Associates (HSMA) Programme
Is this a new AVE? (insert '**Yes/No**' below)
No
Is this an update of a previously submitted AVE?(insert '**Yes/No**' below)
Yes
If this is an updated AVE, please provide the title and year of submission of the linked AVE (insert below)
Health Service Modelling Associates Programme (2021)

2. Concise impact Statement (maximum 100 words)

Briefly summarise, in plain English the impact of the research - what has changed, for whom, (and how, and to what extent) and why did this matter?
Programme participants develop skills in advanced operational modelling techniques while directly addressing important service questions - increasing the capacity of the system to use these approaches at the same time as having direct impact on current problems. Recent HSMA projects have included contributing to planning safe and effective COVID-19 vaccination clinics, safeguarding vulnerable individuals by transforming the analytical capabilities of Devon and Cornwall Police, demonstrating the need for Paediatric Critical Care Units across the South West to bring care closer to home and building an AI-based tool to better understand the concerns of the public about their local police forces.

3. Background and impact information

Please provide a short paragraph in each box - around 250 words

Background summary

Describe briefly the key research insights or findings that led to the impact in this AVE, including why the research is important (*e.g*. overall prevalence of condition, and cost to society and/or NHS and social care) and the hoe long the research has taken to get this point (insert below).

The Health Service Modelling Associates (HSMA) Programme is currently in its fourth iteration and continues to not only provide significant training in Operational Research and Data Science for staff working in health, social care and policing, but – crucially – supports associates to apply these skills to projects that generate real impact and change for their service users and organisations. Associates primarily work in analytical roles, but not exclusively, and we have welcomed a number of clinicians, managers and other roles onto the programme.

Associates are taught extensive skills in modelling and data science, including Discrete Event Simulation (for modelling pathway and queuing problems), Network Analysis and System Dynamics (for modelling whole system interactions), Agent Based Simulation (for modelling behavioural dynamics), Geographic Modelling and Visualisation (for analysing the impact of service location decisions), Machine Learning (for developing decision support algorithms that can help clinicians and managers make decisions), Natural Language Processing (for automating the extraction of information from free text data) and Forecasting methods (to try to predict future levels of activity). Associates are also taught how to program in Python and R from first principles, assuming no prior knowledge of coding. All approaches taught on the programme are Free and Open Source (FOSS) and associates are taught the importance of collaborative development and open science.

Associates are supported to use these new skills on impactful projects of importance for their organisations and service users. They receive mentoring support from experienced Operational Researchers and Data Scientists over the course of the programme.

Impact information

What change happened/is going to happen as a result of the research?

- Please provide details of the change which resulted from the research activities (*e.g.*, changes in policies, guidelines or practice, quality improvement, service redesign or ways of working,improved health outcomes, costs and/savings, *etc*).
- Outline briefly how your research has led to the change described, adding any (qualitative or quantitative) evidence you have to show these activities have led to change (insert below).

For HSMA 3, which ran from October 2020 – September 2021, included 52 HSMAs and seven projects were supported across the programme, working with organisations across the South West.

Example projects include:

- A GP from North Devon developed a generic Free and Open Source vaccination clinic model, available (and applicable) to anyone anywhere in the world. The model allows the user to input their activity and resourcing data, the processes in their clinic, and the capacity of their waiting rooms and car park facilities to predict the queue lengths and times and risks of breaching capacity limits across the clinic.

- Colleagues from Devon and Cornwall Police developed an approach using Network Analysis techniques to help identify the social links between offenders and vulnerable people at risk of future offending. This was compared to a traditional manual investigation, and was found to have identified the same findings in a matter of hours that the manual investigation had taken months to produce. The approach was then used to help develop safeguarding intervention strategies for a community in a Devon city. Fiona Bohan (Performance and Analysis Manager at Devon and Cornwall Police) described the new

approach as having “significant benefits” and “an important part in policing in the future”

In October 2021, the 4th round of the programme, recruited nationally across England. We received over 300 registrations of interest in the programme, and have taken on a cohort of 80 HSMAs who are currently working on 18 projects which are due to complete in September 2022.

Why does this change matter?
Please provide details on who has benefited/been affected (*e.g*. individuals, specific user/affected groups) from the change, and how, and to what extent (*e.g*. local, regional, and/or nationally) (insert below).

A key output of the programme is the skills participants take back to their organisations. It also helps to raise awareness of the potential of modelling and data science techniques to support service improvement and redesign.

The impact from HSMA projects generates real change for patients and other service users. There are too many projects to discuss but details are available on our HSMA Resource Site.

Examples include:

- The HSMA vaccination project led to an efficient system that ensured that patients in North Devon received timely vaccinations, that staff and facilities were used to full capacity and that vaccinations were performed in a safe and socially distanced environment. Local trusts and the South West Academic Health Science Network are helping spread the model’s usage, and the development and release of a free generic version will help to allow others to plan safe and effective vaccination clinics of all kinds in the future.

- The Devon and Cornwall Police network analysis has helped to safeguard individuals at risk of being pulled into criminal activity in a local community, and provided an evidence-based approach to transform investigative systems in these areas.

- A participant from Avon and Somerset Constabulary built an AI-based tool to automatically identify the sentiment of tweets to every police force in the country (and identify key issues being raised) has transformed the way in which the constabulary can respond concerns being raised within their communities.

What was NIHR’s contribution to the change?
Outline the NIHR ARC’s role and contribution towards the change (insert below).

The ARC (with input from SWAHSN) resourced the development and delivery of the Health Service Modelling Associates programme which is delivered by members of the PenARC Operational Research and Data Science team – PenCHORD.

The projects described in this AVE were all mentored by PenARC staff. Mentoring involves working with the HSMAs to help guide them through the modelling process, offer advice and support, and suggestions for project direction. Mentors meet at least once a month with their HSMAs to discuss project progress.

The current round of the programme (HSMA 4) has also introduced the Trainee Mentor Scheme, in which existing Operational Research and Data Science academics and practitioners, as well as HSMA alumni, are provided with full training to support projects within the programme as mentors and therefore increase our capacity to take forward projects. We currently have 11 trainee mentors mentoring projects in HSMA 4, and are

continuing the scheme in HSMA 5.

Where impact is in the early stages yet to be fully realised, describe how the research findings will be taken forward to facilitate impact in the future (*e.g*. knowledge mobilisation, patient and public involvement, capacity building or engagement activities) (insert below).

We have built a community structure to facilitate continued communication with and between participants of the HSMA programme past and present. All HSMAs and HSMA alumni have access to a dedicated HSMA Slack workspace where they can communicate, collaborate and share ideas. A number of HSMA have sign up to be mentors on future rounds of the programme, to help share their knowledge and expertise developed through the programme with others.

Patient and Public Involvement continues to be an important facet of the programme with public collaborators patient representatives involved in deciding which projects to take forward. In the next round we are planning to significantly expand their involvement:

1) PenPEG have agreed to work with staff to co-creating training sessions on meaningful patient and public involvement in projects, and will advise on strategies
2) Associates will be helped to work with their local public/patient groups to ensure that projects provide answers that make sense to service users.

4. Engagement with wider stakeholders

Outline the role/contribution of other stakeholders/partners (*e.g.* other research funders, research teams, health and social care providers, voluntary and community sector, universities, NHS, public involvement groups, commissioners, policymakers, industry, ICS, etc) towards bringing about the change(s) (insert below).

SWAHSN has been a key partner since the inception of this programme with involvement in funding, course design, associate recruitment and impact. We also work closely with the ICS, service providers and Public Health departments in local authorities.

The HSMAs come from health, social care and policing organisations across the country. They include staff from organisations as varied as primary care networks in Devon and Cornwall, the acute trust in Morecombe Bay, Torbay Council and West Midlands Police Counter Terrorism Unit.

Trainee mentors for the latest round come from a wide variety external organisations, including NHS England and NHS Improvement, South Western Ambulance Service NHS Foundation Trust, the University of Southampton, Whole Systems Partnership, West Sussex Council, Avon and Somerset Constabulary, University College London, Surrey and Borders Partnership NHS Foundation Trust, University of Plymouth and NIHR ARC Kent, Surrey and Sussex.

The involvement of (and funding of £333k from) Health Education England will enable us to substantially expand the coverage of HSMA in the future with a plan to recruit for 200 participants and support 40 projects over the next two years. The SWAHSN will help to support the delivery of the programme..

We are working with the Association of Professional Healthcare Analysts (AphA) to explore potential accreditation for the programme which will benefit some participants.

The HSMA Programme leveraged co-funding to a value of £487,743 from regional and national stakeholders during 2021/22.

5. Collaboration/involvement of other NIHR infrastructure or programmes

Please specifically identify other NIHR funded infrastructure or research programmes and/teams, involved in the research, and their role/contribution (insert below).

In addition to support from the CRN to promote recruitment, we have partnered with NIHR ARC Kent, Surrey and Sussex who have provided a trainee mentor for the HSMA 4 programme. They are currently supporting a project using simulation modelling to identify delays in the pathway for the neuro-development assessment service for children in Oxford, which is currently experiencing average waiting times of 2 years for an assessment. The project will use modelling to explore potential interventions to reduce these delays.

6. Dissemination and communication beyond academia/research setting

Please provide details, and examples of how you have communicated the outcomes of your research **outside** the academic or research setting.This may include materials/resources for patients, public, clinicians, health and care professionals, policy makers or other stakeholders, and include alternate formats, style and approaches (*e.g.* workshops, networks, press releases, social media, briefings, infographics, videos, animations, etc).

Our comms team have developed a number of stories about the HSMA programme and its projects, and links to a selection of these stories can be found on the HSMA Resource Site – News. Regular updates about the programme are promoted via our social media channels and we have developed a dedicated HSMA Resource Site.

We run regular presentation events and campaigns promoting the programme to audiences of health, social care and policing staff across the country via national networks such as the Association of Professional Healthcare Analysts (AphA), NHS-R, Health Education England, the College of Policing, and various local and national Public Health networks. We also have a regular column in the monthly AphA magazine.

All materials from the HSMA Programme, including recordings of the lectures and the lecture materials, are made available to anyone anywhere Free and Open Source. Our lecture recordings (as well as videos of some of our past events) can be found on our HSMA YouTube channel, which currently has over 600 subscribers and around 50,000 video views. Our lecture materials from HSMA 3 are available in the HSMA 3 GitHub repository, and the materials from HSMA 4 are available as a series of repositories within a GitHub organisation.

7. Next steps

Please highlight any follow-on funding, collaboration or further research plans. Where applicable, provide further details (including name of organisation, relevant stakeholders/groups, or company - including type of industry, where relevant - research funder details, nature of further research, future plans (insert below).
As described earlier, we have partnered with Health Education England and the South West Academic Health Science (AHSN) to develop and deliver the fifth and sixth rounds of the HSMA programme to a national audience. HSMA 5 will launch in October 2022, and HSMA 6 will launch in October 2023. Each round will have 100 places available (plus an additional 10 places for the Trainee Mentor Scheme) and will support 20 projects each year. We are currently promoting the launch of HSMA 5, and have a Virtual Open Day on 21st June. At the time of writing, we have more than 160 people who have registered their interest so far for HSMA 5. Applications will launch on 21st June, and successful applicants chosen in August 2022. HSMA 5 will build on the success of HSMA 4 by building in new structures to support participants, including the introduction of patient and public involvement training and support, the introduction of "Coding Club" sessions to support those newer to coding to practice their coding skills and the introduction of "Masterclass" sessions which will offer deep-dives into advanced topics relevant to HSMA project work. We will also be expanding the scope of the training programme even further to include teaching on Deep Reinforcement Learning, as well as Relation Extraction and Transformers in Natural Language Processing.
Are there any factors that might prevent or reduce efforts to achieve or further maximise your impact?
Continuing to deliver the HSMA programme at a national scale is dependent on funding to support the high level of resourcing needed to develop and deliver the programme at a large scale. Over the next two years, we will be working with partners and funding bodies to explore options to obtain longer term funding.

8. Evidence and References (if applicable)

Provide a list of the most significant evidence (key sources and/or references) underpinning this example (titles and hyperlinks where applicable) (insert below). Evidence may include: policy documents, reports, datasets, news articles, videos, news reports, testimonials, quotes, weblinks, awards, reviews. ***For publications, please include the link to the Digital Object Identifier (DOI).***

Selected Quotes / Testimonials:

“I enjoyed designing it. It predicts queue lengths, car park capacity and times for every step of the vaccination process in the clinic to avoid overcrowded waiting rooms. In the winter of 2020/1 the country was back in lock down and there seemed no end in sight regarding COVID. The vaccines seemed like a ray of hope and setting up the clinics was instrumental in turning the tide. Being able to use the knowledge gained from the HSMA course to help design the process was fantastic. The clinic has now delivered over 100,000 vaccines.” Dr Adam Kwiatkowski (GP and HSMA, Northam Surgery)

“The need for Social Network Analysis is clear. Criminal and exploitative networks are a huge and costly issue for police, their partner agencies, and the community. SNA, using minimal resource, can identify children at current and future risk of exploitation, as well as those key players within the network who pose the greatest risk. By targeting and removing these key players, and concentrating limited early intervention resources on protecting those at risk in the future, there are potential significant savings both in terms of child harm and partnership spend. This proof of concept has highlighted the significant benefits of embedding this approach in force and, in my view, will play an important part in policing in the future.” Fiona Bohan (Performance and Analysis Manager, Devon and Cornwall Police)

“The course is intense with a vast amount of content, but don’t let that put you off. The intensity is manageable and the process is far more efficient than my prior “self-taught” approach – ultimately you will get out what you put in! The mentors are excellent, and the online delivery model ensures accessibility and national reach – I have met many great people from across the country in a variety of roles/sectors. The team are responsive, and you immediately apply the techniques taught. I would have no hesitation in recommending the programme” Matt Eves (Operational Development Manager and HSMA, Derbyshire Community Health Services NHS Foundation Trust)

"I’ve really enjoyed joining HSMA 4 as a trainee mentor. I retired as a lecturer in Operational Research last year, and I’ve found it great to improve my skills in modelling using Python and other free open-source software. Now I’m able to participate in a project as a mentor and meet a wide spectrum of professionals from the National Health Service and other public services." Honora Smith (HSMA Trainee Mentor and Retired Lecturer in Operational Research, University of Southampton)

Links and resources:

- HSMA 3 Project Presentation event recording (including presentations of the projects described in this AVE)
- HSMA YouTube channel
- HSMA 3 GitHub repository
- HSMA 4 GitHub Organisation
- HSMA Resource Site
- HSMA Webpage on PenARC Website
- The Free and Open Source Vaccination Model developed by one of our HSMAs (described in this AVE)
- HSMA News Repository

- PenCHORD webpage
- PenCHORD Twitter
- PenARC Twitter

9. Health category/ field of research

Please indicate 'YES' to **all** that apply.

UKCRC Health Category	Please indicate 'YES' where applicable	NIHR priority Areas / Fields of Research	Please indicate 'YES' where applicable
Blood		Artificial Intelligence	YES
Cancer and Neoplasms	YES	Equality, Diversity, & Inclusion	
Cardiovascular		Patient & Public Involvement (PPI)	YES
Congenital Disorders		Prevention agenda	
Ear		Health information technology/ digital transformation	YES
Eye		Levelling up (research following burden of patient need)	YES
Infection	YES	Innovative clinical trials	
Inflammatory and Immune System		Research addressing health inequalities	YES
Injuries and Accidents	YES	Healthy ageing	
Mental Health	YES	Multiple long-term conditions	
Metabolic and Endocrine		Med-tech	
Musculoskeletal	YES	Covid-19	YES
Neurological		Public health	YES
Oral and Gastrointestinal		Obesity/ healthy weight	
Renal and Urogenital		Dementia	

Reproductive Health and Childbirth		Diabetes	
Respiratory		Antimicrobial resistance	
Skin		Social care	YES
Stroke			
Generic Health Relevance	YES		
Disputed Aetiology and Other			