

The North Cumbria Research Infrastructure

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Overview

There is a rich research infrastructure in North Cumbria which is not immediately apparent to everyone who lives and works in the area. This document maps some of this infrastructure, what support it can give you and how to access it.

The document has arisen from an engagement and networking event organised jointly by the National Institute for Health Research North East and North Cumbria Applied Research Collaboration (NIHR NENC ARC) and the Centre for Research in Health and Society (CRiHS) at the University of Cumbria on the 4th November 2020 in order to draw people together to learn about support available and to join up key organisations, networks and agencies.

The 'North Cumbria' area is identified rather than Cumbria as a whole due to the geography of the National Institute of Health Research North East and North Cumbria Applied Research Collaboration which only covers North Cumbria. Other NIHR ARCs include South Cumbria and there is collaboration between them and the other infrastructure services. The South Lakes equivalents are signposted throughout the document to enable county wide relevance.

The aim of the 4th November 2020 event, and this information pack is to share information about the research infrastructure and activities across North Cumbria in order to support people across the region to be research active in whatever way is meaningful for them.

Attendees

The event was attended by eleven presenters and eleven participants across health, social care, youth and community sectors and from statutory, voluntary and higher education organisations.

Structure

The event was organised around four questions:

- What is this event about?
- What does the current research infrastructure look like in North Cumbria?
- What research activities are we investing in?
- What Public Involvement and Community Engagement support is there available in North Cumbria?

A range of short presentations were provided under each heading to give a flavour of the research support in the area and time given for questions and further discussion. The presentations are provided below with key points from the discussions in an informal and discursive style. The contact details for all organisations and South Cumbrian counterparts are included to enable you to find out more.

Session 1: Welcomes

Welcome from Professor Brian Webster-Henderson, Deputy Vice Chancellor for Health, Environment and Innovation, University of Cumbria

Welcome to this online event from the University of Cumbria who are now 13 years old and from our Institute of Health which was launched along with the Centre for Research in Health and Society which has transformed our approach to research over the last year.

Events like today are really important networking opportunities and are really important for North Cumbria given the context that we live in, in relation to the realities of deprivation, inequality and poor health outcomes. That makes the conversations today even more important so we network and work together for the common good, advancing health outcomes based on evidence and research in our own communities and our own society.

It's important that we recognize the benefits of mutual support, sharing ideas and resources and of the research culture which we want to generate and extend even further in our day to day workings and lives.

And so to close may I encourage you to get as much as you can out of today from the richness of the conversation, that you connect with colleagues and have dialogue about research and its culture in our region. And so huge welcome to you all again, you are all extremely important to that cause and a warm welcome to Eileen.

Introduction to the National Institute for Health Research, North East North Cumbria, Applied Research Collaboration from Professor Eileen Kaner, Professor of Public Health and Primary Care Research, University of Newcastle and ARC Director.

NIHR Applied Research Collaboration (ARC) North East and North Cumbria



Professor Eileen Kaner

'Our ARC network'



I would like to introduce or re-introduce the ARC – we are now one year into a five year contract. We achieved a £9 million award and £6.9 million of match funding from partners right across NENC. It brings together the six NE universities' and the University of Cumbria into a collaboration.



What is an ARC for?

- ❖ Generating evidence
- ❖ Increasing capacity
- ❖ Developing capability
- ❖ Spreading evidence
- ❖ Supporting implementation
- ❖ Engaging/involving people
- ❖ Linking/spanning networks



'Better, fairer health and care at all ages and in all places'

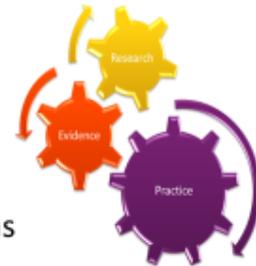
It is useful to revisit what an ARC is for. We are NIHR funded so we are about generating evidence that is relevant to the health and wider social priorities of our region but we're also responsible for building capacity in applied research to help increase skills in our colleagues and stakeholders to

design and deliver applied research. We want to spread the evidence we already have so we can inform implementation and best practice in care. We want to involve and engage our local communities so our research is relevant to them and the outcomes are relevant to them and of benefit to them. Essentially, the ARC is very much a linking and a spanning network, and we're all doing all of these activities so we can help to achieve the vision that we developed together to provide better, fairer health and care at all ages and in all places.



How do ARCs work?

- Pragmatically - 'close-to-the-problem' and 'close-to-the-data'
- Opportunistically – responding to events/policies/innovations
- Boundary spanning - cross sector, disciplines, geography
- Flexibly – using all relevant theories, knowledge, methods, assets
- Being Relevant – generating evidence on regional (national) priorities
- Impactfully – seeking population, patient benefit – improved practice



How will we work – we are pretty pragmatic and close to the data. We are opportunistic and responsive to events like Covid which come upon us. We need to be able to flex and work to those agendas to stay relevant to the people who are delivering services to the people who need our care and support. We are boundary spanning and there are a number of infrastructures in NENC including the Research Design Service and others, and we are trying to glue the pieces together synergistically without duplicating what each other can bring. But we are cross sector and cross discipline and we want to encompass all of the geography in our region. We work flexibly with any relevant theory or knowledge or method or asset that is relevant. We are focussed on primarily regional priorities. The aim of all this is to be impactful, to achieve population or patient benefit and to improve practice and care for the people who live in our region.

Who are we working with?

| Theme | HEI | NHS | LA/PH | VCS | Industry | Total |
|---|------------|-----------|-----------|-----------|----------|------------|
| Multimorbidity, ageing and frailty | 39 | 8 | 1 | 0 | 0 | 48 |
| Supporting children and families | 20 | 23 | 3 | 10 | 0 | 56 |
| Prevention, early intervention and behaviour change | 41 | 10 | 26 | 5 | 0 | 82 |
| Integrating physical, mental health and social care | 13 | 12 | 2 | 0 | 1 | 28 |
| Inequalities and marginalised communities | 29 | 8 | 7 | 8 | 1 | 53 |
| Evaluating change with pace and scale | 20 | 2 | 1 | 1 | 0 | 24 |
| Assistive technologies and data linkage | 23 | 13 | 5 | 7 | 3 | 51 |
| Knowledge mobilisation and Implementation Science | 11 | 8 | 8 | 0 | 0 | 27 |
| Total | 196 | 84 | 53 | 31 | 5 | 369 |

53%

47%

This slide shows who we work with. At the left of the slide you can see all the priority areas for the ARC and on the right you can see the numbers of people who are working with us from across the wider network. We had 369 people associated with the bid when it was submitted but that number flexes as people leave and join the region.

What have we been doing?

- October 2019 ARC began
- November 2019 Launch event; national priority competition
- December 2019 Recruitment - ARC team
- January 2020 Fellow recruitment (n=14) in waves to September 2020
- February 2020 Open funding panel (OFP) call – deadline May 2020
- March 2020 Stakeholder Board meeting; **2 national consortia bids won**
- April 2020 CV-19 LOCKDOWN/NIHR Pause
- June 2020 PhD recruitment campaign (n=23) in waves to March 2021
- August 2020 Feedback on national priority awards/funding confirmed
- **September 2020** Scientific Advisory Board; OFP awards (31 projects; £1.6M)
- October 2020 Annual report (year 1); Training strategy; OFP feedback
- November 2020 Stakeholder Board meeting; website launch



I've mentioned that we are one year old at the end of this month and we signed the contract in October 2019 and launched in 2020. Just as we launched there was a national priority competition which focussed our minds to some extent. But we have spent the first year really trying to build the ARC.

We've recruited the internal team and we recruited fellows to the ARC and we to date have recruited ten 100% FTE ARC fellows and five 50% FTE methodological appointments. These individuals will be the real engine of the ARC. We ran our first open funding competition and had 170 expressions of interest and 54 full applications which went to a stakeholder board in March. In March we also found out that we had been awarded two additional funding national consortia.

Lockdown came in April but we have persisted and continued with our plans and recruitment. We have been recruiting to our cohort of 23 PhD students although this will take several waves to March 2021.

We have the funding confirmed for our national priority awards of inequalities and prevention. In September our scientific board ratified £1.6 million of funding for the open grants, some of which are in North Cumbria.

Our annual report was submitted in October for year one. We had a second stakeholder board chaired by Professor Sir Michael Marmot and our website will soon be launched. So although we may not always be visible there's been a lot of activity under the surface of the ARC.

National priority areas (£15M)

1. Mental health, including children and young people's mental health
2. Adult social care and social work
3. **Prevention, including behavioural risk factors (£1.875M)**
4. Multimorbidity
5. **Health and care inequalities (£1.875M)**
6. ~~Person-centred, integrated care~~
7. Healthy ageing, including dementia and frailty
8. Children's health and maternity

I'll just touch on the national priority areas which takes us from the regional to the national. There are eight national priority areas for additional work. We were successful in winning two out of the seven. We have an extra £7.34 million to pursue work on these. These include all the ARC areas and plans will become more evident as we go through.

Contact details

[Email: arcnenc@cntw.nhs.uk](mailto:arcnenc@cntw.nhs.uk)

[Website: https://arc-nenc.nihr.ac.uk/](https://arc-nenc.nihr.ac.uk/)

Twitter: @NIHR_ARC_NENC

Dr Jane Pearson, NIHR ARC NENC Manager (Jane.Pearson@cntw.nhs.uk)

Professor Chris Price, Deputy Director (c.i.m.price@newcastle.ac.uk)

Professor Eileen Kaner, Director (Eileen.kaner@newcastle.ac.uk)

This was a whistle stop talk but further contact details are provided above so you can find more about us from there.

There was a question about ARCs – there are 15 nationally and the ARCs do collaborate, so please be assured we work together in a non-competitive way. The boundaries are not of our making and are a little strange! The North West Coast ARC covers part of Cumbria and Mark Gabay is the director; he is a GP and is very active, particularly around public involvement.

We are all very keen to have a northern leadership drive across the ARC community. So if I can point out that we will be leading on the national work for health and care inequalities that very much was a northern driven bid as its Clare Bambra's work with Kate Pickett from York and with Manchester, Liverpool and Lancaster. There is a real collegiality across them. It might be worth having a North Cumbria lead conversation about how to work across the region, and we would really support that.

You can contact Mark here: <https://arc-nwc.nihr.ac.uk/team/mark-gabbay/>

Another comment: I am Jon Rushe chair of the North Cumbria Clinical Commissioning Group and of the Integrative Care Partnership Leaders Board for North Cumbria and I have been really enthused by today and we are trying to make some of the things we are talking about today. We have two things – one is the ARC and the other is the university collaboration. The way of trying to bring that together for North Cumbria is to align research and HEIs across the partnership and so we have university representatives to the ICP leadership board. At a strategic level we need to join up research, universities and the ARCs. At a Cumbria wide basis I can help with links to the Health and Wellbeing Board. So do make contact. I will continue to make sure research is embedded across North Cumbria and Cumbria.

What does the current research infrastructure look like in North Cumbria?

Linking with the Centre for Research in Health and Society – Professor Kaz Stuart, Professor of Social and Health Inequalities and Director of the Centre for Research in Health and Society, University of Cumbria.



**CENTRE FOR RESEARCH
IN HEALTH & SOCIETY**

As Brian said, the Institute of Health and the Centre for Research in Health and Society was launched a year ago.

Our Purpose

- Positive transformation of health and social outcomes for all
- Through applied scholarship, research and knowledge exchange
- Leading to excellence in health and social care practice

Our purpose is shown on the slide above and these are very aligned with the NIHR NENC ARC aims and activities. We are really passionate about knowledge exchange into and out of the university.



We will achieve this purpose through the aims shown on the slide above and we seek to achieve these with everyone in our region and inside the university.



We are a large and comprehensive research centre with 190 staff and 46 PhD students who all undertake a diversity of research. We collated these interests into the research agenda shown above. The cross cutting themes span all our work. We also have an area of applied health and applied social science research and also a commercial evaluation unit called Health and Society

Knowledge Exchange. If you are interested in any of the areas indicated above we would be very glad to hear from you in order to develop communities of practice, expertise and research.

Research Centre Strengths



We believe and we hear our strengths are as much about how we work as what we do, and we would be delighted to expand our network today by working with more of you.

Research Centre Support



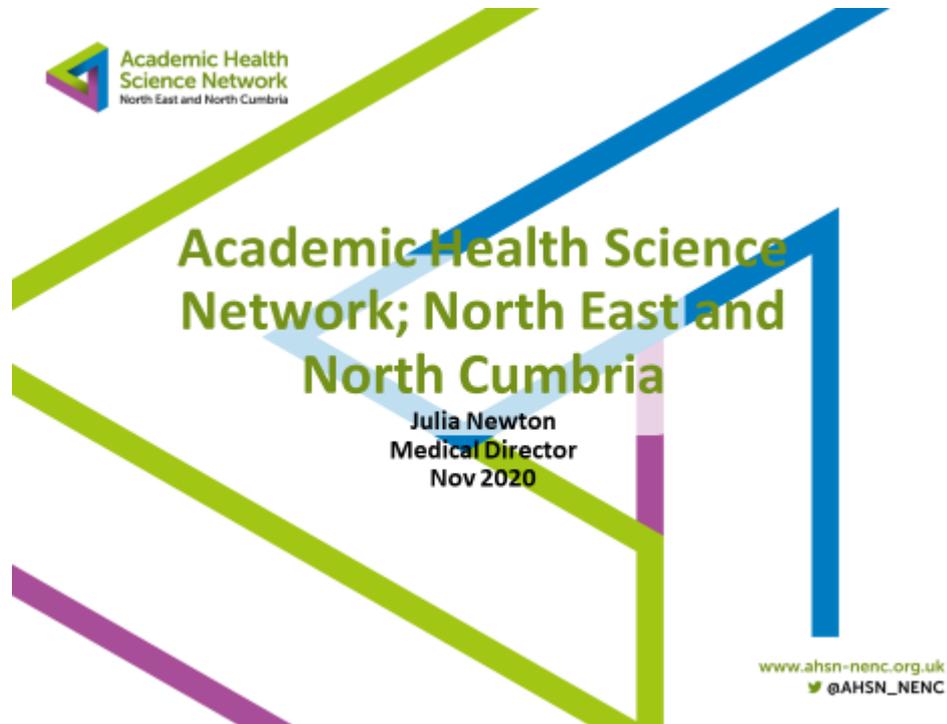
We offer a wide range of support to people within and outside the university as shown in the slide, and again, if you are interested in any of these then please get in touch.



**CENTRE FOR RESEARCH
IN HEALTH & SOCIETY**

- CRiHS@cumbria.ac.uk
- Facebook: CRHealthandSociety
- Twitter: @CentreCrihs

The Academic Health Science Network North East and North Cumbria, Professor Julia Newton, Medical Director of the AHSN NENC.



It's a great pleasure to be here and we already have some fabulous projects happening with Kaz in CRiHS and we hope that is a new and growing relationship.

I am here to talk to you today about the NENC Academic Health Science Network, what we do and what support we can offer you.

The AHSN Network

- 15 regional Academic Health Science Networks (AHSN), established by NHS England in 2013 to spread innovation at pace and scale.
- Re-licensed in 2018 for a further 5 years - 3 national Commissioners
- 3 core objectives

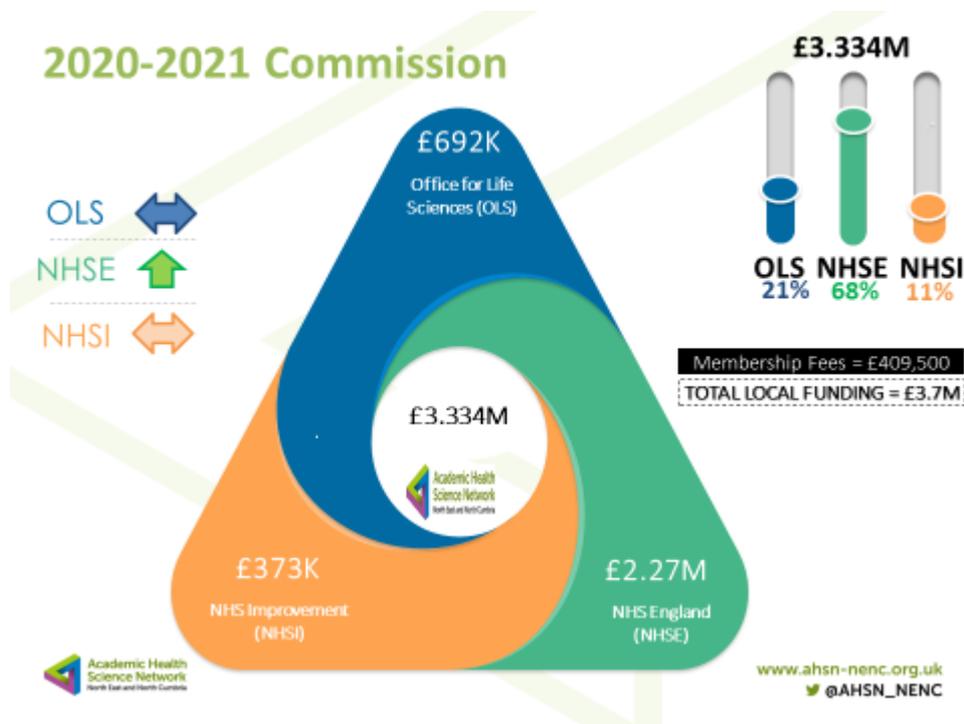


www.ahsn-nenc.org.uk
@AHSN_NENC

There are 15 AHSNs funded by NHS England. We were set up with the intention of taking your applied research and spreading it across the NHS at pace and scale. So we don't directly DO research, rather we support researchers and clinicians to make sure the research they do gets to the right people that need it in a timely way.

In 2018 we were re-licensed and we have three core objectives shown on the slide above.

2020-2021 Commission



These are our three commissioners – predominantly NHS England but also NHS Improvement which supports our patient safety work and the Office of Life Sciences supports our innovation. Our

funding has remained static, although we got more funding across the AHSNs to support the Covid effort, particularly with virtual working and work in care homes.

We are also a membership organisation so all the HEIs and CCGs across our region support us with a membership fee which comes to £400,000 of our total funding of 33.7 million.



With that we deliver a wide range of work. In the context of the NHS improvement in patient safety we only deliver what we are told to deliver by the national leads for patient safety, so that predominantly focuses on supporting networks around maternity and neonatal safety, deteriorating patients and ensuring there are unified early warning scores across all areas of the health care system. We also have been supporting work around adoption and spread of patient care bundles, particularly things around tracheostomy care bundle and emergency laparotomy care bundles in areas that we are directed nationally.

In terms of the Office for Life Sciences, we do a lot in the world of real world evaluation and horizon scanning and support for innovators. And then the area I am predominantly involved with is our NHSE commission, so we have a range of national programmes that we are required to roll out and that occupies about 30% of the resource we're provided with by NHSE.

But we also have a wide range of regional programmes that focus on areas that are deemed as priorities by our integrated care system. So at the moment that's predominantly on cardiovascular and respiratory disease and one example for you is that we're a national outlier for opioid prescribing. So we were asked by our ICS to support a program of opioid reduction across NENC.

The Remit of the AHSN NENC

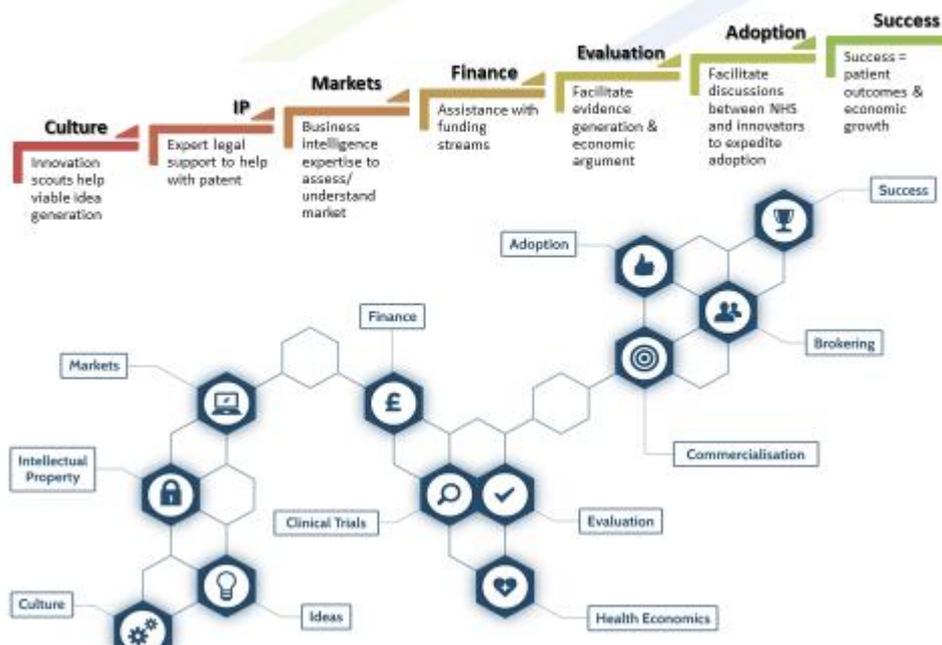
Acting as system wide integrators we:

- Facilitate interactions across stakeholder groups
- Access the expertise of delivery partners
- Work as an honest broker to support collaborative working
- Support health improvement and wealth creation through innovation.



So in terms of our remit, it echoes what you have heard from Eileen in terms of the remit we have to support stakeholders to deliver at the highest possible level for the people of NENC. We act as an honest broker across organisational barriers as a systemic integrator. So we access our delivery partners and commission a lot of our HEIs and FTs to support delivery, and we support health and wealth creation through innovation across NENC.

The Innovation Pathway in Action....



One of the ways we do this is through the innovation pathway. We have all components of this pathway in NENC which is unusual for an AHSN. We support innovators and practitioners and

clinicians with a good idea to take it all the way through the innovation pathway, allowing them to get to clinical practice to benefit patients in a timely way within their own region.



So the core pillars of what we do are around improving population health and transforming patient safety and quality improvement and those are the two areas I oversee. Our economic growth is headed up by our commercial director Russ Watkins and we also drive digital transformation across the region with our newly appointed executive director Dave Belshaw.



What does the AHSN NENC do?

<https://www.youtube.com/watch?v=8MSwWsayAcl>

This is a really useful video that pulls all that together and will give you an even stronger sense of what we do.

Key highlights 2020-2021



When Covid hit we were advised by NHS England to review all our programmes to stop areas that were not covid related and to deploy staff back into the NHS wherever possible. Since then we've continued to balance the work that we've been doing around Covid supporting the procurement of PPE and the control and command centres around digital care, out of hospital care etc., to make sure that innovations were being pulled through as quickly as possible. We've also had a strategy refresh that we're working on currently making sure that we are engaging fully with our ICSD, CRN and ARC and we have had a review of our AHSN and how we sit in the current landscape with Steven Singleton from North Cumbria. We have been hosting the Great North Care Record which is now moving into NECS and we've been recruiting a new Chief Executive Nicola Welsey, new Chief Operating Office Maria Roach and Director of Digital Strategy as mentioned.

We are one of the major partners in a recently awarded Academic Health Science Centre hosted by Newcastle University and we have also been supporting the North east and Yorkshire Region in a recently successful bid for £1.5 million to support the roll out of Digital Solutions in Care Homes. And then just finally in the NENC we are national lead for a number of programmes particularly about optimising lipid management and identifying those with familial hypercholesterolemia. This is now being adopted across the other 14 AHSNs.



There is an AHSN for the North West Coast Region called the Innovation Agency – they can be found here: <https://www.innovationagencynwc.nhs.uk/>

Healthwatch Cumbria – What we do. Debbie Banks, Research and Data Officer, Healthwatch Cumbria.

healthwatch
Cumbria

What we do

Healthwatch were set up in every local authority area in England, by the Health and Social Care Act 2012.

I am Debbie Banks the Researcher for Healthwatch Cumbria who were set up in every local authority in England in 2012.

Healthwatch Cumbria:

- Are an independent organisation
- We champion the views of patients and social care users in Cumbria
- Aim to make services better and improve health and wellbeing
- Gather the views and experiences of people living in Cumbria

The aims as stated above fit very well with the aims of the ARC and CRiHS.

Statutory duties

Involving local people

1. Scrutiny and monitoring of local care services.
2. How they could and should be improved.
3. Obtaining the views of local people.
4. Making reports and recommendations.
5. Providing advice and information.
6. Making recommendations to Healthwatch England.
7. Providing Healthwatch England with intelligence and insight.



We undertake a range of statutory duties as set out above. The findings of reports are passed to the Quality Care Commission and improve the issues facing people in the region.

How do we gather people's views?

The Feedback Centre - on the HWC website

Public engagement - at events

Attending local forums & meetings

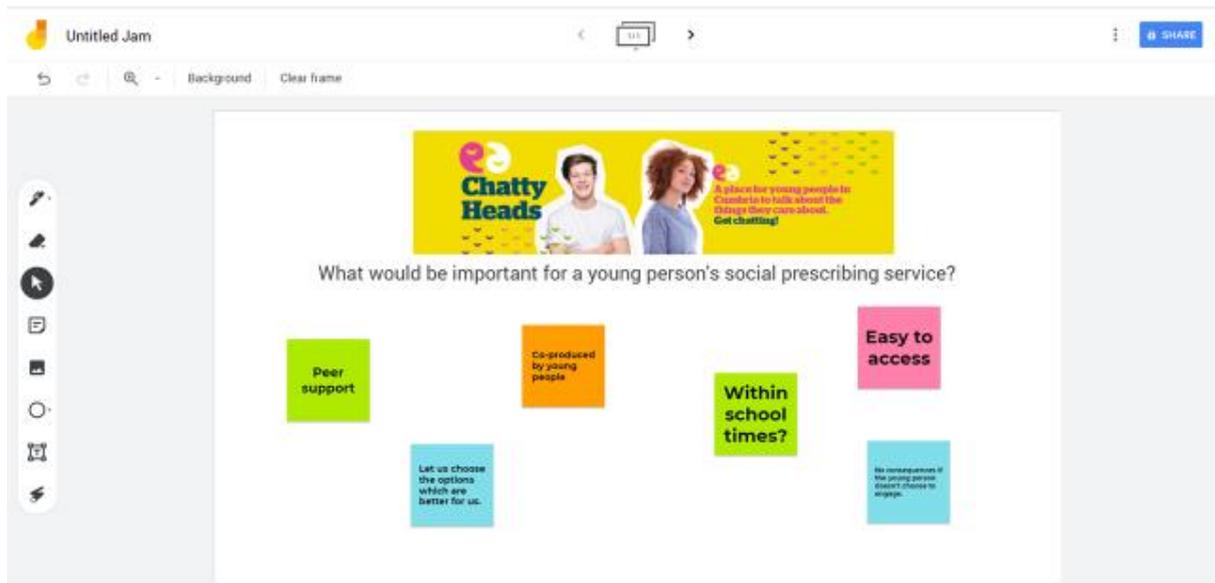
Through surveys & other research

Via our 0300 telephone number

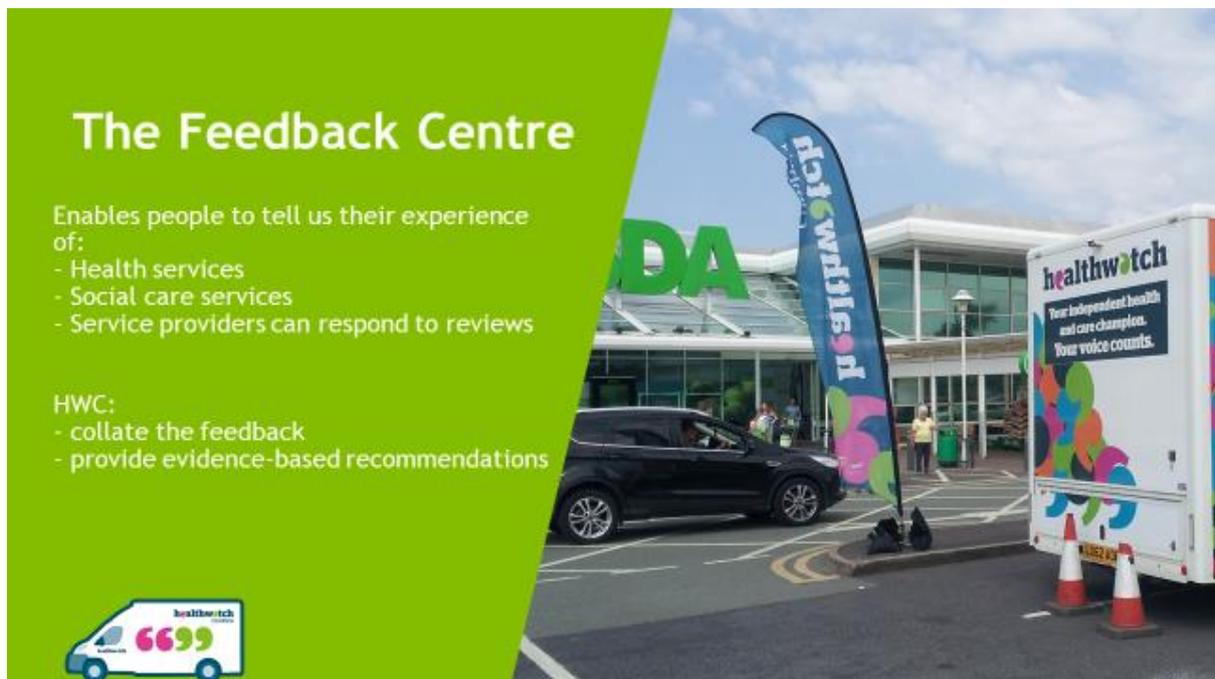
And healthwatch email:
info@healthwatchcumbria.co.uk



We have a range of ways to collect the views of people as shown on this slide, although most of this is now online.



Because our provision has moved online we are using a 'Jam Board' to lead discussions and to collect ideas as shown in the slide above.



The feedback enables evidence based recommendations to be actioned across the health and care sectors.

2020 reports

- Young people's mental health
- Why do people attend A&E?
- Focus on Ulverston
- Focus on Caldbeck
- Series of reports on the impact of the coronavirus pandemic in Cumbria
- The impact of the pandemic on the LGBTQ community in Cumbria and Lancashire



These are some reports that we have written this year.

This gives us the opportunity to bring lived experience and a social narrative to statistical evidence to be able to positively influence policy nationally and practice locally.

We would be delighted to connect with anyone who would like to work with us or use our reports as resources.

You can contact us at: 0300 303 8567, and our website is www.healthwatchcumbria.co.uk.

What Research Activities are we Investing in?

A Local NHS Provider View: Professor Dave Dagnan, R&D Director, North Cumbria Integrated Care.



NHS
North Cumbria
Integrated Care
NHS Foundation Trust

What research activities should we be investing in: A local NHS provider view

Professor Dave Dagnan, R&D Director, NCIC

happierhealthiercommunities.

Local NHS Research Strengths/Opportunities in North Cumbria

- Streamlined access to secondary and much of primary care
 - Developing an integrated/single R&D system within secondary physical health care [for all acute and community care]
 - NCIC supported primary care system, integrated systems working with practices that cover 50% of the Cumbria population.....and growing
- Expertise in setting up locally led projects in partnership with (typically smaller) commercial companies [Investigator Initiated Trials].
- Specific clinical expertise.

happierhealthiercommunities.

I am going to talk about the research infrastructure and priorities within secondary care and to some extent within some of primary care systems in NC. My comments also need to be seen in the context of COVID which will be likely to have an impact on how we organise ourselves in terms of research activities for some time to come. The research systems in NCIC are funded by the NIHR to support

the local implementation of high quality national and regional research programmes and our funding is based upon our activity in these areas.

Compared to other systems in the North East we are a small NHS system in a rural context. In order to facilitate flexibility in how we support research in Cumbria we are developing alliances across the secondary and primary care systems to increase our ability to do research at scale in NC. The R&D system has made sure there is a single process for enabling research to take place across much of the integrated care system. The integrated research system hosted by NCIC also provides a research service to primary care practices that cover 50% of the NC population. That system is growing and is one of the more productive primary carer alliances in the NENC area. The system we have developed offers the opportunity to implement research activities across multiple practices and offers the opportunity to think about which part of the health system studies are best placed. We can support research with patient populations from almost anywhere within the primary care system through to the very specialist acute systems.

We also have expertise in setting up and leading projects in partnerships with (typically smaller) commercial companies; these are called 'Investigator Initiated Trials'. These are led by local clinicians and are responsive to clinical priorities and interests in NC; they account for about 60% of our activity in some areas and support our staff in gaining experience in setting up and running projects. As an organisation we have a wide range of clinical expertise much of which is not yet fully utilised within the research processes described above.

Local priority: Research impact

- Engagement in research is associated with:
 - Lower Hospital Standardised Mortality Ratio
 - Higher CQC ratings
 - Patient feeling informed and confidence with clinicians
- Local impact on services, multiple case studies of impact of research on specific clinical practice.
- Recruitment, engagement, retention of staff and professions

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Our priorities are partly shaped by the impact research has within the wider system. We have published a number of papers from within our own system and looked at national data to demonstrate that higher research activity within the NHS system is associated with lower mortality rates and higher CQC ratings and with patients having more confidence in their clinicians and patients more informed.

We see the immediate and longer-term impact of our research practically and pragmatically on clinical outcomes and we can see specific changes in clinical practice as a consequence of specific studies.

We also see a wider and positive impact of research in terms of enhancing recruitment and retention of staff.

Local priority: Topic areas

- Local priorities [during and post-COVID]
 - Integrating services to provide for patients with complex needs such as – multi-morbidities, frailty, and for older people and socially isolated people or communities.
 - Remote and digital technologies.
 - Workforce development and retention.
 - Evaluation and research focus on service innovation and clinical processes.

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In terms of local priorities, much current activity is linked to COVID (we are implementing as many of the national COVID treatment and observation trials as we can accommodate). Much of the integrated health systems potential impact revolves around integration of services and pathways for people with complex needs; we need to make sure that these changes are fully evaluated and understood and our experience is shared beyond Cumbria. We have interest in remote and digital technologies, particularly during COVID but also as part of how we work in our rural settings; we need to understand how digital practice works and how to maintain learning and practice as we move out of the pandemic. There has been a strong practice interest in workforce and leadership development in NCIC that will continue beyond COVID.

You can connect with Dave at: dave.dagnan2@ncic.nhs.uk

What research activities should we be investing in? Dr Elaine Bidmead, Senior Research Fellow, CRiHS, University of Cumbria.

What research activities should we be investing in?

Elaine Bidmead, NIHR ARC NENC Senior Research Fellow, University of Cumbria.

University of Cumbria

CENTRE FOR RESEARCH IN HEALTH & SOCIETY

NIHR Applied Research Collaboration North East and North Cumbria

Good morning, I am one of the NIHR NENC ARC Senior Research Fellows and as Eileen said I was one of the first to start my role. My role in the first year is to scope the health and social inequalities in North Cumbria and I imagined I would start doing that by looking at the data to see where the inequalities were and in which places. I started to look at available data and began to realise there were a lot of problems with that.

Available data - problems

- ▶ Recency
- ▶ Granularity
- ▶ Mapping

'Often frustrated that the rural perspective is not well served by headline data' (VCSE)

'Less data is now available below District geography which is a problem because Districts are not places' (Councillor)

'The areas covered by wards are too big geographically in many rural areas. Even the LSOAs are too big for parts of the geography' (VCSE)

'Health [agencies] report so differently we cannot really compare or use data with any confidence' (VCSE)

Health and Social Inequalities in North Cumbria - Survey Report - June 2020

One of the problems was recency, although I have been informed by others that does not matter as not much has changed. Another issue is granularity and the level of detail I could get in different

places. Having worked in Newcastle City Council with large data sets of areas with big population density, this data looked very different with such high rurality. And then there is also the difficulty in the way that data sets map onto one another, some of it are at the District Council level, others at LSOA, and others at CCG and so it's hard to get a really good picture. As part of the scoping exercise I sent out a survey to stakeholders and they told me about these issues in North Cumbria. People are frustrated the rural issues are not supported by headline data. At a low level of data individuals may be identifiable, and so we understand some of the reasons, but the headlines mask issues. Councillors feel the geographic areas are too big, and the mapping of data sets meant it was hard to understand one area in enough detail.

In rural areas high level data can result in:

- ▶ Some marginalised communities, and the problems they face, being hidden
- ▶ Limited understanding of the 'problems', and the impacts of these for different groups of people
- ▶ Inappropriate or inadequate policy responses

The result of this is that we can miss some marginalised communities and the issues that face them. It gives us a limited understanding of the problems and the impacts for different groups of people, and if we don't have good understanding that can lead to inappropriate or inadequate policy responses.

What data do stakeholders want

Stakeholders want data that is:

- ▶ up-to-date
- ▶ Localised and focussed
- ▶ Based on consistent measures
- ▶ Easily accessible

'Data broken down to smaller units. Some sort of geographical limit put on the size of the area covered' (VCSE)

'One joined up IT system which all health, social care and voluntary sectors are able to access' (VCSE)

'Anything and everything that shows correlations which will help me focus my representation where it's needed' (Councillor)

'Nuanced qualitative data that begins to unpick complexities' (Councillor).

Health and Social Inequalities in North Cumbria - Survey Report - June 2020

So in the survey we asked people what they wanted, and the stakeholders said they wanted data that is up to date, localised and focussed, based on consistent measures and easily accessible. So they want anything and everything that shows correlations that will help them to focus their representation. Some asked for nuanced qualitative data that begins to unpick complexities and one person asked for a joined up IT system which we could all access from right across sectors. Some wanted data that was broken down into smaller units with some sort of geographical limit put on the size of area covered.

Creating lasting impact

- ▶ Health and social inequality is high on the policy agenda and is frequently discussed at strategy level but the underpinning evidence is limited and often anecdotal
- ▶ There is a need to move from the anecdotal to evidence based understandings
- ▶ There is a need for evidence that takes account of the subtleties amongst and between different communities and which facilitates greater understanding of the causes and consequences of inequality.
- ▶ Such evidence will lead to better policy making and more effective initiatives, interventions and practices.

But as part of the ARC what we want to do is research that can create lasting impact and at the moment, with Covid-19, health and social inequality is really high on the policy agenda. In

discussions I have been having recently, what has been said is that the understanding of inequalities is often limited and based on anecdotal evidence. There is a need for that evidence to take account of the subtleties amongst and between different communities so it can help us understand the causes and consequences of the inequality in more detail.

Yesterday I had a conversation with a CCG colleague and we were talking about obesity and highlighting the fact that if we just tackle people who are obese it doesn't stop people in the future from becoming obese. Also not everybody experiences the same outcomes from obesity – obesity impacts people unequally. We need this much more nuanced understanding and we feel that such evidence will lead to better policy making and more effective initiatives, interventions and practices.

Discussion

The ARC's vision for the North East and North Cumbria is to achieve **'better, fairer health and care at all ages and in all places.'**

So what research activities should we be investing in?

So the ARC in NENC aims to achieve better, fairer health and care at all ages in all places, in order to achieve this aim, I wonder what research activities you think we should be investing in? This early research has suggested that an effective data infrastructure might be a part of that.

Discussion covered the importance of supporting individuals to make their own decisions from their own motivating factors, potentially macro solutions will not fit individuals. There is value in both, but if obesity is the top line we don't make solutions that fit individual people.

A comment from the audience was that there are enormous socioeconomic differences within small communities and geographical areas within Cumbria. They are often small numbers as well, which makes it even more challenging.

There was some discussion about the emergence of a digital inequalities in North Cumbria in the chat, and a number of organisations were keen to work together to explore this further.

There was a discussion in chat about the importance of narratives to bring these to life further.

Public Involvement and Community Engagement (PICE) support available in North Cumbria

PICE Support in the NIHR NENC ARC, Dr Felicity Shenton, PICE lead NIHR NENC ARC.





Public Involvement & Community Engagement

North Cumbria Networking and
Engagement - Virtual Event
4th November 2020



Good morning, so my role is public involvement and community engagement across the ARC. We are very specifically describing it as public involvement because we had feedback at the bid writing stage from voluntary community sector organisations about the importance of it not appearing to be an entirely health focused collaboration. It's really important people are aware we are doing work around social care as well as health. The term 'patient' involvement was therefore not helpful. Community perspectives are really important as we know health and social inequalities affect communities – of place, of people and of interest.

Definitions – What do we mean by public involvement & community engagement?

Public involvement in research is defined as research being carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them, and uses the following terms to distinguish between the different activities:

Involvement – where members of the public are actively involved in research projects and in research organisations.

Participation – where people take part in a research study.

Engagement – where information and knowledge about research is provided and disseminated.

(www.invo.org.uk)

The work we are doing is defined by the NIHR as involve.

National Standards

-  **INCLUSIVE OPPORTUNITIES:** We offer public involvement opportunities that are accessible and that reach people and groups according to research needs.
-  **WORKING TOGETHER:** We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.
-  **SUPPORT & LEARNING:** We offer and promote support and learning that builds confidence and skills for public involvement in research.
-  **COMMUNICATIONS:** We use plain language for timely, two way and targeted communications, as part of involvement plans and activities.
-  **IMPACT:** To drive improvement, we capture and share the difference that public involvement makes to research.
-  **GOVERNANCE:** We involve the public in our governance and leadership so that our decisions promote and protect the public interest.

<https://sites.google.com/nih.ac.uk/pi-standards/home>

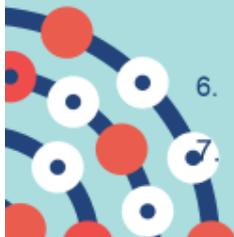
NIHR INVOLVE

They are all based in the nationally agreed standards and so we will demonstrate these across the ARC.

What is happening in the North East & North Cumbria?



1. Developing a Public Advisory Network
2. Developing a Young Public Advisory Network
3. Developing a Public Involvement & Community Engagement (PICE) Strategy
4. Developing PICE training resources (coproduction, peer research etc.)
5. Creating sustainable models of engaging with individuals and communities that are often excluded (LD, BAME, BSL, digital poverty)
6. Contributing to the ARC website www.arc-nenc.nihr.ac.uk
7. Supporting the development of PICE activities across the ARC Themes



Currently we are developing a Public Advisory Network organically including North Cumbria organisations. I'd be really keen to have additional membership from the organisations here and your volunteers or champions. Young people want a separate network and I am looking to develop that, although recent plans were postponed due to lockdown. I am keen that this is not NE centric.

Our strategy is a process rather than a document with lots of opportunities for engagement and we are producing training resources too, to be available for the end of the year online.

We are creating sustainable models of reaching traditionally 'harder to reach' communities. Such as; learning disabilities, BAME, digital poverty, E2L, BSL, rural communities.

What are we trying to achieve:

Better, fairer health and care at all
ages and in all places.



All that work is geared towards the vision of the ARC. Unless we involve people who live with the impact of poverty, austerity, inequality and Covid, we will not have enough information about the day to day impacts of that to make the right difference to the right people.

Please do get in touch and get involved.

Please contact:

Felicity.Shenton@cntw.nhs.uk



There was a question about how to ensure young people can access these opportunities. These opportunities will all be advertised through the ARC network and we would welcome support to ensure they reach young people as widely as possible.

Towards a Training Strategy for North Cumbria from the NIHR NENC ARC, Professor Gill Rowland, NIHR NENC ARC Training Lead



**North East and North Cumbria
Applied Research Collaboration: towards a
training strategy**

Gill Rowlands, Newcastle University
gill.rowlands@newcastle.ac.uk



I am Gill Rowlands, it's great to be here and this is really an introduction as I am new in role and wanting to tell you about what we are planning to do and how you can get involved.

What does the training strategy need to deliver?

- Skills across NENC and amongst our stakeholders to enable delivery of:
 - research/evaluation on local priorities
 - knowledge mobilisation, implementation
 - capacity building, capability development
 - public engagement and involvement, co production of work
 - making a difference to health, well-being, care delivery and outcomes

The training strategy is all about making sure everyone has the skills and capacity to deliver on what the ARC needs to do – high quality research and putting it into practice.

Getting involved

- Listening exercise Spring 2021
- If interested email gill.rowlands@newcastle.ac.uk

NIHR | Applied Research Collaboration
North East and North Cumbria

What we plan to do is to have a listening exercise geographically, so pulling people from North Cumbria together to hear what it is that people think needs to be provided in order to provide people with the skills they need. Resources are limited but there are also lots of resources available too. Hopefully I will see many of you in the new year, please do get in touch.



Practical research for complex problems



Working together, cross-sectors & across geographies

There was a question about whether this training would be available to wider members of the community. Mapping of existing resources and will be important and if it can be opened up then we will do so to as wide a group as possible. That is part of the listening exercise to try to ensure the right people get what they need in order to support health research in Cumbria.

One example of this is the University of Cumbria pilot with the National Youth Agency to develop a level 2 young researcher accredited programme that will be available online. We will keep you posted about that. So it's not just about local link up but also national.

Eileen added that there is a project looking at best practice in terms of people exiting care. We have resources within that project to support a number of people who have had experience of the statutory care system to become co-researchers with us in our work so we will be trying to provide training to support these young people to become accredited.

The Research Design Service – What we do. Dr Louise Hayes, NIHR Research Design Service Senior Research Methodologist and HUB Lead North Cumbria.

NIHR | Research Design Service North East and North Cumbria

The Research Design Service:
what we do
Louise Hayes

4th November 2020
NIHR and CRiHS engagement event

<https://rds-nenc.nihr.ac.uk/>

@nihr_rdsnenc

Who are we?

- We are a team of general and specialist methodologists – including qualitative researchers, statisticians, health economists, PPI specialists, trialists.....
- One of 10 regional Research Design Services, funded by NIHR to *“increase the number and proportion of high quality applications for funding”*

We are funded to provide advice across the NENC, and I do have an office at the University of Cumbria Fusehill Street Campus. We have a broad range of skills, funded by NIHR, and we are one of 10 RDS across England.

Who do we support?

- Investigators preparing research proposals for national peer-reviewed funding competitions in applied health, public health or social care research
- Clinicians, academics and researchers from institutions across the region at all stages of their research career



We will support first grants to professorial applications for fellowships.

What do we do?

- Provide free and confidential advice on all aspects of research study design
- Support clinicians, academics and researchers from institutions across the region at all stages of their research career
- Support applications for funding to national peer-reviewed funding competitions in applied health, public health or social care research to:
 - NIHR funding streams
 - other funders eligible for UK CRN portfolio



We support all stages of research design. We will support more than NIHR applications, for example UKRI or any other peer reviewed grants.

RDS expertise

- **Specialist methodological advisors:**
 - Statistics
 - Clinical Trials
 - Qualitative
 - Health Economics
 - Health Psychology / Behaviour Change
 - Epidemiology and Public Health
 - Evidence Synthesis
 - PPIE (PICE)

The range of support we can offer is signposted on this slide.

More than study design.....



This slide shows all the elements of designing a research proposal and we can support with all of this.

What happens?



This flow diagram shows the process of support, from filling in an initial contact form to access to specialist support.

PPIE

Defined as research being carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them.



Definition of 'public' includes:

- Patients
- Potential patients
- Carers
- People who use health and social care services
- Other stakeholders

Our PICE support might be particularly helpful. We can enable access to a PICE group of people who can review your research proposal. By 'public' we mean a very broad range of people.

RDS consumer panel

- Meet monthly
- On-line review
- Review plain English summary



One way to do that is our RDS consumer panel, and you can present your proposed study to them and they can also provide an online review. They are really helpful at reviewing plain English summaries too.

RDS consumer panel

- Meet ~~monthly~~ flexibly
- On-line review
- Review plain English summary



We no longer meet face to face, but are online instead. This works well and is reducing travel, although there are issues with digital poverty instead.

Contact Us

Email: rds.nenc@nihr.ac.uk

Website: <https://rds-nenc.nihr.ac.uk/>

RDS NENC Twitter: [@NIHR_RDSNENC](https://twitter.com/NIHR_RDSNENC)

Phone (0191) 208 7000

www.rds.nihr.ac.uk ... 'Contact us'



So if you want some support please contact us as above.

The North West Coast RDS can be reached at: <https://www.rds-nw.nihr.ac.uk/>

Statistical Support Across North Cumbria, Professor Dawn Teare, Professor of Biostatistics, University of Newcastle.



Statistical Advice and Support

M. Dawn Teare
Professor of Biostatistics
Biostatistics Research Group
Newcastle University
www.newcastle-biostatistics.com



Population Health
Sciences Institute
Biostatistics
Research Group
Newcastle University

dawn.teare@newcastle.ac.uk

With Louise we had started to do support in Carlisle and planned to do more of it and to give a talk but with recent restrictions that has changed. So instead we are in this space and I am keen to enable people to understand what we can do.

In my day job I am the head of the Biostatistical research group based at the University of Newcastle but we are also one of the anchors in the statistical advisory community that request come through from RDS, so we're at one of the front doors you might say.



Outline

- Stages of Statistical Advice
- Importance of early discussions over design
- Questions to anticipate before requesting statistical advice
- Access to advice

Today's session will cover the points made in the slide and also start to consider how we can reach out to the probably enormous community of statisticians who are out there across the ARC.

Statistical Advice

- Design
- Analysis
- Reporting

Often when I go and talk about statistics, people ask me about the analysis. They've already got their data and they want to know what sort of analysis we should apply and it doesn't matter how often I say you should have come to see me earlier, that's where we end up.

Design Design Design!

- Designing a study and developing a research proposal is an iterative procedure
- Research ideas can take time to develop into clear research questions
- Iterative discussions with methodologists including statisticians help to form a viable, optimal design that can deliver on the objectives
- Serious flaws in design **cannot** be corrected by statistical analysis

So we like to see people early in the process, when they are designing their study so we can support the whole process and align questions to data collection to analysis. The RDS provides an iterative process of consultations and based on the first conversation with you, you may access a range of support services. For example, the PICE group might advise you to change your question or data collection tool, so having these conversations with a community of methodologists is really helpful.

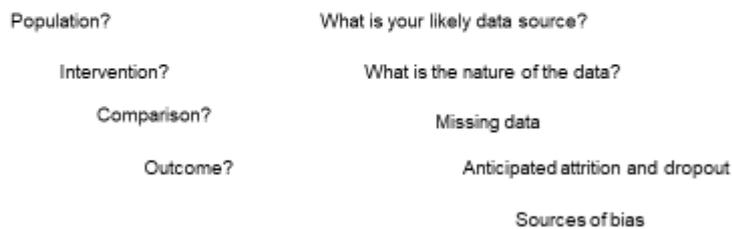
Sample size and power calculations

- Calculating the required sample size is a late stage in study design
- Sample size calculations rely on good quality information and a definite design
- Feasibility or pilot work may be necessary to be able to perform reliable sample size calculations

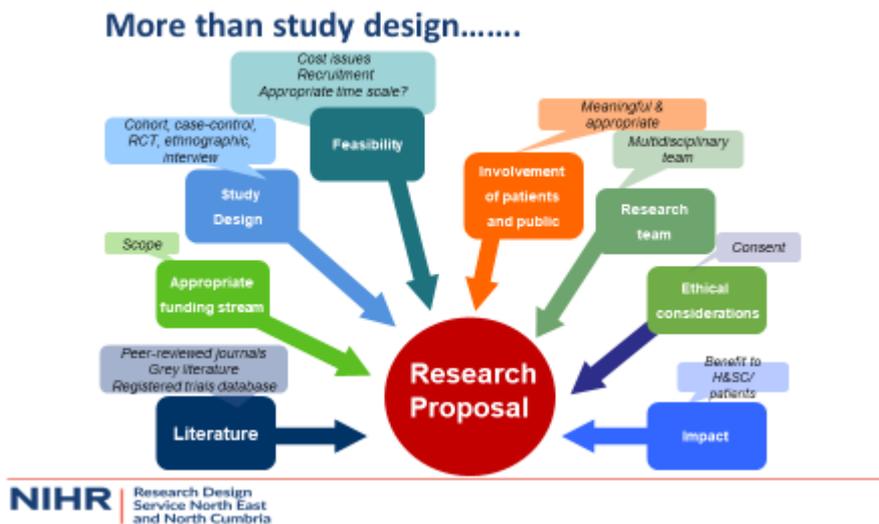
Whilst we can help with sample size, that is only one component of design and will be grounded in the rest of the research design, so please come to us early to discuss all statistical issues.

First stage

What is the research aim, question or hypothesis?



Here are some of the questions you may get asked by a statistician. Different answers will lead to different next steps.



Sometimes people come with well-formed ideas and sometimes they don't. We are integrated into this community of advisors, so the earlier you get to us with a question the better.

Statistical Expertise within RDS

Specialist Statistical Advice Requests to RDS

- **Biostatistics Research Group**, Population Health Sciences Institute, Newcastle University
- **Durham Research Methods Centre**, Wolfson Research Institute for Wellbeing, Durham University

Provides access to early statistical advice, leading to guidance and recommendations for statistical collaborators within the region.

From a statistical perspective you will get funnelled into a community of statistical support from us at Newcastle and from the centre in Durham. We will guide you to the right advisor or community of support. We're still building this infrastructure and so we'd be glad to know who else to connect with.

Access to statistical support and collaborations

- Extensive statistical expertise throughout the region
e.g. observational studies, randomized designs, use of routinely collected data
- RDS should be the first step for accessing statistical guidance.
- Recently appointed methodology ARC fellows will be working to effectively extend the reach of the RDS into the ARC member

Through the ARC we have appointed some research fellows, we have five half time research methodologist fellows. They are all used to working with broad questions and we are wondering on how to extend the reach of the RDS into the ARC with these new roles. They may identify training needs or run events to reach out more effectively. We are still working out how this will operate but it will be good to have a one point of access through the RDS.

Eileen added that entry level training around statistics and economics are important and we may be able to deliver resources to support this with the new methodologists. It's all about the join up across the rich tapestry of support. Whilst the fellows are delivering support we also want them to develop their own areas of methodology, so they are not purely in supporting roles.

There was a question about whether support would be available to peer researchers who do not have statistical skills. The training offer could support these sort of people to have statistical literacy.

A comment was that PICE also needs to happen early, before the research design, not as an after-thought, in order to ensure a quality proposal.

Adhoc Presentation from David Allen, CEO of Cumbria CVS

We are an infrastructure across the region and are interested in the health inequalities agenda. We have 2,500 organisations in Cumbria who are registered and another 2,500 who are not registered. We try to support their capability through training and resources, governance and funding support. We also try to link them into public bodies for increased representation, influence and collaborative working. We also deliver projects ourselves that are health oriented, some health commissioned some local authority funded or lottery or ESF programmes.

I am here today because of the opportunities to provide specific linkage between the academic, health and voluntary sector. It's great to see so many organisations here and I think our potential for collaboration is great. I've been in the voluntary sector all my life and I know how difficult it is for us to access quality education and research to promote or assess the impact of the work that we do. So one of the things I am very keen to do arising from this meeting is to find some ways to broker some of that collaboration and an evaluation of what the third sector can offer.

Some of the specific programmes that we've been involved with include a Health Partnership Officer for North Cumbria who provides a lot of that linkage work. We have a Health Network she manages that has over 600 organisational members who meet and link regularly. It would be great to have some representation from this group on that network.

We have a Third Sector Referral Programme based through the ICC network that provides referral on for colleagues who have patients who can benefit from third sector delivery. They are also now working on a post Covid health and welfare support service across NC. So this is a direct referral to local organisations to prevent re admission post hospitalisation. And we have a couple of funding officers who are trying to increase inward investment from outside Cumbria in health and care services. They do a monthly newsletter and webinar for VCS organisations to come to. And none of it, as far as I am aware, is linked up to the programmes presented so far. So I welcome engagement with you all.

You can contact us on: 01768 800350 and our website is: www.cumbriacvs.org.uk

Or you can contact David at: david.allen@cumbriacvs.org.uk

Concluding Discussion – What could be next steps for us all here today?

Healthwatch were struck by the number of different PICE activities and how much people are listened to. We have a real opportunity to corral these voices and use these as starting points for research and practice decisions. We need to unpick the critical factors underpinning issues in order to respond. Healthwatch do not have the capacity or experience to unpack this and so working with statistical evidence and robust analysis will be a powerful collaboration.

Felicity assured that PICE activities will be embedded at all levels of the ARC, from front line research to strategy to ensure we amplify and join up the voices of people throughout all activities.

Cumbria Youth Alliance are keen to be involved and to work out how to best join in. Carolyn Otley from Cumbria CVS offered opportunity to present to third sector networks which join up many other networks. That would reach youth sectors, community sectors and the funders network.

Eileen commented that two projects on youth experts by experience were funded by the ARC and so we could perhaps join these dots with the PICE work and third sector.

Colleagues from the North Cumbria CCGs and ICP commented that they will create opportunities to present and share this information with their networks to ensure link up to statutory health services. An approach to social care will also be needed.

Felicity closed the event by stating how valuable this thanking everyone for very short presentations which were very valuable. Thank you also to the audience who were really key in joining discussions, in taking this back to their networks, and in creating further opportunities to join up the research infrastructure across North Cumbria.