NIHR | Biomedical Research Centre

NIHR Biomedical Research Centre: Newcastle

Annual Report 2025-2026

NHS
The Newcastle upon Tyne Hospitals
NHS Foundation Trust

Newcastle University

NHS
Cumbria, Northumberland, Tyne and Wear
NHS Foundation Trust

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Foreword

I am delighted to share with you our 2025-26 Annual Report, the first since I became BRC Director. The report is a great chance to reflect on the significant achievements and progress made across our centre over the past year. It showcases the breadth and impact of our work across our research themes and demonstrates how this research is directly benefiting our patients.

Having been appointed as BRC Co-Director in 2025, I was honoured to succeed Professor Avan Aihie Sayer as Director from 1st April 2026 as part of a planned and structured succession. As Director, I am committed to continuing the collaborative leadership approach that has been central to the BRC's success under Avan's leadership. I have also benefitted from working with the expanded leadership team established this year. Professor Rachel Cooper was appointed as BRC Deputy Director alongside Professor John Isaacs while Professor John Sayer and Professor Neil Rajan took on the roles of Associate Deputy Directors. Together, they bring additional expertise, leadership strength and strategic capacity to the BRC.

Throughout the report you'll see that we have established new partnerships and strengthened existing collaborations with industry, attracted investment to advance our research and continuing to share our knowledge including through publications that influence research internationally. We offer a wide range of opportunities and initiatives to support our research community, helping to develop researchers' careers, enhancing our research culture and embedding inclusion practices in everything we do. We also continue to work closely with local communities, ensuring their voices help shape and improve our research.

I hope you'll take the time to explore the many ways in which our community continues to drive innovation and excellence in translational and experimental research, delivering tangible benefits for patients and society.

Professor Andrew M Blamire
Director, NIHR BRC: Newcastle

About NIHR BRC: Newcastle

The National Institute for Health and Care Research (NIHR) Biomedical Research Centre (BRC): Newcastle brings together world-leading researchers and clinicians to facilitate early-stage experimental medicine research and support the translation of scientific discoveries for the benefit of patients.

Our 2025-2026 report highlights how we are delivering impact across our BRC to improve the lives and healthspan of patients. Thanks to everyone across our BRC, to public contributors, partners, collaborators and funders, we deliver the NIHR's mission to improve the health and wealth of the nation through research.

NIHR BRC: Newcastle

Awarded £25.8m by NIHR from 2022-2028. Our internationally renowned researchers work collaboratively across the BRC to share understanding and maximise the value and impact of our research. This critical mass of research excellence combined with synergistic working enable us to realise the benefits of bringing the research together as a BRC and maximise the effectiveness of NIHR's funding to deliver our mission — to transform lives through world-leading research into ageing and multiple long-term conditions (MLTC).

Our research across eight themes

- Ageing, Sarcopenia and Multimorbidity
- Dementia, Mental Health and Neurodegeneration
- Digital Health, Ageing Innovation and Inclusion
- Informatics and Precision Care in an Ageing Population
- Liver Disease, Multimorbidity and Lifestyle
- Musculoskeletal Disease and Inflammation Medicine
- Neuromuscular Disease, Rare Diseases and Mitochondrial Dysfunction
- Skin Disease, Oral Disease and Immunogenomics

In 2025-26 we funded

34
PhD students

79
Researchers

68
Infrastructure support staff

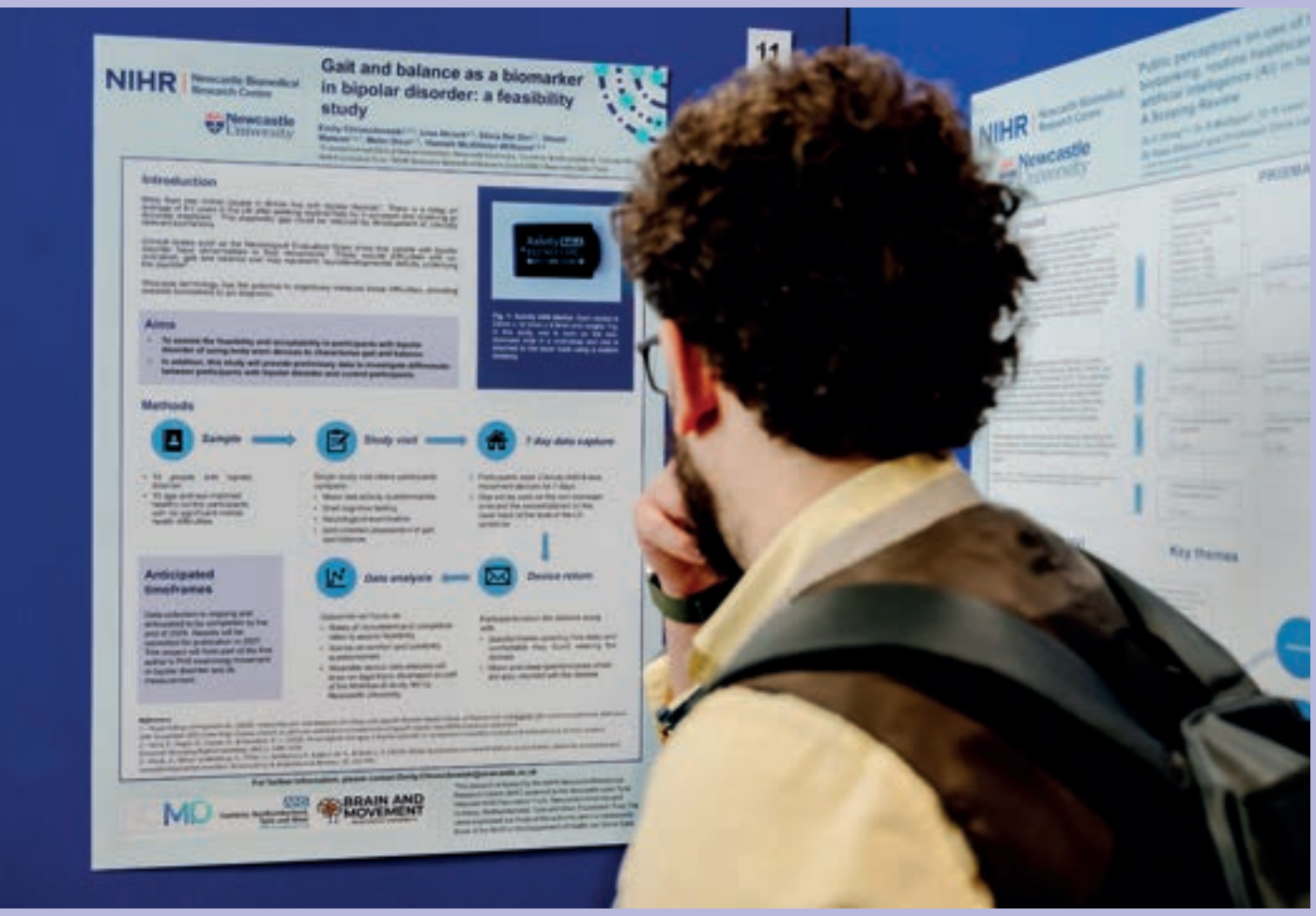
Our people

Our research community comprising more than 300 individuals, benefits from the support the BRC provides to underpin a breadth and depth of world-leading experimental medicine research.

Our impact

NIHR BRC: Newcastle delivers a portfolio of research that turns translational research findings into benefits for patients, society, the economy and the health and care system.

In 2025-26, researchers across the BRC have made significant advances in the understanding of diseases, identified potential new treatments, published findings in leading research journals, attracted further investment in their research and translated scientific breakthroughs into changes in NHS care for the benefit of patients.



Highlights of 2025-2026

1 NIHR-funded research awarded UK's highest national honour – Queen Elizabeth Prize for Education

In November 2025, Newcastle University was awarded the UK's highest national honour for universities, The Queen Elizabeth Prize. This was awarded in recognition of decades of work transforming the understanding, diagnosis and care of people with Dementia with Lewy bodies.

2 Ground-breaking IVF treatment reduces the risk of mitochondrial disease

Two publications in the New England Journal of Medicine, present the most detailed clinical and laboratory evidence to date on the safety and effectiveness of mitochondrial donation, the cutting-edge IVF technique developed by researchers in Newcastle Findings report that the treatment is effective in reducing the risk of otherwise incurable mitochondrial DNA diseases. Following treatment, eight babies born to seven women at risk of transferring serious disease caused by mitochondrial DNA, show no signs of having mitochondrial DNA.

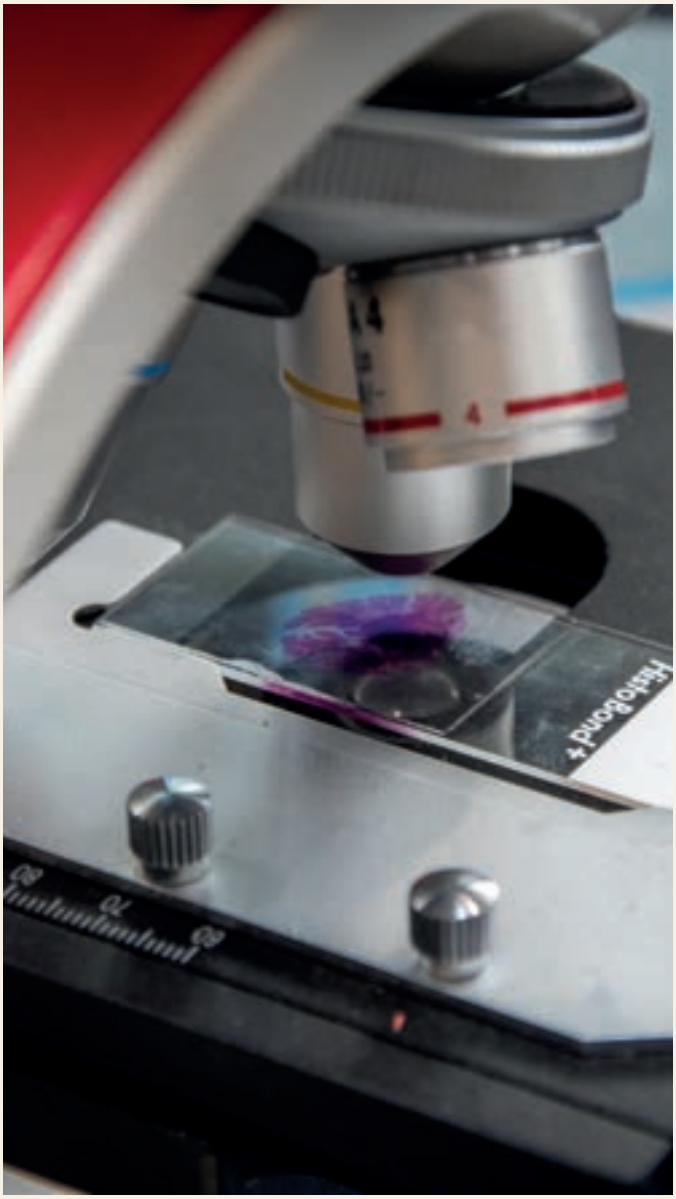
3 First ever licenced symptom therapy for Primary Biliary Cholangitis, linerixibat, is approved by the FDA and MHRA

The first ever licensed symptom therapy for Primary Biliary Cholangitis (PBC), a rare liver disease, was approved by the Food and Drug Administration (FDA) and the Medicines and Healthcare products Regulatory Agency (MHRA). Linerixibat, was approved for the treatment of cholestatic pruritus, an internal itch with a debilitating impact on quality of life, affecting 89% of people living with PBC.

Investment in our research

Newcastle, through Dr Rachael Lawson, is leading a $2.4 million work package within the international Parkinson's Clinical Cohorts Collaborative (PC3), funded by the Michael J. Fox Foundation. The project will combine data from 14 UK cohorts of patients with Parkinson's and 25 years of retrospective NHS clinical data to a more representative dataset. This will improve understanding of how Parkinson's develops and progresses across different groups of patients, leading to more reliable research outcomes, better future treatments, and improved care for people living with the condition.

The Edmond J Safra Accelerating Clinical Trials for Parkinson's Disease (EJS ACT-PD) Trial has now opened to recruitment, with chief investigators based at University College London and Newcastle University through Professor Camille Carroll. EJS-ACT-PD is the first multi-arm multi-stage platform trial for Parkinson's Disease in the UK. This £8.3m trial is funded by the NIHR/MRC EME Programme, Cure Parkinson's, The Michael J Fox Foundation, Parkinson's UK, The John Black Charitable Foundation, The Gatsby Charitable Foundation and Van Andel Institute.



Across the BRC, researchers leveraged over £24m in funding to support new research projects through partnerships with charities, research councils, government organisations and industry.

£24m **funding leveraged**

Newcastle, through Professor Catharien Hilkens, will lead a new £1.8m Engineering and Physical Sciences Research Council (EPSRC) Healthcare Technology Translation Partnership award in collaboration with Cambridge and Glasgow. The project aims to develop a smart injectable biomaterial-based approach for the delivery of therapeutic cells to actively repair cartilage in patients with arthritis.

A £3 million international research programme, ARCADIA, has been funded by Arthritis UK to improve understanding of when inflammatory arthritis is truly in remission. Led by researchers including Dr Ken Baker and Professor John Isaacs, the five-year project will develop biological tests and biomarkers to identify remission more accurately. This could help create new treatments and management approaches, enabling more people with inflammatory arthritis to achieve and maintain drug-free remission.

Professor John Issacs leads the north of England and Scotland training programme for the new LEGACY IIII Network which will establish ten specialist lymph node research centres across the country. Co-led with Oxford and Cardiff, this national network is expected to be transformative for British science in this growing field, helping to drive forward research through targeted training and strategic regional development. It will enable substantial benefits nationally and globally across discovery science in infection and immunity, drug and vaccine development, commercial partnerships, and related fields such as cancer research.

Disseminating our research

Publishing research allows others to check the findings, learn from them and use them. Sharing research helps improve research and turns findings into better knowledge. This can lead to changes in clinical practice for the benefit of patients.

The RAMUS study

Researchers from across the BRC have published findings from the RAMUS study in Lancet Rheumatology. The study found that increases in creatinine seen in patients with rheumatoid arthritis taking tofacitinib reflects a reversal of muscle loss rather than kidney damage. This will lead to future research into treatments for muscle loss. In Nature Medicine, Newcastle researchers report that Semaglutide may help heal the liver by reducing scarring and inflammation, making blood protein levels look more like those of healthy individuals.

Semaglutide

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Myo-Guide

In collaboration with researchers across Europe America and Asia, researchers in Newcastle have published the Myo-Guide web diagnostic platform in the Journal of Cachexia. An AI tool has been developed to analyse muscle MRI scans and suggest likely neuromuscular disease diagnoses. It performed as well as or better than expert clinicians in testing and is now available worldwide through the Myo-Guide website- to support patient care and research.

Steatohepatitis and liver fibrosis

Researchers in Newcastle have identified a potential treatment for patients with steatohepatitis and liver fibrosis. Findings from key clinical trials have been reported in Lancet Gastroenterology and Hepatology.

PSORT study

Newcastle researchers published findings from the PSORT study in Communications Medicine. The study found biological links between psoriasis and obesity and identified markers that can help predict disease severity, improving understanding of the condition and supporting more personalised care.

2025-26 impact in numbers:

589

Publications

374

Active research projects

1550

Participants recruited to clinical trials

Delivering impact for the benefit of patients

Reducing drug treatments for patients with rheumatoid arthritis

Researchers at NIHR BRC Newcastle led two clinical trials involving 160 people with rheumatoid arthritis to see whether patients whose condition was well controlled could safely stop their medication. The studies showed that around half of participants were able to stop treatment without their arthritis worsening, and researchers developed new blood tests that could help predict who could do this safely. The findings have already led to a new NHS drug tapering service in Newcastle, helping patients avoid unnecessary medication risks while reducing treatment costs and supporting more personalised care in the future.

Using AI to reduce blood clots

The Newcastle upon Tyne Hospitals NHS Foundation Trust partnered with AI company Solventum to develop a system that reviews radiology reports and identifies patients with suspected blood clots in their veins. By spotting these patients earlier, clinicians can improve treatment and help prevent avoidable hospital acquired clots. Sharing this information with clinical teams has also reduced the number of blood clots in patients by improving the use of preventative blood-thinning medication. This frees up nursing time each day, which is now devoted to direct patient care and clinical education. This work has received national recognition, including the Health Service Journal Partnership Award for the Most Impactful Use of Technology on Clinical Practice in 2026.

Spotlight on research in rare diseases

Newcastle has a distinguished history of research and clinical care in rare disease, leading in the discovery, diagnostics, treatment and care of many diseases and groups of disorders.

Our experts have unique insights into building and evolving diverse networks in care and research. They have played a key role in the launch of the European Reference Networks (ERNs) for rare disease, establishing and coordinating three of the 24 Networks, more than any other centre in Europe.

Advancing research excellence in rare diseases

Newcastle researchers are leading major national and international efforts to improve diagnosis, treatment, and clinical trials for people with rare diseases. This includes leading the £12 million LifeArc Centre for Acceleration of Rare Disease Trials, which aims to make clinical trials more efficient and increase opportunities for patients to take part in research across the UK. Researchers are also helping to develop new diagnostic tests, biomarkers, and treatments for rare mitochondrial diseases through the LifeArc Centre for Rare Mitochondrial Diseases, a national partnership with leading universities, charities, and patient organisations.

In addition, Newcastle leads the UK Rare Disease Research Platform, funded by the MRC and NIHR, which brings together researchers, clinicians, and patient groups from across the country to improve the diagnosis and treatment of rare diseases. By coordinating research across multiple conditions and leading key research networks, Newcastle is helping to accelerate discoveries and deliver better outcomes for patients and families affected by rare diseases.

Step-change in rare disease diagnostics

Researchers in Newcastle have developed a new protein-based diagnostic test that works alongside genetic testing to diagnose rare mitochondrial disorders more accurately. The test has already helped identify conditions that previously went undiagnosed and can deliver results much faster than traditional methods, supporting urgent patient care. It is now being assessed for routine NHS use, with the potential to enable earlier treatment decisions, reduce uncertainty for patients and families, and avoid the need for invasive diagnostic procedures.

Influencing clinical guidelines for equitable care in rare disease

Researchers in Newcastle are helping to improve care for people with rare diseases by developing national clinical guidelines. Their work has contributed to new care recommendations for children and families affected by Kabuki Syndrome, the first UK guidelines for patients with inherited POT1 gene changes linked to cancer risk, and improved guidance for managing recurrent ear infections. These achievements are helping to standardise care, support clinicians, and improve patient outcomes across the NHS.

Working together

The BRC sits at the heart of a world-class translational research environment in the North East and North Cumbria (NENC) region, actively collaborating with a wide range of NIHR funded infrastructure.

Together with the NIHR Applied Research Collaborations (ARC) Chief Operating Officer (COO), our BRC COO co-chairs the NIHR Operational Leadership group, bringing together Directors and Managers of a diverse range of NIHR infrastructure across the region. This group provides a collective voice and catalyses initiatives to turn scientific discoveries into innovation and adoption in clinical practice for the benefit of patients.

Our BRC is a partner in a new Public Partnership Training Programme. Designed to support inclusive and collaborative research across the NENC, this joint initiative between Newcastle Health Research Partnership (NHRP) and regional NIHR infrastructure offers 32 free sessions tailored to the stages of the research cycle, as well as research inclusion sessions. It is open to research staff, PPIE professionals, public contributors, health professionals and Voluntary, Community, and Social Enterprise (VCSE) staff based in the region.

NENC Research and Innovation Ecosystem Leadership Board

A new NENC Research and Innovation Ecosystem Leadership Board has been established bringing together the Newcastle Health Research Partnership, with regional research and innovation directors, NIHR infrastructure directors and the Integrated Care Board NENC. It aims to ensure the NENC harnesses its full research and innovation potential.

National Leadership

Internationally renowned researchers across our Research Themes continue to influence national NIHR cross-infrastructure and cross-BRC collaborations.

Theme Co-Lead Professor Avan Aihie Sayer co-chairs the Multiple Long-Term Conditions (MLTC) Cross-NIHR Collaboration (CNC), an initiative bringing together a range of NIHR infrastructure to address complex MLTC research questions. Theme Co-Lead Professor Miles Witham co-leads the Interventions and Prevention workstream and BRC Deputy Director Professor Rachel Cooper co-leads the Health Inequalities Cross-Cutting Group.

Our Dementia, Mental Health and Neuro-degeneration theme is playing a key role in influencing policy and practice through its membership of the new NIHR Dementia Policy Research Unit (PRU).

The theme is also active in three Translational Research Collaborations (TRC). Theme Co-

Lead, Professor Hamish McAllister-Williams, has been appointed joint chair of the mood disorders workstream of the NIHR Mental Health TRC and for the Mental Health Mission. A Mood Disorders Research Clinic Network has been established involving 15 sites linked to BRCs, including Newcastle. Theme Co-Lead, Professor John-Paul Taylor, is Deputy Chair of the Dementia TRC. Member of the BRC Leadership Track, Professor Alison Yarnall, leads a workstream in outcome measures and digital mobility outcomes in the newly established Parkinson's Disease TRC.

Members of our Musculoskeletal Disease and Inflammation Medicine theme are active in the NIHR Versus Arthritis Musculoskeletal TRC.

Building partnerships with industry

Industry partnerships are vital to our strategy, translating discoveries into benefits for patients and economic growth. Companies are attracted by the access we can provide to experienced clinicians and scientists, patient cohorts, robust delivery infrastructure and our collaborative ethos.

Our strategy is to help BRC investigators at all career stages develop the confidence and skills needed to engage effectively with industry, and to accelerate research translation through greater industry involvement.

In June 2025, we delivered the inaugural BRC Industry Month, comprising a programme of targeted events and initiatives designed to support the BRC community engage with industry partners. The programme aimed to accelerate the translation of research along the translational pathway to deliver meaningful patient benefit.

This year, we invested in three research projects designed to increase translational research activity across our partner organisations while supporting the development of high-quality collaborations with industry partners:

Enabling Data-Driven Parkinson's Care: Industry Co-Development of the SMaRT-PD Platform

This project is developing SMaRT-PD, a digital tool that helps patients and clinicians better understand how Parkinson's symptoms change over time. By combining data from wearable devices, patient-reported experiences and clinical records, it provides a more comprehensive picture of an individual's condition and supports more continuous, personalised care. Working with KPMG, the team will enhance the software, test it using real-world data and prepare for future clinical trials so it can eventually be used in NHS settings. SMaRT-PD aims to enable more proactive and responsive Parkinson's care, improving outcomes for patients and supporting better-informed clinical decision-making.

Precision tuning of bone marrow organoids for disease modelling and therapeutic testing using the Caf-1 system

Partnering with the spin out company MarraBio, the team plan to develop a bone marrow model to study blood and lymphoid cancers. It could also be used to study problems with immune cells and common cancers that spread to bone, such as breast, prostate, and lung. The project will generate preliminary data and strengthen future major funding applications for these advanced models that replicate human tissue environments more accurately and more ethically than animal models.

Digital technologies for managing chronic fatigue: Wearable devices and smartphone app

Fatigue is a common and debilitating symptom of many long-term conditions, yet reliable ways to measure and predict it remain limited. This project will identify an accurate ECG-based wearable device to monitor heart rate variability, link it to the developed FatigueSense app, and test its usability with people experiencing chronic fatigue. The aim is to provide personalised insights into fatigue patterns, helping individuals better understand and manage their symptoms.

In 2025-26 we had

43

New partnerships

37

Continued partnerships

Research capacity development

We build capacity through collaborative leadership and training opportunities that develop a flourishing interdisciplinary pipeline of translational researchers for the future.

Bringing people together to support career development

1 Research Capacity Development Celebration Event

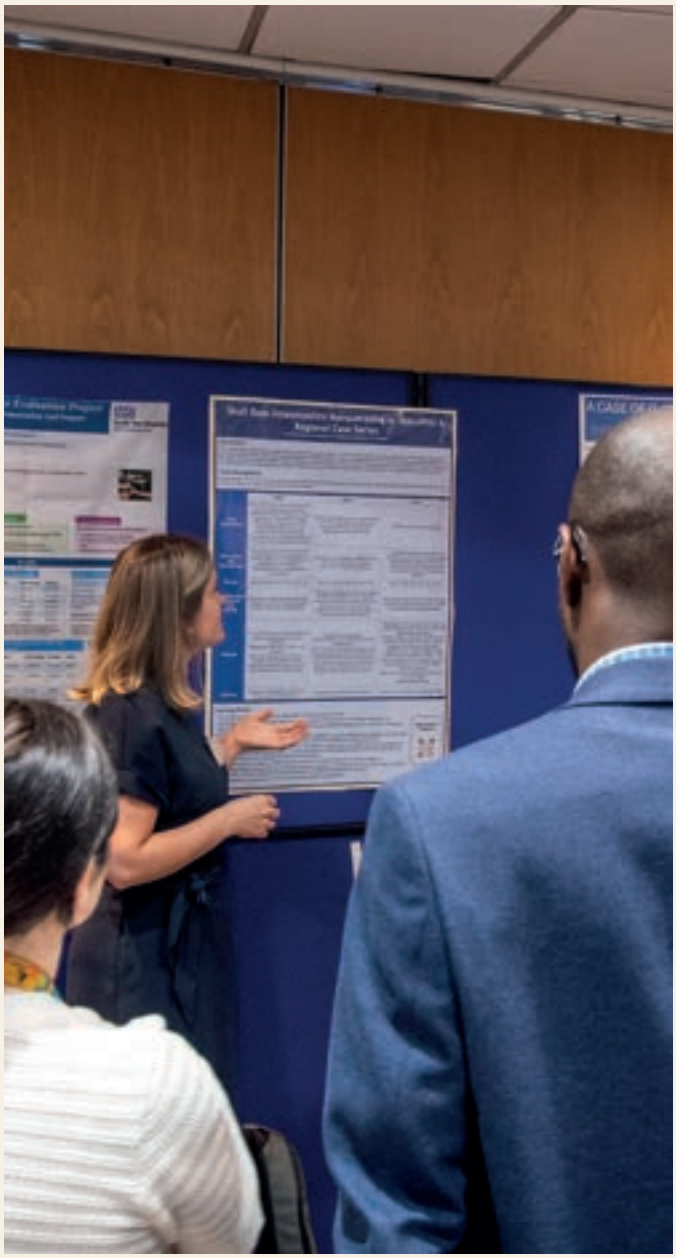
In March 2026, we welcomed over 200 people to celebrate research excellence across the BRC and the richness and diversity of the people who make this possible. Our focus this year was on research capacity development. The programme featured talks from researchers at pre-doctoral, doctoral and post-doctoral career stages and attendees were invited to explore a vibrant display of research posters created by BRC PhD students. There were also a range of opportunities to find out about the research being conducted across the regional NIHR infrastructure, our partners and support available to researchers.

2 The annual joint NIHR BRCs: Newcastle and Leeds training event

The annual joint NIHR BRCs: Newcastle and Leeds training event held in September 2025 brought together over 150 Rheumatology researchers across the Northern and Yorkshire regions. Co-sponsored by industry, it brought together trainees and specialists from medical, healthcare professional and biomedical backgrounds.

3 Digital Health and Care Summer School 2025

Co-organised with the Engineering and Physical Sciences Research Council (EPSRC) NorthFutures Digital Hub, the Digital Health and Care Summer School brought together BRC early career researchers and students from across the region to develop skills in digital health, fostering cross-sector engagement between academia, healthcare and industry.



Developing researchers for the future

The BRC continues to invest in training and career development across the research workforce.

Two medical (MBBS) students received NIHR BRC: Newcastle bursaries to undertake intercalated degrees focused on inflammation and ageing.

We awarded four Healthcare Professional Internships, supporting six-month secondments between Newcastle and Northumbria Healthcare NHS Foundation Trusts, building on the success of the flagship programme and complementing the recent NIHR HCP Internship Programme Award secured by Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust. We are strengthening links with institutions across the North East and North Cumbria to expand our Healthcare Professional Internship Scheme in translational and experimental medicine research.

The BRC's Bioinformatics Training Course, which launched in 2024, expanded to include data management, biostatistics and coding for translational scientists, attracting 89 biomedical and clinical trainees in 2025. Following its success, the programme is expected to be rolled out across NIHR infrastructure in 2026/27.

In November 2025, in response to feed-back from our researchers, NIHR BRC: Newcastle launched a six-month mentoring pilot programme for early and mid-career postdoctoral researchers across a range of health and research disciplines. Seven mentor-mentee partnerships have been established and are now taking part in the programme. The pilot will be evaluated to inform a larger organisation-wide mentoring scheme, helping to support researcher development, career progression, and research capacity across the organisation.

Preparatory fellowships and career development funding

Congratulations to our BRC-supported researchers who achieved significant success in securing prestigious fellowships and awards in 2025-26:

Dr Mark Eisner was awarded a Clinical Research Training Fellowship jointly funded by LifeArc and the British Association of Dermatologists.

Dr Jack Leslie secured a Cancer Research UK Career Establishment Award.

Dr Helen Rogers became the first dentist to receive an NIHR Advanced Fellowship

Dr Wezi Sendama was awarded a Medical Research Council Clinician Scientist Fellowship to investigate disordered inflammation in the lungs of older pneumonia survivors.

Dr Simone Webb secured a Career Development Fellowship from the Royal Society to study nervous system regulation of immune development

Dr Calum Hamilton received an Alzheimer's Research UK Fellowship to advance postdoctoral research into ageing, cognitive decline and neurodegenerative disease.

Dr Cen Cong secured a UKRI Metascience AI Early Career Fellowship from the EPSRC.

Leveraged funding for research capacity development

Across the BRC we continue to attract funding that supports career development.

Members of the Musculoskeletal Disease and Inflammation Medicine Theme are co-awardees of an MRC Centre of Research Excellence grant that includes a PhD training programme.

Alzheimer's Society Clinical Partnership funding awarded to the Dementia, Mental Health and Neurodegeneration Theme has enabled the establishment of a national Lewy body Dementia Doctoral Training Network.

Dr Helen Devine from our Neuromuscular Disease, Rare Diseases and Mitochondrial Dysfunction Theme leads the Early Career Researcher Academy within the national EXPErimental medicine Route To Success in Amyotrophic Lateral Sclerosis (EXPERTS-ALS) clinical trial platform alongside NIHR BRC: Sheffield. They work across multiple NIHR BRCs, Motor Neurone Disease charities and LifeArc to build an integrated multidisciplinary environment for Amyotrophic Lateral Sclerosis research.

Equality, diversity and inclusion

We are committed to ensuring our research excellence is enabled by an inclusive environment that prioritises equality and diversity.

In 2025-26 we offered a range of EDI initiatives and activities:

1 Training and awareness raising of research inclusion

We are strengthening equality, diversity and inclusion (EDI) training and raising awareness of research inclusion across the NIHR BRC: Newcastle. We have offered a programme of anti-racism workshops, covering topics such as active bystander and allyship trainings, alongside a series of informal EDI conversations focused on subjects identified by colleagues. The first session explored the concept of the 'Accent Ceiling' and its impact on career progression and leadership experiences.

In partnership with the BRC's PPIE team, we have also delivered a range of Research Inclusion workshops at events including the Northern BRCs Meeting, the Northern Centre for Mood Disorders Forum and the Celebration of Research Excellence. These workshops promote understanding of the breadth of the NIHR Research Inclusion strategy and definition, while providing practical guidance on inclusive research design and effective engagement with diverse communities.

2 Research Inclusion Fund

NIHR BRC: Newcastle is raising awareness of research inclusion. In 2025-26 a fund was created to support inclusion activities, launched at the EDI & PPIE Leads Research Inclusion Workshop. Through this fund, a culturally appropriate Let's Talk Research resource leaflet will be created. The funding will support the creation of an inclusive resource that is tailored for use in promoting ageing research and starting research conversations with under-served communities in the West End of Newcastle.

3 EDI input into BRC processes

The EDI Group has played an active role in decision making, particularly in relation to processes and the design and delivery of events e.g. advising on inclusive themes and speaker diversity, ensuring events are aligned with EDI priorities. This input has improved the reach and quality of events and reinforced EDI as a core consideration.

At the NIHR BRC: Newcastle Celebration of Research Excellence event, speakers showcased examples of research inclusion in their presentations and there was a dedicated research inclusion breakout session with over 200 attendees on the day.

4 Inclusive recruitment

We are committed to adopting inclusive practice for advertisement and recruitment to training posts according to NIHR guidance. We have invested effort into attracting people from diverse backgrounds beyond protected characteristics including geography, socio-economic background and profession.

Patient and public involvement and engagement

We work with public contributors at all stages of the research cycle, assuring the relevance of research that meets patient need as well as maximising research quality, value and impact.

Our BRC-wide Patient and Public Advisory Group (PPAG) oversee activities across our eight Themes and work closely with regional infrastructure partners through the Creating Connections forum to ensure shared learnings and widen research involvement. This year, we have enlarged to 11 members and diversified our PPAG by increasing the number of women, younger people, members from rural communities and socioeconomically deprived communities.

Innovative and tailored recruitment approaches

Over the last year we have built relationships with community organisations, faith groups and voluntary sector partners like HAREF Connected Voice network for ethnic minority communities, Newcastle Elders Council, Rainbow Home for LGBTQ+ Asylum Seekers, Liver North charity.

We are working with regional Premier League football clubs like Newcastle United and Sunderland AFC to engage people living with dementia from socially disadvantaged backgrounds through walking football.

We have co-produced accessible “Let’s Talk Research” resources to support research conversations with older people in community settings, and provide tablet computers for Liver Disease, Multimorbidity and Lifestyle theme participants to reduce digital exclusion, increase trial recruitment and improve patient survey completion rates.

Support and adjustments to remove barriers to participation

Researchers across our themes have adopted a range of approaches to reduce barriers to research participation. These include taking research directly into communities.

The Parkinson’s Research Interest Group within our Dementia, Mental Health and Neurodegeneration Theme held events across Newcastle, Sunderland, Darlington and Cumbria, helping to overcome geographical barriers.

Through our Ageing, Sarcopenia and Multimorbidity Theme, we have improved inclusion by providing plain-language materials, translating information into multiple languages and developing culturally tailored resources.

Through our Informatics and Precision Care for an Ageing Population Theme, we have enhanced accessibility by using inclusive venues, offering meetings outside standard working hours and providing hybrid attendance options.

We are also supporting public contributors to develop their skills and confidence through funded completion of the Certificate in Public Involvement and Co-production at Northumbria University.

PPIE in numbers

1671

Public contributors involved in PPIE

395

PPIE activities

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PPIE in numbers

85

Partnerships and collaborations

41

PPIE groups

Our impact - A case study

Open-IBD Lived Experience Advisory Panel (LEAP) – Transforming IBD research

The Open-IBD study is a large research programme involving 2,000 people with suspected inflammatory bowel disease (IBD). It is led by researchers from Newcastle NIHR BRC and the Wellcome Sanger Institute. From the start, the study aimed to involve people with lived experience of IBD in shaping the research.

Early discussions with patients highlighted concerns about taking part in research soon after diagnosis and showed the need for a more supportive and patient-focused approach. In response, the Open-IBD Lived Experience Advisory Panel (LEAP) was created.

LEAP brought together ten people living with Crohn's disease or ulcerative colitis, alongside researchers, clinicians and charity partners. Rather than simply giving feedback, panel members worked as equal partners in the study. They helped redesign participant information, improve recruitment processes, contribute to data collection plans and provide recommendations directly to study leaders.

The impact of LEAP was measured through recruitment data, feedback from participants and staff, and a structured "You said, We did" approach, which tracked how panel recommendations led to changes. Recruitment exceeded expectations, and feedback showed that LEAP-led improvements enhanced the participant experience.

LEAP members helped make study materials more compassionate by recognising the uncertainty and anxiety people often experience while waiting for an IBD diagnosis. Their feedback also led to practical improvements, such as reducing questionnaire burden, removing unnecessary sensitive questions and including important issues such as fatigue in study assessments.

The team developed a structured "You said, We did" framework

The panel developed into a trusted long-term partnership between patients and researchers, helping to create a culture of shared decision-making. Through their involvement, panel members gained research skills and confidence, while researchers developed a stronger understanding of patient-centred research.

The Open-IBD experience shows that meaningful public involvement can improve research quality, recruitment and participant experience, making studies more inclusive, relevant and responsive to the needs of people living with IBD.

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NIHR BRC: Newcastle

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The NIHR Biomedical Research Centre: Newcastle is part of the NIHR and hosted by The Newcastle upon Tyne Hospitals NHS Foundation Trust in partnership with Newcastle University and Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust.

For latest news, events and opportunities, follow us on LinkedIn and Bluesky:

NIHR Biomedical Research Centre (BRC): Newcastle

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