Keele UNIVERSITY

Impact Accelerator Unit

20 Years of Public Involvement

Showcase event

Thursday 17th September 2026

Welcome



The formal beginnings of our patient and public involvement and engagement in research (PPIE) began with coproduction of the successful application for our Primary Care Research Centre of Excellence funded by Arthritis UK. We started with eight founding members and a dedicated PPIE team working closely with researchers. Our local Primary Care Research Consortium also played a key role in getting our newly formed Research Users Group (RUG) established.

The success of the Centre of Excellence in leveraging over £50 million in grant income since its inception, with the National Institute for Health and Care Research (NIHR) contributing to this funding, secured the ongoing sustainability of the RUG membership and PPIE team. With Keele becoming a member of the NIHR School for Primary Care Research in 2008, this offered additional support and led to our contribution to the NIHR Standards for Public Involvement in Research. We also partnered with Keele colleagues to deliver a prestigious UK Research and Innovation (UKRI) funded public involvement infrastructure award (SeePer) within the University.

Ten years later, Knowledge Mobilisation and impact acceleration of research joined with PPIE to become the Impact Accelerator Unit (IAU). This developed our Link Group where public members and our Knowledge Broker initiated public involvement in mobilising research knowledge. We were now offering public involvement throughout the whole of the research cycle.

The COVID pandemic saw Keele RUG members step up in several ways: they offered their time and resources to review national NIHR grants at pace; they offered advisory sessions for clinical services that were rapidly changing their systems from in person to online; they developed our template for inclusive hybrid working; and importantly they offered vulnerable public members practical ways to remain engaged and involved.

Regionally, we have enjoyed close working with our nationally and internationally recognised partners in research participation and engagement. Working together with our funders, the NIHR, the Medical Research Council, Arthritis UK, and the National Institute for Health and Care Excellence (NICE), the European Alliance of Associations for Rheumatology (EULAR) and the Health Innovation West Midlands, collaborations help us drive excellence in PPIE practice and research.

For example, with funding from Midlands Innovation Health and the NIHR Regional Research Network, we appointed a Race Equality Ambassador to champion equality and cultural competency. The NIHR Race Equality Framework for Public Involvement in Research, which we coauthored, became our guide. We have gone further still and have transformed our partnerships with communities to form our People and Communities strategy to be inclusive of people from all communities and ultimately diversify our RUG membership.

PPIE capacity building is one of our many success stories, with public members and several colleagues joining us today who have taken Keele's passion to benefit wider settings: regionally, nationally, and globally including Low- and Middle-Income Countries. From Ethel and Agnes that became our legendary characters in making PPIE accessible, to new grants such as the Mental Health Research Group (COMPAS; NIHR) and Listening, Involving and Forging Trust in Musculoskeletal Research (LIFT; Arthritis UK, Orthopaedic Research UK and the Kennedy Trust) we continue to shape our principles and ambitions for public partnerships.

It's my privilege to thank the NIHR School for Primary Care Research for co-funding our 20-year celebration. Researchers come and go but our public members and communities are Keele's constant research and impact companions, and we offer heartfelt thanks to you all for life changing research that impacts the nation.

Professor Krysia Dziedzic

Director, Impact Accelerator Unit, 2026

Keele UNIVERSITY

Impact Accelerator Unit

Agenda

Event chaired by Natalie Knight

Time	Session	Speaker(s)
10am	Event opens	
10am - 10.20am	Welcome and opening remarks	Professor Kevin Shakesheff (Vice Chancellor)
10.20am - 10.45am	Where we started: The early years of public involvement at Keele	Professor Pauline Ong, Adele Higginbottom, Professor Clare Jinks
10.45am - 11.10am	Milestone moment: Arthritis UK Centre of Excellence and early impact	Professor Danielle van der Windt and Professor Melanie Holden
11.10am - 11.30am	Break	
11.30am - 11.55am	The evolution of impact: Knowledge Mobilisation and the Impact Accelerator Unit	Professor Krysia Dziedzic, Laura Campbell, Linda Parton
11.55am - 12.20pm	Growth, inclusion and collaboration with the School for Primary Care Research	Professor Christian Mallen, Halle Johnson, Dr Sarah Harrisson, Samina Begum
12.20pm - 1.30pm	Lunch and networking	
1.30pm - 1.55pm	The Power of Partnerships	Dr Alice Moult and Dr Krysia Canvin
1.55pm - 2.20pm	Public contributors panel: Reflections from the journey so far	Chaired by Professor Clare Jinks
2.20pm - 2.40pm	Break	
2.40pm - 3.15pm	Interactive session: Shaping the next 20 years	Coordinated by the events committee
3.15pm - 3.30pm	Closing remarks and thanks	Professor Krysia Dziedzic

The story of Public Involvement at Keele University

2006

Public involvement became part of research at the Research Institute for Primary Care and Health Sciences at Keele, when the Research User Group was established with eight members. Members had musculoskeletal conditions and many had previously been participants on research studies. Very quickly this became a core group who met every three months to advise researchers on research questions, research methods and dissemination.



Keele's first public involvement meeting (2006)

2008

The Research Institute for Primary Care and Health Sciences gained Arthritis Research UK Centre of Excellence in Primary Care status. Public members were integral to the bid and the interview process. Keele became a member of the NIHR School for Primary Care Research in 2008 (a funded collaboration of nine leading primary care departments in England) and has led this School since 2021.

2009

As the Research Institute expanded, demand for the Research User Group members grew. More members were recruited to help with the workload, from GP practices that already worked in partnership with the Research Institute, and from previous participants of existing studies. They started as a Virtual Panel group, who initially worked via email, but quickly preferred coming in to work face to face with research teams. There were 19 members in total and a Patient and Public Involvement and Engagement User Support Worker was employed to support them.

2011

The Patient and Public Involvement and Engagement team was created and included a new User Support Worker with lived experience, employed from being a member of the Research User Group and the previous User Support Worker became a Patient and Public Involvement and Engagement Coordinator. The Research User Group now had 68 members.



Keele's first public involvement conference (2011)

2013

The Patient and Public Involvement and Engagement team expanded again, employing a Patient and Public Involvement and Engagement Research Associate. Another member of the Research User Group joined as a volunteer, helping to support members in research meetings and worked with the team to produce glossaries of research related terms for Research User Group members to refer to.



Planning support for public contributors (2013)

2014

The Patient and Public Involvement and Engagement team developed a bespoke series of training workshops for the Research User Group members and for researchers working with the public. A comprehensive set of 21 guides covering the research process supported their learning.



Training workshops (2014)

2016

The Impact Accelerator Unit was formally launched with national and international implementation projects. With work in implementation and knowledge mobilisation growing, the Link Group was founded – a Patient and Public group dedicated to knowledge mobilisation activities.

A 10 year celebration of Patient and Public Involvement and Engagement at Keele took place, which included reflections on past achievements, a keynote on the evolution of public involvement, presentations from the Research User Group, sustaining excellence in Patient and Public Involvement and Engagement, creative engagement and new ventures in young people's mental wellbeing, implementation, and international public involvement.



The Link Group (2016)

The EULAR Centre of Excellence in Rheumatology was awarded to Keele University and the Haywood Academic Rheumatology Partnership for the first time.

After the User Support Worker became the Patient and Public Involvement Projects Coordinator in 2015, the Patient and Public Involvement and Engagement team expanded again, with a new User Support Worker in research and implementation joining the team.



Celebrating 10 years of public involvement (2016)

2017

This year's Research User Group event focussed on Public Involvement in Knowledge Mobilisation and implementation and showcased the work of the newly formed Link Group.

2019

The School for Primary, Community and Social Care at Keele was established.

An event was held to celebrate the Primary Care Centre Versus Arthritis Centre of Excellence, with public contributors presenting on the day.

The Patient and Public Involvement and Engagement team went to Sri Lanka for the second time following a successful visit in 2018, to support public involvement activities.

Keele became a test bed site for implementing the National Institute for Health and Care Research's new standards for public involvement in research.



Primary Care Centre Versus Arthritis celebration (2019)

2020

The COVID global pandemic hit and Patient and Public Involvement and Engagement continued during lockdown. The School of Medicine and the School of Primary, Community and Social Care merged together into one School of Medicine.



Seldom Heard Voices (2021)

2021

Work started on the Race Equality Framework, a significant milestone in public involvement.

BeeFree launched, a project with substantial co-production, which bridged mental and physical health support.

A new User Support Worker joined the team to support the ever-growing number of Research User Group and Link Group members.



Public Involvement workshop OARSI (2022)

2022

The Impact Accelerator Unit hosted the first pre-conference workshop on Patient and Public Involvement and Engagement at OARSI 2022 in Berlin. The Patient and Public Projects co-ordinator became the Patient and Public Projects Officer.

2023

An ITN film 'Joint Health' was commissioned, which showcased co-production and the importance of patient and public involvement and engagement in research.

A school wide Patient and Public Community of Practice was established to share learning and best practice. A community focussed annual event took place.



Keele public involvement on ITN (2023)

2025

To be more inclusive and equitable a decision was made to change the name of the Patient and Public Involvement and Engagement team and the Research User Group. The Patient and Public Involvement and Engagement team are now called the People and Communities Team and the public contributors are the People and Communities Group.

2026

20 years of Public Involvement at Keele is marked by a celebration showcase event.

There are now over 250 public contributors, 25 community partners and a core People and Communities team - made up of a Projects Officer, a User Support Worker, a Race Equality Ambassador and a Research Inclusion Associate. The team continues to sit within the Impact Accelerator Unit, championing the power of the public and community voice in research and knowledge mobilisation.



The Impact Accelerator Unit

Transforming research into real-world impact through knowledge mobilisation, public partnerships and research inclusion.



Impact Accelerator Unit 2017

Established in 2016, the Impact Accelerator Unit (IAU) is based in the School of Medicine at Keele University and is the home of Public Partnerships. The unit acts as a bridge between research and practice, accelerating the uptake and impact of evidence into everyday care, to improve the health of our population. The IAU works closely with patients, public members, community groups, healthcare professionals and academic staff to share research findings and work together to determine how best to put that evidence into practice. With strong foundations in knowledge mobilisation theory and practice, public partnerships, research inclusion and co-production, the IAU is inclusive of all kinds of patient, public and community partnerships in all activities.



West Midlands Academic Health Science Network Innovative Team of the Year 2017 - Highly Commended

> *"An extraordinary group of medics, academics and patients who work together to potentially change practice.... quite breath-taking."*
>
> - Public member



Impact Accelerator Unit 2018

www.keele.ac.uk/iau

Public involvement in research - the Research User Group

The first Research User Group (RUG) meeting was held in 2006 and was established by Professor Pauline Ong. The group initially consisted of 11 members of the public living with musculoskeletal conditions, many of whom had previously taken part in research studies. Over time, this developed into a core group of eight members who met every three months to provide researchers with advice on research priorities, study design, methods, and the communication of research findings.

As the Centre grew, demand for public involvement increased. In 2009, additional members were recruited to help support the expanding workload. These individuals were identified through GP practices that already worked in partnership with Keele, as well as from people who had previously participated in research studies. They formed a Virtual Panel, providing feedback and advice via email.



First meeting 2006

Around 20 members joined the Virtual Panel. However, it quickly became clear that many valued the opportunity to meet researchers and other members in person. As a result, the Virtual Panel members were invited to become full Research User Group members and attend face to face meetings.



2014



2014

Also in 2009, Research User Group members recognised the need for dedicated support to coordinate the growing amount of public involvement activity to support the public members; a dedicated Patient and Public Involvement and Engagement (PPIE) team was established.

Over the years, the number of research studies seeking public involvement has grown significantly, alongside a growing community of people wanting to contribute to research. The roles for public members also grew and included members joining Trial Steering Group Committees, monthly research study team meetings, and many members becoming a public co-applicant on research grant applications. To support the public members, training sessions were offered.



2015

In 2016, the Impact Accelerator Unit was established, and the Patient and Public Involvement team joined the Unit. This then gave public members the opportunity to be involved with the process of implementing research findings into health care by using patient power. When COVID hit, the team had to quickly re-think and change practices and processes. All meetings became online. Resources were made, including a digital guide, to help public members join online virtual meetings.



Winner - Patient and Public Involvement and Engagement 2021



RUG Steering Group 2016



Public Involvement event 2017

In 2021, the Impact Accelerator Unit won the NIHR Clinical Research Network West Midlands award for Patient and Public Involvement and Engagement.

With a decade of work into developing inclusivity in public involvement in research, the names of the Research User Group and the Patient and Public Involvement and Engagement team have been updated. Today, the team is proud to be known as the People and Communities Team, and our public contributors are valued members of the People and Communities Group.

> *"It has been inspiring to see how public involvement has developed over the past 20 years. We are incredibly proud to now have more than 250 People and Communities Group members who contribute to a wide range of research activities and play a vital role in shaping the future of health and care research."*
>
> - *Patient and Public Involvement and Engagement Projects Officer*



Public partnerships event 2024



Public involvement in knowledge mobilisation - The Link Group

As the Impact Accelerator Unit's implementation and knowledge mobilisation portfolio grew, so did the need to proactively and meaningfully include patients and the public in translating evidence into everyday practice. Led by a Knowledge Broker, the Link Group was created in 2017, made up of people with a diverse range of personal, professional and volunteering experience, coming from sectors including charity, community, education, local authorities, the NHS and business. Patient and public involvement in this space supports the Impact Accelerator Unit to establish two-way relationships and collaborations throughout a wide range of patient and public networks to mobilise knowledge.

The Link Group has co-designed the funding for and delivery of implementation and knowledge mobilisation activities locally, nationally and internationally. They co-produce open and accessible evidence-based resources for use in clinical practice, often supporting the translation of complex recommendations into public friendly, accessible, engaging content in a range of formats for different demographics. They have co-created a Dissemination and Knowledge Mobilisation toolkit to support researchers and knowledge mobilisation practitioners to think about knowledge mobilisation from a public and community context. This toolkit has been included in Arthritis UK 's Primary Care Centre impact report. They have also co-written an implementation glossary of terms to support public members working in implementation and knowledge mobilisation.

Notable projects that the Link Group have been integral to include BeeFree (co-produced animation and website providing mental health support for people with long term pain), a patient explanation package for osteoarthritis (co-produced an animation and accompanying leaflet), Moving Forward (the co-development of an accessible and visual summary of current musculoskeletal research evidence) and the development of an osteoarthritis guidebook. Going forward, the Link Group will be working more closely with community partners to continue to mobilise knowledge to where it is most needed.



Link group 2017


Keele
UNIVERSITY
Research Institute
for Primary Care
and Health Sciences
NATIONAL STANDARDS
for PUBLIC INVOLVEMENT
6 STANDARDS
keele.ac.uk/ppie
The Keele difference


STAFFORDSHIRE
POLICE




NICCE





Public Involvement highlights

Keele public contributors feature on ITN

Patients and the public and researchers from the School of Medicine worked with ITN in 2023 to produce an information film on World Arthritis Day; to help patients with arthritis and osteoporosis access support and services to improve their treatment. The programme, titled 'Joint Health', featured Keele's co-produced osteoarthritis patient explanation package 'Osteoarthritis and You.' It showcased research that found steroid injections are helpful for people with hip osteoarthritis (HIIT Trial), and also showed how new technology developed at Keele helps the NHS to tailor treatment for osteoporosis patients (Improved Fracture Prevention – the iFraP tool). The film crew recorded a co-production session in action, filming how public members, clinicians, researchers and knowledge brokers work together to develop these vital evidence-informed resources. One of the public contributors was interviewed for the film.



ITN film 2023



https://youtu.be/1Q0CmBgACiI?si=CB0YV1PVIal4fUEV



Patient Explanation Package for Osteoarthritis

Led by Professor Clare Jinks

Between 2019 and 2023, Keele University ran a study called the PEP OA Study (Patient Explanation Package for Osteoarthritis) to help explain osteoarthritis. Many people think osteoarthritis is only caused by ageing or what used to be known as “wear and tear.” When they think this, they may avoid helpful things like exercise or losing weight, which could help them. Seven meetings with public contributors were held over the study and across both research and knowledge mobilisation activities. In 2022, patients and the public with osteoarthritis worked with researchers, clinicians and a knowledge broker to co-produce a simple animation and leaflet titled ‘Osteoarthritis and You,’ to bring the evidence-based osteoarthritis explanation to life.

www.keele.health/oa/video





Moving Forward

Led by Honorary Professor Kay Stevenson

Musculoskeletal conditions (pain in the joints, ligaments, muscles, nerves, tendons) can have a huge impact on a person’s quality of life, as well as affecting their family, friends, carers and the wider society. Published in 2018, the NIHR Themed review, ‘Moving Forward: Physiotherapy for Musculoskeletal Health and Wellbeing’, brings together high-quality research from over the past decade, including Keele research, with the aim to give a clear direction to patients, physiotherapists, researchers, commissioners and planners of physiotherapy and musculoskeletal services. The Impact Accelerator Unit worked with the Chartered Society of Physiotherapy and the NIHR Centre for Engagement and Dissemination to pro-actively move this important evidence into clinical care, prioritising research to embed into patient pathways. This work included the co-production of a public facing version of the full review with the Link Group and the Chartered Society of Physiotherapy, so that patients can understand why they receive the treatment they do.

www.evidence.nihr.ac.uk/collection/moving-forward-a-guide-for-the-public

STarT Back - Stratified Care and Targeted Treatment for Back pain

STarT Back trial led by Professor Jonathan Hill, IMPacT Back implementation study led by Professor Nadine Foster, implementation led by Honorary Professor Kay Stevenson and Dr Adrian Chudyk as National Institute for Health and Care Excellence (NICE) Scholar

The STarT Back approach enables healthcare professionals to quickly and easily group patients according to the treatment likely to work best for them, improving quality of life for people with lower back pain and delivering cost-savings for the NHS. Research carried out at Keele was published in the Lancet in 2011. It was followed by a study called IMPacT Back, which was a before and after study looking at the effectiveness of introducing the STarT Back approach into normal primary care settings. The results were positive, finding that GPs and nurses used the tool in their everyday practice. Public members were included in monthly team meetings, bringing lived experience of musculoskeletal pain and attended training sessions every three months alongside the research team.



STarT Back is now recommended by The National Institute for Health and Care Excellence (NICE), who provide independent advice on which treatments should be adopted by the NHS, as well as the Royal College of General Practitioners, the Department of Health National Spinal Taskforce, British Pain Society and the National Back Pain and Radicular Pain Pathway. UK economic evaluations suggest that STarT Back is cost-effective. A 2021 model estimated NHS savings of around £135 per patient over ten years, alongside improvements in quality of life. Earlier research estimated six-month savings of £34 in healthcare costs per patient and about £400 in work-absence costs per employed patient. It has been translated into 41 languages. The Link Group were integral to the co-production of a patient information leaflet 'So you think you have back pain?' which was endorsed by NICE and highly commended in the British Medical Association Patient Information Awards 2019. The STarT Back approach has since been combined with an evidence-based app designed to help low or medium risk patients manage their low back pain - 'SelfStart.' Public contributors tested and refined the content and appearance of the app, commenting: "It's like having a friend in your pocket," supported the roll out of the initiative to First Contact Physiotherapist practice and co-created patient and health professional focussed information.


British Medical Association Patient information awards 2019 - Highly Commended

www.keele.health/startback

Contribution to the Research Excellence Framework

The Research Excellence Framework (REF) is an assessment of research across all Universities in the UK that happens every 7-8 years. In REF, universities are scored on the quality of their research. This is based on their outputs (e.g., academic journal articles), how well the university supports research, and the real-world difference that their research leads to (the 'impact'). The higher the quality score, the more funding the university gets from central government in the form of 'Quality-Related Research' funding. Impact is assessed through 'impact case studies'. These are short documents submitted to REF that show how an area of research has led to real-world changes. In health research these could include benefits to patients, changes in health care practice or changes in policy. Each case study document includes several sections that summarise the impact, describe the research that underpins it, describe the impact in more detail and give evidence to back it up. For the last REF in 2021, public contributors were asked to give feedback on Keele's health related impact case studies, which gave valuable information to improve the content and presentation. The team are now preparing for REF2029 and are keen to create more opportunities for public contributors to shape impact case studies. In addition to inviting public members to attend and contribute to impact training workshops, they are involved in reviewing the REF2029 impact case studies. In June 2026, the team held an event at the Wade Conference Centre, in which public contributors spoke with the impact case study authors, to give their comments on the case studies and discuss how they could be improved. Written and verbal feedback ranged from specific recommendations to increase impact and its measurement, to guidance on the narrative and storytelling. Case study authors are now working with this feedback, and more sessions like this are planned between now and the REF submission.

MIDAS - Joining up data and action to improve musculoskeletal health

Led by Professor George Peat

The MIDAS Programme was a five-year research initiative aimed at improving the support and care for people living with musculoskeletal conditions. The study, funded by the Nuffield Foundation and Versus Arthritis, focused primarily on populations across North Staffordshire and Stoke-on-Trent. The research findings were complex and extensive. A key strength of the MIDAS programme was the sustained involvement of a Public Advisory Group of seven members who worked closely with the research team through regular monthly meetings and engagement across all stages of the project. Their input helped ensure the study remained inclusive and responsive to public concerns, particularly around the risk of excluding underserved populations. The group successfully influenced several aspects of the study, including the provision of paper questionnaires with telephone support, additional support for GP practices in deprived areas, the design of a booster doorstep survey, and the identification of analyses focused on hidden need. These contributions enhanced both the accessibility of the research and the relevance of its findings, and members strongly endorsed this model of involvement for future studies.

BeeFree and BeeFree to Work

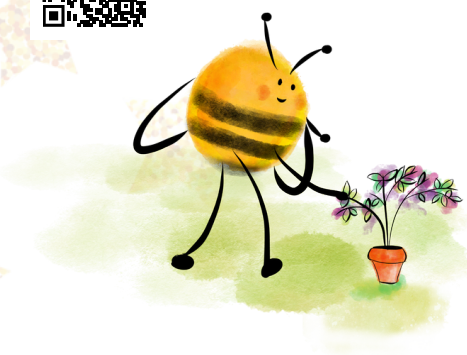
Core team: Honorary Professor Kay Stevenson, Dr Tom Kingstone, Nicola Evans, Laura Campbell, Professor Gwen Wynne-Jones.

The BeeFree project began at the end of 2019. It aimed to address the need for high quality evidence based resources to support the 1 in 5 people in the UK who experience pain that has gone on longer than 3 months and who may be experiencing poor mental health.

Patients and public members worked alongside the knowledge mobilisation team and a brand and marketing company to co-produce a website, a positive and informative animation, free online training for healthcare professionals, public and volunteers, and a library of local support resources. They were an integral part of the multidisciplinary task and finish group which also included healthcare professionals, charities, hospital volunteers and researchers. The work took place during national COVID lockdowns and demonstrated how public partnerships and creative co-production could work online as well as face to face. Patient and public members of the Link Group then championed the resources in their own networks.

The website has since been expanded to include 'BeeFree to work,' a suite of interactive resources to help people to make a personalised action plan to manage pain in the workplace. This work was funded by the Haywood Foundation. The BeeFree platform is now being considered by other research teams at Keele to provide resources for other health related conditions.

www.beefree.org.uk







First BeeFree Community of Practice 2019

Global Patient and Public Involvement and Engagement

Following an initial visit in 2018, in 2019 two of the Patient and Public Involvement and Engagement (PPIE) team travelled to Sri Lanka to present a workshop entitled 'Establishing and Sustaining Meaningful Patient and Public Involvement and Engagement in Research' at the National Institute of Mental Health.



PPIE workshops Sri Lanka 2019

The trip focused on building research capacity in South Asia and the aim of the workshop was to introduce researchers and other stakeholders to the value of involving patients and the public in research.

It explored how meaningful PPIE can strengthen research and how it could be developed and sustained in Sri Lanka. Whilst there, the team also visited Rajarata University of Sri Lanka, joining a community led workshop, which discussed how the communities within different villages in Anuradhapura used Health Promotion to address issues affecting the wellbeing of adults and children in the areas in which they lived.



The workshop explored how the community used simple techniques and methods to reduce non-communicable diseases, risk factors and reduce substance use among males in villages and reducing malnutrition among children. The team ended their trip with a field visit to Madawachchiya, Anuradhapura, where they were invited to a house in the village which also served as a base of operations for the community. The villagers who had conducted health promotion projects within Madawachchiya presented their projects.

In 2025, the Impact Accelerator Unit Director was an invited speaker to the Sri Lanka 2025 Twins conference to talk about Community Engagement and Involvement and knowledge dissemination.



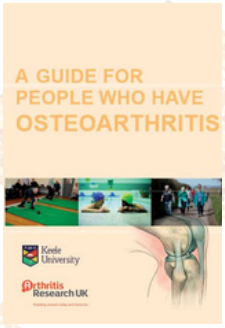


International osteoarthritis public involvement

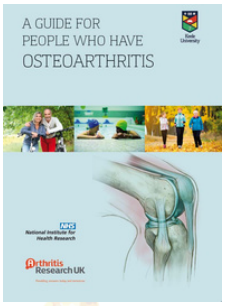
Research and implementation led by Professor Krysia Dziedzic

A linked series of projects beginning with research and ending in local, national and international implementation of innovations involved public contributors throughout.

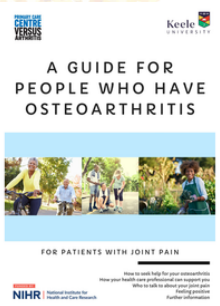
The feasibility, acceptability and impact of implementing a new approach to supported self-management for people with osteoarthritis in primary care was first investigated in the MOSAICS study - a mixed methods study with a nested cluster Randomised Controlled Trial. Four key innovations are at the heart of the approach; an evidence informed patient information guidebook; quality care measures; a model consultation; and healthcare professional training. Public members were involved throughout the study, including in co-application for funding, steering group membership, osteoarthritis guidebook development and selection of measures of self-reported quality of osteoarthritis primary care. The implementation of the innovations developed in MOSAICS was first carried out in the West Midlands (Joint Implementation of osteoarthritis Guidelines Across the West Midlands - JIGSAW), before expanding to international pilots and guidebook adaptation in Europe (JIGSAW-E), Scotland, New Zealand and West Africa.



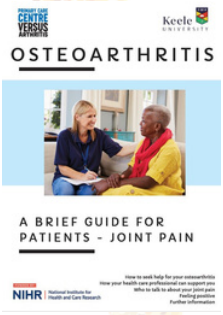
England 2011



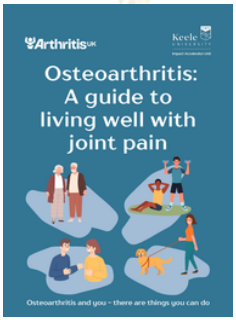
England 2014



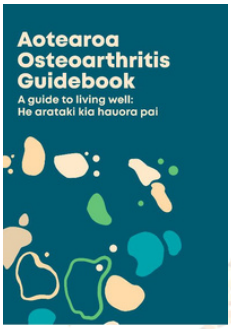
England 2019



Brief version



England 2026



New Zealand



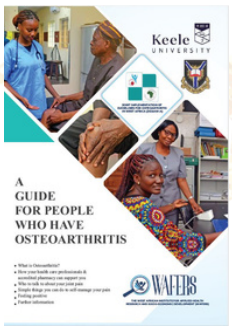
Netherlands



Denmark



Scotland



West Africa

www.jigsaw-e.com

www.keele.health/guidebook-osteo-resources-public/



International Community of Practice 2016

Public involvement was threaded throughout research and implementation work. Notably, the JIGSAW-E Patient Panel was an international group of 17 patient champions who all had experience of osteoarthritis from the five countries which were part of JIGSAW-E (England, Netherlands, Denmark, Norway, Portugal). Patient Panel members provided contextual advice to their project team about what patients in their country thought about the JIGSAW-E approach and linked to charitable organisations in their respective countries. They were instrumental in the cultural and linguistic adaptation of the original English Osteoarthritis Guidebook, which was co-created in a genuine partnership of researchers and public contributors through joint reviewing of evidence and integrating this with patient stories.



International Patient Panel 2016

Work continued with JIGSAW- West Africa to explore the experiences, current care gaps and concerns of people living with osteoarthritis in Nigeria and to co-produce a contextually and culturally relevant osteoarthritis guidebook there.



JIGSAW -West Africa 2024

Scottish academic and public contributor colleagues developed a culturally appropriate version for their country, and the team in New Zealand worked with the Māori community and members of the Impact Accelerator Unit to create a long and short version across the Aotearoa region.

EULAR Patient Research Partners (PRPs) and PARE: Embedding the Patient Voice in Research

The European Alliance of Associations for Rheumatology (EULAR) is committed to ensuring that people living with rheumatic and musculoskeletal conditions play an active role in shaping research, healthcare and policy. Two key mechanisms for achieving this are the Patient Research Partner (PRP) initiative and the EULAR PARE (People with Arthritis and Rheumatism in Europe) network. EULAR Patient Research Partners are people with lived experience who work alongside researchers as equal members of research teams. PRPs contribute throughout the research cycle, helping to identify research priorities, review study materials, advise on accessibility and recruitment, interpret findings, and support dissemination. Their involvement helps ensure that research is relevant, meaningful and focused on outcomes that matter to patients.

EULAR PARE brings together national patient organisations from across Europe to strengthen the patient voice within rheumatology. Through annual conferences, educational programmes, advocacy campaigns and collaborative projects, PARE promotes knowledge exchange and patient-centred approaches to research and healthcare. Activities include sharing examples of good practice in patient involvement, showcasing patient-led research, influencing health policy, supporting public awareness campaigns, and providing opportunities for patients and researchers to learn from one another across countries and healthcare systems.



EULAR Patient Research Partners 2025

Keele University has been actively involved in both initiatives through the Keele Research User Group and participation in European research collaborations. Public contributors from Keele have undertaken EULAR PRP training and contributed to international research programmes, including the Horizon Europe-funded STRATA-FIT Consortium and INSPIRE initiative (Implementing the updated EULAR recommendations for patient research partner involvement in research). Keele public contributors have also shared examples of patient involvement at EULAR PARE conferences, presenting the co-production and dissemination of patient resources and work on osteoarthritis research implementation of clinical guidelines. These activities demonstrate how meaningful patient and public involvement can enhance the quality, relevance and real-world impact of musculoskeletal research.

REINVENT

Led by Professor Krysia Dziedzic and Dr Alice Moult

The REINVENT project aimed to implement the NIHR Race Equality Framework with an underserved group of young people from ethnically diverse communities in the West Midlands. The project used dance and creative approaches to build relationships and enable meaningful involvement in health research. Working together, members of Eloquent Praise & Empowerment Dance Company, young people, community leaders and researchers co-designed and co-delivered workshops, a dissemination event and evaluation. The project demonstrated how creative, culturally relevant and equitable approaches can increase confidence, create spaces for young people to share their perspectives and strengthen their engagement in research. The project tested the feasibility of creative knowledge mobilisation as a way of strengthening relationships. REINVENT generated practical recommendations for future inclusive engagement with young people and demonstrated how existing community relationships can become sustainable pathways into research. It showed ways of moving beyond representation towards trusted partnerships, shared power and community led involvement.



Eloquent Praise & Empowerment Dance Company, 2023

CAM-Pain

Led by Professor Kate Dunn

The CAM-Pain Research Programme aimed to learn what happens when children with painful joints and muscles visit their doctor, and what the children and parents thought about their pain and clinic visits. Researchers brought together a public involvement group of children, young people and parents to provide input on the research programme. This group have met throughout the last four years, advising on all aspects of CAM-Pain. They influenced this work by, for example, telling researchers what words to use when asking children about musculoskeletal pain and its management, how to invite and involve children in this research, and how and where to communicate research findings. A Community of Practice, including children, young people, parents and professionals, advise researchers on how to get research into practice, for example by discussing what would help children, parents and healthcare professionals to trust the information produced. Researchers have worked with these groups, along with children from schools and young people with rheumatology disorders to develop a new package of information and self-management support for children and their parents, called Pain Navigator. This resource is currently being tested by sharing it in schools, clinics and online, to see how people use it and what they think about it.
https://painnavigator.co.uk/




Collab Training Academy CIC




Discussion session 4
OARSI
How can OARSI support and improve the inclusion of the patient perspective in OA projects?
Think about:
• OARSI annual congress
• OARSI recommendations


Keele University
Expert Citizens CIC
Welcome to our
Community Conversatio
partnership and trust with underserved groups



Public involvement support for infrastructure and growth

EULAR Centre of Excellence


Keele University School of Medicine

The School of Medicine, in partnership with Midlands Partnership University NHS Foundation Trust's Haywood Hospital, is recognised as one of the best rheumatology centres in Europe. The partnership has now been awarded the European Alliance of Associations for Rheumatology (EULAR) Centre of Excellence status twice – first in 2021 and again in 2026. The title honours Keele's outstanding links with local NHS partners and the university's high-quality multidisciplinary research into musculoskeletal conditions like osteoarthritis, inflammatory arthritis, pain and osteoporosis. The strength of the partnership's patient and public engagement was integral to the renewal bid, which outlined how people with lived experience of Rheumatic and Musculoskeletal diseases shape all aspects of our research, including the development of patient focussed research questions, co-design of grant applications, contribution to research advisory groups, and knowledge mobilisation and implementation activities. Our public contributors have been involved in a range of EULAR workshops and conference sessions, particularly in relation to practical co-design approaches and methodology, helping to shape priorities in line with patient-identified needs.

www.keele.health

Led by Laura Campbell and Dr Adrian Chudyk

Keele.Health

As the Impact Accelerator Unit grew, so did its portfolio of work and co-produced information for patients, training for healthcare professionals and other resources to support knowledge mobilisation activities and implementation of research. Following feedback from public members, the idea of one central website to house all these resources came about and www.keele.health was created in 2000. Public members co-designed the images, branding and layout. It is now a library of evidence-based information for both public and health professional audiences, arising from Keele's research.



www.keele.health

Arthritis UK Primary Care Centre of Excellence



By working alongside public members and healthcare professionals, Keele University specialises in providing high-quality evidence that has been designed to directly address the challenges that are faced within primary care. We were awarded the status of Arthritis Research UK Primary Care Centre of Excellence in 2008 and again in 2011 (the charity has subsequently changed its name to Versus Arthritis in 2018, and Arthritis UK in 2025, in line with this we are now known as the Arthritis UK Primary Care Centre of Excellence).

Public contributors were integral to achieving the Centre of Excellence status in 2008. They were interviewed by the assessment panel, explaining the key contributions they made towards the Centre's work – feedback by assessors described them as 'inspirational'.

Achieving Centre of Excellence status underlined contributions to public involvement in research both internally and externally and provided resources for its expansion and sustainability. More public contributors joined the Research User Group, dedicated Patient and Public Involvement Coordinator and User Support Worker roles were created and Patient and Public Involvement became an essential element of the Centre's research programmes. Involving members of the public early on increased the quality, relevance and dissemination of our research, and in particular, focused attention on patient benefit.

Under leadership of Professors Peter Croft, Elaine Hay and Christian Mallen, the Centre has received over £5.3 million of infrastructure funding from Arthritis UK, to support network creation, capacity building, identifying research areas, obtaining additional funding, and integrating and championing patient and public involvement. The centre has leveraged £50 million in grant income since its inauguration, with the National Institute for Health and Care Research (NIHR) contributing most to this funding. The NIHR funded research across all four research themes, including several programme grants collaboratively funded with Arthritis UK.

Overall, this has propelled the Centre to the forefront of primary care arthritis research, leaving a legacy that will continue to improve the lives of people living with arthritis. The Centre was showcased in a Versus Arthritis Impact report in 2024.

The Race Equality Framework and the evolution of working with community groups

Led by Professor Krysia Dziedzic and Natalie Knight

The National Institute for Health and Care Research Race Equality Framework (REF) journey began with membership of the NIHR Race Equality Public Action Group and the co-authorship of the Race Equality Framework for Public Involvement in Research. The IAU then appointed a Race Equality Ambassador, a post funded by Midlands Innovation Health and joined 15 national pilot partners in adopting the REF to improve racial equity in public partnerships. The IAU had a strong legacy of an established of public involvement practice. Public contributors wanted an increase in the diversity of the public involvement membership. The REF provided a structured approach to embedding race equity in practice and partnership working.

This work was strengthened through the Clinical Research Network West Midlands and Improvement & Innovation (I&I) funded "Building Trust and Taking Action" project (2022–2023) and funding from Midlands Innovation Health, which funded the role of Race Equality Ambassador and expanded on the 'community conversation' approach to developing trusted relationships with underserved and racially minoritised communities. The role is now also funded by the NIHR Biomedical Research Council. The scoping work, and relationship-centred approach of the REF principles, highlighted communities as partners and as trusted patient advisors, such as Seldom Herd Voices Forum - an example of embedding the REF in practice and community engagement within the research. The creation of a dedicated Race Equality Ambassador role further embedded the REF principles through consulting on over 18 funded research studies. Across these studies, REF culture had shifted practice towards co-production, equitable community partnerships and community engagement, shaping research from design through to delivery and dissemination (2023-2026).

Today the REF legacy has been the network of diverse community organisations and leaders, creating partnerships that now regularly contribute to research prioritisation, funding applications, recruitment strategies and public involvement activities. The case study has been cited by the Midlands Health and Care Inequalities Commission. Through the new community engagement studios, researchers, community leaders and public contributors co-create ideas, shape research and develop innovative solutions, creating more equitable opportunities for public contributors within the IAU.



Seldom Heard Voices group 2023




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Public partnerships and future steps

Mental Health Research Group

Led by Professor Carolyn Chew-Graham and Dr Gary Lamph

The new Mental Health Research Group at Keele aims to improve the mental health of our communities through co-production of inclusive and accessible community and primary care research. £11 million of funding from the National Institute for Health and Care Research will fund 5 years of work which aims to understand the mental health needs of the population in the North West Midlands (North Staffordshire and Shropshire), explore the unmet mental health needs of older adults, research the coexistence of mental health and physical health problems and improve how people with complex emotional needs are identified and treated in primary care and community organisations. The whole programme of work was developed with people with lived experience of mental health difficulties and local community organisations, who will continue to work with researchers throughout and who will be involved in knowledge mobilisation and implementation activities. The Keele based group will be working with colleagues from the University of Birmingham, Kings College London, and the Midlands Partnership University NHS Foundation Trust.

The LIFT network - Listening, Involving and Forging Trust in Musculoskeletal Research

Led by Professor Krysia Dziedzic

The LIFT network has been funded by Arthritis UK in partnership with Orthopaedic Research UK and the Kennedy Trust. It is designed to ensure that healthcare research is inclusive and removes barriers stopping people from participating. The network aims to support patients with lived experience of musculoskeletal conditions to play a crucial role in shaping healthcare research and will focus on improving access for underserved communities. The network will also support researchers studying musculoskeletal conditions who struggle incorporating PPIE into their research. The goal is to ensure that both researchers and participants have the tools they need to make research as impactful and helpful as possible for the patients that need it most. To achieve this, LIFT will build accessible UK-wide PPIE infrastructure, with hubs in Leeds, Aberdeen and Manchester, giving all researchers links to people with lived experience, regardless of their seniority or their location. The network will also work with researchers to strengthen their pre-award PPIE to help them develop stronger, more inclusive funding proposals, as well as creating practical tools, training, and resources for researchers to share best practice.

PROTECTS - PRevention of Osteoporotic fractures Through Equitable Case finding and Treatment Support

Led by Professor Zoe Paskins

PROTECTS is a five-year study. It aims to prevent broken bones caused by osteoporosis. The study is funded by the National Institute for Health and Care Research. It has received £4.8 million in funding.

Osteoporosis is a condition of weak bones. This means bones can break more easily, sometimes after a small trip or fall. Some people are less likely to be offered checks or treatment for osteoporosis. PROTECTS will focus on men, people from different ethnic backgrounds, people living in poorer areas, and people living in care homes.
The research team will develop and test new ways to help GP practices find people who may have an increased chance of osteoporosis and broken bones. People at risk can then be offered bone health checks, advice and treatment if they need it.

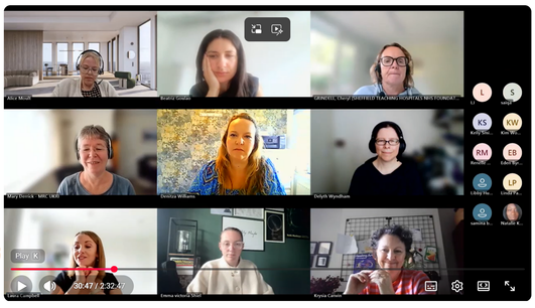
The team will work with patients, carers and local community groups. They want to understand what bone health means to different people. They will also ask what can make it harder to get bone health checks or treatment, and what information people need. Together, they will create clear information for patients. This will explain bone health checks, treatment choices and how people can take part in decisions about their care. The information will be available in different languages and formats to meet different reading needs.

Patients and members of the public will be involved throughout the study. They will be part of a Community of Practice. This is a group of patients, members of the public, researchers, healthcare staff and other organisations who will work together to improve osteoporosis care. They will also work with experts in sharing research. These experts will help make sure that the study findings reach GP practices, patients, carers and the public in useful and easy-to-understand ways.

EXEMPLAR - EXperts EMpowered to do public involvement in fundamental scientific research: a Participatory Learning and Action Research project

Led by Dr Alice Moult and Dr Krysia Canvin

EXEMPLAR will look at how we can support meaningful public involvement in fundamental scientific research and is funded by the UK Research and Innovation Medical Research Council. Fundamental science aims to develop theoretical knowledge. It is also known as basic



or pure science and examples include mathematics, physics, chemistry and biology. It differs from applied health research, which aims to answer specific clinical questions or solve healthcare practice-related problems. Public involvement in fundamental scientific research is much less common than in applied health research. Previous studies suggest that fundamental scientist-researchers think that involving the public is not feasible and/or necessary. These studies also suggest that fundamental scientist-researchers find it challenging to communicate with the public about their research because of the technical procedures and specialist terminology involved.

EXEMPLAR will form a partnership between public involvement experts, the public and fundamental scientist-researchers to co-produce a toolkit to equip teams with the practical resources and information needed to carry out public involvement at all stages of their research, supporting them to overcome challenges and undertake meaningful and inclusive involvement.

Knowledge Mobilisation Incubator

Led by Professor Krysia Dziedzic and Dr Alice Moult

The Knowledge Mobilisation for Research Inclusion Incubator is a National Institute for Health and Care Research (NIHR)-supported initiative, running until June 2028. The Incubator was established to strengthen inclusive knowledge mobilisation across health and care research by bringing together a national network of researchers, community groups, public contributors, and under-represented health professionals. Its aim is to build capacity, skills and confidence in knowledge mobilisation, ensuring that research knowledge is shared, used and applied in ways that are meaningful, accessible and inclusive. Through networking opportunities, career development support, funding signposting, and a programme of co-produced events and webinars, the Incubator creates connections between people who generate research and those who can benefit from and apply it.

The Incubator held its online launch on 12th November 2025, marking the start of a collaborative initiative designed to showcase the breadth and potential of knowledge mobilisation within the NIHR. The event featured contributions from a diverse range of speakers, highlighting innovative approaches to making research more inclusive and impactful. Building on this momentum, an in-person event was held on 5th February 2026, bringing together researchers, community partners and public contributors for a day of learning, collaboration and vision-building. Throughout 2026, the Incubator has continued to deliver a series of webinars aimed at early career researchers and underserved communities. A dedicated two-day workshop will be held addressing the recognised gap in knowledge mobilisation methods training. Together, these activities are helping to develop a more connected, skilled and inclusive community of knowledge mobilisation practitioners across the UK.

Thank You

We would like to thank all our public contributors and community partners past, present and future for sharing your experiences of living with a health condition with us. Our research simply could not be done without the generosity of your knowledge, time and expertise – thank you for all you do.

Also thank you to:

- The School for Primary Care Research (SPCR) for part funding this event
- The 20-year showcase event committee: Adele Higginbottom, Laura Campbell, Kylie Salmon, Alice Moult, Alicia Rutter, Christina Farrall (public contributor)
- Arthritis UK
- The National Institute for Health and Care Research (NIHR)
- Mark Elsmore, for creating our celebratory image of Keele Hall to mark 20 years of Public Involvement in research at Keele University.

Glossary

APPLIED HEALTH RESEARCH - Applied health research uses scientific theories to answer specific clinical questions or solve healthcare practice-related problems. It focusses on translating scientific discoveries into practical solutions for real world settings and often involves collaboration across various disciplines.

COMMUNITY OF PRACTICE - A group of people who share a common interest in the same problems or topics and who interact regularly online or face to face, to learn together, deepen their knowledge, build relationships and share expertise.

CO-PRODUCTION - A collaborative approach where all stakeholders work together to design, develop, and deliver interventions, recommendations or change, sharing power, responsibility, and expertise.

DISSEMINATION - A one-way process where research findings are provided to specific audiences by targeted channels and planned strategies.

FUNDAMENTAL SCIENTIFIC RESEARCH - This is also called pure research, basic research, basic science, or pure science. It aims to expand theoretical knowledge and often fuels the technological innovations of applied science.

IMPLEMENTATION SCIENCE - the scientific study of implementing interventions / innovations into practice. (**IMPLEMENTATION –** the process of doing this.)

KNOWLEDGE MOBILISATION - Moving knowledge to where it can be most useful and transforming it to be accessible to different audiences. Knowledge mobilisation approaches help us to think about how we can get the right knowledge to the right people, in the right format, at the right time.

MUSCULOSKELETAL CONDITIONS - Affecting the muscles, joints and skeleton.

RHEUMATOLOGY - a branch of medicine that deals with the investigation, diagnosis and management of people living with rheumatic and musculoskeletal diseases.





Keele Hall, © Mark Elsmore 2026

With heartfelt thanks to local artist Mark Elsmore, who painted this beautiful image of Keele Hall to mark 20 years of public involvement in research at Keele.