BETTER LIVES TODAY, BETTER LIVES TOMORROW

Research Strategy 2022-2026

RESEARCH VERSUS ARTHRITIS

A RESEARCH STRATEGY BY YOU, FOR YOU

Versus Arthritis is a community of and for every person in the UK living with arthritis and other musculoskeletal conditions*, their carers, family and friends.

It is also a community of the many pioneering researchers and healthcare professionals we support, our passionate volunteers across the UK's four nations and, of course, our dedicated staff. Together, we are united in our ambition to demand and deliver better answers for people with arthritis.

In developing this research strategy, we listened to our community. We heard from our staff, our Fellowship Expert Group, our research volunteers, our three Versus Arthritis research advisory groups, our paediatric Clinical Studies Group, our Senior Stakeholder Group (including our Centre Directors), our four national volunteer engagement groups and our young persons panel.

This report was produced by the Research Directorate at Versus Arthritis, with support from the Research Engagement team and cross-office representatives.

The lead authors were Dr Wendy Lawley, Dr Sarah Rudkin and Dr Neha Issar-Brown. Jo Buchan, Jacqueline Brealey, Dr Natalie Carter, Dr Devi Sagar, Dr Katherine Free and Dr Craig Bullock provided editorial guidance and communications support.

The Versus Arthritis Brand and Digital team led on graphic design. Versus Arthritis is very grateful to all those who reviewed this report and provided valuable feedback, in particular the Research Strategy Development Group members and people with arthritis who shared their personal stories, pictures and comments.

20.3 MILLION
people living with arthritis or MSK condition

1,200
active researchers supported by Versus Arthritis

9,000
health and social care professionals in our network

1,000
volunteers

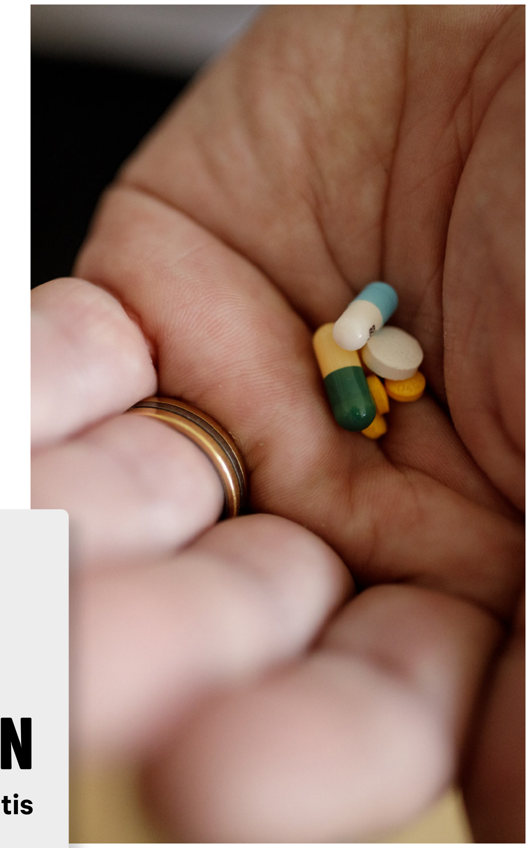

Image taken at the NIHR UCLH Clinical Research Facility

Image taken at the NIHR UCLH Clinical Research Facility

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*** Nomenclature and abbreviations**
MSK – musculoskeletal
We have used the terms arthritis and MSK to represent the broad range of 150 or more MSK conditions affecting the bones, joints, muscles and spine, as well as rarer autoimmune conditions.

EXECUTIVE SUMMARY

This research strategy has been developed with people with arthritis at its core. It strives to accelerate pace and precision – to create more and better-tailored solutions that directly benefit people with arthritis, translating discoveries more quickly and efficiently into practice. It outlines a charity-wide approach to drive faster scientific investigation, bolder innovation and better knowledge application – advancing the understanding of arthritis and other musculoskeletal conditions and the treatment and care of people living with them.

We will focus our investment and influence on four priority areas over the next four years (2022-26):

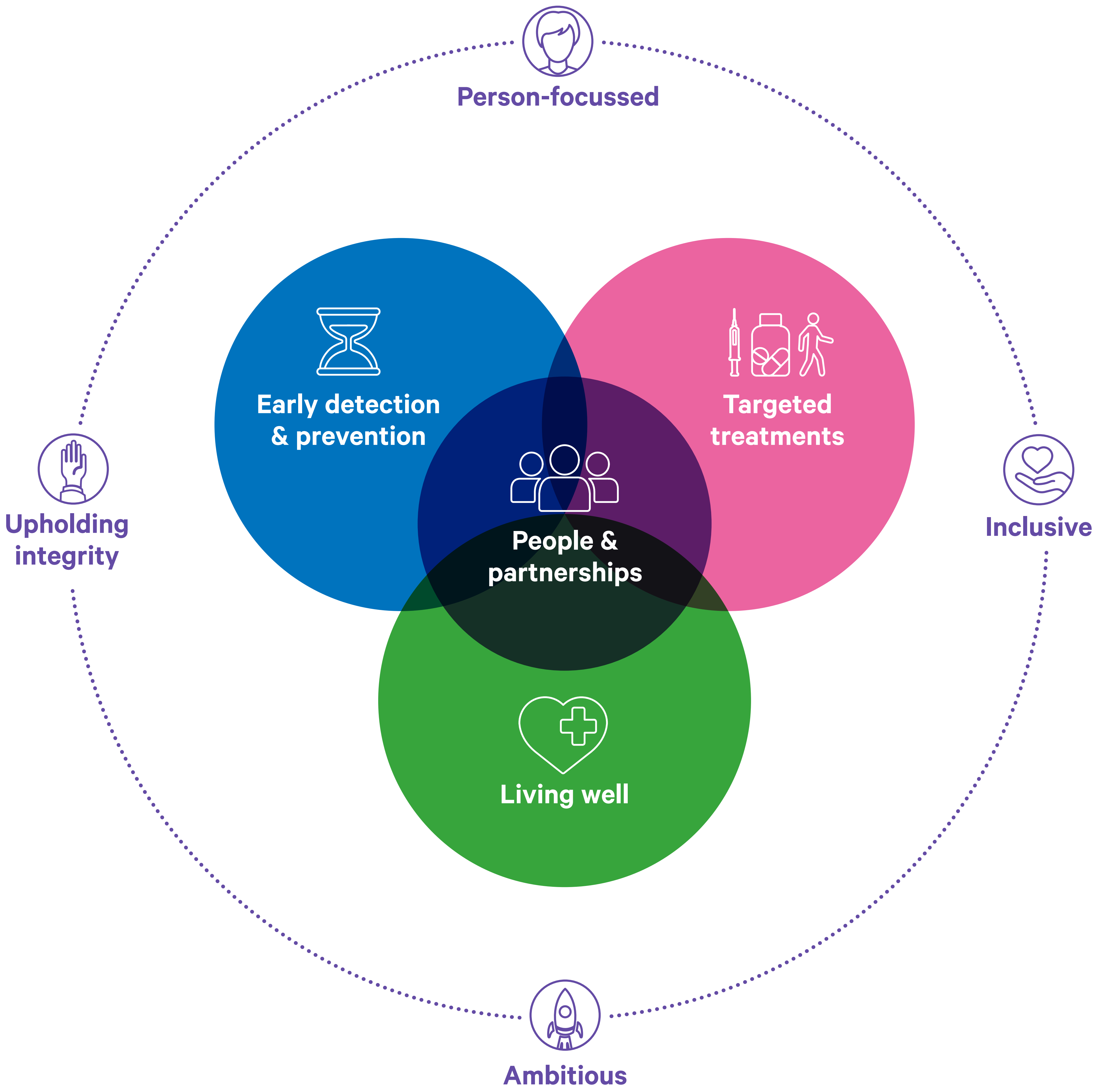
1. Early detection and prevention: Spotting the biological signatures of arthritis early to maximise the opportunities for timely intervention and preventing it from getting worse.

2. Targeted treatments: Taking the guesswork out of treatment by increasing effective, reliable and timely drug and non-drug solutions to reduce, manage or cure disease.

3. Living well: Addressing musculoskeletal health inequalities for individuals and wider society by striving for better musculoskeletal health and care at home, in leisure, at work and in communities.

4. People and partnerships: Making Versus Arthritis the partner of choice – for our funding partners, the life-sciences industry and our researchers.

We will bring to bear both our financial resources and our voice. We will demand the unmet research needs of people with arthritis are recognised and met. We will maximise the inclusion of musculoskeletal research in initiatives across the UK research sector.



FOREWORD

Versus Arthritis is the UK's largest charity dedicated to supporting people with arthritis. This is our first research strategy. It builds on our strengths and successes and puts the person, not the condition, at its core. It identifies four priorities with a singular vision – to enable ground-breaking solutions for people with arthritis. Now and in the future.

One in four of us are living with arthritis or a related musculoskeletal condition – the biggest single cause of pain and disability in the UK. The impact for individuals and society is profound and increasing – the progression of some of the most prevalent forms of arthritis extend over several years, even decades.

Often the condition is not detected until it reaches an advanced stage, prolonging the pain and isolation of those living with the condition and their loved ones.

In highlighting **early detection and prevention** as one of our priorities, we are not only being ambitious but also inclusive. Arthritis can affect anyone, including children and young people, all ethnicities and backgrounds. It is not an inevitable part of ageing.

Ellen Miller, Acting CEO

We are here for everyone and we don't want to wait until arthritis has taken the best years of anyone's life. We want to stop arthritis in its tracks as quickly as possible. Our goal is to find treatments that offer hope of remission or cure. Treatments that work.

Disease, treatment and prevention approaches need to take into account individual variability in genes, environment and lifestyle - a precision medicine approach. There needs to be a push for faster translation of the findings of research into medical practice and meaningful health outcomes. By prioritising **targeted treatments**, we will help our researchers to discover more precise and effective treatments. We will give people with arthritis more treatment options that reliably and effectively alleviate disease, because this is a person-focussed strategy.

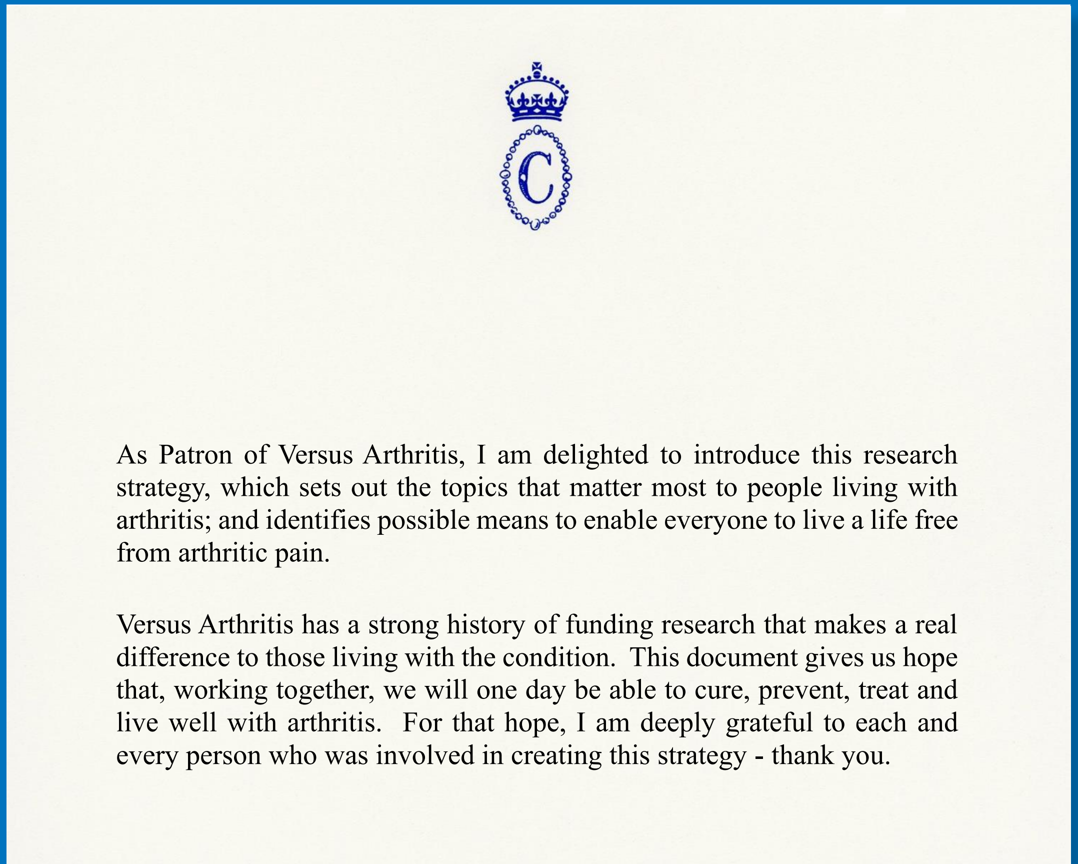
Our aim is to invest in solutions tailored to individuals, not the condition. This means treatments that offer greater choice and allow a person to lead a healthy, fulfilling and independent life – free of the debilitating impact of arthritis, and the pain and anxiety of not knowing whether a treatment exits, or if it will work.

Rodger McMillan, Chair of Trustees

We want to offer choice and control to people with arthritis, because living with arthritis can severely limit both. Arthritis, often co-existing with other chronic conditions, doesn't just affect our health but also our overall well-being – our relationships, our work, our leisure, our sense of self and our independence. Our priority area **living well** aims to help people with arthritis to "own" their health and will also address social inequalities in musculoskeletal health. We will harness and combine the power of data (derived from people's lived experience) and technology to inform the development and implementation of tools and resources that people need to take control of their symptoms, their health care and their lives. This will help researchers and clinicians to keep providing better, "real world" solutions that will enable people with arthritis to remain at work, engaged in their communities and the wider society. To live well.

Finally, our **people and partnerships priority** will enable researchers to push the boundaries of musculoskeletal research and help us forge partnerships that embolden our mission to defy arthritis. At the same time, we will uphold our integrity and strive for excellence because that is what everyone who supports us deserves.

Jane Taylor, Chair of Research volunteer network



As Patron of Versus Arthritis, I am delighted to introduce this research strategy, which sets out the topics that matter most to people living with arthritis; and identifies possible means to enable everyone to live a life free from arthritic pain.

Versus Arthritis has a strong history of funding research that makes a real difference to those living with the condition. This document gives us hope that, working together, we will one day be able to cure, prevent, treat and live well with arthritis. For that hope, I am deeply grateful to each and every person who was involved in creating this strategy - thank you.

Camilla

HRH The Duchess of Cornwall

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Better lives today, Better lives tomorrow

01

WHERE WE COME FROM

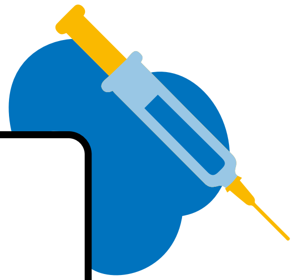
Our strong track record of enabling life-changing breakthroughs

CELEBRATING OUR SUCCESSES

In laboratories, clinics and communities

Our research is as diverse as the communities we serve. We are pioneers in supporting scientific research that has led to ground-breaking medical treatments, as well as new self-management tools, psycho-social interventions, epidemiological insights, exercise programmes and more.

We have a rich legacy of picking research that delivers, investing in life-changing interventions – from the bench, all the way through to clinics, communities and people's homes. Our achievements show that research not only has the potential to offer solutions – both drug and non-drug – but also the best possible mix of solutions, giving people with arthritis choices and the chance to live their lives to the full.



1936

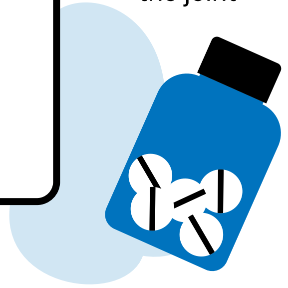
The Empire Rheumatism Council was funded by Dr William Copeman

1953

Genetics shown to play a role in rheumatoid arthritis for the first time

1977

Proteins involved in the breakdown and damage of cartilage identified in the joint



1986

First health questionnaire allowing rheumatoid arthritis patients to self-assess their functional ability developed

1989

TNF shown to play a key role in inflammation in rheumatoid arthritis

1990

First biobank for the collection and storage of samples from people with rheumatoid arthritis established

1994

Obesity shown to be a major risk factor for osteoarthritis of the knee

1999

Taking heparin and aspirin was shown to prevent recurrent miscarriage in women with antiphospholipid syndrome

2000

First anti-TNF therapy licenced, these drugs have since transformed the lives of almost 2 million people with inflammatory conditions

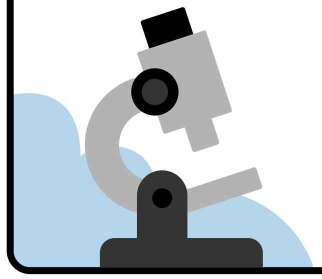
2004

People with fibromyalgia found to process pain differently due to altered brain mechanisms

2007

The ESCAPE-pain trial showed exercise is effective at improving symptoms of knee pain

Over 15,000 participants. Saved NHS time & money



2008

Our first centre of excellence was opened, bringing together experts working in key strategic areas. We now fund 13 research centres across the country

2012

arcOGEN, the largest ever study into the genetics of osteoarthritis, revealed eight new genetic regions associated with this condition

2012

The STarTBack questionnaire enabled targeted treatment for back pain, reducing sick days by 50% and saving the NHS up to £34 per patient

2014

Rat cartilage was successfully repaired using stem cells

2017

Adalimumab and methotrexate in combination shown to reduce eye inflammation and prevent blindness in children with juvenile idiopathic arthritis

2017

First cartilage cell transplantation procedure for arthritis approved by NHS for early knee osteoarthritis

Reduced pain. Improved quality of life. Delayed joint replacement.

2018

a nurse-led care and education initiative shown to improve outcomes for people with gout

90% less gout attacks

2019

Advanced Pain Discovery Platform, an investment in partnership of £28 million, launched to change the future of pain research in the UK

2020

Arthritis researchers contributed to the fight against Covid-19 due to parallels with autoimmune disease

2021

First biomarker for fibromyalgia identified, paving the way for improved diagnosis and treatment

THE FUTURE

Addressing unmet needs and influencing change to continue the push against arthritis

Supporting world class research

At Versus Arthritis, we have supported and championed life-changing research into arthritis for many years.

Our remit includes over 150 musculoskeletal conditions, each with distinct research legacies, successes, and challenges.

We are the UK's largest public funder of research into arthritis and related musculoskeletal conditions. We invest in cutting-edge research across the UK, from laboratory-based projects to clinical trials and projects affecting health services and self-management.

Since genetics was first shown to play a role in rheumatoid arthritis in 1953, through to the licensing of the first anti-TNF therapy in 2000 and updated National Institute for Health and Care Excellence guidance on how to treat gout in 2018, Versus Arthritis-funded research has continued to deliver life-changing breakthroughs for people with arthritis.

£112.8M

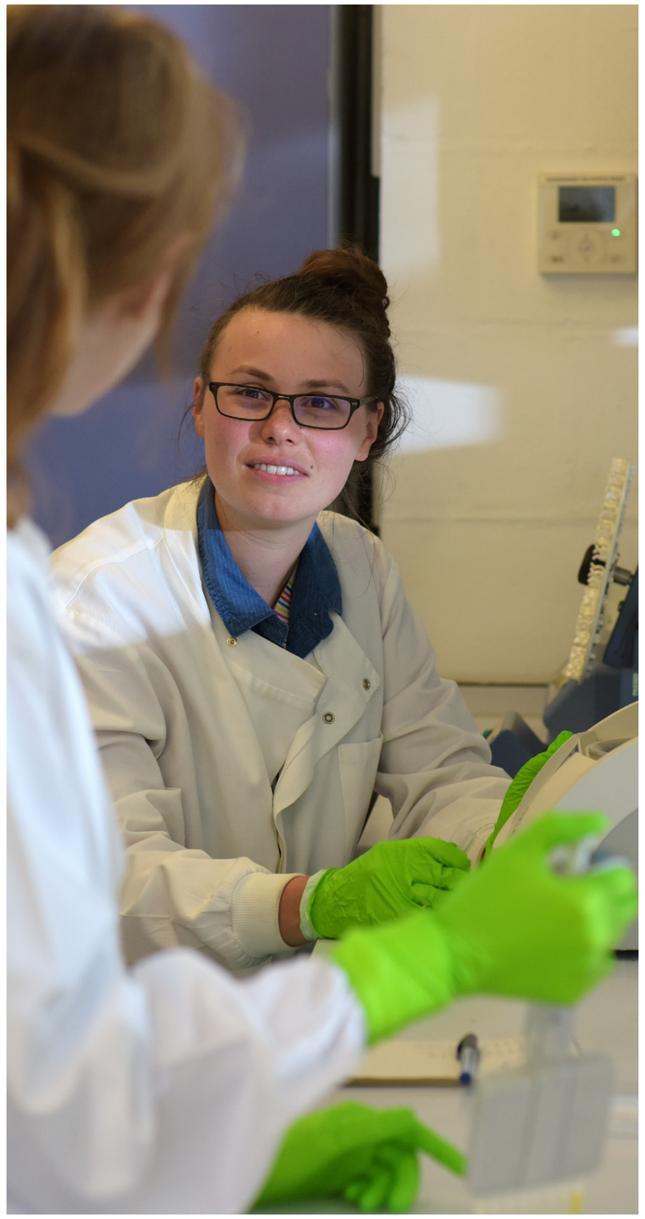
Currently invested in cutting-edge research

(April 2021)

Exercise to reduce the pain of osteoarthritis

Versus Arthritis funding supported the initial development of ESCAPE-pain, a six-week programme of education, exercise and self-management.

It has transformed the care of people with hip and knee osteoarthritis, benefitting more than 15,000 people so far. The programme has been shown to improve the quality of life for people with arthritis, while also saving the NHS time and money.



> *“I was diagnosed with rheumatoid arthritis in 1978. For 20 years I took a range of drugs, with varying degrees of success. And then the world changed. In 2004 I was started on infliximab and it is no exaggeration to say anti-TNF has changed my life.*
>
> *In fact, it has enabled me to have a life – the one I really wanted, that has been full of all sorts of experiences, from playing with my grandchildren to snorkelling with turtles. Things I never expected to do when I was that frightened 23-year-old in a hospital bed. And that is the power of research.”*
>
> **Frances Borrer, Research volunteer**

Leading the way in genetic association studies

Versus Arthritis has led the way in supporting large studies designed to reveal the genetic basis of arthritis.

Researchers at our Centre for Genetics and Genomics at the University of Manchester are world leaders in the genetics of inflammatory arthritis.

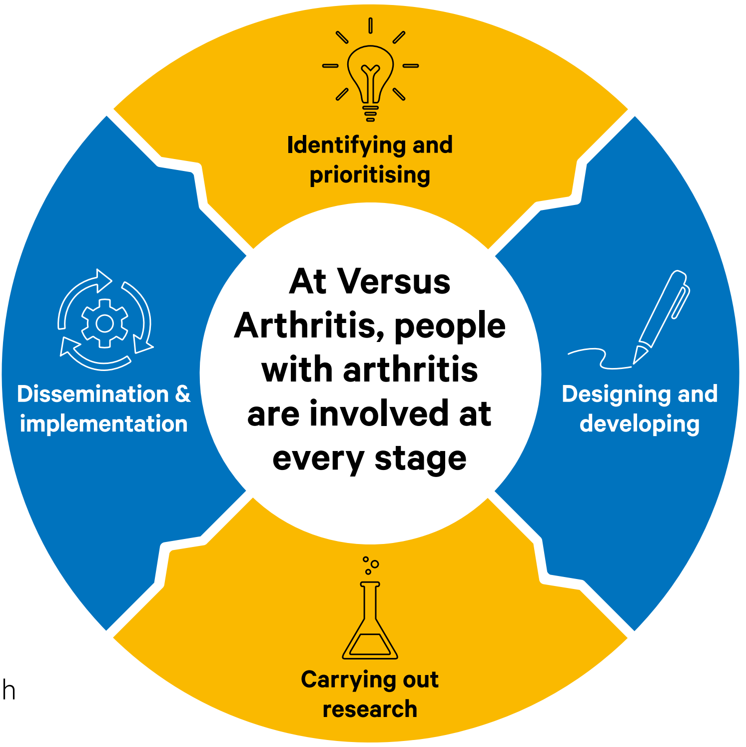
Their work was crucial in identifying genetic markers specific to psoriatic arthritis, demonstrating for the first time that it is a discrete condition rather than psoriasis and rheumatoid arthritis co-existing in the same individual.

We also funded the arcOGEN consortium, the largest ever study into the genetics of osteoarthritis. It revealed eight new genetic regions associated with the condition, more than doubling the number of susceptibility loci known at the time.

Involving people with arthritis

The issues that matter most to people with arthritis should be at the heart of research. We are proud to have led the way among research charities in ensuring people with arthritis, with their diverse voices and experiences, are actively involved in all our decision making.

Through close collaboration with our research volunteers, all our research activities are now informed by the voices of people with arthritis, a process that began in 2008 with the establishment of the USER group. We continue to seek ways to extend involvement in our work and with our partners – to ensure our research delivers maximum benefit for people with arthritis.



Understanding, treating and preventing chronic pain

We know that pain is the number one priority for people living with arthritis. We are supporting research at the University of Aberdeen in Scotland to carry out a programme of work that will approach chronic pain from a variety of perspectives.

The research aims to improve our understanding of what causes fibromyalgia chronic pain, and how best to treat and prevent it. Working closely with around 1,000 people who experience chronic pain, this study will also map out their current journey through the healthcare system and look at how to design new and more patient-centric services.

Professor Gary Macfarlane, who is leading the study, explained, "I hope at the end of the programme we'll have a much better idea of the things that are critical to making the correct diagnosis and delivering good quality care for people."

> *"It was a huge privilege as a patient to sit with the world's best pain researchers and come up with a set of priorities to create the pain roadmap, to help researchers and the charity identify key questions and prioritise what should be funded."*
>
> **Colin Wilkinson,**
> **Research volunteer**

Targeting our investment

Versus Arthritis has increasingly adopted a strategic approach to investing in pioneering research.

Our Versus Arthritis Centre of Excellence model was adopted to enable multidisciplinary research in key areas of need for people with arthritis – from primary care, to sports and exercise, to tissue engineering, to wellbeing at work. As a result, more than £50 million has been invested across 12 specific areas in 13 centres over the last decade.

In recent years, we have issued a number of 'challenge' calls, aiming to inspire research into specific scientific areas. These challenge calls include 'Stacking the odds towards a cure' – to help improve the odds of finding a cure and more effective treatments for different forms of arthritis; and 'Pushing frontiers in health research' – seeking breakthroughs leading to positive changes in relevant health services.

We have increasingly established strong and valuable working partnerships to maximise the impact of our research funding.

We formed a partnership with the National Institute for Health Research to address priorities from our Pain Roadmap. Three Versus Arthritis Centres of Excellence receive funding from the UK Research and Innovation Medical Research Council, and one centre is co-supported with Great Ormond Street Hospital Children's Charity.

Innovative cross-disciplinary funding has been developed in partnership with other charities, such as the Connect Immune Research initiative, where we are working to understand how immune disorders are linked.

The same is true of our joint fellowships with MQ Mental Health Research: Transforming Mental Health, which researches the impact of MSK conditions on mental health.

Our centres of excellence

Primary Care

Pain

Biomechanics & Bioengineering

Tissue Engineering & Regenerative Therapies

Adolescent Rheumatology

Sport and Exercise

Osteoarthritis Pathogenesis

Epidemiology

Genetics & Genomics

Inflammatory Arthritis

Health & Work

MSK Ageing

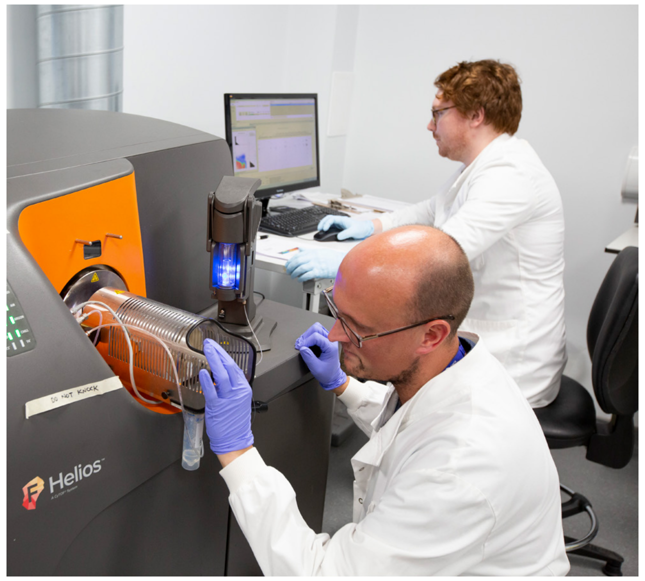
Advanced Pain Discovery Platform

The Advanced Pain Discovery Platform is a £28 million partnership between Versus Arthritis, UK Research and Innovation, the Medical Research Foundation, Eli Lilly, and Health Data Research UK. This ambitious research platform launched in 2019 following extensive work by Versus Arthritis to bring together partners interested in addressing some of the challenges outlined in our Research Roadmap for Pain. Europe's largest single investment in pain research will support multidisciplinary consortia, project grants and a data hub to address the complexity of pain across a spectrum of conditions.

Establishing future research leaders

Versus Arthritis is committed to building a world-class workforce by supporting research careers and building skills within the UK arthritis research community.

Over the last 20 years, we have invested around £82 million to support the careers of over 400 researchers through individual personal awards.



> *"In 1988, Versus Arthritis awarded me a Clinical Research Fellowship. That award was the platform for my subsequent career development. During that period, I fell in love with research! My Fellowship award led me into a greater appreciation of the importance of research and the tremendous good that can ensue from it. I will forever be grateful for my award for all that it has enabled me to go on and achieve."*
>
> **Professor Adewale Adebajo MBE**
> **Consultant Rheumatologist at Barnsley NHS Foundation Trust, Professor of Rheumatology at University of Sheffield**

Over the past 20 years we have invested

£82 MILLION

to support the careers of over

400 researchers

79 FELLOWSHIPS

currently supporting the future leaders of musculoskeletal research

(April 2021)

02

WHERE WE ARE

Mapping the scale of the impact, together

MAPPING THE SCALE OF THE IMPACT, TOGETHER

The lived experiences of arthritis

There are an estimated 20.3[i] million people in the UK with musculoskeletal conditions. Around 1 in 3 people worldwide live with one or more of these conditions and their impact for individuals and society is profound.

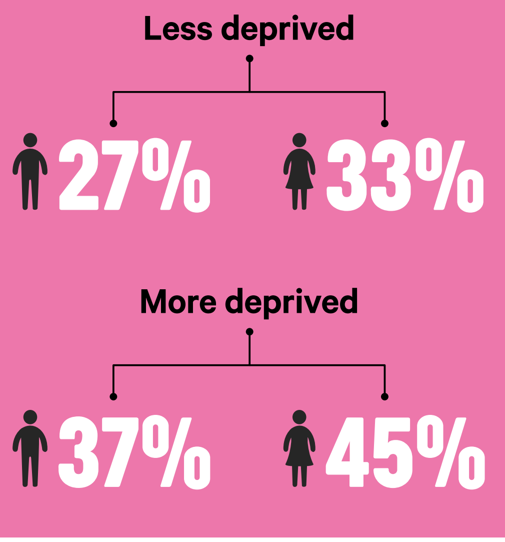
Our State of Musculoskeletal Health reports provide a picture of the overall impacts of MSK conditions in the UK. Arthritis causes pain and disability that substantially reduces people's quality of life, and accounts for 22% of the total burden of ill health in the UK[i]. Nearly half of women living in the most deprived areas have chronic pain, compared to a quarter of men in the least deprived areas

The cost of working days lost due to osteoarthritis and rheumatoid arthritis alone was estimated at £2.58 billion in 2017 and is predicted to rise to £3.43 billion by 2030[ii].

Our recent survey found that the use of painkillers was high in people with arthritis, despite 1 in 3 people finding them ineffective. People with arthritis said access to effective treatment and support can be a 'postcode lottery'. The time taken to get a diagnosis can be incredibly stressful and delays in getting effective treatment are detrimental to physical and mental health.

CHRONIC PAIN IS MORE COMMON IN AREAS OF DEPRIVATION

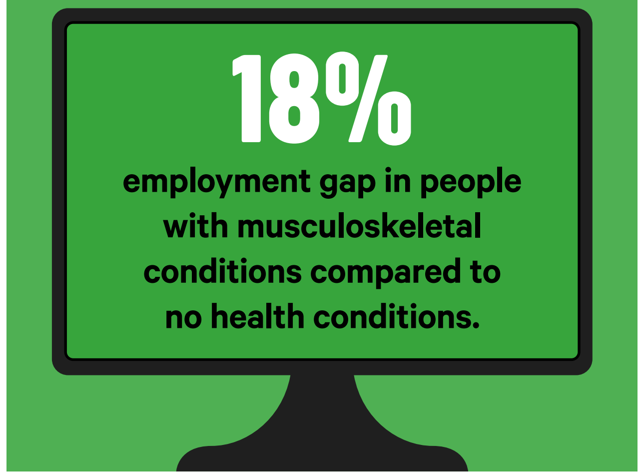
Among people living in the most deprived areas, about 4 in every 10 men (37%) and between 4 and 5 in every 10 women (45%) reported chronic pain. For those living in the least deprived areas, about 3 in every 10 men (27%) and about 3 in every 10 women (33%) reported chronic pain.



depression is four times more common among people in persistent pain.

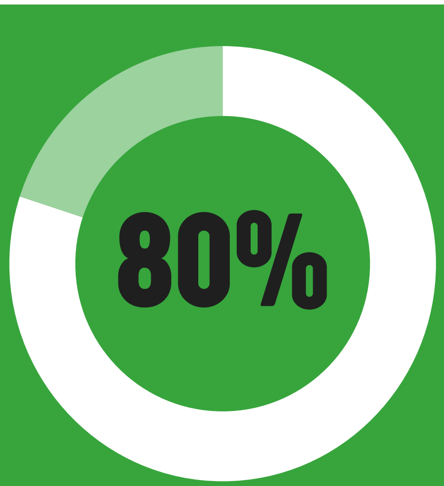
THREE OUT OF TEN

people over 45 living with a major long-term condition also have a musculoskeletal condition.



18%

employment gap in people with musculoskeletal conditions compared to no health conditions.



80% of people living with arthritis said they experience pain most days.

20.3 MILLION

people live with a musculoskeletal condition such as arthritis or back pain in the UK, the biggest single cause of disability in the UK.

THE UNMET RESEARCH NEEDS

During 2020, we conducted an evidence review, giving us a snapshot of the value and potential of arthritis research and the gaps that need to be addressed – our Case for Support for Musculoskeletal Research. We know research we and others have funded has changed lives and plays a key role in supporting people with arthritis to live well. However, we also know there is much more work to do:

- Research into arthritis does not receive a level of funding proportionate to the scale of the problem.
- The current research and healthcare landscape is not sophisticated enough to meet the complex needs of people with arthritis and lacks a 'whole person' approach.
- Research outcomes are not implemented quickly enough to provide consistent, practical improvements in diagnosis, care and treatment.

To add to this insight and shape our four-year research strategy, we spent October 2020 to February 2021 undertaking a number of listening activities to capture the lived experience of people with arthritis, and the expertise of researchers and healthcare professionals. We gathered the insight of over 150 members of our community in our supporting reference document – The Gaps and Opportunities for arthritis research.

We heard that the gaps in arthritis research are vast. As things stand, there is much more research needed to develop an accurate scientific understanding of arthritis, to properly characterise disease, to better understand and manage risks, and to detect, diagnose and treat arthritis. We lack a full awareness of the influence of psychological and social experiences at the individual, community and environmental levels. Versus Arthritis cannot address these gaps alone and our strategy therefore targets those areas where the need is most urgent and the potential for impact greatest.

The impact of Covid-19

The Covid-19 pandemic severely limited our research activity, but our researchers demonstrated exceptional agility and resilience. The musculoskeletal research community pivoted swiftly applying their arthritis-related understanding of immunity and inflammation to the management of coronavirus infection. Covid-19 can be associated with the symptoms of musculoskeletal diseases, notably fatigue, providing an incentive to align research agendas and apply what we've learned about the effects of Covid-19 on musculoskeletal systems to arthritis diseases and vice versa. The pandemic has also fundamentally altered the way medical research is designed, reviewed and funded, with future implications for our research funding.

> *“It was a privilege to be involved in the development of the new research strategy. The whole process was open, consultative, patient-focussed and thoughtful throughout, and has resulted in a powerful strategy that will guide Versus Arthritis's research ambitions for future years.”*
>
> **Professor David Ford, Professor of Health Informatics, Swansea University, Research Strategy Development Group member**

DEBS DULAKE

Research volunteer,
Research Strategy
Development Group member

> *“We began with what seemed like an impossible task, but everyone had the same vision – to ensure the future of research was done with and for those with musculoskeletal conditions. People with musculoskeletal conditions are at the centre of every pathway ensuring that research has meaning and impact on many lives.”*

03

WHERE WE WANT TO BE

Looking to the future: Research Versus Arthritis
Better lives today, Better lives tomorrow

LOOKING TO THE FUTURE:

Research Versus Arthritis –
Better lives today, Better lives tomorrow

Our priorities and principles

This four-year strategy is driven by the needs of people with arthritis. That is why it focuses on research with the greatest potential to improve the quality of their lives - translational research; turning observations in the laboratory, clinic and community into interventions that directly improves the health of individuals and populations.

We want to facilitate the creation and application of scientific knowledge and rigour to improve treatment options, clinical practice, and policy. We want to bring about more precise and faster diagnoses, more effective and targeted treatments, and more holistic care pathways.

We want the lived experience of people with arthritis to inform research and care provision – taking and translating the experience and voice of people with arthritis back to the laboratories and clinics.

This means involving people with arthritis in research design and assessment, as well as making them more aware of and able to participate in ongoing research. To achieve this, we will focus our investment and influence on four priority areas over the next four years (2022-26):

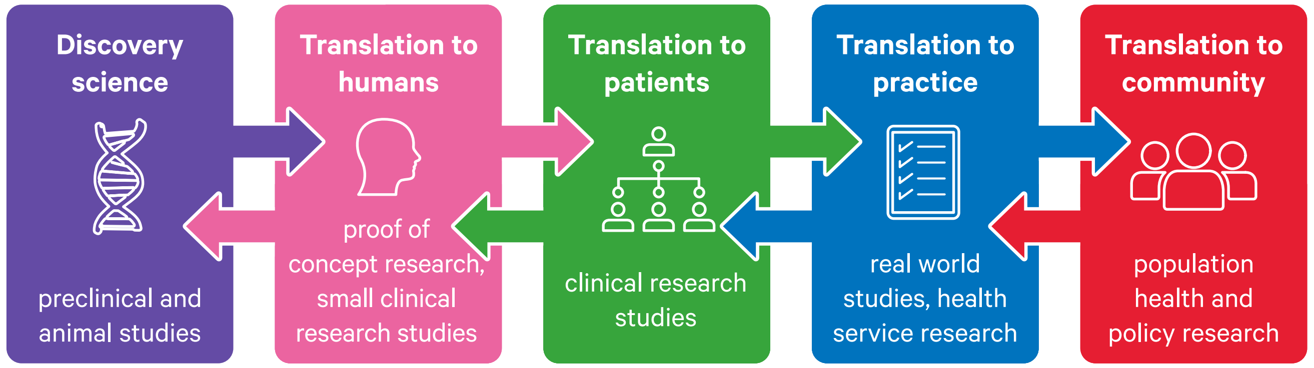
1. Early detection and prevention: Spotting the biological signatures of arthritis early to maximise the opportunities for timely intervention and preventing it from getting worse.

2. Targeted treatments: Taking the guesswork out of treatment by increasing effective, reliable and timely drug and non-drug solutions to reduce, manage or cure disease.

3. Living well: Addressing musculoskeletal health inequalities for individuals and wider society by striving for better musculoskeletal health and care at home, in leisure, at work and in communities.

4. People and partnerships: Making Versus Arthritis the partner of choice – for our funding partners, the life-sciences industry and our researchers.

The changes we want to see are longer-term targets beyond the duration of this strategy. Our short-term activity for the next four years will aim to focus the research agenda in these priority areas to meet some of the current unmet needs.



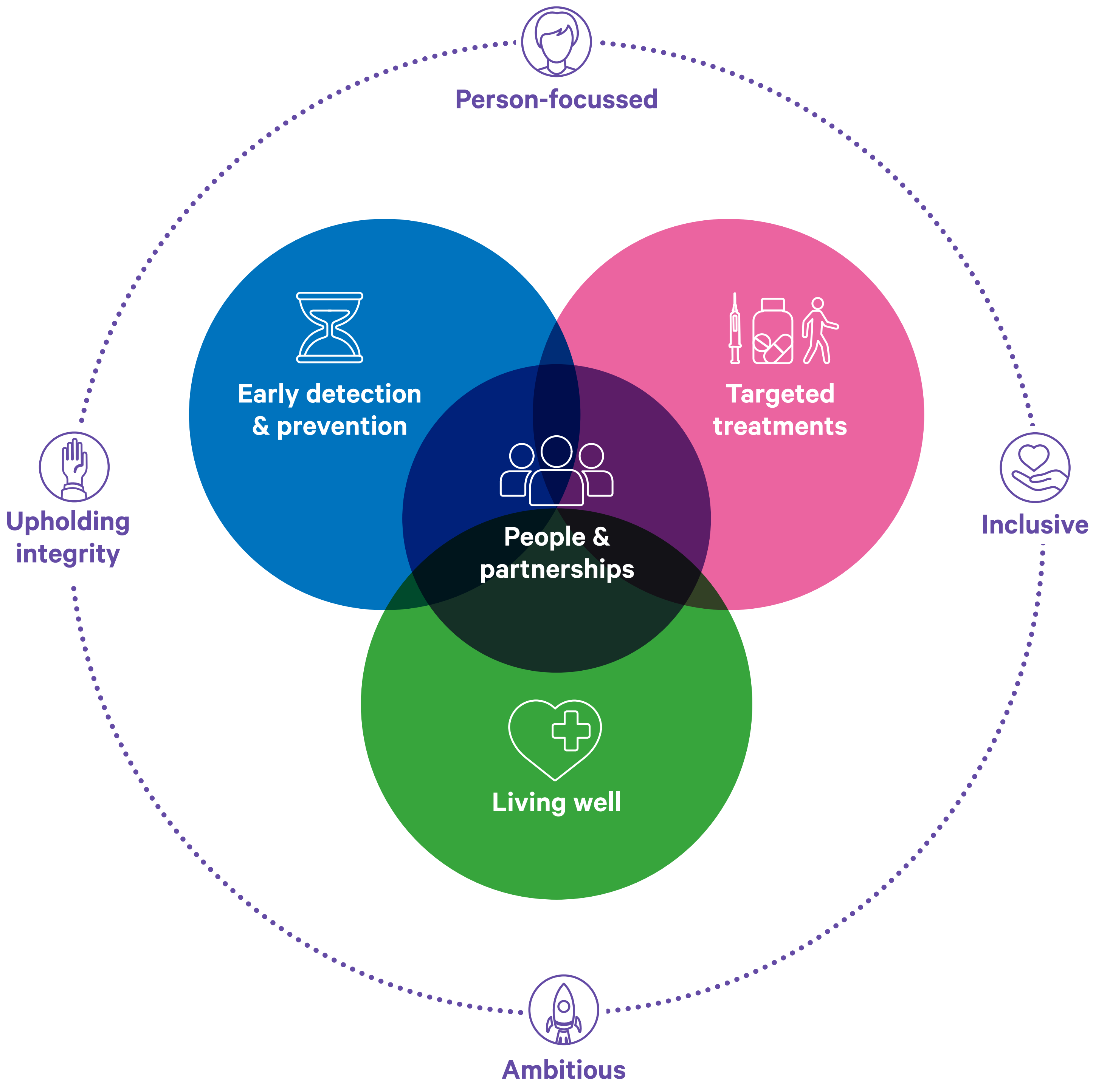
DR NEHA ISSAR-BROWN

Director of Research

> *"This strategy is striving for Pace and Precision. Our four priority areas are driven by the need to bring ground-breaking scientific discoveries directly to people with arthritis at pace and with precision – more and better interventions for quicker and more accurate diagnoses, targeted and timely treatments and personalised approaches to care. Solutions tailored to the individual, taking into consideration not just their genes but also the environment they live in – the experiences of living with arthritis.*
>
> *For us, it is not just a four-year Research strategy. It is a roadmap for change – we want to put Musculoskeletal research and our researchers on the map. We are calling on other funders, our partners in the life-sciences industry and beyond who share our vision to collaborate with us like never before to make innovations happen, faster and better. To make arthritis preventable, manageable or treatable. Not inevitable."*

OUR PRIORITY AREAS FOR 2022-2026

where we seek improvements for people with arthritis



Our research principles

Person-focussed

We ensure people with arthritis are active partners across our whole research cycle and consistently feel valued, through a culture of co-design. We invest in solutions tailored to individuals, not a disease.

Inclusive

We ensure people with arthritis from a diverse range of backgrounds, cultures and experiences are partners and participants in our research activities and those of our collaborators. We represent the full life-course of the population through our research. We promote diversity, equity and inclusivity across our researcher community.

Ambitious

We defy arthritis through need-inspired, excellence-driven, innovative and impactful research delivered at an increased pace.

Upholding integrity

We provide honesty, rigour, transparency, as well as care and respect for those involved in our research – both researchers and the people benefitting from it – and accountability for our role in creating a positive research environment.

PRIORITY AREA: EARLY DETECTION AND PREVENTION

Spotting the biological signatures of arthritis early to maximise opportunities for intervention and prevent it getting worse.

The unmet needs

There are many types of arthritis, and they develop differently. Diagnosis is often not swift or straightforward.

Patterns of early symptoms (pain, stiffness, swelling, fatigue) can be similar across diseases and these diseases can co-occur with other (inflammatory) and chronic conditions. Blood tests and imaging may not definitively aid quick and confident diagnosis. At present, there is no routine clinical management that incorporates technological advancements such as genetic risk scores or ongoing symptom tracking.

People report that sharing early symptoms with healthcare professionals can feel worthless. At the same time, incorrect and delayed diagnoses can lead to years of needless disease progression and irreversible joint damage, reduced function, and mobility. There is an urgent need for better tools and biomarkers to diagnose arthritis accurately and as rapidly as possible after symptoms begin, particularly in children and young people.

Preventative, lifestyle factors including physical activity, healthy eating, and sleep and stress management and other types of effective healthy living are not targeted towards musculoskeletal health. Neither is there support for people coping with a diagnosis of a long-term musculoskeletal condition.

Research does not routinely inform health information and care; implementing research solutions as quickly as possible to maximise benefits for people with arthritis is essential.

The changes we want to see

We want to ensure people sustain good musculoskeletal health through the effective prevention and early detection of MSK diseases. We want to take the uncertainty out of diagnosis and treatment, reducing anxiety for those waiting for a diagnosis and reducing the inevitability of living with long-term disability.

We want to ensure people with arthritis across the UK benefit from the successful delivery of the government's strategy for genomic healthcare, including genomic prevention and a seamless interface between genomic research and healthcare delivery. We want multidisciplinary services across community, primary and secondary care to provide effective support around the point of diagnosis.

We want emerging research evidence and research-driven solutions to be rapidly implemented into healthcare policy and practice for screening, early detection and prevention.

Our actions over the next four years

- We will invest in research to understand the pre-disease pathophysiological mechanisms underlying symptom development and risk. This includes research using digital biomarkers and digital health tools/technology to enable early diagnosis and reducing the impact of disease, including through prevention.
- We will invest in the development of reliable pre-symptomatic markers and diagnostic disease indicators and biomarkers to predict and detect arthritis at the earliest possible stage.
- We will advocate for the use of genetic risk scores as part of routine clinical management for arthritis conditions known to be genetically linked.
- We will invest in understanding the social and psychological factors and health inequalities that influence and/or predict disease development.
- We will promote accurate and consistent collection and use of diagnostic data across all healthcare settings. Where relevant, we will promote and invest in better linkage and harmonisation of existing datasets.
- We will work in partnership to support health service research, to learn how best to implement knowledge about early detection and diagnosis. We will actively engage with decision-makers to optimise their selection of evidence-based services.

> *"If we can understand the pre-disposition can we be better at prevention and quicker at diagnosis?"*
>
> *"Diagnosis has to be much earlier"*
>
> *"I want everybodywho does not have an MSK condition to know what their musculoskeletal health is and how to look after it in order to prevent future musculoskeletal diseases"*
>
> *"Prevention is vital"*
>
> **LISTENING ACTIVITY CONTRIBUTORS**

Predicting osteoarthritis after knee injury – the KICK study

Joint injury is a significant risk factor for osteoarthritis. However, it's not currently possible to predict those who will go on to develop joint problems after injury. The KICK study, led by Dr Fiona Watt of our Centre for Osteoarthritis Pathogenesis, followed a group of patients for five years following a knee injury. Within two years, 15-20% of participants were showing signs of knee osteoarthritis. The study identified biological markers with potential to help predict the future risk of arthritis. The long-term aim is to develop a tool that calculates people's future risk of osteoarthritis at the time of injury.

PRIORITY AREA: TARGETED TREATMENTS

Taking the guesswork out of treatment by increasing effective, reliable and timely drug and non-drug solutions to reduce, manage or cure disease

The unmet needs

Finding effective and tolerated treatments for some types of arthritis can be a trial and error process.

For some types of arthritis there is variation in the individual effectiveness of treatment. People are left not knowing if a treatment will work or for how long, and when or why their symptoms get worse.

For some types of arthritis there are few treatment options. Where individuals are experiencing arthritis alongside other long-term conditions treatment options are complicated.

People with arthritis feel a holistic approach – looking at a person with multiple conditions, symptoms and experiences, rather than individual conditions – is lacking.

The pain, fatigue and mental health issues associated with arthritis are not routinely captured or treated alongside the symptoms of the muscles and joints. Innovative tools that enable and encourage people to digitally track their own health outcomes and share them with the professionals who provide support are needed.

Research-driven symptom and disease treatment is often not swiftly or routinely adopted into health information and care guidelines.

The changes we want to see

All people with arthritis – including children and young people and those, particularly older people with multiple long-term conditions – are treated appropriately, reducing the prospect of living with symptoms. Treatment approaches applying a holistic approach, including the management of pain, mental health and fatigue, will ensure that people get the treatment that's right for them at the right time.

We want both clinical and care pathways adopt an approach to disease treatment that takes into account individual variability in genes, environment and lifestyle – a precision-medicine approach. It would harness biological data combined with an individual's lived experience (including multiple long-term conditions) to predict their disease prognosis, identify the most effective treatments and minimise the risk of side-effects from long-term treatment.

Emerging research evidence to be rapidly incorporated into treatment guidelines, and health and social care policy and practice.

Our actions over the next four years

- We will invest in ambitious precision medicine approaches, targeted treatments and personalised interventions that develop reliable ways to halt or reverse disease progression. This includes research that identifies specific groups of people with distinct mechanisms of disease, lived experience or particular response to treatments to understand when and in whom a treatment may or may not be effective.
- We will invest in research seeking to understand how diseases are linked, and where what is learned about one disease can be used to tackle other diseases.
- We will support research into disease-agnostic pathways to understand common mechanisms of disease, particularly chronic inflammation, autoimmunity and immune-mediated inflammation.
- We will invest in the development of reliable, cost-effective psychotherapeutic and social intervention alternatives to drugs or surgery alone. This includes research on the impact of arthritis on mental health.
- We will invest in research that harnesses and utilises data tracked and gathered in digital health and tools from healthcare settings and patient reported outcome measures to better inform treatment development.
- We will work in partnership to support health service research, to learn how to create and implement large-scale holistic treatment, including for pain, fatigue, mental health and co-morbidities.

> *"I want a cure for arthritis as well as live treatment improvements and improved quality of life"*
>
> *"Monitoring needs to go beyond just squeezing joints. There has to be a better way to establish levels of degeneration in a more timely manner and ways to defer further decline to the point of surgery"*
>
> *"There should be more alternatives to drugs"*
>
> **LISTENING ACTIVITY CONTRIBUTORS**

Predicting a patient's response to anti-TNF treatment

Anti-TNF therapies have revolutionised the treatment of inflammatory arthritis. However, not all patients respond to treatment, and finding the right drug for each individual is a process of trial and error. Research involving both the Centre for Genetics and Genomics and the Centre for Epidemiology identified changes to gene activity in patients who responded well to treatment with the anti-TNF adalimumab. These findings could make it possible to identify people who are not responding well to treatment so they can be given an alternative– improving their chances of effective treatment and saving the NHS money.

PRIORITY AREA: LIVING WELL

Addressing musculoskeletal health inequalities for individuals and wider society by striving for better musculoskeletal health and care at home, in leisure, at work and in communities

The unmet needs

The likelihood of developing arthritis and the experience of living with arthritis varies considerably across different groups in society, including by ethnicity, gender and deprivation.

Support for people with arthritis does not always take into account people's social, economic and environmental circumstances. There is a low level of ability to find, understand, and use information and services to inform decisions and actions (health literacy). Easy access to information, treatments and support is very difficult for people with arthritis to manage across multiple conditions.

Self-management is crucial and there is need for better information, tools, services and opportunities to support self-management.

Better approaches to managing chronic pain and fatigue are needed, allowing for more and better alternatives to medical treatment alone.

There is not enough routine support for people in and returning to work, or sufficient guidance for employers on how to change working practices to support people with arthritis.

The multidisciplinary support people need from health, care and public health services can be lacking and inconsistent.

The changes we want to see

People with arthritis feel in control of their health and are well equipped to manage their physical and emotional wellbeing. They are supported by knowledgeable health and care professionals, employers, educational institutions, and their families and communities.

Individual and community support is understood and valued as a vital part of helping people with arthritis manage their self-care and live well. People with arthritis are making informed choices about evidence-based interventions to support their health and wellbeing.

Healthcare and public health services are well informed by relevant, good-quality health data and knowledge to generate, evaluate and implement definitive models of person-centred care. This includes supporting individuals moving from paediatric to adult services. People experience clear, consistent and integrated care across clinical and community settings.

In the digital heath landscape people with arthritis are encouraged to support better development and capture of outcomes reflecting patients' or caregivers' perspective on the impact on their lives and experience. Transfer of data between platforms allows easy analysis to better understand and address health inequalities.

Our actions over the next four years

- We will invest in understanding the social and psychological factors influencing and predicting disease progression and outcomes. That understanding will inform how the different needs of different groups, including older people, people living with multiple long-term conditions, and children and young people, are met.

- We will invest in understanding how health services, local communities, and employers best work together to improve the lives of people with arthritis

- We will invest in understanding the most effective ways to engage people with arthritis and local communities in different types of supported self-management, covering areas such as physical activity, mental health and social isolation. We'll support research into how to increase the uptake of proven self-management interventions, particularly using digital health tools.

- We will advocate for the most effective ways to create meaningful and sustainable improvements in health services using health surveillance data. We will support initiatives learning how best to harness and bring together (existing) diverse sources of data, including health, social care and other national sources and data from people tracking their own health outcomes.

- We will share research-driven solutions with people with arthritis, and relevant services and professionals, in ways that help people with arthritis to manage their condition.

New technologies to monitor arthritis flares remotely

Arthritis flares occur more frequently when treatments are not working well. Doctors need to be able to identify flares to reduce joint damage and disability, and improve condition management.

There are few user-friendly methods to allow patients to safely and reliably collect blood samples at home so their clinical team can monitor flares between appointments.

That's why we've awarded funding to Dr David Gibson from Ulster University in Northern Ireland to develop and evaluate a blood-collection device and associated mobile phone app to allow patients to safely and reliably monitor their condition at home.

> *"I want everyone who has an MSK condition to be well-informed to self-manage their condition and seek help when they need it"*
>
> *"Chronic diseases need chronic monitoring"*
>
> *"I want to ensure that future generations do not have the struggle as we have"*
>
> **LISTENING ACTIVITY CONTRIBUTORS**

PRIORITY AREA: PEOPLE AND PARTNERSHIPS

Making Versus Arthritis the partner of choice – for our funding partners, the life-science industry and researchers

PEOPLE

The skills, expertise and resources needed in the research landscape to make a step change for people with arthritis are diverse. This strategy puts having the right skills and the right partners at our core:

People – our researchers, clinicians and healthcare professionals who find the solutions that transform lives.

Partnerships – the funders, pharmaceutical, biotechnological and other industry partners with a shared vision and purpose who seek to do things bigger or better.

The unmet needs

The scale of the challenge in arthritis research demands a concerted effort from our community. Researchers and healthcare professionals are a fundamental part of our community. However, the visibility of musculoskeletal research in the UK is lacking. This has resulted in a dwindling pool of talented, established researchers – the innovators and leaders of tomorrow. There is a need to not just train but also retain the best minds in arthritis research. There is also a need to build diversity and equity in research and healthcare across the UK, focusing on the gaps in capacity and skills, as well as increasing multidisciplinarity.

There is a role for funders in bringing the two communities – the people who find solutions and those who benefit from them – even closer. Researchers need to be empowered to incorporate the views of people with lived experience into their research, and people with arthritis need to be confident that research they co-produce will benefit them, future generations and society.

The changes we want to see

A career in arthritis research becomes the destination of choice for the best minds from across all scientific disciplines. An established cohort of highly skilled and established experts lead talented, multidisciplinary teams who attract, train, and help nurture the next generation of researchers in the UK. Arthritis researchers at all career stages have access to sustainable career paths.

There is an increase in the numbers of skilled arthritis researchers and health professionals working across all four UK nations.

Research into arthritis leads the way in genuine co-produced, holistic and honest patient and public involvement and engagement in the research studies undertaken. The lived experience of people with arthritis informs and complements the skills and expertise of researchers to generate efficient, effective and accessible real-world solutions.

Our actions over the next four years

- We will focus our investment on building the capacity and numbers of researchers in mid-career stages, providing fellowship support for excellent intermediate researchers who are committed to working in the field of arthritis research and are seeking to establish themselves as independent researchers.

- We will explore how to help our current and future researchers enhance their careers, by looking at where to build on our existing mentoring networks and relationships.

- With the help of our research advisory/clinical study groups, we will continuously review the skills gaps in arthritis research to better address the distinct needs across the UK nations. Where necessary, we will create opportunities for skills-sharing and collaboration in a targeted manner.

- We will examine the needs of researchers and industry, and enhance our patient and public involvement and engagement support to researchers. We will incentivise co-production right from the outset of any research project, as appropriate for the area of research.

Dr Chrissy Hammond uses zebrafish to research the genetics of osteoarthritis. Based at the University of Bristol, Chrissy received a Versus Arthritis Career Development Fellowship (CDF), and has gone on to be awarded a Versus Arthritis Senior Research Fellowship. She says:

> *“I was lucky enough to secure a Career Development Fellowship, which really allowed me to establish my group and a research niche. The support I received during my CDF and the success of the work during it inspired me to apply for the senior fellowship.”*

Dr Chrissy Hammond,
University of Bristol

PARTNERSHIPS

The unmet needs

The cost of the impact of arthritis far outstrips the level of research investment, with fewer funding avenues for arthritis research and competition with many other conditions for profile and funds. Funders, pharmaceutical, technological and digital industry and policy stakeholders are pivotal in supporting the development and scaling up of solutions for arthritis.

There is need for more proactive and greater collaboration between funders, with additional investment to truly drive the translational agenda in arthritis research. There is a need to work together to maximise the benefits for people with arthritis.

The UK has a richness of valuable patient cohorts (health and research) available for research purposes, many though function independently, are not harmonised with other resources and are underused. There is an unmet need to facilitate ease of data linkage and analysis.

The changes we want to see

Arthritis research, researchers, and the experiences and voices of people with arthritis get attention and investment proportionate to the scale of the impact.

Arthritis research becomes attractive for public, private and industry investors. Collectively they drive the research agenda towards the clinic, the people living with the condition and society.

Versus Arthritis becomes the partner of choice to make groundbreaking discoveries happen.

Our actions over the next four years

- We will engage in increased and more efficient partnership management, with greater emphasis on building and participating in (funding) consortia to increase the scale of investment and impact for people with arthritis.

- To deploy our resources efficiently in areas where we cannot achieve the desired scale or profile alone – such as multiple long-term conditions, rare diseases, health service capacity and collective immune mediated inflammatory conditions – we will work in partnership.

- Where possible, we will prioritise data-harmonisation and linkage, ideally in partnership with other funders, instead of investing in competing, long-term projects and infrastructure initiatives.

- We will aim to increase the likelihood of clinical and commercial success of our funded and future portfolio with more innovative models of collaboration and involvement of commercial partners.

Working in partnership to create the UK JIA Biologics Register

Working together in partnership allows us to do more for people with arthritis. Versus Arthritis and the British Society for Rheumatology were already carrying out independent studies at hospitals across the UK to look at the safety and effectiveness of biologic and biosimilar therapies for treating juvenile idiopathic arthritis (JIA). We partnered to bring these separate strands of work together as the UK JIA Biologics Register, which is the world's largest group of children and young people involved in JIA research.

The CLUSTER consortium brings together patient and parent networks, leaders in childhood arthritis, Juvenile Idiopathic Arthritis-associated uveitis, bioinformatics and industry to create biomarker tests to personalise treatment, find and test new treatments and predict disease outcomes for childhood arthritis.

> *"We are proud to leverage the power of partnership with Versus Arthritis and deliver on our common goal to address the ongoing huge unmet needs of people living with arthritis."*

Dr John Ioannou, Global Head of Medical Affairs, Rheumatology, UCB Pharma – Global biopharmaceutical CLUSTER partner

Preventing sight loss in JIA

The SYCAMORE study, funded jointly by Versus Arthritis and the National Institute of Health Research (NIHR), showed that adalimumab in combination with methotrexate is effective at controlling uveitis in children with Juvenile Idiopathic Arthritis (JIA). The trial's results provided a new treatment option for uveitis and had a major impact on how young people with JIA receive care around the world, reducing the risk of sight loss and improving their quality of life.

Recruitment to trials for JIA is often a challenge as the number of patients is small. Aware of the importance of this work, we supported the research team to adapt the recruitment process and improve communication between ophthalmology and rheumatology departments, ensuring that the study could continue.

"The Sycamore study funded by NIHR and Versus Arthritis is the first trial of biologic in children with JIA-associated uveitis. This study has led to approval and access to adalimumab for children with JIA-uveitis across more than 70 countries globally benefitting thousands of children."

Professor A. V. Ramanan, Professor of Paediatric Rheumatology, University of Bristol / University Hospitals Bristol NHS Foundation Trust

OUR CHARITY-WIDE APPROACH TO DELIVERY

We want to see increased recognition of the need to prioritise arthritis research across the UK research sector. And we want to develop the culture of knowledge mobilisation, accessing and using quality research outputs.

We will continue to drive forward the UK arthritis research system, we want to put arthritis research and our researchers on the map, nationally and internationally.

Our activities, involving people with arthritis, will aim to deliver cross-charity impacts in service delivery, health information, health intelligence, health and social care improvement, digital services, policy and influence work as well as our income generation.

We will respond flexibly to the changing world around us over the next four years, incorporating new ideas and aligning with relevant new initiatives, to advance our longer-term research endeavours. We will consistently evaluate, test, learn from and adapt our approach to research. We will pro-actively listen and engage, communicate, and inform until research is everyone's business.

Working together to shape health policy in Wales

The research community has been working alongside Cymru Versus Arthritis to influence policy and improve services for people with arthritis in Wales. Professors Valerie Sparkes, Director of the Biomechanics and Bioengineering Research Centre Versus Arthritis, and Professor Ernest Choy, Director of the Cardiff Regional Experimental Arthritis Treatment and Evaluation (CREATE) Centre, have worked with Cymru Versus Arthritis to shape the Welsh Government's guidance document: Arthritis and Long-term Musculoskeletal Conditions in Adults. The document covers guidance for health and social care professionals on arthritis and musculoskeletal conditions in Wales. It will help clinicians make informed decisions and advise health boards on designing, planning and managing person-centred services for adults living with arthritis and long-term musculoskeletal conditions.

Research advisory/clinical study groups

Our research advisory/clinical study groups have an integral role in continuously identifying unmet needs in arthritis research and informing our prioritisation of research areas.

They gather and connect the communities; people with arthritis, researchers and practitioners across the research spectrum – from discovery and translational science, treatment development and evaluation to disease management and health service research.

Our advisory groups will help inform our activities in our priority areas and find ways to keep listening to diverse groups of people. Our 'Gaps and Opportunities for Arthritis Research' document will be dynamically updated to further inform our focussed activities.

WHAT WE WILL DO, WHAT WE WILL NOT

To begin to realise the long-term changes we want to see, over the next four years we will need to refocus our efforts in line with the priorities identified by and with our community. This will require increased investment in some areas and reduction in others. Our four priorities lay out what we will invest in or advocate for and what we will not. Guided by our research principles, we aim to be honest and transparent in our approach to be able to deliver against our vision and this strategy.

Person-focussed

We ensure people with arthritis are active partners across our whole research cycle and consistently feel valued through a culture of co-design. We invest in solutions tailored to individuals, not a disease.

- We will not fund research – alone or in partnership – which is not informed by the needs of people with arthritis and/or does not involve them meaningfully across all stages of research.

- We will not penalise but incentivise co-production and support our researchers, funding partners and people with arthritis to enable more, better and holistic involvement and engagement.

- We will deliver our new research involvement offer, which will extend and deepen our partnerships with people with arthritis, allowing their voice and perspectives to influence our work further.

- We will restructure our committees and funding panels to ensure there is representation and co-leadership from experts across science and lived experience.

Inclusive

We ensure people with arthritis from a diverse range of backgrounds, cultures and experiences are partners and participants in our research activities and those of our collaborators. We represent the full life-course of the population through our research. We promote diversity, equity and inclusivity across our researcher community.

- With a biopsychosocial approach – recognising the interconnection between biology, psychology and socio economic factors – we will not exclude any musculoskeletal condition, area of research, stage of life, or ages from applications to any of our initiatives.

- Where a research proposal involves the participation of people with arthritis (e.g. epidemiological studies, experimental medicine approaches, early phase clinical studies), we will not fund research that is not able to demonstrate appropriate representation and diversity (ethnic, socioeconomic, gender) as relevant to the aims of the proposal.

- We will not fund research that does not conform to the principles of the national centre for the replacement, refinement and reduction of animals in research (NC3Rs), or that do not account for genetic, sexual, immune and microbiome diversity in animal models.

- We will fund health service research that accounts for differences in local environments, noting that specific needs of the four UK nations devolved healthcare and research funding contexts require tailored solutions.

Ambitious

We defy arthritis through need-inspired, excellence-driven, innovative and impactful research delivered at an increased pace.

- We will be bold, innovative and ambitious in our approach and not be restricted to traditional funding mechanisms – we will develop, test and tailor novel funding and peer-review models with a specific ambition to be agile and reduce the time taken from grant submission to award without compromising on scientific excellence.

- We will not limit our funding offer, providing a mix of response-mode schemes, strategic initiatives and long-term investment in networks of excellence (as guided by our research priorities), but restrict pump-priming initiatives to targeted areas only.

- While open to all partnership opportunities, we will encourage and prioritise consortia-building, and will take on a convening role to bring non-traditional and niche funders on board. Some priority areas will only be delivered in partnership (as indicated within our Partnership priorities).

- We will not exclude discovery science proposals but will emphasise that the route to translation from laboratories to people with arthritis should be clear and will be prioritised.

Upholding integrity

We provide honesty, rigour, transparency, as well as care and respect for those involved in our research – both researchers and people benefitting from it – and accountability for our role in creating a positive research environment.

- While we will not be running any dedicated PhD fellowship schemes over the next four years, we will continue to provide hands-on career support and activities to all career-stages and all our existing fellows, including PhD fellows.

- We will ensure our framework of expectations for the people we fund reflects our developing organisational equality, diversity and inclusion agenda and commitment.

- We will ensure any data generated from Versus Arthritis-funded research conforms to principles of open access.

- We will actively influence improvements to research bureaucracy and governance.

EVALUATING OUR IMPACT

We want ground-breaking solutions to spot and stop arthritis in its tracks. We want to offer people with arthritis choice and control, so they can live fulfilling lives. The long-term changes we want to see stretch beyond the duration of this research strategy, but they have informed our short-term activities over the next four years. Continuously monitoring and evaluating the impact of these activities will ensure we continue to demonstrate the difference that our investment is making and are accountable to our supporters.

We will establish priority area-specific success metrics that our organisational committees and groups will check on an annual cycle, ensuring we are achieving our targets in line with our research principles. This will guide adjustments in our operational planning and strategic decision-making. We know that research has longer-term impact, far beyond the "end date" of the funded research award. We also know that those impacts can be diverse and we will ensure we innovate and adjust our monitoring to capture the true impact and diversity of our investment. We will further invest in disseminating and showcasing the wider impact, reach and potential of our research.

We play an active role in monitoring the performance of our research and supporting its delivery. We will align with San Francisco Declaration on Research Assessment, assessing research outputs through a range of impact measures. These will go beyond academic impact alone (academic publications, journal metrics) to include the qualitative contribution to science and society, influencing policy and practice.

These measures include:

1. Increased innovation, agility and pace in our funding models and decision making
2. Greater involvement and participation of people with arthritis in research
3. Increased number and/or value of our strategic collaborations and partnerships
4. Greater visibility and engagement within the arthritis research community at national and international level
5. Concerted communication and increased dissemination of research to diverse audiences, including outside of the research community
6. Increased contribution to and influence on musculoskeletal health policy, practice or product development in all four nations
7. Greater support for current MSK researchers to build a healthy and sustainable research community

Any and all of the above measures will complement our overarching measure of success – improving the lives and choices for people living with musculoskeletal conditions, now and in the future.

Endnotes

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[i] Global Burden of Disease Collaborative Network (2020). Global Burden of Disease Study 2019 (GBD 2019) Results. Institute for Health Metrics and Evaluation (IHME), Seattle

[ii] Arthritis Research UK Report. The Nation's Joint Problem 2017

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