A research roadmap for pain

ARTHRITIS RESEARCH UK

Our vision:
An end to pain

A society that understands pain, recognises its impact and is inherently designed to support people in pain.

A healthcare system that empowers people to remove the limits of pain.

A research community that works together to better treat, manage and prevent pain.

Executive summary

By some estimates chronic pain affects between one-third and one-half of the UK population, a huge number of whom suffer from musculoskeletal disorders. The depth and scale of the problem of chronic pain cannot be overstated; with significant dissatisfaction from current pain treatments and slow progress in developing new treatments, research is urgently needed to better understand, treat and manage musculoskeletal pain.

We believe that this paper is a first of its kind; co-produced by people living with pain, healthcare professionals and researchers. It sets out a research roadmap, drawing together the 14 most vital challenges that we believe must be addressed in future pain research. It is the fervent belief of those who helped put these priority challenges together that progress in these areas will transform the lives of people living with musculoskeletal pain, but also address the wider national burden of pain. To enable this transformation, we have identified close collaboration between healthcare professionals, academics and people in pain as being vital to delivering change.

Our ambition and expectation is that this roadmap for pain research should mark a moment of transformation in how we and others invest in the future of research into pain, and ensure that the spotlight shines on this most pressing of public health issues. The challenge is huge, but so is the prize of taking away the daily impact of pain on the lives of those with arthritis and related conditions.

Liam O'Toole
Chief Executive Officer, Arthritis Research UK

Foreword

Chronic pain is life changing for people with arthritis and other musculoskeletal diseases. It colours everything and prevents people from living a full life. It is important that we don't look at pain in isolation, simply as a symptom. Pain is a problem in and of itself. It has its own biology, related but separate to the diseases of arthritis and other related conditions. Whatever its cause, and whatever maintains it, pain and associated fatigue have a huge influence on the body's systems, disrupting the harmony of how the body and the mind work. They affect our appetite, our ability to sleep, how we think and move, and because of this, they stop people functioning the way they want to.

This is why we must develop our understanding of pain and find new and better ways to treat pain, and its consequences.

People with arthritis are the driving force behind this roadmap for pain research. They have played a pivotal role throughout this project. Their insight into what life with pain means has influenced our thinking as researchers, helping us to identify the greatest challenges and how we might tackle them.

I would like to thank everyone involved in this unique project: people who live with musculoskeletal conditions, academic researchers, health and clinical leaders alike have ensured the most important challenges have risen to the surface. It is an honour to be working with Arthritis Research UK to deliver pioneering research to improve the lives of millions of people currently living with pain.

Professor Stephen Holgate
Chair of the Arthritis Research UK Pain Expert Group

Planning the journey

Over the next few pages we outline 14 priorities that future pain research should address. The majority of these priorities are grouped into four themes:
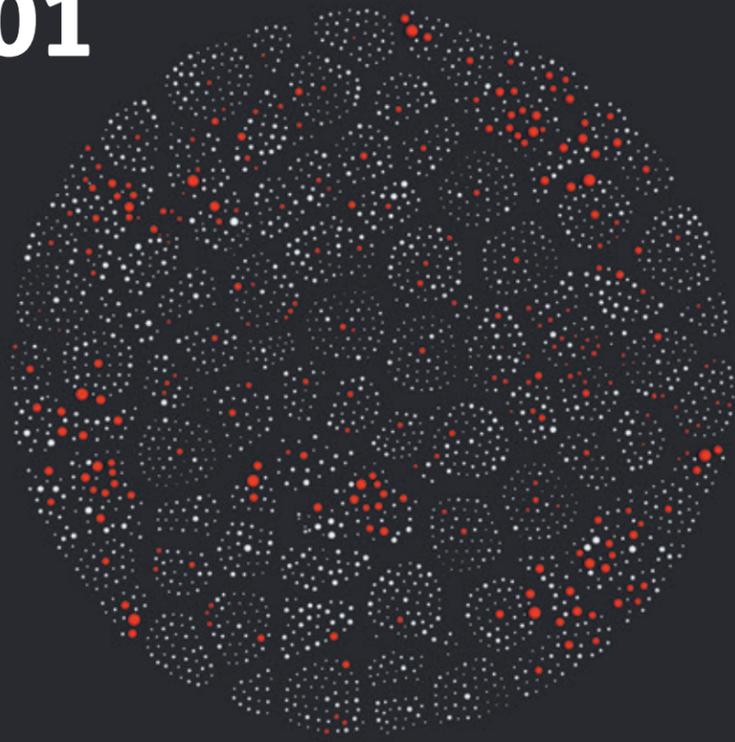
Understanding complexity

Stratification
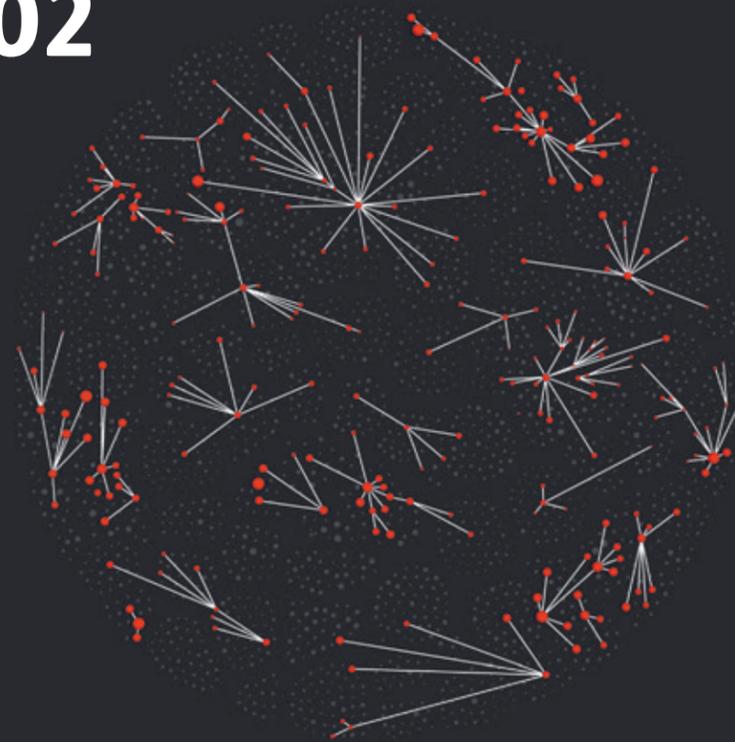
Management and support

Prevention

Underlying each of these themes are four additional enabling priorities. While three of these can be considered research priorities in their own right (technology, data and industry), collectively the four enablers thread through each of the other priorities to support the delivery of change. For example, advances in modern technology can help drive our understanding of complexity, but also enable better management and support of pain.
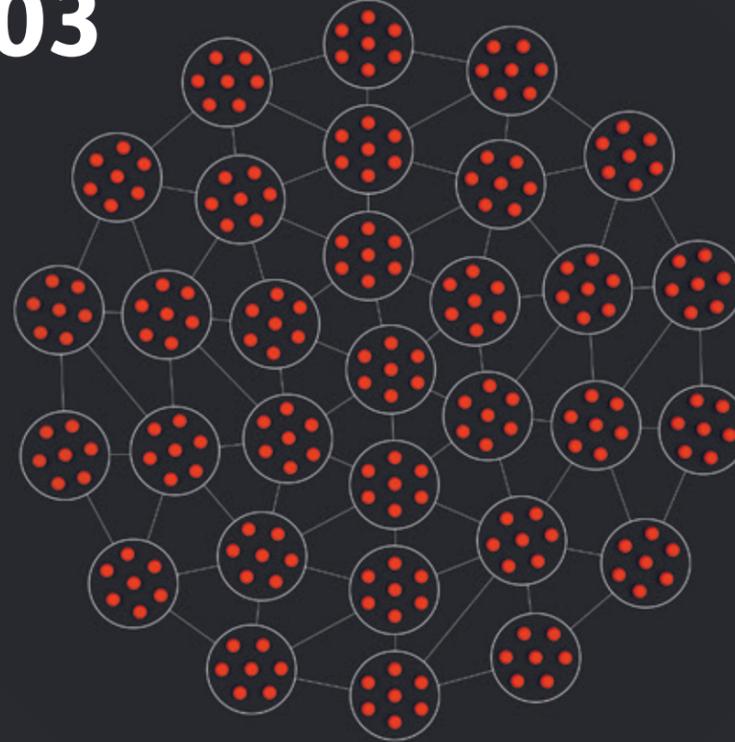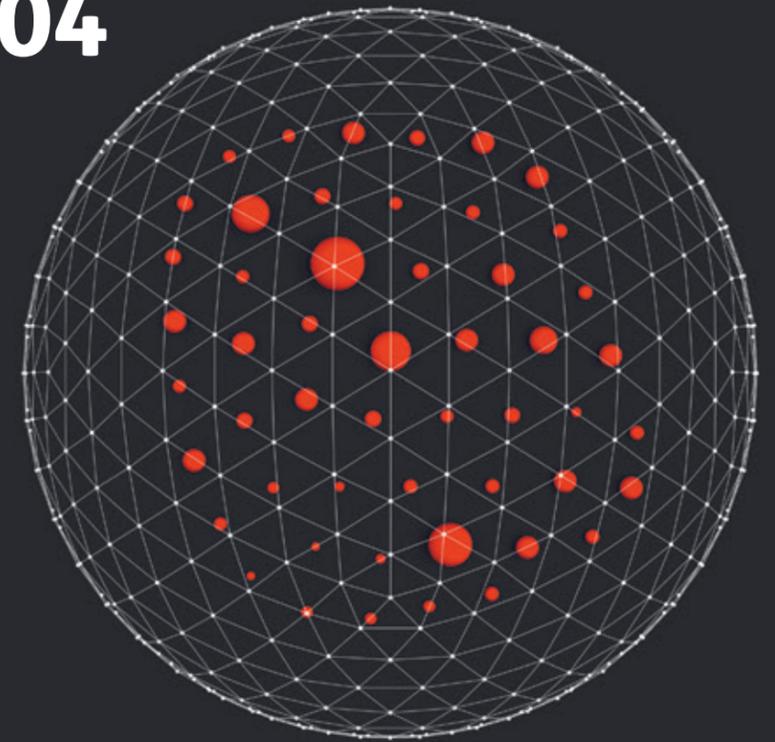
01

Understanding complexity
Unravelling the complex and fundamental mechanisms of musculoskeletal pain.

Priorities:

» Developing experimental models of pain
» Dissecting the relationships between pain and comorbidities
» Relating early life experiences and pain in later life
» Engaging under-represented and hard-to-reach groups

02

Stratification
Personalising musculoskeletal pain research and care.

Priorities:

» Identifying phenotypes for stratification
» Refining the assessment of pain

03

Management and support
Identifying models of care and support across all environments.

Priorities:

» Identifying models of supported self-management
» Developing practical support for the workplace
» Designing new products and solutions
» Revisiting the organisation of healthcare services

04

Prevention
Preventing future musculoskeletal pain.

Priority:

» Developing a public health strategy for pain

Enabling themes

Technology
With recent advances in technology there is significant potential to exploit novel approaches to the research priorities and improve care for people with musculoskeletal pain.

Data
There is a wealth of research and clinical data that has been, or is being collected for musculoskeletal pain. If made available to researchers, this data could unlock new understanding of musculoskeletal pain and ultimately improve care.

Industry
Progress towards developing new treatments, approaches, products or solutions for people with musculoskeletal pain cannot be achieved without the expertise and know-how of industry. Similarly, industry will benefit from the insight, knowledge and expertise obtained from closer working with charities, patients, academics and clinicians. We must work in partnership to deliver on this research roadmap.

Collaboration
Cross-disciplinary collaboration between healthcare professionals and academics is vital if a real step change is to be made for people with musculoskeletal pain. Involving and engaging people with musculoskeletal pain in addressing these research priorities is also key to ensuring research and care remains relevant to, and meets their needs.

This roadmap is the first of its kind making plain what scientific, clinical and patient-support advances need to be made. This guidance will focus where innovation is required to reduce the burden of pain on the individual and society.

Professor Rose Maciewicz, *Member of the Arthritis Research UK Pain Expert Group*

A painful problem

Understanding, treating and managing pain is among the greatest challenges facing society today.

Research in this area is underfunded and public understanding and recognition of the enormous personal, economic and social cost of musculoskeletal pain remains low. Current treatment options are often ineffective and have undesirable side effects. Limited understanding of underlying musculoskeletal pain mechanisms means we cannot offer effective treatments to the right person, at the right time.

Identifying the most pressing musculoskeletal pain research questions, and navigating their unique complexities, means we will deliver change for people with arthritis and improve their quality of life. Through pioneering research endeavours, such as our Pain Challenge funding call, we will use this research roadmap to invest carefully to ensure the greatest impact.

This research roadmap has been co-produced by experts in pain, people with arthritis, healthcare professionals and researchers. It has been guided by people who know what it means to live in pain. Although its scope is broad and ambitious, this research roadmap seeks to break down the barriers facing people in pain, researchers and healthcare professionals.

Through our leading role in this endeavour, we recognise that we cannot achieve transformational change alone. It is by working in partnership with others that we will ensure the greatest impact for people with musculoskeletal pain.

A detailed technical report of the workshop that informed this strategy is available on our website.

The only way we'll make progress is through research. This roadmap will start a step change into the research of pain if we all: people in research, health and care, and people in pain work together to make it a reality.

Colin Wilkinson, *Vice chair of the Arthritis Research UK Patient Insight Partner Group*

An overview

Our journey to this research roadmap uncovered many strands of insight, which we have distilled to a succinct number of key priorities. Working with our pain expert advisory group, we have gathered these 14 key questions and challenges for pain research into the four themes on pages 7-10. Each of these priorities draw on our collective research strengths in the UK, spanning discovery science, clinical and applied health research.

This research seeks to accelerate our understanding of the mechanisms which underlie musculoskeletal pain and its effects on the whole body. In its broadest sense, this discovery research encompasses genetics, epigenetics, human physiology, experimental medicine and behavioural science. Through this broad approach we will help facilitate the identification and development of new drug and non-drug approaches to treat and manage musculoskeletal pain, as well as increase our understanding of musculoskeletal pain mechanisms.

By identifying and addressing these challenges, we also seek to accelerate the development of new interventions for musculoskeletal pain by promoting and catalysing innovative approaches which reappraise how clinical and human experimental research should be designed and conducted. Innovative use of appropriate methodologies will ensure the development of new treatments and interventions that meet the needs of people with musculoskeletal pain.

Finally, through these challenges we strive for the identification of the most suitable and sustainable models of care and support for people with musculoskeletal pain, working across all environments – at home, at work and within the healthcare service.

Our journey to the pain research roadmap

Gathering insight

We began this journey by reviewing and collecting insight into musculoskeletal pain. This included patient surveys, literature, existing pain strategies and intelligence from many meetings with key stakeholders.

Our pain expert group

To help us develop this research roadmap and review and filter the insight, we put together a pain expert group of multidisciplinary pain stakeholders (details in acknowledgements).

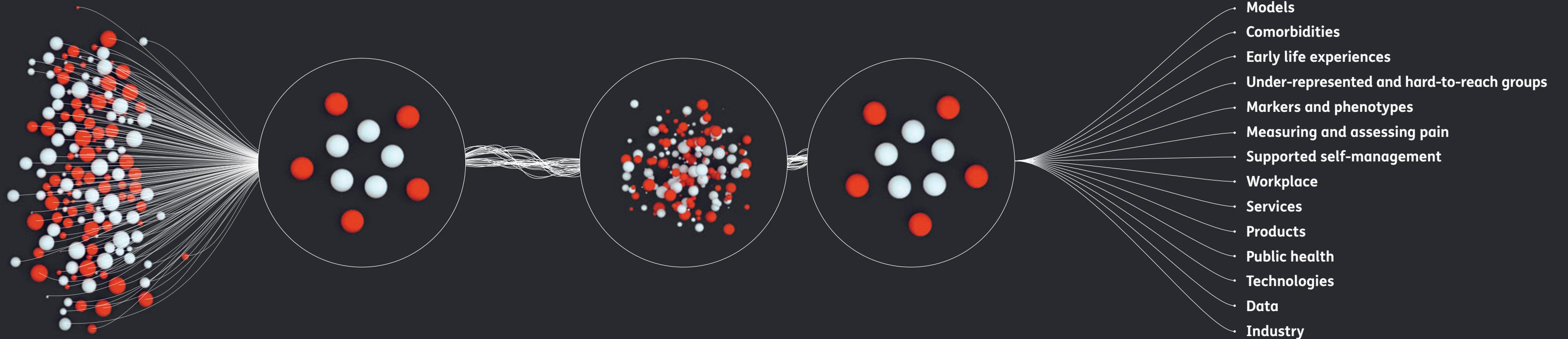### Workshop: Generating ideas and identifying unmet needs

In February 2017 we brought together a large group of key stakeholders to help generate ideas for the research roadmap and uncover the key challenges facing musculoskeletal pain research.

Identifying research priorities

Our pain expert group collectively reviewed all of the outputs from the workshop, identified the key themes that emerged, and distilled them into this research roadmap.

Our pain research roadmap

The 14 points identified in this research roadmap represent a list of priorities for research funders to further explore and invest in. Each of the points is founded on patient need and insight and has been co-produced with direct patient involvement throughout.

- Models
- Comorbidities
- Early life experiences
- Under-represented and hard-to-reach groups
- Markers and phenotypes
- Measuring and assessing pain
- Supported self-management
- Workplace
- Services
- Products
- Public health
- Technologies
- Data
- Industry

Our pain research roadmap priorities

1. Models
Models of animal and human experimental pain do not fully reflect the complexities of pain experienced by people with arthritis. *How might models be refined and new ones developed to overcome this?*

2. Comorbidities
The complex bidirectional relationship between pain and other conditions (comorbidities) is poorly understood. *How can we better understand this relationship, particularly focusing on fatigue and mental health?*

3. Early life experiences
We know that early life experiences can influence pain across the life course and into later life. *What are the key mechanisms and consequences of this, and how can they inform strategies for prevention and the development of new treatments?*

4. Under-represented & hard-to-reach groups
Musculoskeletal pain has a greater impact on under-represented and hard-to-reach groups, but research in diverse groups is lagging behind. *How do we reach and engage these groups in pain research to ensure it speaks to and meets their needs?*

5. Markers and phenotypes
The ability to stratify patients for clinical decisions and better research study design would transform our approach to managing musculoskeletal pain. *Can objective markers for musculoskeletal pain be identified and can we target treatments for individual patients on the basis of their sensory phenotype?*

6. Measuring and assessing pain
We are limited in our ability to measure and assess musculoskeletal pain, both in clinical and research settings. *Are there different approaches that better reflect the impact of pain on the individual? Can we develop or improve measurements of physiological pain correlates (for example, imaging) and key behaviours relevant to pain, disability, fatigue and mental health?*

7. Supported self-management
Models of supported self-management are being developed for people with musculoskeletal pain. *How can we identify the best among these, improve and develop them where needed and ensure their delivery is supported and appropriate for people with musculoskeletal pain?*

8. Workplace
Musculoskeletal pain impacts heavily on the workforce with huge socio-economic implications. *How can research support new and sustainable models of workplace practice to help people with musculoskeletal pain maintain healthy working lives?*

9. Services
People with arthritis have told us that rheumatology and pain healthcare services are not currently organised to meet their needs. *What can be done to achieve a more responsive and effective support service for people with musculoskeletal pain?*

10. Products
Access to simple products and solutions to help people with musculoskeletal pain in their daily lives can significantly impact on quality of life. *How can we work to bring the most innovative designers, researchers and people with arthritis together to develop new products and solutions?*

11. Public health
A long-term public health strategy could prevent the development of future musculoskeletal pain. *How will research help achieve this and who should deliver it?*

12. Technologies
Novel technologies and methodological approaches have the potential to transform pain research. *How will these be exploited to improve data collection and develop new treatment approaches for pain?*

13. Data
There is a wealth of existing clinical and experimental data on pain. *How can we access the most valuable and relevant data that focuses on musculoskeletal pain? What is the best approach to collecting and interpreting relevant clinical and experimental pain datasets from existing sources?*

14. Industry
The whole research environment must work more effectively with industry to deliver the step change needed for people with musculoskeletal pain. *How will this be translated to meaningful and sustained practice?*

With a few selective words our ambition is to convey critical expert thinking and mobilise even greater action.

Dr Stephen Simpson, *Director of Research, Arthritis Research UK*

Guiding the journey

As we worked to bring this research roadmap to life, it was increasingly evident that innovative musculoskeletal pain research alone will not be sufficient to improve the quality of life for people with arthritis. Musculoskeletal pain represents a burgeoning global public health priority in its own right, and must be recognised as such if society, government and research funders are to address the issue. The world we live in should be inherently designed to support people with pain, without stigma or exclusion. At the same time, government should prioritise and invest funding into research and the healthcare system to better support people with musculoskeletal pain and empower them to manage their pain.

It was also clear that greater collaboration between disciplines and professions, as well as people with musculoskeletal conditions, would be needed to successfully answer the questions set out in this research roadmap and achieve the greatest impact.

This is why this roadmap is the beginning of our journey. We are committed to working with partners to address the challenges in this research roadmap. Additionally, we will increase awareness and public understanding of musculoskeletal pain to support the successful delivery of this strategy.

For those living with it, pain colours everything: I can't think of another initiative that has the potential to transform the day to day life of so many people.

Dr Jane Taylor, *Chair of the Arthritis Research UK Patient Insight Partner Group*

Paving the road for success

We have already invested in emerging areas of exceptional science, such as the microbiome, and we are not afraid to take bold actions that may lead to patient impact. This approach will continue as we invest in delivering this roadmap. Since 2015 we have supported pain as a priority area of research, committing over £5M in new awards. We will further increase our portfolio in 2018 with a third dedicated Pain Challenge round. We have also invested a further £2M to continue our support of the Arthritis Research UK Pain Centre at the University of Nottingham.

The charity has a long history of nurturing and supporting extraordinary research leaders and will continue to support musculoskeletal pain research leadership to help deliver this roadmap, and position the UK as an international leader in understanding the causes, impact and solutions to the huge unmet burden of pain. We have used the collective power of the patient, scientific and clinical communities to help co-produce this roadmap and we will continue to enable and support collaborative ventures and workshops, allowing great minds to meet.

To support delivery of the challenges laid out in this research roadmap, we are pioneering new and ambitious research funding calls, such as our Pain Challenge. We will continue to challenge the academic community to devise solutions to the problems identified in this research roadmap and we will be innovative in our future calls and funding mechanisms to ensure their success.

Following our merger with Arthritis Care, we are uniquely placed to support policy, health and social care improvement through our new areas of work, leading to tangible positive impacts to the lives of people with musculoskeletal pain.

I can't think of a future without this type of research. It's a lifeline and I don't know where I would be without it.

Susan Moore, *patient partner and workshop participant*

A pathway to transformation

As we address the challenges laid out in this research roadmap, and continue to influence others to join us in this fight, the lives of people living with musculoskeletal pain will be transformed. Through better understanding of the mechanisms causing musculoskeletal pain we will seek new and improved approaches to detecting, treating and managing different types of musculoskeletal pain. At the same time we will work with healthcare professionals and the healthcare service to ensure people with musculoskeletal pain get the support and recognition needed.

Susan Moore, a patient partner who contributed to the development of this report through our workshop, summed up the importance of what we are trying to achieve: "I can't think of a future without this type of research. It's a lifeline and I don't know where I would be without it. The biologics I use to treat my rheumatoid arthritis have really worked for me, they've kept me out of a wheelchair, and that is all down to research. Being part of the patient group has made me realise chronic pain is being taken seriously. It means a lot to me to know experts are recognising there are different types of pain and I feel I am listened to and believed."

Acknowledgements

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For further information or to find out more about the work we do, visit our website or get in touch.

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