

Arthritis Research UK welcomes the opportunity to contribute to the National Institute for Health Research (NIHR)'s survey 'NIHR 'Health Futures' 20 year forward view.' We understand the purpose of this project is to inform NIHR's strategic thinking so that the NIHR strategy is informed by a rational view of the future, broadly shared by the scientific and health community. We would be happy to discuss this submission further.¹

1. In relation to your area of interest (discipline or geography), what differences do you foresee in the state of health and provision of healthcare in England in 20-30 years' time? In your answer, please consider if/how these changes might affect some populations (within England) differently to others, i.e. socioeconomic, ethnic groups and/or geographic groups.

Differences in state of health

(Note: differences in the provision of healthcare are included in response to Question 3).

- **Growing burden of musculoskeletal disease**

Within the next 20-30 years there will be a growing number of people living with long-term painful disabling musculoskeletal conditions in the UK. Musculoskeletal conditions are already the leading cause of years lived with disability (YLDs) in the UK, and accounted for 30.5% of all YLDs in the UK in 2010.² Around a third of people aged 45 years and over in the UK, a total of 8.75 million people, have sought treatment for osteoarthritis and 10 million people in England and Scotland alone have back pain.^{3,4} Between 2010 and 2015 there was a 5% increase in these conditions in the UK.⁵ This trend is set to continue, for example, taking into account the increase in obesity, growth and ageing of the UK population it is estimated the burden of knee osteoarthritis alone will increase from 4.7 million people in the UK in 2010, to 6.5 million by 2020, reaching 8.3 million by 2035.⁶ There is a significant relationship between deprivation and numbers of people living with chronic pain conditions including arthritis and back pain.⁷

This is an area where research effort falls short of need. Data produced in 2015 by the UK Clinical Research Collaboration (UKCRC) found that research funding into musculoskeletal conditions was lower than the comparative burden of disease.⁸ This is also despite evidence the investment in research into musculoskeletal conditions has resulted in improved health outcomes, and significant return on investment (ROI) that is comparable to research in other disease areas, and far exceeds the Government's expected social discount rate.^{9,10}

- **Multi-morbidity**

As the survey recognises, multi-morbidity is an area where 'the historical scale of scientific effort' does not match need.¹¹ The number of people with multi-morbidity is growing: by 2025 there will be an estimated 9.1 million people living with multi-morbidity (two or more long-term conditions) in the UK.¹² This is not solely a problem of the elderly, over half of the people who live with multi-morbidity are under 65 years of age.¹³ A number of risk factors affect the prevalence of multi-morbidity; generally the prevalence of multi-morbidity is higher in women, people living in deprived areas and older people.^{14,15,16}

Musculoskeletal conditions are commonly found as part of multi-morbidity. Among people over 45 years of age who report living with a major long-term condition, more than three out of 10 also have a musculoskeletal condition.¹⁷ By age 65 years, almost five out of 10 people with a heart, lung or mental health problem also have a musculoskeletal condition.¹⁸ Musculoskeletal conditions are found both with other long-term physical health conditions and mental health problems. For example, people with rheumatoid arthritis have an increased risk of cardiovascular disease.¹⁹ Around a third of women and over 20% of men with arthritis may also have depression.²⁰ Musculoskeletal conditions cause pain and functional limitations which affect quality of life and make living with multi-morbidity harder.²¹

Research funders, including the NIHR, should work collaboratively to ensure there is a flourishing research agenda covering multi-morbidity which, crucially, must include musculoskeletal conditions.²² Areas of research should include prevalence, impact, models and pathways of care, outcome measures, and the individual perspectives of people and healthcare professionals towards multi-morbidity.²³

- **Frailty**

Within the next 20-30 years the UK is expected to have a larger population of frail, older people. Although there is no accepted clinical definition of frailty, unintentional weight loss, loss of muscle mass and strength, self-reported exhaustion and loss of mental capacity are recognised characteristics of frailty.^{24,25} There are currently 1.8 million people in England aged over 60 and 0.8 million people aged over 80 living with frailty.²⁶ Frailty is often, but not exclusively, linked to the ageing process. It is estimated that 10% of people over 65 are frail, and 25%–50% of those aged 85 or over experience frailty.²⁷ However, the Health and Employment After Fifty (HEAF) study has found that at least one component of frailty was reported by one in three adults aged between 50 and 64.²⁸

People living with frailty have the highest rates of unplanned admissions to hospital among health and care service users.²⁹ Frailty is also highly associated with inability to work in people aged 50-64.³⁰ This is an area which warrants research attention. For example, despite considerable evidence for interventions such as Comprehensive Geriatric Assessment (CGA) in community settings in the US, there is a lack of equivalent research evidence to support the use of these interventions in the UK.^{31,32}

2. What do you think will be the key drivers of the changes you have described?

Key drivers of the changing state of health

The state of the UK's musculoskeletal health over the next 20-30 years will be affected by:

- **Population ageing:** By 2040, nearly one in four people in the UK (24.2%) will be aged 65 or over.³³ People are living longer, but they are also living longer with ill health.³⁴ (*See response to question 1 for the growing impact of multi-morbidity*). There is a need to consider how to prolong healthy life expectancy and create a positive vision of meaningful, fulfilling older life. In terms of musculoskeletal health, for example, the likelihood of having osteoarthritis, the most common form of arthritis, increases with age.³⁵ A third of women and almost a quarter of men between 45 and 64 years in the UK have sought treatment for osteoarthritis, rising to almost half of people aged 75 and over.³⁶
- **Rising levels of obesity:** Trends project 11 million more obese adults in the UK by 2030 (compared to 2011).³⁷ There is a strong association between conditions of musculoskeletal pain and excess weight. Obesity is the single biggest avoidable cause of osteoarthritis in weight-bearing joints.
- **Rising levels of physical inactivity:** People in the UK are around 20% less active now than in the 1960s. If current trends continue, our population will be 35% less active by 2030.³⁸ Physical inactivity is a leading risk factor for global morbidity and accounts for 5% of disability adjusted life years (DALYs) in the UK.³⁹ Much of the UK population is at increased risk of developing a long-term musculoskeletal condition (e.g. osteoarthritis) due to their physical inactivity.⁴⁰

Key drivers of the changing state of healthcare

Healthcare for people with musculoskeletal conditions will change over the next 20-30 years in response to factors including:

- **Prevention:** Changes to population demographics are likely to place a growing demand on health and care services. In this context, preventative approaches will be increasingly important. As the NHS 5 Year Forward View stated 'to ensure the future health of the nation, a sustainable NHS and economic prosperity, we have to take preventative approaches seriously'. It called for a 'radical upgrade in prevention and public health'.⁴¹ In the case of musculoskeletal conditions, this means that a greater emphasis must be placed on modifiable risk factors (for inflammatory conditions: smoking; for conditions of musculoskeletal pain: injury, obesity and physical inactivity; for osteoporosis and fragility: smoking, alcohol intake, poor nutrition including insufficient vitamin D and physical inactivity).
- **New models of care:** The NHS Five Year Forward View emphasised the need to dissolve the traditional boundaries that exist within healthcare services (between primary care, community services, hospitals, mental health services and social care) and to establish new models of care which are integrated around people. In particular, it recognised that supporting people with long-term conditions requires an ongoing partnership model, rather than a system that responds to 'single, unconnected episodes' of care.⁴²

A broad range of new models of care are being introduced across the country, including, for example social prescribing services⁴³, integrated care pioneers⁴⁴ and the use of care navigators.⁴⁵ Across these models, one of the most important principles is to expand and strengthen primary and 'out of hospital' care. It is essential that all new models of care are robustly evaluated to provide an evidence base on those interventions which deliver the best outcomes and experience for people, alongside value for money.

- **Novel treatment options:** Research and innovation is expected to deliver a broader range of treatment options. In the musculoskeletal field, this has been seen previously in the revolution of biologic therapies developed from the early work on tumour necrosis factor (TNF) blockade for inflammatory forms of arthritis. Growing domains, such as stem cell and regenerative medicine in providing new avenues for cartilage repair offer great promise in the longer term, as do therapies that reverse autoimmunity and return the immune system to a state of self-tolerance. The role of dendritic cell-based therapies offers promise here.^{46,47}

Whilst new treatments, and increased treatment choice, are positive, the potential for more sophisticated treatments may also increase treatment costs. Treatment approaches are set to be increasingly stratified or personalised, through the increased use of genomics (and other 'omic' approaches) in diagnosis. (*See response to Question 3 on a wider definition of stratification*).

- **Patient and public involvement:** There is increasing public demand for people to be active partners in their own health and care, and to adopt a shared role in monitoring their health and taking decisions about their healthcare. Individual access to, and ownership of, health and care records as well as the increased use of health and fitness trackers (wearables) will contribute to this agenda. More broadly, the charity sector plays a key role in bringing the perspectives and priorities of patients around their healthcare needs and preferences together to inform the research agenda.
- **Cognitive computing and its impact on healthcare:** Cognitive computing involves 'self-learning systems that use data mining, pattern recognition and natural language processing to mimic the way the human brain works'.⁴⁸ Its goal is to create systems that are capable of solving problems without requiring human assistance. There is increasing recognition of the value of cognitive computing in healthcare, as seen in initiatives including IBM Watson Health.⁴⁹ This technology is already being applied in clinical trials matching and in supporting clinical decision making.⁵⁰ Arthritis Research UK is exploring its potential to support people with musculoskeletal conditions to access information to support self-management, through an on-line interface.

- **External context:** The long-term implications of Brexit on free movement of healthcare professionals across the EU (and therefore on healthcare system staffing) as well as on medicines pricing and availability remain to be determined.

3. In your view, what will be the major trends in health and healthcare in England over the next 20-30 years? (Going beyond your immediate area and expertise).

Major trends in healthcare that could support better people with musculoskeletal conditions over the next 20-30 years include:

- **Non-drug interventions:** There are a range of non-drug based interventions that people with musculoskeletal conditions use to manage their symptoms, improve their quality of life and to support their ability to live independently. These include manual therapies (particularly physiotherapy) and orthotics (including insoles, braces splints, callipers and footwear⁵¹) which have historically been grouped within NHS services, alongside physical activity and weight management services which fall within the wider remit of public health and which local authorities are mainly responsible for providing. Availability of these forms of intervention are not subject to the same requirements as drug interventions. For example, when the National Institute for Health and Care Excellence (NICE) approves a drug treatment, it must be provided by the NHS within three months. However, there is no equivalent process to ensure the timely or equitable provision of non-drug interventions. There is a need to extend the evidence base underpinning the use of non-drug interventions, and establish the economic case for their use. Greater emphasis should also be placed on non-drug interventions in national strategies such as the Accelerated Access Review (AAR).⁵² In addition, there should be a greater focus on the evaluation of physical aids which support or enable independent living.
- **Stratified healthcare:** There has been considerable attention on the growing potential of 'stratified', 'personalised', 'precision' or 'P4' medicine – based on the grouping of patients by risk of disease, or response to therapy, using diagnostic tests or techniques.⁵³ As such understanding increases, the power of patient stratification and precision medicine is advancing. These approaches offer the possibility of more targeted and effective treatments for individuals whilst also improving healthcare system efficiency. For example, in the musculoskeletal field, the MATURA consortium is working to identify biological and genetic markers in blood and joints which predict how patients will respond to anti-inflammatory drugs.⁵⁴

In addition to furthering these approaches, there is a need to take a broader view of the concept of 'stratified healthcare' and place greater emphasis on patient centred stratification approaches which direct people to the most effective forms of care, which may not necessarily be pharmacological. The STarT Back tool (a simple prognostic questionnaire that stratifies people with low back pain into matched treatment packages) is an example.⁵⁵

- **Supported self-management:** Self-management refers to the actions taken by people to recognise, treat and manage their own health, either independently or in partnership with the healthcare system.⁵⁶ Self-management approaches are particularly important for people with long-term conditions, who typically spend far more time managing their own health than they do in direct contact with the healthcare system. The Five Year Forward View recognised the increasing importance of supporting people to manage their own health and included a specific commitment to do more to support people with long-term conditions to help them manage their own health.^{i,57}

However, this is an area where stronger evidence is needed to guide the development and implementation of effective approaches. Research to develop more effective patient education and self-management programmes was recently identified as a recommended research focus

ⁱ 'We will invest significantly in evidence-based approaches such as group-based education for people with specific conditions and self-management educational courses, as well as encouraging independent peer-to-peer communities to emerge.'

area within 'RheumaMap: A research roadmap to transform the lives of people with rheumatic and musculoskeletal diseases.'⁵⁸

4. Are there any commonly discussed issues related to the future of health and healthcare in England which you believe to be overstated? If so, why do you believe them to be overstated?

- N/A

5. Are there any issues that are underrepresented in the debates around the future of health and healthcare in England? If so, please describe them and explain why you think they merit greater attention.

Issues of relevance to musculoskeletal conditions that are under-represented in relation to the future of healthcare in England include:

- **Pain:** Estimates suggest that 14 million people live with chronic pain in England alone and that 25% of them lose their jobs because of it.^{59,60} Much of this chronic pain (~70% by some estimates) is experienced by people with arthritis and other musculoskeletal conditions. For many people with arthritis, pain has a substantial impact on all aspects of life, causing significant disability, morbidity and mortality. Despite recent advances in the management of arthritis and improved outcomes for joint replacement surgery, ongoing moderate and severe chronic pain remains a substantial daily problem for a large proportion of people with arthritis. This pain lasts for decades, is poorly alleviated by current treatments (many of which have ongoing side effects) and is associated with fatigue and depression.

This is an area of clear unmet need: in terms of understanding mechanisms, developing effective treatments and empowering and enabling effective means for people to manage their pain on a daily basis. Tremendous untapped potential exists for new avenues of treatment and interventions to be explored and exploited.

Arthritis Research UK's 2018 'Pain challenge call'⁶¹ outlined the need for a future research agenda, in priority areas, to:

- Advance our understanding of musculoskeletal pain.
- Prevent, diagnose or evaluate the risk of developing musculoskeletal pain.
- Develop or test new approaches to treating and managing musculoskeletal pain and associated comorbidities, fatigue and mental health.
- Evaluate existing approaches to managing musculoskeletal pain, including the provision, delivery and organisation of health and social care services.⁶²

- **Microbiome:** The term 'microbiome' refers to the entire genetic material of microbial communities within the human body, including pathogenic and commensal microorganisms. As the complexity of the interplay between the microbiome and man are unravelled, new discoveries and important medical advances are likely and are already emerging.

Research on the microbiome has the potential to impact on a broad spectrum of health conditions. In the field of musculoskeletal disease, there is an increasing body of evidence demonstrating a link between the microbiome and inflammatory arthritis - specifically, studies have shown an altered microbiota in arthritis patients suggesting a role in the development of rheumatoid arthritis. However, the level of investment in this research field does not meet need. While there are significant potential benefits, much remains to be established.⁶³ Over the past two years Arthritis Research UK has supported catalytic pathfinder and programme awards in this growing area to stimulate new discovery, translation and avenues to harness the microbiome in novel treatments for arthritic conditions.⁶⁴

- **Rare autoimmune rheumatic diseases:** Rare diseases are those that affect less than 1 in 2,000 people.⁶⁵ Around 20% of rare disease are non-genetic and of these a substantial component are rare autoimmune rheumatic diseases. They fall into two groups: autoimmune

connective tissue diseases and systemic vasculitis.⁶⁶ A recent report, from the British Society of Rheumatology, cites the lack of an evidence base as a key barrier to introducing new treatments for these conditions into clinical practice. It recommended a collaborative cross-sector approach to research into rare rheumatic and musculoskeletal Diseases (RMDs), with a focus on epidemiological data and research into best practice in delivering care.⁶⁷

Specifically, this highlighted the need for:

- Strengthening of research in complex and/or severe autoimmune conditions.
- Research on how services can be managed to ensure optimal treatment for patients.
- An expansion in epidemiological research and in research partnerships with the pharmaceutical industry.
- Research for rare conditions to be better linked into the wider research community at a regional, national and international level.

- **Children and adolescents – and the transition to adult services:** The need to conduct research in children and adolescents is well recognised. Without it, 'child-specific treatments for diseases are not developed and diseases with no close analogies in adults are not studied'.⁶⁸ Consequently, the progress of clinical care for young people is held back. However, research involving young people can be limited by methodological challenges and other factors.

In the musculoskeletal field, children and adolescents with inflammatory rheumatological conditions continue to have significant, specific unmet needs, related not only to clinical care and the transition between paediatric and adult care settings, but also due to lack of knowledge and research specific to the biology, disease patterns and treatment responses.⁶⁹

In July 2015, the NIHR CRN: Children / Arthritis Research UK Paediatric Rheumatology Clinical Studies Group (CSG) set out a Clinical Research Strategy which identified the key clinical research priorities that would change clinical practice in paediatric rheumatology.⁷⁰

This remains an area where research has the potential to drive improvement in health outcomes. The Arthritis Research UK Centre for Adolescent Rheumatology (in partnership with Great Ormond Street Hospital, University College London and University College London Hospital, and with funding provided by Great Ormond Street Hospital Children's Charity (GOSHCC)) is a national leader in research targeting this age group.⁷¹

- **Health services research:** Health services research (also called 'health systems research' or 'health policy and systems research') examines how people get access to health care practitioners and health care services, how much care costs, and what happens to patients as a result of this care. This objective of this relatively young research field is to identify the most effective ways to organise, manage, finance, and deliver high quality care; reduce medical errors; and improve patient safety. As the burden of multi-morbidity grows (*see response to question 1*), health services research may play an important role in understanding how care can best be delivered to people with multiple health conditions.

Arthritis Research UK's 'Health Services Research Initiative' seeks to produce evidence on the quality, accessibility and organisation of health and care services relevant to people with arthritis, and to provide new knowledge on the benefits, costs and wider impacts of public health interventions. It covers four themes incorporating:

- health and care service improvement,
- health promotion/prevention,
- health economic evaluation, and
- health data intelligence and linkage.⁷²

We will seek to partner with other research funders to drive forward the generation of evidence leading to health service improvement.

- **Research infrastructure:** Alongside specific research fields, it is essential to ensure that the need for research infrastructure and support is also adequately represented in debates around the future of health and healthcare. There is a need for co-ordination across the UK's

- research ecosystem, and for continued international collaboration to maximise research potential.

Medical research charities contribute capital spending as well as directly funding research and should be included in future consideration of the overall research landscape. For example, Arthritis Research UK has invested in thirteen centres of excellence that span the spectrum of research into musculoskeletal health and disease and this considerable investment in capacity and infrastructure has leveraged considerably in terms of training, new expertise & skills as well as multi-disciplinarity of research teams.

Arthritis Research UK, June 2017

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