SUBMITTED ALONGSIDE RESPONSE ID: ANON-3JT5-V92X-Y

1) How can we best increase knowledge and understanding through research, including by achieving bigger breakthroughs?

Versus Arthritis is the charity formed by Arthritis Research UK and Arthritis Care joining together. We work alongside volunteers, healthcare professionals and researchers to develop breakthrough treatments, campaign for arthritis to be a priority and provide support. Our remit covers all musculoskeletal (MSK) conditions which affect the joints, bones and muscles.¹

Versus Arthritis welcomes the Government's vision for the UK to be a global science superpower and seeks that medical research charities are included in realising this vision. Charities are often the only funders in early-stage, preliminary research and Versus Arthritis was the largest UK funder of research into musculoskeletal (MSK) conditions in 2018. Investment from medical research charities is a vibrant component of the UK's world leading R&D base, supporting basic research through to clinical trials and translation. The unique position of many medical research charities as both patient organisations and research funders means that the impact of charity investment in UK R&D cannot be readily replaced by funding from other sources. We are also a member of the Association of Medical Research charities (AMRC) whose members have invested £14 billion in research in the UK since 2008, with £1.9 billion in 2019 alone.²

AMRC-funded researchers have responded flexibly and creatively to COVID-19 but charitable research has been profoundly affected.

 The proposed <u>Life Sciences-Charity Partnership Fund</u> will help protect the contribution charities can make to the Government's vision for UK R&D as independent, strategic funders of high-quality science and innovation.

Research co-development during the COVID-19 pandemic has demonstrated what can be possible when a 'whole patient' approach is adopted. Moving forward, Government investment must focus on patient need and the potential impact for beneficiaries. Whilst funding research to understand and tackle individual diseases will remain important, the Government must fund partnerships which address common platforms and mechanisms to achieve efficiencies of scale and maximise the impact of research investment. This includes recognition of the impact of multimorbidity and the issues experienced by the UK's ageing workforce and society must inform the Government's forward research agenda.³ For example, the MRC/ESRC/BBSRC-Versus Arthritis Advanced Pain Discovery Platform is Europe's largest ever single investment in pain research and will support large-scale and ambitious multidisciplinary consortia to pursue innovative, ambitious research questions in a 'condition agnostic' manner.

 The Government should promote research which addresses the complex interdependencies of multiple long-term conditions and prioritises their prevention. The Government must ensure a balanced combination of funding strategies to support basic discovery science, incremental, progressive R&D and high risk, high return R&D through a variety of funding mechanisms offering both responsive and challenge-led funding.⁴ Versus Arthritis has formed a partnership with NIHR to address chronic pain priorities in disease management and applied health research,⁵ while the Versus Arthritis MedTech proof of concept partnership with an Innovation and Knowledge Centre was critical to the early development of a bespoke technology package for complex knee surgery.

- Government support for partnership-building with and between charities will help develop and deliver the range of funding mechanisms required to drive successful outcomes from complex research challenges.
- 2) How can we maximise the economic, environmental and societal impact of research through effective application of new knowledge?

MSK conditions comprise more than 150 diseases and are the greatest cause of Years Lived with Disability (YLD) in the UK.^{6,7} MSK conditions affected an estimated 18.8 million people across the UK in 2017, and one in eight people in England report living with at least two long-term conditions, at least one of which is MSK related.⁸ Research in 2008 estimated that rheumatoid arthritis and osteoarthritis resulted in an annual economic cost of £30.7 billion.⁹

Despite this growing health burden, public funding for MSK research has been static since 2014 and would require a 2.3 fold (£200 million) increase to match disease burden. For example, the five year DHSC/PHE Strategic Framework for MSK health supported by Versus Arthritis recognises that the public health system is not as effective as it could be to prevent, maintain and improve MSK health, and activities to address this will require commissioning and influencing MSK public health research.

- Therefore, the Government must prioritise investment into R&D that delivers improvements on a quality of life basis and addresses common health conditions like arthritis which result in significant costs for individuals, employers, the health service, and the wider economy.
- This should include committing to an uplift in NIHR funding in line with uplifts in R&D expenditure.

Government investment in research implementation is essential to improve the success of embedding non-drug research interventions into healthcare settings. Simple, low-cost innovations can be transformational in healthcare but implementation is a complex, multi-faceted process. An evidence-based health and care system requires research commissioners to be responsive to metrics of implementation, with implementation strategies funded as a core element of healthcare research. The Versus Arthritis-supported STarT Back Tool, an example of evidence-based implementation of stratified care for non-sinister back pain, led to a significant reduction in disability and halved the time off work without increasing health care costs.¹²

- Support for health services research implementation is missing from the Accelerated Access Review and we await the Government's comprehensive guidance on Excess Treatment Costs (ETCs) which must provide clarity on financial support for trialling non-drug and primary/community care interventions.
- We ask the Government to recognise that implementation of non-drug innovation requires dedicated time and coordination from healthcare professionals and this requires committed funding as part of the wider R&D strategy.

Bold questions must be chosen and investigated within the right environment. The Council for Science and Technology recommended that when seeking highly ambitious breakthroughs, 'people, process and governance structures' will be critical for success. ¹³ A lack of translation of biomedical research into health and social care innovation is widely recognised and Versus Arthritis welcomes the creation of an ARPA-style body to boost transformative-style research in the UK. ¹⁴ We note the recent recommendations of the Council that some challenges do not require new research and innovation, but instead require implementation through public engagement, trust and regulation. ¹⁵

- Charities can work with Government as facilitators of implementation to maximise the economic, environmental and societal impact of research.
- 3) How can we encourage innovation and ensure it is used to greatest effect, not just in our cutting-edge industries, but right across the economy and throughout our public services?
 - Versus Arthritis welcomes the Government's commitment to an Innovation Expert Group and seeks that medical research charities are represented within the Group to ensure their distinct knowledge and experience of collaborating across the UK Life Sciences sector is included.

Data is essential in driving improvement in MSK health at a local and national level. We welcome NHSX's vision of researchers being viewed as an integral part of a modern and digitised NHS.¹⁶

• To achieve this the Government must deliver urgent improvements in the quality and availability of data about MSK conditions.

The Versus Arthritis Centre for Epidemiology uses innovative research to advance the use of digital data and improve its analysis in epidemiology. Versus Arthritis funded the REmote Monitoring of Rheumatoid Arthritis (REMORA) project which was the first study to demonstrate that patient-reported symptoms can be collected using a smartphone app and successfully transferred directly into NHS electronic health records.¹⁷ In partnership with the Nuffield Foundation we fund research to collate data from GPs, rheumatologists, social care and community service providers, patients and the wider population.¹⁸

 The expertise and public trust in relation to health and care data held by medical research charities must be harnessed by the Government to fully maximise outputs from public R&D investment.

Innovation flourishes in an area of early adoption, but better metrics of societal gain are needed, with real-time, real-life data used to validate impact. The NHS Long Term Plan proposes a new scheme to ensure patients benefit from faster uptake of proven affordable innovations including health tech products. Versus Arthritis agrees that the NHS must become a place of early adoption whether for a device, a model of patient care or a virtual software package. We welcome the Government's commitment to reduce bureaucracy and tackle regulatory barriers as a means to improve uptake and validation of research outputs.

The BioIndustry Association estimates that private investment in R&D needs to increase by 70% to meet government targets towards R&D spend at a rate of 2.4% of GDP by 2027 and argues that partnership is essential to bridge the 'valley of death'.²¹ It is important to consider how public funding should be used to crowd in private funding, help incentivise industry co-investment and sustain the flow of ideas from the research base into commercial uses.²²

The medical research charity sector is distinctive in that it catalyses and supports the whole research ecosystem and thrives on partnership.²³ Charities like Versus Arthritis empower patients to manage their own condition through research solutions and innovative commercial products. For example, Arthr is a stand-alone commercial venture originating from Versus Arthritis innovations and links solutions-focussed research activities with commercial opportunities; championing innovation to help people live better with arthritis.²⁴

- The Government should ensure that Innovate UK and other vehicles for public R&D investment are equipped and accessible to medical research charity ventures which maximise delivery of social capital.
- 4) How can we attract, retain and develop talented and diverse people to R&D roles? How can we make R&D for everyone?

In 2019, medical research charities funded over 17,000 researcher salaries in the UK, including 1,750 PhD students.²⁵

 Medical research charities must be involved in the development of the proposed R&D People and Culture strategy.

Versus Arthritis is building a world-class workforce by supporting research careers and increasing skills capacity within the MSK research community. Versus Arthritis currently supports a portfolio of 79 live fellowship awards across five core fellowship schemes: three at early career stages (£8.7 million); and two at mid to late career stages (£14 million). 86% of our fellowship alumni from the past ten years were research active in 2019 and at least 15% of Versus Arthritis Fellows were Professors within their MSK specialty in June 2020. However, attracting diverse professions into clinical MSK research and retaining senior clinical researchers is challenging despite a range of suitable funding mechanisms.

Research funding is unbalanced across career stages with substantially more early career research opportunities compared to mid-career which risks the loss of talented researchers from the sector. This issue is predicted to increase as a result of COVID-19 as universities are put under financial pressure and stop recruitment of new lectureships. An increasing focus on challenge-led research calls impacts early career researchers who require funding before they can produce preliminary data and compete with more established researchers.

There was a modest decline in the proportion of clinical academic NHS medical consultants between 2004 and 2017.²⁶ Rheumatology was one of nine specialities with less than 50 clinical Fellows in 2017, and among those, there was a lack of senior academic leaders. Flexible new ways of engaging with clinical research are required to create a health system can optimise engagement with research and provide dedicated research time for NHS staff while building practical research capacities through healthcare curriculums and incorporating flexibility into postgraduate training.²⁷

• The Government must increase support and incentives for clinicians that have obtained a PhD to remain on a clinical academic career path.

Versus Arthritis is delighted that its individual fellowships are eligible for fast-track endorsement within the Global Talent visa Exceptional Talent and Exceptional Promise categories.

 Versus Arthritis supports recommendations from the charity sector calling on the UK Government to ensure that visa costs do not reduce the attractiveness of the UK to the world's scientists and researchers.²⁸

As the UK leaves the EU, the future immigration system which the Government has committed to develop must enable the UK to attract, recruit and retain global scientific talent at all professional levels, and to continue collaborating with international partners. It is in the best interests of the EU and UK for research workers to be able to travel easily to work and share expertise. Reciprocal arrangements between the UK and the EU will be fundamental to smooth functioning of research programmes and should be addressed as part of ongoing negotiations relating to the UK's participation in Horizon Europe.²⁹

 The Government must agree and introduce reciprocal mobility arrangements with the EU to support future research programmes.

5) How should we ensure that R&D plays its fullest role in levelling up all over the UK?

Medical research charities fund activity in every region of the UK and last year almost half of charity funding was spent on research outside of London and the South East.³⁰

 Versus Arthritis welcomes the Government's commitment to establish an R&D Place Advisory Group and seek medical research charity

representation to ensure their distinct knowledge and experience of collaborating across the UK Life Sciences sector is included.

Versus Arthritis recognises the importance of funding excellent science regardless of geographical location, building on regional strengths and national collaborations. Versus Arthritis has established 13 Centres of Excellence, each focussing on discrete MSK research challenges ranging from genetics and epidemiology to biomechanics and primary care; from sport and exercise to health and work; from adolescence to ageing.³¹ Versus Arthritis Centres of Excellence includes institutions from across England, Scotland and Wales. Seven Centres comprise multiple partners; three include NHS Hospital Trusts. The Centres involve 14 institutions in Northern England and eight in Southern England, which includes six in London and the Golden Triangle. Three Versus Arthritis Centres are funded in partnership to maximise their reach and impact; two with MRC and extra support from the host institutions and one with Great Ormond Street Hospital Children's Charity.

6) How should we strengthen our research infrastructure and institutions in support of our vision?

Versus Arthritis recognises the Government's commitment to work with other funders to consider opportunities to fund a greater proportion of the full economic cost of research projects in universities. Along with AMRC and other medical research charities, we are committed to working in partnership with government to continue funding vital research for patients and the public and to ensure no reduction in the strength and capacity of the UK's world-leading research base.

 The proposed <u>Life Sciences-Charity Partnership Fund</u> will help protect the contribution charities can make to the Government's vision for UK R&D as independent, strategic funders of high-quality science and innovation.

87% of all AMRC charity funded research takes place in universities.³² The nature of strategic institutional support allows universities to adopt internal allocation mechanisms which pursue their strategic priorities, further incentivise research excellence and deliver the best return on investment.³³ The Charity Research Support Fund (CRSF) underpins charity investment in university research across England and enables researchers who receive charitable funding to recover costs of research that charities do not pay. Medical research charities are committed to continuing to work in partnership with government through the CRSF to ensure the sustainability of charity-funded research in universities. However, charities are concerned by the failure of the CRSF to keep pace with growing levels of charity investment (excluding the impact of COVID-19). This is challenging the sustainability of charity-funded medical research in universities.

 As part of the R&D plan, and focus on research sustainability brought by the pandemic, Government should invest in the CRSF to bring it in line with current levels of charity investment and protect the unique partnerships between universities and charities. It is important to recognise that COVID-19 has resulted in a challenging time for medical research charities and any increase in the proportion of Full Economic Cost (FEC) which charity funders are required to pay could exacerbate this.

 The unique position of charitable funders should be recognised and reflected in future discussions or reviews relating to FEC of university research.

7) How should we most effectively and safely collaborate with partners and networks around the globe?

Effective collaboration first requires identification of the best expertise in the world, followed by development of the most appropriate means to bring it together to address a research challenge. An example of this is the Centre for Sport, Exercise and Osteoarthritis Research Versus Arthritis which is based at the Nottingham Universities Hospitals NHS Trust in conjunction with the Universities of Oxford, Southampton, Bath, Loughborough and Leeds. The consortium is strengthened by several international collaborators, utilising expertise from Sweden, the Netherlands, Australia and USA.

Across the EU, the Innovative Medicines Initiative (IMI) is the world's biggest public-private research partnership, with MSK priority diseases represented across a number of IMI programmes.³⁴ Versus Arthritis is a partner in IMI-APPROACH – an applied public health research project involving international companies, universities, research organisations, public bodies, non-profit organisations and SMEs. IMI-APPROACH will establish an osteoarthritis platform containing data from over 10,000 patients and healthy volunteers to support clinical trials for personalised treatments.³⁵

 Participation in future IMI funding rounds will be jeopardised unless the UK secures full association to Horizon Europe as domestic organisations, including charities like Versus Arthritis, will be less attractive partners for EU-based collaborators.

The UK contributed to nearly 20% of total EU health programme research in 2007-2016. MSK research in the UK has improved health & clinical outcomes across the EU and globally. Versus Arthritis-funded research pioneered the treatment of rheumatoid arthritis with biological agents and UK researchers are involved in almost all rheumatoid arthritis research programmes at EU level.³⁶

Versus Arthritis agrees with AMRC and others that Horizon Europe association should be a core part of the future relationship of EU & UK for research not least because clinical trials are reliant on EU-UK collaboration, close research partnerships accelerate life changing medical research and shared global challenges require joint solutions.³⁷

 Full UK association to Horizon Europe, with as few restrictions on access as possible, must be at the heart of any EU-UK science deal. The impact of poor MSK health on individuals and society globally is profound with around 1 in 3 people worldwide living with chronic MSK conditions. There is a demographic shift globally with people from all countries living longer with chronic disease. The burden shift is from communicable to long-term non-communicable disease, which commonly includes MSK conditions. Global leadership is urgently required to address this global health challenge.³⁸

- Versus Arthritis calls on the Government to support community-wide engagement to gather UK best practice and implement an effective mechanism for UK researchers to engage with Low and Middle Income Countries as their incidence of MSK conditions increases.
- 8) How can we harness excitement about this vision, listen to a wider range of voices to ensure R&D is delivering for society, and inspire a whole new generation of scientists, researchers, technicians, engineers, and innovators?

Medical research charities act as a direct link between the public and R&D, supporting a pipeline from basic research to translation and implementation. Charities increasingly put the patient's voice at the core of their mission and use the delivery of patient outcomes as the touchstone of every decision.³⁹

Charity funders offer unique opportunities for people with lived experience of their condition and their representatives to contribute to the co-design and prioritisation of publicly-funded research activities. Versus Arthritis published A Research Roadmap for Pain – a paper co-produced by people living with pain, healthcare professionals and researchers.⁴⁰ People with arthritis were the driving force behind this roadmap and played a pivotal role throughout the project.

A Versus Arthritis UK-wide survey highlighted the significant impact of COVID-19 on people with arthritis' physical and mental wellbeing, along with a need for improved support, information, and advice. As a result, Versus Arthritis launched a UK-wide campaign to ensure that people with arthritis and MSK conditions are a priority at national and local level as part of COVID-19 recovery. 15,000 people supported the 'Impossible to Ignore' campaign within the first two weeks of its launch.

Public awareness of R&D is high, with 72% of people saying they know what it is and 86% able to identify the most straightforward examples.⁴¹ However, a sometimes narrow perception of R&D was identified as a risk for the sector. Supporting researchers to tell their story will be an essential factor in increasing public awareness of the tangible benefits R&D can offer throughout society.

We agree that there is a need to inspire a new generation into STEM roles, and ensure the UK has a diverse, skilled & motivated workforce. Versus Arthritis recognises that achieving a successful research culture will require collective responsibility and change at all levels, and welcomes opportunities to collaborate with new Government initiatives to support this.⁴²

• Government should involve medical research charities in developing its comprehensive R&D plan, harnessing their understanding of the

system, their expertise in talking to the public and patient communities about R&D and the public's trust in charities.

 Government should ensure that the views of patients and the public are sought out and included in any decision making processes in the comprehensive R&D plan that will affect them.

We would be pleased to discuss any of the above submission in more detail.

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