

Summary

Medical research charities are a key pillar of the UK's globally competitive life sciences sector and are well placed to deliver on the Government's Spending Review ambitions. Charities respond to the research priorities of the British people; make life better and healthier for people across the UK; and bring in investment to deliver innovation and growth.

For medical research charities to be able to help the Government build back better, the Government must provide support and investment in two main areas:

1. Investing to sustain a diverse life sciences ecosystem

We welcome the Government's ambition to cement the UK's position as a scientific superpower. Previous investment in science enabled the UK's rapid response to the COVID-19 pandemic. The UK's research base is globally competitive because of the unique diversity of funders. The best way to meet the government's 2.4% commitment now is to support a robust ecosystem for the life sciences, which allows government, industry and medical research charities to invest with confidence in a sustained way. Charities have been badly hit by the pandemic, and so an effective partnership between government and charities is more important than ever to ensure the sector stays strong.

We call on the Government:

- **to continue short term financial support for charity-funded early career researchers over the next 3 years to sustain the talent pipeline.**
- **to continue to prioritise block grant funding to universities through QR, and to maintain and boost the Charity Research Support Fund to safeguard charity-university partnerships.**
- **to ensure that medical research charities are part of crucial discussions about the long-term sustainability of research in universities.**
- **to work with charities and universities to ensure that the CRSF is as transparent and effective as possible for all parties.**

2. Investing to advance clinical research

We welcome the Government's ambition to make the UK the best place in the world to develop and test new treatments and technologies. Investment is needed to deliver on the commitments of the Life Sciences Vision and the UK Clinical Research Delivery plan, to embed research across the NHS, attract commercial investment and improve patient care.

We call on the Government:

- **to invest £775 million in clinical research to deliver the ambitions of the Life Sciences Vision and to make the UK a global life science hub.**
- **to invest the £400 million needed to unlock the potential of data for R&D, and to support both infrastructure and effective engagement.**

Charities have a vital role to broker partnerships and help deliver the key health challenges of the Life Sciences Vision. The Government has committed to provide an additional £22 billion by 2024 to cement the UK's position as a science superpower. **Supporting charitable funding is a good investment decision for Government, to deliver on the priorities of SR21, to accelerate health impacts from research, and to improve the lives of people across the UK.**

The Association of Medical Research Charities (AMRC)

AMRC is the membership organisation of the leading medical and health charities funding research in the UK. We represent over 150 medical research charities of a variety of sizes; from household names such as Cancer Research UK, Wellcome and the British Heart Foundation to smaller charities who invest in specific areas of unmet need. Over the past 10 years AMRC charities have spent £14.5 billion on research in the UK, supporting nearly half of all publicly funded medical research. Charities have a crucial role in the life sciences ecosystem, driven by patient priorities and tackling areas of unmet need to accelerate the delivery of health benefit.

Many of our members are submitting separate responses to the Spending Review, focusing on the needs of their specific disease areas and the impact of the COVID-19 pandemic and backlog on treatment and research. In this response, we look at sector-wide issues, how medical research charities can help deliver the Government's priorities, and the support that will be needed to make it possible.

Introduction

“The single most important thing... that I've learnt is the massive benefits to our country, to our society, to our economy of investing in science.”

*Prime Minister Boris Johnson, 7 July 2021
Science & Technology Committee on the response to the pandemic*

The COVID-19 pandemic has demonstrated the crucial importance of a strong research base to enable a rapid response. The UK's world-class scientists have informed public health decisions, scaled up diagnostics, trialled treatments and interventions, and developed new vaccines, all within unprecedented timescales. Never has the impact of investment in research and innovation been more apparent.

We are therefore strongly supportive of the Government's commitment to cement the UK's position as a global scientific superpower. The ambition to reach 2.4% of UK GDP invested in R&D by 2027 is welcome, and the commitment to significantly increase public investment in research to £22 billion by 2024-25 is an essential first step to deliver it.

Alongside government and industry funders, medical research charities are a key pillar of the UK's globally competitive life sciences sector. Charities have a crucial role to support the Government deliver on the priorities of Spending Review 2021, by responding to the priorities of the British people, ensuring that research is used to make people's lives better and healthier across the country, and by bringing in investment to deliver innovation and growth.

In order for medical research charities to be able to help the Government to build back better, the Government must provide support and investment in two main areas:

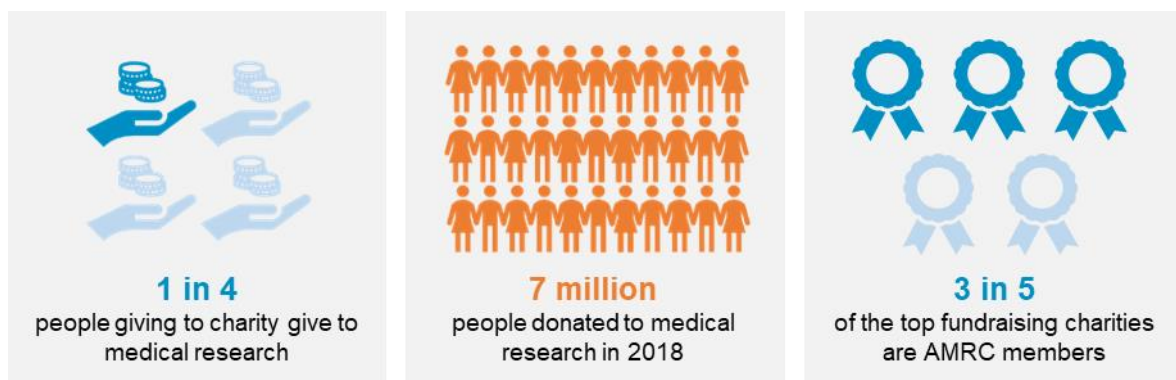
- to sustain a diverse life sciences ecosystem
- to advance clinical research and deliver the ambitions of the Life Sciences Vision.

Now is the time to deliver the investment needed to translate the Government's exciting vision for life sciences into real benefit for patients, society and the economy.

Medical research charities can deliver on the Spending Review ambitions

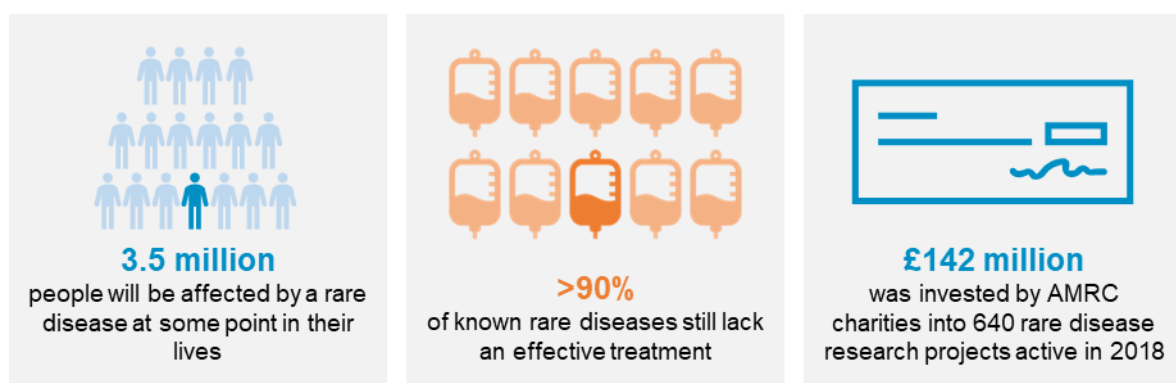
Charities respond to the priorities of the British people

Charity funding is the only form of research funding which is directly informed by the public. Every year, British people choose to donate hundreds of millions of pounds to fund medical research. Charities therefore play a vital role in connecting the public with R&D and can target investment into conditions that matter to British people, such as cancer and cardiovascular disease ([see case study: Investing in the North of England to address health inequalities](#)).



Sources: CAF (2019) CAF UK Giving 2019: An overview of charitable giving the in UK; Charity Financials (2017) Top 100 Fundraising Charities Spotlight

People often choose to support research on conditions and diseases where there is unmet need. Rare diseases devastate lives but the small numbers mean there is little investment. 67 AMRC charities fund research on rare diseases, and 27 exclusively fund research into a rare disease ([see case study: Making a difference for rare diseases](#)).



Source: AMRC (2019) Spotlight on Rare Diseases

Investing in the North of England to address health inequalities

Every week in Yorkshire, 592 people are diagnosed with cancer. People living in the region are more likely to develop cancer than anywhere else in England. **Yorkshire Cancer Research** aims to close the gap between Yorkshire and the rest of England, contributing to the government's 'levelling up' agenda, by funding pioneering research to save lives in the region. In each of the years to March 2019 and 2020, people chose to donate approximately £5 million to the cause, which is complemented by revenue share from the commercialisation of a cancer therapy based on underpinning work funded by Yorkshire Cancer Research in the early 2000s. The charity is currently able to support a range of research programmes and services, including two major clinical trials at the University of Sheffield, to explore ways to improve early detection of bladder cancers and new prostate cancer treatments. During 2019/2020, over two-thirds of people recruited to cancer specific clinical trials in Yorkshire were taking part in trials funded by Yorkshire Cancer Research. The charity aims to invest £10 million every year to tackle Yorkshire's biggest cancer problems.

Making a difference for rare diseases

Duchenne muscular dystrophy (DMD) is a rare genetic muscle wasting disease, usually diagnosed in early childhood and affecting 2,500 people in the UK today. **Duchenne UK** have invested more than £9 million in DMD medical research over the last ten years, including funding pre-clinical research into a gene therapy that is now being tested in the clinic. Duchenne UK proactively invests at every stage of drug development, to overcome barriers and get treatments to patients as quickly as possible. For example, to address the lack of clinical trials for DMD available in the UK, they set up the DMD Hub, a network of trial sites where they funded additional staff to run clinical trials under a pump-priming model to ensure sustainability. Duchenne UK have also launched Project HERCULES, which unites 8 leading pharmaceutical companies as well as regulators, academic, patients and clinicians to create data and tools to ensure patients can access available treatments quickly.

Charities deliver health benefit for patients

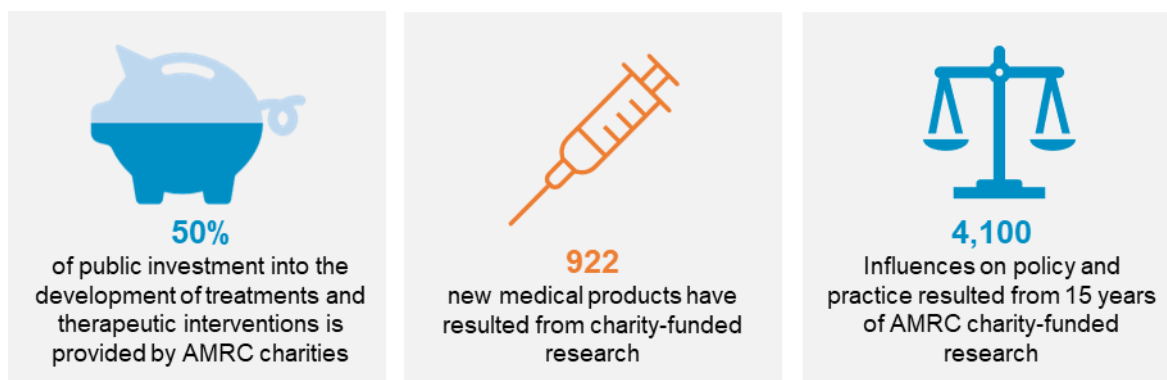
Medical research charities are mission driven, investing strategically where there will be greatest health impact. Charities cover the whole spectrum of research to tackle a condition, from basic research through to uptake of innovation in the NHS, and demonstrably improve patient outcomes and make life better and healthier for people (see [Key products and interventions supported by charity funding](#)).

Charities are particularly effective funders because they:

- **Bring a sense of urgency.** There is no time to lose, especially when a disease is life-limiting or affects children, and so charities focus on investment to identify and remove barriers and roadblocks to accelerate delivery (see [case studies: Investing in underpinning enablers to accelerate research; Making a difference to rare diseases](#)).
- **Focus on cost-effective research.** Often with limited resources, charities make targeted investments to ensure value for money, for example exploring the

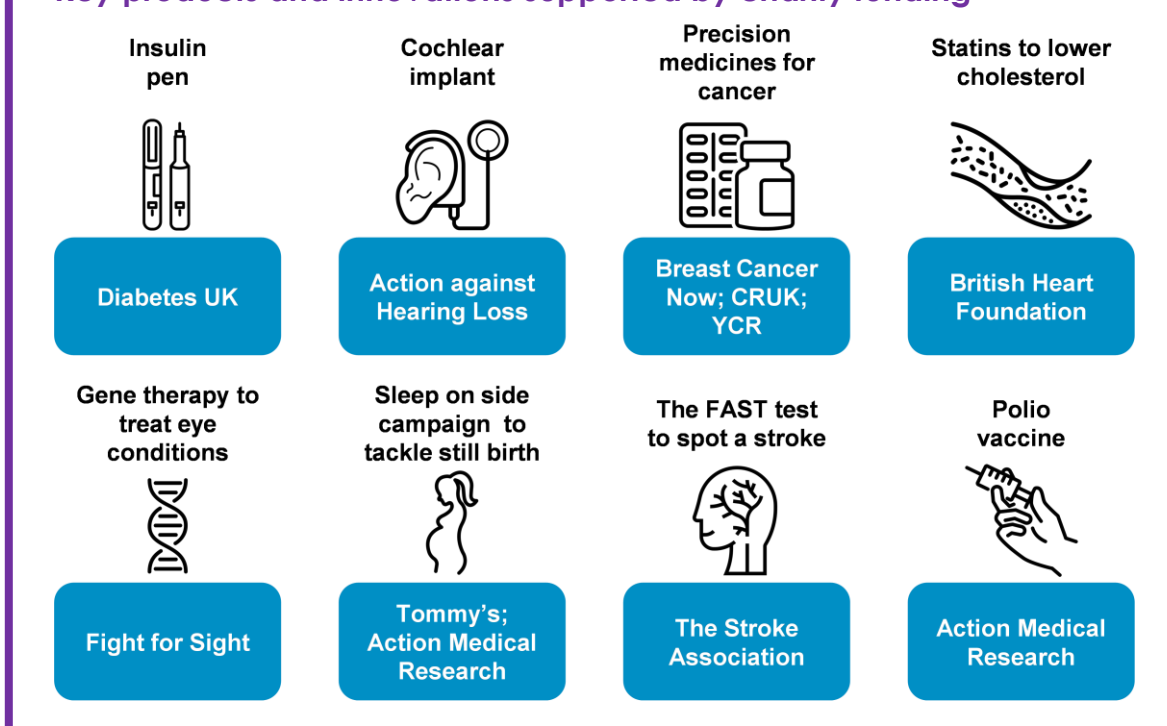
repurposing of existing drugs (see case study: Repurposing medicines to help patients quicker).

- **Are directly connected with patients.** 83% of AMRC charities use patient voice to help shape their research strategy.ⁱ This means that funding is directed where it will make the most difference to patients (see case study: Focusing on chronic pain). Involving patients also ensures more efficient development of treatments and can increase the uptake of products (see Key products and interventions supported by charity funding).



Sources: AMRC (2020) Without Charities; AMRC (2021) Medical research charities: our sector's footprint in 2020; AMRC (Forthcoming) Making a difference: Impact report 2021

Key products and innovations supported by charity funding



Investing in the underpinning enablers to accelerate research

Around 10,500 people in the UK live with cystic fibrosis (CF), a life-limiting, inherited disease. As the largest charity funder of CF research in the UK, the **CF Trust** invests £4.7 million a year on studies to tackle the underlying cause, and to understand and treat the symptoms. As well as directly investing in research projects, the charity also focuses on supporting the underpinning infrastructure that is needed for research. For example, they created and manage a Clinical Trials Accelerator to enable hundreds of people with CF to take part in clinical trials across the UK. The Trust also runs the UK Cystic Fibrosis Registry which holds data, with consent, from over 99% of people with CF in the UK. This is essential to monitor the safety and efficacy of treatments, making it possible to provide access to Kaftrio and other life-saving drugs through the NHS. The Registry has also been used to deliver a randomised trial comparing interventions for children in the UK, and for research using AI to predict the risk of worsening symptoms.

Repurposing medicines to help patients quicker

Many charities now explore the opportunities of drug repurposing – finding new uses for existing medicines. This can significantly reduce the costs and time taken to identify new medicines for patients, as highlighted when the RECOVERY trial identified dexamethasone and tocilizumab as effective treatments for COVID-19. **Cure Parkinson's Trust** set up the International Linked Clinical Trials initiative, which screens drugs already approved and available for other conditions and prioritises ones that might be effective treatments for Parkinson's. The initiative has screened over 2000 drugs since 2012 and has been instrumental in bringing 15 promising drugs to trial. A phase 2 study funded by **Parkinson's UK** has also shown that rivastigmine, a commonly prescribed dementia drug, could help prevent falls and improve the quality of life for people with Parkinson's. This has now progressed to phase 3 trials, and has benefitted from rapid progress through clinical trials due to its existing safety data.

Focusing on chronic pain

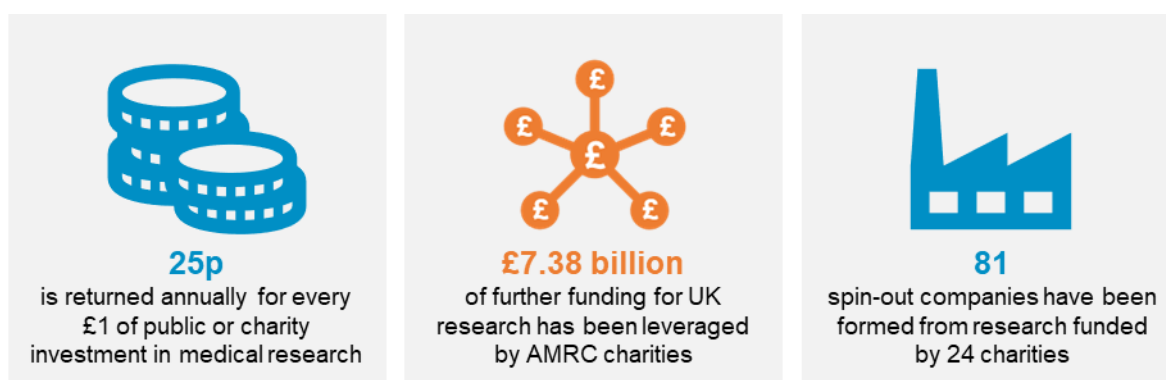
Based on in-depth consultation with people living with musculoskeletal condition, **Versus Arthritis** refocused its research agenda to tackle chronic pain. Chronic pain is estimated to affect up to 28 million people in the UK, but there is still no effective treatment and the impact of musculoskeletal pain on the workforce has huge socioeconomic implications. Working with people living with pain, healthcare professionals, and researchers, Versus Arthritis developed a Roadmap for Pain, identifying key research challenges that need to be addressed to understand, treat and prevent pain. Versus Arthritis brought together a coalition of funders from charity, public and private sectors to invest in tackling the problem. For example UKRI, Versus Arthritis, the Medical Research Foundation and Eli Lilly have partnered to develop the Advanced Pain Discovery Platform, a five year, £28 million initiative. This is the single largest and most ambitious programme of pain research across Europe, including a national pain data hub for research services with Health Data Research UK. NIHR and Versus Arthritis also launched a joint funding programme, supporting research to reach diverse and under-represented groups, who are particularly impacted by musculoskeletal pain, and to develop new approaches to help people maintain healthy working lives.

Charities help to crowd in industry funding

Charities provide funding for early stage (often high risk) research, de-risking it so that other funders can then engage and deliver benefits. For example, they often support pilot studies and demonstrator trials to test the feasibility of innovative approaches, making it more attractive for industry to invest (see case study: [Working with industry to improve respiratory diagnosis](#)).

They also invest in the resources and data assets needed to underpin research in specific disease areas, supporting many breakthroughs that would not otherwise have been possible (see case study: [Investing in underpinning enablers to accelerate research](#)).

Charities convene partnerships, bringing researchers and industry together with patients in a unique way to focus on the specific challenge.ⁱⁱ They actively facilitate the commercialisation of discoveries by creating spin-outs and partnering with industry (see case studies: [Driving translation and industry investment](#); [Building an alliance to accelerate drug discovery](#)).



Sources: Glover et al., (2018) Estimating the returns to United Kingdom publicly funded musculoskeletal disease research in terms of net value of improved health outcomes; AMRC (Forthcoming) Making a difference: Impact report 2021

Working with industry to improve respiratory diagnosis

Asthma UK has been working with Innovate UK to develop accurate, low-cost tests to diagnose asthma. Currently, there are still no tools to accurately diagnose asthma or its sub-types which leads to significant problems both with under- and over-diagnosis. The NHS needs simple and reliable tests to identify what type of asthma someone has, so that doctors can tailor treatments to control symptoms more cost-effectively. Asthma UK and Innovate UK have brought together academics, pharmaceutical companies, diagnostics firms, and patients to tackle this challenge, hosting a series of workshops and a dedicated joint funding call.

Building on this work, Asthma UK & British Lung Foundation and DHSC have now funded a £1.3 million programme to develop a national research platform to rapidly evaluate new tests to diagnose COVID-19 infection (the CONDOR platform), and improve the accuracy and speed of diagnosis of respiratory conditions.

Driving translation and industry investment

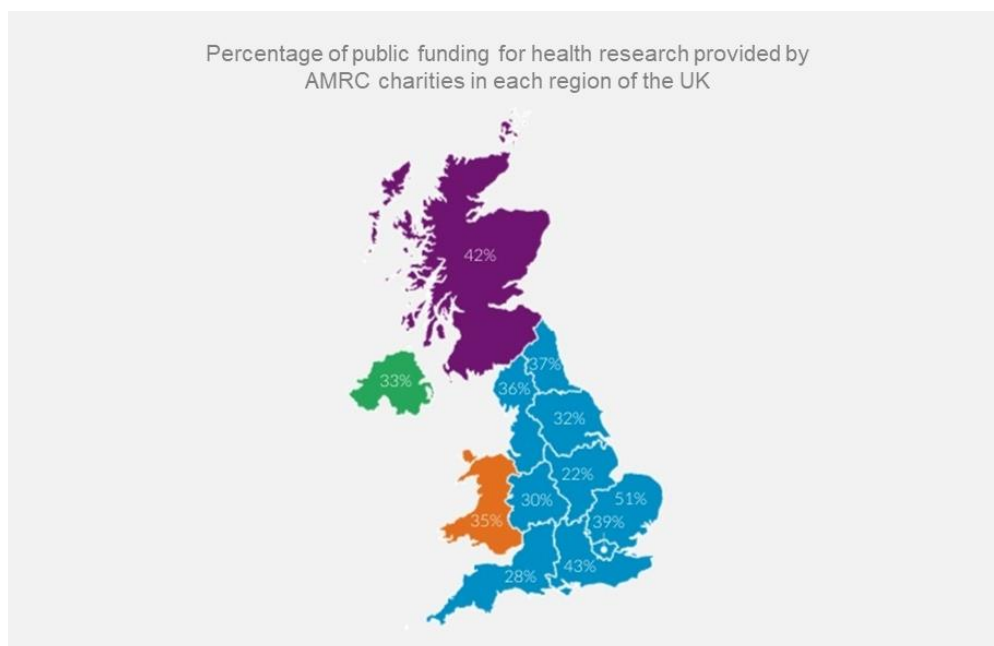
Cancer Research UK is the second biggest licensor of new cancer medicines globally, fuelling the pipelines of large and medium sized pharmaceutical and biotech companies. Their work with industry has yielded 10 major alliances for therapeutic drug discovery and 11 marketed cancer drugs that have treated hundreds of thousands of patients around the world. The charity has been involved in the formation and development of over 60 companies, raising over £2.3 billion in total.

Building an alliance to accelerate drug discovery

In 2015 **Alzheimer's Research UK** set up a £30 million Drug Discovery Alliance to bridge the gap between discovery science taking place in universities across the UK and drug development expertise in pharmaceutical companies. Researchers at three institutes, at the universities of Oxford, Cambridge and University College London, are working with industry to translate new findings from academic research into potential treatments as quickly as possible. The Drug Discovery Alliance is now one of the largest and most coordinated efforts to find new drugs for dementia. The Alliance works in tandem with the Dementia Consortia, a partnership between Alzheimer's Research UK, world leading pharmaceutical companies and partner contract research organisations. The Consortia teams up leading researchers in universities across the world with UK-based drug discovery experts, funding research for novel targets and treatments for dementia.

Charities are delivering on the 'levelling-up' agenda

Medical research charities fund research in every region of the UK and play a key part in making people's lives better across the country. Nearly half of charity funding was spent on research outside of London and the South Eastⁱⁱⁱ (see map and case study: [Investing in the North of England to address health inequalities](#)).



Source: Analysis of UKCRC (2020) UK Health Research Analysis 2018 (map created in Visme)

Charities also invest in common conditions where there is low investment but significant need, for example mental health. Over a quarter of public funding into mental health research is provided by AMRC charities. Charities are particularly well placed to support research to ensure healthier lives for everyone, to tackle multiple long-term conditions and to help address the health inequalities across the country (see case studies: [Supporting mental health research](#); [Tackling health inequalities](#)).

Supporting mental health research

One in four people are affected by a mental illness each year, but only 6% of public spend on medical research goes into mental health. **MQ Mental Health Research** is the first major charity exclusively funding scientific research into mental health, investing over £21 million since 2013 into projects across different scientific disciplines and conditions. MQ's work has led to several important contributions, including the MQ Adolescent Data Platform, a data resource for researchers and policymakers to drive improvements in young people's mental health, the development of a novel way to create 3D brain circuits in a lab dish to investigate the biological basis of mental health and the development of a screening tool that predicts which young people are most at risk of developing depression. Most recently, MQ has helped to shape a road map for research into the neurological and mental health impacts of the COVID-19 pandemic.

Tackling health inequalities

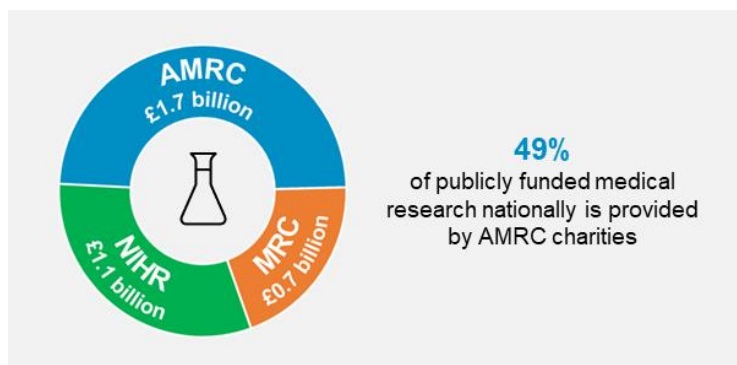
Ethnic background can affect the risk of common diseases and conditions, including heart disease and diabetes. Work funded by The **British Heart Foundation** (BHF) has highlighted systemic health inequalities. For example, by working with people in the London boroughs of Brent and Southall since the 1980s, researchers have investigated why diabetes is more common in certain ethnic groups. They have shown that people from a South Asian or African background are twice as likely to develop type 2 diabetes before the age of 80 than White Europeans. During the Covid-19 pandemic, the BHF also funded research to explore which genetic, demographic and lifestyle factors related to cardiovascular health are important in the increased risk of severe consequences of COVID-19 infection.

Building on the UK's genomic capabilities to respond to COVID-19

Building on the UK's genomic capabilities, the medical research charity **LifeArc** has provided £5 million funding to support the work of the GenOMICC COVID-19 study. In partnership with Genomics England, and with additional funding from DHSC, researchers will investigate the genetic risk factors that mean some people are affected more severely by COVID-19. LifeArc's funding will support the costs of patient enrolment and sample acquisition to enable rapid insights to help find new treatments.

1. Investing to sustain a diverse life sciences ecosystem

To deliver the UK's Plan for Growth, and achieve investment levels of 2.4% GDP, will require a diverse range of funding sources. The UK's life sciences sector is globally competitive because of the multiple funders that support it, including significant investment from medical research charities. AMRC charities provide half (49%) of publicly funded medical research nationally, investing £1.7 billion in medical research in 2020. This diversity is a key factor that sets the UK apart, with the contribution of medical research charities particularly unique in comparison to other countries.



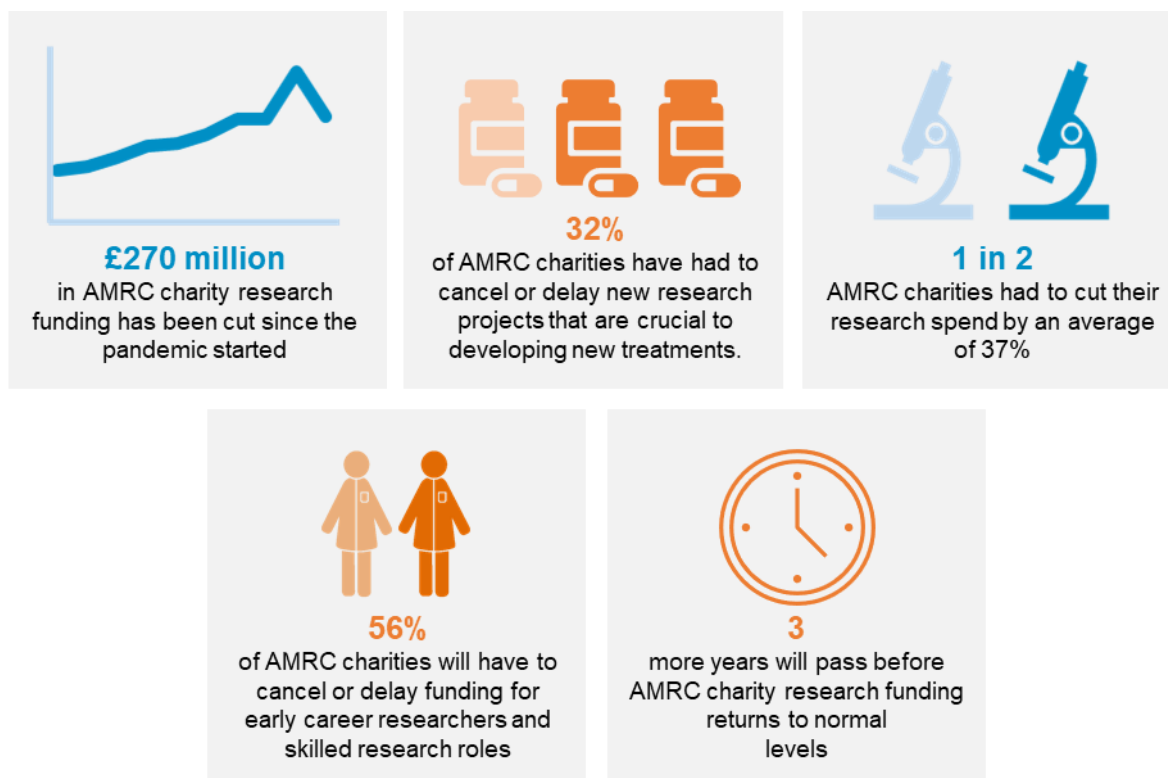
Source: AMRC (2021) Medical research charities: our sector's footprint in 2020

The rapid response to the COVID-19 pandemic was only possible because of previous and sustained investment in the UK research base from multiple sources. For example, ongoing Government and charity support for genomic sequencing over many years enabled the UK to become the world-leader in sequencing the SARS-CoV-2, with the COVID-19 Genomics UK Consortium pioneering large-scale, rapid whole genome sequencing to understand viral transmission and evolution.^{iv} The extraordinarily fast development of a COVID-19 vaccine by the team at Oxford built on several decades of investment, from both MRC and Wellcome. The researchers had already used the same vaccine technology to produce candidate vaccines against other pathogens, including flu, Zika and MERS, giving them a head start in the race to develop a vaccine, which could then be picked up by AstraZeneca.

Together, charities, government and industry funders support the talent and infrastructure required for an effective innovation pipeline. The different funding elements are integrated and interconnected – without one, the others will not be as successful. Recognising the different contributions of each player, the Government must ensure tailored support is provided to each to maintain, foster and support the diverse ecosystem needed to deliver the government's life science ambitions.

Supporting charities to recover from the pandemic and Build Back Better

Medical research charities have a crucial role in delivering an effective life sciences ecosystem, and without them, the sector would be less dynamic and less productive. However, charities were particularly hard hit by the pandemic, which had an unprecedented impact on charity fundraising. In 2020-21, two in three AMRC charities experienced a drop in income. This has led to a significant impact on charity-funded research in universities and clinical research. The most recent evidence collected by AMRC found that member charities have had to cut £270 million in research funding since the pandemic started.



Sources: AMRC (2021) COVID-19: One year on for medical research charities; Institute for Public Policy Research (2020) Research at Risk: Mitigating the impact of COVID-19 on Health R&D Investment

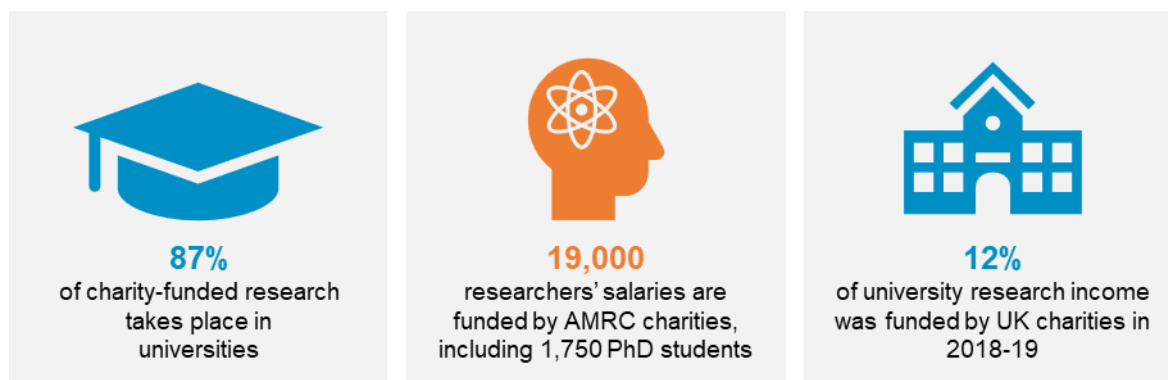
To put things into context, the British Heart Foundation (BHF), which funds more cardiovascular research than MRC and NIHR combined, has had to cut its research spend in half this year, from £99.7 million to £51.9 million. Cancer Research UK (CRUK) has also cut its research spend by £45 million, in addition to the £44 million it cut at the start of the pandemic.⁹ Charities are doing everything they can to honour existing commitments to research projects and researchers. For many, this will mean sacrificing future plans.

In May 2021, the Government recognised the need to support charity research by allocating £20 million for charity-funded early career researchers. These funds are crucial to ensure that charities do not have to cancel support for PhD students and post-doctoral fellows, the key to future research. Given AMRC charities estimate that it will take another three years before charity research funding returns to normal levels, **we call on the Government to continue short-term financial support for charity-funded early career researcher over the next 3 years to sustain the talent pipeline and ensure charities can recover and continue to play their part.**

But for the UK to build on its strengths and cement its position as a world-leader in research and innovation over the next decade, the contributions of medical research charities need sustained support. Charities have partnered effectively with Research Councils, Innovate UK and Research England for many years, supporting innovative approaches and collaborations. At this critical juncture, an effective partnership between government and charities is more important than ever.

Ensuring the sustainability of charity-funded research in universities

Charity research funding is a vital component of the research funding landscape for universities, with 87% of charity-funded research taking place in universities.^{vi}



Source: AMRC (2021) Medical research charities: our sector's footprint in 2020

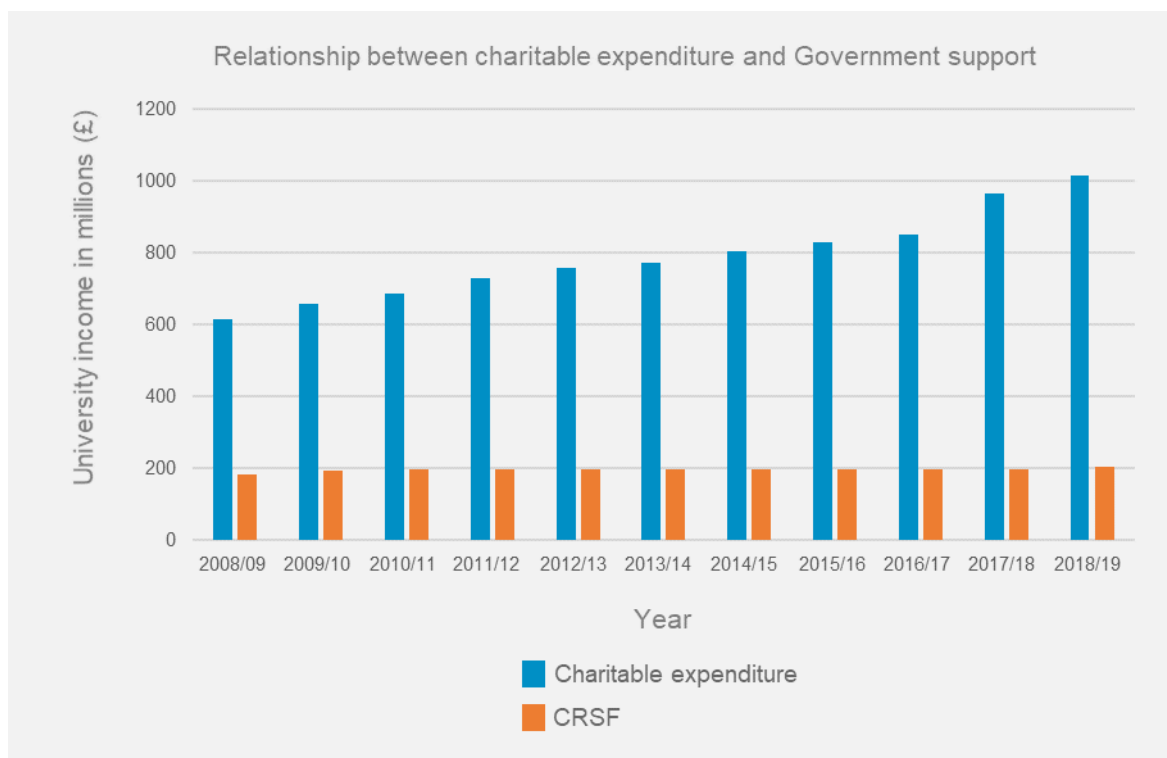
The Quality Research (QR) block grant from Research England builds excellence in universities by giving them stability and flexibility to make strategic decisions about their research activities, and to invest in talent and infrastructure. **We call on the Government to continue to recognise the importance of block grant funding to universities through QR, and to provide an uplift to QR to increase the sustainability of the system.**

One vital part of QR is the charity research support element (known as the charity research support fund - CRSF), which aims to give universities the flexibility to offset the indirect costs – estate costs and institutional support – not covered by charitable grants.

Charities exist because of generous donations from the public and philanthropists. The views and wishes of people who donate are important. When people donate, they expect their money to be spent on research to ultimately benefit patients. This means that charities pay the direct costs of research and the CRSF is needed to enable universities to pay the indirect costs required for charity funded research to occur. Without the CRSF, charities, especially smaller and medium sized charities, would find it challenging to fund research.

The CRSF is therefore critical to the sustainability and long-term stability of university-charity research in the UK, but the fund has been stagnant - and in real terms has declined in value - over the past decade.

From 2011-2018, the CRSF remained at £198 million per year meaning that, in real terms, the value of the fund decreased 8% due to inflation and rising charitable spending (see graph). In 2018/19, the Government provided a small uplift, increasing the CRSF by 3% to £204 million per year.^{vii} Even with this increase, and despite potential short-term reductions in charity funding, the CRSF remains out of step with levels of charity spend. The CRSF contribution has fallen from 28p for every £1 of charity investment in 2010/11 to less than 20p per £1 in 2017/18^{viii}. By 2030 the CRSF is expected to provide less than 12p per £1 of charitable investment, less than half of what it represented in 2012.^{ix}



The current pressure on the CRSF is threatening the partnership between Government, charities and universities that allows the public to support medical research that delivers their priorities. **We call on the Government:**

- to maintain and boost the Charity Research Support Fund to keep pace with charity investment and to safeguard charity-university partnerships;
- to ensure that medical research charities are part of crucial discussions about the long-term sustainability of research in universities, given their considerable investment in the sector; and
- to work with charities and universities to ensure that the CRSF is as transparent and effective as possible for all parties, including considering ways to ensure that the Government has greater recognition for its contribution to support charity-funded research.

2. Investing to advance clinical research

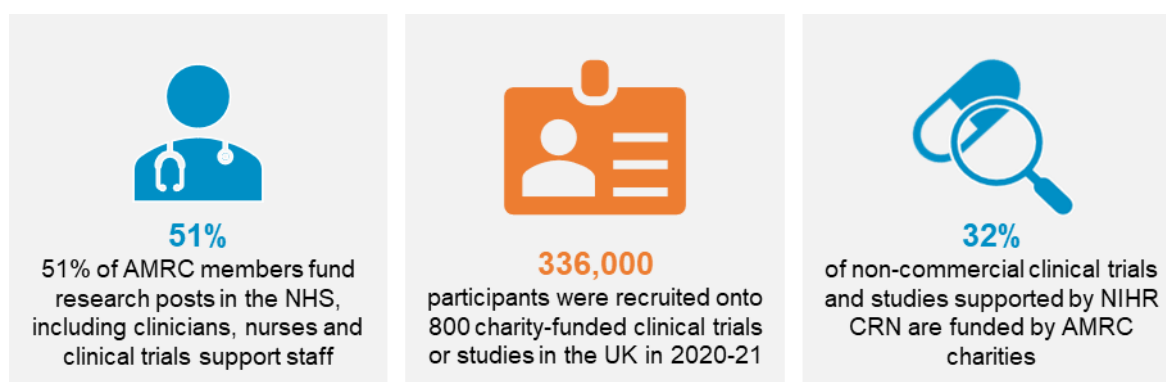
The UK's clinical research environment lies at the heart of the Government's ambition for the UK to be a global hub for the life sciences. Earlier this year, the Life Sciences Vision^x and The Future of UK Clinical Research Delivery^{xi} set out the Government's plans to make the UK the destination of choice for clinical research, with an emphasis on embedding research across the NHS, and harnessing the potential of genomic capabilities and digital technology to improve patient care. In order to attract pharma and tech companies to invest post-Brexit, the UK must be able to demonstrate it is the best place to undertake clinical trials, with a facilitating regulatory regime. Medical research charities welcome the direction of travel. Investment is needed to deliver on these ambitions, to help the UK become a global science superpower and to maximise the potential of innovative services across the NHS.

Investing in clinical research delivery

COVID-19 has highlighted the importance of research as an integral part of the healthcare pathway and has raised public awareness about the benefits of clinical research to unprecedented levels. The rapid set-up of the RECOVERY trial, which has now recruited over 43,000 participants at 186 trial sites, demonstrated the potential of embedding efficient, large-scale clinical trials into routine clinical practice. But it was only possible because of existing investment in clinical research infrastructure (see case study: [Building on the UK's genomic capabilities to respond to COVID-19](#)).

Clinical research delivers:

- Improved patient outcomes: evidence shows that patients treated in research-active NHS settings have improved outcomes^{xii}, lower mortality rates^{xiii} and increased confidence in the care being delivered^{xiv}.
- Increased NHS staff satisfaction and engagement.
- Economic benefits for the NHS and the broader economy. Clinical trials are a major source of inward investment in the life sciences space. The NIHR Clinical Research Network supported clinical research activity generated £2.7 billion GVA in 2018/2019, with the estimated income for the NHS from life sciences companies totalling £355 million.^{xv}



Source: AMRC (2021) Medical research charities: our sector's footprint in 2020

Over the past year the UK's healthcare system has been put under immense pressure, which has impacted on every element of service delivery, including clinical research. At the height of

the pandemic, more than 70% of all clinical studies in the UK were paused or cancelled. Despite the very best efforts of the Recovery, Resilience and Growth programme, a significant percentage of studies remain paused due to the pandemic and those studies that are open are struggling to recruit patients. There is still a long way to go before the UK's clinical research activity is back to pre-pandemic levels.

It is clear that investment is needed to build resilience into the system, to address workforce capacity issues, and to develop a longer-term recovery plan. This is essential in order to:

- **Ensure the UK maintains its global competitive advantage**
Other countries – including China, Australia, and the US – are becoming increasingly competitive, actively growing their ability to conduct trials across all phases and attract companies to invest. The UK must invest to remain one of the top destinations to deliver early phase trials.
- **Support the 'levelling up' agenda**
Currently, unequal distribution of research opportunities across the country is making it difficult to address health inequalities and holding back the 'levelling up' agenda. Investment is needed to support the ambition in the Government's Clinical Research Vision to "to make access and participation in research as easy as possible for everyone across the UK, including rural, diverse and under-served populations". An effective evidence base will also be essential to inform the work of the new Office for Public Health Improvement and Disparities.

There is a time-limited opportunity to transform clinical research in the UK and ensure long-term sustainability. Now is the time to invest, to build on existing capabilities and to support the capacity and infrastructure needed to make the UK the best place in the world to trial new treatments and technologies. Embedding clinical research will ensure early access for patients and help to deliver innovative services across the NHS, maximising the work of the Accelerated Access Collaborative. **We call on the Government to invest £775 million in clinical research to deliver the ambitions of the Life Sciences Vision, to make the UK a global life science hub, and to improve the lives of people across the UK.**

Investing in underpinning data and digital infrastructure

We welcome the ambition of the Government's Health and Care Data Strategy. Patient data is crucial to improve individual care and advance medical research, and the vision to improve the availability of data and connect it more effectively across the system is the right one. Many of our members are making strides forward in this space; nearly a third hold or support patient data assets, including patient data registries.

For too long, siloed uses of data have hampered progress. Priority must be given to improving the quality, completeness, availability and interoperability of datasets. The response to the COVID-19 pandemic has demonstrated the importance of access to data in near real-time, while also highlighting the risks of using patchy or incomplete data that is not representative of the whole population. Crucially, the Data Strategy also recognises the need to improve the collection and integration of data across the social care system, allowing an evidence base in social care to be built up for the first time.

The focus on using data more effectively to improve the recruitment of patients to clinical trials, through the new Find, Recruit, Follow programme is important. As demonstrated by the DigiTrials programme, and the unparalleled success of the RECOVERY trial, more efficient use of data to identify and recruit appropriate people for trials can reduce the time and costs of undertaking clinical research.

The move towards greater use of Trusted Research Environments (TRE) will be crucial, to improve the security and privacy of health data and ensure a safe setting for research. The introduction of TREs must be appropriately resourced to ensure that researchers can access data in a responsible and streamlined way, with access to cutting-edge data science technologies without introducing additional delay.

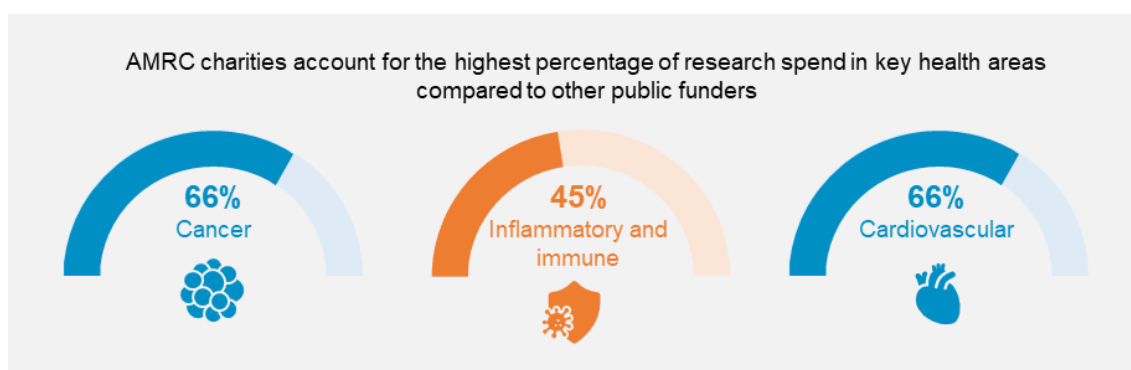
The government and NHS must demonstrate a trustworthy approach to rebuild public confidence. This must include a commitment to transparency, and meaningful, well-resourced public engagement and communications. Medical research charities are discussing with NHSX and NHS Digital how they can help support these efforts.

Delivering the ambition and promise of the Health and Care Data Strategy will need significant investment, both for infrastructure and for effective engagement. **We call on the Government to invest the £400m needed to unlock the potential of data for R&D.**

Addressing healthcare challenges to make people's lives better across the country

The Life Sciences vision identifies key healthcare challenges including mental health, aging, respiratory disease, cardiovascular disease, cancer, neurodegeneration and dementia that must be addressed to improve lives across the UK. Learning from the response to the COVID-19 pandemic, we must take the same innovative approach to translate research and drive innovation, in order to deliver more rapid benefit for patients.

Public and charitable medical research funders will be central to tackling these challenges. Public donations are particularly targeted to dementia, cancer, cardiovascular disease, asthma and mental health, and fund a huge amount of research in these areas.



Source: AMRC (2020) Completing the puzzle

Charities are already leading disease-specific research initiatives that put the UK on the global map, for example the International Cancer Grand Challenges. These include bold, strategic approaches, such as the “moonshots” that will define the next decade and beyond.

For example, the UK is well-placed to lead the world in dementia research, building on the strengths of the research ecosystem and the NHS foundations. There is an increasingly rich drugs pipeline with currently over 150 trials into potential dementia treatments. The Dementia Moonshot is the much-needed next step. To deliver the ambition, the Government must invest to expand research infrastructure so that the UK is ready to host a growing number of dementia clinical trials.

Similarly, with respiratory conditions there is potential to build on the UK's existing research excellence to drive inward investment. Respiratory diseases now affect 500m people globally, with increasing prevalence in China and India. There is a real opportunity for the UK to become a global leader of innovation for respiratory diseases, with charities working alongside the Office for Life Sciences and UKRI to explore the creation of a new virtual Institute for Respiratory Research and Innovation. Such an approach would help address long-standing disparities in respiratory outcomes, particularly in the North of England and devolved nations. By bringing the patient voice to the table, and building on existing relationships across the ecosystem, charities can act as facilitator, brokering new partnerships and collaborations with industry that will be essential to deliver on these major healthcare challenges.

Conclusion

We welcome the Government's commitment to significantly increase public investment in R&D to £22 billion by 2024-25. This investment will be absolutely crucial for the Government to deliver on its ambition to cement the UK's position as a scientific superpower. We look forward to seeing further details about the trajectory of how this funding will be delivered.

Directing some of this new investment to support charitable funding would help the Government deliver its ambitions to make the UK a global life science hub. It would send a strong signal to the British public that their priorities are recognised and supported by Government. It would enable charities to develop partnerships to bring in industry funding. And above all, it would support charities to accelerate the delivery of medical research to address key healthcare challenges and make people's lives better across the UK.

ⁱ AMRC (2021) Medical research charities: our sector's footprint in 2020;

ⁱⁱ <https://www.amrc.org.uk/Blog/telling-the-sectors-full-story>

ⁱⁱⁱ AMRC (2020) Spotlight on Place: Medical research charities fund vital research that benefits every corner of the UK

^{iv} <https://www.cogconsortium.uk/>

^v Burki (2020) Cuts in cancer research funding due to COVID-19

^{vi} AMRC (2021) Medical research charities: our sector's footprint in 2020

^{vii} Research England (2018) Circular letter: Funding for higher education institutions for 2018-19

^{viii} <https://www.amrc.org.uk/blog/the-crsf-terrible-name-but-vital-in-underpinning-charity-research-in-universities>

^{ix} Public First (Forthcoming) Exploring Options for Partnership Support for Charity-Funded Medical Research at Higher Education Institutions

^x OLS (2021) Life Sciences Vision

^{xi} DHSC, The Executive Office (Northern Ireland, The Scottish Government and Welsh Government (2021) The Future of UK clinical Research Delivery

^{xii} Midlands Engine (2021) MIDLANDS ENGINE HEALTH, Focus on: Clinical Trials

^{xiii} Downing et al., (2017) High hospital research participation and improved colorectal cancer survival outcomes: a population-based study

^{xiv} Jonker et al., (2019) Patients admitted to more research-active hospitals have more confidence in staff and are better informed about their condition and medication: Results from a retrospective cross-sectional study

^{xv} KPMG (2019) Impact and value of the NIHR Clinical Research Network: Financial years 2016/17 – 2018/19