A proposal from the Association of Medical Research Charities, 3 June

To preserve the distinct contributions of charities to the UK’s research base and to harness their role in supporting the UK’s post-Covid-19 economic and social recovery, we are proposing a government-charity co-investment scheme that provides a level of match funding from government for future charity research over the next three years via a Life Sciences-Charity Partnership Fund.

We propose to co-design the Fund between government and charities and have indicated underpinning principles to be used as a basis for further development.

1. Purpose of the Life Sciences-Charity Partnership Fund:

- To preserve the world-leading research capability that medical research charities have built in the UK that will ultimately provide benefits to patients, including the breadth of charity research across disease areas that includes rare and less common conditions;
- To mitigate the risk of losing the capacity and skills built by the sector within universities and the NHS, setting back the quest for transformative outcomes for patients by a significant number of years;
- To harness contributions from medical research charities towards a R&D-driven economic and social post-Covid-19 recovery;
- To fulfil government ambitions to be a global science superpower by capitalising on the UK’s unique charity sector.

2. Why the Life Sciences-Charity Partnership Fund is needed:

- The short-term economic impact of Covid-19 will have longer-term consequences on R&D and the continuity of charity-funded medical research now and in the future.
- Medical research charities are a vital part of the UK’s diverse research base. In 2019 AMRC charities funded half of publicly funded medical research nationally by collectively investing £1.9 billion in UK R&D, the same as both public funders the Medical Research Council (MRC) and the National Institute for Health Research (NIHR) added together.
- Charities invest in the UK’s skills pipeline and have made long-term investments in research capacity and capability. In 2019, 17,000 researcher salaries were funded by AMRC members, including 1750 PhD students.
- The role that charity investment in UK R&D plays cannot be readily replaced by other funders. Many charities are both patient organisations and research funders, bringing unique contributions to UK R&D as a result of their strong relationships with patients and insights into patients’ experiences and their priorities.
- The drop in fundraising income charities are experiencing due to Covid-19 will impact charity research investment. AMRC’s members are planning for an average 41% decrease in their research spend in FY20/21, resulting in a projected reduction in UK medical research investment of between £252m - £368m (this analysis does not include funding from the Wellcome Trust).
• It is important to note that the £750 million extra funding to support frontline service charities made available by the Chancellor in April has not benefitted charitable medical research unfortunately.

The UK’s publicly funded medical research sector and the impact of the shortfall in charity investment (when the Wellcome Trust is not included AMRC charity spend is £0.925bn):

• The pandemic has had an immediate impact on charity research. More than two thirds of AMRC’s members are deferring upcoming grant rounds and withdrawing future funding.
• There will be an impact on the future skills pipeline as well as capacity with funding for leading institutes and under-funded disease areas at risk (see annex 2 for further information).
• As a sector, medical research charities 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.
• Charity investment in medical research contributes towards the government’s research ambitions including providing funding across every region in the UK, leveraging private investment and contributing to economic prosperity (see annex 3 for further information).

3. Principles underpinning the Fund:

• A co-funding scheme based on a partnership between government and charities that ensures vital medical research charity investment in R&D remains part of the UK’s diverse research base.
• Provision of at least £310m of funding from government in FY20/21 to bridge the projected shortfall in sector spend. This funding would be matched by funding from charities to ensure overall sector investment is maintained.
• A duration of at least three-years to support the sector to recover and to mobilise donations from the public at a time when the power of R&D is firmly planted in the nation’s mindset. On average charities anticipate that it will take 4.5 years before their spend on research in UK universities fully recovers to normal levels.
• An opportunity to leverage further funding from industry and philanthropy to harness charity contributions towards an R&D-driven economic and social recovery.
• Co-design between charities and government to develop a mechanism that meets shared aims and ensures funding is delivered across the breadth of AMRC’s members.
• Built on the vision for charity modernisation set out in AMRC’s On the Front Foot report, embedding forward-thinking approaches and examples of charity leadership.

4. Parallels with existing post-Covid-19 schemes:
• The government’s £500m Future Fund co-investment scheme provides support for innovative companies that have faced challenges as a result of the Covid-19 pandemic. There is no equivalent scheme for charities that invest in innovative research.
• A scheme for medical research charities would address this gap and reflect the importance of both business and charity investment in UK medical and health research. The return for the government’s co-investment would be the public benefit brought from the contributions of the charity sector and the boost to the UK’s world-leading R&D base.
• A Fund for medical research charities should not be based on loans.

5. Why the Fund should not be based on loans:
• Medical research charities typically award research grants which do not offer a financial return (in the rare cases where charity IP creates value, this occurs many years in the future).
• Therefore, if a loan was given to a charity to pay for a research grant, repayment would have to come from fundraising or from the charity’s reserves.
• Fundraising is uncertain and has become even more so in the current climate. As it restarts, asking the public to donate to repay a loan would be challenging.
• Attracting major donors and corporate giving is reliant on the charity’s charitable spending ratio. With a proportion of funds going to repay a loan, that ratio would be lowered and there is a high risk that would make giving less attractive to these important donors.
• Many charities can’t provide the necessary security for a loan and not all charities have the power to receive loans in their memorandum and articles of association. As this scheme will apply to multiple charities, this leaves potential for inequality in which medical research charities can benefit from the scheme.
• Charity loan schemes typically work for service delivery charities who are able to finance repayments from the income gained as a result of providing a service.
• Bridging the financial shortfall faced by charities through loans would mean delaying rather than minimizing the impact. The loan would have to be repaid and interest payments made in future years would mean reducing the funds available for research.

6. Opportunities to leverage additional investment using the Fund:
• The Fund could be used as a tool to leverage further R&D investment by providing an opportunity for industry partners, investors and philanthropists to invest in research designed around patient needs, capitalising on the attractiveness of the UK’s unique medical research charity sector.
• The Fund could be used to **mobilise and support the British public’s efforts to fund research** at a time of economic challenge when the value of R&D is clearer to the public than ever before.
• The Fund would contribute to **government’s central ambition to invest unprecedented levels in R&D** and for the UK to be the global hub for life sciences.

7. Why government investment in charity-funded medical research is worthwhile:

• **Securing a vibrant component of the UK’s world leading R&D base that supports science from basic research through to clinical trials and translation**; over the past 10 years AMRC charities have spent £14 billion on research in the UK.

• **Driving economic recovery**; every £1 of public or charity investment in medical research delivers a returns equivalent to around 25p every year, for ever. Charity investment in translational research drives the creation of spin out companies to commercialise a new product or process. Last year funding from AMRC members led to the creation of 61 unique spin out companies.

• **Attracting international talent and boost the UK’s skills pipeline**; in 2019 AMRC members funded 17,000 researchers’ salaries, including 1,750 PhD students and the UK’s charity sector is unique world-wide.

• **Funding across the breadth of the UK**; 81% of AMRC members fund research across the whole of the UK and last year almost half of charity funding was spent on research outside of London and the south east. Over half (53%) of patient recruitment onto charity-funded clinical trials and studies took place outside London, the East of England and the South East.

• **Ensuring public buy-in and support for an R&D-driven recovery**; charities play a key role in linking between the British public and R&D. In 2018, more than 7 million people donated directly to medical research via charities.

• **Harnessing the role that charities play in brokering vital collaborations and partnerships, leveraging investment across UK life sciences**. Charities coalesce research investment around patient priorities and unmet needs. In 2018 awards from AMRC members led to £2.7bn of further funding from a variety of research funders.

• **Promoting investment in early-stage, preliminary research, de-risking complex research topics** that private and public funders can then drive forward. For example, Cancer Research UK is the second biggest licensor in the world, fuelling the pipelines of companies such Astra Zeneca, Novartis, Roche and multiple mid-sized biotechs.

• **Supporting bold funding decisions driven by a focus on moon-shot goals that aim to make a real difference to people’s lives**. For example, Breast Cancer Now’s ambitious target that by 2050 everyone who develops breast cancer will live and the British Heart Foundation’s £30 million Big Beat Challenge to develop a transformational solution to a significant problem in any heart or circulatory disease.

• **Charities are built on strong governance and research processes**. AMRC’s members adhere to robust peer review standards and are audited every five years.
Annex 1 - Medical research charities are contributing to the national effort to combat Covid-19

Many charities have rapidly established enhanced patient support services, supported the secondment of clinical research staff to the NHS front line and contributed to the research effort with funding and infrastructure. Examples include:

**Contributing to the national research effort:**

- **The Wellcome Trust** are supporting global research efforts through their founding investment in CEPI, the Coalition for Epidemic Preparedness Innovations of $100 million, with a further commitment of up to $50 million to set up the COVID-19 Therapeutics Accelerator. In addition, Wellcome has made available £10 million to support urgent coronavirus research in lower and middle income countries.
- **LifeArc** created a £10 million fund to progress research into treatments for COVID-19.
- **The Crick Institute**, funded by both Wellcome and Cancer Research UK, has been repurposed as a testing facility, to help combat the spread of infection and allow key workers to perform lifesaving duties and remain safe.
- Many **Cancer Research UK** laboratories throughout the country are providing vital testing kit and skills.
- **Anthony Nolan** has loaned its ‘automated liquid handling units’ to research scientists based at one of the UK’s new COVID-19 testing laboratories.
- **Diabetes UK** have launched a COVID-19 Rapid Response Research Call to further the understanding of COVID-19 in relation to people living with diabetes.
- **MQ: Transforming Mental Health** are working with the Academy of Medical Sciences, people with live experience, funders and the public to create a robust mental health research response to COVID-19.
- **The UK Dementia Research Institute**, funded by Alzheimer’s Society and Alzheimer’s Research UK alongside the MRC, is contributing in a number of ways to the UK’s capacity for COVID-19 testing.
- **MS Society** is using the UK MS registry to survey people about COVID-19 and collect data on how the virus is affecting people with MS to learn if people on disease modifying treatments are more susceptible.

**Providing support services and advice to vulnerable patient communities:**

- A coalition of 21 **cancer charities** (One Cancer Voice) have provided common advice to all cancer patients on the outbreak.
- **Diabetes UK** had 1.5 million users of their digital platform (an increase of 92.8% on March 2019) and they are now working to support local groups to meet remotely.
- **The British Heart Foundation** have experienced a 125% uplift in the number of calls to their patient support helpline and have launched a Coronavirus Support Hub which highlights the latest expert information, plus support from specialist nurses.
- **Asthma UK and British Lung Foundation** have launched a post-COVID Hub and helpline for people left with breathing difficulties after COVID-19, their family members, carers, healthcare professionals, policy-makers and researchers.
- **The Cystic Fibrosis Trust** have doubled staffing on their helpline and are providing shielding advice, public health guidance and weekly videos from a leading clinician on Covid-19.
- **Alzheimer’s Society’s** Dementia Connect support line received nearly 3,300 calls in March alone and their Talking Point service has seen a 600% increase in sign-ups.
- **Versus Arthritis** has launched a Virtual Assistant to help people with arthritis get relevant health information related to COVID-19 quickly.
Annex 2 – Supporting charity-funded research will protect the UK’s medical research capacity and capability

A reduction in charity investment in research will impact on the future skills pipeline, including PhD studentships, fellowships and other awards, as well as research capacity with funding for leading institutes and under-funded disease areas at risk.

Over half of AMRC’s member charities are concerned that there would be a disproportionate disadvantage to certain researchers due to disruptions in charity-funded research funding. Charities view that early career researchers are most at risk including PhD students, post docs and fellows.

For many charities, PhD studentships and project grants make up the majority of their funding. These types of funding are attractive to early career researchers so future cuts and reductions could mean a loss of talent that will affect capacity in individual research areas in the future.

More than half of AMRC’s members have indicated that the impact of Covid-19 on their research portfolio has, or will have, implications for the UK’s ability to attract research talent and global research leadership.

AMRC member examples:

Cancer Research UK

- CRUK is a significant funder of the UK cancer research workforce and a reduction in its funding will limit the opportunities for the next generation of cancer researchers.
- Anyone earlier in their career is most at risk, including PhD students and post-doctoral researchers, as well as undergraduates unable to find a postgraduate research post.
- Early career researchers are more likely to be on shorter-term contacts and more reliant on funding opportunities being available in the immediate future – presently it looks like these opportunities will be scarcer.
- Without a research role to go to, like a PhD or a postdoctoral position, many talented students and early career scientists could leave cancer research and potentially science altogether. Or they could leave the UK if posts are available elsewhere.
- Limited training opportunities for early career researchers could impact the cancer research ecosystem for many years to come.

Other examples from member charities are available which can be shared in due course.
Annex 3 – Charity R&D investment contributes towards the government’s research ambitions

1. Leveraging investment from industry and contributing to economic prosperity

Many medical research charities invest in early-stage, preliminary research and act to de-risk complex research topics so that that private and public funders drive them forward.

Charities often act like businesses and seek collaborative partners to speed up the development of treatments for patients. In the last 5 years\(^1\):

- Funding from medical research charities leveraged over £70m in funding from UK and international industrial companies;
- Researchers funded by nine AMRC charities (including Wellcome Trust) reported creating over 60 spin out companies; and
- Researchers funded by AMRC charities have contributed to the production of 300 medical products including drugs, medical devices and cellular and gene therapies for therapeutic intervention, diagnostic tools for imaging and medical devices.

Charity examples of innovative partnerships include:

The **Dementia Discovery Fund**: a ground-breaking new partnership between charity, industry and government designed to speed up the discovery and development of new treatments for dementia. The fund is managed by SV Life Sciences, a venture capital firm, providing the investment management skills needed for the project to meet its goals and succeed financially.

**Breast Cancer Now Catalyst Programme**: The programme brings together world-leading researchers and the US pharmaceutical company Pfizer to pool resources so that innovative breast cancer treatments can be developed. Pfizer has committed $15 million USD (around £10 million) in funding over three years to ensure this research can happen. Researchers will be granted unprecedented access to at least 14 of Pfizer’s existing drugs and drugs currently in development.

2. Funding bold ideas towards challenge-oriented goals

Medical research charities fund high-risk research that attracts and mobilise world-leading scientists, clinicians, innovators and entrepreneurs to tackle health research challenges, significantly increasing the probability of developing solutions.

Charity examples of high-risk challenge-led funding approaches include:

**Cancer Research UK Grand Challenge**: The Grand Challenge is the most ambitious cancer research initiative in the world: a series of £20 million awards seeking international, multidisciplinary teams willing to take on the toughest challenges in cancer, and providing the freedom to try novel approaches, at scale.

**British Heart Foundation Big Beat Challenge**: The Big Beat Challenge (BBC) is a global competition that will culminate in a single research award of up to £30 million. The BBC challenged researchers to form international, multi-disciplinary teams and identify and

\(^{1}\) From a dataset collected by 40 of our members (covering 45% of AMRC member’s annual research spend) via the online platform Researchfish.
propose transformative solutions to significant problems in heart and circulatory disease, with a clear route to patient benefit.

**Versus Arthritis Pain Challenge:** The Challenge call aims to fund ambitious and innovative research that will have a significant impact on tackling the pain of musculoskeletal diseases. Chronic pain is a substantial daily problem for a significant number of people with arthritis but remains an under-researched area. Therefore, the charity has stepped in to take the lead and close the gap. Versus Arthritis leveraged £12 million in government funding to create a joint £24 million fund between the charity and UK Research and Innovation (UKRI) generating a research platform, known as the Advanced Pain Discovery Platform, which brings together experts from biological, psychosocial and cognitive pain research fields.

The **Francis Crick Institute:** The Institute is a visionary partnership between two charities (Wellcome and Cancer Research UK) and the Medical Research Council (MRC), UCL, Imperial College London and King's College London. The Crick’s ambition is to discover the biology underlying human health, improving the treatment, diagnosis and prevention of human disease, and generating economic opportunities for the UK.

AMRC charities are also involved in vital research activities to make a difference for **rare diseases.** In 2018, AMRC charities invested £142 million into 640 rare disease research projects. Charities often provide the only investment in research for rare and less commons conditions or provide seed funding that encourages others to invest.¹

### 3. Levelling up and providing funding across every region in the UK

Medical research charities fund research 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.

- 81% of AMRC members fund research across the whole of the UK.
- AMRC charities fund the majority of grants in 11 out of the 12 regions of the UK when compared to other public funders.
- 53% of patient recruitment onto charity-funded clinical trials and studies was outside the London, the East of England and the South East.

**Charity examples of research investment across the UK include:**

- Cancer Research UK's long-term investment in state-of-the-art facilities has helped create a thriving network of research at 90 institutions in more than 40 UK towns and cities.
- North West Cancer Research is dedicated to tackling cancer across the North West and North Wales. A partnership led to a world class institute at Bangor University and resulted in the recruitment of independent internationally renowned research team leaders.
- In Edinburgh, the British Heart Foundation invested £10 million into a data science centre, alongside Health Data Research UK (HDRUK), which promotes the safe and ethical use of data for research into the causes, prevention and treatment of all diseases of the heart and circulation.
- Parkinson’s UK and the University of Sheffield launched Keapstone Therapeutics Ltd in Sheffield which uses virtual biotech and an innovative disease-modifying therapeutic approach to motor neuron disease and Parkinson’s disease.

¹ [https://www.amrc.org.uk/Handlers/Download.ashx?idMF=fb75e129-d4ab-44b0-94c3-206d6886095e](https://www.amrc.org.uk/Handlers/Download.ashx?idMF=fb75e129-d4ab-44b0-94c3-206d6886095e)