Unlocking the investment power of medical research charities

How the Charity Research Support Fund enables the unique contributions of charities to health and well-being

November 2017
Overview

Increasing the Charity Research Support Fund (CRSF) will strengthen the wider UK life sciences ecosystem, a key sector identified within Government Industrial Strategy, by supporting further charity investment.

AMRC and our members are calling on Government to enhance the CRSF in real terms in line with inflation and charity investment.

Since 2010, the CRSF has been fixed at £198 million per year. During this time, the relative value of the fund has been eroded by both inflation and an increase in charity funding.

Enhancing the CRSF, as recommended in the Life Sciences Industrial Strategy, will strengthen the vital partnership between charities and Government that underpins charity investment in universities. This partnership is vital to provide universities with the security that the indirect costs of charity research will be met.

About AMRC

The Association of Medical Research Charities (AMRC) is the national membership organisation of 140 leading health and medical research charities.
Charities are a crucial part of the UK’s research ecosystem

Medical research charities play a key part in the UK’s uniquely diverse funding base for life science research. This base, comprising funding from public sector, industry, charity, philanthropic and venture sources, is a differentiating strength which has contributed to the UK’s world-leading position in life sciences.

In 2016:

“Charities play a crucial role in the UK’s medical research landscape, creating a much more diverse funding landscape than most other countries and ensuring that excellent research can be funded. This is likely to be a factor in the UK’s first-place ranking among the G7 for citation impact in medical research. They also play a valuable role in patient/public engagement, facilitating clinical research. The CRSF is essential to ensure that conducting charity-funded work is financially viable for universities, allowing us to make full use of this sector to advance the UK’s health and our world-class research.”

-- Professor Sir Robert Lechler, President of the Academy of Medical Sciences
Medical research charities invest with a long-term vision in human capital and the development of skills. In 2016, AMRC member charities were funding 1900 PhD students’ grants in universities across the UK, worth over £225 million. Charities are committed to growing the skills pipeline to deliver future generations of researchers trained in new and emerging fields, who are equipped to work across disciplines in order to tackle complex research challenges.

Charities are often the only funders in early-stage, preliminary research – de-risking ambitious projects for future investors, and paving the way for other funders such as industry. In the last five years, funding from medical research charities leveraged over £70 million in funding from UK and international companies.

Patients are at the heart of many medical research charities. The research that charities fund is often in response to patient need, and aims to communicate and meet these needs. Thanks to this close relationship, many medical research charities are funding research that could result in truly transformative outcomes for patients.

Charities are increasingly seeking innovative and novel approaches to investing in research, in order to maximise the benefits for patients. They often act like entrepreneurs and seek collaborative partners to achieve transformative goals. In the last five years, researchers funded by nine AMRC charities created over 39 spin out companies; and contributed to the production of 300 medical products including drugs, medical devices and diagnostic tools.

Charities can bring together university researchers, funders, small and medium-sized enterprises, regulators, patients and others in areas of unmet need. Working together, they can more efficiently define problems, craft research proposals and identify funding sources to expedite solutions through cross-disciplinary, lateral and radical thinking.
Charity investment in R&D is aligned with the aims of Government’s Industrial Strategy

Charity investment in R&D has a significant impact on the UK economy and aligns with many of the aims of the Government’s Industrial Strategy. Every £1 of public or charity investment in medical research generates monetised health benefits of 7-10p each year, forever, as well as 15-18p of additional spillover benefits in the wider economy.¹

“Although Autistica is the largest funder of autism science in the UK, we are still a small charity. For us, the overhead costs of research could be crippling. The CRSF enables us to spend every penny we can on life-changing autism research.”

-- Jon Spiers, Chief Executive, Autistica

Charities of all sizes are crucial. In particular, small charities can play a key role in sustaining research into rare and under-funded conditions.

Charities invest in excellent research across the breadth of the UK

Since 2008, medical research charities have invested nearly £11 billion in UK universities. In 2016, 88% of all UK medical research funded by AMRC’s members took place directly in universities.

Charity investment in universities spans across the UK. In 2016, AMRC members funded research in all regions with Scotland and North West England both among the top five areas for AMRC member investment.

¹RAND Europe, Health Economics Research Group at Brunel University and King’s College London (2014) Medical Research: What’s it worth? Estimating the economic benefits of cancer-related research in the UK. Commissioned by: Academy of Medical Sciences, Cancer Research UK, the Department of Health and the Wellcome Trust
The CRSF

The Charity Research Support Fund (CRSF) underpins charity investment in university research across England (similar funds are provided in the devolved nations). The Fund means that universities can effectively leverage research funding from charities; it enables researchers who receive charitable funding to recover costs of research that charities do not pay. These costs include estates, shared IT and administration overheads.

Charities exist because of donations from the public and philanthropists; in 2016 over 8 million people donated to medical research. The views and wishes of people who donate, particularly at a time of increased scrutiny on charities, are of paramount importance.

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, e.g. estates, shared IT and administration.

Government have a responsibility to ensure that universities are funded in a sustainable way. For universities, particularly those in receipt of high proportions of charity funding, the CRSF is a key part of this.

“The CRSF makes a great difference to the way we fund research to reach our goal of ‘A world free of Motor Neurone Disease’. It allows us to assure our supporters that the money they raise is being spent directly on research that will hopefully lead to key developments in scientific understanding of MND and towards improving treatments.”

-- Sally Light, Chief Executive, Motor Neurone Disease Association

The CRSF is an element of Government funding administered to universities as part of quality-related (QR) research funding. In England, it is allocated by Higher Education Funding Council for England (HEFCE) before April 2018, and through Research England, under UK Research and Innovation (UKRI), after April 2018.

It was introduced in 2006 at £135.5 million. Since then this fund has supported significant charity funding of research in universities. However, the fund is now falling short – as is set out below.
Realising the full potential of the CRSF

The CRSF must be increased to unlock the contributions of medical research charities to create and sustain a healthy and dynamic research environment in universities, thus taking forward the aims of Government’s Industrial Strategy.

AMRC and our members are calling on Government to enhance the CRSF in real terms in line with inflation and charity investment.

Our call is supported by the sector and echoed in the recommendations to Government set out in the Life Science’s Industrial Strategy.

Since 2010, the CRSF has been fixed at £198 million per year. During this time, the relative value of the fund has been eroded by both inflation and an increase in charity funding. This means that the value of the fund has fallen from 28p of CRSF for every £1 received by universities from charity funders in 2010/11 to under 20p of CRSF per £1 in 2017/18.

The real-terms decrease in the CRSF is threatening the partnership between Government, charities and universities that allows the public to support university medical research.

“Partnering with the charity sector allows universities to develop links with end-users, such as patients. The ongoing availability of the CRSF is a prerequisite for the sustainability of this crucial university research.”

-- Simon Kerridge, Director of Research Services, University of Kent
Universities are telling us it is increasingly difficult for them to cover the costs of doing charity-funded research and the sustainability of medical research charity investment in universities is at risk.

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"Charity-funded research would not be possible without the CRSF. Charity money is critical for university research, and it has enabled many early projects to reach fruition that were not sufficiently advanced for other sources of funding."
-- Epilepsy Research UK-funded researcher

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Enhancing the CRSF, as recommended by the sector in the Life Sciences Industrial Strategy, will strengthen the vital partnership between charities and Government that underpins charity investment in universities, while providing universities with the security that the indirect costs of charity research will be met.

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"Over the past 55 years BHF funded research has helped to put the UK at the forefront of cardiovascular science. An increase in the CRSF will enable us to continue this work and help secure the UK’s future as a world leading force in research"
-- Simon Gillespie, Chief Executive, British Heart Foundation
The CRSF: making charity-funded research happen

The following case studies reflect the important role of the CRSF in underpinning investment from medical research charities.

**Alzheimer’s Research UK**

Alzheimer’s Research UK is the UK’s leading dementia research charity, and the second largest charity funder of dementia research in the world. Their current funding commitment is £27 million in world-class research at leading universities and research institutions across the UK. To date they have funded £79 million in research projects. As research experts, they are committed to finding new ways to diagnose, prevent, treat and cure dementia.

Their research strategy is targeted to deliver research that offers the most potential for health benefit. Increased and sustained investment in research is critical to help deliver the treatments and outcomes that will offer hope to people living with dementia and reduce the massive societal and economic burden.

Alzheimer’s Research UK has heard anecdotally that researchers are being discouraged by their institutions to apply for Alzheimer’s Research UK grants, likely due to the freeze on the Charity Research Support Fund and the increased costs of overheads to HEIs.

**Arthritis Research UK**

Arthritis Research UK invests in breakthrough treatments, the best information and vital support for everyone affected by arthritis. They combine cutting edge research and the expertise of people with arthritis to make everyday life better for all 10 million people with these conditions in the UK. The pain and functional limitations caused by musculoskeletal conditions can significantly impact people’s quality of life, limiting independence and the ability to participate in family, social and working life.

Arthritis Research UK currently funds more than 300 research awards, worth in excess of £120 million across more than 70 institutions in the UK, the majority of which qualified for CRSF. Since 2013, they have invested around £20 million each year in high-quality cutting-edge research, careers and infrastructure. The CRSF is vital in enabling and underpinning funding by Arthritis Research UK to unlock the potential of its research in universities.

In 2015/16, each £1 of funding received from Arthritis Research UK secured an additional 72p from other funding sources. This approximates to £85 million of follow-on funding leveraged by Arthritis Research UK grant holders, underpinned by the CRSF.
**Autistica**

Autism is the single most expensive medical condition in the UK, costing more than cancer, heart disease and stroke combined. In adults, it is estimated to cost the UK economy at least £29 billion a year. In contrast, less than 1% of the funding invested in those conditions is spent on autism research.

By the end of 2017, Autistica – the UK’s leading autism research charity – will have increased the amount spent on research into autistic adults by 800%, contributing £1 million directly and leveraging between £1.4 and £1.9 million from other funders. By 2021 they aim to have raised and invested a further £10 million to prevent the early death of adults with autism.

The research infrastructure created by Autistica at Newcastle University – including the world’s first cohort of over 1000 consented autistic adults – has put the UK at the forefront of research into ageing with autism. International funders and life science companies have now indicated their interest in funding specific research in the UK, in preference to the US, as a direct result of Autistica’s Ageing with Autism Programme and other investments.

The CRSF has underpinned the success of Autistica’s Ageing with Autism programme. As a charity funded entirely by donations from the public they need to be able to assure donors that their money is spent directly on ground-breaking research. If Autistica had been forced to meet the additional £260,000 costs of this research without the financial support provided by the CRSF, they would have struggled immensely to find the extra funding, at best delaying the programme, at worst making it financially unviable.

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**British Heart Foundation**

The British Heart Foundation (BHF) is the largest independent funder of cardiovascular research in Europe. The charity funds more than half of all academic heart research carried out in hospitals and universities. In 2015, the BHF committed to investing £500 million in life saving research over five years. This is entirely funded through the generosity of the UK public.

This investment provides the backbone for academic careers in cardiovascular research in the UK, with over 4,000 staff currently funded by BHF awards. The charity also supports six Centres of Research Excellence and three Centres of Regenerative Medicine. Papers that acknowledge BHF funding have a world-leading citation rate and analysis shows that on average every £1 the BHF invests in research generates an additional £1.20 in further funding.

The Charity Research Support Fund (CRSF) plays a vital role in the sustainability of this research. If the fund did not exist and the BHF were required to pay in the same way as Research Councils, the charity could fund less than two thirds of the research it currently supports. The loss, reduction or continued freeze of the CRSF could have profound consequences for university research and the UK’s ability to contribute to cardiovascular research at a globally competitive level.

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2 CardioScape, A survey of the European cardiovascular research landscape, 2014
3 UKCRC, UK Health Research Analysis 2014, 2015
4 Analysis by Clarivate Analytics, BHF Research evaluation report, Outputs, outcomes and impact of BHF funded research: 2015-16, 2017
5 BHF Research evaluation report, Outputs, outcomes and impact of BHF funded research: 2015-16, 2017
The Institute of Cancer Research, London

The Institute of Cancer Research (ICR), a college of the University of London, is one of the 10 highest recipients of charity research funding in the UK higher education sector – around 80% of their peer-reviewed grant income comes from charities.

In the 2016/17 academic year, the ICR received £8.9 million of CRSF funding, based on receiving an average of around £40 million of eligible charity funding in the previous two years. Charity funding makes up around 16 per cent of the ICR’s unrestricted institutional funding and around 50% of core funding, and has a significant impact.

The erosion of the value of the CRSF since 2010 means that the ICR currently faces an annual shortfall of £6 million in CRSF funding, and will have effectively lost £24 million over the last 10 years. These sums have a fundamental impact the ICR’s ability to resource and support world class research.

Scientists at The ICR have spear-headed the identification of genes in cancer, improvements in cancer screening regimes and the development of novel therapies. These achievements have led to significant benefits to cancer patients.

Charity funding plays a crucial role in the UK’s success as a world leader in research. The erosion of the CRSF fund risks damaging the UK’s international competitiveness, and the ICR’s ability to sustain its research and continue to improve outcomes for cancer patients through research.

MND Association

In 2016, the Motor Neurone Disease (MND) Association committed over £1.9 million of new funds to ground-breaking biomedical research into MND. MND research is an area of considerable unmet need; there is only one licensed drug for people with MND in the UK. There is limited industry interest in this area of research and, without the MND Association, there would be very little funding for basic biomedical research that aims to understand MND at a cellular level.

The Charity Research Support Fund plays an important role in the sustainability of MND research in the UK. The Fund ensures that the MND Association can continue to fund their full research portfolio in universities. If the charity had been required to pay as Research Councils do, this would have amounted to a further £500,000 across all of their new biomedical projects awarded in 2016. This equates to around 20% of the Association’s entire research budget for the year. Finding that amount of extra money would not have been feasible for the Association and, as a result, they would have had to significantly reduce their funding portfolio.

A cut of £500,000 in the MND Association’s research budget would have a significant impact. For example, in 2016, this sum totalled all new PhD Studentships (£380,000) and all the Small Grants (£94,000) awarded by the Association. Small grants are awarded as ‘pump-priming’ funding in new areas of research, or may support a researcher to complete key studies to ensure their results are of high impact. Loss of these funding streams would have resulted in a significant impact on the skills pipeline for MND research in the UK.
Appendix

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