



**Maximising impact through collaboration**



The Association of Medical Research Charities (AMRC) is a national membership organisation of leading medical and health research charities.

## Our vision

A strong and vibrant UK sector recognised for its contribution to health and medicine for the benefit of patients

## Our mission

To support and promote the collective effectiveness of charities whose principal activity is medical research or the funding of medical research in the UK

Our members are central to everything we do. We:

- Provide services and **support** that enable member charities to be effective research funders
- Demonstrate **leadership** in developing solutions to key challenges facing the sector
- **Influence** the external environment to enable the work of medical research charities.



# 'AMRC's strength lies in our ability to promote partnership, collaboration and mutual trust'

## Welcome

The past year has been challenging for AMRC and our members. The impact of the economy, public spending cuts and new legislation affecting health and social care have prompted us to re-evaluate our work and our priorities.

Change has been inevitable as we have sought to do 'more with less' but throughout the year we have been determined not to lose key infrastructure. Nowhere was this more important than with research, where, notwithstanding the range of funders, we can point to a sector that maintains the highest standards of peer review.

This year we said goodbye to Simon Denegri, whose tenure at AMRC saw the association gain in influence with funders, the private sector and government. Simon recognised that AMRC's strength lies in its ability to promote partnership, collaboration and mutual trust – qualities that will serve us well as we move forward under Sharmila's leadership.

Our role is to support our members in their mission to fund the highest quality medical research that will benefit patients. We work together to ensure that the wider landscape for medical research is the best it can be.

Throughout this review there are examples of how we are respected by our members for this support and leadership, and are regarded by our stakeholders as *the* place to hear the voice of medical research charities and engage with the sector.

With the changing environment and the implications for our activities as funders, it is an opportune time for AMRC to look at our strategic direction and ensure that we are delivering a service that is appropriate for our members and the wider sector. We look forward to working with you over the coming year as we develop a strategic plan to guide us through the next five years.



Lord Willis of Knaresborough,  
chair, AMRC



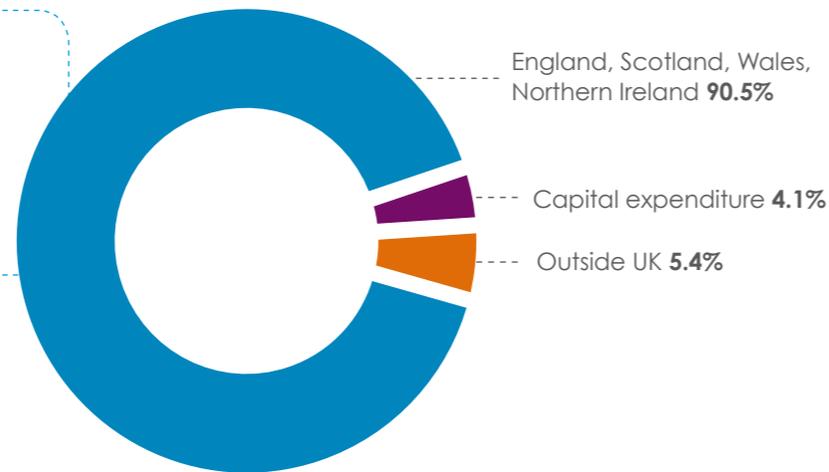
Sharmila Nebhrajani, incoming  
chief executive, AMRC

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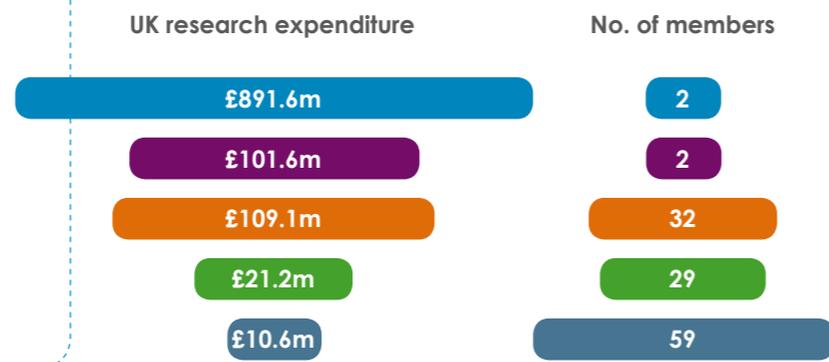
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## Charity-funded research

Charities play a significant role in funding medical and health research across the whole of the UK. In 2010-11, AMRC members invested £1,253m in medical research, here and overseas.  
*AMRC research expenditure database*

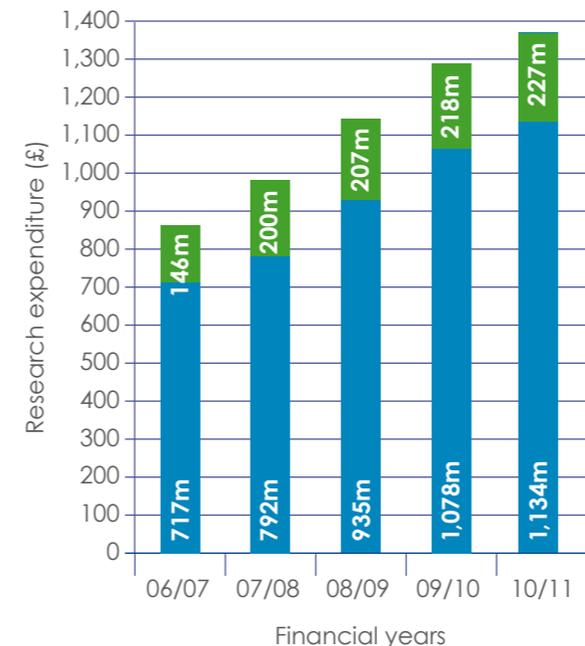
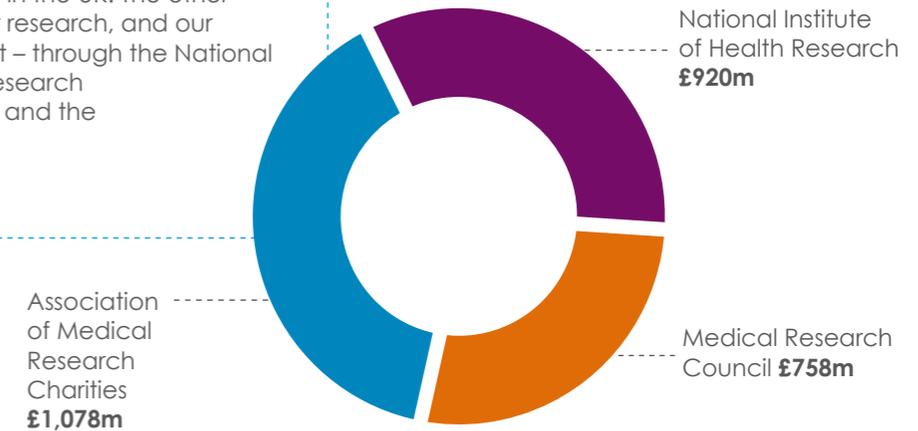


We represent the diversity of charity-funded research in the UK: AMRC members include the largest medical research charities in the country, alongside many smaller charities. They support research in laboratories, institutes and in the NHS, from fundamental studies on how our bodies work and what goes wrong when we develop diseases to applied and translational research with the potential to be developed into new treatments.  
*AMRC research expenditure database, collected 2010-11. NB graphic not to scale*



■ Over £200m ■ £15m – £200m ■ £1m – £15m ■ £500,000 – £1m ■ Less than £500,000

Our members support approximately one third of all publicly funded medical research in the UK. The other major source of public funding for research, and our biggest partner, is the government – through the National Institute of Health Research, the research arm of the Department of Health, and the Medical Research Council.  
*AMRC research expenditure database, MRC and NIHR annual reports, 2009/10*



More than 80% of our members' research funding is invested in UK universities. Charities fund the directly incurred costs of research. The government partners this investment with a funding stream, termed the charity research support fund (CRSF) in England, designed to meet the indirect costs of this research, which fall outside charitable objectives. Similar funds support the full economic cost of charity-funded research in universities in Scotland, Wales and Northern Ireland.  
*AMRC research expenditure database, Higher Education Funding Council for England, Scottish Funding Council, Higher Education Funding Council for Wales, Department for Employment and Learning (Northern Ireland)*

■ amount spent by AMRC member charities on research in UK, not including capital expenditure  
■ amount via CRSF in England and equivalents in Scotland, Wales and Northern Ireland

# 'I'm sure every charity would like more money, but we have to do the best with the resources that are available'

'Raising awareness of a rare disorder and encouraging more scientists and clinicians to want to do research on CGD [chronic granulomatous disorder] is not easy. It's also a huge challenge to keep research momentum going in this squeezed financial environment and to make sure that every project we fund is a winner. The CGD Society can't offer core funding but we have seen great returns through providing what we call seedcorn funding – grants of £35,000 to £40,000 a year.

We rely on a robust peer review process and a solid strategy, backed by AMRC's guidelines for small charities, to ensure that we make the right decisions. It is absolutely essential to be as transparent, fair and free of conflict of interest as we can be. We send every application, regardless of its size, to three reviewers. Whether the award is for £10,000 or £10m, we need a return for the money our donors put in the tin.

Broadening our medical panel has reaped huge benefits. Alongside our CGD experts, we've brought in expertise in gene therapy, infection and inflammation. This has truly widened our horizons. We've always had a great publication record for our research; now we're seeing our funding bringing in larger pots of money. One grant of £100,000 to a team in the US led to a \$2.2m grant from the National Institute of Health for work on developing next generation antibiotics. We are currently really excited about a new CGD gene therapy clinical trial, starting this year, using tools developed through our funding.'

Supporting research funders

'An evaluation service to look at the impact of our research funding is high on my wish list from AMRC. It's one of the hardest things to tackle but it's absolutely fundamental to be able to analyse our research strategy, look at what's worked and benchmark that against other charities.'

Dr Susan Walsh, research and support programme manager, Chronic Granulomatous Disorder Society





APPG on Medical Research summer reception

'Working closely with AMRC through the APPG on Medical Research really helps us convey messages to the heart of parliamentary debate and facilitates engagement between parliamentarians, researchers and patients on important issues in medical research, most recently around the health and social care bill.'

**Professor Sir John Bell, president, Academy of Medical Sciences**

The All Party Parliamentary Group on Medical Research brings together experts and practitioners, parliamentarians and policymakers to highlight the importance of health research. Our scientific adviser, Lord Turnberg, chairs the group, which is supported by the Academy of Medical Sciences, AMRC, Cancer Research UK, the Medical Research Council and the Wellcome Trust.

Science minister David Willetts saw the impact of our sector first hand, meeting scientists, research funders and patients at our summer reception in parliament.



TalkScience@BL

'Working with AMRC on Patients Participate! helped us focus on what would really make a difference for charities, patients and the public.'

**Dr Karen Walshe, research officer – biosciences, The British Library**

Communicating complex scientific information in accessible and engaging ways is a huge challenge. We asked over 40 member charities how they did it and what would help them talk to patients, supporters and the public about medical research. We joined the British Library and UKOLN, at the University of Bath, in the Patients Participate! project to look at ways to communicate scientific knowledge clearly to everyone.

## Encouraging meaningful engagement

'I am very impressed by the brilliant work done by Y Touring and AMRC, which has gained the sustained support of the Wellcome Trust. In the present climate this is especially pleasing and a tribute to high standards.'

**Dame Joan Bakewell, patron, Y Touring**

AMRC's partnership with Y Touring Theatre Company continues for another five years, with a Wellcome Trust £1m strategic award. Five new plays will debate biomedical research and its effects on individuals and society. The first, on the theme of 'pharmacogenetics' – the science of tailoring medicines to fit genetic make-up – will tour UK schools, be seen by young and adult audiences in cinemas nationwide, and be performed at the Royal Albert Hall during National Science and Engineering Week 2012.



Mind the Gap, Y Touring Theatre Company

'We were delighted to win in two categories. As our commitment to funding paediatric research has grown, so has our need to communicate how this research can leave a lasting legacy. Our *Breakthroughs in children's medicine* guides sought to capture this story from the perspective of the people involved in Great Ormond Street Hospital's 160-year history. The judges' comments reassured us that our message was clear and accessible to a non-specialist audience.'

**Adam Kamenezky, scientific research manager, Great Ormond Street Hospital Children's Charity**



AMRC Science Communication Awards 2011

'The fact that it gets more difficult year on year not to give a prize to all the entries is a measure of how the awards have driven up standards to a remarkable degree.'

**Professor Ray Tallis, emeritus professor of geriatric medicine and author, AMRC Science Communication Awards judging panel**

'Hearing loss affects 10 million people in the UK. By joining forces with other organisations under the AMRC umbrella, Action on Hearing Loss contributes to a unified and compelling message to government about the changes needed to help us conduct research that can deliver treatments, therapies and interventions that will benefit everyone.'

**Rob Burley,**  
head of public affairs,  
Action on Hearing Loss



## 'Working with fellow AMRC members to embed medical research in the health and social care bill, we're improving opportunities for research throughout the health system'

Patients and the public overwhelmingly want the NHS to support research on new treatments. When surveyed, 93% told us their local NHS should be encouraged or required to support research. And more than seven in ten said they would like to be offered opportunities to be involved in trials of new medicines or treatments.\*

The health and social care bill is an opportunity to embed research throughout the health system and to build a better environment that fosters research and innovation for medical research charities and others working with the NHS to conduct research.

Through PAWG, our policy network, we are working with members and partners to influence the debate. As the bill progresses through parliament, we are pressing for clarity and commitment in key areas of concern for research.

\*Ipsos MORI, 2011. Public support for research in the NHS. AMRC: London

'Working together reinforces our individual messages and combining forces to create a *Challenge for government*, tailored for the Scottish elections, was a major success. It helped put medical research on the election agenda and proved valuable in discussions with opinion-formers.'

**Fiona Selkirk, Medical Research Scotland**

In May 2011, Scotland went to the polls. With our PAWG Scotland network we worked to make science an election issue, producing five calls to build on Scotland's record of world-class medical research. We are now sharing information throughout the network and engaging with the new government to ensure that science is given the priority it deserves.



Connecting charities and policymakers



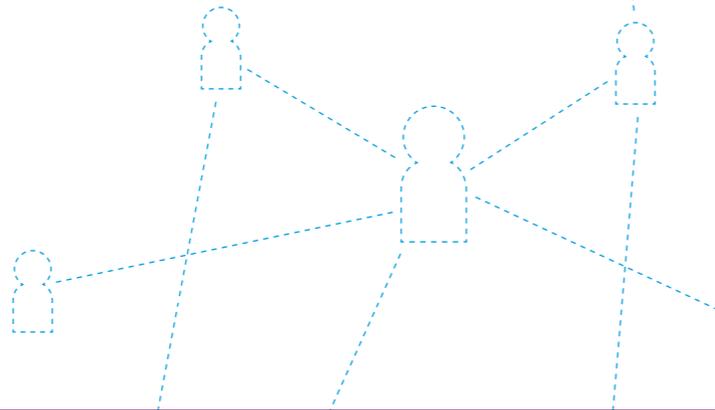
## Highlighting collaborations

# 'Seeing the MRC co-funding with Fight for Sight really encourages eye researchers'

'At Fight for Sight, we firmly believe that clinician scientists play a valuable role in translating research into benefits for patients, which is why we wanted to collaborate with the MRC on their clinical research training fellowship scheme.

We believe the collaboration has galvanised the sector and raised the profile of eye research. It's also given us increased credibility in this area and we've attracted some crackingly good candidates. Our involvement helped encourage more people to apply for fellowships, and three ophthalmology fellowships were funded out of a total of 24 awards in the first round. We're not large but we are the largest UK charity dedicated to funding eye research, so it's really important that we collaborate with other organisations to help prevent sight loss and treat eye disease.

Funding eye research is what we do – our researchers know that. Seeing MRC co-fund with us demonstrates that eye research is of national importance and that eye researchers can compete with the best clinical researchers in the UK.'

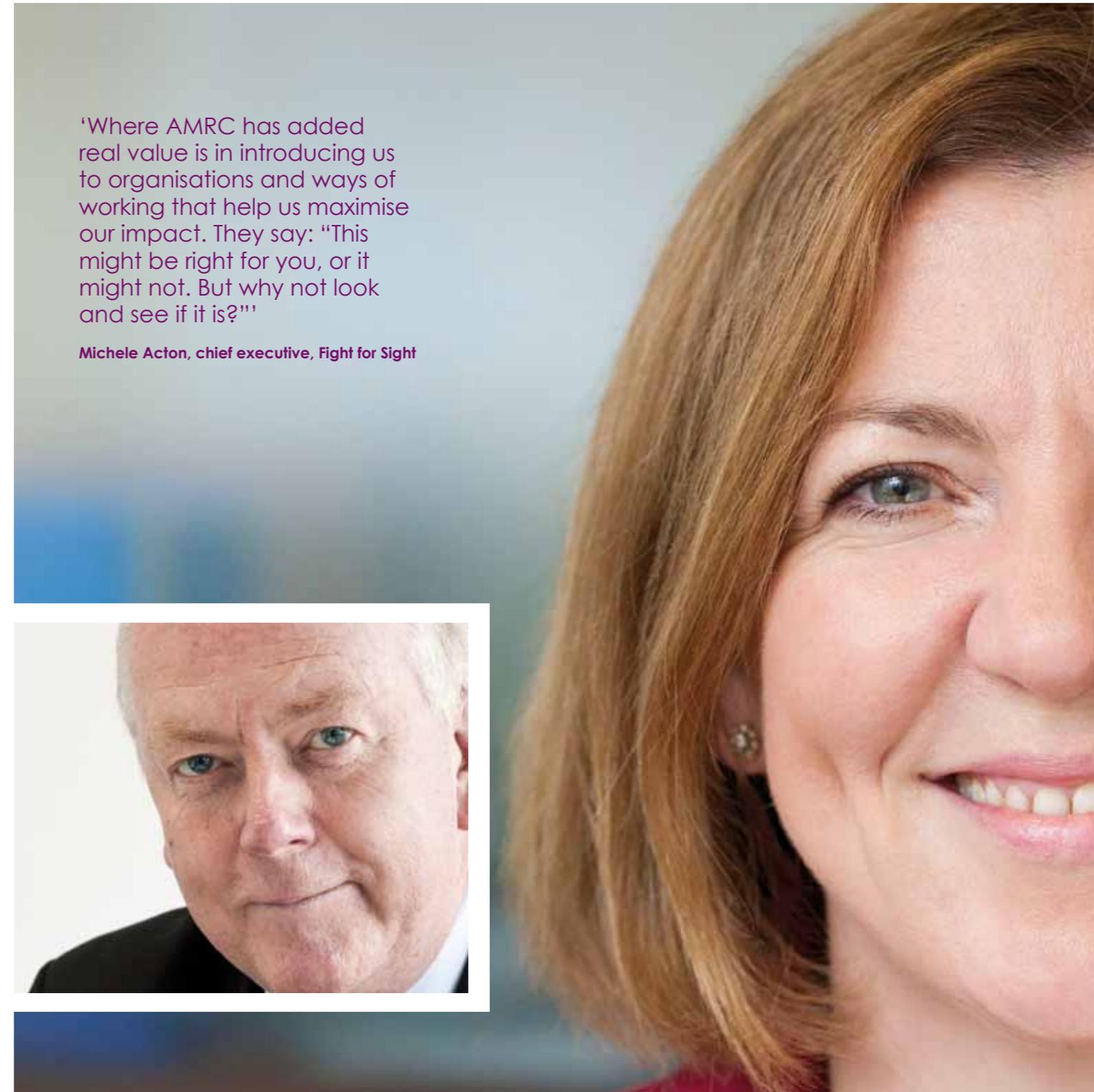


'In pooling resources, we get more than the sum of our investment. Charities bring a valuable connection to patients, both as research participants, and in really helping us to understand their views on controversial aspects of research. When we co-fund with charities we also attract new and different groups of young clinicians and scientists. This is essential if we are to make progress in understanding disease.'

**Sir John Savill, chief executive, Medical Research Council**

'Where AMRC has added real value is in introducing us to organisations and ways of working that help us maximise our impact. They say: "This might be right for you, or it might not. But why not look and see if it is?"'

**Michele Acton, chief executive, Fight for Sight**



# ‘Medical research charities were incredibly valuable partners as we argued that ‘Science is Vital!’’

Imran Khan, Campaign for Science and Engineering

It has been a year of outstanding achievement for AMRC. We supported members with practical help and guidance, steered a working group developing advice for charities on intellectual property, coordinated wider membership of UK PubMed Central and audited members’ peer review processes.

Our Science Communication Awards challenged members to show us their outstanding examples of engagement and science communication. And we took stem cell science on the road with the UK National Stem Cell Network, visiting Edinburgh, London, Manchester and York. Fourteen members have approached or now work with the James Lind Alliance, involving clinicians and patients in agreeing priorities for research.

We continued to grow our policy networks of members and key strategic partners. Joining forces with industry bodies ABPI, BIA and ABHI, we hosted party conference discussions. We also raised the profile of medical research during the elections in Scotland. Charities stood alongside the scientific and engineering community to make the case for continued investment in UK science, and the government duly recognised science and research as growth areas.

‘Being able to show a collaborative and joined-up approach between industry and medical research charities was a powerful selling point for policymakers ahead of the spending review.’ Nigel Gaymond, BIA

Working in partnership

‘MRC-funded research groups are supported by over 100 UK-based charities. Working with AMRC has helped us understand small charities’ requirements and identify organisations that could take part in a pilot of a joined-up approach for gathering output data.’ Dr Ian Viney, Medical Research Council

‘AMRC played a key role in designing and facilitating a process through which members could join UK PubMed Central. Eight new funding organisations joined UKPMC in 2011 – each now able to ensure that the outputs of the research they fund are freely and widely available.’

Alison Henning, Wellcome Trust

‘We want the best possible environment for MND research to prosper. Asking researchers to deposit their research papers into UK PubMed Central was too good an opportunity to miss.’ Dr Belinda Cupid, Motor Neurone Disease Association

‘Benefiting from innovation: intellectual property advice for medical research charities was a hit with the charity sector, the government, academia and industry. We will all work with AMRC to build on the report, support AMRC members and boost the intellectual property credentials of the medical research charity sector.’ Dr Doug Brown, Multiple Sclerosis Society

‘The stem cell roadshows were excellent. We were fortunate to have such knowledgeable speakers with the skills to engage a lay audience and put across the exciting discoveries in the stem cell and regenerative medicine fields.’

Shirley Nurock, Alzheimer’s Society Research Network Volunteers

# amrc

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