Charities at the heart of UK life sciences

Annual Review 2013–14
It is my great pleasure to welcome you to our review of 2013–14. This has been a year of great achievement for AMRC and its members. Our members play a major role in the medical research community, putting the patient voice at the heart of the life sciences. For four of the last five years, charities’ spending on research here in the UK has increased, amounting to £1.3bn last year. Our charities are dedicated and innovative; no wonder medical research is our most popular charitable cause.

The life sciences sector is uniquely strong in the UK and, throughout the year, our members worked in partnership with the life sciences community. A major AMRC workstream exploring successful ways of navigating the industry-charity relationship and examining the next steps for our sector will come to fruition this autumn, with the launch of our revised guidelines on working with industry – truly an essential partnership.

At AMRC, our role is to support our members. We provide opportunities for charities to connect with each other and the wider research community. Our mission is to represent the collective charity voice as we all work together, ensuring that the environment for medical research is the very best it can be.

As incoming chief executive, I am indebted to my predecessor, Sharmila Nebhrajani, for the strong foundations she established while at AMRC. Her passion and drive saw the association grow in both size and stature. I hope to bring my knowledge and experience of the biotechnology, pharmaceutical and charity sectors to ensuring the collective charity voice remains as strong and influential as ever.

AMRC and its members face an exciting and challenging year – with a general election and a spending review on the horizon. We will continue to work with our members to ensure that they in turn can continue to fund lifesaving research to improve the lives of patients, their families and carers.

Aisling Burnand MBE
chief executive, AMRC
Charity funding: integral to life science success

£1.5bn
AMRC members spent £1.5bn on research in 2013, mostly on UK-based projects.
AMRC research expenditure database 2013

£1.3bn
Together our members spent £1.3bn on research in the UK – accounting for over a third of all publicly funded UK medical research.
AMRC research expenditure database, 2013; MRC and NHF annual reports 2013. Spending on research by health departments in Scotland, Wales and Northern Ireland not illustrated

Funding across the UK
In 2013, AMRC charities funded research in 364 institutes, universities and NHS facilities across the UK.
AMRC research portfolio database 2013; grants active 2013

At all stages of the research process
61% of charities fund research on disease prevention and the development of new diagnostics and treatments.
AMRC research portfolio database 2013; grants awarded in 2013 were coded according to the Health Research Classification System
59% of charities fund research to understand the cause of disease.
30% of charities fund research to advance disease management and health services.
Charity funding for research year-on-year

Research is a long-term commitment, requiring sustained investment over many years. AMRC member charities have consistently spent more than £1bn on research in each of the past six years, in large part thanks to the public who make medical research their number one charitable cause.

AMRC research expenditure database: capital spend not included

133 members

AMRC members include the largest medical research charities in the UK: Cancer Research UK, the British Heart Foundation and the Wellcome Trust. All our members, large and small, work to the same high standards, ensuring that every pound they spend on research is invested in lifesaving research of the very highest quality.

UK research Number of members

£999m 2
£135m 3
£138m 45
£12m 17
£10m 66

Financial years

2008 2009 2010 2011 2012 2013

0 200 400 600 800 1,000 1,200 1,400

UK research spend (£)

Funding essential health research

Cancer, infection and generic health research (research applicable to multiple diseases and conditions) receive over 50% of funding.

AMRC research portfolio database: grants awarded in 2013 were coded according to the Health Research Classification system (HRCS) to give a detailed picture of the areas of health research supported by our members. Some grants were not coded because they were outside the HRCS coding system (3.3%) or had insufficient information (4.3%).
Charities are evolving from a primary emphasis on grant funding to becoming a driving force to advance scientific development and lead innovative, patient-centred research. It is clear that to achieve these goals we will all increasingly seek opportunities to develop novel partnerships and collaborations.

Fifty-six AMRC charities, seven research councils and the NHS are using Researchfish to measure research outcomes and impact and inform future strategy. Whether using a shared tool to measure research impact or co-funding a research project, AMRC provides a platform for our members to pool resources and knowledge. Funding from charities can be the vital step in getting treatments to patients. Throughout the year, we saw examples of charities not only supporting early stage, proof-of-concept research but also leveraging government funding, providing a significant stream of follow-on funding for research council-funded projects. Some are developing research infrastructure and supporting collaborations with industry. Others are establishing shared mechanisms, such as the Charities Open Access Fund, which will help scientists and researchers make the results of their research more freely available.

Through tools like Researchfish, the sector is beginning to look ‘under the bonnet’, in order to understand the complex interrelationships between funders. This will be vital information for those seeking to develop complementary funding strategies.

“Thanks to early studies funded by Sparks and other charities, researchers were able to get further funding from the MRC and industry to set up clinical trials looking into the effects of cooling therapy on newborn babies who had been starved of oxygen. This technique has now been adopted by the NHS, saving around £200m a year.”

Julia Ambler, director of medical research, Sparks

“The Myeloma UK Clinical Trial Network brings together researchers, the NHS, patients and pharmaceutical companies to prioritise the most promising myeloma drugs, and to break down the barriers that delay clinical research studies so they can be delivered more quickly and effectively.”

Eric Low, chief executive, Myeloma UK

“We have a real duty to make the end results of supporter-funded research freely available, and we know that greater access and use of research results maximises its impact. AMRC was instrumental in drawing together the expertise of the open access partners to form consistent policies and processes. This will make it easier and more cost-effective for ourselves, researchers and universities, and allow a stronger collective voice in our advocacy.”

Matt Kaiser, head of research, Leukaemia & Lymphoma Research

Encouraging collaboration

Fifty-six AMRC charities, seven research councils and the NHS are using Researchfish to measure research outcomes and impact and inform future strategy.

For every £1 a charity spends, the government gives universities up to an extra 28p for the indirect costs.

The Charity Research Support Fund helps pay for the indirect costs of research, ensuring that charities fund only direct costs, in line with their charitable objects. As charity funding grows year by year, CRSF will need to keep pace.

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Patient records have the potential to make a huge difference to medical research in the UK. Giving researchers access to the data stored in these records will allow them to better understand disease and develop treatments that can save and improve lives.

In 2014, we updated our position statement on the use of patient data for research. Regulations governing use of these data are ambiguous, and as a result it can be difficult for researchers and people in charge of the data to follow them. We called for a clearer and more agile regulatory framework in order to provide safe and efficient access for researchers and meet the challenges posed by new technologies.

Charities have unique insights into the needs of both patients and researchers. They understand the potential of data held in patient records to improve the care that people receive and to be used in the development of new treatments. Over the past 12 months, we have worked with our members to promote the ethical sharing of data for research. We believe it is possible to share data to facilitate research while protecting patient confidentiality, so that people can be confident that the personal nature of their information is respected. The controversy of the care.data programme highlighted the need to make this case in a compelling way and to ensure that robust safeguards are put in place to protect privacy.

Alongside several members, we supported a public awareness campaign to help everyone weigh up the costs and benefits of sharing their information. We gave evidence to the Health Select Committee on the care.data programme and, through the APPG on Medical Research, held roundtable discussions with APBI and Genomics England on building public trust around the use of personal data in research.

In the coming year, we will continue to raise awareness of the value of patient records for research and monitor the progress of care.data. And we will work with NHS England, the research community and our members to support the sharing of patient records for research.

Unleashing the power of patient records

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Championing research in the NHS

Since publishing Our vision for research in the NHS, AMRC has been working with its members and other research funders, NHS England, and regulatory bodies to make that vision a reality.

Promising steps have been taken over the past year. The Health Research Authority is implementing its single assessment for NHS R&D approvals, which will streamline the process for researchers, NHS England has, for the first time, included research in its standard contracts for NHS organisations commissioning services, and the Shape of training review has been completed, which states that research should form an essential part of a doctor’s training.

But all this is work in progress. We need everyone to work together to embed a culture of research in the NHS. More can be done to give patients opportunities to take part in research, to help NHS staff see the importance of research, and to ensure that the NHS is able to conduct high-quality research and adopt new treatments. It is also essential that the NIHR and MRC budgets are protected in future spending decisions to ensure a healthy stream of medical innovation.

A new survey conducted on behalf of the National Institute for Health Research Clinical Research Network (NIHR CRN) shows that 89% of people would be willing to take part in clinical research if they were diagnosed with a medical condition or disease. An all-time-low figure of just 3% said they would not consider it at all. The survey also reveals that 95% of people think it important that the NHS carries out clinical research.

AMRC will continue to work with the NHS to encourage patient-centred research, and to ensure that new commissioning mechanisms do not prevent charities carrying out valuable research in the NHS.

In our vision for research in the NHS, we called on the NHS to ensure:

• Every patient is offered opportunities to be involved in research
• All NHS staff see the importance of research
• The NHS conducts high-quality research and adopts new treatments.

“Championing research in the NHS”

“At the Stroke Association, we worked with the Greater Manchester Collaboration for Leadership in Applied Health Research and Care, local NHS trusts and stroke networks to develop a stroke assessment tool, which is now being used throughout the UK, improving how the NHS identifies and meets the needs of patients who have had a stroke.”

Dale Webb, director of research and information, Stroke Association

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• Every patient is offered opportunities to be involved in research
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“Flexibility within the clinical academic pathway is vital if doctors are to be encouraged to build research into their careers. It’s great that the Shape of training review recognises this. The Medical Schools Council strongly supports multiple entry points to attract, incentivise and retain the most talented doctors and to provide research opportunities for all.”

Katie Petty-Saphon, director, Medical Schools Council

30% of non-commercial research on the NIHR portfolio is funded by charities.
Research involving animals plays an important role in increasing our understanding of medical conditions and in finding new treatments and cures. It has been a key policy area for AMRC this year, as we supported our members to strengthen their communications and research processes. Not all members fund animal research, but we all agree that, for now, it is a necessary part of the research process where there are no alternatives.

With the help of our Animal Research Working Group, we published policies and guidance, helping everyone integrate the 3Rs (replacement, reduction and refinement) into their peer-review practices for grants involving animals. We’re also starting to collect more detailed data on the research using animals that our charities fund. In this way, we will have a clearer view of the breadth of our members’ research, and how animal research fits into this bigger picture.

In 2014, we signed the Concordat on Openness on Animal Research, signalling our sector’s commitment to communicating openly about research involving animals. We have since released guidance for members on meeting the Concordat’s commitments, published a leaflet for the public explaining why medical research charities fund animal research, and held a press officers’ workshop with the Science Media Centre, where charities, universities and journalists shared examples of openness and transparency.

82 member charities have taken part in animal research-related activities with AMRC in the past two years.

Animal research

“Charities have a much closer relationship with patients and the public than many in academia and industry. In the past, some feared that being open about animal research might damage that relationship, and many kept quiet. Under the leadership of AMRC, and with the Concordat nudging things forward, that culture is really changing. Household names are now proudly talking about the use of animals as part of the great stories they tell about pioneering scientific research into new treatments and cures.”
Fiona Fox, chief executive, Science Media Centre

“Talking openly about research involving animals can still be a daunting and lonely experience for many charities, so attending AMRC’s workshop was enormously helpful. It gave us all a chance to discuss our experiences and concerns in a safe and supportive environment and learn from the experts like the Science Media Centre. I came away with much more confidence and knowledge about how to effectively communicate about animal research.”
Claire Bale, research communications manager, Parkinson’s UK

“The new strategic partnership between the NC3Rs and the AMRC demonstrates the importance charities are placing on laboratory animal welfare and the search for technologies which minimise animal use in medical research.”
Vicky Robinson, chief executive, NC3Rs

“Animal research is an essential element in helping us find new treatments for heart disease, and British Heart Foundation is committed to being open about when and why we fund animal studies. One of the key roles of the AMRC is to enable charities to share best practice so that use of animals can be kept to a minimum.”
Peter Weissberg, medical director, British Heart Foundation
Our highlights in 2013-14

We received 58 entries to our AMRC Science Communication Awards. Over 150 people attended the awards reception in Whitechapel Gallery.


In the run-up to the May 2014 European elections, we coordinated an awareness campaign with members and partners. Thirty-five candidate MEPs pledged to support medical research in Europe.

Our policy and research teams provided 16 consultation responses and written evidence submissions on behalf of the sector.

Attendees across our 26 events topped 1,000, providing many opportunities to foster collaboration, share experiences and shine a spotlight on our members’ work.
The benefits of membership

**Quality hallmark**
AMRC membership is the hallmark of quality research funding.
All members demonstrate to donors and the public that every pound invested by AMRC charities is going to research of the highest standard through:
- Publishing a research strategy
- Producing a clear policy on conflicts of interest
- Funding high-quality work by following AMRC standards in peer review.
We assess charities’ peer review processes when they apply for membership and audit them every five years.
Universities, government and funding bodies use AMRC membership as an indicator of quality.

**Collective voice**
AMRC is the strong collective voice for medical research charities in the UK.
AMRC members are part of a network of over 130 medical and health research charities, funding £1.3bn of medical research in the UK.

**Your funding goes further**
- Charity Research Support Fund (CRSF) providing up to 26p for every charity pound, amplifies AMRC member funding in universities when awarded through open competition.
- Under AcoRD, AMRC members only pay the direct costs of clinical research in the NHS, with additional funding support from the regional networks.
- Members with an annual research spend of up to £25m can use the Researchfish research outcomes tool at no cost until 2015.

**Support**
- One-to-one support
- High-quality training workshops and seminars on emerging issues facing our members
- Pragmatic guidance and toolkits which members can use in their own work
- Our peer review audit demonstrating that our members work to the highest standards and ensuring that our principles keep pace with best practice

**Influence**
- Influence the policy, regulatory and research environment, enabling members to achieve their aims
- Scan the horizon for key developments
- Interpret the environment, providing information about the world in which members operate
- Represent the collective charity voice to government, partners and other stakeholders

**Connect**
- Collect and share sector data
- Create opportunities for members to share learning, avoiding duplication of effort and maximising the value of all they do
- Offer opportunities for charities to work with industry and public funders
- Encourage collaboration and share best practice
- Promote members’ work to each other and the wider world
- Support the medical research charity community

To find out more and discuss whether membership would be suitable for your charity, please contact Dr Sara Ellis, head of member engagement and communications: s.ellis@amrc.org.uk 020 7685 2624