

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

With thanks

To the many members of AMRC who supplied images

- 1 Grant Burton Photography
- 2 Sparks
- 3 Chest Heart & Stroke Scotland
- 4 JDRF
- 5 Great Ormond Street Hospital Children's Charity
- 6 Association for International Cancer Research
- 7 Great Ormond Street Hospital Children's Charity
- 8 Chest Heart & Stroke Scotland
- 9 JDRF
- 10 Great Ormond Street Hospital Children's Charity
- 11 Kidney Research UK
- 12 Grant Burton Photography
- 13 Autistica – photo by Michael Crabtree
- 14 Cancer Research UK
- 15 British Heart Foundation
- 16 Cancer Focus Northern Ireland
- 17 Myeloma UK
- 18 Arthritis Research UK
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- 22 Sparks
- 23 British Lung Foundation
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Charities – a unique contribution

Welcome to our review of the past 12 months – the first of my tenure as chief executive. I've spent much of my first year meeting members as part of developing our new strategy. The more I have listened to our members and stakeholders, the more I have been struck by the unique contribution charities make to research across the UK.

Our member charities, often funded by donations from patients, carers and families, really do represent the patient voice in research. In the UK they collectively invest over £1bn every year. This investment is independent of funding by government and industry, but our members can and do collaborate with both. And there is no doubt in my mind that the fact that the UK leads the world in the life sciences is due in no small part to the contribution of charity-funded research.

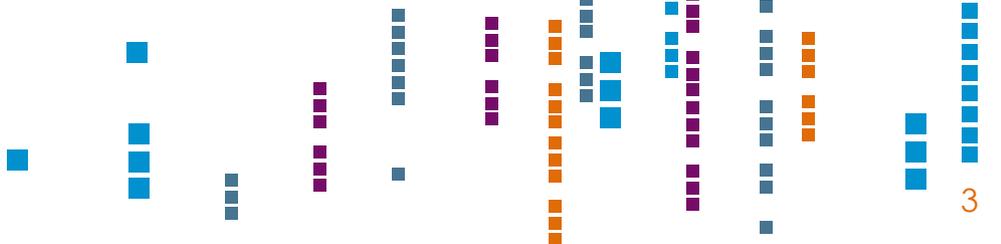
But notwithstanding that strength, demand for new therapies and cures increases. Funders will not only need to do more with less, a notion with which we have all become a little over-familiar. They will also need to do things more speedily with less.

Collaboration between charities, industry and the government to translate research rapidly, from lab to hospital, will be key. Charities are often highly innovative and agile and can play a unique role in bringing these advances quickly to patients.

So, I believe that charities, with their fiercely guarded independence, their commitment to the very best science and their tenacious support from patients and the public, are in a position to bring their unique contribution to the research landscape.



*Sharmila Nebhrajani,
chief executive*



Charity-funded research in 2011

Charities fund over £1bn of medical and health research in the UK.

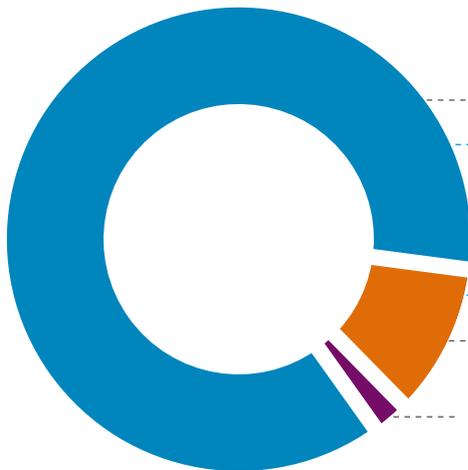
*AMRC research expenditure database 2011;
MRC and NIHR annual reports, 2011*

National Institute of Health Research
£921m



AMRC member charities
£1,137m

Medical Research Council
£798m



UK **£1,137m**

Overseas **£121m**

Capital projects **£34m**

AMRC members invest in medical research, here and overseas.

AMRC research expenditure database, 2011

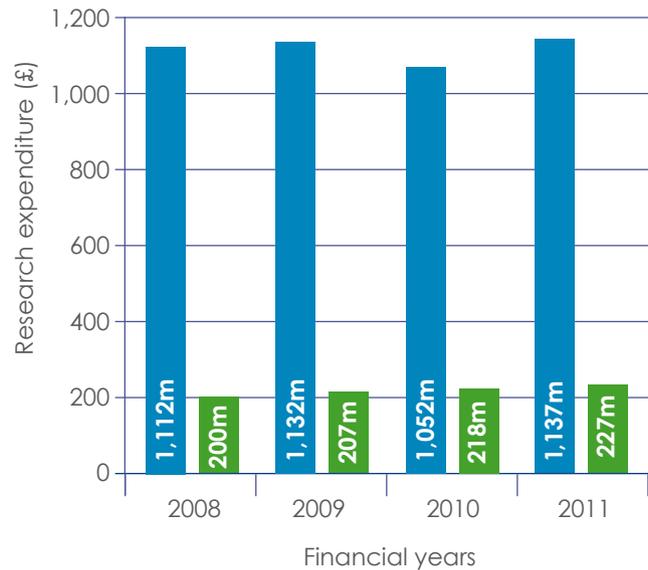
Supporting research of the highest quality

In spite of tough economic circumstances, AMRC member charities have together invested over £1bn in research in each of the past four years.

Within that, 2010 was a tough year for our members, with spend £80m down on 2009. While a third of that is attributable to adjustments in accounting, more than 50 members reported falls in expenditure.

The overall figure has recovered in 2011, but this hides a mixture of growth and contraction, and members tell us they expect pressure on funding to continue.

Government support via the charity research support fund (CRSF)* has continued, and from October 2012 similar support, under the AcoRD^o agreement, will be available to AMRC members funding research in the NHS.



- Amount spent by AMRC member charities on research in UK, excluding capital expenditure
- Commitment from CRSF in England and equivalent funds in Scotland, Wales and Northern Ireland

AMRC research expenditure database, excluding capital expenditure, HEFCE, Scottish Funding Council, HEFCW, Department for Employment and Learning (Northern Ireland).

This year we changed the way we collect and analyse our members' expenditure data to improve consistency and speed up data collection. Figures from 2008 and 2009 were reported previously as 2009–10 and 2010–11, and have been restated accordingly.

**Charities' investment in research in UK universities is amplified by a government funding stream, termed the charity research support fund in England, which meets the indirect costs of research, ensuring that charities fund only the direct cost of research, in line with their charitable objectives.*

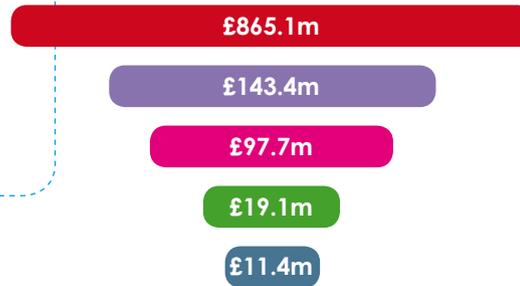
^oAttributing the costs of health and social care Research and Development

A diverse membership

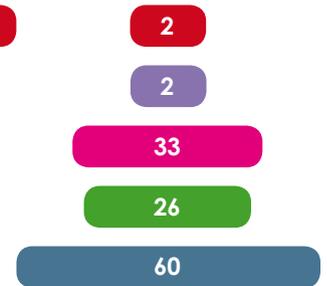
AMRC members include the largest medical research charities in the country and the smallest.

AMRC research expenditure database, 2011. NB graphic not to scale

UK research expenditure



Number of members



With a diversity of purpose

Our member charities, often funded by donations from patients, carers and families, really do represent the patient voice in research.

Many of our members were established to fund research – hence it makes up the greatest part of their charitable activities.

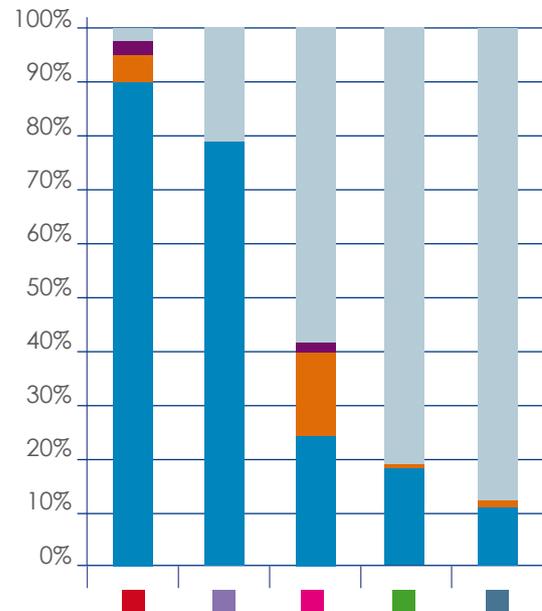
But for others, their focus includes welfare, support, care, education and information, alongside investing in research.

Spending as a proportion of total charitable activities

- Research in UK
- Research overseas
- Capital projects
- Other non-research charitable activities

AMRC research expenditure database, 2011

Total spending on charitable activities
£958m £182m £420m £110m £96m

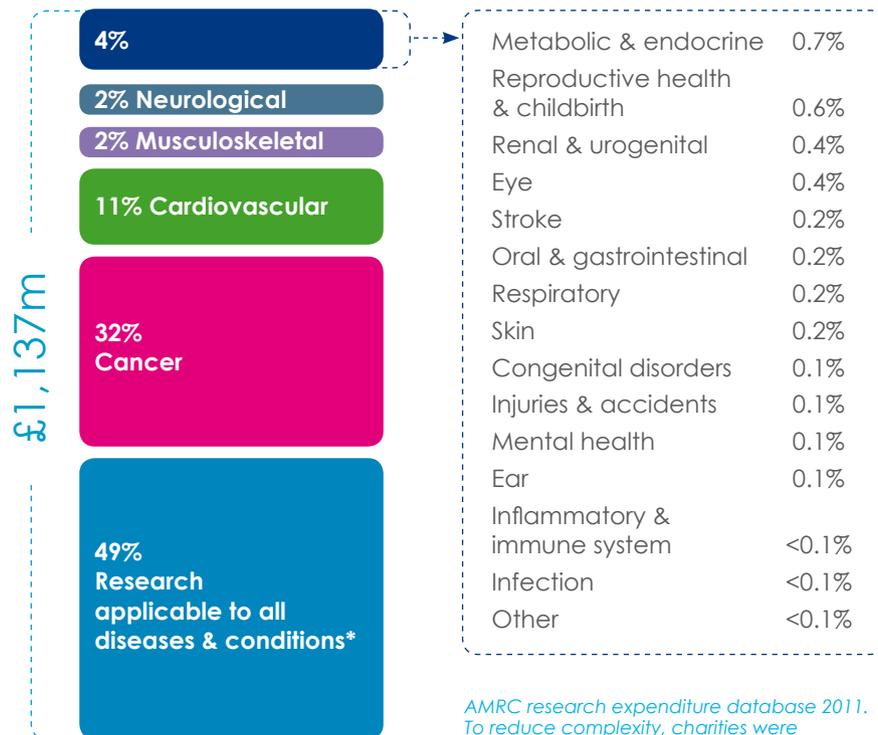


■ Over £200m
 ■ £15m – £200m
 ■ £1m – £15m
 ■ £500,000 – £1m
 ■ Less than £500,000

Supporting diverse research areas

For the first time we present AMRC members' headline research spend, categorised by the Health Research Classification System (HRCS).

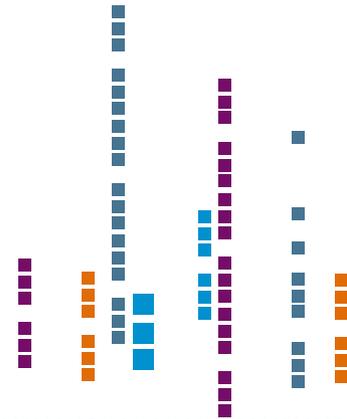
Using this preliminary analysis, in 2012–13 we will analyse members' grant data according to HRCS, to build a more detailed picture of UK health research funding.



AMRC research expenditure database 2011.
To reduce complexity, charities were assigned a single health category; in practice many charities fund across several categories

* Equivalent to HRCS class generic health relevance

Charities finding their unique space in the research landscape



Tenovus spends about £1m a year on research, alongside what we spend on patient care and support. A few years ago we reviewed everything we do, and even questioned whether we should continue to fund research. We identified distinctive research areas where Tenovus could make a real difference. Our new research strategy avoids duplicating other funders and is relevant to people in Wales affected by cancer.

Wales attracts less research funding per capita than other areas of the UK and we are a net exporter of life science graduates. So Tenovus now invest £0.5m each year in PhD studentships to help build capacity and develop future research leaders.

It's vital that we identify the best projects to fund – and that's where we rely on peer review. This takes up a lot of resources, especially when you have a small team. When I first started at Tenovus, I attended several AMRC training courses. That grounding, plus meeting research managers from other charities, was invaluable.

We talk a lot about how charities couldn't function without volunteers. For Tenovus, that means volunteers in shops, fundraising groups and on support lines. But the incredibly busy people in the research community who give their time to read over our applications are also Tenovus volunteers as far as I'm concerned!

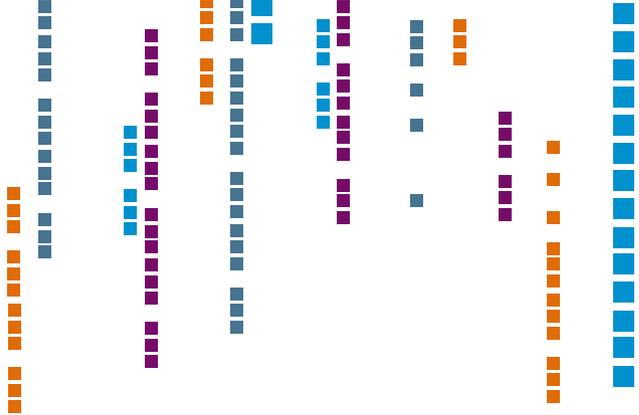
Evaluation and demonstrating impact are increasingly important, not only internally but also so we can say to everyone who supports us: this is what we achieved with your contribution. We've just signed an agreement to start using *Researchfish*, which I believe will help. Not only with the immediate outputs, publications, but also with tracking the longer-term benefits of our research.



*Dr Ian Lewis,
assistant director of research, Tenovus*

'AMRC is really useful for us in working with other charities across diseases. A lot of our collaborations are with other cancer charities. But as we expand into health, wellbeing and prevention, we have increasingly more in common with other charities.'





'We're embedding research and evaluation in everything we do.'

IMPACT

Medical research is the UK's most popular charitable cause, with 11 million people donating an average £11 month.

Source: NCVO/CAF (2011) *UK Giving 2011*

'We've got a great student at the moment. He's a very bright guy, and he's probably going to be a really big name in cancer research one day. I want to be able to say in five years time, "Look at everything this guy's achieved – we helped. Without charity funding he couldn't have done it." And I want an evaluation tool to help me do that.'

Dr Ian Lewis, assistant director of research, Tenovus



Charities and industry working together to benefit patients

JDRF is absolutely focused on finding the cure for type 1 diabetes. But along the way our research has the potential to deliver other benefits – better treatments, devices and drugs.

Looking at our global research portfolio, we realised a lot of great ideas weren't crossing that translational research gap and reaching patients. So we set out to stimulate some of that research. We talked to industry, biotechs, pharmaceutical companies and regulators and asked what was holding back funding in that space. Quite often, it was attitudes to risk.

Well, we can't take that risk away, but we can help minimise it by bringing the credibility of the JDRF name and a perspective on what matters to patients. That's where our *Industry Discovery and Development Partnerships Program* comes in. We offer companies investment to enable them to take on a discovery, prove it works, get other investors involved and take it to the next stage.

Glucose-responsive insulin is an exciting development. JDRF funded the initial research, which was then picked up by a major pharmaceutical company with

the resources to take it through to the next stage of development. At the same time, we put out a call for research proposals to develop different types and delivery of insulin. Planning to award just one prize, the quality was so good we gave three. So now there are four possible routes that might benefit patients. That's why JDRF puts money into the translational space – to get vital developments to people.

'Medical research charities like JDRF are in the wonderful position of having an overview of our patients' experience of disease. That's what we live – all day every day, though our supporters.'



*Karen Addington
chief executive, JDRF*



IMPACT

Public spending on medical research can stimulate private R&D investment – an extra £1 from public funders can generate £2.20–£5.10 from industry.

Mestre-Ferrandiz and Sussex (2009) Forward together: Complementarity of public and charitable research with respect to private research spending

'Why should JDRF give anything to a company? Well, first of all, it's not given; it's an investment, with clear milestones and a chance of real payback at the end.'

Karen Addington, chief executive, JDRF

**Join us in
finding the cure for
type 1 diabetes**

Charities funding more clinical research than ever

It's our 60th anniversary next year – and we've been funding research for 57 of those years.

This is an exciting time for charities to be funding clinical research. In many fields there are more opportunities, than say ten years ago, because research has now reached a point where it can be translated into patient benefit.

In the early days, our research focused on the basic biology of MS. But we've come to understand so much more in the past ten to 15 years. We're now making a concerted effort to translate that knowledge into new services and potential treatments. Our members

and people affected by MS expect us to do that, and we hope to be able to fund even more clinical research in the future.

Although there have been various forms of guidance on attributing research costs in the NHS, sometimes it hasn't been clear who is responsible for what. AMRC played a key role in showing how important the charity sector is in funding clinical research and helping to negotiate AcoRD (Attributing the costs of health and social care Research and Development). It benefits all AMRC members which support research in the NHS, and we all really welcome it. It gives us a strong set of guidance to work

to, and it gives us the assurance that charities can continue to focus on funding the direct costs of clinical research.

In our experience, there are still issues around getting excess treatment costs covered. If those costs end up falling to a charity, overall we'll end up funding less research. So in future we'll need to work together to make sure AcoRD is implemented and enforced appropriately.

'AMRC is a strong, coherent, influential, national voice on sector-wide issues. Attributing research costs and excess treatment costs affect all medical research charities. AMRC is there to gather our evidence and present it in a way that can really influence change.'



*Dr Doug Brown,
head of biomedical research, MS Society*



IMPACT

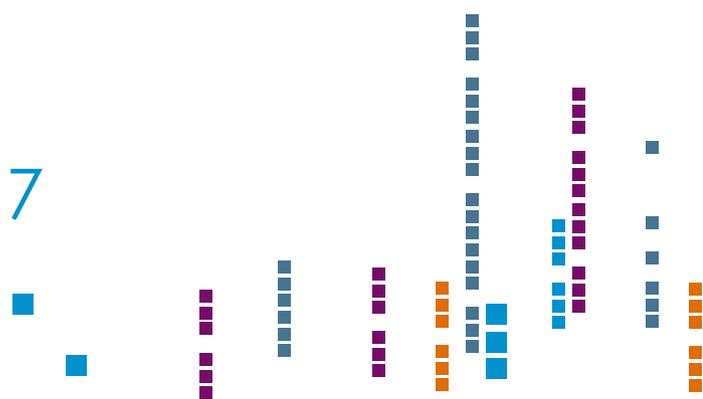
In 2011 AMRC members funded 32% of active NIHR-led studies.

Source: National Institute of Health Research

'The UK is unique in its ability to carry out non-commercial clinical studies, because we have funders committed to this type of research, and we have the NHS. Effective partnership with the NHS is vital for this research to continue to develop new treatments for patients.'

Dr Doug Brown, head of biomedical research, MS Society

Our strategy for 2012–17



This summer we set out to develop a new strategic framework for 2012–17. We held four workshops around the country, inviting our members to think about what they need from AMRC in the future.

The outcome, our new strategy, holds at its heart two essential thoughts:

- AMRC membership is a hallmark of quality
- and AMRC should be the strong collective voice for medical research charities in the UK.

Our new vision

Charities delivering high-quality research to improve health and wellbeing for all

Our new mission

To achieve our vision, AMRC will:

- Support our member charities to fund research of the highest quality
- Be a strong collective voice for medical research charities
- Interpret and influence the political and regulatory environment
- Encourage innovation and collaboration
- Emphasise the importance of public investment in researchers and research infrastructure

...and demonstrate AMRC membership as the hallmark of credible medical research charities.

Our new strategic framework has three elements:

1

SUPPORT

AMRC should help members meet their charitable objectives. We will:

- Offer high-quality training and seminars, and ensure that the topics we cover reflect emerging issues facing our members
- Focus on producing pragmatic guidance and toolkits, which our members can use in their own work
- Continue to operate a rigorous audit of the peer review processes on which our quality hallmark is founded.



2

INFLUENCE

Our role is to ensure as positive a climate as possible for research charities. We will:

- Scan the horizon for key developments
- Interpret the legislative and political environment so our members don't have to
- Represent the collective charity voice with government, partners and other stakeholders.



3

CONNECT

Medical research charities comprise a vibrant community with enormous potential to collaborate and learn from each other. We will:

- Share with our members the valuable quantitative data we collect from them
- Offer opportunities for charities to work with industry and public funders
- Create opportunities for members to share learning, to avoid duplication of effort, and maximise the value of all they do.





Our highlights of 2011–12

Membership

AMRC membership at the end of the year stood at 123, including three new members

Peer review audit

We completed an audit of members' peer review processes, demonstrating our members' continued commitment to the highest quality research

Embedding research across the NHS

We worked with member charities to respond to the health and social care bill and influenced stakeholders to establish research as a statutory duty throughout the NHS

97 per cent of the public believe it's important for the NHS to support research into new treatments, according to a poll of nearly 1,000 adults commissioned by AMRC, Breast Cancer Campaign and the British Heart Foundation

Agreement on clinical research costs

We negotiated with the Department of Health a new mechanism for costing clinical research in the NHS, which recognises that charities can only pay the direct costs of research

Collaborating with industry

We joined forces with the UK life sciences industry bodies ABPI, BIA and ABHI to host discussions at the party conferences about what MPs and the government can do to help us deliver treatments more quickly to patients, and grow the life sciences sector in the UK

Promoting the importance of data for research

Patient data continues to be a key issue for AMRC

We discussed the importance of patient data with our members, promoted awareness of how critical access to data is for research and distributed a leaflet to GP surgeries across the UK

Providing high-quality information, guidance and training

Members rated providing information, guidance and best practice our top strengths in last year's member survey

Our workshops and training events attracted 160 delegates from 76 different organisations

We posted over 130 articles on our policy blog, which doubled its page views in 2011–12

Delivering a new strategic plan

Over half our members took part in four strategic review workshops around the country and responded to our online survey, helping us to develop a new strategic framework for 2012–17

amrc

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