AMRC submission to House of Lords Science and Technology Committee Inquiry on ‘Setting science and technology research funding priorities.’

The Association of Medical Research Charities (AMRC) welcomes the opportunity to submit written evidence to the inquiry.

AMRC

AMRC is a membership organisation of the leading medical and health research charities in the UK. Working with our member charities and partners, we aim to support the sector’s effectiveness and advance medical research by developing best practice, providing information and guidance, improving public dialogue about research and science, and influencing government.

Established in 1987, AMRC now has 120 member charities that contributed over £935 million\(^1\) to research in 2008-2009 aimed at tackling diseases such as heart disease, cancer and diabetes, as well as rarer conditions like cystic fibrosis and motor neurone disease. Over the past six years AMRC charities have spent over £4 billion on research in the UK, contributing significantly to our knowledge and understanding in the life sciences, medicine and health.

Our evidence is based on the views and opinions expressed by member charities in response to an AMRC survey conducted in September 2009\(^2\). Comments from members in response to the survey have been included in text boxes in our submission where relevant.

We are aware that many of our members have also submitted written evidence to the Committee. These naturally reflect concerns specific to their field. Nonetheless we believe consistent themes emerge which we hope the Committee will note in the course of its inquiry.

What is the overall objective of publicly-funded science and technology research?

With respect to medical and health research AMRC believes that the overall objective of publicly-funded science and technology research is to improve health and wellbeing, prevent and cure disease where possible, and diagnose, treat and ameliorate where not.

How does the UK’s science and technology research funding strategy and spend compare with that in other countries and what lessons can be learned? In this regard, how does England compare with the devolved administrations? How will the current economic climate change the way that funds are allocated in the future?

The UK has a diverse and vibrant medical research charity sector which contributes approximately one third of all public funds to research in the UK. Of the £935 million of spent by our members on research in 2008-2009, approximately 83% was spent in England, 14% in Scotland, 2% in Wales and 1% in Northern Ireland\(^3\). This pattern of expenditure has remained consistent in recent years and we do not anticipate significant changes in the foreseeable future.

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\(^1\) Based on AMRC subscription data collected 2008/09
\(^2\) Online survey conducted by AMRC in September 2009 to which 26 member charities responded in full.
\(^3\) Op cit
AMRC data shows that the UK charity sector is second only to the US in terms of its expenditure on medical and health research and far exceeds the contribution to research by NGOs in Canada and Europe. The UK sector is also a global leader in terms of its expenditure as expressed as a proportion of all public funding on research.

More over, the uniqueness of the research charity sector in the UK is even better defined by a number of other factors: a commitment to funding research of the highest quality according to a common set of principles; a unity of purpose on key issues such as the necessity of animal research; a dedication to working alongside other partners in the UK research enterprise and, of course; the huge public support on which its work is founded.

A dominant theme for research charities currently, as for other funders, is the impact of the economic downturn. Although AMRC’s evidence points to the sector’s expenditure being down by only 4% overall this year, this hides wide variations within our membership with smaller research charities – and by their nature those funding research into less common disorders – being particularly hard hit. Our forecast is that 2010-11 will likely be more difficult still as our members are impacted by the consequences of public service cuts and the drawing of funds away from research for other initiatives.

Nonetheless our survey of members about the recession in March 2009 demonstrated that research charities are committed to developing strategies that will enable them to maintain their commitment to science through this period – for instance, almost two thirds (63.9%) of members who responded to our survey at that time said they were looking at co-funding opportunities.

How are public funds for science and technology research allocated?

Overall, AMRC believes that the UK now has a more robust strategy for medical and health research since the establishment of the Office for Strategic Co-ordination for Health Research (OSCHR) in December 2006. This has included a sensible prioritisation of cross-cutting themes such as e-Health, translational research and public health research. It has also been supported by significant Government investment. We would also affirm that these initiatives have done well to target and focus on specific areas of concern while maintaining an appropriate balance in funding: basic v applied etc.

“We believe that OSCHR has been tackling the right questions over its first two years, although it is still far from clarifying and optimising the routes through which translational research is funded.”

Although it remains early days for OSCHR, the results of its work are beginning to influence the strategic thinking of the wider funding community including medical research charities. In our survey, just over two fifths of charities (42%) who responded said that the establishment of OSCHR, the National Institute of Health Research (NIHR) and associated reforms to improve clinical and translational research had influenced their research funding strategy either a great deal or to some extent.

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4 Ipsos MORI poll: September 2008 (Commissioned by AMRC)
5 AMRC subscriptions data for 2009-2010
“The creation of OSCHR has improved transparency in the way clinical and healthcare research funding is allocated and has encouraged us to investigate the possibility of developing funding partnerships as part of our strategy to provide more people with the opportunity to participate in clinical research.”

But the overall impact is patchy; continuing opaqueness in decision-making processes plus a lack of concerted effort to engage the charity sector in general is undoubtedly preventing many other AMRC members from seizing opportunities – and this despite OSCHR prioritising such engagement activity in its first progress report in 2008.

When asked, 88% of the members who took part in our survey felt that the way in which public funds are allocated to science and technology research could be more open and transparent to them as research funders. Comments from our members included the following:

“It is very difficult to find details on what is being spent in a specific research area. For example it is currently impossible to determine what funds are going towards gene therapy. It is important to know what support is being given to inform charity decisions.”

“Our status as a patient-representative charity which also funds research seems to vary from one funding stream to another – and in some cases, there is no opportunity at all to partner with academia or industry in initiatives of core importance to us.”

“At present, high level policy decisions on how research funds are allocated seem to ‘filter down’ in a rather haphazard fashion to charitable organisations, unless they happen to possess a dedicated public affairs team. Greater effort should be placed on establishing a more effective communication process.”

It is also clear from our survey that Government and its agencies need to work hard to counter the perception of smaller medical research charities in particular that the system is unfairly biased against their involvement:

“The amount of money small charities give to research precludes involvement. the assumption here is that spending more money means better quality research which it doesn’t. this is unfair. It’s not all about money.”

Medical research charities are cognisant of the difficulties for Government in consulting with a wide range of stakeholders and in a way which does not hamper effective decision-making. However, there is a strong view from our members (80% of respondents to AMRC’s survey) that charities could be engaged earlier and on an ongoing basis:

“Bring the stakeholder groups together at an early stage, include condition specific charities where appropriate. We know what needs to be done, what isn’t being done and we know where money is being wasted.”

“The more information available, the greater the likelihood that common funding priorities can be identified and the smaller the chances of inadvertently creating ‘research gaps.”

“We think that more effort needs to be made with communication to help researchers understand the changes in place following the establishment of the Office for Strategic Health Research (OSCHR), and to make it easier for them to know where they should apply for funding.”

7 OSCHR, Chairman’s First Progress Report, 2008
Are existing objectives and mechanisms for the allocation of public funds for research appropriate? If not, what changes are necessary?

Approximately seventy per cent (70%) of research charity funding goes to higher education institutions (HEIs) across the UK, and AMRC and its member charities continue to support the dual support system for funding research in the UK.

For medical research charities the most significant recent development within the context of this system has been the establishment by the Government of the Charity Research Support Fund (CRSF). Set up in 2006, CRSF is an important acknowledgement that charity funds should not be used to pay for indirect costs associated with research and provides funds to universities to cover some of these overheads.

CRSF’s operation has been strengthened in recent years with revised guidance from the Higher Education Funding Council for England (HEFCE). Nonetheless significant questions remain over whether the monies available through CRSF are sufficient going forward. In addition, AMRC believes that HEFCE, universities and university associations could be doing much more to raise awareness of CRSF within institutions and, with it, the importance of medical research charities as a source of income. Unless and until these issues are addressed we remain concerned that researchers are being discouraged by their institutions from applying for charity grants as amply highlighted in Breast Cancer Campaign’s report earlier this year: ‘Full Economic Costing (fEC): the effects on charity-funded research.’

Against this background, it is absolutely essential that Government commits itself to CRSF and appropriate funding levels for this mechanism in the long-term if charities are to continue to be a growing source of research investment income in coming years. A message echoed in the recent Research Councils UK/Universities UK review of fEC.

The Committee may also wish to note that a not dissimilar system for funding allocation has also been established by NIHR for clinical trials and studies in the NHS. Under this scheme, NIHR will meet the NHS support costs of eligible funding partners. Once again, however, the process by which eligibility is granted has been opaque and not without its difficulties for charities to navigate. Following representations from AMRC NIHR is now looking to improve this process.

How is publicly-funded science and technology research aligned and co-ordinated with non-publicly funded research? How can industry be encouraged to participate in research efforts seeking to answer societal needs?

AMRC member charities are increasingly active in looking to form collaborative funding arrangements with other partners including industry and the research councils. It is also clear that the recession has brought into sharper focus for all funders the potential opportunities and greater reach through co-operation.

From the response to our survey, it would appear that AMRC members are generally – but not always – positive about their experiences although we would urge that collaboration continue to be prioritised by all funders going forward:

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8 ‘Full Economic Costing: the effects on charity-funded research’ Breast Cancer Campaign, 2009
“Our experience has been with the MRC in terms of clinical training fellowships and this was extremely positive and they were very easy to work with.”

“Our experience of collaborating with the MRC has been overwhelmingly positive. We collaborate on two fellowships, and have found MRC eager to collaborate and willing to pick up the FEC aspects of the grants.”

“Since a lot of charities for rare diseases are small or medium size trying to partner with the MRC feels like we are supporting the MRC rather than the other way round.”

“We recently made considerable efforts to establish a partnership with the MRC. The problem is that the MRC funds overheads that the charities are excluded from and this makes transparency - what exactly is the money used for - difficult. Since a lot of charities for rare diseases are small or medium size trying to partner with the MRC feels like we are supporting the MRC rather than the other way round.”

How can industry be encouraged to participate in research efforts seeking to answer societal needs?

A recent report by the Alzheimer’s Research Trust has indicated the potential opportunities that could arise out of better co-ordination of research funding across different sectors – public, charitable and private. The study completed by the Office of Health Economics, found that publicly-funded basic research – science carried out to understand fundamental principles, such as what causes Alzheimer’s disease – appeared to stimulate particularly high levels of private investment. For example, one US study analysed in the report suggested that a £1 investment in basic research led to £8.38 of further investment over eight years.

Looking across AMRC’s membership as a whole it is clear that an increasing number of medical research charities are forming highly innovative and dynamic relationships with industry in which the focus is on identifying research priorities for future funding. We expect this trend to continue and are ourselves conducting a short piece of work this autumn to explore how patients and patient groups can be more influential with industry in ensuring their research efforts are focused on societal needs. This will build on previous work conducted by AMRC and contained in our report: ‘An Essential Partnership: Principles and Guidelines for Working with Industry.’

To what extent should publicly-funded science and technology research be focused on areas of potential economic importance? How should these areas be identified?

AMRC and its member charities would urge that, should there be a debate around research priorities, it must be couched in terms of the socio-economic benefits or rate of return as explored in the Wellcome Trust and Academy of Medical Sciences 2008 report ‘Medical Research: What’s it worth?’ rather than just economic importance.

Although almost half the member charities who responded to our survey (48%) said they did not feel that public funding is sufficiently aligned with societal needs and only 16% did, this hides a wide variation of opinion on how such needs should be identified. However, the primary concern from their comments is the need to ensure that funding was focused on long-term objectives rather than short-term aims:

10 ‘Forward Together,’ Alzheimer’s Research Trust, 2009
11 AMRC/National Voices/James Lind Alliance Workshop: ‘Does industry listen to patients and if so why?’ October 2009
12 AMRC 2007
“Societal needs have to be judged on a very long-term basis which is done quite well by existing mechanisms. It would be a mistake to create mechanisms which made the funding more reactive to perceived societal needs as that is likely to lead to short-term fluctuations in funding levels, which could be very harmful for research.”

However, there is much more widespread support within the sector (63%) for finding suitable mechanisms by which the public and patients can be engaged and involved in discussing future research priorities and by which they can participate in funding decisions:

“Yes, with caveats. I think public engagement is very important in setting priority areas, but it needs to be informed by expert thinking on how tractable these areas are, and in developing a research strategy to meet these needs. We have developed a network of over 150 'voices' who we involve in developing research strategy as well as in policy and campaigns. At the moment we are running a survey asking them where they feel the most important research needs are, based on their own personal experience. We would not claim that this is academically robust research, but we are finding that one issue in particular - the problem of accurate diagnosis and prognosis - is cropping up very regularly. This is certainly something we will take into consideration when we develop our new research strategy next year.”

We feel that this debate should therefore not be couched only in terms of identifying the most appropriate research questions for future funding but also in terms of finding the best mechanisms for involving the public and patients in such discussions. This should be on an ongoing basis and managed in ways in which all participants are clear about the role they are being asked to play and with what purpose.

We would be happy to discuss these issues in more detail with the Committee.

Simon Denegri
Chief Executive
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