Response to NHS Chief Executive’s Open Call for Evidence and Ideas

Respondent ID: 301

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NHS Chief Executive Innovation Review – call for evidence and ideas

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

In 2009-10, public funders invested almost £3 billion in health research in the UK, with over £1 billion coming from AMRC’s 127 medical research charities.1 In the same year, over 3,000 clinical studies were conducted in the NHS; 37% were funded by AMRC member charities. This investment contributes to the UK’s strength in biomedical science, bringing economic benefits. All our members are focused on benefiting patients and share a commitment to funding the highest quality research and many have a strong patient group allied to them.

The public overwhelmingly believe the NHS should support research into new treatments. 93% believe their local NHS should be encouraged or required to support research.2

We are a key member of the medical research sector and value the opportunity to contribute to this review. As recognised at the outset, the NHS has taken valuable steps in building an innovative infrastructure, but has yet to realise its potential as a world leader in innovation. As the UK’s unique medical research charity sector incorporating strong patient engagement, we can help the NHS realise this aim.

Charities get involved in innovation
The priority for medical research charities is to invest in research that identifies preventions and develops treatments which will improve patient care and the lives of people with medical conditions. Innovation – adopting and diffusing new ideas, technologies and processes throughout the NHS – is essential to achieving this.

Many medical research charities have direct links with people with medical conditions. This patient link enables them to bring invaluable insights to the design and conduct of the research they fund – ensuring studies are people-focused, improving recruitment rates and targeting the research agenda towards the needs of the patients. This can valuably underpin successful innovation.

**Case study 1 – Arthritis Research UK User Committee**

Arthritis Research UK has developed a Stakeholders Research Review (USER) committee with the remit to provide a user perspective on research that the charity may fund. USER comprises frontline healthcare professionals, who are not research-active, and informed lay members. USER members consider: strategic importance; potential of the research to lead to clinical benefit; issues of practicality. USER provides a brief report which is circulated to the relevant funding committee to inform the peer review process. These views ensure that the best science with the best chance of practical uptake is funded.

http://www.arthritisresearchuk.org/research/our_research_strategy/funding_research/user_committ ee.aspx [accessed 31 August 2011]

**Charities can pull innovation through the health system.** Their focus on funding research of high scientific quality with the goal of developing new treatments is recognised by researchers, “working with charities brings with it the discipline of making us concentrate on timelines and moving research on in a timely fashion.”

**Charities are innovative funders.** Their focus on patient benefit, alongside medical research charities’ responsibility to their donors to maximise the value of their investments, drives them to be innovative funders, forming strategic partnerships to support new research institutes and collaborating with others to support research in new areas. They are also keen to encourage commercialisations; some work closely with universities to identify intellectual property and advice on exploitation, while others provide funds for development and support.

**Case study 2 – Asthma UK co-funding a translational research unit**

The MRC and Asthma UK Centre in Allergic Mechanisms of Asthma, formed in October 2005, is a partnership between MRC, Asthma UK, Imperial, KCL and Queen Mary’s University. This link provides a wealth of experience in researching asthma in the primary care community and access to a network of General Practices and their patients in the East End of London. This is critical as most asthmatic patients in the UK are now looked after by their GPs.

http://www.asthma-allergy.ac.uk/Default.aspx [accessed 31 August 2011]

**Charities can provide complimentary funding**

Medical research charities complement other funders’ portfolios, funding research that would not ordinarily be supported by public funders – this is often research which will pull innovations towards market ready products and applications.

**Case study 3 – Stroke Association investment in later stage applied research**

In an analysis of funding in 2004-05, the Stroke Association invested more than 60% of its budget in later stage applied research (treatment evaluation and disease management) while the profile for public funders in stroke research showed a higher proportion of funding for basic research. Further detail here: http://www.amrc.org.uk/ensure-the-discoveries-we-fund-reach-the-patients-who-need-them_drive-innovation-of-new-treatments-to-help-patients_stroke-research-funding [accessed 31 August 2011]

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Charities can play a role in identifying market opportunities

**Case study 4 – UK DUETS**
The UK Database of Uncertainties about the Effects of Treatments (UK DUETS) works with patients, carers and clinicians to identify where more research needs to be done into the effects of treatments – in effect flagging up opportunities for further research to improve treatments, some of which could entail small changes which make a dramatic difference. A number of medical research charities have taken part in this process, with the ‘top ten questions’ becoming an integral part of their research funding strategy.


**Case study 5 – Action on Hearing Loss Translational Research Initiative for Hearing (TRIH)**
Action on Hearing Loss has established a Translational Research Initiative for Hearing (TRIH) which is focused on supporting translational research to advance medicines to protect and restore hearing, and silence tinnitus.

The initiative is designed to support translational research:
Through a new funding scheme
By facilitating partnerships between industry, academics, investors, philanthropists and others
By engaging patients to support, and to demand, new treatments and cures for their hearing loss and tinnitus.

Action on Hearing Loss has developed tailored portals for different partners in the process:
- **TRIH Funding Scheme** – supporting translational research in hearing loss and tinnitus.
- **TRIH Partnerships** – a platform by which industry can enter hearing research in a low-risk way.
- **TRIH Research Hub** – a service to assist companies in easily identifying partners (academic groups & contract research organisations) to carry out specific tests or assays.
- **Clinical Trials Database** – a means of engaging patient support for, and participation in, clinical trials for hearing loss and tinnitus globally.


Charities can provide vital early investment in spin-outs

**Case study 6 – Yorkshire Cancer Research has a well-developed commercial development awards scheme providing programme-related investment (i.e. funding spin-outs)**

Approximately six years ago, trustees of Yorkshire Cancer Research were faced with deciding whether to fund a spin-out company founded between one of the charity’s programme award holders and his university. The programme was of long standing and there was a general desire to assist if that was legally possible.

However, at the time the prospect of a medical research charity supporting an early stage biotechnology company was considered too inherently risky to sanction.

Existing Charity Commission guidance on social investment provided a legal and regulatory framework for those charities wishing to explore investment in commercial ventures that are directly aligned with their main charitable purpose.

In line with this guidance, Yorkshire Cancer Research has developed a policy of programme-related investment, allowing them to run a commercial development awards scheme.
From our perspective as medical research charity funders, we would prioritise the following actions to foster innovation.

**Action at a national level in the NHS**

The changes proposed in the white paper *Liberating the NHS* and underway in the Health & Social Care Bill should not be viewed as separate to measures fostering innovation.

The government has committed to embedding a culture of research and innovation across the NHS and public health system. We already have a very successful basis in our multi-stakeholder system underpinned by the infrastructure provided by the National Institute of Health Research (NIHR). Work to build on this and embed a culture of research and innovation throughout the system, developing a health research workforce that can meaningfully engage patients and the public in the design and conduct of research, and take up new ideas, technologies and processes, will be vital to foster successful innovation in the NHS.

**Actions:**

**Embedding a culture of research and innovation** - To achieve this, engagement with research – through existing and new initiatives – should be led, valued, supported and recognised at all levels of the NHS and public health system. This will require clear research leadership and accountability at all levels, education and standardised national metrics measuring and rewarding performance. This should be accompanied by tailored education and training to enable the workforce to meaningfully engage; the workforce must be supported to be involved in research, utilise research and evaluation, and take responsibility for procuring and introducing innovation where appropriate.

**Patient and public involvement in research and innovation** – Successful patient and public involvement is key to successful innovation and should be led at a national level. The NHS commissioning board director-level role with responsibility for patient and public engagement offers an opportunity to lead this work and develop appropriate support for involvement in research across the system.

**Patient data offers an invaluable resource for successful innovation** – National level work to develop safe and secure systems and governance arrangements that enable researchers to access both anonymous and identifiable patient information for research, while protecting patients and researchers will greatly enhance our abilities to innovate.

**Streamlining regulation** – Successful innovation is undermined by our overly complex regulatory and governance environment which leads to increases in the cost and time needed to navigate research approval processes. Ongoing work to develop a streamlined single regulatory and governance pathway reducing the time and financial burden of initiating research projects, has the potential to foster innovation. For this to be successful, consideration must be given to the ease of engaging with the new pathway and communicating the process of change.

**Creating a strategic system that can take up innovations** – a more innovative system must not just be better at fostering new ideas, it must also have the strategic oversight to identify where future ideas, technologies and processes can be valuable to the whole system. The NHS and public health system needs a single body with responsibility for taking such national strategic oversight, engaging with both internal and external partners to identify and communicate opportunities and create a clear pathway to drive long-term change.

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**Action at a local level**

Planned changes to the NHS and public health system will see responsibility for commissioning and health improvement moving to local clinical commissioning groups and local authorities. It is important that work to embed research and innovation across the health system is valued, understood and supported at a local level.

**Actions:**

Support must be developed to ensure clinical commissioning groups value research and engage with existing and new research networks and initiatives to ensure this shift of responsibilities does not introduce barriers to research and innovation. Opportunities to share risks and collaborate in making initial investments in research should be signposted to ensure high initial capital investment does not act as a disincentive to supporting innovation. The setting of tariffs should be explored to ensure savings released by delivering new technologies are realised by that provider rather than falling within the budget of another, so inadvertently acting as a disincentive for innovation.

Clinical commissioning groups must be responsible and accountable for promoting innovation to embed a supportive culture, with a clear system to recognise and reward success.

There should be a focus on upskilling the local workforce to value and engage with research, involving patients and the public – so empowering healthcare professionals to approach healthcare innovatively, seeking new ways to deliver care and streamline processes to improve patient care. Local champions can be key to driving the adoption of innovation in the NHS. The NHS workforce and research managers should be prepared and supported to see medical research charities as natural partners.

As outlined, charities can play a valuable role in the innovation pathway – through investment, developing research networks and building relationships with patients and the public. We look forward to interacting with those leading strategic oversight of NHS innovation to understand and articulate each other’s challenges, identifying the ideas, processes and technologies that will provide real value for patients.

Please contact me if you would like any further information.

Yours sincerely,

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