

Response to Sir David Cooksey review of UK Health Research

1. What are the strengths and weaknesses of the MRC and NHS R&D programmes at present? How do each of these support the research and training needs of the NHS, social care, industry and academia? Does more need to be done?

- The Stroke Association is pleased to observe that the funding of stroke research appears to be rising up the agenda for the MRC and the NHS. However, the current funding opportunities do not address the issue of capacity building and research training within the NHS for stroke. This is particularly important for stroke research, which is essentially a 'young' field of research in comparison to many other conditions such as diabetes, heart and cancer. This issue is even more crucial within nursing and allied health professions as development of centres of excellence within these disciplines is still in its infancy. There are at least 300,000 people in England currently living with the effects of stroke and requiring long-term care¹. There is currently limited evidence to support specific rehabilitation techniques (as demonstrated by the National Clinical Guidelines for Stroke²), capacity issues within rehabilitation research should therefore be a priority.
- Changes in clinical training, including the attempts to standardise this, have made it more difficult to develop an interest in research early in a medical career. The establishment of clearer career structures for research staff is highly desirable. The introduction of research grades within the NHS would also make appointment to certain research posts easier.
- The possibility of moving between clinical and academic work should be encouraged. More flexibility is required with regard to research training awards to allow for individuals to take career breaks, make career changes between clinical and research later in their careers or work part-time. This flexibility is particularly needed to encourage more individuals to pursue research careers within the Allied Health Professions. A research culture should be created which is attractive to all researchers at all stages in their career.

¹ Reducing Brain Damage: Faster access to better stroke Care. National Audit Office, November 2005.

² National Clinical Guidelines for Stroke, Royal College of Physicians, 2nd edition, June 2004.

2. What do you believe are the key scientific and organisational challenges facing health research, and underpinning training, in the UK over the next decade? How might the UK Government best help address those challenges? What do you believe should be the Government's objectives for health research, and why?

- The key objective should be to establish a culture within the NHS where research and development is seen as a priority and integrated as much as possible with patient care. At present only 44% of hospitals that admit stroke patients within England, Wales, Northern Ireland, Isle of Man and Channel Islands are currently involved in stroke research. Only 24% of hospitals participate in 3 or more studies³.
- The new research fund should focus on ensuring that there is sufficient infrastructure support for research to be carried out in the NHS, and work towards a situation where all patients should have access to research as part of their treatment.
- The single health fund should provide an environment where medical research charities are able to maximise their impact and contribution to the research community.

3. What should be the Government's priorities for health research? Is there anything it should stop doing or funding? What is it not doing or funding that it should do, and, in the absence of further sources of support, what can it lower in order to release the necessary funds?

- Priorities for health research should take into account the spend on research by the charities. Disease areas receiving little funding from charities should be counterbalanced by Government funding. For example in 2000/01 £2.6 million was spent on stroke research by charities, in comparison to the £43 million spent on coronary heart disease research by the charity sector. Government funding does not currently offset this in-balance at all, despite the annual direct healthcare cost of stroke being £2.8 billion in comparison to £1.9 billion for coronary heart disease. In 2004/05 the Department of Health spent £9.4 million on stroke research in comparison to £52 million on coronary heart disease research¹.
- Research into long term care and rehabilitation is not currently a priority with the MRC or Department of Health. This should be addressed by the new research fund. There are at least 300,000 people in England currently living with the effects of stroke and requiring long term care¹. There is currently limited evidence to support specific rehabilitation techniques, (as

³ National Sentinel Audit of Stroke 2006, Royal college of Physicians, in press

demonstrated by the National Clinical Guidelines for Stroke Stroke²) more research into this area is desperately needed.

4. How should decisions be taken on the balance between the long-term economic and social benefits of a high quality biomedical research base; and the needs for research to improve healthcare and other public services? What is the appropriate balance between public funding for investigator-led and priorities led research? How do we balance funding for basic science, translational science and applied science? Is this something that should vary over time? What mechanisms should be used to make judgements about this balance?

- The UK Health Research Analysis conducted by the UK Clinical Research Collaboration indicates that there is a large in-balance between funding available for basic research versus translational and applied science⁴. Research into long-term care is not even covered by the analysis at all. The new health fund should look to address this in-balance so that more funding is distributed towards translational and clinical research.
- A larger percentage of the funding budget should be allocated to priority led research so that researchers are encouraged to undertake research in less popular fields, such as stroke. Funding streams should also encourage multi-centre trials to be undertaken within disciplines where this is currently very difficult, such as rehabilitation.
- Investigator led research should still have a place to encourage less experienced researchers to become established.

5. In your experience, how have the results of publicly-funded health research in the UK been used, both in the development of new treatments and to influence / change wider policy and healthcare practices? What lessons can usefully be learned to improve the uptake of advances in science and medicine?

- Within stroke care, the Royal College of Physicians produces the National clinical Guideline for Stroke². All recommendations within the guidelines are supported by research evidence.

6. How might better links be forged between 'basic', translational and applied researchers, working across the whole field of health research, from the laboratory bench to the front line of the NHS? How might better links be forged across disciplines, e.g. with engineers, physicists, and social scientists?

⁴ UK Health research Analysis, UK Clinical Research Collaboration, May 2006.

- There needs to be some way to ensure that Health Services research can fund clinicians providing a service which sometimes requires new systems to be treated in parallel with existing services.
- The development of a research passport for researchers would be an advantage. Researchers would then be able to work in multiple clinical settings without having to get honorary contracts on each occasion.
- Multidisciplinary research should be encouraged, especially in the area of translating promising theoretical research into the clinical environment.
- Funding bodies need to be creative in their awards to researchers to allow them to focus on their research work. The notion of moving between clinical and academic work should be a plausible one and not limited by age. Some awards are currently age limited, and take no account of moves between clinical/academic work or career breaks.
- The current research programmes of DH and MRC do not have a single mindset or agreed approach to translational research and ensuring that new treatments are delivered to benefit patients. Increased strategic priority needs to be applied to this area.

7. How can the Government encourage translation, entrepreneurship and innovation in health research to improve public services in the UK?

- There needs to be priority given to research into implementation not just innovation. The importance of translating research “from bench to bedside” should not be underestimated. Incentives could be offered to trusts that implement research findings – e.g. reducing the CNST (Clinical Negligence Scheme for Trusts) costs to trusts if they persistently perform well against key National Audit targets.
- Involving research charities and the voluntary sector will allow identification of areas that are neglected and research “gaps” which could be targeted for major patient benefit.

8. How can UK health research funding be most effectively used to provide the appropriate infrastructure for basic, translational and applied research, whether funded by the UK public sector or other sectors? How can UK health research funding be most effectively used to support the work of NICE, facilitate innovation and collaboration with industry, and address market failures in the application of healthcare?

- Greater support needs to be given to joint funding initiatives between voluntary, public and private sectors.

- Health Services research will be greatly helped by the development of the Electronic Patient Register. However the current safeguards for patient confidentiality are unduly cumbersome and restrictive and this issue if simplified would greatly enhance research.
- Continuous revision and implementation of initiatives that differ only slightly from one another should be avoided.

9. What lessons should the UK learn from other countries in making the proposed changes to the institutional arrangements for the funding of health research?

- No comment.

10. In implementing the single fund for health research, to what extent should the MRC and DH / NHS R&D be merged or brought together? And to whom should the single, ring-fenced fund be accountable? Please provide reasons and any supporting evidence for your response.

- The balance in the membership of the new grant giving body should be very carefully weighted between clinical research and basic science. Currently there appears to be excessive emphasis on “basic” bench research at the expense of clinical and HSR research.
- There needs to be a fairer system for measuring the quality of research than the current impact factor methodology which tends to devalue clinical research compared to basic science where there are a greater number of very high impact journals.
- The new grant giving body needs to ensure that the needs of patients, clinicians and the NHS are given appropriate priority, and that performance is properly audited. Revisions of the funding strategy need to be undertaken at regular intervals as circumstances change.
- In order to maintain and improve research quality, the highest standards possible in peer review should be maintained.

11. To what extent does the success of recent innovations in health research (e.g. Clinical Research Networks) and the proposed structures rely on the new Connecting for Health NHS IT system, and to what extent should it do so?

- Connecting for Health is a very new system, and perhaps is not the answer as yet. Good local IT initiatives and systems exist which should be gradually developed. Massive change “all at once” should be avoided.

12. Given that NHS R&D is currently devolved, but that the work of Research Councils is not, how can these functions work best together to maximise the health and economic benefits to the UK?

- The role of medical research charities as major funding organisations, organisations deriving and delivering benefit from medical research, and as sources of public engagement and involvement has often been underplayed in the past. The review needs to acknowledge the fundamental role of research charities in funding research of direct benefit to patients and the public, and in determining research strategies that reflect the needs of particular conditions. The research charities are uniquely positioned to advise on areas where more research investment is required which would be of direct benefit to the public.
- Involvement of charities has the potential to break down traditional organisational and cultural barriers and ensure that the research community, including patients and the public are working as one in support of a common agenda. Charities, along with others such as industry, should be seen as key stakeholders whose research expertise, independence and closeness to the donating public can bring legitimacy to the new organisation.
- The new organisation must develop strong governance, superlative peer review, and have strong, politically independent leadership, perhaps via an independently chaired board. The board will ensure that the necessary mechanisms are in place to identify research priorities, identify key areas of overlap, and engineer a sense of purpose and unity.
- Lines of accountability must be clear and transparent.
- The board should work to create a research culture which is outcome focused in terms of health benefits and wider economic prosperity, and that is attractive and inclusive to scientists and researchers at all stages of their career.

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