

HM Treasury consultation on the Cooksey Review of UK Health Research

Response from the Institute of Education, University of London

The Institute of Education's mission is to pursue excellence in education and related areas of social science and professional practice. Institute staff have an active interest in research related to health, particularly: the health and well-being of children, young people, and families; children's services and environments; evaluation of social interventions; sexual health, reproduction and social exclusion; public involvement in policy and research; evidence informed policy and practice; and cohort studies of education and employment, family and parenting, physical and mental health, and social attitudes.

In line with these interests and our institutional setting, I am writing to provide our institutional response to the questions raised in the Cooksey Review of UK Health Research. Given our current experience, this response focuses in particular on the following questions:

The strengths and weaknesses of the MRC and NHS R&D programmes (1)
The key scientific and organisational challenges (2)
The Government's priorities for health research (3)
Balancing priorities (4)
Forging links between 'basic', translational and applied researchers (6), and
Connecting for Health (11).

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 MRC has extensive experience of funding largely investigator-led basic, translational and applied research, and providing training and career support through personal awards. The emphasis on 'medicine' within its title may indeed reflect a key interest, even though this same term poorly reflects the scope of its activities as it currently funds experimental medicine, health services research and public health research, and provides clinical fellowships to clinical scientists including doctors, dentists, nurses, midwives and other Allied Health Professionals.

The Department of Health funds research to ensure the policies and services provided by the NHS are based on the latest and most reliable evidence, and

respond to the needs of the public. National programmes, such as the Health Technology Assessment (HTA) programme, the Service Delivery and Organisation R&D programme, and the Methodology R&D programme commission research to meet the needs of the NHS. *Best Research for Best Health* announced the reinstatement of responsive research which has been lacking since the demise of the regional R&D programmes.

A particular strength of the NHS R&D programme is its commitment to, and growing experience of, public involvement in all stages of the research and policy/ practice cycle at national and local levels. The INVOLVE initiative, for example, has provided a focus for large and small scale actions across the country. The HTA programme has been a flag ship for public involvement on a national scale. Both programmes have developed methods and resources to support public involvement, often working together. The newly established UK Clinical Research Networks are well placed to build on these initiatives with Trusts and individual research projects.

Public involvement in basic research is often seen as more challenging. However, there are excellent examples beyond the MRC and the NHS. The Alzheimer's Society's Quality Research for Dementia is a thriving programme with sustainable systems for involving carers in funding decisions. Further afield, successful public involvement has been reported by The Netherlands Asthma Foundation.

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?

A major challenge to a quality health service underpinned by rigorous research is that of bridging the gap between frontline practitioners, managers, service users, policy makers and researchers. Research and clinical practice is easily integrated in medical schools where clinical academics combine patient care with teaching and research. In other disciplines, such as nutrition, nursing or health promotion, practitioner led research tends to be small scale, under funded and poorly supported by methodological expertise. Where they do not naturally evolve, there is a need to invest in good quality academic-practitioner partnerships.

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?

The health and well-being both of the nation and of individuals are crucially dependent upon the funding and conduct of good quality research. This includes studies of direct relevance to the NHS but also research into fundamental health inequalities and their economic, social and individual determinants. Economic research, sociological and psychological research and nursing research are all important in this respect, as is research within the fields of health education and social care. Future arrangements must make adequate provision for the conduct of this kind of enquiry in partnership with, where relevant, the ESRC and other funders.

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?

At present, the balance of funding across biomedical research and applied research about health care and public services is decided at a number of different levels. The NHS R&D programme funds research of direct benefit to the NHS and its users. Some of this is more speculative translational research, such as that within the remit of the new Invention for Innovation research programme (encompassing the New and Emerging Applications of Technology and Health Technology Devices programmes); and some of it is more applied such as the Department of Health's Policy Research programme or the NHS Service, Delivery and Organisation programme.

The MRC funds basic, translational and applied research and makes decisions within the organisation.

Further basic, translational and applied research relevant to health and health services is funded by research councils for economics and social science, biotechnology and biological sciences, engineering and physical sciences, and the natural environment. Decisions about the appropriate balance to be struck between funding for basic, translational and applied research need to be informed by the roles of all these funding bodies, not only by the MRC and Department of Health.

Investigator-led and priorities-led research are not simply alternatives, but options at either end of a spectrum. Priorities may be very precise, as in the research questions framed by the HTA for commissioning needs-led research where systems support those 'who use, manage and provide care in the NHS' develop priorities and refine research questions. However, priorities may also be broad, as in the Economic and Social Research Council's thematic priorities, or the MRC's health priorities. There are opportunities for investigator-led research even within broad priority areas.

Where investigators are encouraged to address their own ideas, there is a need to consider the role of peer review. Is peer review conducted merely to check the quality of the science proposed to answer the investigators' research questions; or is it legitimate for peer reviewers to comment on the importance of the investigators' research questions? In the case of the former, peer review by suitably qualified and experienced scientists is sufficient. In the case of the latter, consideration needs to be given to the range of perspectives invited to comment on the utility of addressing the investigators' research question, and the clear distinction between comments on the research questions and comments on the research methods.

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?

The starting point for bringing people together is not only the principle, but practical tasks that require it for their successful completion. Such tasks exist at the stages of commissioning research, conducting research and using the research findings.

In the commissioning of research different models have been adopted by the Health Technology Assessment programme, and the Department of Health Policy Research programme. The HTA programme is coordinated by researchers and managers who support virtual and personal interactions between clinicians, researchers and public advocates in setting research priorities. Priority setting activities are structured around multidisciplinary panels and formal procedures for wide consultation.

The Department of Health Policy Research programme also bridges conventional divides between policy makers and researchers, not with new structures and procedures, but with R&D staff who 'broker' contracts that capture the interests of policy makers and the capacity of research teams. Policy makers are then well placed to engage with the research team through project Advisory Groups and in other ways, to offer their perspective in guiding the work, and to make use of the findings and support their wider dissemination.

Successful examples of using research findings are the clinical guideline development groups of the National Institute of Health and Clinical Excellence (NICE), and the setting of policies and standards for newborn bloodspot screening. NICE convenes multidisciplinary guideline development groups, including public advocates, who are supported by researchers employing standard procedures for informing the groups, facilitating discussion and drafting guidelines. The UK Newborn Screening Programme Centre employed a similar approach for convening working groups to set policies and standards that required the expertise of laboratory scientists, epidemiologists, information managers, clinicians and parents.

The common characteristics of these initiatives include funding to support broad involvement in discussions and decisions, investment in long standing arrangements for nurturing working relationships and building on achievements and organisational learning, and, in some cases, researchers subsuming their academic identities in specially established organisations (e.g. NICE, National Coordinating Centre for the HTA, UK Newborn Screening Programme Centre) that focus on the task in-hand working across organisational and disciplinary boundaries.

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?

The Connecting for Health NHS IT system provides a route for recruitment and data sharing to underpin efficient and comprehensive observational or intervention studies with long term follow-up (long-term follow-up in research often being seen as a priority by patient groups). Many such studies will be linked into Clinical Research
IoE/directorate/consultations

Networks. The extent to which, or how, Connecting for Health should support such research needs to be balanced by ethical concerns about the protection of privacy and public priorities. Debate about these issues has begun amongst researchers, and the MRC has commissioned a public consultation about data sharing. Nevertheless, care needs to be taken to ensure transparency about research and data sharing policies, if public outcry about the storage of organs is not to be repeated in relation to the storage, and sharing, of data.

This response has been prepared on behalf of the Institute of Education by Dr Sandy Oliver, Reader in Public Policy in the Social Science Research Unit at the Institute. Please contact her direct if you have any queries on the response [s.oliver@ioe.ac.uk or (0)20 7612 6747]

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