

Response to the Cooksey Review from the University of York

Opening Statement

We welcome the announcement that the Review of UK Health Research funding will 'encompass the full spectrum of health research... including public health and social care research'. However we are profoundly concerned that neither the detailed remit for the consultation nor the review questions reflect this wide-ranging objective. It is noted that there is currently a SCIE review of Social Care Research Capacity and it would have been helpful if these two consultations had been linked. This highlights the need for more joined-up planning within the wider sphere of health care.

A broader definition of 'social care research' would include the range of social factors that impact on individual health and wellbeing and that are therefore likely to affect the incidence of illness; demand for and use of health services; and the effectiveness and health outcomes of clinical treatments.

These issues are currently not central to either the MRC or the NHS R&D programmes. Equally, without appropriate safeguards, they risk being marginal to the proposed single health research funding stream. Such safeguards should include the ring-fencing of an element of the single research funding stream for public health and social care research; and the involvement of a wide range of appropriate stakeholders in decisions about the strategic priorities and detailed spending decisions relating to this element of the integrated budget. Safeguarding resources for social care research is particularly important as it is proposed that the new single funding stream should include some research funded by research councils other than the MRC, including the ESRC. It is therefore to be hoped that representatives of the ESRC and other research councils will have a central role in the governance of the new integrated health funding stream.

It is unclear from the review what the benefits of merging the two organisations would have as both have currently very different foci, for example NHS funding is concentrated at the patient outcomes end of medical/health research, and research council funding more at the laboratory end, although the MRC does put a proportion of its effort into funding into clinical trials and health services research. A single organization might be more responsive and strategic than two to emerging technologies and new cell/ molecular science with translational potential, and to gearing up new basic or applied laboratory studies in response

to a new challenge such as SARS or Avian influenza. Without knowing how well these two major funders collaborate now it is hard to know whether an amalgamation would make a real difference. They certainly must be talking to each other much more than they did since the formation of UKCRC .

Whilst anything that simplifies and streamlines process would be welcome, there is a need to ensure that researchers are able to take risk in new and untried research areas, via responsive funding, rather than being dictated in research terms by policies and centrally directed policies.

Finally, whilst the current consultation is welcomed, this should only be viewed as a first iteration on how a revised system might look. Whilst the generic idea may be of interest, the details of such a scheme, such as the precisely how health research management should be undertaken need further discussion. For example the UKCRC, and NIHR do not include representation of the Universities who conduct most of the research and employ most of the researchers, which would be unhelpful.

Review questions

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?*

Both the MRC and the central programmes of the NHS R&D programme have a reputation for funding high quality research. One of the strengths of the NHS R&D programme is its central programmes such as the HTA, SDO and Patient Safety Research programme, which are envied internationally as being strategic and focused on meeting the research evidence needs of the HNS, policy makers and practitioners. It will be important to ensure that these attributes are not lost in any national restructuring. This theme is developed later in this response under question 4. However, other parts of the NHS R&D spend such as the research capacity units and the Culyer monies distributed to health care organisations often do not represent value for money and are not focused on high quality research (if research at all). Both the MRC and the NHS R&D programme invest in capacity development through various personal award schemes. These serve a vital function, though these could be better articulated to ensure career progression for health researchers or high potential, no matter their discipline or professional group.

In recent years more emphasis has been given to the dissemination of research findings (from both the MRC and NHS R&D Programmes), however further improvements could be made. If funders are unaware of previous or ongoing research, duplication of effort can occur. Initiatives such as The National Research Register (NRR), The ReFeR Database and the new UKCRC Research Database are invaluable tools for commissioners of research as they provide easy access to completed and ongoing health research. However, too many databases essentially capturing the same or similar information could lead to confusion and also to duplication of effort. Streamlining of existing resources may help to avoid confusion and duplication and should be considered as part of an overall strategy.

Experience with the ReFeR Database suggests that not all research is lodged in the way it should be, which in turn means the database is not comprehensive. The research governance system recently introduced into the NHS should improve reporting. NHS R&D offices are obligated to submit information for inclusion on the NRR, about the status of all studies approved by Trusts. It has also become a requirement that researchers submit final (and in some instances interim) reports to the all NHS R&D offices from which they have gained approval, or risk being in breach of the terms of the framework. We would support systems and funding to ensure (1) even better pursuit and capture of final research reports (2) archiving of reports in full, as electronic documents on a central national resource and (3) systematic collection of the messages from research. Such systems would improve access to research findings that fail to be published in journals and would provide data to populate databases of unanswered treatment questions such as DUETS.

The funding reforms are not tackling some of the major issues facing health services researchers particularly problems of research bureaucracy. Whilst there is a need to ensure that there is adequate governance and monitoring of research, this needs to be carefully balanced against the need to remove barriers to research.

Neither the MRC and NHS R&D programmes provide extensive or adequate support for research or training in social care.

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?

Research into the social, economic, structural, behavioural and cultural factors affecting health and well-being (including factors affecting needs and demands for, and responses to, publicly-funded health services) should be integral to Government objectives for health research. Similarly, research into effective social care services and other forms of social support should be prioritised as a key objective, as these services underpin and complement health services and therefore have a major impact on the effectiveness of applied scientific and biomedical research. In addition, it is important that research related to children's health encompasses the role of social care and other forms of social support. With the transfer of policy responsibility for children's social care from the Department of Health to the Department for Education and Skills (in England), this link is at risk of being lost.

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?*

There is concern to ensure that within the new integrated funding stream, resources for social care and public health research should be ring-fenced. Both strategic priorities and detailed funding decisions relating to these ring-fenced resources should be determined by appropriately qualified stakeholders, including representatives from the ESRC, professional social care organisations and bodies representing the users of health and social care services.

Research priorities need to reflect the needs of the NHS, but at the same time research must be allowed to follow a scientifically innovative and evidence-based approach. In the past the MRC may have found this easier than NHS R&D.

It is also important to ensure that funding is available to support the development of methodological work in health research. The recent report from the UKCRC suggests that overall funding (including from MRC and NHS R&D) for methodological development is small (UKCRC, UK Health Research Analysis).

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?

Currently, there appears to be a strong emphasis on biomedical research, but not all NHS priorities can or should have a pharmacological solution. There is no clear emphasis on research focusing on public health, primary care, diagnostics, health service delivery or social care – yet these are all key areas of investigation that can and will contribute to the delivery of quality health care.

While welcoming the increased focus on research for health, there is an anxiety that a single, ring-fenced fund will weaken the strong links between health and social care research and policy-making that the Department of Health has fostered since the 1970s.

First, the consultation document does not make clear that the NHS R&D programmes are separate from the DH Policy Research Programme (PRP) and, indeed, funded by a different vote. The PRP has a history of commissioning research issues relevant to policy-making, long before they appear on the ‘radar’ of the research councils. Further, it supports research in ‘Cinderella’ areas – for example, community care, sexual health, learning disabilities – that both the MRC and, to some degree, NHS R&D have largely ignored. (The recent MRC-managed research initiative on sexual health was fostered and wholly funded by the PRP). Over the past 30 years, PRP has supported streams of high-quality research in university-based research units that have made major contributions to knowledge in these and other neglected areas. By doing so, it has also created a cadre of researchers with a deep understanding of the policy process. Other countries have had to invent completely new institutions (for example, the Canadian Health Services Research Foundation) to achieve something similar.

It seems unlikely that a single fund, held at a distance from policy-making, would be able to respond flexibly and in a timely manner to urgent policy need. It is therefore recommended that a budget for policy-related research should be retained within the Department of Health, and at least at current levels.

In addition, in recent years the national NHS R&D programmes, particularly the Health Technology Assessment (HTA) Programme and the Service Delivery and Organisation (SDO) Programme, have opened up areas of research that neither the health care industry nor providers have wished to address themselves. The HTA has answered questions about interventions already in use in the health service, introduced by the health care industry and/or providers without adequate evidence of their effectiveness and cost. The SDO programme has commissioned social science research about organisational form and function in health care, issues that the NHS has been historically reluctant to address.

In both cases, such questions have also fallen between the stools of the MRC and ESRC; the HTA because the interventions are not new, and the SDO because the research is applied. Yet, the questions addressed by both programmes are ones that have clear policy relevance. Any new structures for a single budget for health research should protect their ability to commission research that might be uncomfortable for industry and health care providers.

In terms of the balance between investigator and priority led research, both are needed and public funding should encourage both. There is strongly felt belief that a single health research fund must not become one that exists to respond solely to the politically driven priorities of government. The role of the MRC as a research funder has many advantages above that of the Department of Health including its ability to (a) respond to the priorities of the research community; (b) view health and health research much more broadly than what is encompassed by *medicine* or even the *NHS*; (c) manage protected budgets that are not vulnerable to redeployment when NHS finances are depleted.

It is important that any new funding mechanisms ensure that there is scope for responsive funding and that there is scope for currently “unfashionable” research. There is a need for high quality public health research with a focus on scientific understanding of health determinants and inequality in health which needs sustained and longer term support. This need could be seen as an example of a previous lack of policy interest.

There needs to be a balance between project and programme funding. Programmes of research need longer term funding but clear process of peer

review is needed to ensure programmes continue to deliver on their scientific aims and objectives.

The proposed population-based model to ensure the distribution of resources across the whole of England will need to address the costs currently associated with administrating R&D at the local level. Every NHS trust maintaining an R&D office is an inefficient use of finite resources, and there is a case for streamlining local processes for research administration into an 'MREC' style regional format.

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?*

Clinical practice has undoubtedly been influenced by the results of research through the implementation of NICE guidance, although changes to practice have been variable (Sheldon, 2004). At the same time empirical research has raised questions about whether health research is being appropriately communicated to and used by health care decision makers (Dash, 2003). There is evidence that planned dissemination works (Mason, 1998, 2001; Grimshaw, 2004; Ryan, 2004), and that greater emphasis should be placed on promoting the findings from research (particularly from systematic reviews). Organisations like the Centre for Reviews and Dissemination (CRD) have demonstrated that it is possible to successfully communicate in ways that enhance the consideration and uptake of findings in practice. However, most research commissioning bodies still focus on passive publishing and making research 'available' rather than taking a more active role. Improving uptake will require greater investment on the 'D' and on infrastructure than is currently present in the MRC and NHS R&D Programmes. Consideration could be given to a research programme in knowledge transfer that focuses not only on the implementation of research but on learning from other sectors and on assessing how best to increase research utilisation in decision making contexts.

Evidence-informed public policy is clearly high on the agenda and its importance in improving effectiveness and efficiency, and improving accountability and trust in government has been acknowledged (Strategic Policy Making Team, 1999). However, moving to a position where most policy is evidence-based will take time and will involve changing policy-

makers perceptions of research (too long, too detailed, not practical and often delivered at the wrong time). Greater use of research in policy making is likely to require a better understanding and closer links between producers and users of research.

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?*

By providing additional resources to enable staff in NHS R and D grants to publish their work in scientific journals and to promulgate their work beyond the NHS. Universities will be key in providing the environment for allowing interdisciplinary networks to develop.

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

Whilst the general intention to facilitate collaboration with industry and to seek appropriate sources of funding from outside the public sector to support research is welcomed, there are some concerns about potential over-reliance on non-public sources.

First, one of the strengths of existing programmes such as the HTA is that questions can be asked which industry may prefer to leave unanswered and which health care providers are unlikely to raise. The independent oversight of evaluations means that wide ranging alternatives can be compared rather than the focus being only on new technologically or innovatively driven interventions in which there may be substantial commercial interest. Similarly, existing service delivery methods can be investigated by independent evaluation even when incumbent providers may have vested interests in maintaining the status quo.

Second, there is a danger of distorting priorities if attempts are made to pass too much responsibility for funding research to providers. In particular there is a large sector of small independent providers of social care who, unlike large corporations, do not have the ability to fund research. These providers are often concentrated in sectors of social and health care which already are proportionally underfunded and under-researched. There is a need for public

funding both to support research in such areas and to aid the translation of research to improve public services

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?*

There is a lack of capacity currently available to meet the growing demand for evidence needed to support NICE. Additionally, a compulsory trials register could be considered where industry is responsible for making their research identifiable and accessible.

At the same time NICE needs to do more to be seen to be independent with greater transparency around its evidence informed decision making processes – recent decisions around MS drugs and the Secretary of States intervention on trastuzumab undermine NICE as an independent and impartial body and raise (whether justified or not) suspicion of government / pharmaceutical influence. The public funding of research therefore has an essential role to play in ensuring that priorities for research are not dictated purely by commercial interests and ability to pay.

The research community can support the study and evaluation of health service interventions and policies. The existing programmes of Health Service Technology Assessment and Service and Delivery Organisation are very important and should continue to be supported. The scientific bases of the HTA programme helps maintain academic rigour and support organisations like NICE. Maintaining distinctions between programmes has been helpful and there is support for maintaining streams of funding within any new funding body.

One method to ensure that research is used effectively is to support the training of researchers and as such this should be an important priority of any new body.

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?*

There has been a long history of different attempts to set research priorities both in the UK and elsewhere. In the US for example the division of the National Institute for Health into disease areas stifles important social science and public health research which have a broader focus. Any new body should consider health and health interventions in their broadest context. Considerable care is now delivered outside the NHS and it is an important scientific priority to ensure such care is researched.

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.*

- A merged fund could offer real benefits in terms of improved coordination of the funding of health research, which in turn would help to avoid the duplicate funding of similar work. The intention behind the proposals to improve strategic planning of all health research and to ensure a seamless coverage of all relevant issues, avoiding gaps and duplication that may arise from the existing separation of funding sources is welcomed. However, as the MRC and the NHS R&D programmes have traditionally tackled quite different areas of medical/healthcare research, it is important that whatever new funding mechanisms are put in place the entire spectrum of research is recognized, including activities in the middle ground which clinical trials and systematic reviews of therapeutic interventions occupy. Considerable care will be needed to design an effective and efficient mechanism for making decisions across such a diverse research agenda. In addition the new arrangement must impose the scientific and management standards of the existing Medical Research Council.

There is also a danger that the structures become cumbersome and costly to administer. There appears to be a tendency in the public sector to assume that the creation of larger, all-encompassing structures will produce automatically a stream-lined and cost-effective system (eg the current merger proposals in the police sector and the long history of merger of organisational structures in the health service). However, evidence for such approaches is scarce and there is a danger that a larger proportion of the available research budget will be swept up in administering the infrastructure required for allocating resources using more centralised mechanisms.

Close attention will need to be given to distinguishing carefully those functions that are most likely to be organised efficiently at a higher level from those that should remain more devolved. It would be disappointing if, rather than improving the research commissioning process, the proposals instead created an unwieldy and costly centralised structure.

It is essential that any new mechanisms support an evidence-based approach to research, with newly funded research building systematically on what is known already. In the case of clinical research, new studies should be preceded by a systematic review of existing evidence. This is an obligatory part of applying for funding to the MRC for new clinical trials, but it appears to be rarely enforced, is often done poorly and not reviewed critically.

It is clear that any new body must have clear independence led by a person appointed managerially independent of civil servant or ministerial direction. It is important that not only day to day decision on scientific funding is taken at arms length from political pressure but also to insure that strategic decisions are independently taken. This will ensure that the new body has the full confidence of the research community.

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?*

This has not yet impacted on the work of the University

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 allocation of funding on an open, competitive basis to a large number of researchers is perhaps best achieved via centralised systems. This can prevent the duplicate funding of similar work, and can facilitate multi-centred approaches. Centralised systems also facilitate clearer and easier access to funding for investigators without, as the MRC experience demonstrates, concentrating resources in one particular area of the country. Finally, centralised systems may make it easier to demonstrate a clearer return on investment for NHS R&D.

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