

RCN Response to the Cooksey Review

Introduction

The Royal College of Nursing welcomes the opportunity to respond to the Cooksey Review of UK Health Research. We recognise that this timely review has the potential to ensure the appropriate future allocation of research funding to underpin innovation and improvements in all sectors of the UK health economy.

With a membership of over 380,000 registered nurses, midwives, health visitors, nursing students, health care assistants and nurse cadets, the Royal College of Nursing (RCN) is the voice of nursing across the UK and the largest professional union of nursing staff in the world. RCN members work in a variety of hospital and community settings in the NHS and the independent sector, including the workplace. The RCN promotes patient and nursing interests on a wide range of issues by working closely with the Government, the UK parliaments and other national and European political institutions, trade unions, professional bodies and voluntary organisations.

Before examining each of the review questions in turn, the position of the RCN is presented

RCN Position

The Nursing strategies endorsed by the UK Governments specify that nursing practice should be underpinned by the best available evidence and make explicit the requirement to undertake research. The research concerns of nursing include patient's experiences, the effectiveness of nursing interventions in sustaining health and managing illness and in ensuring optimal patient outcomes. Through research, knowledge is developed to underpin the provision of safe and effective care.

A funding source is acknowledged in less than one third of published nursing research (Rafferty 2000) making nursing research relatively invisible. Limited funding means that much nursing is written by lone authors, producing research in fulfilment of research degrees and often investigating easily accessible topics. Consequently topics and outputs can be unattractive to organisations that fund research and may lack relevance to nursing practice and patient care.

Education contracts expressly forbid Universities from using nurse education money to support research activity. Nursing departments in Universities are eligible for Research Assessment Exercise (RAE) monies, but the subject of nursing receives less money than almost any subject in UK Universities.

Government funding of research which specifically addresses the concerns of nursing is relatively limited. It includes initiatives across the UK to develop research capability in

the Nursing, Midwifery and Allied Health Professions (for example £9M investment in Scotland); the DH “Policy Research Programme” (£2M for “nursing quality initiative” in 2003/04); the DH “Service Delivery and Organisation Nursing and Midwifery programme” (2005/06 budget £550K).

Whilst these funding streams are valued, they are relatively short term, leading to stop-start research. The development of comprehensive programmes of research to specifically address the concerns of the nursing professions (which are closely aligned with the concerns of patients) are therefore difficult to achieve and sustain in the current culture which the UKCRC have ably demonstrated, is dominated by biomedical research (UKCRC 2006).

Unlike nursing, medicine has benefited from a dedicated research council. In 2005/2006, the Medical Research Council (MRC) had £48.7m to invest in research training and £247.3m in national medical research facilities. It provided support for existing research teams in Higher Education Institutions (HEI’s) and funded the best new science, via grants and other new awards.

Without a strong portfolio of clinically relevant nursing research, patient care is compromised. Whilst nurses have been eligible to apply for funding from the MRC and indeed the Economic and Social Research Council (ESRC), the priorities of these organisations have not reflected the concerns of the nursing professions. This may be as a result of the relative weakness of the nursing voice in health care research commissioning arenas despite the fact that there are more than three times as many nurses as there are doctors in the UK and nurses are reported to deliver 80% of direct patient .

In the light of these concerns, RCN members voted unanimously at this years Congress that the RCN should lobby for a Nursing Research Council. This illustrates the disenchantment that nurses have with the existing research councils. It also reflects the fact that the establishment of the National Institute of Nursing Research in the USA has lead to well funded excellent research programmes that have positive implications for patients, families and communities. This review could not have come at a more opportune time.

The scope and terms of reference for the Review are laudable. It is crucial that health research addresses issues of relevance to health nationally and internationally and that the UK’s research funding priorities are in line with the Government’s health objectives and the needs of the National Health Service. Nonetheless, it is also important that the Haldane Principles are upheld and day to day funding decisions are taken at ‘arms length’ from Government ministers.

It is a given that research funding should always be awarded on the basis of excellence and through rigorous and systematic peer review. Accepting this principle, funding should be accessible for **all** health research disciplines. It should also be available for research across the full spectrum of health research from basic to applied research and to a range of appropriate methodologies. The emphasis on translational health research and its relationship to economic benefits is welcome.

RCN Response to 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?

The major strength of the MRC is the focus on international research excellence. It is recognized as a high quality “brand”. Nonetheless, as its title suggests it is mainly supportive of medical research rather than health research and this is seen as a major weakness.

In contrast to the MRC, the NHS R&D Programmes, while also having quality as their watchword, have provided substantial funding for the full range of health and social care professionals. They have also encouraged capacity building in disciplines new to research by funding studentships, bursaries and fellowships. Furthermore, unlike the MRC, the research projects funded by NHS R&D Programmes tend to cross the spectrum of health and social care research. Whilst benefiting from strong links to policy bringing NHS strategy and research closer together, the weakness of the NHS R&D programmes is that they seek more short term research output linked to policy aims and assume greater translation from research to practice which can be influenced by competing agendas.

Neither has systematically invested in programmes of research to develop the evidence base to inform nursing practice which is anomalous in light of the fact that nursing teams deliver 80% of direct patient care. Whilst investment in the research training of the disciplines new to research is welcomed this should be progressed within the context of a viable clinical academic career.

Both the MRC and NHS R&D programmes have mechanisms for public and patient involvement in prioritising what research gets funded. Whilst the MRC does this through its Advisory Group for Public Involvement and the NHS R&D programmes does this via advisory and commissioning groups, there is room for improvement which will have funding implications. Translational and applied research especially would benefit from the necessary funding as well as time to facilitate meaningful involvement in all stages of the research process including: prioritizing topics, reviewing applications, governance of funded studies, design, undertaking of research and its dissemination. The new single funding stream should recognise the importance of involvement and both model and finance its structures and processes accordingly within itself and the studies it funds.

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 medical profession no longer represents the largest professional group in UK universities. This distinction now falls on nursing and the allied health professions. The same is true within the NHS. However, the funding provided to build capacity among

these disciplines has been miniscule in comparison to that channeled to medical researchers. Ironically, in most cases it is these groups that are closest to patients, families and communities. Therefore, one of the major challenges is how best to prepare these health professionals to undertake high quality clinical research. This can only be achieved with an increase in funding to build capacity and research expertise. As alluded to above, the MRC has not made much of a contribution to this goal.

There should be greater incentives within both the NHS and the University sector to collaborate in health research to improve the quality and the relevance of health research.

Underpinning training and support for effective involvement of patients and the public requires significant investment. Whilst funding applicants are frequently asked to demonstrate user involvement in their proposals, equipping them with the skills to do it is a particularly under-developed area yet one which is required to fulfil the current policy objectives on user involvement in research.

Other scientific challenges include harnessing the expected increase in information management and technology, telecare, the implications of the human genome project, managing risk while encouraging innovation, the ethical dilemmas associated with stem cell research and new, yet expensive and scarce technologies. These challenges can be addressed through the following:

- Utilise opportunities for multi professional research training recognising that some disciplines have a greater need than others;
- Develop technology in the context of the best research evidence of both clinical and cost effectiveness;
- Develop a clear and strong ethical framework within which the developments linked to the human genome can be furthered;
- Encourage innovation within a risk assessment framework.

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?

According to the World Health Organisation (1999), the 21st century offers a bright vision of better health and social care for all. It holds the prospect not merely of longer life, but superior quality of life, with less disability and disease. However, fundamental changes are taking place in health and social care and these are likely to increase as we move towards 2015. The drivers for these changes include new discoveries, new treatments and globalisation.

Specific challenges will be a continuing shortage of resources, greater demand for cure and palliation, emphasis on care closer to home, a better educated and assertive public, a greater incidence of diseases of old age, changing family structure and globalisation of

health care. International travel will lead to an increase in new diseases in some parts of the world and faster transmission of virus related illnesses.

Therefore, the government's priorities for health research should be to fund more research into old age and chronic diseases from pathology through to the support, treatment and caring of these individuals.

The public fund the MRC and the NHS R&D Programmes and therefore more research should be undertaken into issues that affect the general population and that are of immediate importance to communities. The balance between bioscience, translational and applied research is weighted towards bioscience research (UKCRC 2006). This balance must be recalibrated; blue skies research takes many years for any results to percolate to the general population and many of the projects do not result in evidence that has a direct impact of patient care. In contrast, translational and applied research have rapid impacts on clinical knowledge and skill development. Obviously, the watchword is quality.

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 judgments about this balance?

Internationally, the NHS is unique in terms of the provision of health services and many billions of pounds are required to keep it functioning. Because of its complexity there are a number of problems in terms of how best to manage and maintain the NHS in order that the populations obtain the best possible health care. Many of these problems can be addressed through research projects and programmes in the form of translational science and applied science. Within the MRC the balance is in favor of basic science while there is more of an equitable balance in the NHS R&D Programmes. The balance should be determined by the health priorities of the UK government and balanced against the need to invest in programmes of research long term.. This may alter over time; for example during times of impending disease crises (e.g. Avian Flu, AIDS, CJD) more funding may need to be channeled into basic science. Similarly, during times of crises in the NHS (e.g. long waiting lists, increased trolley waits, staffing shortages) or demographic crises (e.g. chronic illness, elderly care) more funding may be channeled into translational and applied sciences.

Sound judgements about this balance may be realised through equal representation of personnel in decision-making at all levels reflecting expertise in the full spectrum of health research encompassing a wide range of methodological expertise.

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?

There are many examples within acute, community services where publicly funded research has underpinned improvements in the health of the population. These include research that drives the NICE, SIGN and NIH guidelines. Other examples include research outcomes showing the effectiveness of behaviour therapy with acutely ill psychiatric patients, of folic acid in the prevention of spina bifida, of TENS in the management of chronic pain, of the importance of nurse practitioners and medical assistants in relation to NHS staffing policy.

The question posed above - **What lessons can usefully be learned to improve the uptake of advances in science and medicine?** illustrates once again the emphasis there is on funding research into advances in medicine. This ignores the largest group of health professionals who are undertaking research with limited funding from the NHS R&D Programmes and even less from the MRC.

Where research is focused on clinical patient centered problems, there are benefits in terms of decreased morbidity and mortality. Many of these patient centered problems are complex and challenging to research. They often require a range of research expertise and innovative methodological approaches to address them. They do not lend themselves to RCTs or to medical research alone.

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?

There should be incentives for multidisciplinary research. These may include for example special funding arrangements. Incentives should be put in place to encourage researchers to collaborate across the bioscience, translational research applied research interfaces. The same principle should be applied to promoting research collaborations between researchers in different fields of science. This will also be stimulated through research priorities and calls for research proposals that emphasise partnerships between different disciplines coming together to work on research programmes. For example, a research programme that focuses on rehabilitation of stroke patients can bring together patients and carers, engineers, computer scientists, allied health professionals, nurses and physicians.

Such collaborations could also be encouraged if a greater emphasis was placed on this by the Research Assessment Exercise or the metric system that may replace the RAE post 2008. .

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

Entrepreneurship should be a core element in the curriculum of all health professional courses. Similarly, universities and the NHS should include innovation and knowledge transfer as criteria for promotion and advancement. KTP schemes that have proved so successful in industry should have a greater emphasis on health care. Health researchers should have greater exposure to different organisational environments during their training and career development.

The MRC and the NHS R&D Departments tend to focus their funding on the generation of new knowledge rather than the application of this knowledge to practice through translation, entrepreneurship and innovation. The latter is often denigrated as evaluation research and audit. Ring fenced funds should be made available to support 'proof of concept' research, practice developments and research into technology and knowledge transfer.

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?

This will not happen by continuing with the *status quo*. Rather, there must be a strategic decision to fund the infrastructure to underpin basic, translational **and** applied research. Funding streams should be available to train health researchers in the most appropriate and robust methodologies for undertaking translational and applied research. Alongside this there should be ring fenced funds to support such research. There is the need to ensure that the Board of the research funding agency is composed of peer reviewers and experts from different disciplines and with expertise in different methodologies.

NICE **and** SIGN produce excellent evidence based guidelines. However, such guidelines are not self executive and therefore research into the application of these into practice and an evaluation of their effectiveness and efficiency is required. The view that translational research is indicative of weak or soft science has to be challenged if it is to be utilized to improve the quality of patient care.

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 are lessons to be learned from the USA and Canada. In the former the NIH has a number of research institutes that focus attention on the Government's research priorities. The UK NIHR reflects this model. One of the drawbacks of the US NIH is that all the institutes have their base in Bethesda, Maryland. In contrast, the Canadian Institutes of Health Research (CIHR) are spread geographically across the country. This illustrates the

value that the Canadian government places on geographic diversity as well as disciplinary and methodological diversity. This model could be used in the UK NIHR with institutes having bases in the four countries of the UK.

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 main difference between the two funding streams is MRC is investigator-led research and DH/ NHS R&D is commissioned research. The limitations of these current funding streams is their failure to address the concerns of nursing practice as stated above - patient's experiences, the effectiveness of nursing interventions in sustaining health and managing illness and in ensuring optimal patient outcomes

A new single funding stream must embrace the broadest spectrum of health research, health researchers, and research methodologies. It must include sustainable funding to support programmes of research to develop the evidence base to underpin nursing practice. The body which administers the single funding stream should incorporate equal representation of personnel in decision-making at all levels reflecting expertise in the full spectrum of health research encompassing a wide range of methodological expertise. This body should be accountable to the public through their elected representatives and decisions on scientific merit should continue to be by independent peer review.

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 question is based on the assumption that innovations in health research such as Clinical Research Networks are successful. Their capacity to support translational and applied research should be evaluated. All of the current coordinating centers are have a medical focus and support a narrow methodological perspective. This does not give due regard to the devolved administrations or the importance of having plurality with regard to discipline or methodology.

The reliance on Connecting for Health NHS IT is not strong nor should it be. While this would have the potential to encourage research collaborations, IT systems become outdated easily. The NHS has a poor history of robustness within its IT systems and if predicated upon this link research could suffer if problems of IT interdigitation occurred.

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?

Devolution has resulted in the development of a number of health and social care strategies based on country differences and needs. Research should not ignore such

fundamental differences rather it should support the development of the infrastructure within each of the four Countries of the UK to support their research priorities. A recent issue of Research Fortnight (Mar 06) showed that the MRC mostly funded universities in England and the other three countries did less well *pro rata*. Furthermore, in those universities where nursing and allied health professionals are the healthcare majority, the MRC funding was low. Therefore, if the new single fund merely became a bigger version of the MRC, research from the largest professional groups in the health service who have greatest contact with patients would decline. A new single funding stream must offer added value, build on current strengths and address the limitations of current funding streams.

Rafferty AM, Traynor, M (2000) Measuring the outputs of nursing R&D: A Third Working Paper, Centre for Policy in Nursing Research, LSHTM, London

UKCRC (2006) UK Health Research Analysis.

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