

Response to the Cooksey Consultation on behalf of Greater Manchester Primary Care Research Governance Partnership (ReGrouP)

This response is prepared on behalf of the Greater Manchester Primary Care Research Governance Partnership (ReGrouP). ReGrouP was established in 2005 and covers the Greater Manchester PCTs, streamlining the research management and governance systems and processes across the 14 Trusts. A list of organisations represented on the ReGrouP Steering Group can be found at Appendix A.

1. What are the strengths and weaknesses of the MRC and NHS R&D programmes at present?

The major strength of the MRC R&D programme is its international reputation for commissioning high quality medical research which can make a significant improvement to individual patient care and health outcomes, together with its focus on long-term research and individual excellence. A weakness is the lack of focus on research related to and carried out by other health and social care professionals and patient-focused research. MRC has not traditionally commissioned policy research nor research to identify the most effective forms of service delivery and organisation.

Conversely, the NHS R&D Programme has made a significant contribution to research related to and carried out by professions other than medicine and to broader aspects of health care delivery, including policy-related research and service delivery and organisation research. It has also contributed to developing research capacity within non-medical health professions. NHS R&D funding provides the only source of public funding to support research infrastructure within the health service, without which only limited research involving patients, carers, organs, tissues, or data could be carried out.

Consequently, the combined strength of the MRC and NHS R&D Programmes is that they present a relatively balanced portfolio of research activity in that the main areas of research activity of the MRC are in underpinning research and aetiology, whereas in contrast the research profiles of the Health Departments are generally focused in treatment evaluation and health services followed by detection, diagnosis and disease management. The MRC and the Department of Health have achieved this by focusing on and developing specific areas of research commissioning expertise.

Many of the perceived weaknesses of NHS R&D programmes have been identified in Best Research for Best Health and implementation plans are being developed to address the issues of excessive bureaucracy and historical funding regimes. The new streamlined research programmes will enhance the research being commissioned and the creation of research networks will improve recruitment of participants to research studies.

Both MRC and NHS R&D programmes need to improve the interface with the commercial sector and this is being addressed through the UKCRN. Both

have traditionally significantly under-resourced primary care research and more focus needs to be given to this area.

How do each of these support the research and training needs of NHS, social care, industry and academia?

Please also refer to the response to question 2.

The MRC are renowned for producing world-class researchers and their intention to develop research translators, with the necessary and appropriate skill mix to ensure research findings are taken up in practice is laudable.

The NHS R&D programmes have made great progress in supporting R&D capacity and capability development since the Culyer¹ report particularly in promoting and supporting the development of research in the areas of primary care, nursing and allied health professionals. However more needs to be done to develop multi-disciplinary research skills in public health and social care..

Does more need to be done?

The development of multidisciplinary research is necessary to achieve successful implementation of research findings from basic science through to clinical interventions and this presents challenges which need to be overcome. Current training provision does not entirely address these issues. Capacity building for health service management and commissioning research needs to be considered. Support for the development of skills for systematic reviews of research evidence and methodologies and skills in implementing research into practice should continue, alongside skills to carry out research. .

The system needs to be created in line with commissioning a patient-led NHS, so that priorities do not get blurred, especially in areas which have not been traditionally research active.

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?

¹ Supporting research and development in the NHS. A report to the Minister for Health by a Research and Development Task Force chaired by Professor Anthony Culyer. London, HMSO. September 1994.

Scientific Challenges:

The research community needs wide access to technologies, databases and other scientific resources that are more sensitive, more robust and rigorous and targeted on health priorities including patient benefit and public health.

Research in public health can be technically difficult. In addition health data for monitoring the health of the population and for evaluating the effects of health interventions is often of poor quality. Finally, evidence-based principles still need to be established to determine the cost effectiveness or otherwise of public health and preventative policies or their practical implementation.

Research to provide Health Intelligence for commissioning needs to be strengthened, as does scientific evidence for and evaluation of health and social care policy. Particularly, research to establish the most effective models of commissioning by PCTs and practices is required, as is evaluation of new models as they are implemented.

Organisational Challenges:

Major change within the NHS, together with the implementation of the new contract has left clinicians under great pressure with research and training often taking a back seat, this together with the decline in numbers of medical academics represent key challenges facing health research and underpinning training. The framework outlined in the Walport² report on clinical academic careers offers a framework for addressing these concerns and reversing the decline for doctors. The Finch Report which is due to be published soon will address the development of a clinical academic framework for nurses. Incentives need to be developed for recruitment and retention of clinical scientists, together with a clear career pathway for junior doctors, dentists nurses and allied health professionals on how to pursue a research career. Currently there is a lack of a clear route of entry, a lack of a transparent career structure, lack of flexibility in the balance of clinical and academic training together with a shortage of properly structured and supported posts upon completion of training.

The Follett³ review recognised that NHS bodies and universities have separate responsibilities for medical education and research and for their associated clinical service, but that neither can fulfill these responsibilities without close joint working with the other to integrate separate responsibilities within a framework of clear accountability with delineated lines of reporting. Underpinning joint working are interdependent contracts, a formal agreement on the procedures for the management of poor performance and the

² Medically- and dentally- qualified academic staff: recommendations for training the researchers and educators of the future (the 'Walport report'). The Academy of Medical Sciences. March 2005.

³ A review of appraisal, disciplinary and reporting arrangements for senior NHS and university staff with academic and clinical duties. Sir Brian Follett and Michael Paulson-Ellis. September 2001.

development of a jointly agreed annual appraisal and performance review process, based on that for NHS consultants, and combined in a single set of documentation, to meet the needs of both partners and that feed into joint strategic planning and service development processes.

The new NHS appraisal scheme will be applied to clinical academics in respect of their clinical service for the NHS. Thus without a new approach, clinical academics will face a series of overlapping but separate processes: NHS appraisal, university appraisal and performance review, NHS award schemes, and GMC requirements for evidence demonstrating fitness to practise in the field of academic medicine. This is unsatisfactory as well as unsustainable in the long term.

The principle of joint working is further supported by the report of the Nuffield Trust Working Group on NHS/University Relations entitled *University Clinical Partnership: Harnessing Clinical and Academic Resources*, as well as *Clinical Academic Careers*, the report of an independent task force chaired by Sir Rex Richards, published in 1997. Both reports emphasised the necessity for robust relationships between the NHS and universities if medical education and research are to be delivered. The reports highlight the peculiar problems faced by clinical academics that appear to have two posts with separate employers and yet actually have a single professional job.

The review emphasised that a clinical academic post is a single post held by a whole person. It should therefore be recognised that the balance of activities of that whole person can and should vary over his or her career to avoid artificial barriers to such flexibility. At present one significant barrier is the NHS distinction award and discretionary points scheme. This is structured in such a way that only clinical academics with six or more weekly sessions of clinical service under an honorary contract are eligible for full awards: those with fewer sessions have their awards reduced *pro rata*. This is the key reason why honorary contracts normally specify six NHS sessions, even though in many cases not all of these are spent on patient care or direct clinical service. The review suggests the award scheme should cover the whole job of clinical academics holding honorary contracts irrespective of the number of sessions specified in that contract, and should thus recognise that everything that a clinical academic does, whether service, teaching, research or management and administration, is of benefit to the NHS. This would enable NHS and university managers to make more realistic decisions about the number of NHS sessions to be provided, and to vary them, perhaps very substantially, from year to year to meet their needs and an individual's career development, without artificially debarring him or her from access to the award scheme. The award scheme is currently under review, providing an opportunity for change.

In some instances the clinical service of academics in a particular specialty is provided by the university department as a whole, enabling in an ideal world that service to be organised for individuals in block periods of intensive clinical work, leaving other periods free for concentrated activity on teaching and especially on research. Concerns have been expressed that an emphasis on detailed individual clinical job plans works against this desirable flexibility.

Joint working between NHS clinical directors and university heads of departments should enable such departmentally based arrangements to be maintained and appropriately reflected in the job descriptions and job plans of individuals.

Clinical academics in public health medicine have emphasised that it is much less easy in their discipline to distinguish between clinical and academic work, and thus to be specific about separate accountabilities for different parts of the overall role. It has also been pointed out that much of the specified documentation for NHS consultant appraisal is not fully appropriate to public health work. In these cases careful joint work needs to be undertaken by NHS and university managers to adapt the principles set out in the report to the needs of specific groups of staff.

In relation to other professions The Wellcome Trust is supporting the development of a framework to support research nursing careers and it is anticipated this will be rolled out to allied health professionals.

There also needs to be a clear ability for PCTs to be able to understand and plan for treatment and excess treatment costs to avoid perverse incentives entering the system. There should also be clear links with researchers and commissioners to ensure consistent approaches.

How might the UK Government best help address those challenges?

The UK Government could address the above issues through identifying the benefits of joint working and identifying and sharing models of good practice. Aspects of the impact of NHS R&D policy should be analysed for the risk of perverse incentives and real incentives arising in the system eg PBR, GP/Consultant contracts etc. Government needs to demonstrate a clear commitment to and policy direction for addressing these challenges. In addition, management and clinical commitment to these policies should be supported as well as from the academic and scientific communities.

Any new institutional arrangements should build on the NHS R&D Programme's successes in capacity building through the RDSUs and research commissioning designed to strengthen the scientific health research skills base.

What do you believe should be the Government's objectives for health research, and why?

The science and innovation framework (HM Treasury, DTI and DfES 2004)⁴ makes a powerful case for research. MaGNet fully support the Government's objectives for health research as succinctly outlined in the Terms of Reference of the Cooksey Review namely ensuring research priorities are firmly grounded in the Government's wider health objectives and are a key priority for the NHS to ensure the continued delivery of world class basic science and ensuring delivery of high quality translational health research to deliver real economic as well as health benefits. Together with the objectives set out in the NHS R&D Strategy: Best Research for Best Health to create a health research system in which the NHS supports outstanding individuals, working in world class facilities, conducting leading-edge research focused on the needs of the patients and the public.

3. What should be the government's priorities for health research?

The goal of the NIH in the USA is to acquire new knowledge to help prevent, detect, diagnose and treat disease and disability from the rarest genetic disorder to the common cold. Whilst it is recognised that research in these areas is essential the UK Government needs to facilitate the NHS to evolve from dealing with acute problems through more effective management of chronic conditions to promoting the maintenance of good health (Wanless 2004)⁵

There should be more "translational" research which looks at not just getting research from the molecule to the clinic, but also looks at the public health implications and feeds into bodies such as NICE and national commissioning bodies. Furthermore, there needs to be enhanced level of funding for systematic reviews of research to support the implementation of research into practice.

The National Service Framework (NSF) approach should be extended to other disease areas and integrated with recommendations from NICE, particularly clinical guidelines. Comprehensive research programmes should be established for future NSFs that enable them to be reviewed and updated in the light of emerging evidence and analyses of cost effectiveness. NICE should play a major role in examining older technologies and practices with a view to assessing appropriateness or cost effectiveness.

Priorities should be set through an expert committee who has knowledge of all the different bodies associated with research in the UK to provide an expert overview. It is also important to involve bodies such as the National

⁴ HM Treasury, DTI and DfES 2004 Science and Innovation Investment Framework 2004-1014. London.

⁵ Derek Wanless. Securing good health for the whole population: final report. HMSO.

Innovation Centre to look at developing models of getting research and innovation into practice.

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?

It is difficult to target future investment when it is hard to predict which basic science advances will eventually provide benefits to health.

The UK Health Research Analysis Report⁶ mapped the current UK-wide research portfolio for the years 2004-05 and concluded that one third (34.1%) of spending is concentrated in underpinning research, aetiology, accounts for another third of the funding (34.5%) and the remaining third (28.9%) is spent on research into detection and diagnosis of disease. A relatively low total of 2.5% of funds is dedicated to research focused on the primary prevention of disease, or conditions or promotion of well-being and research funding focused on the primary prevention of disease needs to be increased, together with rigorous health economic evaluation of policy decisions and the effectiveness of public health interventions.

We should be able to look to other countries for demographic comparisons regarding where the best population outcomes can be produced relative to research spend.

The report shows that the distribution of funds across different types of research activity varies between individual funding organisations and across different areas of health and disease. Of the total research funded one quarter is applicable to all diseases or relevant to general health and well-being whilst three quarters relates to research that can be attributed to specific diseases and areas of health. Of the latter sum two thirds is spent on cancer, neurological, infection, cardiovascular, inflammatory, immune, mental health, and metabolic, endocrine and musculoskeletal research. The new system should be able to respond to Public Health challenges which may be uncovered through research such as Childhood obesity, and have a mechanism of bringing them to ministers attention in a timely fashion.

⁶ Fox-Rushby JA, Disability Adjusted Life Years (DALYs) for Decision-Making? An Overview of the Literature (2002) Office of Health Economics

Generally the pattern of research funding follows the ranking of burden of disease as measured by the Disability Adjusted Life Years⁷ (DALY) rates for the UK. However in the areas of respiratory, oral and gastrointestinal comparative research funding is lower than the relative burden of disease and for infection the relative research funding is higher than the UK DALY ranking. This may indicate that research funding in the disease areas of respiratory, oral and gastrointestinal may need to be increased and the research funding for infection may need to be reduced to free up funding for use in other areas. Cancer receives comparatively the highest level of combined health specific funding but this is not reflected across all the different research activities with 40% of funds in prevention spent on infection and mental health receiving the highest proportion of funds within health services.

Geographically London received 33.3% and Oxford received 8.9% of research funding. The introduction of the Clinical Research Networks should begin to help to address any disparities in geographical spread of R&D funding whilst maintaining the delivery of high quality scientific research. A good spread of population is desirable to enhance research awareness in staff and access to higher numbers of relevant populations. A cluster model might produce an increased financial burden of treatment costs on a small number of PCTs.

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?

Basic and applied research and investigator and priorities-led research are all important but need not be equally funded. It is important that research

funding decisions are impartial, transparent and informed. Much research that had its origins in fundamental science could never have been predicted to be instrumental in health improvement or to have commercial benefit. The new system should allow innovation to develop from ideas which arise from research projects as well as encouraging serendipity through well organised networks. An example of this is “lean thinking” which has the capacity to support development of systems in a range of organisations. There should be a form of evaluation for implementing innovations into practice.

Roland (2006)⁸ identifies that research funders need to adopt evaluation methods that are appropriate for their research and the different methodologies and their associated metrics need to take account of the often long, risky and incremental nature of research these will inform the decisions on the balance between long-term economic and social benefits of biomedical research and service improvements. This will necessitate research funders working together to ensure consistency in data collection and analysis to demonstrate the impact of research.

The National Innovation Centre or similar should be collecting information on HEIs and SMEs who specialise in innovation and product development to allow the flow of ideas to reach the NHS and benefit the whole system rather than a few specific Trusts.

What mechanisms should be used to make judgements about this balance?

Research is a long-term investment that can be difficult to balance against the day-to-day needs of the NHS. Better evaluation of the impacts and outputs of research are vital to identify where adequate value for money is not being achieved by current spending. The paucity of current evaluation tools should not be a barrier and models should continue to be developed which can be shared across the NHS. Account should be taken of the extent to which relevant existing research findings are not being implemented and where there are gaps in the evidence for clinical practice.

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 practice?

⁸ Medical Research: assessing the benefits to society. A report by the UK Evaluation Forum, supported by the Academy of Medical Sciences, Medical Research Council and Wellcome Trust and Chaired by Professor Martin Rowland. May 2006

What lessons can usefully be learned to improve the uptake of advances in science and medicine?

Personal experience leads us to the view that research evidence uptake is ad hoc – depending on the clinical and other leaders in these areas. Stronger incentives are needed to support the use of EBM.

Poor links between researchers and policy makers have previously resulted in delays in the adoption and development of research outcomes into policy and practice. It is laudable that in recognition of this MRC intends to develop research translators, with the necessary skill mix to ensure research findings are taken up in practice. In addition ways of changing professional practice are reviewed by the Effective Practice and Organisation of Care Group of the Cochrane Collaboration. (Links to the National Innovation Centre could also be useful). Engagement and involvement of service commissioners in the use of research evidence for commissioning decisions should also be encouraged as a mechanism for improving the uptake of advances in health-related science.

Roland (2006) suggests the research community should consider how it can engage in active and informed dialogue with policy makers (and the public) about the achievements, applications and broader implications of research for society.

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, eg with engineers, physicists, and social scientists?

Applied research can be perceived as second-class. One way to address this is to promote and support the development of multi-disciplinary work through identifying and sharing good practice. The role of the independent sector should also be considered in this response.

Government should identify this as a policy issue, and support the development of networks across the boundaries between the range of researchers from basic to translational, and involving non-academic clinicians who may have additional knowledge of gaps in research and who are expected to implement research findings in practice. Public and patient involvement in such networks should also be required, as should involvement from health and social care commissioners.

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

The public sector in the UK can learn from the experiences of the USA and Canada who have identified that advances in knowledge and managing innovation are the central drivers of the most innovative economies.

The most prosperous and innovative companies obtain the best results within sectors where new knowledge is being applied intensely and there is capability to innovate or to spend on R&D. Identifying issues and opportunities and focus on the benefits and management of innovation is key. They identify that knowledge-based industries embrace innovation and are key drivers of productivity, economic growth and improvements in standards of living.

They conclude that promoting networking and interaction amongst firms and between public and private sectors, ensuring an adequate intellectual property regime and creating strong scientific and technical resources to create an environment conducive to innovation are fundamental to success.

In the USA innovation is encouraged with the introduction by the NIH of the Director's Pioneer Award that encourages investigators to take on creative, unexplored avenues of research that carry a relatively high potential for failure, but also possess a greater chance for truly groundbreaking discoveries if successful. The value of negative findings in adding to knowledge needs to be recognised.

In evaluating the socio-economic impact of research it is crucial to ensure that methods of research evaluation do not encourage funders to pursue only safe but predictable lines of research and stifle innovation. Bureaucracy of ethics and research governance should not stifle innovative projects with under researched groups, whilst at the same time ensuring sound governance and respecting research participants' safety and dignity in recruitment processes.

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?

This point has been addressed in previous answers.

- Better more accessible models of translation.
- Identify what needs to be done and form should follow function (it may vary from sector to sector).
- Identify the role of the private sector in this.

Research needs to become hardwired into the NHS so that even the most remote Trusts can be research and innovation literate, from Board level to service delivery. This can be addressed through education and training, but it might also be included in pay awards and achievement of "gateways" through the agenda for change pay awards. This system needs to be underpinned by good IT. Currently R&D infrastructure is inadequate, particularly in primary care, with insufficient staff with the relevant skills and knowledge for governance and no career progression, so supporting and embedding

research in Trusts can be difficult without research champions and managers. Clinicians will find it difficult to engage with research if there is insufficient support within the Trust. We fully agree that research governance and systems need to be streamlined and efficient but this needs adequate levels of R&D infrastructure and staff.

The NHS R&D Programme has an extensive track record in funding NHS infrastructure and this experience must be retained and built on in the new arrangements. As currently, commercial research should continue to fully fund the infrastructure costs arising from its research in the public sector.

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?

Clearly there need to be links and the funding streams need to request that funding recipients behave appropriately in their dissemination strategies in relation to their contracts with the funding bodies. NICE particularly should be feeding its recommendations for future research back to the commissioning bodies, whether the MRC, NHS R&D or other funders, who should take these into account when determining research priorities for tendering and funding. Basic scientists should be encouraged to consider the potential practical applications of their research and the Higher Education Funding Council's Research Assessment Exercise should be reviewed to ensure that there are no disincentives to maximizing benefit from any intellectual property generated by university-based research

There needs to be clear links to NICE in terms of information transfer and peer reviewed reports should be able to be shared without infringing copyright of subsequent articles. Future research projects could be identified from reports and reviewed by the funding panel. Market failures should be analysed and addressed by a body (perhaps the National Institute for Innovation and Improvement) who can then address learning points from the failure and identify any research questions which can be referred back to research commissioners.

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?

In May 2002 the National Institutes for Health (NIH) in the USA developed a "roadmap" for medical research in the 21st century. The purpose was to identify major opportunities and gaps in biomedical research that should be addressed to make the biggest impact on the progress of medical research. They recognised that the opportunities for discoveries have never been greater, but the complexity of biology remains a daunting challenge. The creation of the single funding stream for research is the catalyst to ensure new scientific knowledge is transformed into tangible benefits for people as outlined in Best Research for Best Health.

We may also be able to learn from poorer countries with limited budgets about targeting areas for maximum population benefit.

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?

Please also refer to the answer to question 12.

The MRC and DH/NHS R&D have a number of common aims:

- Encourage and support high-quality research with the aim of improving health and care.
- Attract, develop and retain skilled researchers.
- To advance and disseminate knowledge and technology to improve the quality of life and economic competitiveness in the UK.
- Promote user involvement.
- Ensure value for money

It can therefore be argued that there will be benefits in merging the two funding streams. There is a perception too that NHS R&D funding is second-class and the merging of the two funding streams would counteract this. It is vital that high impact funding streams are not dismantled or diluted.

However the MRC and DH/NHS R&D have distinctly different foci with the MRC focusing on medical research and DH focusing on health service research. If the two are to be merged successfully not only are robust and transparent funding systems and stewardship fundamental but also a clear strategy for ensuring **all** areas of research of benefit to patients and the public have equal access to funding is essential. It would essentially prove to be very poor value for public money if basic and biomedical research is funded to the detriment of health service and public health research, which consider for example:

- how to get the right service/treatment to the right people at the right time
- how to ensure that people delivering the services/treatment are effectively trained, managed and deployed
- prevention of ill-health and therefore the need for (often costly) treatment in the first place.

Whilst recognising and valuing the type of research funded by the MRC it should be apparent from the above that over-reliance on that type of research without considering its application in real clinical and public health practice would be detrimental to the population and hence to the economy. Equally, over-reliance on health service and public health research would not represent best value for money. The danger of merging both funds into one organisation is that one or other 'paradigm' would predominate to the detriment of a balanced national portfolio of both clinical and health service research. The MRC, whilst excellent in its own terms, has no experience of commissioning the type of research funded by the DH/NHS R&D Programme

(nor funding the service support costs to the NHS), and vice versa: maintaining both sets of expertise within a single body would likely make that body large, bureaucratic and potentially unwieldy. Consequently the funds should continue to be managed separately but with closer liaison and collaboration to ensure that together the single fund maximizes benefit to health care, the economy and all relevant branches of science.

Allocation of resource should be predominantly through peer review, including informed users, response mode funding and programme grants for applied research in areas of high priority. There should be links to commissioning and different funding mechanisms are required to ensure funding is flexible and meets short-term and long-term objectives and meets basic science and service requirements. The Arthritis Research Campaign⁹ found that smaller project grants appeared to provide value for money that was at least as good as longer-term project streams.

To reduce wastage in terms of time and resources there should be clarity of any funding systems and application processes from the outset with explicitly defined structures and time lines. Research programmes need to be developed across disciplines and organisations in a well thought out, cost effective way rather than as a 'knee jerk' response to a 'call' with a deadline of only a few weeks. Any further changes to funding systems should be made with a view to establishing some stability of process.

**And to whom should the single, ring-fenced fund be accountable?
Please provide reasons and any supporting evidence for your response.**

Any proposed new arrangements for accountability of the single, ring-fenced fund should reflect the Haldane principle, which requires that day-to-day decisions on Research Council scientific funding must be taken at arms length from ministers. The National Institute for Health Research, set up by the DH as part of the Best Research for Best Health strategy, should be constituted as an 'arms length' body, comparable to and on an equal footing with the MRC. The Department of Health and Department of Trade and Industry should make clear policy commitment to the equal value of basic science, applied research and translational research in meeting the needs of the health service, patients and the public, the economy and the scientific community.

If there is however to be a single organisation distributing the single fund, this should be accountable to the Secretary of State for Health, given that the NHS is the primary customer of all forms of health research

⁹ Wooding S, Hanney, S, Buxton, M Grant, J 2004 The returns from arthritis research. Arthritis Research Campaign

11. To what extent does the success of recent innovations in health research (eg 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 Health¹⁰ is an unprecedented opportunity to use information technology (IT) to reform the way the NHS in England uses information and thus improve services and the quality of patient care. It was not originally envisaged that it would support research. The core of the programme will be the NHS Care Records Service where relevant parts of a patient's clinical record will be made available to whoever needs it to care for the patient, subject to patient's consent. There is potential for researchers to use this data too, subject to the NHS Care Record Guarantee, which sets out the principles to protect the confidentiality of patient records. Patient data will be available, subject to ethical approval, that is demographically, geographically, socially and ethnically diverse, covers the complete patient journey and provides access to coded longitudinal patient-level data that will support epidemiological research and studies into the effectiveness of health interventions. The issue of protecting patient confidentiality whilst giving researchers access to data needs to be addressed as an urgent priority.

The benefits from realisation of the new IT system in relation to R&D remains unexploited at this time with respect to the untapped potential of routinely collected patient data within the electronic patient records to support the implementation of the NHS R&D Strategy: Research for Best Health and the objectives of UKCRC. The introduction of topic specific and local research networks, that are focused on improving patient recruitment to clinical trials, and the objectives of the Treasury in relation to working with the pharmaceutical industry to promote the UK as a world leader in clinical research to improve the UK's economic success. At this moment it is unclear how the proposed National R&D Database will be linked to Connecting for Health, however it is clear that the burgeoning networks will have a huge demand for IT support which needs to be connecting for health compatible.

Currently, however, the Connecting for Health Programme is experiencing some challenges:

¹⁰ Summary of the Department of Health: The National Programme for IT in the NHS, National Audit Office, June 2006, London

- The National Data Spine went live in June 2004 but achievement of additional functionality has been delayed by up to 10 months.
- The delivery of the first phase of the NHS Care Records Service will now be nearly two years later than planned.

In the interim this has led to many NHS trusts developing local solutions for instance, Salford Royal Hospitals' information sharing system with Salford Primary Care Trust in relation to diabetes and the Northwest Institute for Bio-Health Informatics (NIBHI). NIBHI is a collaboration between the Universities of Manchester, Liverpool, Lancaster, Central Lancashire, Salford, Liverpool John Moores, Daresbury Laboratories and AstraZeneca. NIBHI aims to facilitate the application of Bio-Health Informatics theory into practice and ensure that Bio-Health Informatics research is informed by the needs of the biological, clinical and population health research in academia and in the pharmaceutical and biotechnology sector of England's Northwest. NIBHI offers a focal point for the coordination of Northwest Bio-Health Informatics research, development and training, facilitating collaborative activities within and between the academic, industrial and health communities. These developments, whilst understandable given the delays outlined above, have the potential to undermine the benefits of a comprehensive national IT programme. Innovative bodies such as NIBI should be networked together and their outputs harnessed or developed more widely, if appropriate.

Other initiatives have resulted in the creation of databases that contain information which researchers would find invaluable but there is no national repository of information on these disparate databases and researchers come across them serendipitously. For example the King's Fund worked with Primary Care Trusts (PCTs) and GPs to develop a free software tool, the Patients at Risk of Re-hospitalisation (PARR), to help the NHS identify patients most at risk of being admitted to hospital to underpin the management of complex needs of patients with long term conditions. The tool is triggered by an emergency admission and uses data from previous hospital admissions, day case care, clinical specialities and electoral wards to provide a score showing how likely it is that an individual patient will be admitted as an emergency in the next year. A key advantage of it is that the tool is simple to use and patients can be categorised in ways that are logical and useful by surgery, locality and by diagnosis. PCTs can use this data to take a strategic view of the local population, comparing localities and informing service redesign and resource allocation. This data is potentially useful for researchers, particularly in the light of the anticipated delays in implementing and realising the benefits of Connecting for Health.

Whilst there is potentially major benefit to clinical and health research from the Connecting for Health IT system it would be a high risk strategy indeed for the success of new structures to rely on this, given the known delays and difficulties in implementing national Government IT systems. Any interim arrangements, such as the development of local or Network-based IT systems should, as far as possible, be developed to be compatible with each other and, in the future, with Connecting for Health

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 maximize the health and economic benefit to the UK?

A common robust and transparent framework for the stewardship, governance and administrative structures to underpin delivery of the new objectives is required. Existing structures should be evaluated to identify whether they are fit for purpose and whether the terms of reference and membership of existing committees and groups can be amended or whether new structures/committees need to be developed to ensure delivery and accountability.

It may be possible to withdraw NHS R&D budgets from the devolved governments and create a centralized UK health fund. If this is not achievable, liaison and collaboration mechanisms which link all the health research funds with each other as well as with the MRC should help to ensure that all health-related publicly funded research maximizes the health and economic benefits to the UK.

Appendix A

Greater Manchester Primary Care Research Governance Partnership (ReGrouP)

This response is submitted on behalf of the ReGrouP Steering Group, which consists of representatives from the following organisations.

Ashton, Leigh & Wigan PCT
Bury PCT
Bolton PCT
Heywood & Middleton PCT
Rochdale PCT
Oldham PCT
North Manchester PCT
Central Manchester PCT
South Manchester PCT
Trafford North & South PCTs
Salford PCT
Stockport PCT
Tameside & Glossop PCT
Health R&D NoW
Northwest SHA
University of Manchester
Manchester Metropolitan University

27 July 2006