

Macmillan Cancer Support

Review of UK Health Research

Comments from Macmillan Cancer Support

Macmillan Cancer Support is grateful for the opportunity to provide input to the review of UK Health Research. Our comments are made from the position of an organisation that works in partnership with the NHS and social care and through lobbying and campaigning to develop and improve care and support for people affected by cancer, funds research into cancer care and support and is an active member of the National Cancer Research Institute. Our comments are made with respect to the terms of reference provided, with particular reference to the health, science and economic objectives, and to the list of review questions provided. We have not answered all the questions in turn but rather addressed the issues covered by many of them in formulating our response, which we have presented under three main headings. Our comments drawn on the knowledge and experience of our staff, trustees and advisers.

For further information or any queries in relation to these comments please contact:

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1. Greater emphasis on health and economic objectives

- ***The strengths of the MRC in basic science need to be maintained.***
The MRC has had a long and successful history since its creation in 1911. It was established to address medical and health issues of concern at the time and has continued to do this throughout its history. Its achievements have included developments of importance in both fundamental and applied research – in many instances the latter have derived from the former. Major examples include the identification of the structure of DNA, playing a substantial role in the sequencing of the human genome, the creation of monoclonal antibodies, the synthesis of the synthetic penicillins, the finding that folic acid prevents neural tube defects, discovery of the link between smoking and lung cancer, the establishment of standards and a framework for clinical trials and many others. The benefits of some of these advances are only now being realised. The MRC has achieved this through a balanced portfolio of research which blends science driven and needs led research – and provides the opportunities for the training of basic and clinical research workers. A major measure of its success is the award of 24 Nobel prizes over the course of its history. A failure to take steps to preserve this quality of

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science would be to the detriment of British science and to the NHS which is the major end user of the products of its research.

- ***The strengths of the NHS R&D programme complement those of the MRC and lie in the health and economic objectives but spend is relatively small and needs building up.*** The NHS R&D programme has a much shorter history than the MRC having been created following the report of the House of Lords Select Committee on Science and Technology in 1988. There have been some limited achievements including a greater awareness of the significance of research for the development and improvement of clinical and public health policy and practice, the establishment of the Health Technology Assessment Programme, which has done much to underpin the achievements of NICE, and the formulation of a system for ensuring that the necessary service support is provided for the conduct of clinical research (although there are significant flaws in this – see below). Other programmes have had a limited impact. It is disappointing that the new Department of Health (DH) research strategy, Best Research for Best Health, makes so little reference to other organisations who have made significant (and in many instances greater) contributions to clinical and public health research and to the development of essential elements of the research infrastructure. It is also noteworthy that the majority of the objectives itemised in the report are already the focus of significant activities by partner organisations. These include the MRC and the Medical Research Charities.
- ***The Health Research Analysis published by the UK Clinical Research Collaboration (UKCRC) in May 2006 reveals research into prevention and disease management, which address most of the health and economic objectives along with health and social care services research, to be the areas of lowest investment in the UK health research portfolio and thus the biggest gaps to address.*** The areas covered by these UKCRC Research Activity Codes address many of the questions posed in the invitation to submit comments to this review but are poorly developed in the UK for many reasons. These include a lack of appropriate methods to address the complex problems they pose, little academic reward in terms of high impact publications and funding and linked to both such research is not seen as being attractive to be involved in. However, this sort of research is often the highest priority for patients (The Macmillan Listening Study, in press) and has the potential to deliver significant health and economic benefits to the UK. Focussing health research into the causes and treatment of disease and ill health only addresses a minority of its burden on the UK since there are more people living with or affected by chronic long term conditions or the aftermath of treatments for acute conditions than there are new cases of disease and ill health, e.g in the UK there are around 300,000 new cases of cancer each year but over one million people are living with a cancer diagnosis. This difference and thus the burden on the UK will only increase as the effectiveness of treatments continues to improve.
- ***Incentives need to be created for more research to address the health and economic objectives to drive up quality and increase the research base.*** There are no simple or ‘right’ answers to what the Government’s priorities should be or the appropriate balance between

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investigator-led and priorities-led research. However, it is clear that the gaps identified by the UKCRC analysis need to be addressed but without destabilising the basic and clinical science base. This can be achieved by setting realistic targets for gradual and sustainable increases in funding and activity in the areas of lowest investment and meeting these by prioritising a significant proportion of increases in budgets from spending reviews towards them while maintaining other areas of investment or increasing them less.

- ***DH and MRC could influence spend in other organisations through the UKCRC to help address the above issues.*** The lessons learnt from the working of the National Cancer Research Institute (NCRI) in increasing investment in areas of need should be considered as a model for the UKCRC (which is modelled to a considerable extent on the NCRI anyway).
- ***Patient and public involvement is key to the translation of research findings into health and economic benefits.*** The real benefits from the active involvement of patients and the public in setting priorities for, conducting, disseminating and implementing health and social care research are only just starting to be realised. It is still the exception rather than the norm but where it has been widely adopted the benefits are clear in terms of ensuring research is relevant to the health and social care needs of the relevant population and has an impact on it. For example the Alzheimer's Society Quality Research in Dementia programme, in which all the research must have active involvement as appropriate from people affected by Alzheimer's disease, is now embraced with enthusiasm by both basic scientists as well as applied researchers for helping to increase the relevance and impact of the research. The Macmillan Listening Study, which investigated what people affected by cancer understand about cancer research and what their priorities are, showed that the public can engage in the discussion of complex scientific issues and that they recognise the importance and so prioritise the health and economic objectives for more research, but not to the exclusion of basic and clinical research.
- ***More emphasis needs to be placed on the implementation of research findings as part of the application process for funding.*** In order to ensure that a higher proportion of the findings of research are translated into health and economic benefits researchers should be required to address implementation when they apply for research funding rather than leaving this until after the research is completed or to others as so often happens. A closer partnership between the research and health and social care communities, which was inherent in the original aims of the NHS R&D Programme, will go a long way to achieving this but it will require incentives to make it work more effectively. A requirement to address implementation as a condition of research funding would help. The use of collaborative grants to bring together groups of researchers and service developers is also a powerful tool that has been used by the NCRI to address some of the gaps in the UK cancer research portfolio.

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2. Career development for clinical researchers

- ***There must be major commitment to the development of career structures for clinical researchers along lines proposed by the Walport Report and this must include all healthcare professions.*** We cannot rely on full time academic researchers to identify and address all of the research issues of importance to the health and well-being of patients and the public. It is vital that there is also a cadre of skilled and research active clinicians and that a sustainable career path is developed for clinician researchers of all disciplines not just medicine
- ***The economic crisis the NHS faces is a strong disincentive to the involvement of clinicians in research.*** Any time spent by clinicians conducting research is time away from clinical care and in the current climate in the NHS this is strongly discouraged. Funding is needed for clinicians to support time out of clinical care to pursue research and a supportive culture must be developed where this sort of activity is valued and supported for its contribution to the development of better health and social care.

3. Protecting health research funding

- ***The NHS R&D budget is smaller now relative to the NHS budget than in 1997 when it was brought together as the NHS R&D Levy despite recent high profile increases and is lower than in most economically developed countries.*** Because three quarters of the NHS R&D Budget is R&D Support for NHS providers and so follows the research of DH's research partners the amount of money that DH has to address the objectives it is best placed to pursue is very limited and the erosion of this budget over the past 10 years has severely restricted the achievements of the NHS R&D programme. There must be a real commitment to increase and sustain the part of the budget available to address the health and economic objectives
- ***Removing the NHS R&D Budget from the direct control of DH will protect it from further erosion to bail out the NHS.*** One of the reasons the NHS R&D budget has been eroded in recent years is due to it having to compete in the annual spending review with money for patient care where it has consistently lost out, exacerbated most recently by the deepening financial crisis the NHS is in. The creation of a ring-fenced budget is essential to protect this investment in the future of health and social care services through research.
- ***The allocation of R&D Support for NHS providers needs radical reform, as recognised in Best Research for Best Health, so that it follows and supports clinical research activity.*** Its allocation must be outside the control of DH in order to remove potential conflicts of interest with respect to patient care. Since the creation of the NHS R&D Levy the R&D Directorate has not been allowed to allocate this funding equitably on the basis of clinical research activity due to the potential economic and political impact of destabilising NHS providers, most particularly in London, who have historically relied on this to subsidise their patient care budgets.

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The opportunity now exists to address these inequities in NHS budgets once and for all.

- ***A non-departmental public body (NDPB) should be established to manage and promote research, training and career development programmes funded by the single ring-fenced budget with a single line of accountability to the Office of Science and Innovation (with strong functional links to DH)*** It is essential that the case for establishing the single budget should be rigorously examined and a possible merger of MRC and NHS R & D should only take place if it is manifest that substantial advantages will flow from such a merger, otherwise serious damage may be inflicted on the clinical research enterprise. There will need to be a rigorous system of evaluation and to ensure the most benefit this should be UK-wide not just restricted to England. The board/council of such a newly created NDPB should include the major stakeholders and these should include medical charities and the end users of research. A new structure which brings elements of these together will only operate successfully with a full and unequivocal commitment to partnership on the part of both the MRC and NHS R & D and as such could build on what has already been achieved by the UKCRC. In developing the administrative arrangements there are lessons to be learned about accountability from recent changes in the USA to the National Institutes for Health under the current administration.

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