THE FOUNDATION FOR SCIENCE AND TECHNOLOGY

The Academy of Medical Sciences

DINNER/DISCUSSION SUMMARY

Building stronger partnerships in medical science research in the UK

Held at The Royal Society, 6-9 Carlton House Terrace, London SW1Y 5AG on Wednesday 30th April, 2003

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In the Chair: **The Rt Hon the Lord Jenkin of Roding**

Speakers:
Professor John Bell FMedSci Regius Professor of Medicine, University of Oxford
Sir John Pattison FMedSci Director of Research Analysis and Information, Department of Health
The Lord Turnberg FMedSci Scientific Adviser to the Association of Medical Research Charities

SIR JOHN PATTISON, indicated that the Department's interests were more in applied than pure research, notably in fields of treatment, where it aimed to work jointly with other bodies, though gaps still existed, for example in the field of prevention. The Department aimed at integration with the Medical Research Council, notably through concordats which sought to avoid unintended clashes and to ensure a full understanding of work being undertaken. A new development was the institution of Funders' Forums, of which an excellent example was in the field of cancer.

The Department's work divided up into overall strategies, expert reviews, for example in the difficult field of chronic fatigue syndrome, specific commissioning of programmes and building capacity. Objectives comprised

- Support of the UK science base, by providing £300m p.a. to major hospitals undertaking research;
- Research into needs and priorities for NHS national programmes, control trials using multi-disciplinary teams, staff recruitment on a substantial scale for study for a two-year prostate cancer study;
- Service delivery and organisation, evaluating outreach service in critical care and cancer services for which no in-house research capability existed;
- Innovation in new and emerging fields, notably with a commitment to genetics such as the bio-bank, five genetic knowledge parks and collaborative involvement between universities, industry and funders;
- Capacity building, focussing awards on areas not well-covered, such as primary care, public health, nursing and the evaluation of complementary medicine as well as sustaining networks and infrastructure;
- Policy research programmes into the impact of nutrition, behavioural studies of eating fruit and vegetables and counselling increased consumption and funding social care research.

The Department also supported work in specific fields such as the National Cancer Research Institute, the National Institute for Mental Health, providing networks of small numbers of highly qualified staff, work with older people – a difficult field-research into heart failure and the development of remedial devices and the institute of a policy for screening diabetics by the year 2005.

LORD TURNBERG, described the work of the medical charities. The Association of Medical Research Charities numbered 113 members making an annual contribution of £593m in 2001/2 (£640m in 2000/1) of which 84% came from 4 charities: Wellcome Trust (272.9m), Cancer Research UK (£158m), British Heart Foundation (£45.3m), and Arthritis Research Campaign (£21.3m). Medical research charities, however, fell into different categories, such as endowed, profession or patient and carer led, philanthropic, institutional, corporate, departmental or stake-holder based which made it impossible to treat them alike. The field illustrated democracy in action. They could be regarded neither as alternative research councils nor as funding councils for universities nor alternatives for NHS priorities nor commercial funders.

An analysis of their existing beneficiaries by subject matter showed that 45.2% went to general medical research, 30.42% to cancer and leukaemia, 11.59% to heart, lung and stroke, 4.29% to arthritis and orthopaedics and the remaining 7.87% to neurology and mental health, genetic conditions, children and fetal health and other specific diseases.

An analysis by type of grant showed that in 2000/1, 31% went to units and departments, 28% to projects, 16% to personal support, 10% to programmes, 3% to Ph.D. studentships, 2% to equipment and 2% to other purposes. By recipient 71.%% went to universities, 12.5% to independent and charity institutes, 7.5% overseas, 6% to NHS and 2.5% elsewhere, including research councils.

Identifying the key characteristics of the sector, Lord Turnberg pointed out the charities were legally confined to benefiting public purposes and were dependent on continuing public support, comprised a broad range of stakeholders and mainly specialist small players, required partnership support for infrastructures, and were not an alternative to government.

The limitations of these characteristics made charities dependent on manpower, research facilities and patients. Types and objects varied and their funds came from different sources. Close collaboration with others was necessary and research strategies had to be mutually understood. Good examples of collaborative strategies could be found in the Biobank, British Heart Foundation chairs, units of the Rheumatism Council and of Cystic Fibrosis and programmes of Cancer Research UK, bringing together medical schools and NHS Trusts.

Recent reports underlined the need at Government level for joint strategic bodies. Existing arrangements showed a lack of representation from the academic community or the charity world. Infrastructure had not kept pace with funding. Ad hoc discussions took place but there was a lack of permanent forums. More work was needed to bring together different research

strategies, a need which was underlined by current EU developments in clinical sciences.

PROFESSOR BELL outlined the problem by describing the scope of enquiry of the working party he chaired examining impediments to medical research and which was covering the fields of data protection, animal research, tissue access and banking, research governance, clinical and translational research, funding and organisation culture. Clinical research was fed by basic medical research on the one hand and by work in pharmaceuticals, biotechnology and device industry on the other and had a reciprocal relationship with the NHS. Clinical research had been declining until the emergence of work in microbiology about 1975.

Classifying clinical research under the following heads: experimental medicine, Phase I and II Trials, Disease Networks (NTRAC), Phase III IV, Prospective studies – drug and disease monitoring, Imaging, Genomic epidemiology and Translation of new technologies into practice, Professor Bell indicated that work carried out in these fields in the UK was less than adequate and was far outstripped by that in the USA.

In fields of experimental medicine such as clinical physiology, clinical pharmacology and proof of concepts enabling technologies such as Biomarkers, Surrogates and 'Omics' were proving necessary tools. Other examples of progress were the development of antibodies to treat inflammatory diseases, clinical trials of HIV vaccine which were now under way and new methodologies making possible the detection of disease at an earlier stage.

Although the UK did provide Clinical Research facilities, its contribution to their running costs, provision of adequate career structures and rewards for clinical scientists and research and research grants were not adequate.

Instancing some UK facilities Professor Bell listed NTRAC, the half-dozen UK facilities for translating genetic knowledge into clinical, cytongenetics – financially demanding, ACGH microassay the Biobank, a landmark epidemiological development.

He emphasised the need, for clinical research, of efficient modern methodologies of patient recruitment and of IT to generate adequate statistics. Cohort studies ideally required half a million people. He particularly emphasised the need for clinical scientists in a formal career structure rising to the grade of professor. Without these the biopharmacological industry would be seriously handicapped in a field where international competition was intense. Access to experimental medicine was also vital. It was necessary to build up networks of disease expertise and to provide an adequate IT infrastructure giving information about health outcomes. Support was needed for experimental medicine and trials for pharmaceutical and biotechnical products to ensure new therapies.

He described a system of partnerships, centred on the NHS R&D component, collaborating respectively with industry, the universities, the MRC and charities and with NHS Trusts and NICE.

In discussion the following points were made:

- There was merit in trying to introduce a research component into a non-research culture, but this was subject to limitations. It was difficult to build everything up from scratch.
- Partnership facilitated a pooling of resources when those of individual partners were inadequate. Universities were weak in infrastructure; they also suffered from a constant turnover of personnel. The NHS was also weak in infrastructure. Projects on a sufficient scale such as the Biobank and a genome project which provided immensely valuable spin off the NHS resulted from an IT project and work on developing an HIV vaccine. It was regrettable the Government funding for these was not greater.
- Competition provided a valuable spur in research but it was not always compatible with full partnership collaboration. The ideal appeared to be for competition to show the way forward and then for partnership to step in to foster development.
- An essential element for the development of experimental medicine was an adequate patient base, but suitable patients often proved difficult to find. Experience suggested that the population showed no reluctance to participate. Methods were needed, however, to identify suitable patients. Without these progress would be impeded. Patient groups had, for example, been crucial in discussions on stem cell research.
- Similarly, the international standing of research centres turned on their ability to recruit skills in every field.
- Conflicting views had been expressed about the value of asserting rights of intellectual property as regards the results of research. In some instances recognition of intellectual property rights had had great value and, under the Health and Social Care Act, the Secretary of State was given power to exploit these. There had, however, been other instances where the benefits had accrued to everyone except the original researches. It was important to protect the freedom of knowledge transfer. The sharing of knowledge gave opportunities for working in partnership. This was not, however, a matter over which the Government had any control.
- The matter of university funding gave rise to a number of problems. There had been a shift in the balance between teaching and research. It was in any event arguable that funding related to grading was damaging. The training of a researcher required a period of at least fourteen years. A more secure and substantial source of funding for training and research itself was needed than what could be expected from sources such as the Medical Research Council, universities or the Wellcome Trust. There appeared to be confusion as to which Department in Government should most appropriately assume responsibility for medical research. It was admitted that unforeseen pressures had coincided in such a way as to create a critical situation. It was doubtful whether adequate funding could be found for research in twenty-eight separate schools of medicine. The resolution of this issue was of the highest importance.
- Although the NHS provided the best vehicle for research it was inadequately funded for this purpose. A serious gap existed which it was important to fill and partnership arrangements might provide the way forward.
- Weaknesses in the existing arrangements were to be found in the lack of adequate research training and of research methodologies. This was compounded by the absence of any single individual funder. There were fields of research which might only appeal to the NHS and for which that service might have to assume responsibility. It was imperative that the quality of research there should not appear to be lower than elsewhere.
- One of the obstacles in the way of training in research and methodology was that clinical demands swamped training.
- There was some evidence that some research projects were of little value and it was important to find ways of ensuring research funding was not wasted.
- It also had to be borne in mind that some researchers had little awareness of work already carried out and care was needed to avoid funding being dissipated on the duplication of work already done.

Sir Geoffrey de Deney