

Foresight

Making the future work for you

Health Care

2020

Healthcare Panel

Contents

Chairman’s Foreword.....	2
Summary of Key Recommendations	4
Health Care and Health Services.....	6
Information	17
Health Services, Industry and Academia	23
Sustainable Development, Health and Health Care.....	27
Research, Development and Technology.....	31
Repair, Regeneration and Transplantation	38
Health Engineering	42
Brain and Mind.....	44
Endpiece: The Usefulness of Foresight	50
Panel and Task Force Members	52
The Foresight Programme	56

The views expressed in this document should not be taken to represent those of the Office of Science and Technology, the Department of Trade and Industry, or the Department of Health.

The views and recommendations expressed in this document represent the broad consensus reached through the work of the Panel and its task forces, and its consultation with key stakeholders. They do not reflect the personal views of the members or the organisations they represent.

The Office of Science and Technology or the Department of Trade and Industry does not accept responsibility for any action taken based on the views and recommendations in this document.

Chairman's Foreword



Sir Michael Peckham
School of Public Policy
University College London

Foresight Healthcare Panel Chairman

This exercise, carried out by a group of busy people drawn from a wide range of backgrounds, convinced us of the importance of standing back from everyday activities to look with a longer perspective at the future. We believe there is a case for putting foresight activity on a sounder and more permanent footing.

We have looked at some of the major trends likely to affect the future of health care and made proposals for actions that we believe should be taken now. We hope the suggestions we make have relevance to a wide audience.

Some of the action points are for the Research Councils and Higher Education Funding Councils as well as the National Health Service and its staff. We hope that the issues raised and the proposed actions will be of interest to the Wellcome Trust, other charitable bodies and the voluntary sector more generally. We also evoke issues that are relevant to the interests of the public, to patient groups and to individuals. Finally, there is a strong theme relating to industry, the conditions and opportunities for industrial innovation and the relationships with academia and the health service.

Each of our recommendations is designed to take advantage of new opportunities or to correct current shortcomings that might be inhibitory to progress. We have attempted to set technological changes in a broad social context, but inevitably, we have not been able to cover the myriad facets of health care.

I am grateful to the members of the Panel and Taskforces for their commitment and enthusiasm, to other colleagues who made valuable comments and suggestions, and to all those who took time and trouble to respond to the consultation document.

I would like to record my special thanks to Tim Willis and Elaine Nichols of the Office of Science and Technology for their commitment and excellent support, and Sally Welham in the School of Public Policy who, as always, provided invaluable assistance.

Summary of Key Recommendations

The crucial challenge in health care is to use innovative ways of exploiting knowledge and information to prevent disease and disability. To emphasise this, our recommendations are set out in summary form under the broad headings of prevention, information and innovation.

PREVENTION

PREVENTING ADULT ILL- HEALTH THROUGH INTERVENTIONS IN CHILDHOOD

Establish a non-governmental forum for children's health (Recommendation 20)

Develop a strategy for brain development, brain function and learning (Recommendation 41)

PURSUING HEALTH OBJECTIVES AT GLOBAL LEVEL

Integrate health objectives into international development policies (Recommendation 21)

HEALTH THROUGH SOCIAL CHANGE

Improve health through social policy innovation (Recommendation 19)

PREVENTING ILL-HEALTH CAUSED BY ENVIRONMENTAL DEGRADATION

Create a Health and Natural Environment Forum (Recommendation 22)

PREVENTION OF ILL-HEALTH THROUGH EDUCATION

Reduce socio-economic determinants of mental ill-health through education (Recommendation 35)

PREVENTING DISEASE BY CHANGES IN EXTRINSIC FACTORS TO MODULATE GENETIC RISK

Support for genetics, brain imaging and clinical research in neuropsychiatry (Recommendation 39)

Launch a 'phenotype' research initiative (Recommendation 28)

PREVENTION OF ACUTE EXACERBATIONS OF CHRONIC DISEASE

Expanded role for non-professional staff with an advocacy/mentoring role (Recommendation 36)

Development of long-term active symptomatic care (Recommendation 7)

Prioritise prevention in neuropsychiatry (Recommendation 37)

INFORMATION

INTELLIGENCE ABOUT TRENDS AND LIKELY FUTURE DEVELOPMENTS

Foresight to be an in-built, on-going function in health care (Recommendation 1)

Foresight to be associated with implementation planning (Recommendation 42)

OVERSIGHT AND DEVELOPMENT OF INFORMATICS

Establish a National Health Informatics Forum (Recommendation 14)

USE OF THE INTERNET

Design of a cyber health system (Recommendation 13)

INFORMATION HELD BY INDIVIDUALS

Patient-owned web-based health records (Recommendation 12)

Definition of genetic information held by individuals (Recommendation 25)

GENERATING KNOWLEDGE

Create a national strategy for clinical trials (Recommendation 29)

USES OF INFORMATION

Genetics and insurance: continuously up-dated forward projection (Recommendation 27)

Public awareness of informed consent and recording of essential data (Recommendation 11)

IMPARTING INFORMATION

Education sector role in health sciences and technology (Recommendation 26)

INNOVATION**A FAVOURABLE MILIEU IN GOVERNMENT**

Priority for strategic planning of services (Recommendation 2)

INCLUSION OF THE LAY VOICE IN HEALTH MATTERS

Build a national focus of expertise in public participation (Recommendation 10)

HEALTHCARE STRUCTURE, OPERATIONS AND FUNCTIONS

Range of options to meet future challenges to be actively explored. (Recommendation 3)

Systematic analysis of rolled-back health care (Recommendation 4)

Introduce a new strategy and methodology for personnel planning (Recommendation 9)

Define the specific requirements for home-based care (Recommendation 5)

Create a NHS Clinical Research Organisation (Recommendation 29)

EXAMINING DEMAND FOR HEALTH CARE

Establish a health care 'laboratory' for modelling demand (Recommendation 6)

Lifestyle medicines to be assessed and kept under review (Recommendation 40)

PLACING DIAGNOSIS ON A RATIONAL BASIS

Establish a National Health Diagnostics Advisory Group (Recommendation 8)

Explicit criteria for genetic testing and screening (Recommendation 23)

CREATING A COHERENT ACADEMIC BASE

Research Councils and HEFC mechanisms for cross-disciplinary R&D (Recommendation 18)

Integration of mathematics, biology, medicine and engineering/physical sciences (Recommendation 34)

SUPPORTING RESEARCH AND PLATFORM TECHNOLOGIES

Establish a Health Engineering Consortium (Recommendation 33)

Ensure support for stem cell research and development (Recommendation 30)

Push platform technologies for tissue engineering and cell-based therapies (Recommendation 31)

Integrate blood and tissue resources into tissue engineering programmes (Recommendation 32)

Maintain UK research in functional imaging including PET technology (Recommendation 38)

TRANSLATING RESEARCH INTO DEVELOPMENT

Establish and maintain the conditions for industrial innovation (Recommendation 24)

Recognise technology transfer as a profession with steps to enhance efficiency (Recommendation 15)

Establish a London science park with the four major schools of the university (Recommendation 16)

Ensure access mechanisms for early development funds (Recommendation 17)

Health Care and Health Services

1 Starting Point

- 1.1 The Foresight Panel took as its brief the provision of independent advice on trends and decisions that would shape the health care of 2020. Our focus was therefore on the future and we have not commented on on-going initiatives although we welcome the Government's proposals to strengthen and increase funding for the NHS and the steps taken to encourage and sustain biotechnology, bio-informatics and the science base.
- 1.2 Given the changes that will occur over the next two decades, it is essential that major trends affecting health care continue to be identified clearly, monitored and their implications kept under review.

RECOMMENDATION 1

We recommend that foresight is an in-built and on-going function of health care.

An early task should be to review foresight methodology and to invest in methodological development. Our preference would be for a foresight network rather than a single focus of activity. The health care foresight function should be adequately resourced in terms of manpower and funds and be conducted at arm's length from government. The scope should encompass both technological changes and the organisational and social environment in which they are used. Potential applications of science and technology should be considered in relation to health problems that call out for solutions and UK health care should be examined in the context of European and global health.

2 What Follows?

- 2.1 The attainment of a high quality health care system must continue to have high priority to enable the UK to exploit opportunities for social and technological innovation that would benefit health and national competitiveness. The Panel affirmed strong support for the ideals of the National Health Service: the opportunities for society in terms of physical, mental and economic health offered by comprehensive health care are clear and the UK has skills and expertise to take advantage of them. Given the tempo of scientific and other changes both short term planning and the formation and updating of longer term strategy will be increasingly complex and demanding.

RECOMMENDATION 2

To permit longer term thinking, mechanisms are needed within government and the health service to ensure that the task of forming future strategies is given high priority and not caught up with short-term planning or current service problems.

If this is not ensured the risk is blight. One example is genetics where the view of those in the field is of under-investment at service level while planners wait for the brave new world to unfold.

- 2.2 It is unlikely that by 2020 structures for providing health care will be as they are now, in this or in other countries. Health care in general will have entered a period of profound change some of the elements of which are beginning to be discernible. The time is right to engage the public in discussions on how to decentralise and depoliticise UK health care. A recurrent theme in discussions of the Panel has been the urgency of making full use of the talents available to the health care system not only in relation to science and technology but also in relation to the development of public services, social policy and education.
- 2.3 By 2020 interactions between the public and private sectors in health care are likely to have extended and to have become more pluralistic. In responding to such trends it will be essential to bear in mind that a comprehensive national system with universal coverage and registration such as the NHS, offers great potential advantages, particularly in terms of equity of access to health care and equity of outcome. This will be increasingly important as new growth areas such as genomics and informatics, risk exacerbating disparities between individuals and groups in society. A coherent national system is strongly positioned to provide a unique resource for population studies, as well as a powerful source of information about health and about the impact of public health and clinical interventions. It opens the way to proactive partnerships with the voluntary sector, with other sectors such as education and employment as well as with industry for the development and testing of new products. Taken forward in this way, the brand name of the NHS should carry weight in terms of inward investment of R&D and stimulate the export of know-how and products from the UK.
- 2.4 It is conceivable that the NHS in twenty years time will concentrate on the developmental aspects of health care and on the use of its brand name to permit a range of carefully chosen organisations to provide specified services to explicit quality standards. Recognising the potential of the National Health Service should not preclude dispassionate examination of the longer term advantages as well as the disadvantages of the different forms that services might take over the next two decades, including an evolution along the lines set out above. Any future arrangements should be designed to address projected as well as current needs, ensuring that services that ought to change are not locked into contracts that are impossible to change. Appropriate, alternative models of providing health care could be field-tested in different locations, ensuring that they are well-designed and associated with rigorous evaluation, so that the outcomes can inform public policy.

RECOMMENDATION 3

We recommend that a range of options to meet the challenges on the previous page should be actively explored.

3 Rolled-back Health Care

- 3.1 Historically, hospitals and community-based care have been worlds apart with the specialist centre at the pinnacle of the health care landscape. By rolled-back care we mean a shift towards home-based and community care with appropriate use of costly hospital services. Developments in informatics and related disciplines will provide huge scope for achieving this. There will be substantial knock-on effects. For example, in services employing electronic systems and other technologies, the roles and numbers of staff will change, in some cases dramatically.
- 3.2 There will also be consequences for teaching hospitals, the role of which need to be redefined. Much of the education of doctors and other professional staff will take place in the community and in hospitals that are not currently connected with a university. Electronic media and networked systems will be used increasingly for education and training. Pharmaceuticals may be introduced and tested in the 'real-world' environment of primary care. This will shift the locus of evaluative research to the community setting. Genetic screening and support will be predominantly a primary care responsibility. Academic medical centres should actively integrate population and clinical sciences and link to a much broader range of health care in the community. They should also take active steps to bridge the gaps between physical, biological and social science addressing specifically the interface areas we identify in this report.
- 3.3 Electronic consultations, community-based specialist clinics, availability of intensive care expertise and technology in acute wards, specialist skills in primary care and generalist skills in the hospital environment should each contribute to the more rational use of services. Too often these are considered individually and in isolation and what they could add up to is poorly understood.
- 3.4 A range of developments will offer possibilities for enhancing home-based care, for example health workers with an advocacy, mentoring and advisory role, internet-based advice, enhanced role for community pharmacists, patient-owned records and monitoring and other technologies based in the home environment.

RECOMMENDATION 4

We recommend that the potential for rolled-back care is carefully evaluated through systematic analysis of current and likely future trends.

The project which might be commissioned from a network of collaborating groups, should examine the different elements that could contribute to eliminating the bipolar hospital/community approach to health care. It should consider the likely impact of trends highlighted in this report, and identify the obstacles to and feasibility of introducing new processes and interventions relevant to rolled-back care.

We allude to home-based care in recommendation 5. An important aspect is self action/care by lay people. Community-based personnel could facilitate this, helping patients to gain access to and use sources of information and also give advice. We suggest that there is a role for a new cadre of health advocate/ mentor with these skills (also see recommendation 37).

The views of 'expert' patients with chronic disease that are well-informed about their condition should contribute to the review. They should be involved in the planning and monitoring of services as well as in decisions about their own care.

The analytical review should include a searching appraisal of the design and organisation of the next generation of hospitals, defining the range of tasks to be performed in them bearing in mind technological, health and other trends. Architects and designers should pay greater attention to personalising care, supporting the actions that patients themselves take in relation to their own care.

The review should draw on expertise in such areas as spatial analysis, transportation, architecture, bioengineering and health technologies, systems engineering, human behaviour, informatics and have input from medical and other professional staff.

The potential place for a nation-wide network of smaller hospitals should be examined. These intermediate hospitals could have particular responsibility for chronic disease management and offer support and facilitate "self" support.

RECOMMENDATION 5

We recommend that the specific requirements for an expanded home-care programme are characterised and the feasibility of meeting these requirements is assessed.

A working group set up to tackle this should have strong input from the voluntary sector. An umbrella organisation such as the National Council for Voluntary Organisations might take the lead, ensuring wide-based participation from community health, home-based technologies, information and communications and the hospital sector.

The remit should be to determine how existing and likely future interventions and demographic and other trends will exert an impact on care in the home. The findings should be used to inform future building practice and design including requirements for information technology. The prime emphasis will be on the management of chronic disease and disability, particularly but not exclusively in the elderly.

Based on the outcome and the derivation of one or more models of future home-based care, we recommend that well-designed pilot studies are set in train with appropriate in-built economic and other evaluation measures.

4 Demand and Need for Health Care

- 4.1 The evolution of demand and need for health care over the next two decades will be determined by a complicated mix of inter-related factors. Steps to offset adverse social and economic factors must have high priority. Effective preventive strategies could reduce demand: this is one hoped-for outcome of genome research. Immunisation against infectious disease has been highly successful in conditions such as poliomyelitis. Technological and other changes however may result in the increased use of services. One example is the uncoupling of mortality and morbidity seen in coronary heart disease and stroke. With better survival there is a trend towards multiple episodes of intense usage of health care.
- 4.2 Increases in disease prevalence in conditions such as diabetes will impact on demand. Other factors that will push up service-use are the adverse consequences of health care, for example, drug-resistant infections and inappropriate or sub-optimal interventions.
- 4.3 Family changes mean that a large segment of voluntary activity has vanished and this is certain to have significant consequences for future health care demand since most unpaid caring is done by women and the commitment of looking after elderly relatives is increasing.

RECOMMENDATION 6

We recommend that a health care 'laboratory' is established to model the impact on demand for care of technological, demographic and other trends.

This should not be in a single site but based on a flexible multi-site collaboration. The initiative should include the development of a tool-kit of modelling methods to investigate the effect of factors that could increase or reduce demand. This proposal should be integrated with recommendations 4, 5, and 9 to define organisational requirements for ensuring adequate care provision. Methods used in other settings such as systems engineering and mechanism design should be drawn on.

The initiative should focus on how demand will be expressed and the supply chains which will be in place to meet it. UK companies should have an interest in being actively involved in area.

Organisational questions such as the optimal size of operational groupings and working practices should also be addressed since efficiency both in internal functions and in the influence exerted on other sectors will have a bearing on the use of services.

5 Chronic Disease

- 5.1 Chronic disease management will be a cornerstone of future health care. Many acute problems are exacerbations of chronic underlying pathology that is often unrecognised and even (currently) undefined. We anticipate substantial advances in understanding the mechanisms underlying some chronic diseases and increasing development of strategies designed to limit disability arising from them. Evaluation of the cost-effectiveness of these new treatments must employ sophisticated economic models that appropriately account for the potential impact on long-term costs to the broader health and welfare system, as well as to employers. In addition to new primary and secondary preventive methods, symptomatic management of chronic conditions will reach a high level of sophistication, with attention focussed not only on quality of life but also quality of death.
- 5.2 Stroke, the incidence of which is projected to increase by 30% over the next two decades, is a case in point. Stroke is recognised now as a collection of syndromes with different underlying specific mechanisms. In addition to preventive strategies based on what is currently known, understanding the biological features of these symptoms offers the prospect of target-specific preventative therapies. The impact of these treatments may be maximised by considerations of individual genotypes as well as lifestyle and environmental risk factors. Treatments will need to be initiated early and perhaps continue throughout life. Determining how organ function affects thrombotic mechanisms and coagulability will focus research on organ-blood vessel circuitry and the control of gene function for example in relation to endothelium. One outcome will be a shift to therapies based on specific vascular circuits.

RECOMMENDATION 7

We recommend that priority is given to the development of long-term, active symptomatic care.

Although much has been achieved in the evolution of health care, a new departure is needed to place the understanding and management of symptoms on a higher plane than it is at present. It should be evidence-based and deliver the best quickly. The diagnostic and care management process must involve patients' experiences more directly especially if fresh insights into disease and the effectiveness of treatment are to be gained. The obstacles to this in terms both of time and training have to be recognised. More effective interventions are required for intractable symptoms that impair quality of life. Methodological development is also needed to provide techniques for deriving and using self-observation by patients with slowly evolving pathology. To ensure that such methods are used in practice, a number of test cases should be monitored; a good example is the management of chronic pain.

6 Diagnosis

- 6.1 By 2020 diagnosis will have been placed on a fundamentally different and more rational basis. Much of current practice is not underpinned by evidence, unnecessary tests are carried out and there are issues of sensitivity, specificity and quality assurance. The use of advanced information and communication technologies will permit tele-diagnosis and the centralisation of complex and expensive diagnostic services. At the same time engineering advances will lead to lower-cost imaging and other diagnostic methods that can be used in the community and home environment.
- 6.2 There will more radical changes. Traditionally, pathological diagnosis has been based on the judgement of one or more individual observers with errors or differences of opinion in a minority of cases. Ways of increasing automation and regularising diagnostic procedures to take out human error need to be developed, for example for cervix cancer screening. The patterns of image signals that form the basis of diagnosis are susceptible to mathematical analysis, and may be made easier by additional data. Many of the elements of 2020 diagnosis can be discerned now. Planning should be undertaken to draw together the different elements and to fill in gaps in knowledge, for example on the evidence to support different diagnostic practices.
- 6.3 Diagnostic tests are better developed by commercial companies than by academia although research and the early stages of development often take place in a university setting. A number of issues arise. Commercial incentives such as public-private funding, tax breaks or prolonged patent protection may be needed particularly when tests might have limited application. Potentially useful diagnostic methods arising from university research may need to undergo preliminary testing within the academic ambit. Currently

this is made difficult by meeting specified standards and regulations. There is a case for one or two centres to be set up to provide the requisite facilities for researchers to carry out early testing of diagnostic methods and products such as vaccines. The results might feed back into research programmes or be sufficiently encouraging to enter commercial development pathways.

RECOMMENDATION 8

We recommend the setting up of a National Health Diagnostics Advisory Group.

The group should have wide representation and lay the basis for a new, more rational approach to diagnosis. It should advise on future diagnostics opportunities and a strategy for realising them. This includes the rationalisation of diagnostic services, build-up of an evidence base to diagnostic practice, diagnostics research, commercial development and early testing facilities for the academic sector and for small/medium enterprise companies (see para 16.2). In the latter case the setting up of at least one national facility should be considered.

Intelligent systems for data analysis in medicine should be further developed and disseminated.

A specific issue to be explored is the extent to which image and signal analysis in medicine could replace individual diagnostic judgement for example in histopathology or cytology. A related question is to determine how to integrate the analysis of signals from diverse sources such as magnetic resonance, electrocardiography and genetic testing in order to convert data into clinical information to produce a coherent interpretation of the patient's current state.

7 Health Care Staff

- 7.1 There will continue to be a reallocation of tasks between nurses, doctors, pharmacists and other staff. In some cases new technologies will make jobs redundant and there will be a need for fresh skills for example in informatics and regeneration medicine. The ability of individuals to adapt to new circumstances by relinquishing old skills and acquiring new ones will be a key consideration.
- 7.2 Ways must be found of putting motivators in place so that there are incentives to change. This calls for a reorientation of professional education training towards the use of information and problem-solving, the design of incentives for skills synergy rather than tokenistic teamwork, new training methods such as simulators for surgeons, and the analysis of medical decision-making to identify critical points where errors may arise. In the latter specialist skills are needed from other fields such as psychology and ergonomics.

RECOMMENDATION 9

We recommend that a new strategy and methodology is set in place for the longer term forward planning of personnel requirements in health care.

Consideration needs to be given to the future role of the health professional in 2020 health care. Properly developed and applied the human mind is unsurpassed in handling complex information about complex problems. To make use of this in the clinical context depends upon the availability of time as well as on education and training. If the professional role is not developed, inertia and disaffection could seriously limit progress. Workforce and health service planning should address this longer term requirement. The pastoral care, quality of life and job satisfaction of health service staff should be given the highest priority.

A prime objective must be to ensure that appropriately trained staff can use technologies to access, and adapt to, a changing knowledge base. Forward planning should be carried out systematically in relation to technological, demographic and other trends. Professional demarcations will become increasingly blurred with the emphasis on required skills. In future more attention will be given to different skill groupings to replace the variable interactions that currently exist between parallel hierarchies. Different professional groups should not be considered in isolation and policies should be based on an assessment of specific inputs from health professionals and the input in terms of skills and training required to achieve them.

The tasks that will need to be undertaken in community and home-based care should be described in detail and used as a starting point for decisions about future staffing, training and job content.

It will be essential that responsibility, intensity of work and highly-skilled tasks including academic commitments, are recompensed at an appropriate level. This is crucially important if the NHS or its successor is to shift from a reactive to a proactive organisation. The performance of those in positions of responsibility whether managerial or otherwise should be assessed in relation to their ability to stimulate and sustain innovation. Training should reflect this requirement.

8 The Public Voice

- 8.1 We anticipate far-reaching changes in the part lay people, including patients, play in health care. These are likely to have profound consequences for medical and other staff as well as for the services they are responsible for. The number and influence of vocal patient groups will increase and the trend towards the internationalisation of health interest groups will grow. Groups asked to provide tissue samples or clinical information may strike deals with companies for services or equity. Increasing the possibilities for consumer choice and consumer representation places responsibility on individuals as well as groups: the views that are pressed hardest may not represent those of society. The trend towards consumer involvement in health care will accelerate, some individuals and groups having more influence than others.
- 8.2 The health service provides a unique interface between scientifically-trained personnel and members of the public of all social and educational backgrounds. To take advantage of this an investment is needed into methods and mechanisms for public participation to create a balanced relationship between lay people and the health systems they fund to serve them. This raises the general question of how to promote public debate and to elicit public views.

RECOMMENDATION 10

We recommend the establishment of a unit or preferably a network to provide a national focus of special expertise in the field of public participation in health matters.

The unit should maintain an awareness of approaches in health and other sectors here and abroad. Among the issues a public participation unit/network might investigate are the impact of public attitudes on innovation, regulation and recruitment particularly to high risk/high profile specialities such as paediatric cardiac surgery, the benefits and possible negative effects of high-profile public enquiries, imaginative ways of introducing concepts of science, innovation and risk/benefit into educational curricula at all ages, the introduction into professional training of customer service concepts with regular feedback on performance and ways in which the regulation of health care professionals should take account of input from public and patients.

The scope of the unit/collaboration should also include ways of ensuring lay people to influence the processes of health care, and strategies for involving patients in their own care.

- 8.3 | The modifications made to the way scientific issues will in future be handled within government following the bovine spongiform encephalopathy experience should be formalised and made public. This should include clarification of proposed mechanisms for the early detection of potential hazards, assessment of risk, early formation of cross-government strategy, mode of communication with the public, research priorities and practical steps being taken to address a particular problem. Information on topical issues that concern the public should be made available. A current example in relation to variant Creutzfeld-Jacob disease might be progress in developing a diagnostic test.

RECOMMENDATION 11

We recommend that the public should be made fully aware of the potentially adverse consequences of decisions made in their name, that are likely to make population research and the recording of essential health data relevant to their longer term interests extremely difficult or even illegal.

Arising from an interpretation of the Data Protection and Human Rights Acts, information that was previously passed to cancer registries and other databases or that were crucial for understanding and controlling disease, may only be made available in future with the informed consent of individual patients. This could have profound effects on monitoring prevalence, incidence and outcomes, and seriously compromise efforts to get at the roots of disease causation, to document responses to treatment and to gather information on new disease threats and adverse effects including the sequelae of vaccination.

Information

9 Electronic Health Care and the Internet

- 9.1 Futuristic scenarios are not difficult to depict. It is much more difficult to translate current reality into a future system based on the opportunities outlined in this document. An early step must be to correct current infrastructural weaknesses in the NHS in information handling. It is widely recognised that the organisation is at least a decade behind the commercial sector in information technology and its uses. Yet there are many members of staff who are knowledgeable about IT and interested in its practical application: they could advise hospitals and primary care groups on what needs to be done.
- 9.2 As a first step a detailed NHS IT audit is needed. This should gather the opinions of staff. Senior clinical staff, wards, operating theatres and managers should have computers linked to the internet and all junior staff should have access to a computer in their work environment. A renewal programme for hardware and software should be planned: there is little point in investing in a system if it is not upgraded. The NHS should consider purchasing links to major journal and relevant medical and other websites. All pathology, radiology and other diagnostic departments should be linked through an institutional network so that results can be obtained without using the telephone.
- 9.3 Through a single entry point there should be access to recommended and vetted multiple websites run by physicians and other specialists. These systems that could adapt and grow with change, would not be dependent on the NHS but could be aided by NHS grants. The infrastructure for information technologies and information and knowledge management will be crucial to the efficiency of health care systems.

10 Health Biography

- 10.1 For individuals to hold and own their health records would signal a profound change in relationship between the public and health services. We anticipate that each person will have his or her own health biography held in an encrypted form on the internet and include clinical, genetic, and other relevant personal details. The individual will be able to add to the record, for example about the course of chronic ill-health and responses to treatment.
- 10.2 Ways will need to be found of maintaining confidentiality while allowing the record to be supplemented automatically by evidence-based recommendations. The individual would gain access to information through a smart card or biological identifier. Patients will authorise doctors or other professionals to have access to all or part of their records. Since the record would be owned by the individual it would be theirs to divulge or even sell selected aspects of information for example to commercial companies. Linkage between care in hospital or in the community including pharmacy use, will be crucial.

- 10.3 Each record will have a unique number and confidentiality/privacy assured. One possibility will be to make use of approaches such as hashing algorithms where health service number, credit card and other numbers are combined to produce a unique number that cannot be traced back to the individual. This would permit records to be linked including if necessary monitoring the purchasing of food and alcohol while maintaining the privacy of the individual. Anonymised records could be used for automated data extraction for research and policy development.

RECOMMENDATION 12

We recommend that prototype models of electronic patient-owned health records created and maintained on the internet, are designed, piloted and evaluated.

This should draw on international and UK experience of patient-owned or maintained records and records using web-based systems in the health and other sectors. One way forward would be for consortia composed of people from the health sector and from other fields including commercial companies, to bid for development funds ear-marked for this purpose.

- 10.4 Records could have details of interventions automatically attached, for example anaesthetic records during an operation. Professional behaviour could be distorted by loss of their privacy. A logical consequence of a patient's right to hold their own records and control use of those records should be that professionals also have the right to keep personal records of their own, in which they are able to record matters relating to their professional experience and the patients they see which they wish to keep confidential. This needs discussion. Patients could suffer if professional staff are inhibited from recording details that they do not wish to put into a patient- held record.

11 Cyber Physician

- 11.1 By 2020 we envisage that the first point of contact with health care will be through a 'virtual' cyber-physician (CP). Accessed through a TV screen, the CP system will replace other forms of triage such as the telephone and give access to information about professionals, hospitals and other aspects of health care. Access to part or all of the user's health biography would require use of a smart card or a biological identifier such as retinal vessels.
- 11.2 A CP system would bring into sharp relief the role of face-to-face contact between user and professional. It could make more explicit the demand and need for health care. It could be a mechanism for improving quality, chronic disease management and be a powerful research resource. The CP would be backed by knowledge bases and provide the means for creating a huge database of routine information including records kept by patients themselves.

- 11.3 Professionals would make use of a cyber expert facility to access information and to compare skills, and results. They could interact with other professionals in 'research in action' collaborative networks to overcome differences in practice and outcome. Many of the elements of a CP system are already available and rapid progress can be anticipated driven by commercial incentives.
- 11.4 The feasibility of CP systems as an integral component of health care needs to be clarified and the necessary elements, time-course and implications understood. The latter include the potentially profound effects on staffing and on the economics of health care. A further issue is equity of access to such a facility. This is one of many technological developments that could increase rather than reduce disparities.

RECOMMENDATION 13

We recommend a feasibility study to inform the design of a cyber health system.

This should be a research and development priority. Proposals for funding should be invited from consortia that include industry, universities and health service staff. We believe that this should be done without delay in view of the rapid pace of change in this field.

12 Using Information and Knowledge.

- 12.1 There will be a sharp increase in the number and range of systems and organisations that supply information to support health care. These 'infomediaries' will guide patients and professionals. More needs to be known about the health information needs of doctors, nurses, other staff, patients and the public, and the technologies required to meet those needs.
- 12.2 The processes whereby the information is collected, integrated, sorted, and synthesised are rarely explicit. More openness about how information is gathered and validated is essential. Evidence-based health care in the UK is an example of such a development. It may be impossible to always kite-mark the quality of information but it may be possible to specify appropriate processes.
- 12.3 Members of the public will be able to gather information on any health subject and information available to professionals will also be available to lay people. They will be able to interact with others with similar interests globally, use software that will help assess their health risks, use decision support systems and buy health related products (including drugs) and services. Some websites will gather information from experienced patients rather than experts.

- 12.4 Clinicians will have access to information and decision support at the point of care through a computer screen in offices/surgeries and through PDA's/mobile phones on wards or in other circumstances, including emergencies. This information support will have the potential to provide reliable answers to clinical questions through connection to a large valid, constantly updated database, and be electronic, portable, fast, easy to use, and anticipate information needs. Such a system would complement rather than threaten the human aspects of the clinician-patient interaction.
- 12.5 The credentials of those responsible for internet-based services could be encrypted on the website like a watermark in a banknote. This would permit users to identify the accrediting body.

13 Research on Informatics

- 13.1 Research is essential to underpin the development of informatics, such as systems and tools required to manage knowledge. Examples include numerical modelling and other tools that help to transform data into information; geographical information systems and quality control; search algorithms for accessing complex data rapidly; on the health information needs of clinicians, patients, and the public, the technologies required to meet those needs and research into how needs might be met; on how information can lead to change and the global market for knowledge products that engender change; and on the development by the private and public sectors of information systems that require minimal technical skills.

RECOMMENDATION 14

We recommend that a National Health Informatics Forum is established to set the public agenda on biomedical and health information.

This should be a multi-interest non-governmental group with a remit to develop and drive forward a multidisciplinary, multi-interest research and implementation strategy that addresses not only technical, but also professional, social and ethical issues.

National priorities should be set for health informatics research and development and long-term funding agreed between the NHS, Research Councils and other agencies.

The Forum should make a realistic assessment of the costs, benefits and risks of developing electronic health care information systems. The scope for public-private partnerships should be explored.

- 13.2 The Forum should advise on a wide range of issues, some of which are outlined below. With respect to regulation of web-based systems there is much to be said about a light-touch. Some suppliers of hospital information systems and clinical information systems have left the UK because of the over-complex arrangements for procurement and what is perceived as planning blight.
- 13.3 Specialists in health informatics are needed in primary and hospital settings. These medical or non-medical personnel will possess particular skills in knowledge management. Incentives will be needed to attract such people bearing in mind that they will be in demand in the commercial sector and currently pay structures in general in the NHS are not attractive. Clinicians who already possess these skills should be empowered to use them.
- 13.4 An understanding of health informatics will be required by all health professionals. Postgraduate degree courses, other on-the-job training courses and high quality distance-learning and virtual workshops are needed.
- 13.5 Information systems that can be used at the point of care need to be developed as a priority. Research bodies and industry should prioritise the development of intelligent, active systems that will support decision making in a range of circumstances from primary care teams to hospital general managers and from the general public to molecular geneticists. In addition to social and health gains, good decision-support systems are a marketable commodity and private companies as well as the public sector should be encouraged to invest in them.
- 13.6 Realistic ways need to be devised of targeting financial, human or training resources to help alleviate the widening information gap between richer and poorer communities and countries and between the information-rich, internet-enabled and the information-poor, internet-denied in this country.
- 13.7 Standards are needed for data to pass between formats including publicly available and generally accepted "minimum specifications" that relate to technology and language. Support is required to develop and maintain a process for ongoing review of requirements for clinical data in the NHS and genetic databases used in biomedical research.
- 13.8 Government should consider the form that independent and publicly accountable bodies should take to oversee and regulate privacy, the availability and sourcing of information, the accuracy of the data held, access to information (by whom, to which subsets, for what purpose) and the ethical implications of health information.
- 13.9 The NHS could become an incubator and supplier of clinical or management information systems for worldwide application. To achieve this would require strategic investment by the public sector as a dominant UK purchaser of health information systems.

- 13.10 | Internet technology will play an important role in continuing education and development, and in the revalidation of professionals, particularly the revalidation of multi-professional teams rather than of individuals. Also, virtual technology to learn practical skills will find increasing application.
- 13.11 | Information systems will be heavily used by education and training-providers at all levels - teachers, education ministers, medical schools, research councils, and curriculum designers. A fundamental skill for all professionals will be the ability to continue to learn and adapt to new circumstances and knowledge. The information skills needed will not primarily be technical because technology will adapt to those who are technically unskilled. These core skills need to be defined to inform the development of education and training programmes.

Health Services, Industry and Academia

14 Entrepreneurial Culture

- 14.1 Innovation in industry needs to be matched by innovation in the public sector as well as in government departments. Quality of linkages between Higher Education Institutions, industry, government departments and voluntary organisations, reward for innovation and organisational improvement in public services, high quality, relevant and accessible education, low inflation, and population awareness of science and technology issues, are some of the contributors to an entrepreneurial culture.
- 14.2 The Panel has been made aware of the widespread perception in this country that there is a UK culture antipathetic to the successful entrepreneur. This may not apply to all sectors but in the context of health care, health care industries and universities it could be a serious inhibitor. While we favour action and leadership to correct this, there is a case for a social study to examine the issues in detail.
- 14.3 The mobility of researchers between the public and private sectors should be encouraged. Industrial personnel should spend time in academic environments: currently, the trend is more towards academics working in industry. The aim should be a free flow between the sectors: public sector employment conditions are a major constraint.
- 14.4 The number of politicians and civil servants and industrial leaders who are informed about scientific matters should be a cause for concern. Government web-sites should make clear what the background skills and experience of politicians and officials are. There should be greater exchange of personnel between Departments of Health and other government departments with responsibility for policies that impact on health.
- 14.5 It is crucially important for the biotechnology sector in the UK to flourish and there is concern that other EU countries are taking over the UK lead in this field. The tension in health care between innovation and resource control will become increasingly evident as governments try simultaneously to introduce incentives for discovery and the exploitation of discovery, while seeking to screen and selectively admit new technologies.
- 14.6 For the NHS to develop a competence and major involvement in health care development would demand a re-orientation from its current reactive stance to be proactive towards the take-up and purchasing of key innovations in order to avoid R&D and other capacity being lost to other countries. Ineffective and inessential methods and medicines need to be identified, de-marketed and removed from the health service. We have emphasised that information is a key factor in competitiveness including the handling of NHS information within linked data-bases and the creation of patient-held records.

15 Technology Transfer

- 15.1 The UK has established a strong presence in the pharmaceutical, biotechnology and life sciences sector. The encouraging progress in establishing biotechnology in the UK could be slowed by bureaucratic and other obstacles including access to support for developing ideas, regulatory arrangements, ethics approval, use of animals, clinical trials arrangements and NHS unresponsiveness. For the UK's position to be sustained, the systems and processes for increasing the efficiency with which ideas and discoveries are taken to market must be sharpened and kept under constant review.

RECOMMENDATION 15

We recommend the development of technology transfer as a profession and that steps are taken to enhance its efficiency.

The technology transfer profession should establish its own body with a budget and secretariat. The technology transfer function should not be bound up in university or other administrative hierarchies. It needs to be positioned so as to optimise the identification and selection of research outputs for commercial development. Some of the larger universities have already established wholly-owned commercialisation subsidiaries with technology transfer that compares favourably with international standards, and with links to venture capital companies and other funding sources. Preferably managers of such companies should have a successful track record in industry. Academic pay scales are not conducive to attracting the best people. Multi-institutional consortia should be considered and there are some existing examples on which to build.

RECOMMENDATION 16

We recommend that consideration is given to the establishment of a London health science park

London deserves particular attention with regard to technology transfer and the links between academia and commercial companies. A high proportion of UK public and private health research funding goes to London's academic centres. However the capital may under-perform in generating biotechnology or informatics start-ups. The large multi-faculty schools do not collaborate to any great extent even on issues such as technology transfer. The outputs of London's scientific effort in terms of commercially exploitable discoveries should be reviewed to see whether outputs are consistent with the input of resources. The four major schools of the university should jointly explore the scope for collaboration, particularly the creation of one technology transfer facility for health research.

16 From Idea to Development

- 16.1 The continued development of first class basic research is needed to support applied, developmental research on health care problems. The lack of a coherent mechanism for supporting projects that take research findings into early development will be increasingly disadvantageous. The take up and commercialisation of bioscience research requires funds to test the feasibility of an idea. This often calls for modest amounts of money to further develop an idea, secure an intellectual property position or finance a market survey. These are essential to secure a commercial opportunity through licensing or venture finance. A development gap is perceived to be a limiting barrier, although a shortage of good, commercially interesting ideas may also be a problem. Both tasks need to be addressed: flushing out commercially exploitable ideas and injecting financial support to develop them.
- 16.2 The development of diagnostic tests for infectious diseases and vaccines is a specific example of a field in which integrated action is required between academia, health services and industry. Vaccines for infectious diseases and for reproductive medicine are a priority for poorer countries and increasingly relevant to the developed world. Nucleic acid vaccines that mediate their protective effect through T lymphocytes require specialised facilities to produce DNA at regulatory standard for human medicines. Dedicated facilities are also needed to test new vaccines for safety and immunogenicity.
- 16.3 Although larger companies are likely to be involved in the later stages of product development and in marketing, academic groups and small/medium enterprises will be increasingly at the forefront of discovery and early development. For the UK to exploit its strength in science and medicine, one or more well-equipped and easily accessed facilities are needed for the early trialing of prototype vaccines by academics. The case for such facilities also used for diagnostic tests is included in recommendation 8. This would allow early products to be tested and premature approaches to industry avoided since in many cases the results would feed back into research.
- 16.4 Variant CJD is a pressing contemporary problem where research is likely to have wider benefits for example in understanding the biology of Alzheimer's disease and amyloidosis. The urgency of developing a diagnostic test for vCJD requires combined government and private sector funding. Until there is a test - as was shown earlier for HIV - it is difficult to follow pathological changes, to diagnose infection on blood samples and to carry out epidemiological studies.
- 16.5 It is difficult to raise an antibody against prion protein. Research at basic level to elucidate molecular mechanisms in protein-protein interactions depends upon an effective integration of biology and chemistry. Biological chemistry is one of the many examples in this document where vertical disciplinary structures threaten to inhibit progress.

RECOMMENDATION 17

We recommend that an efficient mechanism is established to permit early development funds to be accessed quickly and flexibly.

Current mechanisms for allocating funds through the Research Councils to support research and early development once a commercial idea has been identified are not as responsive or as they need to be. This responsibility could also conflict with the support of basic research. A new mechanism and efficient processes are needed to provide rapid access to pre-competitive pilot study funding. The criteria for allocation need to be in line with objectives and there should be strong input from individuals in the commercial sector. Although this affects many fields of activity we suggest that this is an issue the proposed Health Engineering Consortium (recommendation 33) should address as a priority.

17 Integrated Disciplines

- 17.1 Increasingly in research and in development we will be dealing with complex systems requiring a wide range of knowledge and expertise. Collaborations that manage to develop synergy between different contributors produce exciting and often unexpected results. Centres that are designed to assemble a spectrum of skills may not succeed if they become inward looking and if vertical disciplinary preoccupations still predominate. For future needs, a network that can add, contract or re-orientate in relation to fresh demands and ideas, will often be a more productive model than a designated centre. Emphasis should be given to understanding the respective roles of centres and networks as well as combinations of both in terms of problem solving and the translation of discoveries into new products and processes.

RECOMMENDATION 18

We recommend that the Research Councils and the Higher Education Funding Councils, preferably in partnership with the Wellcome Trust, produce proposals for mechanisms that are specifically designed to address the need for cross-disciplinary research and development.

Innovation at the interfaces between disciplines may be thwarted rather than helped by some aspects of current organisation and resource allocation. Biological chemistry, biology and materials science, neuroscience and social sciences, and mathematics, computer science and biology are four of the many examples where integrated activity will be crucial for future progress. A strategy is needed for integrating activity in these areas. University faculty structure and HEFC policies should also give impetus to cross-disciplinary linkages. Examination of the issues would be best done on a case-by-case basis taking examples such as tissue engineering, bio-informatics or protein structure and function.

Sustainable Development, Health and Health Care

18 Social Innovation

- 18.1 The essence of sustainability is flexibility. This needs to be an in-built characteristic of health care and of society more generally. Education, recognition of innovative capacity, and coherence across sectors, disciplines and government departments are some of the ingredients. Health systems that are an excessive drain on national economies reduce sustainability. Tolerating serious health disparities within and between countries and giving low priority to environmental health hazards does as well.
- 18.2 Innovation in social policy is less spectacular than advances made through scientific discovery and technological development. The challenge is to use technological innovation for social betterment as a way of improving health and health care.
- 18.3 Increasingly social policy initiatives and policies and plans related to science and technology will need to find common ground. Social and economic problems are potent causes of ill-health and technological changes threaten to increase rather than reduce the disparities between the poor and those who are more affluent. Tackling ill-health with an armamentarium of imaging devices and novel medicines makes little sense if health-related social policy development is not pursued with comparable vigour. Many of the proposals in this document bear on this problem, for example those for education, public participation, disciplinary integration, rolled-back health care, integrated social care and health care and the positioning of health at the centre of policies for the natural environment and international development.

RECOMMENDATION 19

We recommend that a strategy is formed to exploit the potential for health advancement through social policy innovation, contributing to the latter through the intelligent use of scientific and technological advances.

The remit for developing a strategy for pursuing health objectives through social innovation should be given to an independent high-level group with members selected from a wide range of backgrounds. The group should be able to draw on government, Research Council and other interests while remaining independent of them. Its remit would be advisory and it would report to government.

19 Children

- 19.1 The contributions, attitudes and requirements of the next and subsequent generations will be influenced by factors that impact on their health and development. Particularly in childhood, medical advances, social background and education interact strongly. The first years of life lay the basis for competence and coping skills that affect learning, behaviour and health. The environment a child is brought up in exerts a crucial influence on later development. Children thrive in environments that meet their developmental and physical needs. Development from the prenatal period to the age of six is rapid and shapes longer term outcomes. Supporting development during this period can have durable benefits.
- 19.2 One new variable is the impact of genetics on human reproduction and through this the potential of making choices that will affect children.
- 19.3 Spermatozoal DNA can be injected into ova which can be placed in donor women or into surrogate mothers. Both the male donors and female recipients could be selected using genetic or other criteria. Fertilised human ova grown in vitro to the early embryo stage can be selected for implantation. During pregnancy it is possible to test the foetus for structural and genetic abnormalities, perform in-utero surgery and monitor metabolic function. Genetic tests can be performed at birth and eventually some level of genetic profiling may become feasible. Stem cells from cord blood can be collected and stored for immediate use for example as a transplant to a sibling, for future use in autografting or for the purposes of tissue repair and regeneration. A commercial company has already been set up to store neonatal stem cells. In due course on the basis of genetic profiling it will be possible to devise a 'life' plan including diet and lifestyle. This type of development raises the wider issue of proxy consent for children.
- 19.4 These techniques bring benefits but they also raise ethical questions. For example, to what extent is it ethical to work to ensure "desirable" qualities or try to "remove" undesirable qualities in children.
- 19.5 Individual aspects of social and other developments relevant to children are subject to scrutiny by various bodies but a more comprehensive and continuing overview is needed to consider technology-driven interventions in a social context.

RECOMMENDATION 20

We recommend that a mechanism is established for maintaining an overview of the development and well-being of children.

This could take the form of a non-governmental Forum sponsored by government departments that have a particular remit for children. A major objective should be to provide advice and recommendations for action to government. These should include initiatives and services to foster the development of children in different economic, social and cultural circumstances. It should cover conception, pregnancy, birth and infancy, parental and family support. There should be a methodological review and the development of indicators of children's health and well-being for routine use.

20 Globalisation

- 20.1 Globalisation in relation to industry, regulation, health interest groups, illicit drugs, health care advice and provision, population flows, as well as disease itself, all impinge on national health care provision. For example, the agreement on Trade-Related Aspects of Intellectual Property Rights affects the production of and access to drugs and vaccines, and the General Agreement on Trades and Services covers receipt and supply of health care and foreign investment in health.
- 20.2 The health of the UK population will therefore be increasingly influenced by international factors. At the same time, the UK through its domestic and foreign policy, patterns of energy use, industrial production, research, education, and health care provided directly and electronically by UK-trained professionals, can exert an influence on health beyond its borders many ways. The interconnectedness of processes across the globe points to the need for stronger mechanisms to promote global health governance, for example, in relation to patients going abroad for uncontrolled treatments that have major cost implications for the UK when they go wrong.

RECOMMENDATION 21

There should be an explicit cross-government strategy for the integration of health objectives into international development policies, treaties and conventions.

This should be a clear objective recognising that in parallel with the spectacular nature and promise of scientific discovery and technological progress, the world is afflicted by wars, erosion of civil liberties, abuse of human rights, avoidable epidemics, massive burden of injury and the needless pruning back of life expectation.

With increased travel and population migration the diseases of poorer countries will become increasingly the problems of affluent countries. Diseases such as HIV/AIDS threaten social stability in regions where the problem is of epidemic proportions with significant potential global consequences.

There are specific issues relating to the surveillance of disease. Funding for European and wider international networks for the surveillance of infections such as HIV/AIDS, legionnaire's disease and vCJD should be put on a firmer footing with political support to ensure a sustained effort. Investment in the UK in surveillance has declined, a trend which should be reversed.

21 Environment

- 21.1 By 2020 the complex inter-dependencies between changes in the natural environment and human health will be better understood. However by the time the magnitude of the impact is appreciated it may be extremely difficult, costly or impossible to tackle.
- 21.2 Even though research, modelling and policy development in relation to natural environment and health is of crucial importance, it risks being at the margins of mainstream funding interests and policy concerns. While research into the effects of environmental changes on health should be actively supported and pursued, a coherent and co-ordinated effort is needed to model future events in order to inform policy decisions taken now that will affect the longer term.

RECOMMENDATION 22

We recommend that a Health and Natural Environment Forum is established to develop a strategy in which health considerations are placed at the forefront of environmental policy.

The remit of the Forum should be to understand how human activities impact on the environment, and the way in which the environmental changes that result exert adverse effects on human health.

The Forum should be broad-based drawing on inputs from each of the Research Councils and examine issues such as air pollution, landfill including the disposal in the soil of exempt waste such as abattoir offal, renewable energy and energy-efficient technologies. Health considerations should provide an impetus for policies against global warming including the development of renewable energy sources. The Forum should also cover health and the built environment - both health care buildings and others including schools, homes and places of work.

Environmental issues and their proven or presumed adverse consequences for health will achieve a much higher profile and the quality of linkages between the Department of Health, Department of Environment, Transport and Regions, and the Environment Agency will be crucially important and subject to increasing scrutiny.

Research, Development and Technology

22 Genes

- 22.1 There is intense effort in medical research and in the biotechnology and pharmaceutical industries to develop new genetic tests and treatment based on genomics. Mapping the human and other genomes marks the start rather than the end of a process. There are high hopes for the future but so far the impact of genomics on health care is limited.
- 22.2 For some conditions such as cystic fibrosis a single gene defect if in the homozygote causes disease, but even here the situation is complex with more than 900 mutations of the gene so far identified. Furthermore the correlation between genetic defect and phenotype is far from simple. A distinction has to be made between inherited disorders and genetic susceptibility. For most common conditions such as heart disease and cancer, genetic constitution and probably the interaction of many genes, plays a role in causation but extrinsic factors such as environmental pollution, diet and lifestyle are likely to be as important if not more so.
- 22.3 The time course for genomics developments is difficult to predict. Genetic tests are already becoming available some of them as over-the-counter kits. Genetic treatments, either gene therapy or the development of novel drugs from targets emerging from human genome research, are further away, perhaps more than a decade, although some are currently in clinical trials.
- 22.4 The high profile of genetics has raised expectations. The longer-term promise is real even though the time course for the generation of novel therapies is likely to be protracted. During this developmental phase incentives are needed for industry to pursue the objective of delivering new improved treatments. This places responsibility on government to create a climate favourable to continued investment in R&D.
- 22.5 Genetics is already exerting an influence on medicine primarily in relation to inherited conditions. Examples include: prenatal diagnosis and termination of pregnancy, marriage and pregnancy advice, selection of embryos for implantation, treatment with missing gene products, for example haemophilia, treatment with modified diet, for example phenylketonuria, potential for surgical treatment for high risk patients for example colectomy or mastectomy, molecular classification and targeted treatment in a broad range of diseases including as breast cancer, diabetes and hypertension and tailored drug schedules in relation to genetically-determined pharmacokinetics.
- 22.6 These are at the margin of what might be achieved particularly in common chronic diseases. The main opportunities for the future include: novel forms of treatment based on the analysis of gene function; gene transfer either to somatic cells or germ-line cells; disease prevention methods based on the modulation of environmental interactions with genetic risk factors; the directed growth of stem cells to produce tissues and even organs that can be used to repair or replace damage inflicted by age or disease.

23 Genetic Tests

- 23.1 The availability of tests before treatments are available already poses a problem. Even now an increased genetic risk of Alzheimer's disease in middle life can be diagnosed in a minority of cases on a blood sample when a child is born but unfortunately little can be done about it. The utility and ethics of such testing is therefore highly controversial.
- 23.2 As the number of genetic tests increases there will be intense pressure to apply them either selectively or in the context of screening. To take cancer as an example, at present there is limited testing in the NHS for some high penetrance cancer susceptibility genes with relatively rare mutations for example in breast cancer, colorectal cancer, melanoma and childhood cancers. Low penetrance genes (1-2 fold elevated risk), and medium penetrance genes are unlikely to be used in predictive testing. It is likely that several medium penetrance genes will be discovered for each cancer with mutations affecting 1 in 50 to 1 in 500 of the population. Testing for mutations in individuals from family clusters will increase and there will be demand for whole population testing. A broader economic and social analysis of the potential impact of this testing is necessary.

RECOMMENDATION 23

Government should ensure that there are well-defined criteria for genetic testing and screening.

The rationale of genetic testing and genetic screening - including cascade screening as well whole-population screening - must be robust and be clearly linked to subsequent actions that are beneficial to the individuals concerned.

24 Industrial Innovation

- 24.1 The perception of the biotechnology and pharmaceutical industries is of a lack of understanding within health care of what developments in genetics could offer. This is compounded by a lack of clarity about responsibilities for integrating genetics into medicine and health care more generally and by inadequately informed committees with which health care industries work. If the UK is to be at the forefront of exploiting genome research and other rapid growth areas in science and technology, an environment favourable to industrial innovation and R&D investment is a crucial requirement.

RECOMMENDATION 24

We recommend that the conditions favouring a continued commitment in health care to industrial innovation in the UK are clearly characterised, established and maintained.

In particular:

- a clear indication to industry of what is likely to be acceptable to government in terms of new products and interventions arising from research and development in relation to rapid growth areas such as genetics and tissue engineering;
- a strong science base organised to facilitate cross-disciplinary research;
- efficient and commonly agreed arrangements for clinical trials - increasingly in primary care - including those conducted on genetically-defined groups of patients;
- avoidance of excessive bureaucracy;
- explicit licensing and '4th hurdle' criteria for eventual genetic and other preventive or therapeutic interventions;
- efficient technology transfer;
- methodology for forward projections of economic and health care demand/need;
- effective ethics scrutiny and debate with well-designed training programmes for ethics committee members in fields where novel interventions are anticipated such as disease-related genetics and pharmacogenetics;
- public familiarity and sympathy with the objectives of health research and development;
- explicit presentation to, and discussion with, the public about the place of research using mouse and other animal models, for example to elucidate gene function, as well as about efforts being made to devise and use alternative approaches.

25 Genetic Profiles

- 25.1 Sequencing the entire genome of individuals is unlikely to be either desirable or usable. However, broader screens may prove useful in assessment of the individual's future health risks, for example, using single nucleotide polymorphism maps in genome "scanning". Such maps which could suggest predisposition to conditions such as cancer, diabetes and cardiovascular disease, and could become part of an individual's health biographical record.

RECOMMENDATION 25

The genetic information it is feasible or desirable for an individual to have and retain should be clarified.

Clarification is also needed on how such information might be used and what ethical, legal and social issues are likely to arise. These tasks require public participation, the contribution of industrial producers and a government role including possible legislative and other actions.

26 Education

- 26.1 Genetics has substantial implications for education. It is a forbidding subject to most people and it will exert a major influence on our thinking and lives. Everyone should have some understanding of the main issues including the notion that there is no such thing as a perfect genome. Infinite variety is the norm - we are all in some way atypical. Because of the shadow of eugenics and the science fictional predictions of developments such as cloned humans, genetics could increase negative attitudes towards science and technology.
- 26.2 Genetics could be a test case for engaging with the public on the moral and ethical as well as the health and industrial aspects of technological innovation. For example the public mood about animal experimentation is in conflict with arguments by academics and industry in favour of using animals in order to find out how genes work. This is viewed by researchers and particularly by biotechnology and pharmaceutical companies as an obstacle to be overcome by informing the public more fully about the rationale and long-term benefits of genetics. Clarification and discussion with the public is needed about the place of animal experimentation in, for example, genetic functional analysis.
- 26.3 Another relationship with education is the use of genetic information and molecular methods to gain a deeper understanding of the biology that underlies brain function. This includes the mechanisms that control and influence the plasticity of the brain in childhood and intellectual development. The genetic basis for some behavioural traits will be understood and some of these traits may be linked to cognition. For example those affected by Fragile X syndrome may have an inability to recognise abstract symbols such as numbers, to do arithmetic or use money. Understanding the role of the protein produced by the gene will help elucidate the basis for this specific learning defect.

RECOMMENDATION 26

We recommend that the education sector considers the contribution that could be made to teaching and learning by health sciences, and the contribution it could make to public understanding of academic/industrial viewpoints and lay perceptions about science and technology.

27 Genetics and Insurance

- 27.1 As we prepare this report the UK has become the first country to approve the use of the results of genetic testing (Huntington's disease) for insurance purposes. By 2020 scans across the genome of individuals are likely to produce profiles of risk for many conditions. Some genetic characteristics could be protective and risk factors may interact.

RECOMMENDATION 27

We recommend that insurance companies together with geneticists and others including health service and public interests should jointly prepare and continuously update a forward projection of the likely implications of genetic advances for insurance.

28 Phenotype Research

- 28.1 The National Health Service is ideally placed to exploit opportunities to be derived from the successful integration of clinical and genetic information. This will be beneficial to the efficiency and performance of health services as well as to UK health care industries. The requirements for achieving this include a strong presence in clinical research/documentation, efficient information systems, good clinical trials networks, well developed knowledge management, methods for data extraction and analysis, and the build up of a tissue resource.
- 28.2 To relate genetic features and disease manifestations, a fresh commitment is needed to understand the features and natural history of disease and the recovery from and response to medical, surgical and other interventions. This includes observations that patients themselves make as well clinical observations. A lack of knowledge will hinder correlations between genetic findings and different forms of disease that are currently classified within the same diagnostic category but which with molecular taxonomy can be subdivided in relation to disease mechanism.

RECOMMENDATION 28

We recommend that research funders, including NHS R&D, and preferably with European and other international partners, collectively design and launch a high-profile 'phenotype' research initiative that involves clinicians and patients.

29 Large-Scale Trials

- 29.1 The case for large-scale epidemiology and the analysis of large data sets is clear, as is the need to store blood and/or tissue samples. Detection technology is becoming so sensitive that only minute quantities of human tissue will be required for acquiring as much genetic information as is needed. The scale of trials for genetics and other purposes will emphasise the need for large networks many in routine settings outside academic centres. Planning for large-scale trials in the NHS should start now including the routine storage of blood cells to create DNA databases.

RECOMMENDATION 29

We recommend the formation of a national strategy for clinical trials.

This should jointly involve the Medical Research Council, Wellcome Trust, other charities, industry and NHS Research and Development. It should be associated with the national co-ordination and collection of donated blood samples for disease-related genetic study. Such action could provide a unique genetic blood pool from which to conduct research that would place the UK in a strong position commercially as well as academically. A DNA-based drug surveillance system is also needed to ensure post-approval monitoring of patients who have their blood stored. This will permit adverse events to be reported and interpreted in relation to genetic features and allow the development and design of future safer medicines.

As part of this strategy we recommend that the NHS should examine the feasibility of establishing a Clinical Research Organisation.

This might be part of a commercial wing - 'NHS Enterprises' - that could take responsibility for all aspects of the interface with industry. It would provide appropriate backup in pharmacology, genomics and other areas, with a clear and transparent pricing policy. From the perspective of small/medium commercial enterprises as well as larger companies, it could also be important for the NHS to establish an effective, centrally administered technology transfer mechanism of its own.

30 Integrated Science and Technology

- 30.1 To achieve correlations between gene function and normal and abnormal physiology and to elucidate the role of environmental factors that contribute to disease causation is a hugely complex task. An essential requirement is integration between mathematics, physics, computing, biology and medicine.
- 30.2 A strong technology base in the UK is indispensable to realise the potential for making genetic information useable and accessible to all. Included here are electronic and digital storage devices and information technologies and systems including software development. Grid computing will enable the tackling of very large scale and ambitious mathematical

problems. By 2020 silicon based processing is likely to be reaching a peak and optical computing may be coming on stream.

30.3 The government has made an encouraging start in creating a favourable environment for bioinformatics but the momentum needs to be maintained. We are aware that a number of UK bioinformatics companies have been acquired by non-UK interests. The situation with regard to UK bioinformatics should be kept under review to ensure that there is a continuing strong presence in this field.

30.4 There is current interest in systems biology and the development of integrated models of genome structure, gene products, and gene function at the level of cells, tissues and the whole organism. Given the levels of complexity it is doubtful whether anything other than gross and simplistic modelling will be achieved over the next few years. By 2020 better integration of known actions at each level is likely. One practical interest of work in this field is the modelling of metabolic pathways to predict drug effects and to develop new treatments.

Repair, Regeneration and Transplantation

31 Regeneration Medicine

- 31.1 Regeneration medicine will become a major component of health care. It will encompass the use of stem cells, tissue engineering, xenotransplantation, use of artificial organs, induced repair/regeneration and the modulation of ageing processes.

32 Xenotransplantation

- 32.1 Xenotransplantation using organs from the first generation of transgenic pigs will enter clinical trials within the next five years. Clearly, there will be major ethical issues to be resolved. Assuming limited success and no problems such as a major infection there will be an impetus to continue the development of better methods for genetically modifying and propagating pigs. However in pigs perception of risk from endogenous retrovirus is likely to inhibit progress. It may be possible to address the problem by genetic engineering to remove the key retroviral part of the pig genome. Cloning pigs has already been achieved by nuclear transfer from foetal cells and adult cells and the first genetically modified pigs are being produced. The supply of donor-derived human tissue for allo-transplantation is unlikely to meet demand even with more enlightened donor supply programmes. There will be unmet needs during the next twenty years for heart transplants and kidney transplants. If xenotransplantation can be shown to be feasible and safe - even for a limited number of organs - there could be high demand.

33 Stem Cells

- 33.1 The identification and propagation of human embryonic stem cells capable of differentiating into any somatic tissue has been a major landmark. This offers the prospect of determining the lineage of stem cells and selecting for different tissues and in due course organs. These developments open the way for conserving neonatal cord blood stem cells for regenerative purposes in later life. The control of development and differentiation will yield a variety of useful cells for allotransplantation.
- 33.2 The demonstration that adult somatic cells can be re-programmed by nuclear transfer raises the possibility that an individual's cells may be customised for autologous transplantation. There will be an intense scientific effort to understand re-programming. It is likely that reasonably pure human cell populations for certain neurones and for cardiomyocytes will be available for allo-transplantation within the next ten years. Other cell types such as liver and pancreas should be available within 20 years. There will be key issues concerning the scale-up and quality assurance of such populations of cells which may impact on overall feasibility.
- 33.3 Re-programming of adult cells for autologous transplantation is more speculative but there is every chance that this will be achieved in the laboratory by 2020 although whether it will be widely available is debatable. Recent advances have revealed that more

adult tissues than previously suspected contain stem cells. Techniques for identifying and multiplying these cells are being developed with initial success claimed for skin, cartilage, tendon, bone, muscle and blood vessels.

RECOMMENDATION 30

We recommend continued strong support for stem cell research and development with the aim of exploiting the opportunities that arise to benefit patients.

We recognise that there is great sensitivity to some aspects of stem cell research. These and the ethical questions that arise must be addressed. It is important however that work in this area does not stall because of misunderstandings. The scientific community must be able to present the state of progress and future options with great clarity.

34 Tissue Engineering

- 34.1 Tissue engineering will open up new areas of regenerative medicine making possible a wide range of tissue reconstruction and repair possibilities for chronic conditions. The development of devices for implantation into damaged tissue will assist tissue repair, for example by aiding tissue adhesion, orienting cells correctly, trapping inflammatory cells and releasing the appropriate cytokines locally. Such systems might be used routinely in surgery. Cells removed from a patient will be expanded by growth in a three-dimensional 'scaffold' for later reimplantation into the patient. The biology and engineering of scaffolding will be an important field of research in tissue engineering where both mechanical properties and biological and mechanical control mechanisms need to be addressed. A third area touched on above is the use of stem cells from other sources which may involve gene manipulation.
- 34.2 Successful tissue engineering will be achieved in the near future in the replacement of tissue including skin (for burns and skin ulcers), tendon and ligament repair, skeletal muscle repair, cartilage and bone repair including joints, bladder wall repair and a variety of uro-genital, oesophageal and pharyngeal repairs often of developmental defects.
- 34.3 Achievement in several of these areas will allow treatment of large groups of patients for whom there is little effective treatment at present. The replacement of complex organs such as kidney, most endocrine organs and perhaps heart and liver is further away.
- 34.5 Regenerative transplants using human cells for diseases such as Parkinson's disease, spinal injury, osteoporosis, macular degeneration and diabetes where there is premature death or loss of function of specific cell types and failure of the body to replace or restore them will become possible. Problems that might be tackled in this way encompass the major diseases of the elderly population where there is currently huge unmet need. If the anticipated advances over the next 20 years are only partially met, and new realistic treatments involving the widespread use of organ or cell transplantation do become available, it is clear that health care provision will have to be substantially modified.

- 34.6 The long-term aim of many tissue engineering applications is to treat age-related and chronic degenerative disorders which have large and growing social, personal and financial implications for UK health. Tissue engineering could increase costs in the short term but the objective would be to reduce health and social care costs overall through single-stage, conservative surgical procedures, avoidance of multi-stage procedures and repeat interventions, which are costly in surgical and convalescence bed time.
- 34.7 The potential impact of tissue engineering over the next 20 years is immense. It is already generating new drivers and requirements in the area of biomaterials. The next generation of support matrices will be biologically smart, providing biocompatible cues and regulation to cells. Bio-mimicry (based chiefly on the use of natural macromolecules or their derivatives) appears to be the most promising approach for novel bioartificial materials. Cell acquisition which is a major and limiting issue for tissue engineering is likely to be addressed through a combination of the use of autologous mesenchymal progenitor cells and in vitro modification, including genetic manipulation. Tissue engineering will be a major stimulus to these areas of cell biology over the next 20 years.
- 34.8 Another growth area is the engineering support for large scale, long term growth of tissue constructs to maturity in vitro. This will require the development of advanced forms of sterile culture of 3-dimensional solid and hollow structures. The elements of such systems are already under development through current research in biophysics, biochemical engineering and minimally-invasive clinical monitoring.

RECOMMENDATION 31

We recommend that the platform technologies which will be key to the future progress of tissue engineering and other cell-based therapies should be identified and strategies developed for supporting them.

Consolidation of UK expertise and intellectual property rights in these platform technologies (critically in cell control biology, tissue imaging and monitoring, cyto-mechanics and biomaterials and biochemical engineering) is essential to place UK industry at the forefront of what promises to be a revolution in surgical and chronic disease management. In addition to immediate needs for cells and materials, the manufacturing and service requirements to support tissue engineering will be significant. District hospitals might well use tissue engineering devices off the shelf or automated cell/tissue fractionators to seed preformed devices with an individual patient's cells. Early forms of 'customised autologous tissue' devices, for example for cartilage, are already in construction. Aside from the obvious opportunities for biotechnology companies to produce the tissue engineering implants themselves, there are potentially large commercial openings for high technology engineering devices for cell preparation and automated culture. This includes advanced bioreactors for long term off-site growth of tissues and production of novel, bioartificial smart materials, probably based on natural substrates, through which biological regulation can be achieved post-implantation.

RECOMMENDATION 32

We recommend that the opportunities presented by the NHS and its integration with national blood fractionators and tissue banks are fully exploited.

The possibilities of sourcing materials and handling patient cells and tissues would be unique. Incorporation of these organisations into advanced tissue engineering programmes would provide the means to achieve individualised tissue engineering of the patients own graft tissues.

Cell-based therapies (especially tissue engineering and tissue repair services) should make a major contribution to clinical progress in tackling chronic, debilitating and age-related diseases. Managed imaginatively, this developing field could represent a major new area of wealth creation for UK industry in future decades and limit the export of wealth and employment that would occur if these methods become available from non-UK companies.

In this as in other areas it is vital for the NHS to signal effectively to industry what the real priorities and needs are in health for the next ten to twenty years and that it can realistically fund its needs. This will motivate industry to align itself with NHS needs.

Health Engineering

- 35.1 Physical and engineering sciences will play a pivotal role in the further development of biology, medicine and health care in areas such as whole systems engineering, mimicry of natural sensor/effector pathways, image analysis, predictive modelling of biological behaviour, and clinical decision support. Physical sciences will be drawn on to understand how molecular processes translate to whole body functions and the clinical applications of genetics will draw heavily on engineering in areas such as microstructure and microarray development, imaging and data mining.
- 35.2 Improved patient surveillance will result from miniaturisation of physical and chemical sensing devices, along with smarter biohybrid ("biosensor") structures. Advances in device miniaturisation will permit lower cost solutions to techniques such as magnetic resonance, ultrasound, chromatography and mass spectroscopy. These will be used in the near-patient context, as is currently the case for bedside electrophysiological and biochemical monitoring systems. New tools in endoscopic surgery, particularly those with a feedback link to navigation will emerge. Clinically viable *in vivo* robotic systems, whilst still some way off, are a likely end result of progress in areas such as microfabrication, material science and biointerfacing.
- 35.3 Advances in enhanced image resolution, and extension into both 3-dimensional and real-time domains are occurring now and these will provide the basis for targeted, structure-conformal therapies, as robotic surgery and metabolic imaging initiated in PET scanning. New imaging modalities and improved resolution from existing methods will also lead to techniques for non-invasive tissue microscopy and tissue architecture visualisation, transforming current approaches to tissue diagnosis. Full 3-dimensional tomographic scanning of flow, perfusion, oxygenation distribution, and probably also endothelial function, will be available to investigate vascular pathology and thrombosis. Cardiovascular diagnosis and treatment will make use of smaller, higher resolution endoscopes including endoscopes that are remote-guided by a focused magnetic field, intelligent stents, for example with drug release based on local environment, plasma oxygen carriers and the targeted release of anticoagulants/angiogenesis factors for example from liposomes using focused ultrasound.
- 35.4 Commercial work with high throughput screening for drug discovery already places demands on computational data processing methods and these should be applicable in the clinical sphere. Nano-bioreactors have been developed for diagnostics allowing thousands of assay wells to be incorporated into centimetre scale platforms. Whatever its technical power, ultimately data processing will need to be assessed alongside any other health technology in regard to clinical benefits. It could be an important means of enhancing mass screening, disease risk assessment and predicting individual prognosis.

RECOMMENDATION 33**We recommend the establishment of a Health Engineering Consortium.**

The consortium would bring together the NHS, Research Councils, industry and other relevant interests including the Royal College of Surgeons and Royal Academy of Engineering. Under an independent Chair it would be given the remit of developing without delay a national strategy for health engineering, including the identification of new interdisciplinary opportunities for scientists, engineers and doctors.

RECOMMENDATION 34

We recommend that ways of creating better integration between mathematics, biology, medicine and engineering/physical sciences should be addressed by government, funding bodies, and universities. In recommendation 18 we point to the need for clearly established processes to facilitate cross-disciplinary activities. We highlight here a particular need.

The interfaces between these fields of research and others including chemistry and social sciences, should be tackled by medical schools, by the universities with which they are associated, and by the Higher Education Funding Councils. Relevant to this is curriculum design in schools, faculty structures and curricula of universities and the organisation and funding criteria of research funding bodies.

Currently there is a gulf between materials science and biology. The future will see an emphasis on implantable materials that are bio-active rather than bio-compatible. Such materials will influence tissue responses for example by incorporating growth factors. Integration on site is needed to bring the relevant disciplines together and to associate this with technology transfer and training. At least two more UK centres are needed to take advantage of the opportunities.

Incentive structures are needed to link research with prototype engineering developments and commercially viable products. Given the fertility of ideas and prototype developments in the UK and the fact that the vast bulk of equipment purchased by the NHS is not produced by UK companies, the challenge of building a new relationship between biomedicine, health care, engineering/physical sciences and industry must have high priority.

The NHS should stimulate rather than be apprehensive of engineering technologies, particularly engineering solutions that could have wider applicability and export potential. Important here are engineering solutions that are relevant to NHS interests and usable by less affluent countries.

Brain and Mind

36 Extent of the Problem

- 36.1 The problem of neuropsychiatric illness is huge and health services have often not performed well in this field. They will be further tested by rising prevalence and a sharp increase in diagnostic and therapeutic possibilities.
- 36.2 Stroke is the biggest single cause of disability in UK adults, head injury is the greatest cause of chronic disability amongst young people, dementia eventually may strike 85% of the population. Depression, schizophrenia, anxiety disorders and phobias are prevalent and profoundly disabling conditions. Added to these are chronic neurological conditions such as chronic pain (a major cause of lost work days/and decreased productivity) and multiple sclerosis. More recently recognised problems include dysthymia and minimal mental dysfunction. At the border between neurology and psychiatry are disorders of learning such as dyslexia. The next 20 years will see the increased medicalisation of conditions, such as attentional deficit in children, hyperactivity and milder age-related cognitive impairments.
- 36.3 Advances are likely to come from a multifaceted approach that builds links between brain and mind. Functional imaging of the brain will progressively shed light on how the brain tackles psychological tasks. Neuropsychiatry is likely to become more eclectic employing a tailored combination of psychological and biological treatments.
- 36.4 An increased understanding of brain function will lead to the dilemma of how to define the limits of "normality". Developments in this field should be closely monitored since potentially they create a new dilemma for society: what are the limits of "normality" and how far should the medical model be allowed to extend in the definition and management of human behaviour?

37 Social Development

- 37.1 Neuropsychiatric problems are a test case for integrating prevention and treatment, managing chronic illness, setting boundaries between pathology and normality, achieving coherence between community and hospital care and integrating the social and medical aspects of care.

RECOMMENDATION 35**A sustained effort to reduce the socio/economic difficulties which could lead to psychiatric problems is an imperative.**

Education must be a major vehicle in achieving this objective. There is evidence that greater educational contact in the school system in the early years can help to break the link in childhood that causes anti-social behaviour. The role of primary education is a strong tool as a preventative measure in educating against drug dependency. Intervention is needed before first use of drugs. After dependency sets in it is not effective and exploitation of dependency occurs. 9 - 12 year olds should be targeted as dependants are already being seen in secondary school.

- 37.2 The schism between health and social care and the administrative and clinical barriers between health and social services results in anomalies such as the build-up of patients unnecessarily detained in hospital beds when they could be in the community.
- 37.3 We believe that proposals for pooled funding between health and social care should be implemented. We recognise that there are possible disadvantages to pooled funding in that new barriers are created, for example, between social work and housing departments. Pilot schemes should undergo careful evaluation.
- 37.4 The severe shortage of nurses in neuropsychiatry is unlikely to be satisfied, especially in areas with a high prevalence of severe disorders.

RECOMMENDATION 36**We recommend extended involvement of non-professional personnel in psychological health.**

Involvement of non-professional staff could take the form of a new cadre of health worker with an advocacy and mentoring role attached to primary care and linking with voluntary workers. They would need an appropriate career structure and basic training in selected techniques. Bringing such people into community care would counter the perception in patients of being unable to identify with professionals. An effective regulatory framework would be essential.

- 37.5 With regard to substance abuse, developments such as cocaine blockers would be likely to be effective only where there is a strong motivation to come off the drug. A better understanding is needed of the transition between recreational users and misusers of drugs: such research requires collaboration between basic scientists and clinicians. Currently it is not being pursued.

- 37.6 Social problems and the complex behaviours related to them may also benefit from advances in basic understanding and the potential for unravelling neurobiological mechanisms. Already brain imaging tools and an understanding of the potential consequences of brain dysfunction are being used by some courts in a similar way to prior applications of defences based on insanity in arguing for diminished responsibility for crimes. People may be tempted to use measurements of the functional activity of the brain to both explain an inability to act morally or to predict future behaviours. An immediate issue is how to address the problem of offenders with psychosis or personality disorders.
- 37.7 The Home Office should introduce computer-based psychological interventions, and virtual social skills modules. These techniques could also benefit young children seen as at risk of offending. The paucity of research into aggressive and antisocial behaviour should be corrected by investing in this neglected aspect of neuropsychiatry.

38 Prevention

- 38.1 A major focus in medicine has been the prevention of illness and this model should be extended to neuropsychiatry. This is possible in a number of settings. For example, there is evidence that conduct disorder in childhood can be prevented if parents are offered appropriate training. There is some evidence that educational interventions during primary school can prevent later drug dependence. There is accumulating evidence that those with a genotype predisposing them to schizophrenia can sometimes be prevented from developing it by avoiding cannabis. Subclinical depression may be prevented by self-help materials, either computerised or in manual form, and appropriate psychotropic drugs can prevent subsequent episodes of depression, bipolar illness and schizophrenia.

RECOMMENDATION 37

We recommend that a higher priority is given to the important but neglected field of disease prevention in neuropsychiatry.

Research in this field has suffered neglect and should have a higher priority among research funding bodies. What is already known and new knowledge derived from future research should be fully utilised to develop strategies - particularly in the community - for prevention. These should take into account implications for the design and functioning of services and requirements for integration with other agencies particularly in the voluntary sector. Important areas of research include an understanding of the basis for vulnerability to mental illness, early detection to avoid chronic disability and the later consequences of psychoactive drug use in early life. An investment is needed into research and the development and evaluation of psychological treatments as well as biologically-based interventions. The future is likely to see increased emphasis on a combination between psychological and biological methods.

39 Imaging

- 39.1 Neuro-imaging methods have become the most powerful and generally applied tools for the dynamic description of pathological changes in the brain. The range of methods will permit pathological changes both in brain structure and function to be followed even at cellular level and computational methods will permit highly sensitive, quantitative measurements of change. Functional neuroimaging methods will identify with increasing precision, alterations in brain function even in the absence of discernible changes in brain structure and effectively allow the visualisation of “thought”. Differences are beginning to be described in the functional imaging of psychotic patients but further differentiation between different groups is unlikely for another 5 years, due to, amongst other things, behavioural variables. Advances in brain imaging will accelerate the identification of biological mechanisms underlying psychosis within the next 5 - 10 years.
- 39.2 Advances in functional imaging will show how drugs enter the brain removing the need for complex markers. Such advances will provide the basis for the improved use of current drugs. Reduced side effects will lead to better take up of drugs and completion of treatments.
- 39.3 Advanced imaging methods will also permit novel interventions to be evaluated in patients with sub-clinical illness, leading to better prevention. The pay-offs of functional imaging for depression are probably less than for psychosis or dementia. PET and SPECT still have an important role in investigating possible new drugs, but ligands need to be developed to assist this research.

RECOMMENDATION 38

We recommend that Government and industry maintain UK research in functional imaging including PET technology.

The UK's strengths in engineering, physics, biology and medicine need to be collectively deployed to further the development by UK companies of advanced neuro-imaging technologies. The combination of techniques, or developments allowing simultaneous data acquisition, will be important, together with the development of the mathematical/computational methods of integrating the data/data types.

40 Treatment

- 40.1 By 2020 we anticipate significant advances in the treatment of neuropsychiatric illness. These will include drugs against new targets, the development of safe chronic therapies for diseases such as dementia and new drug delivery systems. There will be advances in functional neurosurgery based on selective lesions in functional circuits of the brain for example for intractable tremor, anxiety, depression and pain - this promises to make psychiatry at least partially a “surgical speciality”.

- 40.2 | Other developments will include electronic prostheses interacting directly with neural tissue for example optical sensors to drive activity of cells in the visual cortex providing a degree of vision in blind people, or prostheses in patients with limb paralysis from spinal cord injury to drive movements of the hands by linking the brain to arm muscles, bypassing the area of focal injury. Transcranial magnetic stimulation will selectively activate particular circuits of the brain in conditions such as depression and recovery from brain injury. Stem cell transplants will be used to restore activity after injury from stroke or head injury and to counteract deficits for example in Parkinson's disease or dementia.
- 40.3 | Genetic knowledge offers the prospect of identifying those at risk from alcohol or drug dependence; of elucidating biological mechanisms in schizophrenia; changing the boundaries and taxonomy of mental illness; the more accurate definition of psychosis; and the development of a new range of rational drug treatments.

RECOMMENDATION 39

We recommend that planning is undertaken now for the longer term support and development of functional genetics in relation to neuropsychiatry including the linkage between functional genetics, functional brain imaging and natural history research.

Further work is needed on setting arbitrary bands for "normality" and into defining clinical phenotypes with brain imaging. Research is also needed in the integration of imaging techniques such as structural imaging, electrophysiological mapping and functional imaging based on blood flow changes.

41 Lifestyle Medicines

- 41.1 | Lifestyle medicines will enable individuals to manipulate their emotions or behaviour, including mood swings. Medications with selective affects on anxiety, social phobias, dysthymia and other conditions will be forthcoming. There will be progress in understanding the molecular basis of learning and memory, with the promise of pharmacological ways of enhancing these. A positive benefit of understanding mechanisms of learning and memory and their dysfunction would be to develop rational strategies for enhancing educational potential. Learning enhancers could become a part of future education and learning disorders could become as much a neuropsychiatric as an educational problem in coming decades.

RECOMMENDATION 40

We recommend that the current range and use of so-called lifestyle medicines and the potential implications of future developments in this area for government, industry and the public should be assessed and kept under review to inform policy development and health service planning.

42 Brain Function and Learning

- 42.1 As alluded to in para 36.4, advances in biomedicine including genetics promise a deeper understanding of the biology that underlies normal as well as abnormal brain function including the mechanisms that control and influence the plasticity of the brain in childhood and intellectual development. The genetic basis for some behavioural traits will be understood and some of these traits may be linked to intelligence.

RECOMMENDATION 41

We recommend that the Research Councils, Wellcome Trust, relevant foundations and the Higher Education Funding Councils, jointly formulate a strategy for developing a more focussed effort to link research on brain development, brain function and learning.

43 Expert Systems

- 43.1 Among the future applications of information and related technologies in neuropsychiatry are expert systems to aid prescribing and self-diagnosis, and self-treatment made possible by the merging of telephone, personal computer and television. Properly developed, self-diagnosis/care could positively affect quality of life, and the need for health care. Intelligent systems need to be developed to aid prescribing of psychotropic medicines. With the likelihood of prescribing by nurse practitioners, computer-assisted advice will be important. Such a system might give advice on possible medications depending upon confirmed diagnoses; advice against poly-pharmacy and escalating doses; advice about drug interactions; and advice taking into account characteristics of the particular patient being seen.

Endpiece: The Usefulness of Foresight

- 44.1 This report contains the key recommendations from the Foresight Healthcare Panel. It is based on the outputs from Panel and Task Force discussions and responses to our consultation held over the summer. The Panel's consultation document was launched in June 2000, and is available on the foresight website (www.foresight.gov.uk/healthcare) together with responses cleared for publication. The Panel would like to thank all those individuals and organisations who contributed to the activities of the Task Forces, Associate Programmes and the consultation exercise.
- 44.2 The individual findings of each Task Force will be made available to amplify the issues and recommendations in this report. Each group has discussed the specific strategic issues for their area, and they are consequently at different stages of debate and development. The report of the Task Force on Older People, established with the Foresight Ageing Population Panel, is already available on the Foresight website. Foresight will continue to work with business, government, voluntary, regional, service and academic and professional organisations to turn findings into action.
- 44.3 The Panel will also consider the best mechanisms for taking forward its work, including which of its recommendation are prospective candidates for potential funding streams. It will also identify emerging areas for future Panel consideration and the most appropriate way of taking forward its implementation agenda.

RECOMMENDATION 42

We recommend that on the basis of the proposals set out in this report an implementation plan is drawn up with a timetable for action and measurable end-points clearly specified.

Our first recommendation was that foresight should become a regular feature of health care. The benefits derived from foresight have to be set against the cost of the activity itself as well as the costs that would be incurred and the benefits that would accrue if the recommendations were acted on. An assessment is also needed of the opportunities that would be lost if no action was taken. We have not made explicit proposals for substantial increases in funding in relation to our recommendations. Most of our suggestions have resource implications although in the majority of cases resources will be deployed in any event. More importantly we believe that a failure to take action along the lines set out here would mean that major opportunities would be lost to the detriment of health, research and the national economy.

Foresight Healthcare Associate Programmes

- 44.4 An associate programme in molecular biosciences is exploring the possibilities for developing cross-disciplinary postgraduate training; centralising tools and methods for biomedical research on large populations and developing the profile of bioremediation interests within Foresight.
- 44.5 The Institute of Cancer Research involved clinical scientists across its remit looking at cancer genetics; molecular pathology; imaging; radiotherapy; new drug development and models of treatment, care and support.
- 44.6 NHS Estates are addressing the future of the healthcare built environment. Their associate programme involves input from many other organisations and experts, addressing flexibility and standardisation; the digital age; future healthcare resource centres; sustainability and technology and the third age.
- 44.7 Outputs from these associate programmes are appearing on the Foresight website at www.foresight.gov.uk.

Panel Membership

HEALTHCARE PANEL

Professor Sir Michael Peckham
(Panel Chairman),
University College London

Professor Andrew Bradley,
Addenbrookes Hospital,
University of Cambridge

Professor Jessica Corner,
Royal Marsden Hospital

Professor David Delpy,
University College London

Dr Trish Greenhalgh,
Royal Free and University
College Medical School

Dr Melanie Lee,
Celltech Chiroscience Ltd

Alasdair Liddell (until May
2000),

Dr Penny Dash (from May
2000),
Department of Health

Professor Alex Markham,
St James' University Hospital,
Leeds

Professor Paul Matthews,
University of Oxford

Peter McPartland,
Schroder Ventures Life Sciences

Dr Gill Samuels,
Pfizer Global Research
and Development

Professor Alan Suggett,
Smith and Nephew Plc

Stephen Withers,
BUPA Ltd

Oliver Wells,
Association of British Healthcare
Industries

Tony Woolgar,
Pinderfields and Pontefract
Hospitals NHS Trust

HEALTHCARE TASK FORCES

PUBLIC AND PATIENTS

Peter Cardy (Chair),
Chief Executive, MS Society

Ms Sarah Boseley,
Health Correspondent
The Guardian

Ms Maxine Bullen,
West Kent Health Authority

Professor Jessica Corner
Institute of Cancer Research
Royal Marsden Hospital

Dr Angela Coulter,
Chief Executive,
Picker Institute Europe

Professor John Durant,
Director, Science Museum

Barry Hassell,
Chief Executive,
Independent Healthcare
Association

Paul Jenkins,
NHS Direct Project Manager,
NHS Executive

Ms Clara Mackay,
Consumers' Association

Simon Merritt,
Marketing Director,
Crookes Healthcare Ltd.

Professor Tony Moffat,
Chief Scientist,
Royal Pharmaceutical Society
of Great Britain

Nick Partridge OBE,
Chief Executive,
The Terrence Higgins Trust

Dr June Raine,
Director, Post-Licensing,
Medicines Control Agency

Mrs Barbara Stocking,
Regional Director,
NHS Executive South East

INTERNATIONAL INFLUENCES ON HEALTH AND HEALTHCARE

Professor Andy Haines (Chair),
Department of Primary Care &
Population Sciences,
Royal Free University College
Medical School

Professor Sarah Curtis,
Department of Geography,
Queen Mary and Westfield
College

John Eversley,
Public Policy Research Unit,
Queen Mary & Westfield
College

Dr Trish Greenhalgh,
Department of Primary Care &
Population Studies,
Royal Free & University College
Medical School

Professor Martin McKee,
Health Services Research Unit,
London School of Hygiene &
Tropical Medicine

Dr Mary O'Mahony,
Department of Health

Dr Claudia Garcia Moreno,
World Health Organisation

Dr Ian Roberts,
Director, Child Health
Monitoring Unit
Institute for Child Health

Clive Smee,
Chief Economic Advisor
Department of Health

Professor Andrew Webster,
Science & Technology Studies
Unit,
University of York

OLDER PEOPLE

Professor Tom Kirkwood (Chair),
Institute for the Health of the
Elderly,
University of Newcastle

Professor Carol Baxter,
HeBES, University of Middlesex

Professor Graham Collingridge,
Department of Anatomy,
University of Bristol

Professor Martin Ferguson Pell,
Centre for Disability Research
& Innovation,
University College London

Professor Astrid Fletcher,
Director, Centre for Ageing and
Public Health, London School of
Hygiene & Tropical Medicine

Dr Eric Grunwald,
Group Strategy Director, BUPA
Ltd

Dr David Kipling,
Department of Pathology,
University of Wales College
of Medicine

Mrs Elizabeth Mills,
Director, Research into Ageing

Dr Myfanwy Morgan
Department of Public Health
Sciences, Kings College London

Professor Graham Mulley,
Department of Geriatric
Medicine, St James University
Hospital, Leeds

Professor Maggie Pearson,
NHS Executive

Ms Suzanne Riley,
Women's Royal Voluntary
Service

Professor Angus Walls,
Department of Restorative
Dentistry,
University of Newcastle

David Walden,
Head of Social Care
Policy, Department of Health

Professor Gordon Wilcock,
Department of Care of the
Elderly,
University of Bristol

**ORGANISATION AND
DELIVERY
OF HEALTHCARE**

Professor Mike Pringle (Chair),
Chairman,
Royal College of General
Practitioners

Bob Abberley,
Director, Healthcare,
UNISON

Dr Carol Dezateux,
Department of Epidemiology
and Public Health,
Institute of Child Health

Dr Jennifer Dixon,
Kings Fund

Dr Alison Hill,
Director Effective Practice
Programme,
Kings Fund

Dr Raymond Jankowski,
Chair, National Public Health
Primary Care Group,
East and North Hertfordshire
Health Authority

Professor Glyn Lewis,
Division of Psychological
Medicine,
University of Wales College of
Medicine

Dr Tom Ling,
Anglia Polytechnic University

Professor James Raftery,
Director, Health Economics
Facility,
University of Birmingham

Professor Pankaj Vadgama,
IRC in Biomedical Materials,
Queen Mary and Westfield
College

Dr Andrew Vallance Owen,
Group Medical Director,
BUPA Ltd

Tony Woolgar,
Chief Executive,
Pinderfields and Pontefract
Hospitals NHS Trust

Professor David Yates,
Hope Hospital,
University of Manchester

INFORMATION

Dr Richard Smith (Chair),
Editor
British Medical Journal

Professor Anne Anderson,
Department of Psychology,
University of Glasgow

Professor Norman Black,
Director, Northern Ireland
Bioengineering Centre,
University of Ulster

Professor Don Detmer,
The Judge Institute of
Management Studies,
University of Cambridge

Dr Peter Drury,
Head, Information Policy Unit,
Department of Health

Bob Gann,
Director, Help for Health,
Centre for Health Information
Quality

Paul Garner,
BT Advanced Research &
Technology,
BT Laboratories

Muir Gray,
Project Director,
National Electronic Library for
Health

Dr Robin Hopkins,
Haldon House Surgery, Exmouth

Dr John Lackie,
Vice President R & D Strategy,
Yamanouchi UK Ltd.

Professor Chris Taylor,
Chairman UKIHI, Department of
Medical Biophysics,
University of Manchester

Stephen Withers,
Director, European Affairs,
BUPA Ltd

Dr Jeremy Wyatt,
School of Public Policy,
University College London

DELIVERING THE PROMISE OF THE HUMAN GENOME

Professor John Bell, (Chair)
Institute of Molecular Medicine
University of Oxford

Dr Naomi Brecker,
Health Services Directorate,
Department of Health

Professor Dian Donnai,
Department of Medical
Genetics and Regional Services,
St Mary's Hospital, Manchester

Professor Gordon Duff,
Director, Division of Molecular
and Genetic Medicine,
University of Sheffield Medical
School

Dr Ros Eeles,
Institute of Cancer Research

Alastair Kent,
Director
Genetics Interest Group

Dr Melanie Lee,
Research Director,
Celltech Chiroscience Plc

Professor Alex Markham,
Director, Molecular Medicine
Unit,
St James University Hospital,
Leeds

Professor Jean McHale,
Faculty of Law,
University of Leicester

Professor Peter McGuffin,
Director, Social, Genetic and
Developmental Psychiatry
Research Centre,
Institute of Psychiatry

Dr Andy Mountain,
Director, R&D,
Cobra Therapeutics

Dr Nigel Spurr,
Director, Biotechnology and
Genetics,
SmithKline Beecham
Pharmaceuticals

Dr Neil Sullivan
Complement Genomics Ltd

PHARMACEUTICALS, BIOTECHNOLOGY AND MEDICAL DEVICES

Dr Sue Foden (Chair),
Director of Technology,
Merlin Ventures Ltd

Professor David Delpy,
Department of Medical Physics
and Bioengineering,
University College

Dr Jeff Kipling,
Director of Science and
Technology, ABPI

Professor David Lane,
Department of Biochemistry,
University of Dundee

Professor Richard Lilford,
Director of Research &
Development,
NHS Executive, WM Regional
Office

Andrew McKeon,
Head of International and
Industrial Division,
Department of Health

Peter McPartland,
Schroder Ventures Life Sciences

Dr Gillies O'Bryan-Tear,
Medical Director,
Bristol Myers Squibb

Dr Gill Samuels,
Senior Director Science
Policy and Scientific Affairs,
Europe, Pfizer Global Research
and Development

Professor Michael Smith,
Dean of Research for Medicine,
Dentistry, Psychology and
Health
University of Leeds

Dr Trevor Twose,
Chief Executive,
Twose and Company

Dr Anthony Walker,
Chief Executive,
Onyvax Ltd

Dr Barrie Ward,
Chief Executive,
Kudos Pharmaceuticals

Oliver Wells,
Association of British Healthcare
Industries

NEUROPSYCHIATRIC HEALTH

Professor Sir David Goldberg
(Chair),
Institute of Psychiatry

Harry Cayton,
Chief Executive,
Alzheimer's Society

Ms Judi Clements,
Chief Executive
MIND

Dr Colin Dourish,
Research Director,
Cerebrus Limited

Dr Rebecca Fuhrer
Department of Epidemiology
and Public Health,
University College London

Professor Susan Greenfield,
Director of the Royal Institution
of Great Britain

Dr Ray Hill,
Neuroscience Research Centre,
Merck Sharp and Dohme
Research

Professor Peter Huxley,
Institute of Psychiatry

Professor Eve Johnstone,
Head of Department of
Psychiatry,
University of Edinburgh

Professor Martin Knapp,
Director, PSSRU,
London School of Economics

Dr Paul Lelliott,
Director of Research,
Royal College of Psychiatrists

Professor Paul Matthews,
Director, Oxford Centre for
Functional Magnetic Resonance,
Imaging of the Brain, University
of Oxford

Daniel Nadis,
Chief Executive,
Ultramind Group plc

Professor Nick Tarrier,
Department of Clinical
Psychology,
University of Manchester

TRANSPLANTATION

Professor Andrew Bradley
(Chair),
Department of Surgery,
Addenbrookes Hospital,
University of Cambridge

Dr Nik Brown,
Science & Technology Studies
Unit,
University of York

Dr Robert Brown,
Department of Plastic &
Reconstructive Surgery and
Tissue Repair Unit,
University College London

Professor John Clark OBE FRSE,
Roslin Institute, BBSRC

Professor Adam Curtis,
Department of Cellular
Engineering,
University of Glasgow

Dr Peter Doyle,
Department of Health

Professor John Fabre,
Institute of Liver Studies,
Kings College Hospital

Professor Tim Hardingham,
Wellcome Trust Centre for Cell
Matrix Research,
University of Manchester

Professor David Linch,
Department of Haematology,
University College London

Professor Alan Suggett,
Group Director of Technology
Smith and Nephew Plc

Mr John Wallwork,
Director of Transplantation
Service,
Papworth Hospital

Dr David White,
Director of Research,
Imutran Ltd

SECRETARIAT

Tim Willis

Elaine Nichols

Barbara Djangmah

Office of Science and
Technology

The Foresight Programme

The UK Foresight programme brings together the voices of business, government, the science base and others to look at what might happen in the future and what we need to do now to secure long-term competitive advantage and enhanced quality of life for all.

The programme was launched in 1993 following the Government White Paper on science, engineering and technology, *Realising our Potential*. It has a panel-based structure and operates on a five-year cycle. The current round of Foresight began in April 1999 and work has been carried forward through three thematic and ten sectoral panels.

Each Foresight panel looks at the future for a particular area, identifying the challenges and opportunities that the country is likely to face over the next ten to twenty years and beyond. In doing so, Foresight aims to bring about a culture change for the better in the way organisations relate to each other and to the future.

All panels consider the implications of their conclusions for education, skills and training and sustainable development.

This report - and those of the other panels - represent the culmination of over a year's intensive research, debate and discussion. They provide the basis from which panels and others will work to help turn the recommendations into action.

Foresight panels:

- | | |
|---------------------------------|---------------------------------------|
| ■ Ageing Population | ■ Financial Services |
| ■ Crime Prevention | ■ Food Chain & Crops for Industry |
| ■ Manufacturing 2020 | ■ Healthcare |
| ■ Built Environment & Transport | ■ Information, Communications & Media |
| ■ Chemicals | ■ Materials |
| ■ Defence, Aerospace & Systems | ■ Retail & Consumer Services |
| ■ Energy & Natural Environment | |

A further industry-led panel is looking at Marine issues and there is a task force addressing the impact of E-commerce on business processes and supply chains.

Copies of the full reports for all panels are available from the Foresight web site at www.foresight.gov.uk or by sending a fax to the Office of Science and Technology on: 020 7215 6715.

Foresight also supports an ever-increasing programme of activities for younger people. Further details can be obtained via the fax number above or at www.youngforesight.org and www.visionsonline.org

