The Commission on Representing the Public Interest in the Health Service

In February 1999, ACHCEW announced the setting up of an 'independent commission' to look at how to represent the public interest in the health service. This followed on from the recognition by member CHCs that there needed to be a debate about the future of CHCs, and that this was best put in the context of representing the public interest. A significant amount of work had been done in this area and it was felt that ACHCEW's role, in setting up the Commission, was to provide a forum of different models for the future to be scrutinised, and ways forward in representing the public interest to be identified.

The Commission attracted a wide range of respected and influential members.

The Terms of Reference

To recognise that the ultimate purpose of the NHS is to serve the public interest and to identify the ways in which that public interest can best be served by the achievement of a full and effective system of public accountability.

Members of the Commission

Will Hutton (Chair)

Will Hutton became Editor of the Observer in March 1996 and was Editor-in-Chief of the Observer since July 1998.

He joined the Guardian in 1990 as Economics Editor and was appointed Assistant Editor in 1995. A former stockbroker, he spent ten years at the BBC where he worked from 1978 1988. Will Hutton's positions included Economics Correspondent for Newsnight (1983-1988),

Producer and Director of the Money Programme (1981-1983) and Senior Producer on The Financial World Tonight (1978-1981). He was Editor-in-Chief for the European Business Channel from 1988-1990.

Will Hutton was awarded 'Political Journalist of the Year' by Granada TV's What The Papers Say for his coverage on the 1992 ERM crisis.

His book The State We're In was first published in 1995 and has sat high on the best-seller list ever since. It is widely regarded as a highly important book earning Will Hutton headlines such as 'why this book is such a danger?'

Will Hutton is a member of the governing council of the Policy Studies Institute and is governor of the London School of Economics. He is also chair of the Employment Policy Institute, a think tank on employment matters.

Professor Conor Gearty

Conor Gearty was Professor of Human Rights Law at King's College London and a Barrister at Essex Court Chambers. He was the author of numerous books and articles on human rights and civil liberties, including (with KD Ewing) Freedom Under Thatcher; Civil Liberties in Modern Britain (1990); His Struggling Against the State: Civil Liberties and the Rule of Law in Britain, 1914-45, co-authored with KD Ewing, will be published this Summer by OUP.

Susie Parsons

Susie Parsons was the Chief Executive of the Commission for Racial Equality.

Susie Parsons' work experience spanned the health service, local government and the voluntary sector. Having begun her working life as a teacher of French in an inner-city school in London, Susie Parsons subsequently held the posts of Director of Community Education for Shelter, Housing Projects Officer at North Kensington Law Centre,

Secretary to Paddington and North Kensington Community Health Council, General Manager of the London Energy and Employment Network and Head of Press, Publicity and Information for the London Borough of Hackney.

She was appointed to the post of Executive Director of London Lighthouse in September 1994 and became its Chief Executive in January 1997.

Professor Allyson Pollock

Allyson Pollock was head of the Health Services and Health Policy Research Unit at the School of Public Policy, University College London, and Director of Research and Development at University College London Hospitals Trust.

She trained in medicine in Scotland and worked in hospitals in Edinburgh and Leeds before moving to London. She had worked in London since 1987 and had extensive senior experience of working in health authorities in Newham, Tower Hamlets, Hackney, Camden & Islington and Merton, Sutton & Wandsworth.

She spent a year in the United States in 1995-6 as a Harkness Fellow. She was published widely on a number of areas including health policy, rationing, cancer epidemiology, information and statistics and long-term care.

Joyce Struthers

Joyce Struthers was elected Chair of the Association of Community Health Councils for England and Wales (ACHCEW) in July 1998. She is ACHCEW's representative on the Management Board of the BMA's Doctor/Patient Partnership and on the Middlesex University Ethical Committee for the Practice of Traditional Chinese Medicine.

Joyce Struthers served as a generalist member of North Bedfordshire Health Authority from 1985 to 1989. Shortly afterwards, she became a

member of the North Bedfordshire Community Health Council, which she chaired from 1992 to 1996. She was a Marriage Guidance (now Relate) counsellor from 1971 to 1983, a voluntary worker in the Bedfordshire Divorce Conciliation Service from 1982 to 1994 and Vice President of Bedfordshire Care Support Network for People with Learning disabilities from 1989 to 1997.

Joyce Struthers worked as an approved Lay Assessor with the Quality Control and Inspection Unit of Bedfordshire County Council's Social and Community Care Department. She was the CHC observer on the Bedfordshire Joint Planning Team for Mental Health Services and the Bedfordshire County Council Quality Control Advisory Committee.

Stephen Thornton

Stephen Thornton had been Chief Executive of the NHS Confederation from December 1997. He had previously been Chief Executive of Cambridge and Huntingdon Health Authority since 1993.

His NHS career began in 1979 when he was recruited to the National Graduate Management Training Programme. He trained at Manchester Business School and held a number of hospital appointments in the Manchester/Salford area before moving to Cambridge in 1983 to take up post of Administrator at Fulbourn Hospital. In 1985 he became one of two hospital level General Managers in the Authority. He was responsible for managing services for mentally ill people, people with learning difficulties, general community health services, and health promotion services.

He moved to the East Anglian Regional health Authority in June 1989 initially as head of Corporate Development to lead the Region's implementation of the 1990 Reforms, where he co-directed the "Rubber Windmill" simulation exercise, winner of the European Health Care Management Association award for excellence in management. He subsequently held the posts of Director of Performance Management and Director of Planning at the RHA.

Stuart Weir

Stuart Weir was Senior Research Fellow in Democracy and Human Rights at the University of Essex; Director of the Democratic Audit at the University of Essex; an international Consultant and Training Adviser on the Consolidation of Democracy and Human Rights; and an active academic and journalist. He is currently engaged on a project to measure democracy country-by-country throughout the world for International IDEA (Institute for Democratic and Electoral Assistance). He was also an Associate Consultant to the British Council.

The Democratic Audit had published 18 reports on democratic matters, some of which Stuart Weir authored and all of which he edited. The most influential of these have been three reports on quangos, or para-statal organisations, in the United Kingdom, one of which was published jointly with Channel 4 TV, which broadcast a documentary, Behind Closed Doors, based on the Audit's researches.

Evidence for the Commission was received from the following organisations ...

Age Concern England . Bedfordshire Health . Blackburn, Hyndburn and Ribble Valley Health Care NHS Trust . British Medical Association . Bromley Health Authority . Cheltenham and Gloucester College of Higher Education . City & Hackney Community Services NHS Trust . Communications Forum . Cornwall Healthcare NHS Trust . Dacorum Hospital Action Group . Dorset Health Authority . Dyfed Powys Health Authority . East Kent Community NHS Trust . East Kent Hospitals NHS Trust . General Dental Council . General Medical Council . Harlow Primary Care Group . Kingston and District Community NHS Trust . Liverpool Health Authority . Medical Protection Society . Mencap - the Royal Society for Mentally Handicapped Children and Adults . National Aids Trust . National Children's Bureau . National Consumer

Council . National Health Service Consultants' Association . NHS Cymru Wales/Welsh Office . NHS Executive North West . NHS Executive South East . NHS Support Federation . Norfolk Mental Health CareNHS Trust . North & East Devon Health Authority . North Essex Health Authority . Nottingham City Hospital NHS Trust . Oldham NHS Trust . Pain Concern (UK) - Lothian Group . RADAR The Disability Network . RNIB-Royal National Institute for the Blind . Royal College of General Practitioners . Royal College of Nursing . Royal College of Paediatrics and Child Health . Royal College of Physicians . Salford and Trafford Health Authority . Sefton Council . Sefton Council for Voluntary Service Sefton Health . The Haemophilia Society . The Long Term Medical Conditions Alliance . The Relatives and Residents Association . The Royal College of General Practitioners . The Royal College of Midwives . The Royal Orthopaedic Hospital NHS Trust . The Royal Society for the Promotion of Health . UKCC . UKPHA - UK Public Health Association University of Essex . W.A.T.C.H - Watford Against Threats to Close Hospitals . West Hertfordshire Health Authority . West Kent Health Authority . West Surrey Health . West Sussex Health Authority . Weston Area Health Trust

Individuals

Alan Bedford . Albert Weale . Caroline Nichols . Evelyn Mc Ewen . Guy Daly\Howard Davis . John Pearson . John Walsh . Lynda Bagley . Margaret Tozer . Martyn Smith . Mick Rolfe, Howard Lawes, Denise Holden . M.C.T. Morrison Steve Turner . Terry Ewington . Donald Roy

Community Health Councils

Airedale . Anglesey . Association of West Midlands CHCs . Association of Welsh CHCs . Barnsley . Basingstoke & North Hampshire . Bath & District . Bristol &

District . Bromley . Bury . Cambridge . Canterbury and Thanet . Central Lincolnshire . CHC Development Association . Cheshire . Central Chester & Ellesmere Port . Croydon . Coventry Darlington and Teesdale . Dewsbury District . Doncaster . Dudley . East Birmingham . East Dorset . East Herts . East Suffolk . Exeter and District . Eastern Regional Association . Great Yarmouth and Waveney . Greenwich . Gloucestershire . Haringey . Harrogate & District . Hillingdon . Kensington & Chelsea and Westminster . Kidderminster and District . Leeds . Leicestershire . Lewisham . Medway & Swale . Mid Downs . Newcastle . Northallerton District . North Bedfordshire . North Birmingham . North East Essex . North East Wales . North East Warwickshire . North Devon . North Gwent . North Tyneside . Northamptonshire North . North Staffordshire . North Tyneside . North West Anglia . North West Regional Association . North West Surrey . Oxfordshire . Preston . Plymouth and District Pontefract and District . Regional Association of London CHCs . Richmond and Twickenham . Salford . Scarborough & North East Yorkshire . Sheffield Society of CHC Staff . Solihull . South Birmingham . Somerset . South East Regional Association of Community Health Councils . Southend District . Southern Derbyshire . South Warwickshire . South West Association of Community Health Councils . South West Surrey . Tameside & Glossop . Trafford . Trent Regional Association of CHCs . Tower Hamlets . Wakefield . West Dorset . West Essex . West Midlands Association of Chief Officers . West Suffolk . West Surrey & North East Hampshire . Winchester & Central Hampshire . Worcester District

Department of Health/NHS Executive (NHSE)

The Department of Health is headed by the Secretary of State, supported by Ministers and the NHS Policy Board. This Board is responsible for providing independent policy advice and supporting the Secretary of State in holding the NHS Executive to account for its management of the NHS. Members of the Board come from within and outside the NHS.

The NHSE is the operational wing of the Department of Health. It is headed by the Chief Executive of the NHS, who is the principal policy adviser to the Secretary of State on all matters relating to the NHS. The remainder of the board of the Executive is made up of the directors of the Regional Offices and all NHS Executive directors.

Eight Regional Offices, staffed by civil servants, act as local agents of the NHS Executive. The Regional Offices are responsible for monitoring the performance of purchasers and providers, and managing the implementation of national NHS policies and priorities, and overseeing the commissioning of regional specialities. In addition the Regional Offices are responsible for the establishing arrangements Community Health Councils.

Regional Health Authorities - RHAs (until 1 April 1996) Each RHA had a Chair and five non-executive members appointed by the Secretary of State together with up to five executive members. Two of the executive members, the general manager and the chief finance officer, were ex-officio members. The remainder were appointed by the Chair and non-executives together with the general manager. The RHA was accountable to the Secretary of State.

Accountability of the Department of Health The Secretary of State is accountable to Parliament for the actions of the Department of Health and the provision of a National Health Service.

The House of Commons Health Committee is able to examine the expenditure, administration and policy of the Department of Health and

associated public bodies. It consists of a number of Members of Parliament with membership reflecting the overall number of MPs in each political party.

The public Accounts Committee of the House of Commons, supported by the Comptroller and Auditor General and the National Audit Office calls the NHS to account for the way the NHS budget is spent. The Audit Commission is an independent statutory body that audits NHS and local government spending and examines value for money in the use of resources.

The Health Service Ombudsman has responsibility and powers to investigate charges of maladministration in the NHS and will take up complaints from members of the public when these fall into the remit of the Ombudsman's office. The Ombudsman publishes the results of these enquiries and is required to report to the House of Commons Public Administration Committee.

Health Authorities

Health authorities' key tasks are:

- Assessing the health needs of their local population
- Drawing up strategies for meeting those needs
- Determining local targets and standards to drive up quality and efficiency in the light of national priorities and guidance Supporting Primary Care Groups/Local Health Groups in their area, allocating their resources and holding them to account

The health authority has a lay Chair appointed by the Secretary of State and a Board of executive and non-executive members. The non-executive lay members have a majority on the Board. Each health authority is accountable to a Regional Office or the Welsh Office for carrying out its statutory functions.

Special Health Authorities

Special Health Authorities (SHAs) administer some NHS services in England, for example, National Blood Authority. They are accountable directly to the Secretary of State.

Trusts

The Boards of Trusts are made up of executive and non-executive directors. The Regional Offices monitor the performance of Trusts. Trusts are required to hold their Board Meetings in public.

Primary Care Groups As sub-committees of health authorities PCG Boards are accountable through their Chair to the Chief Executive of the health authority. PCGs are required to take a number of measures, for example, produce annual accountability agreements in order to promote a measure of openness and accountability.

Commission for Health Improvement A Commission for Health Improvement will be established to oversee clinical governance. It will offer an independent guarantee that local systems to monitor, measure and improve clinical quality are in place and will be able to intervene on the direction of the Secretary of State or by invitation from PCGs, health authorities and Trusts.

Northern Ireland

In Northern Ireland the Department of Health and Social Services (DHSS) is required to secure the provision of an integrated service designed to promote the health and social welfare of the population. The DHSS's Health and Social Services Executive (HSSE), headed by a Chief Executive supported by six directors, is responsible for overseeing the delivery of an efficient health and social care service.

Four Health and Social Services Boards act as agents for the DHSS. They have a non-executive Chair, 6 non-executive and 6 executive directors. The non-executive directors are appointed by the Minister but the appointment of the Chair has to be with the approval of the Secretary of State.

Health and Social Services Trusts (HSS Trusts) provide health and social services. Each is managed by a Board that has up to five non-executive directors and a non-executive Chair who appointed by the DHSS with the approval of the Secretary of State, In addition there are five executive members who are employees of the Trusts.

Health and Social Services Councils perform similar functions to Community Health Councils in England and Wales.

Scotland

The Scottish Parliament is responsible for the NHS in Scotland. Members of the Scottish Parliament will decide how they wish to work, so it is not yet clear how they will exercise their powers to make legislation. They have, however, recently established a Health and Community Care committee.

As is the case with the Welsh Assembly, the Scottish Parliament will determine its relationship with public bodies, including health boards/authorities and Trusts. They will appoint, fund, direct and hold all public bodies to account. At the present time health boards are accountable to the Scottish NHS Management Executive and Trusts report to the Secretary of State through the Management Executive.

Wales

In Wales there is no intermediate management tier. The five health authorities work directly with the Welsh Office Health Department in policy and management areas. Accountability is via performance

agreements and an annual review.

The Welsh Assembly will be responsible for decision-making but will not have primary legislation powers. They will have powers to make secondary legislation.

The Foreword

The NHS was founded to deliver free and equal access to comprehensive health care - one of the great leaps forward of the century, both in promoting the nation's health and entrenching social citizenship. The NHS retains its national mandate: to provide the same care to every British citizen irrespective of location or income, financed by general taxation and publicly owned and accountable. Ever since its foundation it has commanded extraordinary popular affection and loyalty. Its medical and non-medical staff alike has been strongly committed to its success and values. Indeed they have been one of the NHS's strongest and most enduring assets.

However, there is now a gap opening up between what the NHS is able to deliver and the expectations and needs of its users. The stress signals vary. Complaints, for example, are growing across the system; the bill for clinical negligence suits is £2.8 billion and climbing; and there are widespread and popular campaigns against hospital closures. The groundswell of criticism and unease is backed by recent opinion poll evidence, indicating that the NHS is widely thought to be deteriorating.

There are three main reasons for these disturbing trends. First, funding for the NHS has never kept pace with need. Governments have sought to manage this problem by redefining what the NHS provides, so eroding the principles of comprehensive care and services free at the point of delivery. A growing number of services - NHS dentistry, optical services, some routine elective care and the majority of long term care services - that used to be provided by the NHS have in effect been privatised and left to individuals to fund. Within the NHS rationing has

increased, but the criteria vary between health authorities. At the same time there is a consistent inability to raise standards of provision in line with the public's rise in living standards and its accompanying expectations.

The second reason is closely related to the first. Important inequalities have followed the introduction of the internal market. Aiming to devolve decision-making and responsibility to promote efficient resource allocation, the consequence of the new structure was the introduction of major inequalities between local NHS providers and fund and non-fund holding GPs. The new Labour government recognises these deficiencies but its 1999 Health Bill only partially addresses the problem. The financing of new hospital construction through the Private Finance Initiative (PFI) will lead to the progressive privatisation of the NHS's infrastructure. The new Primary Care Groups (PCGs) and Primary Care Trusts (PCTs), who are to run integrated, unified budgets for the total health care in their areas, will be placed under intense financial pressure to continue contracting out and privatising further services. Inequity will thus be built into the NHS's core structure.

But the third reason for the gap, and which directly concerns this Commission, is the erosion of the democratic structures and mechanisms within the NHS that protect the public interest. This has coincided with the increasing insistence, in all walks of British life, on more accountability, more information and higher standards in decision-making and subsequent execution. The NHS as a major British national institution is inevitably exposed to the full force of these developing trends. The government seeks to address the issue through regulation and regulatory structures. But in the absence of adequate, strong democratic structures the public is increasingly using the NHS's inadequate complaint mechanisms or even the courts to seek redress of grievances; a development that is bound to increase further when the Human Rights Act (1998) becomes operational. It is a trend that could ultimately undermine the capacity for rational, collective decision-making that is properly at the heart of the NHS.

The principal route in a democracy to close this kind of trust gap

between the public and the institution is to promote its accountability and thereby secure its legitimacy. The more accountable the NHS, the more the public's sense of its ownership and the more it is legitimate. However, although the NHS's accountability has been debated ever since the service's launch the issue has never been satisfactorily resolved. In general the approach has been that the Secretary of State or minister responsible for health is accountable to the public via the House of Commons, with all the strengths and weaknesses of the British system of parliamentary accountability (in Scotland and Wales accountability has been devolved to their respective health ministers and assemblies). Over the NHS's history there have been a variety of regimes in which decision-making has been delegated to regional and local level with a varying readiness to incorporate external voices and assert some degree of accountability, but no settled system has been established. In addition there are ad hoc independent inquiries and review panels in response to individual problems and public concerns, and there is a complaints procedure for individual cases. But all are un-backed by any framework of patient rights. In sum the system of accountability is the weakest since the NHS's launch in 1948. It is the least accountable of Britain's major public institutions even though access to health is the prime concern of British citizens. This democratic deficit in the NHS has been widened by recent changes to its structure and is likely to widen still further as the next round of change takes effect.

There is only one formal mechanism for giving voice to the concerns of patients and families - the Community Health Councils (CHCs). But recent structural changes have removed the regional health authorities and downgraded the district health authorities with which they have had formal links. They have no such links with the new Primary Care Groups, which are being set up to drive the re-shaped NHS onwards at the local levels at which CHCs work. CHCs have also in practice acted as local agencies for the redress of grievances, alongside the Parliamentary Commissioner for Health at national level, and they have continued to do so even after the advent of the Patients' Charter. But this has always been an informal, if invaluable, role, and their ability to fulfill it is now even more constrained than previously ever.

The system of accountability in the NHS now needs to be reviewed, overhauled and improved. However, this is not just a question of trying to re-legitimise the NHS and offer patients a more streamlined and effective system for the redress of grievances. It goes to the heart of the rationality of NHS decision-making, and thereby to its efficiency and effectiveness as the nation's provider of health care. It could not be more fundamental.

This Commission was established in March 1999 by the NationalAssociation of Community Health Councils for England and Wales (ACHCEW) in order to examine the issue of the public interest and accountability in the NHS. Although launched by ACHCEW it is fully independent, and its mandate has offered it a wide remit. Our terms of reference are: " In recognising that the ultimate purpose of the NHS is to serve the public interest, to identify the ways in which that public interest can best be served by the achievement of a full and effective system of accountability". (See Annex 1 for membership of the Commission)

What follows is our interim report, representing our thinking after three months of analysis, discussion, research and written and oral evidence and which signals the direction and shape of our final report. It is work in progress, and we have deliberately come to no firm conclusions. However readers will see that we are beginning to establish a relationship between better accountability, more equity and increased economic efficiency,. This will mean not merely a reduction in complaints and lawsuits but also better decision-making and resource use. We are anxious that our work in the next six months should reflect the real concerns and preoccupations of those who work in and use the NHS, and also, of course, the anxieties of the wider civil society. We welcome the views of those any person or associations who can help us advance the discussion and improve our analysis and eventual recommendations. We thank the nearly 200 organisations and individuals who have already submitted evidence (See Annex 2); we very much appreciate the effort and work that has been made to help us so far.

Setting the Scene

The NHS is the outstanding example of a successful public institution. Despite this it has suffered from systematic underfunding throughout its history and has never resolved the tensions over how it should be properly accountable to its users and the wider public. Formally, the Secretary of State for Health is responsible for running the NHS and making its policy in England, and in theory she or he is accountable to the House of Commons, and through MPs, to the electorate. Within the Department of Health, an NHS Executive is responsible for the day-to-day administration of the service. Senior civil servants at the Department of Health Richmond House formally advise the Health Secretary and ministers on major decisions over health priorities, spending, pay and managerial issues, but in effect often take such decisions themselves. The Health Service Commissioner acts as an external ombudsman reporting to parliament over complaints and best practice, and the National Audit Office and the Public Accounts Committee of the House of Commons scrutinise the use of public funds.

However, the Health Secretary alone is the formal guardian of the public interest in the NHS. Scotland and Wales have won powers with devolution to decide on different health priorities from Westminster, but within an overall "block" allocation of spending decided by the Treasury. In addition Scotland has the power to introduce primary health legislation. The arrangements in Northern Ireland have yet to be finalised, pending the establishment of the new constitutional settlement if a peace agreement can be achieved.

Representations by interested organisations are made to the Secretary of State, who is responsible for the establishment of the public interest in health care. Yet while overall spending decisions are made centrally, resource allocation decisions within broad parameters are actually made locally by health authorities, a role soon to be assumed by Primary Care Groups and Trusts. This results in, for example, the inequities thrown up by post-code prescribing where eligibility for treatment depends on the

health authority area in which you live.

The public is ever more ready to debate whether the right decisions over health are being made, and to challenge them when it considers they are not. There has, for example, been a resurgence of local campaigns against proposed hospital closures. This has risen in part from deep trends in British society and culture:; individuals are much more ready to challenge authority, to insist on redress of grievances and to resort to law to pursue their rights. No longer can doctors, clinicians, health managers and politicians decide what they consider to be the public interest in health to be behind closed doors with only nominal consultation, and expect their decisions to remain unchallenged. The case of Child B_ is just one example where a health authority's judgement about health priorities was challenged in the courts; the growing number of patient complaints is another. The man or woman from Whitehall, the local health manager and even the surgeon is no longer felt to always know best.

This trend interacts with a growing insistence that health care must correspond to the best available practice. Whether in faulty breast screening or surgical mishaps, the public is no longer willing to be docile about medical mistakes. It wants compensation and bad doctors struck off the register. It wants proper investigation into mistakes, and recommendations about reformed procedures to be transparently and rapidly put in place. Patients are increasingly willing to protest about poor care - ranging from admissions procedures to treatment and convalescence.

The rapid pace of drug, technological advance and surgical development has opened up new medical possibilities and increased the cost pressures upon the NHS. A richer population expects to see public health care matching the same standards, wealth and choice that are available in the private sector, while remaining profoundly attached to the NHS as a public institution. It does not view private insurance or privatisation of health care as desirable alternatives to the tax-financed NHS. The judgements by health professionals and ministers are being challenged and increasingly contested in areas ranging from gender reassignment to

cancer treatment.

There is also growing concern about health inequalities, exacerbated by wider inequalities in society and the power of particular lobbies and corporate power to secure their interests. The drug company Pfizer, for example, recently successfully challenged the capacity of the Health Secretary to issue blanket instructions to GPs to stop them from prescribing Viagra; instead such instructions now have to be legally executed by changing regulations to schedule the drug.

The emergence of a few very powerful drug companies and their capacity to influence clinical priorities and treatments is one problem; another is how powerful single-issue lobby groups have managed to secure scarce resources while others - mental health, for example - remain Cinderellas. Health experience has always been closely related to income, but the current levels of income inequality are now generating widening and alarming health inequalities. It is well established that the middle classes benefit most from the clinical and other care that the NHS offers as well as being generally more healthy than less well-off groups in society. Yet at the same time the service benefits from their more demanding and critical evaluation of its standards of care. One of the dangers of the emerging crisis is that they may be driven more and more into the private sphere, except for the most acute services, leaving most of the NHS as a second-rate rump. How can the NHS remain a truly national service, serving all the British people, while its services and care are also more equally distributed - and more is done to raise the health standards of working class people and disadvantaged groups?

These are not the only concerns the government must satisfy. There is a growing range of high visibility issues with health implications ranging from the recent BSE crisis to the debate over the potential dangers of genetically modified foods. The difficulty is that the government is suffering the other side of the coin of the accountability and legitimacy gap; it is simply no longer believed or trusted on such issues. The judgements of government scientists are disputed, and even routine warnings to asthma sufferers over potential smog risks are regularly ignored.

In short, a gap has opened up between government and citizen over health care that urgently needs to be closed. The NHS needs to be more accountable, not just to improve its legitimacy, but also to ensure that its decisions correspond to those that the community wishes to make for itself. - and where there are divergences it should to open up a debate that allows everybody to be educated about the issues. A number of submissions to the Commission from professional associations in the NHS have stressed their concern that patients need to be better informed about health issues, so that they understand, for example, the consequences of "no-shows" for appointments or inappropriate abuses of the system. While there has been a general welcome for Patients' Charters as a way of raising the awareness of the public about their rights in the NHS, some NHS staff and professionals have voiced dissatisfaction. There is no reciprocal requirement on patients to use the NHS responsibly and it is felt that they encourage patients to have unrealistic expectations. There is no requirement on patients to, for example, let health staff know if appointments cannot be kept, return equipment when it is no longer needed, or inform their surgery when they change address.

There is a more general official concern that "Do Not Attends" (DNAs), which in some parts of the NHS constitute up to 20 per cent of appointments, are raising costs and represent a casual attitude by patients towards their own responsibilities, suggesting the public is too feckless to deserve more empowerment. However, research_ _ shows that while "forgetting" plays an important part in DNAs, forgetfulness is in part explained by long waiting times, poor systems for telling and reminding patients of their appointments and difficulties encountered in trying to cancel appointments - general system failures. Some hospital initiatives to reduce DNAs have been abandoned because they are not cost-effective. The numbers of hard core offenders is small. DNAs do not undermine the case for making the NHS more accountable; rather they reinforce it.

For their part, patients increasingly refuse to be treated as subjects of a paternalistic health service; they want voice, influence over decisions

that affect them and redress for their grievances. They want the NHS to look out for their individual concerns. There is a growing temptation to turn to the courts and the language of human rights to fill the gap.

There is no doubt that the concept of individual rights has a valuable role to play in securing justice and fairness in particular cases in the National Health Service. There might well also be occasions where the assertion of rights such as the right to life or the right to security of the person (both to be found in the Government's recently enacted Human Rights Act) provide an important means of improving the quality of NHS provision for the general public. But it would be a mistake to see reliance on the courts and human rights as a substitute for thinking hard about issues of principle relating to the public interest and to the proper accountability and therefore the legitimacy of the National Health Service. The assertion of individual rights through litigation is no substitute for the expression of the public interest through collective decision-making rooted in democratic choices, thoroughly canvassed social preferences and with built-in checks, balances and processes of accountability.

The Management and Governance of the NHS

How the NHS is run

The NHS has been organised since its foundation as a top-down central bureaucracy in Whitehall. Aneurin Bevan, its founding father, removed health-care from voluntary and local authority hospitals, doctors and others and rather than devolve its running to local authorities along with public housing, he established what was in effect a nationalised service under the direct control of health ministers_. Its district and regional boards were appointed, not elected; though he softened his refusal to offer a democratic course by offering positions on boards to local councillors and trade union officials. Bevan himself soon came to regret this 'defect', saying that 'election is a better principle than selection'.

But none of his successors has ever tried to remedy the defect: rather the reverse. In 1991, this limited local authority representation was removed

from regional and local boards in a radical re-organisation of the NHS, which also established NHS trusts under strictly managerial boards, replacing representative Regional Health Authorities with Regional Offices of the National Health Service Executive. There was no longer any place for the tenuous links with local authorities which the involvement of council members had given the NHS; the trusts and health authorities/districts lost their obligation to accept local councillors and trade unionists. Instead chairmen are appointed by the Secretary of State, with the inevitable accompanying political and business bias.

Before the 1991 reorganisation District Health Authorities consisted entirely of non-executives who were all unpaid and independent. The 1991 reforms created new-style Authorities, half of the Board members were executives and half non-executives, the latter being paid an honorarium of £5,000 per annum. Before 1991 the structure and composition of the Boards had forced executives to convince the whole of the health authority of the rightness of their proposals - and this produced some lively public debates - but after 1991 the will of the executive went largely unchallenged.

With the abolition of the Regional Health Authorities, leaving only a Regional Chairman in theory to represent the public view in high places, the independent public input diminished to vanishing point at that level as well. The Secretary of State and her or his ministers are nominally in charge of all the major policy-making and decision-taking in the service. Below them at the Department of Health Richmond House are two sets of important civil servants: the first set are the departmental bureaucrats who are responsible for policy; the other set work under the NHS chief executive for the NHS Executive and are responsible for the day-to-day running of the service. In practice, of course, these formally separate functions merge into one another.

It is argued that there is a significant filament of accountability in these arrangements. The regional offices, health authorities, trusts and (soon) Primary Care Groups (PCGs), as well as a host of other public bodies, advisory committees, task forces and the like, are all ultimately responsible to the Health Secretary, who is answerable to Parliament for

all their activities. She or he is also in theory responsible for the actions and decisions of all the officials who serve in the NHS, the department and their other public authorities and bodies. The Health Secretary and others come under parliamentary scrutiny through individual MPs, select committees, Parliamentary Questions, the Parliamentary Commissioner for Health, and public audit. (See Annex 3 for a description of the current NHS structure in England, Scotland, Wales and Northern Ireland)

For Bevan, this idea of parliamentary accountability was a robust check on himself and his successors. He famously declared that a bedpan should not fall within an NHS hospital without the minister hearing of it - and being responsible for it.

But this is not how it has worked for health or any other ministers. Actual experience of a variety of political crises, ministerial blunders and outright scandals has shown that ministers are very rarely held responsible for their own or their officials' mistakes. Indeed, there is now an emerging doctrine that ministers cannot really be held responsible for the administrative actions or mistakes of their officials, who in their turn are not held publicly responsible as they act officially in the minister's name and not in their own right. Further, in the British system parliamentary scrutiny of the Health Secretary and other ministers is inevitably compromised by the fact that the majority of MPs will necessarily belong to the governing party, and they have a primary duty of loyalty to their government and ministers. The idea that it is practically possible for a huge and varied organisation like the NHS to be held responsible through such a narrow route of accountability strains belief and is naïve about the way British politics works in practice. As the Royal College of General Practitioners say in their evidence: " Governance of the health service can hardly be described as democratic… the assertion that the appointment of lay members to authorities mitigates against a democratic deficit seems to us somewhat spurious. Joint working between local [authorities] and health authorities will remain difficult while the former are democratically accountable and the latter remain immune."

Accountability is not divisible and any system must aim to promote accountability to the whole population. Equality means that everyone's needs are assessed and met on an equitable basis, regardless of race, gender, disability, sexuality, age, class or other factors. In particular the Secretary of State for Health and the chief executive of the NHS have accepted that the health service both as an employer and service provider must provide a better deal for people from ethnic minority groups and are taking action to achieve this. Ethnic minorities are well represented in the commissioning and delivery structures of the NHS; for example London's 20 per cent ethnic population is matched by 19.6 per cent of health authority and trust members coming from ethnic minority groups. It is imperative that this balance is maintained by Primary Care Groups and Trusts.

NHS finance and budgeting procedures

Spending as a percentage of GDP has risen from 2.7%GDP in 1948 to around 6.5% today_. The British government's ability to contain the growth of health spending while appearing to provide universal health care coverage has been the envy of the Western world. Part of the reason for the success of the NHS has been the low transaction costs associated with centralised management, the ability as a monopoly buyer to buy services, especially salaries and wages, cheaply, together with pooling risk across the whole population.

But this changed with the introduction of the internal market in 1991 that inflated management costs and weakened the internal economies of scale. The NHS is now facing increasing financial problems; a third of health authorities and trusts are in serious financial difficulties and the cumulative deficit for 1998/9 is £541 million pounds. NHS trusts have a financial duty to break even and so must clear these deficits and move towards break even over the next three years. How they do so is of critical importance to the public, patients and to clinical and non-clinical staff alike.

The problems inherent in the lack of accountability of the NHS are clearly seen in the context of the allocation of spending. Virtually all NHS expenditure (98% in 1999-2000) is funded out of general taxation and national insurance contributions; the only other important source of revenue is patient charges, yielding about 2% of the total budget in recent years. But these simple facts about the funding of the health service, are routinely obscured by the government counting as extra NHS spending income produced from land sales, recycled NHS debt, the 'modernisation fund' and the Private Finance Initiative. Clearly the disposal of existing assets does not count as additional government expenditure. The 'modernisation fund' is top-sliced from the existing revenue settlement, although it is routinely presented as new money. The £2.5bn investment under the Private Finance Initiative is a long-term commitment of future NHS revenue, rather than capital expenditure on the part of the public sector. Repayments of debt by NHS trusts are effectively double counted as a source of revenue by government (NHS trusts can only get the money to repay debts to government from their current revenue allocation!).

There is thus a gap between government's presentation of expenditure plans and the actual flow of funding into the NHS from the taxpayer and charges. This leads to a crucial lack of transparency in the presentation of government spending plans. The Comprehensive Spending Review, for example, disguises the extent to which capital refunds (the recycling of internally generated resources) rather than new money contributes to the overall total NHS budget. In 1998/9 capital refunds amounted to £3.26 billion, equivalent to 8.7% of total NHS funding_.

The new capital charging system, apart from leading to the double counting of expenditure, introduces a distortion into the costing of NHS services, and thus into estimates of efficiency. We are told repeatedly by ministers that trusts should be obliged to meet 'the full cost of their capital', with no acknowledgement that the 'cost of capital', far from being an economic fact, is determined as a matter of policy by the Treasury.

The NHS budget is usually voted as separate capital and revenue installments, but the government has changed the accounting rules and the methods of paying for capital. The introduction of capital charges in 1991, so that trusts now try to make 6 per cent return on their assets, perversely obscures the way in which capital is now paid for. The object is to force more economic use of assets, and generate productivity savings, but the consequence has more typically been deterioration in the financial position of the trusts. How different trusts choose to respond to these financial pressures has never been properly discussed or opened up for democratic discussion.

Throughout the 1980s and 1990s capital investment for hospital and community health services fell and has not yet since returned to the levels experienced in the early 1970s. The NHS now has a backlog in estate maintenance estimated at over £2.5 billion and many of its hospitals are over 100 years old. Although there is a major new hospital building programme worth cumulatively £2.1 billion, it is financed by the Private Finance Initiative, asset sales and unidentifiable redirections of cash to service private sector debt.

Intriguingly by 1998/9 the NHS's capital account was not merely self-financing through land, asset sales and capital returns; it was yielding a cash surplus. Thus the money to fund capital comes from internally generated savings from the NHS budget and not new capital. Capital projects are no longer explicitly related to ear-marked funding streams so it is impossible to see the extent to which NHS funds are being allocated between revenue and capital expenditure and it is difficult to describe the effect on the operating budgets - another major shortfall of accountability.

From the same revenue stream that is being used to fund capital investment under the PFI the NHS is having to fund pay awards ahead of inflation and meet other financial pressures including new technologies, drugs and equipment. They must also clear their cumulative deficits. It is not possible to gauge the extent to which the planned increase in the revenue budget will meet these competing

demands. 2.3 Spending and resource allocation within the NHS

Spending and resource allocation in the NHS

The allocation of resources and budgets within the NHS is of critical concern since it is the basis of equity. The Resource Allocation Working Party (RAWP) in the1970s was responsible for the introduction of a funding formula based on needs. Controls over the workforce had attempted to ensure fairer distribution of clinical labour. Over the years the formulae have been refined in attempts to reflect the health care needs of individual areas and attempts have been made to level up or down spending accordingly. In 1991, RAWP was replaced by a new formula based on what was technically called weighted capitation i.e. the population of given health districts adjusted for socio-demographic measures of need.

Funding to regions and health authorities are allocated through various capital and revenue budgets. Health authorities and in Scotland Health Boards currently administer three main revenue budgets: the largest, a budget for hospital and community health services (calculated from a partial population needs- based formula see above); a budget for community prescribing (partially derived from a needs based formula); and a general medical services budget to pay for health services (other than prescribing) supplied by general practitioners.

It is not always transparent how budgets are set and allocated and there is considerable flexibility both within and outside the resource allocation formulae. Health authorities have considerable autonomy over how they spend resources - but this autonomy is of course constrained and shaped by current demands on the budget, as well as national and local priorities.

Under the NHS and Community Care Act 1990 GP fundholders received their budgets on the size of the patient lists, unlike health authorities that receive their budgets on the strength of serving the population within an entire geographic area. The inflation and deflation of patient numbers on GP lists proved to be a problem in allocating resources; another major difficulty was brokering a relationship between health authorities and

GPs whose funding jurisdictions did not overlap but who shared the same patients. Moreover GP fundholding broke up the principle of risk pooling and risk sharing across the population. In the early stages some health authorities did not have enough left over after meeting their commitments to GP fundholders to meet the needs of their remaining population or even to provide emergency services. The inequities in provision and access and the perverse incentives perpetuated by the system became legend.

The Health Bill currently before Parliament, that seeks to address the problem, only partially reverses the process. Its central initiative is the introduction of Primary Care Groups (PCGs) and Primary Care Trusts (PCTs). Their operations will involve budgets and spending determined by two very different systems of funding and accountability - those of independently contracted general practitioners and the health authority-commissioned hospital and community health services_. The 481 PCGS will hold a unified but cash limited budget covering the three previously separately identified budgets we outlined above. With this they will plan for the health needs of practice lists of around 100,000 (ranging from a low of 50,000 to a high of 250,000) and decide how the funding is to be allocated between community health services, the acute hospital sector, primary care and public health priorities.

The difficulties the Commission is identifying in allocating resources transparently will be compounded. PCTs and PFI services, unlike NHS trusts, will have commercial freedom to manage their budgets and as commercial entities they will also have the freedom to restrict access to key commercial information. Although each PCG will have to publish an 'accountability agreement' which will be open for public scrutiny it is not known what it will contain. Moreover government guidance says public reporting of PCG finance should not be in any detail_. PCGs initially will try to manage budgets by controlling clinicians' referral and prescribing and treatment practice. Cash limited budgets will mean that PCGs will come under pressure to control referrals to hospitals and prescribing even where they are appropriate. GPs for the first time will come up against the same sorts of constraints that the hospital and community sector are facing. It is likely, just as now in the acute and

community health trusts, that Primary Care Trusts' managerial efficiency will thus be ranked more highly as a NHS priority than equity or patient need.

Accountability in the NHS

Community Health Councils

Community Health Councils (CHCs) were established in 1974 as the champion of the patient at local level; the means of asserting the public interest in health, as seen by users, to the relevant health authorities. They were established because there was no appetite to have direct elections to run health authorities, or to allow any part of the NHS to be run by elected local authorities. Instead of being a rather than structural change to promote accountability CHCs were bolted on to the existing structure. They are now the only quasi-independent voice inside the NHS.

Every health district authority has a statutory obligation to have a CHC as its watchdog. There are 206 CHCs in England and Wales. Their membership is voluntary and unpaid, with one half being nominated by local authorities, a third elected by voluntary organisations from among their members and the remaining sixth appointed by the Secretary of State. CHCs have the right to visit NHS premises at any time of day or night and to have their reports on their visits responded to by health authorities and trusts. They have a right to be consulted by health authorities on any substantial variations in service provision. They advise health authorities on what they consider to be the impact of their decisions and, if they object to those decisions, their objection has to be referred through the Regional Office of the NHS Executive (NHSE) to the Secretary of State for his/her adjudication. Generally located in a conspicuous high street site, they have developed a useful and important role in both proffering feedback to health authorities and helping individuals with their complaints.

However, there are severe limits to their effectiveness. When they mount a challenge to the health district they have no funds or legal indemnity to underpin their actions. The business of referring disputed decisions to Whitehall for adjudication by the Secretary of State is time-consuming and opaque. CHCs do not see, for example, the representations made by NHS officers in any disputed referral; and when rulings are made it is not clear why. Although some CHCs are vigorous in their watchdog role, others have become little more than public relations agencies for the health districts authorities. As currently organised, CHCs, while they are formally best placed to play a role in closing the accountability and credibility gap, are falling short of their potential. Some are excellent. Some others are inadequate. The CHC leadership is keenly aware of the shortfall, and there have been recent ongoing initiatives to promote internal and external audit, and to set demanding performance standards. But even the position of the central co-ordinating body, ACHCEW is anomalous; it has no powers to police standards and can only advise rather than instruct.

The autonomy of individual CHCs means that standards vary builds in across the country. They are not accountable for the way they take decisions. Review and performance appraisal is variable. Training is weak, because it is not obligatory. The lack of consistency is exacerbated by the awkwardness of the management establishing arrangements to which CHCs are subjected: Regional Offices of the NHSE are their establishing authority and there are eight Regional Offices across the country, all with different ideas as to how CHCs should be managed.

The right to consultation on substantial variations in service has, over the years, become a mockery. No precise definition of what the word 'substantial' means in this context has ever been forthcoming. At one time it was defined in the House of Commons by the Secretary of State as what CHCs themselves considered 'substantial': latterly, health authorities have made the decisions as to what is or is not 'substantial' and consulted or not consulted on that basis. In addition, the statutory duty to consult CHCs lies with health authorities. It is for health

authorities to decide whether or not to consult on substantial changes proposed by trusts, not the trusts themselves. This makes for confusion and can lead to frustrating buck-passing.

The already very limited statutory rights of CHCs have been eroded over the past decade by changes in the NHS, which have not been matched by changes in legislation affecting CHCs. For instance, CHCs could by right visit and monitor long-stay hospitals: they now have to negotiate visiting and monitoring rights in respect of the residential and nursing homes by which the hospitals have been replaced - and they are not always successful. Much of the recuperative and rehabilitative work, which at one time was carried out in acute hospitals, is now done in patients' homes and is not independently monitored. CHCs have traditionally had observer status with speaking rights at health authority meetings: they have no such status, as of right, in respect of the new purchasers, the Primary Care Groups.

Accountability: Rights to Consultation

If the NHS is to be responsive to the needs of the public, then the public must be involved in the planning and development of services. It follows that consultation with users and potential users of the NHS should be an integral part of managing the Health Service. On paper consultation appears to be straightforward. The definition is uncontroversial: "the communication of a genuine invitation to give advice and a genuine receipt of that advice"_. But whilst there are examples of good practice some health authorities are reluctant to consult on their plans, and in some instances the consultation exercises are clearly inadequate.

It sometimes appears that health authorities have reached a decision before considering responses to a consultation. CHCs, for example, are sometimes presented with a single 'option', suggesting that the health authority has already reached a decision. There are sometimes attempts to implement changes that have not been laid out in consultation documents. And health authorities do not always ensure that documents relevant to a consultation are available at the start of the consultation

period; what is defined as a substantial change to services, as we argue above, allows wide discretion in deciding what should and should not be consulted upon.

The introduction of the internal market has caused further problems in the consultation process. There is no statutory requirement for trusts to consult when they plan substantial variations in services. In short, consultation is ad hoc and discretionary.

Accountability: NHS Complaints Procedures

For the individual patient the complaint procedures represent the most immediate and tangible means of holding the NHS to account. In 1997/98_ the total written complaints are 88,757 for hospital and community health services and 38,093 for family health services.

The complaints procedure divides into two distinct parts. 'Local resolution' where the emphasis is on resolving the complaint on the spot or within 20 working days by the provider of care. If this process of local resolution is unable to resolve the complaint then an Independent Review panel can be set up if an appointed Convenor agrees that it would be appropriate to do so. The Convenor is a non-executive director of the NHS trust subject of the complaint (or a non-executive director of the relevant health authority for complaints against primary care services). The Panel Chairs are appointed by the relevant Secretary of State. The third member is also appointed by the Secretary of State, except in the case of NHS trust Panels, where the relevant health authority makes the appointment. Should the complainant still remain dissatisfied after the findings of a Panel or if the complainant is refused a Panel, they can ask the Health Service Ombudsman to investigate.

In 1997/98 there were 3,261 requests for Independent Review Panel, and 679 Panels established. In the same year the Ombudsman dealt with 964 complaints that had been considered by a Convenor and refused a panel or had been through an Independent Review Panel.

The problems are legion. It is not clear that either Convenors or the review panel are genuinely independent, with many Convenors seeing their role as smoothing ruffled feathers or negotiating an amicable settlement. Costs are high, and the insistence on making a complaint early deters many complainants. One Community Health Council in its evidence commented that: "Independent reviews are very costly - very difficult to set up, and get the correct panel of experts etc., within extremely tight deadlines. Because of this, patients are being pushed to go back again and again for further local resolution in the hope that this will eliminate the need for independent review".

The NHS complaints procedure is even weaker than that for local authorities and social services. There are no rights to complain about entitlement to services. The complainant in the NHS cannot ask for a review panel to be convened. Instead he or she can only appeal to a Convenor whose decision it is whether such a panel should be convened. The Convenor is not independent, as it must be the case in a comparable review by a local authority. The independent review panel convened by the Convenor has a lay chair appointed by the NHS Regional Office. No panel member should have any past or present links with the trust/health authority establishing the panel. And then, to add insult to injury, the decisions of the review panels are also not binding on the trust or health authority. In sum the whole apparatus from the appointment of regional health authorities through to the minutiae of complaints procedures defines the NHS as Britain's least accountable public institution, even though accountability in the Health Service accountability is more important than in any other department of government.

The Public Interest, Accountability and the NHS

The Attractions and Pitfalls of 'Rights'

Our terms of reference recognise that the ultimate purpose of the NHS is to serve the public interest. There can be little doubt that there remains a strong public interest in a well-functioning comprehensive system of health care and that this public interest is a truly national (in the sense of British) one. Of course there have been recent changes in the form of government in the UK but the devolved institutions in Scotland, Wales and (probably) Northern Ireland are likely to be as committed as Westminster has ever been to a system of national health care for their peoples. So here is a subject on which - indubitably - the British people can and do still unite.

We welcome the various initiatives taken within the NHS to improve public involvement. In particular we applaud the attempt to engage the active citizen in decision making in the NHS. We also recognise that the involvement of the public in decision making in the NHS is not without problems and that there are bound to be tensions in relating demand to need; in choosing between the best and the possible; in determining which local, regional and national needs should be accorded preference; and in much else besides. Nevertheless we remain convinced that an effectively accountable NHS requires a far greater public input than exists at present, to assure better decision-making that corresponds to the public's preferences and needs.

It is widely accepted that the NHS can be best protected as well as improved by the achievement of what our terms of reference call 'a full and effective system of public accountability'. We need to debate the best way to bring this about. The debate is as to how best to bring this about. Tempting though individual rights they are as an intellectual idea, and helpful though they are in many situations, we do not believe that it is solely through the enforcement of individual rights via the courts that the public interest can best be protected. When judges are invited to

determine health issues in terms of rights, they usually have before them only a single litigant who is in an adversarial relationship with his or her health authority. In such a dispute, the big picture - the wider public interest if you like - is all too easily pushed to one side. So cases may determine the individual issue before them in a just and equitable way, but they will be forced to do so without regard to the wider issues of resource allocation and accountability that the case might also raise. The public interest can only be extremely imperfectly constructed out of a series of such cases, since as a concept ' the public interest is bigger than and transcends the aggregate of individuals interests that make up the British community. Of course, where Parliament has legislated in a particular way, individuals should be able to insist that the executive adhere to the rules laid down by Parliament. There is scope for litigation in terms of ensuring that the managers of the NHS do not act unlawfully. But we should not ask or expect the judges to use the vague language of rights to provide for us a definition of the public interest in health: that is the responsibility of the nation as a whole.

Freedom of Information

Democratic government requires that those who vote do so on an informed basis. This requires that they have access to as much information as possible to enable them to make fully informed decisions as to how they are being governed and whom to support. This principle holds good for the running of the health service and all public services. If the service is to be truly accountable, then those to whom it is to be held to account need the basic data, analysis and policy decisions on which to judge the performance of the service.

Access to official information is, therefore, an integral part of good government in general and the democratic management of the health service in particular.

Britain's long tradition of official secrecy covering all aspects of government has begun to break down in recent years. A recent revision

of official secrecy, the Official Secrets Act 1989, is reasonably tightly focused and only exceptionally enforced. The trend has been towards ever-increasing entitlement to access to official information.

In 1992, the Conservative Government published a code of practice which was designed to liberalise access, subject to certain exempt categories and tests to weigh the public interest in disclosure against any harm it might cause. In 1995, the NHS got its own code of practice for openness, which applied to all NHS authorities and bodies. Patients also have well-established legal rights to see their own medical records. Manually held records are available under the Access to Health Records Act 1990, and computerised records have been available under the Data Protection Act since 1987. They can also gain access to reports on themselves made by their general practitioners to insurance companies or employers under the Access to Medical Reports Act 1988.

The Labour Government recently published a draft Freedom of Information Bill that will put freedom of information on a statutory basis. This legislation will apply to all NHS bodies, including the new PCGs, if it goes through Parliament in its present form. However the draft Bill will diminish access to official information in a variety of ways. At central government level the public will be denied all data and information about policy-making, and, at the time of writing even background material, regardless of whether or not disclosure would cause harm. Under the Code, the Ombudsman could investigate refusals to give information and substitute his or her own judgement for that of ministers or officials. Under the Bill, the new enforcement officer will be relatively powerless to challenge refusals. NHS bodies will continue to be able to count on a variety of exemptions, including commercial confidentiality, to refuse information; they will be able to inquire into the motives of people seeking information; and they will be able to withhold information indicating that they are guilty of an offence or other misconduct. Many official bodies associated with the NHS, such as those ruling on the safety of drugs, will not be covered immediately, and perhaps not at all.

4.2.6 The Commission views the availability of information as a vital aspect of a democratic and accountable health service. Of course we accept that there must be limits on the accessibility of data. There are valid reasons why on occasion such information should not be revealed. We welcome the government's acceptance in principle of the need for a comprehensive measure on freedom of information, but we are concerned that the overall effect of the draft Bill, as set out, will dilute the gains in access to information that have already been achieved. In particular, we balk at proposals to keep secret all information dealing with government policy and to restrict the powers of the proposed information commissioner under the measure to be an advisor rather than executive protector of rights.

Improving Democratic Accountability: Options to Reform NHS Structures

How can the NHS be made more open, accountable and responsive? There is no single answer or magic formula, but rather a series of changes in structure, conduct and ethos are required. No single one change, on its own, will be sufficient. Changes must make sense on operational and managerial grounds. The Commission is currently debating a variety of proposals, but has not yet adopted a firm position. However, we do have a potential agenda for change, which is as follows:

The first and most obvious answer is to correct the initial 'defect' in Bevan's plan and introduce election in place of selection at district health authority level and to replace governing officials at regional level with elected bodies. At local level, DHA health authorities could be transformed into elected bodies or governance of health could be united with social services within local authorities. At regional level, regional health authorities could be revived as elected bodies, or new elected regional authorities in England could take on responsibilities for major health service decisions, along with the Scottish Parliament and Welsh Assembly in Scotland and Wales. Howard Davis and Guy Daly, for example, in an article in Public Money and Management propose that

the chairs of health authorities should be elected as "local health mayors", part of whose remit would be to ensure wider representation on primary care group boards.

At district level, there are arguments for and against election. DHA Health authorities already exist and could transmute into locally elected bodies with public access to meetings, agenda, and papers, and a right to petition the authorities on particular issues. It can be argued that this solution is preferable to adding responsibility for the local health service to local authorities, which are undergoing major changes; are under-financed; and generally poor communicators. New authorities making a new start are more likely to adopt the open and responsive ethos which is vital to their success; and the public, which treasures the NHS, may be better motivated to turn out and vote for elections to NHS bodies than they have been for local authorities.

The case for handing over responsibility to local authorities is that they are up-and-running as elected bodies. Adding health to their responsibilities would lead to "joined-up government" at local level. Health and social services could be properly integrated and managed in concert. The public might be better motivated to turn out and vote for local authorities which held health portfolios along with social services, education, and so on.

Perhaps the biggest objection to introducing further elections at local level is that the fear of continuing low turnout. There are various reasons for this low turn-out, one of which is the first-past-the-post electoral system which tends to produce party political oligarchies on local authorities and to under-represent opposition parties. Whether health is made the responsibility of health authorities or local government, the degree of participation in elections would turn first on the electoral system chosen, and secondly, on giving the authorities a degree of autonomy sufficient to making them worth voting for.

The wild cards in either proposal would be the new autonomous Primary Care Trusts, PFI hospitals and other PFI financed services. In theory, they could be made responsible to the elected health authorities or local

authorities and their boards would not be required to be elected. They would be made democratically accountable to the elected bodies instead. In addition Primary Care Groups (PCG) are going to be dynamic creatures and do not have the same territorial base as either type of authority and patients sign on across official boundaries. Our view is that the whole idea of PCGs requires a fundamental re-think, as they could easily lead to privatised local services on the US model, and cannot readily be made accountable to local people even if they remain fully within the public service and ambit of health authorities.

No single reform is on its own sufficient. Other changes are necessary to create an overall structure into which the local bodies responsible for health can fit. The most pressing reform is at regional level, as so much significant decision-making and resource allocation in the NHS has to be undertaken at regional level. But the time frames for change are very complex. One way would be to re-establish regional NHS authorities as elected bodies in England alongside the Scottish Parliament and Welsh Assembly in Scotland and Wales. The most sensible answer would probably be to add health to the responsibilities of new elected English regional assemblies, but these at best will take years to establish and they may never materialise. At the very least, appointed bodies ought to be restored and should operate in public. They should contain representatives of local government from their regions, or come under the supervision of the indirectly elected regional assemblies which are supposed to add a democratic gloss to the new regional development agencies. In London, the new Greater London Authority could act as a regional health authority.

The NHS Executive is currently immured within the Department of Health and is impenetrable to public scrutiny. The proposed Freedom Of Information regime would distance it even further from public accountability. There is a strong case for removing it from this shell and transforming the NHS into an Executive Agency. The chief executive would then move into the public domain, as other agency chiefs have done. The strategic objectives of the NHS would have to be set out for public scrutiny and it would be possible to measure the NHS's progress in meeting them. Relations between ministers and departmental

bureaucrats would also be opened up to a degree and the potential for further openness would be there. This is unlikely to be a welcome proposal from the point of view of the Department of Health, as it would "lose" an important part of its being, and a largely unseen influence over the NHS. Finally, of course, the lack of clarity which now obtains leaves ministers and mandarins with a freedom of manoeuvre that is as valuable to them as it is injurious to the public interest.

A robust Freedom of Information Act, framed along the lines of the original white paper published 18 months ago, is vital to good government in the NHS as elsewhere in government. The current draft bill is inadequate, notwithstanding recent concessions, and would do little to improve the quality, openness, effectiveness and accountability of the service.

There are a variety of executive and advisory non-departmental bodies and committees, attached to the department, which also need to be reformed. The Committee for the Safety of Medicines and the Medicines Commission, for example, take decisions on drug safety and regulation which bear upon the reputation of the NHS. These bodies operate largely behind closed doors and are not open to the public or peer group review, unlike their counterparts in the USA. It is a criminal offience to release information from these two bodies. Reform of the NHS must be accompanied by reforms to make such bodies open and accountable as well.

Improving Democratic Accountability - Options on Budgets and Financial Incentives

The budget is the over-riding question for any system of health care, and as we have seen there is little transparency in how overall budgets are set, priorities decided upon, and how the consequent rationing decisions are made. The Commission is not convinced that the current degree of health rationing is necessary for an advanced industrialised society; especially if it means that some health care is simply unavailable, or that the NHS carries very little spare capacity in terms of beds, nurses,

surgeons, operating theatres, community health services, primary care, rehabilitation etc. Small unanticipated increases in the demand for care, like winter flu, can quickly become very disruptive as a result. We will want to assess how decisions are made in a way that voters' continued support for more spending is systematically ignored.

Nonetheless, it is clear that even if more resources were available to the NHS it could not do everything that is asked of it. Priorities have to be decided upon and health needs ranked; rationing in this sense is inevitable in that low priority health needs will clearly have less money diverted to them than high priority needs. Yet there is no clear basis for this assessment. It is not enough to say that NHS managers should simply aim to maximise the number of quality-adjusted life years (QUALYS) of their patients. There is also a budget constraint. In any case there are other objectives to be considered, such as the degree to which any health authority should try to reduce health inequality, improve the position of the worse-off or simply provide as comprehensive a system as possible in order to promote social reassurance, community and social cohesion. Above all there is meeting the government's three-year targets for the growth of health expenditure which can be interpreted as the most important priority, or at least the one health service managers will seek to meet. In short health authorities and, in future Primary Care Trusts, make explicit ethical and value judgements about the appropriate trade-offs between these various objectives that underpin their priority setting which they seek to conceal or at least withhold from public scrutiny; the public input to the debate is nil.

As we explored earlier, the financial calculations over capital investment are particularly opaque. The Commission welcomes the government's requirement that trusts publish detailed business plans accompanying new hospital construction financed under the private finance initiative. However, much information remains confidential, and it is close to impossible to make a judgement on the basis of published information as to what balance has been struck to achieve the financial targets, and what deductions will be made from the revenue account to finance the new servicing costs of any PFI scheme.

Above all the pattern of budgets and pricing constitutes a framework of economic incentives to which NHS medical and non-medical staff naturally respond but which has not been explicitly designed with that end in view. For example the internal market could only ever begin to work if trusts used the same framework of accounting upon which to base the prices they charge NHS purchasers. Although there was a general instruction to base prices on the basis of average cost, some trusts felt they could increase their workload and cash flow by pricing more competitively - at the marginal cost of any additional operation. This allowed them to win extra work at the expense of rival hospitals, but paradoxically placed both in financial jeopardy. The hospital using average cost pricing lost work and revenue, forcing it to lift its prices reflecting the reduced workload and higher average costs; while the hospital winning the extra business found that there was no support for increased investment to raise its capacity except from its revenue account. Both paradoxically moved towards bankruptcy while grossly distorting the pattern of local health care provision.

The examination of how such pricing, costing and budgetary incentives affect organisational behaviour is called mechanism design. Although the heart of mechanism design is to devolve decision-making as much as possible to local decision-makers who have the maximum amount of information, considerable care is then taken by economists to ensure that the mechanism's financial incentives operate to produce the kind of decision-making that is wanted. What characterises the NHS is that no such sustained attempt has ever been made. How GPs, for example, build up a nest-egg in the value of their premises which they own but which are paid for by the government, means that funds are diverted from health care to servicing the acquisition of property. A better deal may be for the government to build and own the premises itself. Nor is it clear, for example, how allocations of funding are set or how they impact upon the rigour of local decision making.

But what should the criteria be that underpin the NHS's mechanism design? Citizens' juries, focus groups and health panels are all possible means of uncovering the public's preferences over health priorities, but

suffer from a systemic democratic deficit. The Commission wants to explore the advantages and disadvantages of each approach, and how they might impact on and interact with other structural changes we are examining such as direct democracy.

Improving Democratic Accountability: Options on Systems, Watchdogs, Patient Rights and Complaint Mechanisms

Some form of organised independent public scrutiny of health services is plainly necessary. The proclamation in1991 that health authorities were to be regarded as 'champions of the people' was clearly absurd. How could the planners and purchasers of health care stand aside and objectively examine the effect of their plans on the users of the services, driven, as they so often have to be, by financial imperatives? health authorities under the current system have become judge, jury and prosecution of their own record.

The only formal check and balance at the moment is the CHC. Successive governments have looked critically at CHCs to question whether they are good value for money and to see whether the public interest in the NHS, to which the present Government has declared itself dedicated, could be better and more economically served by other mechanisms. This would be more reasonable if the NHS had other statutory watchdogs or stronger inbuilt mechanisms of accountability and redress of grievance. In their absence the CHCs, for all their weaknesses, are the only bulwark representing the consumer interest in the NHS.

The right approach is surely to address the CHCs' weaknesses. In Wales, for example, there is to be a period of consultation aimed at developing a "new and reinvigorated model of federated CHCs". England could and should follow suit.

The central issue is to make sure that CHCs have the capacity and rights to monitor and scrutinise the key local health decision-maker, which promises to be the new PCGs and PCTs. The Commission will want to

explore how this might interact with the options on promoting elections or incorporating local authorities into health decision-making. One way forward might be to attach CHCs formally to local authorities with health responsibilities, or to directly elected health authorities, and to give them a formal role of reporting to authorities and the public, as well as a redress role. This would build on the existing CHC functions, so creating an effective network of local bodies with the skills and expert knowledge necessary to carry out effective scrutiny of services, identify needs, investigate complaints, etc. It would make sense to give CHCs more powers and resources and to tie their work to the Patients Charter, making them its local agents.

Then there are the awkward establishing arrangements for CHCs (see page 12). One proposal is that the Commission for Health Improvement (CHI), which will be a Special Health Authority, might become the establishing authority, thus getting way from the inconsistencies of the present system.

As for CHC membership there are arguments for and against continuing with local authority and voluntary organisation nominees. On the plus side, local authorities are the only truly democratic input into CHCs and voluntary organisations are close to local communities. On the negative side, the current process of representation tends to be unsystematic, the same organisations get represented and nominees pursue their special interests rather than the wider picture. There are also important issues over training, standardising performance, ensuring national standards and empowering ACHCEW to co-ordinate and enforce common standards. The referral process for disputed decisions is inadequate, as is the protection offered to CHC members in any judicial dispute.

The Commission will also debate the role of extending and entrenching patient rights. Clearly they have an important role in determining what the public interest is and in ensuring that all of us as individuals are treated fairly and equitably within the health service. Rights can take various forms: (i) legal rights to whatever is guaranteed by statute or delegated legislation; (ii) accountability rights to be consulted over treatment and to be given adequate information; (iii) consent rights to be

given the chance to make an informed choice as to whether a particular treatment should be undergone: (iv) charter rights, to fair treatment in terms of waiting lists, seeing consultants etc. We will want to explore the implications of enlarging and improving rights in all these areas, and of ensuring that the current system of Independent Review panels at least conforms to the best practice in the rest of the public sector.

There are a number of areas in the health service where patients' rights are poor or non-existent. Since the Patient's Charter was launched in 1991 it has raised certain standards in the NHS, though sometimes at the expense of others. However, it could do more to address important issues at the heart of the health service -equality of access to health care, the scope for patient participation on the basis of informed choice and the quality of care and treatment. Many of the standards listed in the Charter are described not as rights but as expectations (i.e. standards of service, which the NHS is aiming to achieve, but which may not be met).

The Patients' Agenda developed by the CHCs proposed not a set of expectations but a set of rights. In addition to proposing new rights it also proposed the strengthening of some existing rights. The Agenda did not consider that patients should have to resort to law if their rights were not upheld, but suggested the establishment of an independent Health Rights Commission with statutory powers to enforce all Charter rights and standards. The Agenda suggested a number of rights in relation to access to care and treatment; health care regardless of the ability to pay; choice and information; advocacy, support and appropriate care; good quality care in matters of life and death; and confidentiality and control over personal information.

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