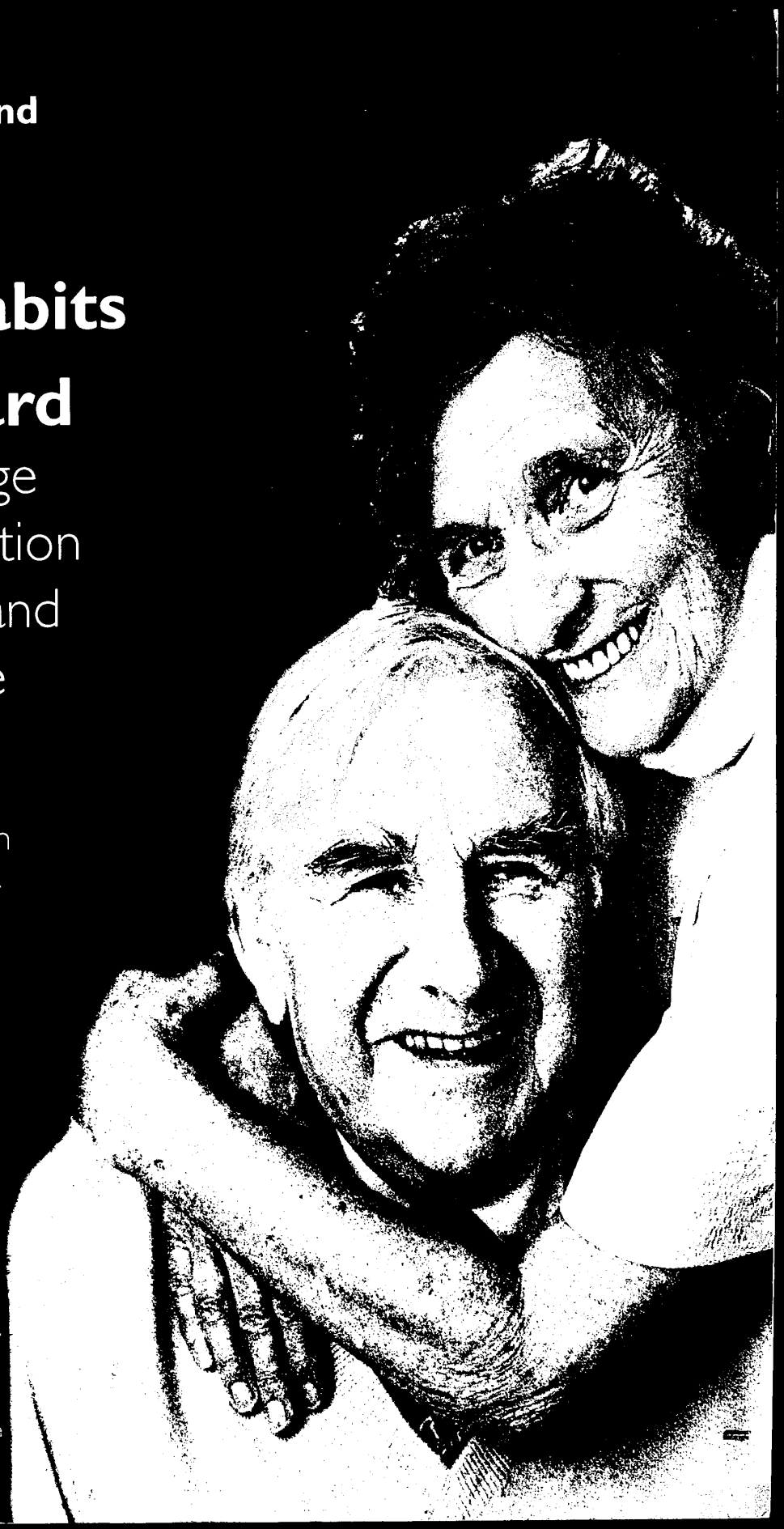
King's Fund

Old Habits Die Hard

Tackling age discrimination in health and social care

Emilie Roberts
Janice Robinson
Linda Seymour



King's Fund
Publishing
11–13 Cavendish Square
London W1G 0AN

Old Habits Die Hard

Tackling age discrimination in health and social care

Emilie Roberts, Janice Robinson and Linda Seymour

King's Fund

Published by
King's Fund Publishing
11–13 Cavendish Square
W1G 0AN

First published 2002

ISBN 1 85717 462 3

A CIP catalogue record for this publication is available from the British Library

Available from:

King's Fund Bookshop
11–13 Cavendish Square
W1G 0AN

Tel: 020 7307 2591
Fax: 020 7307 2801

Printed and bound in Great Britain
Cover image by: www.johnbirdsall.co.uk
Edited by: Caroline Pook and Anita Reid
Layout by: Kita George

Contents

Acknowledgements

Executive summary

Introduction 1

The Government and the *National Service Framework for Older People* 1

Aims of the survey 3

Methods 4

Choice of sample frame 4

Interviewees 5

Interview 5

Results 6

Organisational context 6

Presence of age discrimination in local services 8

Examples of age-related policies or age bars 8

Audits of age-related policies 9

Reasons given for restricting services by age 9

Specialist services for older people and other age groups 10

Arbitrary nature of age cut-off points 12

Staff's flexible interpretation of age cut-off points 13

High-level need versus preventive services 14

Clinical decision-making: 'do not resuscitate' policy 14

Equality of access to acute care 15

Attitudes to caring for older people in hospital 17

Quality of care at the end of life 17

Managers' confidence in health and social care services 17

Perceptions of older people and their families 19

Initiatives for tackling age discrimination 20

Discussion **24**
Age discrimination identified in local services 24
Tackling age discrimination 24
The importance of the *National Service Framework for Older People* 25

Conclusion **27**

Recommendations **28**
Clarify the meaning and consequences of age discrimination 28
Develop benchmarking 28
Introduce age-equality legislation 28
Scrutinise national policy 29
Invest in staff education and training 29
Critically assess specialist services provided to older people 30

Appendix A **31**
National Service Framework for Older People: key objectives

Appendix B **32**
Survey letter sent to potential interviewees

Appendix C **34**
Telephone interview schedule on age discrimination

Appendix D **39**
Characteristics of the interviewees in the survey

Appendix E **40**
Specific examples of discriminatory service provision identified at the time of the survey

Acknowledgements

We would like to thank members of the King's Fund Working Group on Age Discrimination who encouraged us to carry out this survey and gave us valuable advice and feedback.

Above all, thanks must go to the senior managers who participated in this survey and who made time in their busy schedules to share with us their reflections on age discrimination in local health and social care services. We are most grateful to them for their honesty and openness.

Emilie Roberts, Janice Robertson and Linda Seymour

Executive summary

Background

Between May and September 2001, the King's Fund carried out a telephone survey of 100 senior managers working in health and social services in England. The aims of the survey were:

- to find out how much they believed age discrimination was affecting services in their local area
- to discover what they were doing to combat it.

The survey took place following publication of the *National Service Framework (NSF) for Older People* in March 2001. In the *NSF for Older People*, the Government had indicated its determination to 'root out age discrimination' in health and social care, and had directed NHS organisations and local authorities with social services responsibilities to tackle the problem over the coming year.

The survey was conducted with senior managers who have the responsibility for putting the *NSF for Older People* into action, including:

- chief executives from primary care trusts and NHS community trusts
- medical directors from acute and specialist trusts
- directors of social services.

A total of 75 managers took part in the survey, a response rate of 75 per cent, representing a spread of experience in a diverse range of NHS trusts and social services departments across England.

Key findings

Presence of age discrimination

- Three out of four senior managers believed that age discrimination existed in some form or other in services in their local area.
- Many believed that ageism was endemic.
- Some gave examples of discrimination that they felt were justified or favoured older people.
- Only around a quarter of respondents felt there was little or no age discrimination within local services.

Type of age discrimination

- Most of the examples of age discrimination described by senior managers in their services constituted direct discrimination, i.e. policies restricting access to particular units, facilities and treatments by setting upper or lower age limits.

- Far fewer instances of indirect discrimination were described.
- This does not mean, of course, that age-related policies are more prevalent than other forms of discrimination. They may merely be more visible and easily identifiable – especially at a time when managers were being directed to audit age-related policies.

Explicit age-related policies

- In the health sector, there was a strong consensus that explicit age-related policies were on the decline.
- Most managers seemed to believe there were very few written policies specifying age criteria.
- There is likely to be a great deal more 'hidden discrimination', which has grown up through custom and practice.

Managers' understanding of age discrimination

- Some managers expressed confusion and uncertainty, both about the concept of age discrimination and about the criteria used to judge whether discrimination is either unfair or justified.
- This lack of clarity was most obvious when discussing the pros and cons of specialist services organised especially for older people, and clinicians' predisposition to under or over treat people of very advanced age.
- This confusion raises questions about senior managers' understanding of what to look for when 'rooting out age discrimination'.

Motivation to tackle age discrimination

- Action to combat age discrimination was frequently perceived by managers to be a low priority, compared with many other imperatives from Government.
- The number of complaints from older people about their care and treatment was also said to be low, and thus few managers felt any pressure for change from service users or the wider public.

Causes of age discrimination

The main underlying causes of age discrimination identified by respondents were:

- a lack of resources
- wider ageism inherent in society and the health and social services bureaucracy.

The difficulty in tackling these issues at a local level may explain some of the resignation expressed by some senior managers.

Action to combat age discrimination

- Managers revealed wide variations in the extent to which health and social care agencies have succeeded in involving older people in reviewing and developing local services.
- All managers of community health and social services knew of, and welcomed, the growth of older people's forums but they generally considered the involvement of older people in scrutinising policies and practices to be under-developed.
- Managers in acute hospitals were less committed and engaged with the public involvement agenda, and this was borne out by comparatively little evidence of activity.
- In line with Department of Health guidance, all managers were either actively engaged in or aware of steps being taken to put in place 'older people's champions' and local scrutiny groups required to implement the *NSF for Older People*.
- These arrangements were still at an early stage and far from completed in many places.

Conclusion

This survey suggests that efforts to 'root out age discrimination' in health and social care are taking place in a fertile climate of opinion.

- All the managers interviewed thought age discrimination was a 'bad thing' and they wanted to do something about it if it was shown to be a problem locally.
- The Government's stance on the unacceptability of age discrimination as laid out in the *NSF for Older People* appears to be an important driving force in stimulating and reinforcing action to combat unfair age discrimination in local services.

However, the approach of many senior managers is essentially reactive.

- Most are implementing, as required, the milestones set by the *NSF for Older People*.
- But few seem to be questioning the rationale for policies or practices that have evolved over many years, or taking the initiative to put an end to age discrimination in local services.
- This suggests that much more needs to be done to achieve radical changes in the way health and social care services are provided for older people.

Recommendations

The following strategies are recommended to combat further age discrimination. More work will be needed to develop these and the King's Fund will work with other interested bodies to develop these ideas further.

Clarification of the meaning and consequences of age discrimination

This will better equip managers and others in the health and social services sectors to identify age discrimination in their local services and to determine whether or not a particular policy or practice is justifiable.

The early development of benchmarking

This will help to detect hidden age discrimination, by enabling comparison of patterns of referral, treatment, care and support achieved in one locality with those in comparable areas.

Staff education and training

Better awareness of ageing and ageism should be included in educational programmes for staff at all levels. This is likely to need additional resources to ensure the development of appropriate course material and to provide sufficient opportunities for staff to reflect on their practice and change accordingly.

Critical assessment of specialist services provided for older people

Specialist services provided for older people should be critically assessed with the aim of eliminating policies that disadvantage older people by restricting access to good-quality care.

New age-equality legislation

New legislation is needed to outlaw age discrimination in health and social care, and to require local agencies to demonstrate that older people are not disadvantaged in terms of access to, or quality, of services provided.

Scrutiny of national social policies

This should challenge age-related policies and those policies that have a disproportionate effect on older people and may be indirectly discriminating against them.

Introduction

Age discrimination occurs at many levels from system-wide to the individual. There is much evidence to show there are two types of age discrimination – direct and indirect – in health and social care:[1]

- Direct discrimination – this occurs when an individual, or group of individuals, are treated differently because they are above or below a particular age.
- Indirect discrimination – this occurs when a service or practice has no explicit age bias, but still has a disproportionate impact on people in a particular age group.

Age discrimination is not necessarily unfair, with positive action being a well-established mechanism for addressing health inequalities. For example, free prescriptions are given to children and older people aged 60 and over, while specialist services for children, adolescents or older people can be a means of providing the most effective services for these client groups. Nevertheless, age discrimination is commonly understood to have a negative meaning and is therefore a sensitive subject area for service providers.

In older people, age discrimination, in its negative sense, may be caused by a lack of awareness of older people's needs rather than a deliberate intention to treat older people unfairly. It results from prejudice and stereotyped assumptions about older people, in which older people are viewed as a homogenous group characterised by:

- passivity
- failing physical and mental health
- dependency.

The Government and the National Service Framework for Older People

The publication of the *National Service Framework (NSF) for Older People*[2] by the Department of Health, in October 2000, underlined the Government's determination to tackle age discrimination in the health and social care services:

> *NHS services will be provided regardless of age, on the basis of clinical need alone. Social care services will not use age in their eligibility*

---

[1] Roberts E. *Age discrimination in health and social care.* (A briefing note). London: King's Fund, 2000 (unpublished).

[2] Department of Health. *National Service Framework for Older People.* London: HMSO, 2000.

> *criteria or policies to restrict access to available services.*
> (Standard One, *NSF for Older People*)

The *NSF for Older People* radically directs health and social care organisations to take a proactive approach to 'rooting out' discriminatory and ageist service provision. It also sets out tasks and targets that must be met to reach the NSF's standard on age discrimination (*see* Appendix A), including the appointment of clinical champions for older people, reviewing age-related policies and providing adequate training for staff to meet older people's needs.

Aims of the survey

The success of the Government's efforts to end age-discriminatory practices and of the *NSF for Older People* will depend very much on those responsible for putting the directive into action. This responsibility rests at the very highest levels of senior management in the NHS trusts and social services departments.

However, very little is known about how these managers perceive age discrimination and their response to it. The King's Fund therefore decided to conduct a telephone survey of senior managers in a range of health and social care organisations between June and August 2001.

Specifically, the survey aimed to discover:

- whether senior managers perceived age discrimination as affecting their local services and what form such discrimination took
- whether local organisations have the 'infrastructure' in place to deliver the NSF standard on age discrimination
- local examples of good practice in 'rooting out' age discrimination.

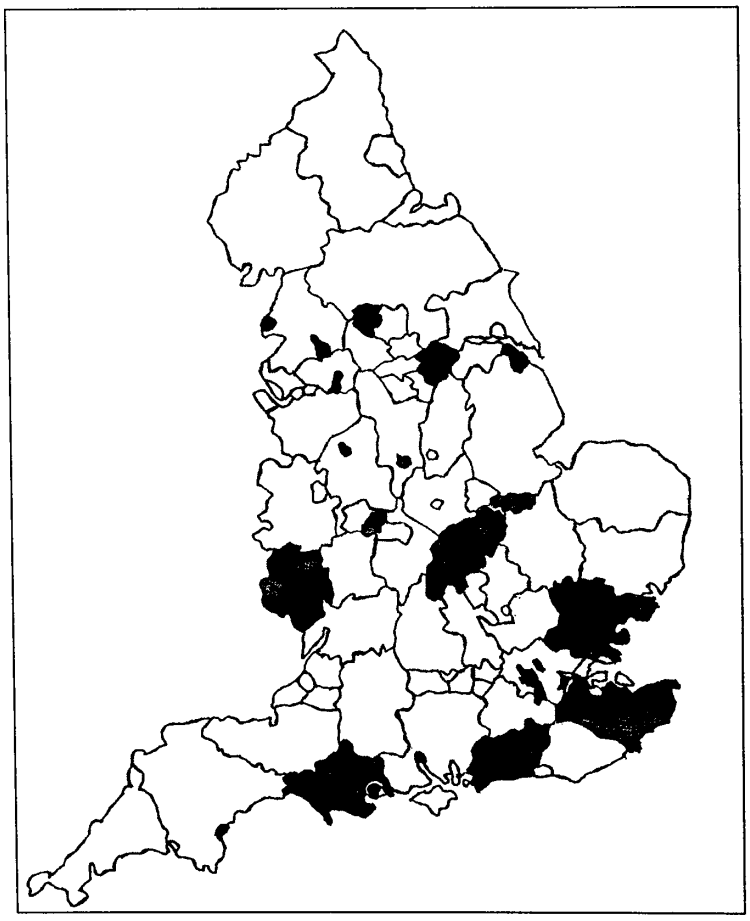
During the course of the telephone survey, participants were deliberately not given a definition of age discrimination before the interview and were free to bring their own perspective of the issue to the discussion.

Methods

Choice of sample frame

A sample of areas was identified using the Office of National Statistics (ONS) classification of local authority areas. This was stratified by a rural/urban split and weighted towards areas with a first- or second-wave primary care trust (PCT). The final sample of 25 areas is shown in Figure 1 below. The aim was to identify a diverse range of areas and organisations in England to be included in the survey.

Figure 1: Local authority areas included in the sample (shaded black)



Within each area, one of each of the following types of providers was selected:

- primary care trust (PCT), or primary care group (PCG), if there was no first- or second-wave PCT
- community health or combined NHS trust
- acute NHS trust or combined NHS trust or single-specialty acute NHS trust
- social services department.

If there were insufficient NHS trusts in a sample area to meet the survey's quota, then substitute trusts were selected randomly from a list of NHS trusts in England.

Interviewees

In May 2001, a letter was sent to a total of 100 senior managers asking if they would take part in a telephone consultation about age discrimination (*see* Appendix B). The managers were assured that the consultation would be both voluntary and confidential. The letters were sent to:

- chief executives of PCT/Gs and community health NHS trusts
- medical directors of acute NHS trusts
- directors of social services in local authorities.

The letter was followed up with a telephone call about a week later. Those managers, initially contacted, who wanted to delegate the interview were allowed to choose their own nominee.

Interview

The interview was semi-structured, i.e. a series of general and open questions rather than a questionnaire. A pilot study, conducted with five senior managers in March and April 2001, had demonstrated that the questions were successful in prompting discussion and in drawing out different perceptions and experiences of age discrimination, as well as examples of good practice. The interviews were carried out in June by two interviewers who asked the same lead questions in the same order, with prompts. Details of the full interview are given in Appendix C. The written notes taken from the interviews were then analysed, drawing out emerging themes.

Results

We obtained a total of 75 interviews from the 100 managers approached initially, or their delegated interviewees; a response rate of 75 per cent. The managers interviewed represented a spread of experience in a diverse range of NHS trusts and social services departments across England. The response was very good in both the PCT/G sample (84 per cent) and community NHS trust sample (84 per cent) and in the social care sample (88 per cent). It was lower in the acute NHS trust sample (44 per cent). Overall, half of the interviews were delegated. Characteristics of the respondents are given in Appendix D.

Organisational context

Managers taking part in this survey were working in an environment characterised by organisational turbulence and financial pressures. The difficulties and uncertainties inherent in this environment emerged as managers talked about their roles and responsibilities regarding services for older people.

Primary care trusts (PCTs)

The PCTs in our sample were new organisations, with none being much more than 12 months old. One PCT had only been established in April 2001 and had not appointed all of its board members at the time of the interview in June.

The PCTs were characterised by small management and administrative staffing levels. They had a range of service responsibilities. Some of the PCTs were at 'Level 3', responsible for commissioning health services. Others had moved to 'Level 4', with a more extensive brief for providing services as well as commissioning them. Some PCTs also had the responsibility of managing premises, such as community hospitals and health centres, in addition to providing community-based nursing and therapies.

PCT chief executives who were interviewed had very wide-ranging roles. Delegated interviewees had various responsibilities, including managing staff, facilities and/or leading on strategic planning and development, while several of them were actually responsible for implementing the *NSF for Older People*, sometimes not just for their own PCT but on behalf of the health and local authorities as well.

Community NHS trusts

At the time of the interview, community services were undergoing devolution to the new PCTs. The community NHS trusts were therefore undergoing major organisational change, and either evolving into specialist mental health/learning disabilities trusts or preparing to be dissolved completely by April 2002. One of the trusts interviewed was a combined community, acute and mental health trust.

This organisational upheaval was reflected in the rapid revision of roles of some of our interviewees. For example, in one community trust being wound down, the interview was delegated to a manager, who it transpired during the interview, was already employed in a different organisation. Another interviewee described 'losing' staff to the new PCTs, but in turn, 'taking' staff from local mental health providers. This manager also said that his organisation was actively seeking to move to care trust status in the 'medium term'. This suggests that the organisational change for some community NHS trusts is unlikely to be resolved by 2002.

Acute and specialist NHS trusts

Acute and specialist NHS trusts tended to be much more stable in terms of the scope and range of services provided. Nevertheless, one trust had recently undergone a major reorganisation of acute services and merged with another trust earlier in the year.

The response to the interview was poorer among acute NHS trusts compared with the community and social care sectors, with only 11 out of 25 (44 per cent) acute NHS trusts agreeing to participate. However, the responding acute NHS trusts comprised a diverse range of organisations, covering rural and urban locations, university teaching hospitals, a hospital split over separate sites, a large combined NHS trust and one single specialty hospital. One hospital served a large retired population on the south coast of England, with the medical director feeling that the trust had developed a considerable expertise in caring for older inpatients.

With one exception, the eight medical directors interviewed had continued working part-time as consultants. The three medical directors who delegated their interview did so to consultant colleagues. Thus, these interviews provide some insight into medical perceptions of age discrimination.

Social services departments

The social services departments included in the survey were demographically and geographically diverse. In organisational terms, they were established 'players' with a long experience of commissioning and providing services for older people.

There was much less mention of the potential benefits of greater structural integration of health and social services than among interviewees in the primary and community trust samples. However, one interviewee was both a joint director of social services and chief executive of the health authority.

Several local authorities had changed the way they were structured from a committee to a cabinet style of working. Some social services departments had been reorganised to separate strategic and provider roles. One of the interviewees was accountable directly to elected council members rather than the director of social services; this may have enabled the respondent to act seemingly quickly to implement change.

The impact of budget constraints on service quality was a consistent and obvious theme. The financial constraints on social services were also often referred to in the PCT and community trust interviews, usually while discussing working in partnership with social services.

Presence of age discrimination in local services

The first part of the interview asked for managers' subjective assessment of whether age discrimination occurred within their services. Interviewees were not provided before the interview with a definition of age discrimination.

Most managers (75 per cent) believed that age discrimination was taking place in some form or other within services in their local area. Only about 25 per cent thought age discrimination was unlikely in their local services, though this was often qualified with comments about the difficulty in spotting it:

> *We don't discriminate on age. I'm not 100 per cent sure it never happens.* (Assistant director of social services)

> *For the sort of work we do, many of the . . . diseases affect the elderly, I wouldn't have thought we discriminate.* (Hospital consultant)

> *We don't commission services like that, there are no specific bars.* (Assistant director, PCT)

Some managers seemed uncomfortable with the term 'age discrimination', and several of the interviewees were guarded in tone. One respondent in social services felt that the age discrimination debate was associated with left-wing politics and this was an important consideration when working with elected members.

Examples of age-related policies or age bars

Most of the examples of age discrimination described by senior managers in their local services were direct discrimination, in which policies restricted access to particular units, facilities and treatments by setting upper or lower age limits (Appendix E). However, it was consistently said that there were very few written policies specifying age criteria or age bar:

> *Going back ten years, we used to have cut-off points, now 94- and 95-year-olds come in.* (Medical director, acute hospital trust)

> *No written policies use age as a determining factor. The only way to find out would be to undertake a piece of comparative work looking at referrals, prescribing, etc.* (Director of primary care, PCT)

Managers in the community trust sample were most likely to identify explicit age-related services. Interviewees often considered such restrictions to be rational, though the respondents did not always personally agree with the underlying reason. For example, one specialist neuro-rehabilitation service limited its programme to people under 65 because of its emphasis on returning people to work.

Among both the community and primary care respondents, chiropody was said to be the most common service said to discriminate by age. It tended to have minimum rather than maximum age limits for access. Older people were not necessarily identified as the main group at risk in this case and neither was discrimination necessarily felt to be unfair.

Indeed, in the community trust sample, older people were more often identified as having better access to appropriate services because community services tended to be designed for patients in older age groups. A common observation was that older people were the 'core business' or the main user group of community services.

Very few examples of indirect discrimination were given, and these reflected some of the major concerns expressed in general by older people, such as limited availability of particular kinds of surgery, drugs and equipment. Interviewees' understanding of the concept of indirect discrimination was often hazy, though not always. The interviews were peppered with qualifications such as '. . . if you could call that discrimination'.

Audits of age-related policies

Virtually all the respondents knew that the *NSF for Older People* specified local audits of age-related policies. In June when these interviews were undertaken, such audits, which were carried out in all of the respondents' trusts, had not been completed. It is therefore unknown how the examples of age-related access to services listed in Appendix E will have been affected by audits carried out since the interview.

Reasons given for restricting services by age

Respondents were more likely to describe age criteria as having 'evolved' rather than as a deliberate strategy to ration services. An exception was a community trust, which had, until recently, limited some stroke and rehabilitation services because of 'volume of demand' to people under 65, even though most patients needing the service were over 65. The health authority had recently funded this service up to age 75.

One PCT chief executive believed rationing by age was justified in principle (though he was not aware that it occurred within his PCT's services), because he believed that younger people had a greater claim to finite resources for

life-threatening conditions. He was the only respondent of 75 to articulate this view.

Generally, however, managers gave a very different reason for restricting community health services by age. Minimum age criteria acted as a form of protection for older people to ensure access to services in high demand:

> *It's a method of rationing, for example, [the] continence [budget] is always overspent . . . You create age criteria to reflect the level of demand, and because users in the older age brackets may not have the same 'voice' as younger users.* (Chief executive, community trust)

Few interviewees used the term 'rationing'. Nevertheless, one of the most common explanations given for age discrimination (direct or indirect) was competing priorities for insufficient resources.

Specialist services for older people and other age groups

Services are often organised and funded for particular age groups, e.g. as in special wards, units, centres or care homes, clinical specialties, or approaches to care. Concerns about specialisation were expressed throughout the interviews, particularly for social services, paediatric, and adolescent and mental health services. Both younger, middle-aged people (e.g. those with early-onset dementia) and older people were identified as being potentially disadvantaged by restricted access to services. One interviewee noted that older people themselves had challenged the 'rigid requirement' to move from adult mental health services to older people's services at age 65.

Social services provision

Social services are typically organised and funded around different age groups (i.e. children, young adults and older people), with older people being by far the largest single 'client group'. This division of services is intended to differentiate (i.e. discriminate) between different groups with different needs, and social services interviewees were therefore asked about the level of provision given to different client groups.

Allocation of resources by age

Although some interviewees felt these divisions can lead to unfair treatment of older people because of, for example, lower levels of funding for services used by older people, not all respondents believed that older people were being treated unfairly. Several respondents said that the different cost ceilings for community care packages reflected the different 'markets' for residential care. Thus, since fewer residential places were needed for younger disabled adults, they tended to be more expensive, with local authorities having little influence over the level of fees for these services:

> *We don't discriminate . . . There are different cost ceilings but that's based on market values. Doesn't stop anyone getting access to services.* (Director, social services)

Another respondent saw the presence of differential cost ceilings as reflecting positive discrimination in favour of younger people rather than negative provision for older people:

> *Historically, we have [over]spent . . . on learning disabilities. We had a lot of large institutions and had to move people . . . as part of community care reforms. So it's more that we've had to positively discriminate in favour of people with learning disabilities.* (Director, social services)

Other respondents were less reassuring. They suggested that older people were more likely than other clients to be placed in residential care or to have less choice over care options. Reference to the market is again made by one of the following interviewees, but all three respondents also acknowledge that the approach of social services to older people is inherently discriminatory. The examples given point to differences in service provision from resource allocation and commissioning through to assessment of need at the individual level:

> *The limit for younger disabled is much higher . . . because residential costs are higher. The market for older people is more 'pile em high, sell 'em cheap'. But also . . . there's a notion of 'it's more important to keep a young person at home'.* (Head of older people's strategy)

> *It's [age discrimination] very noticeable when assessing the needs of younger persons . . . 'Do they have a social life?' and so on. For older people, we take a much more basic view.* (Director, social services)

> *Generally . . . there's less per head for older people. It's historical, when local authorities were charged with eligibility criteria there was great concern about the consequences of an open-ended approach. [Older people are] placed in residential care homes so we don't overspend. It's discrimination because it's not how we would treat . . . children, then it's 'hang the cost'.* (Director, social services)

Historical ageism

Some interviewees expressed the view that historical patterns of service provision have a tendency to become 'norms' for current and future care. Thus, historical attitudes may become part of the culture of service provision and therefore 'invisible' to some extent and difficult to tackle:

> *The obvious comparison is with mental health 50 years ago and the large Victorian asylums. Older people's services are still suffering from the asylum mentality.* (Intermediate care co-ordinator)

> *We expect to pay significantly higher amounts for residential care for younger adults. It's historical, based on lower expectations . . . Some of that will be realistic and some is 'that's the way we've always done it'.* (Director, social services)

> *Our response is age-related. We think it isn't but if you stand back . . .* (Manager, social services adult provision)

Acute and community health services

Specialist services for older people are also a feature of acute and community health services. The debate about whether general or specialist models of care are more appropriate for older people was particularly apparent in the interviews with medical directors. There were conflicting views:

> *It's very well integrated now, general medicine and geriatric medicine . . . We can make certain about not missing diagnoses.* (Medical director, acute NHS trust)

> *In the past, anyone over 70 was admitted to the medical elderly ward. Now all emergency admissions go to [the] acute assessment unit for immediate treatment and then the appropriate ward. It works better. We want medicine of the elderly to disappear [and] to develop . . . a specialism in multi-organ disease or rehabilitation.* (Medical director, acute NHS trust)

> *[There is] medical justification for age-based criteria. The elderly have multi-pathologies. Physicians [caring for the elderly] have a broader perspective than generalists.* (Medical director, combined trust)

Other respondents singled out dedicated elderly wards as the focus for excellent care of the elderly in their organisations, in contrast to the level of skill and knowledge on more general wards. For example, 'most junior doctors at ward level haven't a clue [how to care well for older patients]' (Medical director, acute NHS trust). Furthermore, according to one manager from the PCT sample, older people admitted to general wards in their area, following the closure of local dedicated elderly wards, were at greater risk of neglect.

Arbitrary nature of age cut-off points

Many of the interviewees questioned not so much the specialisation of services as the arbitrary nature of using age to define boundaries:

> *People can have co-morbidities at any age, and if you don't qualify, then you miss out.* (Specialist services manager, community trust)

> *A 65 or so cut-off is arbitrary . . . The biggest client group is 80 plus – very few people under this age are getting older people's services. . . The*

> *over-75 or over-80 age group [needs] a special focus rather than a simple age cut-off.* (Director, social services)

Some respondents believed that the way in which services were commissioned and delivered caused these arbitrary age cut-offs. Services were being designed with age groups in mind rather than around individuals' needs: 'the pathways are nonsensical'. (Specialist services manager, community trust)

> *There are services only for the elderly as well as some only for the young. [Discrimination] is fairly systematic and institutionalised . . . embedded by commissioning and the way this is approached. Users are viewed as client groups – we don't think of a person's journey through life.* (Chief executive, PCT)

> *It's a cultural thing, left over from the purchaser-provider days, [which] encouraged a focus on younger patients, because it was better value for money. Things are changing, consultants' attitudes are changing – they are more willing to treat elders.* (Chief executive, PCT)

A nursing manager in a community trust said there were no explicit age-related exclusion criteria in services, just 'non-thinking discrimination . . . people are working in silos – they didn't plan services as a whole'. Thus, services for younger physically disabled patients operated up until 60, while the geriatric services normally included people over 75.

But would removing cut-offs be enough to ensure a truly needs-related service? Another respondent felt that ageist attitudes on the part of health service staff meant that access to services was sometimes needs-related in name only:

> *[Professionals] don't do enough of assessing need, they see the age first.* (Joint commissioning manager, health authority/social services)

Staff's flexible interpretation of age cut-off points

Many respondents stressed that age limits to specialist services were interpreted flexibly by staff. Many services accepted referrals that breached age criteria according to the individual patient:

> *[There is no] real evidence that . . . policies militate against doing something. A person's capabilities, competencies and support [are all considered].* (Chief executive, community trust)

Nevertheless, the very existence of age criteria seems designed to limit professional autonomy over access:

> *We do have benchmarking [of care package costs by client group]. It's pretty rare that we go outside that. When you're 85 plus, there's a tendency to be offered the mainstream.*
> (Assistant director, adult social services)

High-level need versus preventive services

Social care is increasingly targeted on people with the greatest need. Several interviewees pointed out negative consequences for older people. The first respondent quoted below believes that the lack of low-level preventive services discriminates against the 'younger old', who have less access to statutory support because resources are being targeted towards those with highest need. According to both respondents, the lack of preventive support leads to irreversible loss of independence so further disadvantaging individuals as they get older:

> *Resources targeted towards the most in need and not towards lesser priorities discriminates against younger older people [so that] more people are at greater risk of breakdown. There is no satisfactory formula [to quantify the effectiveness of more preventive approaches].*
> (Director, social services)

> *We've got a declining number of people on statutory provision and a growing population of older people – and what are we providing? Two hours of home care a week [for older people] . . . Even preventive services are about avoiding high-dependency cases – they aren't truly preventive at all.* (Director, social services)

These respondents also gave examples of local initiatives with a preventive impact that they felt had some potential to tackle these issues. These examples were aimed at helping older people to maintain and develop social networks and to keep fit and active by, for example, opening school swimming pools to older people, or providing back up for older people's luncheon clubs.

Clinical decision-making: 'do not resuscitate' policy

Many interviewees referred to age discrimination within clinical decision-making. This was often mentioned in the context of 'do not resuscitate' (DNR) policy and practice. Respondents did not usually have daily experience of such a policy, but they were strongly aware of the way in which DNR had been linked with age discrimination by the media and Age Concern.[3,4]

---

[3] Boseley S: Call to outlaw medical ageism. *The Guardian*, 28 April 2000.

[4] Department of Health. *Government reinforces patients' rights on resuscitation decisions.* Press Release 2000/0490, 5 September 2000.

Although medical managers tended to disagree that the concept of DNR policy was discriminatory in principle, there was some discussion about the uncertainties involved in assessing risk and outcome in individual older patients:

> *When I trained as a surgeon, you didn't operate on anyone over 60; it was the perceived wisdom and the results were appalling. The problem now is that there's no evidence base even though we have an ageing population . . . 60 is not old any more. You have to go on gut feeling [in deciding whether to operate].* (Medical director, acute trust)

> *It's not so much age discrimination as the diseases that present at a certain age . . . So take someone at 90, there's not much [we can do] . . . at the age of 45, we can do something . . . [The age at which doctors start to question the options] it's changing over time but it does still apply.* (Medical director, acute trust)

It is almost certainly true that older people's levels of health and fitness have improved with rising standards of living. The fact that '60 isn't old any more' implies a subjective element to clinical (and wider social) evaluations of quality of life in older age, and touches on a central issue behind the public furore over DNR – to what extent are doctors making clinical judgements based on prejudiced assessments of age-related risk? However, this interview was not an appropriate tool to explore this topic properly.

The evidence we collected was frequently reflective. One medical director described the difficulties inherent, even in shared clinical decision-making:

> *At a meeting, I often say – should we be offering chemo [therapy] to this person of 85 – should we give them that option? . . . But isn't it our job to take on that decision? Patients say 'What would you do if it was you, doctor?' They don't know. Sometimes you see people suffer, and it does them no good . . . it's a very difficult balance.*
> (Medical director, acute trust)

Equality of access to acute care

Concerning access to hospital care, acute NHS trust respondents felt there was relatively little scope (or incentive) for them to discriminate against older people as the trusts had little control over referrals. Not one of the interviewees thought older people were denied access to hospital care, in any deliberate way, because of their age. Occasionally, however, respondents suspected that primary care referrals might be biased towards younger patients:

> *Four or five years ago, GPs still didn't have to refer [for cataract] unless patients were practically blind. Now, that's considered poor practice and it's beginning to change, particularly for children.*
> (Medical director, acute NHS trust)

Interestingly, the concept of the acute hospital as a 'fixer' was quite striking in the interviews with medical managers – 'we do them all – young or old'– who often employed industrial or mechanical metaphors in their accounts of hospital work.

Role of GPs as gatekeepers to hospital care

Interestingly, in our interviews with PCT managers, the role of GPs as gatekeepers was not often raised. Even though we did not ask specifically about this aspect of care, it is perhaps surprising it was not mentioned more often, particularly as a national survey of GPs had recently been published suggesting disturbing levels of age discrimination among GPs.[5] This may be because practice-level data, e.g. referral patterns by age, tends not to be systematically monitored by PCT managers or, indeed, by anyone.

One respondent from an acute NHS trust felt strongly that discrimination was more tangible in the way older people were viewed after admission. 'People are very well managed in the first few days.' But after their initial treatment, she felt that doctors were quick to discharge older patients to residential care, without much thought of the long-term outcomes for the patient or their wishes.

> *[That is the key] decision where patients are not involved and it annoys me more than [older people's] treatment in hospital.*
> (Medical director, acute NHS trust)

[5] Age Concern England. *Two-thirds of GPs back call for inquiry into ageist NHS.* Press Release. 17 May 2000.

Attitudes to caring for older people in hospital

Another medical director from an acute NHS trust wondered if the reality of caring for people with chronic or multiple health problems fell short of the acute professionals' expectations of curing people:

> *Geriatric wards are not popular with staff... There are a lot of people for whom you can't do that much. It's not why they [staff] come into hospital work.* (Medical director, acute NHS trust)

This view was not limited solely to the hospital sector, as demonstrated by a primary care manager from a PCT:

> *If the prognosis is poor for an older person or if they might not achieve the desired outcomes, this can affect staff attitudes.*
> (Primary care manager, PCT)

Although there was little obvious evidence or examples of restricted access to acute hospital care, there were some concerns about how well acute hospitals were serving older people's needs – a more subtle form of discrimination:

> *A lot of government policies prioritise intermediate care... [it seems that older people] don't deserve acute medicine.*
> (Consultant geriatrician, acute NHS trust)

Quality of care at the end of life

Quality of care at the end of life was one of the services singled out for criticism. Two of the medical directors cited examples of heroic interventions which they ascribed to colleague's fears of being labelled ageist, but which prevented people from dying with dignity. Sometimes, the capacity of specialist palliative care services was questioned.

Managers' confidence in health and social care services

Near the end of the interview, managers were asked how confident they would feel about their local health and social care services if they themselves were an older person. This question prompted managers to think about services as a whole, taking the user's perspective. The response was mixed and best summed up by the respondent who was confident that local services:

> *would meet my needs, but perhaps, not in the way I would want them to be met.* (Director, social services)

Managers tended to be more confident about the services provided by their own organisation or services in their own locality than in other agencies or areas, reflecting their knowledge of their own systems and structures.

Respondents from the acute NHS trust sample were especially confident about clinical standards of care. However, this was qualified by concerns about 'process issues', e.g. discharge, and also about the lack of 'creature comforts' in hospital:

> *I would bet that if they [the elderly] come into the care of the elderly wards, they won't like it. But I think we're providing the best care we can.* (Medical director, acute NHS hospital)

Several themes emerged consistently in people's answers to this question, echoing earlier concerns.

Access to care

Access was again an issue for some respondents. People cited complex pathways, poor communication about services and, much more rarely, limited capacity:

> *The access to orthopaedic services is poor and funding is restricted. The amount of care is less than it was and entry-gate criteria are higher. The pot of social services money is not purchasing enough care but once you're into the service, elders will have a different view, it will seem better.* (Chief executive, community trust)

Knowledge of the system

Knowledge of the system was often thought to be important to obtain access to good care and obviously respondents felt that they were relatively well placed in this regard. Respondents with direct experience of family members in receipt of long-term care or in sheltered housing tended to be the most confident.

Role of family and carers

The role of family members and informal carers in providing long-term care was acknowledged. There was some fear of becoming a 'burden' to one's family and, more rarely expressed, about the ageing process itself.

'Slipping through the net'

Criticisms about gaps in services, poor integration and patchy provision (especially for black and minority ethnic elders) were made. A comment made several times was the risk of 'slipping through the net':

> *For nursing care there are three different teams. During the week two different carers go into people's homes four times per day – who's going to review that? There is no care co-ordination between health and social care for older people.* (Head of elderly services, community trust)

Other themes

One of the most striking feature of people's answers was the consistency with which respondents believed that their own needs were more likely to be met because the ageing post-war generation will demand greater respect from society and will be less tolerant of poor services.

In addition, several respondents in social services and community samples stressed the lack of early and preventive services, and of support that addressed isolation and loneliness. Respondents also identified lifetime opportunities as an important factor, particularly in terms of social care. For example, older people with an occupational pension were in a better position to fund good-quality care. There was some perception of statutory social care services as a safety net for poorer older people.

Perceptions of older people and their families

We asked interviewees if patients and older people had voiced concerns about age discrimination within services. Although health service managers cited individual complaints about discriminatory behaviour (often by patients' relatives on their behalf), there seemed to be very little local agitation about age discrimination from older people themselves.

Patients' relatives were identified both as older patients' champions but also as a source of conflict. Relatives were perceived sometimes to have unrealistic expectations or to attempt to influence treatment decisions to their own advantage. One respondent identified the 'flak' that nurses receive from patients' relatives to be sufficient to deter nursing staff from working on dedicated elderly hospital wards.

Older people's expectations of services

A very consistent theme across the whole sample was that older people's expectations of services were low:

> *People are not very good at going out and asking . . . and the services aren't that good at finding unmet need . . . there isn't enough chiropody or rehabilitation. If you want any physical refurbishment done to your home, like stair rails, you can wait a very long time.*
> (Head of primary care, PCT)

A service development manager of a PCT gave an example drawn from her previous work as a district nurse. When she rang older people to make an appointment to visit, none of her patients would state a preferred time; they just expressed relief she was visiting at all.

Finally, one interviewee made the following comment, though stated humorously, about accessing statutory services should she ever need them:

I'm going to be awful, really demanding. (Manager, community trust)

This reflects the double standard faced by older people. Low expectations of care may be self-fulfilling, but conversely if people do demand services to which they are entitled, they may find themselves labelled as 'difficult'.

Initiatives for tackling age discrimination

Infrastructure

Wide variations were reported in the extent to which health and social care organisations have established an infrastructure capable of systematically scrutinising services and taking action to deal with unfair age discrimination.

Older people's forums

Some organisations were much more experienced than others in involving older people and their organisations in reviewing policies and practices. All the managers of community health and social services were aware of local groups and forums that regularly worked with their local councils or NHS trusts in strategic planning and service development. However, even where older people's forums had been established for some time, many managers tended to believe that mechanisms for hearing the views and experiences of older people were markedly underdeveloped. A common refrain was, 'We could always do more.' Managers in acute trusts were far less engaged with public involvement processes.

Response to the *National Service Framework for Older People*

All the interviewees said that the milestones of the *NSF for Older People* were being implemented locally. However, the pace of implementation varied. Typically, interviewees said that age discrimination had been discussed at board level with implementation being facilitated through working groups – often with other health and social care agencies. Many organisations had already appointed older people's champions, and steps were being taken to implement the audit of age-related policies. It was this latter task that seemed to cause the most comment. The timetable was frequently criticised ('absurd'), as was the lack of timely guidance that had been promised by the Department of Health.

Policy initiatives: local examples

We asked respondents to describe any other initiatives taking place that, in their opinion, tackled age discrimination. Most of the examples were of attempts to improve the availability and quality of services for older people (*see* Table 1), but there were also examples directly aimed at tackling discrimination (*see* Table 2).

However, examples of good practice or improved services for older people that were thought likely to tackle age discrimination indirectly were much more

common. Interviewees in the community health and social services sample often identified a shift in the culture of provision, which one respondent described as 'enabling rather than nurturing', and a greater focus on maintaining older people's independence. There was considerable optimism and enthusiasm about the quality of care provided under these initiatives.

National policy developments

National policy developments have also clearly had been influential. In addition to the NSF, respondents cited the following as significant levers for change for older people in their localities:

- 'Best Value' reviews in local government – particularly when the review cut across departmental boundaries
- Better Government for Older People
- Some respondents, particularly within PCTs and community trusts, were positive about the potential of greater structural integration through the Health Act Flexibilities and Care Trusts
- Health Action Zones
- Beacon status
- In the NHS, *Improving Working Lives Standard*[6] strategy on good employment practice.

[6] Department of Health. *Improving Working Lives Standard*. London: HMSO, 2000.

Table 1: Examples of ways in which age discrimination is being tackled locally

Service development	Objective/benefit
Social services sample	
• Direct payments to older people	Promotes user choice and autonomy
• Action based research projects by staff	Staff development and awareness
• 'Softening' eligibility criteria	Fairer access to services
• Best Value reviews on social inclusion and community safety (different councils)	Systematic and cross cutting approach to issues
• 'Grandparents initiative' (Sure Start scheme)	Benefits for young people
• Specialist home care team for dementia	High-quality care
• Beacon award for mental health services	High-quality care
PCT sample	
• Community transport between health sites	Making services accessible
• Intermediate care investment (noted by several respondents)	Promoting independence
• Joint action on cataract services	Expanding access to surgery
• Adult protection strategy	Prevent and tackle elder abuse
• Co-ordinating care of terminally ill at primary/secondary interface	Promotes choice and control
• Specialist service for Irish elders	Addresses specific needs of this group
Community trust sample	
• Intermediate care (noted by several respondents)	Promoting independence
• Re-ablement and rapid response teams	Promoting independence
• Innovation in nursing homes	High-quality care
• Organisational development: 'leading empowered organisations'	Positive organisational culture
• Audit of physical disability services	Identifying gaps in services
• New unit with 50 rehabilitation beds	Investment in high-quality care

Table 2: Summary of initiatives established against age discrimination

Staff education and training
• Training for staff, which includes components on the needs of older people such as the National Vocational Qualification (NVQ) for assistants
• Some diversity and cultural awareness training, again including a focus on age, as well as race, ethnic diversity and disability
Social inclusion and citizenship
• Examples cited by the managers in social services which directly attempted to tackle discrimination tended to be council-wide initiatives, e.g. looking at ways in which older people could participate in community networks, libraries, and leisure facilities
• Schemes bringing older people together with children and adolescents. In one example, this was with the intention of addressing ageist stereotypes of both young and old
• Respondents who reported investment in community and intergenerational relationships were very positive about the potential impact for older people's independence
Employment policies
• Equal opportunities policies frequently mentioned age. However, it was not always clear to what extent policy was being implemented or monitored in this respect
• Primary care trusts and community trusts seemed to be the most flexible employers, many operating 'bank' systems for staff interested in working part-time after retirement

Discussion

Age discrimination identified in local services

The survey results suggest that older people are at risk of unfair discrimination both in health and social care services. Only about 25 per cent of respondents denied that access to or quality of services was related to age. The remainder provided examples of both direct and indirect age discrimination. These did not discriminate solely against the elderly, but adversely affected patients and clients of all ages, particularly with regard to age-related restrictions. However, age discrimination was also perceived as a method of positive discrimination: age-based criteria were seen to favour older people or were viewed as a reasonable proxy of need or specialism. In addition, older people's access to the same types of services varied in different parts of the country.

Respondents in the social services sample were the most consistent in identifying 'institutional' discrimination, i.e. discrimination inherent in service design. Several social services respondents commented that despite their goals to the contrary, older people's services promoted dependency and offered people very limited choices.

Tackling age discrimination

One of the main contradictions in our findings has been that while the interviews did point to various forms of age discrimination, this was rarely seen as a local priority for management action. The *NSF for Older People* was being implemented, but this was being driven by national directives rather than any local imperatives. However, it would be wrong to portray respondents as insensitive or unreflective about services: there was a great deal of enthusiasm in the way that most respondents talked about older people and services.

The most common factors underlying age discrimination identified in the interviews were:

- lack of resources
- widespread ageism in society
- the legacy of historical ageism in the welfare state.

Clearly, the difficulty in addressing these issues at a local level may explain some of the resignation that prevailed in our sample about tackling age discrimination. But there were additional reasons why age discrimination was difficult to address:

- There seemed to be considerable confusion about when age discrimination was justified and when it was not. This was most obvious in the conversations with PCT, community trust and acute trust managers about specialist versus

generalist services where specialist services were defined by an age range rather than a medical or social condition.

- In addition, some managers' understanding of indirect discrimination was unclear, and statements were often qualified with comments such as '. . . if you could call that discrimination'.
- Examples of 'heroic' interventions were ascribed to medical colleagues' fears of being labelled ageist. These examples (although anecdotal rather than based on personal experience) demonstrate that being treated equally can be interpreted as meaning everyone should get the same resources, intervention or service.
- Age discrimination is a relative concept, and involves identifying 'winners' as well as 'losers'. This concept was not only difficult to understand sometimes but, to some extent, was also uncomfortable for managers responsible for providing services to communities as a whole, where services may have conflicting priorities.
- In social services, it was considered that the relative volume of older people as a client group was a barrier to action, and that redistributing resources more equitably would result in little benefit to individuals. The concern about this argument is that it could, in theory, be used to justify reductions or incursions into social services' budgets for older people. However, there is no evidence from this survey to support this notion.
- Some interviewees were uncomfortable with the term 'age discrimination', especially as it is usually seen as being negative, and, not surprisingly, several respondents were guarded in tone. Age discrimination is also a politicised issue, with one respondent in social services associating the discrimination debate with left-wing politics – an important consideration when working, as in this case, with elected members on a Conservative council.
- The difficulty many managers reported in identifying ageism at the level of the individual professional–patient encounter seemed to encourage a view of age discrimination as an abstract phenomenon.

Certainly, in the community health and social services samples, concepts such as citizenship, inclusion and independence were sometimes regarded as more productive ways of approaching many of the same issues about accessibility, quality and outcomes experienced by older people and patients.

Nevertheless, we would argue that age discrimination with its explicit connotation of 'unfairness' is important. Its power comes from the way that it directly challenges our assumptions about older people. In this survey, a relatively brief interview over the telephone yielded many insights into the ways in which services may unfairly affect older people.

The importance of the National Service Framework for Older People

In all of the interviews, it was clear that steps were being taken to implement the NSF in respect to age discrimination. Furthermore, almost without exception, respondents thought that the NSF's explicit reference to age discrimination was a

good thing for older people. However, interviewees were resentful about the time-scale of implementation, the delay in getting guidance on reviewing age-related policies, the number of competing central initiatives and the lack of additional resources. Several respondents accused the Government of double standards in not itself reviewing age-related criteria in national policy, e.g. in social security regulations.

However, it is important to note that this policy does not simply articulate a principle as has happened with previous statements from the Government and professional bodies. It goes much further in requiring organisations to take action to root out discrimination. This, in turn, means that health and social care organisations will be more directly accountable to older people on the grounds of equity in their provision of services to this patient group.

Conclusion

During the course of this survey, we were given many examples of recent or current service developments, commitment to public involvement and partnership working that were likely to have particular benefit, either directly or indirectly, for older people and carers. Many respondents spoke with enthusiasm and, in some cases, with passion. Improving services so that they better meet the needs and aspirations of older people (and carers) will in itself have an impact on age discrimination.

However, the gap between managers' awareness of various forms of age discrimination in services and its comparative low priority for action suggest that age discrimination is not yet widely seen as 'an issue for all of us'. The *NSF for Older People*, with its emphasis on written policies (which from the evidence of this survey are already on the decline), will not challenge ageist organisational cultures, structures and attitudes, in the short term at least, and further strategies are required.

Recommendations

We believe the following recommendations are likely to have a positive impact on age discrimination given the evidence from the survey. However, these may not necessarily be straightforward to implement well nor are they quick fixes. There are also likely to be drawbacks or adverse consequences, which need to be evaluated to a greater degree than is possible here, given the qualitative nature of our survey.

Clarify the meaning and consequences of age discrimination

In view of the confusion around this form of inequality, managers and, we suspect, others charged with combating age discrimination in health and social care would be helped by guidance setting out a conceptual framework for spotting and challenging policies and practices that disadvantage older people. Work underway at the Institute for Public Policy may be helpful, especially if its work could be made accessible and usable by both lay and professional audiences alike.

Develop benchmarking

The *NSF for Older People* promises the development of a benchmarking process to allow referral and service patterns to be compared between different organisations. The evidence from our survey suggests that development of benchmarking should be high priority, as many respondents found it very difficult to identify age discrimination at the individual level. Analysing aggregate patterns of treatment for possible age bias is one way of detecting unwritten discrimination. Such data monitoring was extremely rare among our respondents, with only two mentioning any sort of data-mapping exercise. A start could be made on those aspects of health and social care that are particularly important for older people, e.g. hip replacements, cataract removals or aids for independent living.

Introduce age-equality legislation

By explicitly acknowledging discrimination, the *NSF for Older People* legitimises older people's right to raise discrimination as a strategic issue. But does the NSF go far enough? The survey provides little direct evidence on this. Only one respondent volunteered legal action as an effective way of tackling discrimination. However, legislation that outlawed age discrimination in services and put the onus on organisations to demonstrate they did not discriminate would exert more pressure on managers to change discriminatory practices than can the *NSF for Older People.*

Current UK legislation concerning age discrimination in statutory services is very weak. Under the European Convention on Human Rights (ratified under UK law in 2000), people can legally challenge discrimination only if the consequences

have adversely affected their right to life, family, privacy, etc, and stronger legislation banning age discrimination is urgently required. However, the time may be right to introduce stronger legislation, together with implementation of the EU Framework Directive prohibiting discrimination in employment and occupation on grounds of age. This must be implemented by EU member states, including the UK, by 2006, and could provide the Government with an opportunity to extend anti-age discrimination legislation to health and social care. At the same time, there would be some merit in overhauling current equalities legislation concerning race, sex and disability, on the lines suggested by Lord Lester at the recent Help the Aged annual lecture.[7]

Care will need to be taken in any legislation affecting access to health care to avoid introducing perverse incentives for staff and professionals to act 'defensively' to minimise their risk of being sued rather than maximise their patients' best interests and wishes.

Scrutinise national policy

Besides a lack of resources, managers most commonly identified an inherently ageist society and bureaucracy as a main barrier to tackling age discrimination. Both factors are not easily amenable to local intervention. If the Government is serious about tackling age discrimination, it should make more effort to review national age-related policies, perhaps along the lines suggested in the *NSF for Older People*. This would encourage serious consideration of age-based policies across a wide spectrum of social policies. Such scrutiny would also challenge any policies that indirectly disadvantage older people, such as those relating to long-term care, and that reinforce discriminatory policies and practices at a local level.

Invest in staff education and training

Some managers identified training as a strategy for tackling age discrimination. Typically, the courses described tended to be aimed at front-line staff and postgraduate clinical professionals. However, professional colleges and bodies may need to consider reviewing the pre-qualification training and education given to health and social care professionals.

Older people comprise the largest consumers of health and social care. Diversity training in these sectors should include a component on age and should also be provided to staff at all levels of health and social care organisations, not just those in direct care roles.

Although much can be done to build awareness of ageing and ageism into existing educational programmes at minimal cost to the organisations concerned, additional resources will be needed to stimulate the development of appropriate

---

[7] Lester A. Age discrimination and equality. Help the Aged Annual Lecture, 2001.

course material and to enable staff to have the time to reflect on their practice away from work.

Critically assess specialist services provided to older people

Specialisation of services clearly brings many benefits, especially in developing skills and expertise. However, the rationale for attaching specific age cut-offs, even to specialist services, is difficult to understand, particularly when respondents talked about the need for flexibility at the margins.

For example, why are mental health services for older people deemed to start at age 65 when the overwhelming majority of users will be much older and would be much better characterised by their particular mental and social care needs? Elderly mental health was a specialty that was criticised perhaps more than any other by interviewees. The rationale behind providing a separate category of mental health services for older people is that they will receive better care as a result but this did not seem convincingly so in this survey.

There was clear controversy about the benefits and disadvantages of generic compared with specialist old age services in the acute sector. It was not clear in our interviews if specialist older people's services were being included in the NSF reviews of age-related policies. If age cut-offs are felt to be a useful guide for particular services, then there ought to be an explicit policy statement (subject to review under the terms of the NSF) that justifies this position for older clients, patients and their families. Furthermore, age cut-offs should reflect the age range of the targeted client group. Non-critical use of a notional retirement age as a basis for defining specialist services should be unacceptable.

Appendix A

National Service Framework for Older People: key objectives

Raising the priority of older people's services
• Older people's champions should be established in all health and social care organisations
• Organisations are expected to select a non-executive director or elected council member to take on this role
• Clinical champions will be appointed for older people
Representation and involvement of older people
• All agencies should seek to engage older people
• Patients' Forums in the NHS should be representative of users and will have a designated older people's champion
Review of age-related policies
• By 1 October 2001, all health and social care agencies should have scrutinised relevant policies for age bias, including council eligibility criteria for social care
• The results will be published in the annual report
• From April 2002, any action arising from these reviews should be included in local plans
Comparison of service patterns and practices
• The NSF promises to develop a system of benchmarking to monitor the use of services by older people
Engagement of staff
• The importance of involving staff in discussions about older people's services and of offering adequate support and training to meet older people's needs is clearly stated
• No explicit targets have been set

Appendix B

Survey letter sent to potential interviewees

Dear _____

Age discrimination in health and social care

As you may know, the Government recently published a new *National Service Framework for Older People* which aims to improve health and social services for older people by 'rooting out age discrimination' and promoting health and independence. The King's Fund has, for some time, been aware of discriminatory policy and practice in the NHS and in social services and we would now like to do what we can to help colleagues responsible for local services as they implement this latest NSF.

We plan to establish a development programme to support people providing local services. However, we would like first of all to hear what senior managers think about the opportunities and problems they expect to face regarding age discrimination in health and social care.

I am writing to ask whether you would be willing to take part in consultations we plan to hold with senior managers in different parts of the NHS and social services. These consultations are intended to seek your views about services provided for older people in your area, and to hear about any ideas or concerns you may have about implementing action on age discrimination. We shall also be keen to hear about any recent developments in your area that you think may help to combat age discrimination.

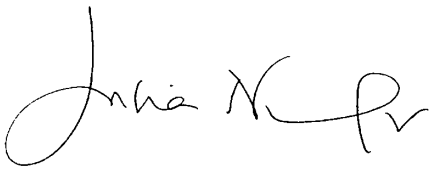
Consultations will be conducted through telephone interviews which should take no longer than 20-30 minutes. The interviews will be conducted by King's Fund staff: Emilie Roberts and Linda Seymour. All interviews will, of course, be confidential and no individual or organisation will be identified in any report.

Information gathered through these consultations will be used to inform the development programme mentioned above. This is intended to help health and social care organisations as they implement the *NSF for Older People* by advising on effective action, and promoting innovative and good practice developments from around the country.

I do hope you will agree to take part in this preliminary phase of the programme. Naturally, we will provide you with feedback from the consultations, and will send you a summary of the key messages arising from our interviews with senior managers.

Emilie Roberts or Linda Seymour will be calling your office in the next week or so to ask whether you are willing or able to help, and, if so, to book a date and time for the telephone interview. In the meantime, if you require any further information, please contact Janice Robinson, Director of Health and Social Care at the King's Fund.

Yours sincerely



Rabbi Julia Neuberger
Chief Executive
Programme

Janice Robinson
Director of Health and Social Care

Appendix C

Telephone interview schedule on age discrimination

Name _____
Position _____
Organisation _____
Date of interview _____

Record of contacts made

If non-responder, record any reason given for not participating here

Introduction

Check if received letter and ask if willing to take part.

If unwilling,

- Repeat that confidential and no individual person or organisation will be identifiable in any report
- Echo aims of the consultation in letter, for example:

Could say that want to get an accurate picture of how age discrimination is perceived by senior managers so that future work on this issue is constructive and relevant, and moves on from simply stating that it exists or doesn't.

- If respondent cites workload/ignorance of issues as factor for not taking part busy, ask if they could nominate someone else that we could approach in their place

Context

1. Can you briefly describe the services that ..... provides? ***(name organisation)***

If talking to a different respondent to that named on the original sample list and their job/role is not clear then also ask:

2. Can you briefly describe your role in the organisation?

Interviewer notes
Interested in thumbnail sketch of all services/responsibilities not just those relating to older people

Age discrimination

3. Now, thinking about age discrimination, as a manager, have you been aware of age discrimination in the services you are responsible for?

If yes, prompt along the following lines (unless already covered in earlier response)

3.1 Do you think this type of discrimination is sporadic or systematic in nature?

3.2 Why do you think age discrimination has occurred on these occasions?

Interviewer notes
If specific instances of discrimination are described, try and probe for source of evidence, e.g. complaints, explicit policy, or personal observation.

Access to services

If respondent employed by PCT/G, ask
4. Is access to primary and community health services in your area ever directly related to a patient's age?

If respondent employed by community or acute trust, ask
4. Is access to your Trust's services ever directly related to a patient's age?

If respondent employed by social services department, ask
4. Is access to social services in your area ever directly related to a client's age?

If no, prompt as follows

For respondents in social services departments
4.1 For example, in many areas, there are different cost ceilings on packages of care for older people compared to other groups

For respondents in community trusts, PCG/Ts
4.1 For example, in some areas there are age-based criteria for chiropody services

If yes, then ask

4.2 Of course, age-based criteria may be justified – do you think that they are reasonable in this case?

Quality of care

5. First, thinking about the physical environment, buildings and facilities

If respondent employed by PCT/G, ask
Do you think there is any difference in the quality of primary and community services provided to older people compared to younger patients?

If respondent employed by community or acute trust ask
Do you think there is any difference in the quality of care that the trust provides to older people compared to younger patients?

If respondent employed by social services department, ask
Do you think there is any difference in the quality of social care services provided to older people compared to younger patients?

Note to interviewers
We're interested in any observable differences even if work to older people's advantage rather than disadvantage

6. Now thinking about staff skills and attitudes towards older people

If respondent employed by PCT/G, ask
Do you think there is any difference in the quality of primary and community services provided to older people compared to younger patients?

If respondent employed by community or acute trust, ask
Do you think there is any difference in the quality of care that the trust provides to older people compared to younger patients?

If respondent employed by social services department, ask
Do you think there is any difference in the quality of social care services provided to older people compared to younger patients?

Age discrimination as a priority issue

7. Has age discrimination been recognised or discussed at board or committee level in your organisation in the last year?

If yes, ask what prompted this?

- evidence of age discrimination in local services?
- priority-setting or other strategic planning?
- the *National Service Framework for Older People*?
- other factor

8. Do you think age discrimination is likely to be an issue raised at senior management level in the coming year?

Age discrimination can be quite subtle and hidden. It's not always easy to observe. So I want to ask some more general questions about older people's services. I want to stress that we're not looking for 'right' or 'wrong' answers here.

9. Would you say that older people's services are a priority in your trust/social services department/PCG (as appropriate)

Interviewer notes
If get a yes/no response, prompt for examples or evidence

Public involvement

10. In what ways are older people formally consulted about services?

11. Are 'harder to reach' older people targeted for consultation, for example, black elders, and older people with mental health or mobility problems?

12. Have older people themselves raised the issue of age discrimination?

Attractiveness of working in older people's services

If respondent is employed in a community trust, PCT or social services department, ask

13. In your current experience, is recruitment and retention of staff for older people's services more difficult than for other services?

OR, if respondent is employed in an acute trust, ask

13. In your current experience, is recruitment and retention of staff in specialties focusing on care of older patients more difficult than other specialties?

NB: don't ask this question to employees of PCGs

If yes, then ask

13.1 What do you think are the underlying reasons for recruitment and retention problems in these services?

Partnerships

14. How effectively would you say that local health and social care agencies work in partnership to meet the needs of older patients/clients? (as appropriate)

Would local services suit you?

15. Hypothetically, if you were an older person in ....., would you have confidence in local services to meet your health and social care needs effectively? (state geographical area)

Tackling age discrimination

16. We are really keen to find out what is being done to tackle age discrimination locally. Are you aware of any action or development that will tackle ageism or age-discrimination in your trust/local area at the moment?

17. Has your organisation attempted to do any of the following:

Tick if yes, and note details below

- Training for staff on ageing or older people's needs
- Inclusion of age in any equality and diversity strategy
- Designate senior managers/non executives or councillors**(if social services)* as older people's champions or leads for older people's services
- Explicit policy statements/goals on age discrimination
- Audit trust/social services age-related policies
- Attract and retain older members of staff in your workforce, for example through a flexible retirement policy

18. Finally, do you think there could be any adverse consequences of highlighting age discrimination as an explicit issue that needs to be tackled in the *National Service Framework for Older People*?

Thank you very much for your time. We will send you a summary of the results later in the summer.

Appendix D

Characteristics of the interviewees in the survey

Organisation	Initial approach	Response rate (%)	Completed interviews (%)		
			Delegated	Male	Female
Primary care trust/group	Chief executive	21 (84%)	13 (17%)	7 (9%)	14 (19%)
Community NHS trust	Chief executive	21 (84%)	12 (16%)	8 (11%)	13 (17%)
Acute NHS trust	Medical director	11 (44%)	3 (4%)	8 (11%)	3 (4%)
Social services dept	Director	22 (88%)	11 (15%)	15 (20%)	7 (9%)
Total			39 (52%)	38 (51%)	37 (49%)

Appendix E

Specific examples of discriminatory service provision identified at the time of the survey

Patient group	Service	Discrimination
Older people	Hospital redeveloped with dedicated wards and staff for elderly. All people aged over 75 and younger patients with multiple pathologies	Direct
Black and minority ethnic older people	Some ethnic minority groups at high risk of heart disease have the lowest rate of access to coronary artery bypass graft	Unclear
Older people	Mental health services (several respondents)	Both
Older people	Health visitors focus on the under fives age group (two respondents). District nurses are struggling to manage 'huge' caseloads including 'high tech' work and palliative care	Both
Older people	In the coronary heart disease programme sometimes (older) people get 'stuck' and don't receive the best care	Direct
Older people	Physical disability unit for younger adults up to age 65; under review	Direct
Older people	Rehabilitation and intermediate care for people up to 65 years	Direct
Older people	Older patients labelled as 'bed-blockers' or 'acopia' (i.e. social admission) suffering from septicaemia and bone fracture	Direct
Older people	Range and scope of services for older people limited compared with other client groups, e.g. domestic cleaning services not available to older people	Direct
Older people	Some GPs treat older patients in a way that younger patients would not tolerate, e.g. an older patient denied treatment in one surgery because their notes were held in a different location	Direct
Older people	Specialist neuro-rehabilitation services focuses on return to work and so have an age restriction of up to 65 years (several respondents in different areas)	Direct
Older people	Stroke team had age criteria because of volume of demand; recently extended up to age 75	Direct

Patient group	Service	Discrimination
Older people	The patient's GP decides whether a general or elderly specialist is required upon hospital admission	Direct
Older people	Waiting times for cataract surgery	Indirect
Older people	Insufficient funding to provide Aricept to Alzheimer's disease sufferers in line with National Institute for Clinical Excellence (NICE) guidelines	Indirect
Older people	Some nursing home residents have poorer access to primary care services	Indirect
Older people	Variable admission routes or care pathways for stroke (two respondents)	Indirect
Older people	Aids and equipment: 'massive areas of discrimination' (several respondents)	Indirect
Younger people	Access to hearing aids	Direct
Younger people	Some of the community hospitals do not take people under 65	Direct
Younger people	Access to rehabilitation and recuperation services limited for people under 60	Direct
Younger people	Chiropody: priority given to older people (several respondents)	Direct
Younger people	Intermediate care and re-ablement service: priority given to older people	Direct
Younger people	Rapid response team limited to people over 65; however, age bar likely to be removed	Direct
No clear view	Care of elderly wards admit people over 77 (two respondents in area)	Direct

ISBN 1-85717-462-3

The King's Fund is an independent charitable foundation working for better health, especially in London. We carry out research, policy analysis and development activities, working on our own, in partnerships, and through grants. We are a major resource to people working in health, offering leadership and education courses; seminars and workshops; publications; information and library services; a specialist bookshop; and conference and meeting facilities.

Published by
King's Fund
11–13 Cavendish Square
London W1G 0AN
www.kingsfund.org.uk

Charity registration number: 20740

First published 2002

ISBN 1 85717 463 1

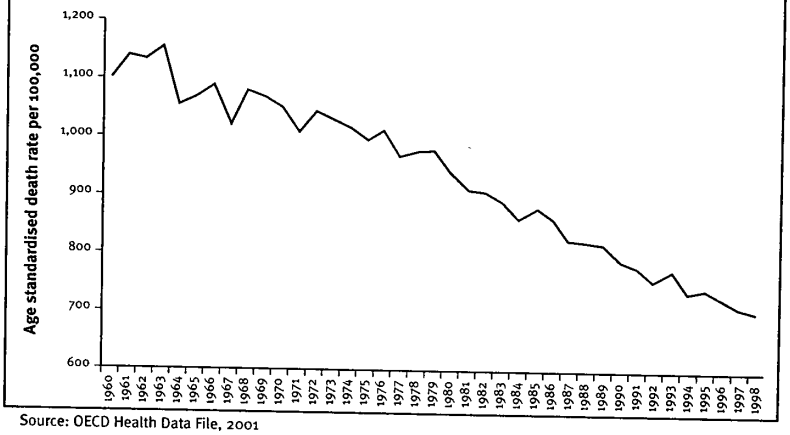
A CIP catalogue record for this book is available from the British Library

Available from:

King's Fund Bookshop
11-13 Cavendish Square
London W1G 0AN
Tel: 020 7307 2591
Fax: 020 7307 2801
www.kingsfundbookshop.org.uk

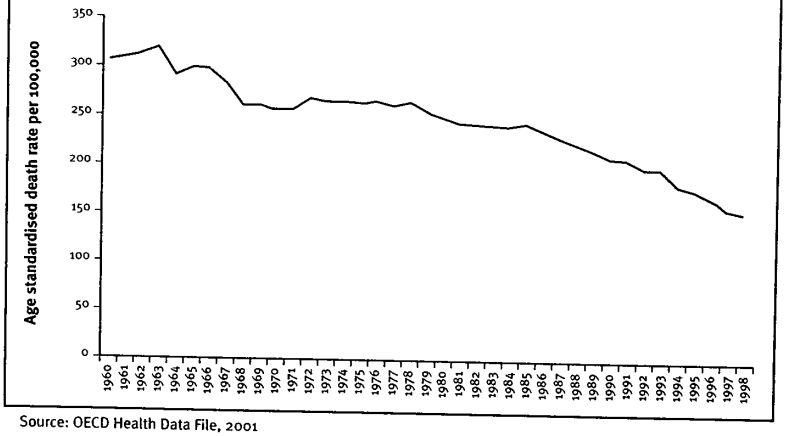
Edited by Andy Bell and Caroline Pook
Cover design by Minuche Mazumdar Farrar
Typeset by Peter Powell Origination and Print Limited
Printed and bound in Great Britain

1 ALL CAUSE MORTALITY UK (PER 100,000 POPULATION, AGE STANDARDISED, REFERENCE POPULATION: OECD COUNTRIES)



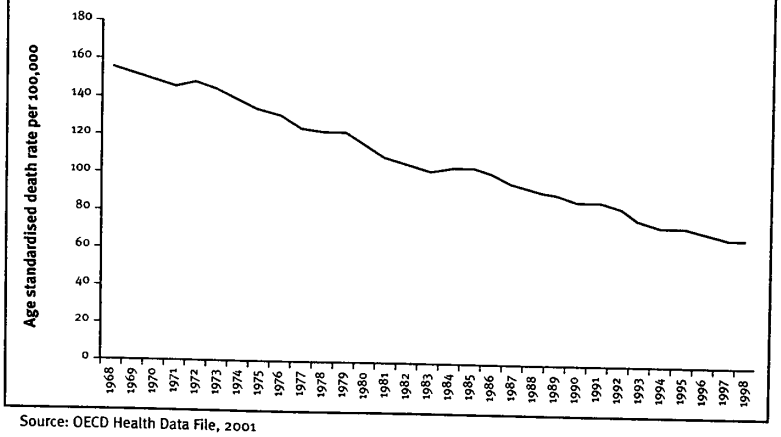
Source: OECD Health Data File, 2001

2 ISCHAEMIC HEART DISEASE MORTALITY UK (PER 100,000 POPULATION, AGE STANDARDISED, REFERENCE POPULATION: OECD COUNTRIES)



Source: OECD Health Data File, 2001

3 CEREBROVASCULAR DISEASE MORTALITY UK (PER 100,000 POPULATION, AGE STANDARDISED, REFERENCE POPULATION: OECD COUNTRIES)



Source: OECD Health Data File, 2001

The Government's commitment to a universal, free, effective health care system available according to need and funded through taxation is beyond doubt.

groups, such as children, older people or minority ethnic communities. Some of these are subject to separate studies (recently completed or under way) and have been omitted here in order to keep the review to a manageable length.

For each policy area, the review sets out Labour's inheritance, initial promises and policies, and their elaboration and extension over the last five years. It then assesses broadly the success or otherwise of the Government's approach. We draw on as much evidence as possible in support of the critique, although some areas – such as NHS funding, waiting and health inequalities – lend themselves better to quantified analysis than others, such as quality assurance, long term care and public involvement. Our verdicts, set out at the end of each section and drawn together at the end of this introduction, provide a brief 'report card' summary of how we judge the Government's record in the period under review.

Emerging messages

We embarked on this exercise without a fixed view of what the final balance sheet might look like. The picture is complex but some clear messages emerge. The Government's commitment to a universal, free, effective health care system available according to need and funded through taxation is beyond doubt. This was made abundantly clear in *The NHS Plan* in 2000[4] and, more recently, by the Chancellor, Gordon Brown.[5]

There is less certainty about the role of the private sector – so long beyond the pale of Labour's ambitions for the NHS. The Government is evidently shifting towards a more positive view of the contribution the private sector can make to health care. In respect of the finance of major capital projects it has already made this shift, and it appears to be preparing the ground for a substantial shift in provision, too. However, it is not yet clear whether this represents a new direction of travel or a stop-gap operation. Are we at the start of a major reconfiguration of the health care system, towards one that is publicly financed and regulated, but independently organised and delivered? Or is this a pragmatic move to lever in extra support for a growing and improving public sector organisation? It seems likely that the Government itself does not know which way to jump and is currently testing the water to see what is politically viable, rather than preparing a principled case for leading in one direction or another.

Pragmatism and principle

Since 1997, unlike the earlier period reviewed by the King's Fund, the ideological basis for Government health policy has lacked definition. Moving away from old Labour's welfare socialism and rejecting the free-market creed of the Conservatives, New Labour has not yet developed a coherent and principled set of criteria to guide its decisions. It has experimented with some ideas – the stakeholder society, communitarianism, the 'third way' – but none seems to fit comfortably or to be robust enough to support a journey through uncharted territory. To fill the void, Labour appears to be ready, on questions beyond its basic commitment to a universal service, to substitute pragmatism for principle. As the Prime Minister famously put it, 'what counts is what works.' One message from this review is that finding out what works is a long-term, costly business that seldom provides conclusive evidence. Where no one is sure what really works, and where there are no clear principles to guide policy-making, there is a danger that the process will become muddled and incoherent at best or, at worst, cynically opportunist. Public

The Government has tried to do too much, too soon, and has relied too heavily on structural change to restore a service suffering from decades of under investment.

A third area of tension is between radical and conservative tendencies. The Government wraps its policies in radical language. It speaks of saving the NHS – through 'modernisation'. But while health policy has seen numerous changes over the past five years, fundamental questions about the future of health and health care have not been fully considered.

The case for a more radical approach rests on evidence about the changing health needs of the population and the changing nature of health care. The prospect of continuing change in medical and information technology suggest that hospitals as we know them today may not be needed in 10 or 20 years time, yet the private finance initiative is locking the Government into traditional patterns of acute care for 30 years or more. The evidence also suggests that community nurses, health visitors, midwives, care workers and community development workers hold the key to health improvement at local level, especially in disadvantaged areas. But the need to extend and strengthen this section of the workforce is not reflected in the balance of investment in recruitment and training, or in the way local services are being reorganised. The Government is extremely nervous of meddling with the traditional co-ordinates of the system. 'Modernisation' is predominantly about more and better doctors and nurses, and more and better hospitals. Ultimately it may not be possible to sustain the NHS without radically altering it – but small 'c' conservatism still has the upper hand.

There are further tensions around long term care and around patient choice. Where the funding of long-term care is concerned, the Government has been unable to reconcile notions of fairness and sustainability, and has not yet come up with a plan that inspires confidence. As for patient choice, it remains unclear whether this really is to be an organising principle for the NHS and, if so, how it can be reconciled with collectivist principles such as equity and efficiency. The drivers towards consumerism in health care, as elsewhere in society, may prove to be irresistible, in which case a decision will have to be made about which of these principles should take precedence.

Achievements

Despite these tensions, there is much to commend in the Government's record to date. It has declined to flirt with alternative funding mechanisms and substantially increased levels of public finance for the NHS. It has introduced, through NICE, a new system for transparent, evidence-based rationing. The Commission for Health Improvement (CHI) is starting to establish itself as an important regulator in the NHS. National Service Frameworks are beginning to provide a new and more standardised perspective on health care. Primary care trusts now command widespread support. NHS Direct and walk-in centres are innovations that have proved popular with users. The Government's approach to two vital issues – improving the quality of health care and workforce management – has been carefully considered, comprehensive and thorough. It has managed to achieve closer integration of health and social care and better regulation of social care – both sorely needed. It has put health inequalities on the policy map and made far greater efforts to reduce them than any of its predecessors.

Failures

There have been some tactical errors, such as the early focus on cutting waiting lists instead of times, and the botched attempt to abolish Community Health Councils. The Government has tried to do too much, too soon, and has relied too heavily on

The impact of government targets and priorities on other areas of treatment and care raise rationing dilemmas that remain obscured and are not being addressed. Local NHS managers and doctors are compelled to make trade-offs between different patients every day, with little support or guidance and barely any reference to the public.

Primary care: Ambitious reforms of primary care have removed many of the worst features of fundholding and appear to command widespread support. But the Government is pushing an under-resourced sector to do too much too quickly. Primary care trusts need more time and resources to make the changes that are expected of them.

Workforce: The NHS remains desperately short of staff in many areas. Many of the causes of this problem date back more than five years. The Government is now making major efforts to tackle the shortages. There are early signs that it has succeeded in increasing staff numbers. It is not clear whether it can hold on to staff and offset the effects of retirement. However, a long-term vision on the future shape and roles of the NHS workforce remains to be formed. Too much of the present effort has been devoted to doctors and nurses, rather than to other equally essential health care workers.

Quality assurance: The Government has introduced radical and far-reaching reforms of the way quality is assured in UK health care. From the regulation of individual professionals to the assessment of whole organisations' performance, Labour's reforms could revolutionise the way the public judges the NHS and its workforce. However, it is still unclear how much they will affect the quality of care received by individual patients.

The private sector: The Government's enthusiasm for involving the private sector in the NHS is insufficiently grounded in evidence. It has gambled that what is built today with private finance will be fit for purpose in a decade or more. Its plans for greater private sector involvement in provision remain unclear. Is it looking to the private sector for expertise it believes the public sector lacks, or hoping private companies will provide a greater stimulus to service improvement? While the case for using spare capacity in the short term is obvious, the Government has failed to define what kind of longer-term relationships it wants to build with the private sector.

Long-term care: The Government has not succeeded in establishing a fair and sustainable system for funding long-term care. It has removed some anomalies from the system, but may well be creating new problems in their place. Integration between health and social services is improving, and both are now better regulated than before to protect users from poor quality care. Progress could still be seriously impeded by acute shortages of funds for social care.

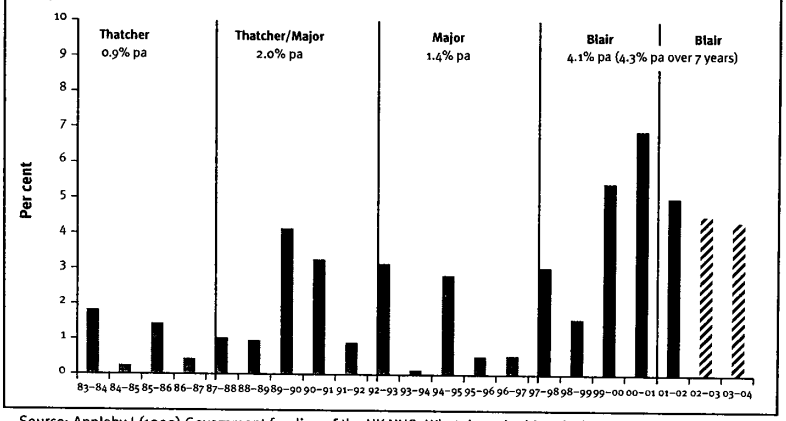
Patient and public involvement: Emerging policies on patient and public involvement suggest a significant change in the culture of the NHS. While the impact to date has been limited, the Government's promotion of enhanced patient choice may begin to knock down the paternalism that has characterised much of the NHS to date.

Health inequalities: The Government deserves credit for putting the 'health gap' on the policy map, but it has allowed it to remain a second-order issue. It has instigated an impressive series of actions to improve health and health care for the poorest in society. To reduce health inequalities, however, it must reverse trends in the opposite direction. It is unrealistic to expect demonstrable progress at this stage. But without

Expressions of a willingness to pay more tax did not seem to be translated into a willingness to vote for parties committed to spending more on the NHS.

While Figure 5 presents the official record of real spending, Figure 6 shows the *volume* changes in NHS spending every year – after taking account of inflation as experienced by the NHS itself (rather than the economy as a whole). In general, these annual volume figures were less than the financial resources apparently available after taking account of inflation in the economy.

6 **PERCENTAGE CHANGE IN UK NHS NET REAL SPENDING (HOSPITAL AND COMMUNITY HEALTH SERVICE DEFLATOR)**



Source: Appleby J (1999) Government funding of the UK NHS: What does the historical record reveal? *Journal of Health Service Research & Policy* 4:2; 79–89 (updated for years 98–99 – 03–04).

From the point of view of setting the budget for the NHS, Labour inherited a process that had remained essentially unchanged for many years: bilateral negotiations between the Department of Health and the Treasury over the annual public expenditure survey (PES) produced a budget for the year ahead (together with indications for planned spending a few years into the future).

The public's perspective

Two further perspectives on NHS funding are also worth noting: the views of the public and comparisons with other countries. Opinion poll evidence of the public's view about NHS funding before 1997 was relatively unambiguous – a majority felt the NHS was underfunded and around six in ten stated they would be willing to pay more tax if it were spent on health, education and other social benefits.[3] Of course, as many commentators suggested at the time, these (survey) expressions of a willingness to pay more tax did not seem to be translated into a willingness to vote for parties committed to spending more on the NHS. Nevertheless, economic growth is closely associated internationally with a public desire to spend more on health care. With increasing standards of living in the UK,* it is not surprising to find that opinion polls consistently report the public wish for NHS spending to increase.

Comparisons with other countries

From an international perspective there are two views: in terms of per capita spending on all health care (public and private), in 1997 the UK ranked 11th out of 15 European Union countries (and 9th on public sector spending only). In terms of the share of national income (GDP) devoted to health care, the situation looked worse, with the UK ranking 14th for total spending and 11th on public spending. At the time of the 1997 general election, such figures did not feature very much in public debate about NHS funding. It was only later that NHS funding would be seen in such comparatively unfavourable terms.

* For example, male real hourly wages in the UK increasing by over 30 percent in real terms between 1978 and 1996.[4]

Over the Government's first term, real spending increased by 4.7 per cent on average per year.

The Government's actions

Increasing NHS funding

Despite its manifesto commitment to retain the Conservatives' spending limits for health, Labour did, in fact, exceed its departmental ceilings in its first two years. While John Major's Government planned to increase cash spending on the English NHS by 3.2 per cent, Labour increased it by 5.1 per cent. Similarly, in 1998/9, Conservative plans for a cash rise of 2.3 per cent turned out to be 5.6 per cent under Labour.[7]

As Figures 5 and 6 show, subsequent levels of spending officially reached new heights for the NHS across the UK; over the Government's first term, real spending increased by 4.7 per cent on average per year. Taken together with spending plans so far announced, across the seven years from 1997 to 2004, average annual real spending per year should reach 5.2 per cent.

These large sums of money – cash increases totalling over £29 billion between 1996/7 and 2003/4 (a 72 per cent rise) – were mainly reached as part of a new process for setting departmental budgets: the comprehensive spending review (CSR). The first CSR, in 1998, set budgets for the following three years up to 2001/02. It aimed to introduce greater certainty into financial planning: the NHS would know how much money it would receive over three years and be able to plan more effectively and efficiently – unlike the previous system, which led to uncertainties about how much money the NHS would receive each year. The CSR also introduced the notion of public service agreements (PSAs) which, in theory, linked public spending to key Government objectives for each department.

While most departments' CSR budgets were maintained, a few – the Department of Health's in particular – were subject to considerable change. The 2000 Budget, for example, nearly doubled the CSR-determined real increase to the 2000/01 NHS budget by announcing an extra £2 billion. And the 2001 Budget announced an increase of £1 billion over three years – again, on top of increases already announced by the 2000 CSR. Of course, the fact that the CSR has not so far fulfilled one of the Treasury's aims (budget stability for the NHS) because of ad hoc additions to the NHS budget should not, perhaps, be criticised too harshly. Nevertheless, while unexpected additions are better than unexpected subtractions, neither encourage efficient planning.

A presentational feature of the 1998 CSR for the NHS was that the amounts for the three years' budgets were rolled up in a way that grossly overstated the size of the allocated increases: a three-year increase of £21 billion was, in reality, an increase of £9 billion. Such 'triple counting' was heavily criticised at the time – not least by the Treasury Select Committee, which stated that, 'There is...no cash bonanza of the type which newspaper headlines might suggest, but a steady increase in real resources.' The Committee recommended that, 'for the sake of transparency, in future the Government should refer to annual increases over the previous year rather than a cumulative total.'[8] Such triple counting has not, at least for the NHS, occurred since. Nevertheless, there may be some reason to believe that over-enthusiastic announcements of large sums of money – although followed by widespread media attention on the true amounts involved – to an extent fuelled public expectations of improvements that the NHS would find hard to meet.

To date, an extra £18 billion has already been added to the NHS budget since 1997/8. Yet there have been persistent complaints that little has changed in the NHS.

levels for the NHS. In November 2001, Wanless produced an interim report.[14] Its conclusion, after testing a number of financing methods against three criteria (efficiency, equity and patient choice), was that the current system of general taxation would not, in itself, give rise to additional resource pressures, and that it is both fair and efficient,* although it provides rather limited freedom of individual patient choice. These conclusions reinforced evidence put forward in *The NHS Plan* and provided some counterweight to ongoing arguments that general taxation was an unsustainable source of funding.

The final Wanless report – which, presumably, will set out a view about actual resource requirements for the NHS over the next twenty years – is due to be published in 2002.

The impact of policy

Where did all the money go?

Figures 5 and 6 show that the Government should achieve its aim of increasing total health care spending to 8 per cent of GDP by 2005/6. To date, an extra £18 billion has already been added to the NHS budget since 1997/8. Yet there have been persistent complaints that little has changed in the NHS. There is also some evidence that a key area of activity – inpatient and day cases – has not been increasing as fast as might be expected, especially given the extra resources injected into the service (*see* Figure 8). The implication of many media stories has been that the NHS has wasted the extra money. The truth is more complicated – and difficult to uncover.

8 PERCENTAGE CHANGE IN NUMBERS OF INPATIENTS AND DAY CASES: ENGLAND

Source: Hospital Episode Statistics

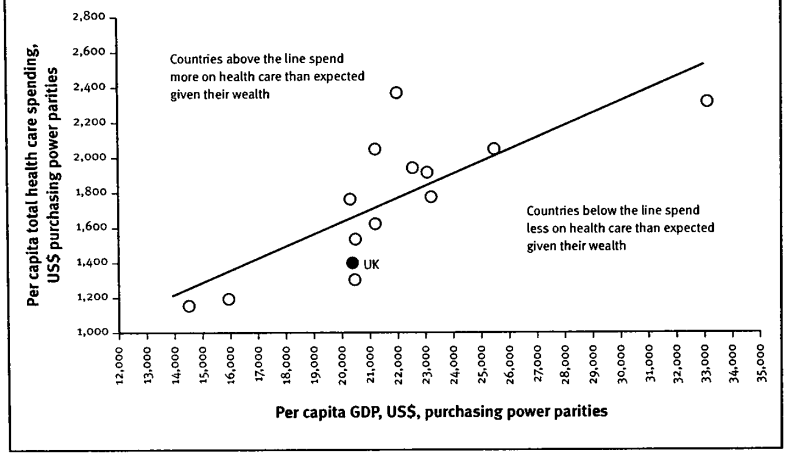
Over the last five years there have been a number of cost and other pressures that have reduced real resources available to the NHS – and potentially its ability to increase activity. For example, NHS-specific inflation (doctors' and nurses' pay rises, etc) has been above rates in the economy as a whole. Dealing with accumulated deficits from previous years has effectively reduced current years' spending as bud-

* As the UK tax system is mildly progressive, 'contributions' to the NHS fall more heavily on the rich than the poor. The tax system is also reasonably efficient in terms of the cost of raising money for the NHS. Social and private insurance systems tend to be less efficient due to the administration necessary to collect payments.

But increased funding has come with strings attached. As part of the largesse, the key political message has been that as the politicians have delivered their part of the deal (more money), now it's the turn of the NHS to deliver (and deliver and deliver).

a persistent and strong relationship across countries between the level of per capita wealth (GDP) and the level of health care spending per head (*see*, for example, Figure 9) a possible guide to spending levels is the amount this relationship indicates the UK should *expect* to spend given its wealth.[17] although the UK economy is the fourth largest in the world, as Figure 7 shows, even among EU countries it only ranks 11th in terms of GDP per head. Nevertheless, Figure 7, which uses 1997 data for the EU, suggests that an 'affordable' level of per capita health care spending for the UK was, in 1997, around 18 per cent more than was actually spent. As it happens, expressed as a per centage of GDP, such a spending level is only marginally more than the Government's current target of 8 per cent.

9 PER CAPITA GDP AND PER CAPITA TOTAL HEALTH CARE SPENDING EU COUNTIRES (OECD DATA, 1997)



Source: OECD Health Data File, 2001

Conclusions

Increased funding expectations

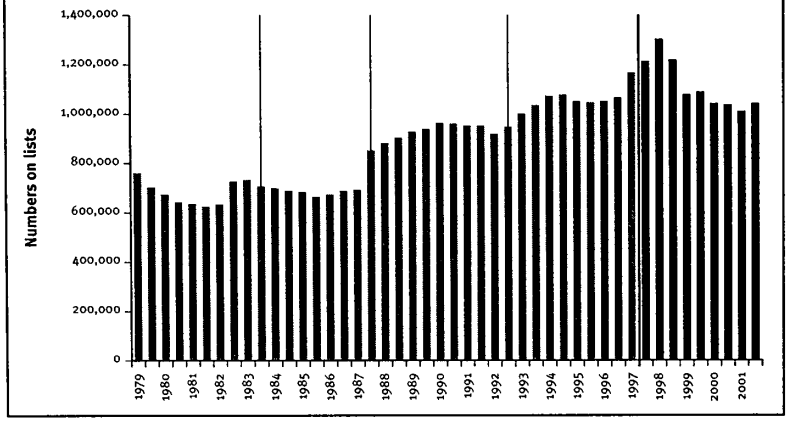
Opinion poll findings that people are willing to pay higher taxes to increase NHS funding are commonly criticised on the grounds that when it comes to voting, the electorate leaves its principles at home. Judging by the wording of Labour's 1997 manifesto, this observation was well taken: prudence in public spending, no income tax rises and a rather indistinct commitment to real increases in NHS funding were the pledges. The reality has been somewhat different. Previous Conservative spending plans were exceeded slightly in the first two years, and, since then, significant extra funds have been channelled into the NHS (although, not as much as initial headlines suggested).

But increased funding has come with strings attached. As part of the largesse, the key political message has been that as the politicians have delivered their part of the deal (more money), now it's the turn of the NHS to deliver (and deliver and deliver) on the modernisation programme laid out in *The NHS Plan*. To link extra funding to tangible changes in the NHS is not exceptional: the Treasury, on behalf of taxpayers, naturally wants to know that the NHS has plans to use the money to improve services. But even if the new rate of increase in NHS funding continues, or is exceeded, there remains a dismal economic message: while more money buys more resources – such as doctors, nurses, equipment and buildings – no matter how much is spent

The key concern for patients is not the number of people in front of them but the speed with which the queue moves.

health authorities. Such differences have been a persistent feature – but their causes have generally defied explanation.

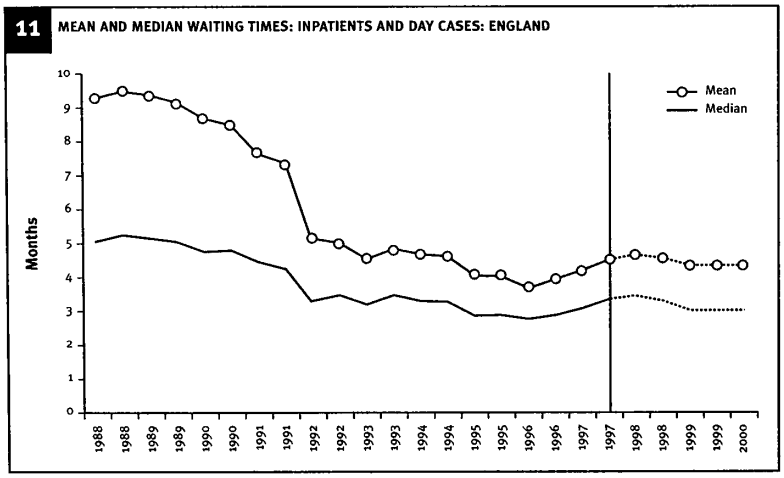
10 INPATIENT AND DAY CASE WAITING LISTS: ENGLAND



Source: Department of Health

Numbers waiting on lists suggests an ordered, first-come, first-served supermarket checkout queue. But *the key* concern for patients is not the number of people in front of them but the speed with which the queue moves. Policy initiatives pre-1997 had in fact achieved some success in reducing waiting *times* for admission to hospital (*see* Figure 11). In March 1997, the average waiting time for hospital admission was just over four months, with half of all patients (the median) being admitted within three months.

11 MEAN AND MEDIAN WAITING TIMES: INPATIENTS AND DAY CASES: ENGLAND



Source: Department of Health

While a majority of patients were admitted to hospital within three to four months, and despite successful attempts to cut the number of very long waits, by 1997 there were still over 42,000 patients waiting longer than a year.

From a patient's point of view, waiting begins with their GP's referral to outpatients. In March 1997, around 3 percent of patients had waited over six months by the time

Between 1998/9 and 2000/01, over £737 million was allocated to health authorities and trusts for specific actions to reduce lists and times.

The Government's actions

Earmarked funding

As with previous waiting list initiatives, policy over the last five years to reduce lists and times has been supported in a variety of ways. Earmarked funding – via the Health Modernisation Fund – has been set aside to tackle targets: between 1998/9 and 2000/01, over £737 million was allocated to health authorities and trusts for specific actions to reduce lists and times.

Investing resources and management

Guidance and best practice on dealing with waiting lists has also been published. And special teams (such as the National Patients Access Team, the Waiting List Action Team and the Task Force) have been set up to help individual trusts address their waiting list problems. Overall, considerable resource and management effort has been focused on meeting the various targets set by Government.

Table 1 details the Department of Health's headline reporting of the war on waiting.

Table 1: Government press releases on waiting lists: May 1997–January 2002*

1997/351	Frank Dobson announces action on waiting lists and times
1998/495	Waiting lists plummet by nearly 30,000 in one month
1998/562	Waiting lists fall by further 20,000 – waiting times fall for five months in a row
1998/064	Waiting list pledges will be delivered – says Frank Dobson
1998/101	'NHS waiting lists will be shorter by April next year' says Frank Dobson
1998/125	NHS delivers 18-month waiting list pledge – nobody waiting more than 18 months for treatment
1998/166	Government gets tough on waiting list targets – list buster appointed to head new team
1998/200	NHS delivers Government's 18-month waiting list pledge
1998/270	The supertanker has turned – Dobson
1998/281	Frank Dobson comments on waiting lists
1998/349	Waiting lists fall by 45,000 – supertankers turns – NHS waiting lists falling faster than ever before
1998/405	Dobson signals another fall in waiting lists
1998/415	Waiting lists down again by record 24,000 August – fall in numbers waiting over one year
1999/0007	Record 31,000 monthly fall in NHS waiting lists
1999/0118	NHS waiting lists fall by 14,200 in January
1999/0184	Record 39,700 drop in waiting lists delivers NHS promise one month early
1999/0278	Dobson hails biggest waiting list fall yet as NHS delivers even more than promised
1999/0332	Waiting lists rise but still 65,000 lower than target – Frank Dobson
1999/0420	Waiting list figures at end of May
1999/0492	Waiting list figures at end of June
1999/0512	John Denham announces £30 million to step up war on NHS waiting
1999/0517	Hospital acts against waiting list irregularities

* Note: Press releases selected using the Department of Health search engine on the basis of the words 'waiting list' in the title or first paragraph of press release text. Statistical press releases were excluded.

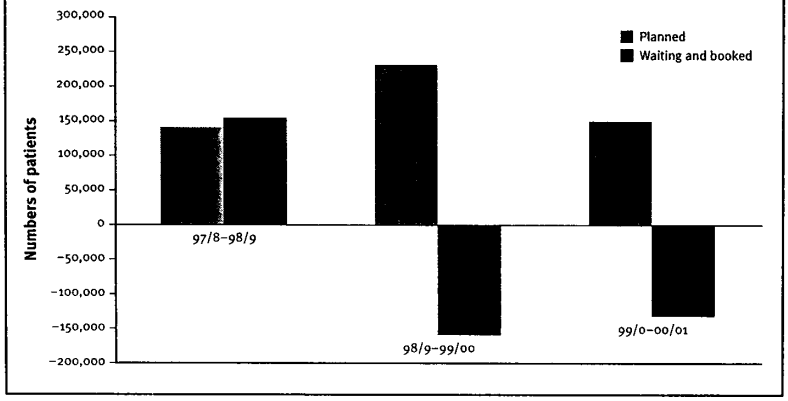
Table 2: Waiting list targets (and milestones) announced since 1997

TARGET	*ANNOUNCED?*	*BY?*	*ACHIEVED?*	*COMMENTS*
Cut inpatient waiting lists by 100,000 from March 1997 level	May 1997 (1997 manifesto)	End of 1997 Parliament	✓	Achieved by March 2000. But National Audit Office queried 'auditability' of the target [7]
No one with suspected breast cancer to wait more than 2 weeks for outpatient appointment following urgent GP referral	April 2000 (*The New NHS*)		✘	Latest quarterly figures for September 2001 show over 1,400 women waiting more than 2 weeks
Numbers of outpatients waiting more than 13 weeks to be cut to 334,000	August 1999	March 2000	✘	Substantial cut – from 512,000 to 400,000 – but target missed
No one to wait more than 4 weeks for treatment for testicular cancer, children's cancers and leukaemia following an urgent GP referral	September 2000 (*NHS Cancer Plan*)	December 2001	?	Information only available in April 2002
No one to wait more than 4 weeks for treatment for breast cancer following diagnosis	September 2000 (*NHS Cancer Plan*)	December 2001	?	Information only available in April 2002
No one with suspected cancer to wait more than 2 weeks for their first outpatient appointment for patients referred urgently	July 2000 (*NHS Plan*)	December 2000	✘	Latest quarterly figures for September 2001 show over 6,454 people waiting more than 2 weeks
Reduce number of those waiting over 12 months for inpatient treatment	July 2000 (*NHS Plan*)	March 2002	**Probably on target**	Numbers fell between September 2000 and March 2001 by 7,000. December 2001 show further falls of 13,200
No one to wait more than 15 months for inpatient treatment	July 2000 (*NHS Plan*)	March 2002	?	'On target. 66 percent of trusts meeting target as at December 2001', DoH, personal communication
No one to wait more than 6 months for inpatient treatment	July 2000 (*NHS Plan*)	March 2005	**Not on target?**	Fell between September 2000 and March 2001 by 29,000, but rose by 13,000 to 277,500 in December 2001
No one to wait more than 26 weeks for an outpatient appointment	July 2000 (*NHS Plan*)	March 2002	**Not on target**	Fell between September 2000 and March 2001, but rose by 2,500, to 84,300 in December 2001
Reduce the number of over 13 week outpatient waiters	July 2000 (*NHS Plan*)	March 2002	**Not on target?**	Fell between September 2000 and March 2001 by 152,000, but rose by 77,200 to 361,000 in December 2001
No one to wait more than 13 weeks for an outpatient appointment	July 2000 (*NHS Plan*)	March 2005		
Maintain the commitment to cut waiting lists by 100,000 from March 1997 level	July 2000 (*NHS Plan*)	Ongoing	✓	But National Audit Office queried 'auditability' of the target
All patients attending A&E to wait 4 hours or less from arrival to admission, transfer or discharge	July 2000 (*NHS Plan*)	March 2004	?	'On target. 77 percent of trusts meeting target as at December 2001'. DoH, personal communication
No patients to wait no more than 24 hours for an appointment with a primary health care professional and no more than 48 hours for an appointment with a GP	July 2000 (*NHS Plan*)	March 2004	?	Target changed to 'next working day' and 'next available appointment'. 'On line to be achieved' – DoH personal communication

Source: Department of Health

As more and more patients crowd into progressively shorter waits, it will become increasingly difficult to cut the longest waits.

14 ANNUAL CHANGES IN NUMBERS ADMITTED FROM WAITING LISTS (INCLUDING BOOKED ADMISSIONS) AND PLANNED CASES: ENGLAND



Source: Hospital Episode Statistics

Other changes during 1999/2000 included reclassifying day cases as outpatients. In virtually all instances of this change, the NAO found that it led, again, to a reduction in inpatient waiting lists. This change was graphically illustrated by movements in waiting lists in Wales, when, in February and April 2001, 4,300 endoscopy inpatients (6 percent of the total list) were removed from the inpatient waiting list. This led to a claimed reduction of 1,300 waiting between March 1997 and April 2001.[9]

Reducing waiting times

In terms of achievement, as Table 2 shows, the picture is mixed. For a number of targets it is hard to judge success or failure as routine data is not yet available. However, on the five main groups of waiting list targets – inpatients, outpatients, cancer patients, accident and emergency and primary care – some information is available:

Inpatients

While recent trends suggest that the number of people waiting over 12 months is increasing, indications from the Department of Health (personal communication) are that the NHS is on course to ensure that, by March 2002, no one waits more than 15 months (*see* Figure 15). However, although there are still three years to go before the deadline looms for eradicating waiting over six months, recent trends are in the wrong direction.

Overall, this 'bunching up' of the waiting list distribution is to be expected: as long waits are squeezed, the numbers waiting shorter periods of time (between 6 and 12 months) will grow. The question is whether the squeeze can push waiting times back to the target maximum of six months by 2005. As more and more patients crowd into progressively shorter (but longer than six-month) waits, it will become increasingly difficult to cut the longest waits. A concern will be the ability of the NHS to increase its level of activity in order to get patients through the system fast enough to make headway into the waiting list. Recent increases in inpatient and day case activity have been surprisingly small – averaging around 2 percent a year since 1997/8, but in 2000/01 only increasing by 0.8 percent. This is certainly too low to do much more than stand still given demand pressures, let alone reduce the number of people waiting over six months.

Cancer patients

Of the waiting time targets for cancer patients, two have been missed and information on two others – a maximum wait of four weeks for treatments for breast cancer and a number of other cancers following an urgent GP referral – is currently unavailable. The NHS Modernisation Board's first Annual Report[10] indicated that these latter two targets are unlikely to have been met for breast cancer and testicular cancer due to shortages of staff and equipment in radiology, pathology and radiotherapy.

Accident and Emergency

The key *NHS Plan* A&E waiting time target – that all patients will wait less than four hours before admission, transfer or discharge – is set to be achieved by March 2004. While there are no regular published statistics to monitor this target, the Department of Health says that over three quarters of trusts had already achieved the target by December 2001 (personal communication). The Audit Commission has recently noted that this target is a step forward from the previous Patients' Charter targets for waiting times in A&E – but that it still needs refinement.[11] Crucially, the three types of patients (those admitted, transferred or discharged) need to be identified separately. This is because 80 percent of A&E patients are discharged, and could mask any indication of performance in the measure of admission within four hours, which is harder to achieve. In other words, targets can be met by increasing the speed of discharge rather than speed of admission.

Primary care

Although the Modernisation Board's Annual Report states that over 60 per cent of practices are already meeting the March 2004 target that no patient should wait more than 24 hours to see a primary care professional and no more than 48 hours to see their GP, it also reports that many areas are having problems. Moreover, the target has been subtly changed, with the substitution of 'next working day' and 'next available appointment' for the 24- and 48-hour limits. As with some other targets there is no standard system for monitoring, but the Department of Health says that the target is on line to be achieved (personal communication).

Conclusions

Waiting lists: the wrong target

Given the findings of the National Audit Office report detailing inappropriate adjustments to NHS waiting lists by many trusts[12] the 1997 manifesto target may remain 'unauditable'. This would be a grave situation in most circumstances; however, there was a more fundamental problem with the pledge to reduce waiting lists: it was the wrong thing to do in the first place. The Prime Minister's defence of the pledge* – equating waiting lists with queues to get into a football ground – failed to recognise that waiting lists do not operate as simple queues: for any individual patient, the *length* of the waiting list is not a good indicator of how *long* they will have to wait.

* 'I know that some people think it [reduction of inpatient waiting lists by 100,000] was a foolish pledge. But to those in any doubt, the length of the waiting list does matter. If you are waiting to get through a turnstile into a football ground...you go the one with the shortest queue!' (Speech by the Prime MInister on outpatient waiting lists, September 1999).

The theoretical and ethical case for a method of organising waiting lists (involving, for example, priority scoring systems) in a way that explicitly recognises their rationing function – as well as their implications for equity and efficiency in the NHS – has been made before.[13] There have also been many suggestions for how such methods might work and the criteria that might be applied.[14,15] More recently, examples of scoring systems from other countries have also been described.[16]

Despite such analysis, the main policy failure since the inception of the NHS, and one that remains an urgent priority, has been the lack of any development of a *systematic* method to control and regulate waiting across the whole health care system, as part of a continued effort to keep waiting times within reasonable limits.

The verdict

Policies on waiting for NHS treatment threaten to distort clinical priorities and divert management energies. Although reducing the time people wait for health care is an important policy goal in its own right, a more evidence-based and systematic approach to controlling waiting is required.

immediately before 1997. Examples include the Department of Health excluding some medicines (such as proprietary cough remedies) from NHS prescription[4] – an example of rationing by excluding a category of good or service; and, further back in NHS history, the introduction of charges for dentistry and optometry[5] – rationing by introducing (partial) charges to choke off 'excess' demand.

Rationing and the internal market

Concerns about rationing were largely peripheral to the principal motivations underpinning the introduction of the internal market by the Conservative Government. However, records of a discussion on rationing health care in the House of Commons show that the then Secretary of State believed that 'the internal market would allocate resources better'.[6] Some independent commentators agreed: the purchaser-provider split meant that health authorities were faced with the task of making the best use of their budgets to improve the health of their populations, creating an opportunity to base decisions on systematic analysis rather than processes that largely reinforced the status quo.[7]

Some purchasers *did* respond to this challenge by initiating explicit rationing procedures using a variety of methods including questionnaire surveys, focus groups, health panels and public meetings.[8] For example, the West Glamorgan Health Authority set up a Local Ethics Committee concerned with 'ethical issues arising out of resource allocation and other health care policy decisions.' Around a fifth of authorities reported using cost per 'quality adjusted life year' (QALY) evidence to assist decision-making, with still others planning to do so.[9] Some GP fundholders set up public consultation groups to help set treatment priorities. A number of health authorities were reported, controversially, to have issued guidance that certain minor surgical procedures (eg, the extraction of symptom-less wisdom teeth) were no longer to be treated on the NHS.[10]

Other health authorities, however, were the subject of fierce media criticism for their handling of what were perceived to be rationing questions. High-profile debates of this kind, especially that of Child B, the child who was refused possible life-saving treatment for leukaemia by Cambridge and Huntingdon Health Authority, damaged the Government.

The policy pledges

Neither the term nor the concept of rationing is politically appealing, so it is no surprise to find little mention of it in political manifestos of any kind. Where priorities *are* mentioned, these are couched in the upbeat language of conditions or services targeted to receive additional funding (rather than the flip side of this: of services *not* to receive priority).

Investing in priority conditions

Labour's 1997 manifesto made no mention of resource allocation or rationing;[11] but *The NHS Plan*[12] set out a number of particular conditions – cancer, heart disease and mental health – to receive priority. Labour's 2001 general election manifesto re-emphasised specific conditions: cancer, heart disease and stroke were marked out to receive priority for 'investment and reform': £1 billion earmarked extra funding by 2004, aimed at preventing 300,000 avoidable deaths over the next decade.[13]

Before NICE could be established, however, a high-profile case in 1999 forced the Government to show its hand on NHS rationing issues. When the impotence drug Viagra was licensed for use in the UK, the Department of Health decided to restrict access to it immediately. In temporary guidance from the Department of Health, doctors were told that the drug could only be made available to patients with a list of pre-existing conditions causing them to suffer from erectile dysfunction – not for all patients who asked for it. In many respects this was a political landmark in the history of the NHS.[17,18] Although not the first time a specific treatment had been excluded, the decision was notable both in terms of the process underpinning it (using evidence on costs and effectiveness) and the recognition, in announcing the decision, of the trade-offs between funding Viagra and other services.

In response, the manufacturers of Viagra successfully took legal action against the Government. They argued that a temporary ban on the drug was unlawful because the Government had not gone through the normal process for placing Viagra on its list of restricted treatments (known as Schedule 11). As a result, the judge agreed that the Government's actions overrode doctors' 'professional judgement', forcing ministers to clarify that their guidance was not binding on the NHS.

The impact of policy

NICE's remit

To date, NICE has published 31 guidance reports. The recommendations of each (and the evidence on cost-effectiveness and net cost impact on the NHS) are summarised in Table 3. NICE has recommended against use in four instances, with a subsequent change of judgement on one – zanamivir (the flu drug, also known as Relenza).[19] A challenging programme of technical appraisals is planned for the future: 28 in 2002 alone.[20] The role of NICE has subsequently been strengthened by making implementation of its guidance mandatory from 2002.

Since its establishment, NICE has embarked on an ambitious programme of technical appraisal and guidance. It arguably represents the most rigorous and *transparent* example of priority-setting internationally. For the first time, the NHS has a systematic, defensible and consistent means of appraising and responding to new health care technologies and their associated demand pressures.

The annual net cost of implementing the guidance NICE had issued by March 2001 is estimated to be between £200–214 million (less than 0.5 per cent of annual spending on the NHS).[21] Guidance issued subsequently suggests a further net cost of between £57 million and £71 million annually. There are, however, problems in constructing these estimates with precision, and they should be treated with caution.

While NICE has said 'yes' more often than 'no' to the technologies it has considered, in most cases the 'yes' is qualified by specified conditions – such as which patients are most likely to benefit. This has required detailed guidelines covering the range of treatment options for different patient groups – an evolving function that is both important and, given the magnitude of the task and often patchy evidence, challenging.[22]

It was this particular issue – the lack of evidence on benefit to particular patient groups – which led to controversy over NICE's appraisal of the multiple sclerosis (MS) drug, beta interferon, late in 2001. In the absence of evidence, NICE assessed costs and benefits for *all* patients, resulting in a technical appraisal suggesting it to

Table 3: NICE Guidance 1999–2002, cost-per-QALY-gained, and the estimated cost impact of health technologies on the NHS

Topic	*Recommendation*	*Incremental cost per QALY (if known):*	*Funding implications for NHS p.a.*
Zanamivir in managing influenza	**No...** not recommended for 1999–2000 **...then Yes, but...** recommended for 2000–1 for some people when influenza levels are high	£9,300–£31,500	+ £2.3 m–11.7 m drug cost only
Removal of wisdom teeth	**No**		- Save up to £5 m
Coronary artery stents for ischaemic heart disease	**Yes** use routinely for patients with certain conditions		? 'Net impact difficult and potentially misleading'
Taxanes for ovarian cancer	**Yes, but...** use after surgery or for patients with recurrent ovarian cancer		+ £7 m net
Selection of replacement hips	**Yes, but...** recommended which types of artificial joint are likely to last longest		- Potential savings up to £8 m
Liquid based cytology for cervical screening	**Yes, but...** more evidence needed to justify nationwide introduction		= Possibly cost neutral
Taxanes for breast cancer	**Yes, but...** use for advanced breast cancer where chemotherapy has failed or is inappropriate		+ £16 m net
Proton pump inhibitors for dyspepsia	**Yes, but...** use only in specified cases		- Could save £40 m–50 m in drug costs
Hearing aid technology	**Yes, but...** insufficient evidence for digital hearing aids, but full range of analogue devices should be available		= Cost neutral
Rosiglitazone for type 2 diabetes mellitus	**Yes, but...** use for patients with inadequate blood glucose control on other medicines		+ Gross £14.5 m
Inhaler systems for under 5s with asthma	**Yes, but...** recommended where other treatments do not work		= Cost neutral if guidelines followed
Implantable cardioverter defibrillators (ICDs) for arryhthmias	**Yes, but...** recommended to prevent more serious problems in specific patient groups		+ £25 m–30 m net
Glycoprotein IIb/IIIa inhibitors for acute coronary syndromes	**Yes, but...** recommended for patients in specific circumstances		+ £30m–31 m net
Methylphenidate for attention deficit hyperactivity disorder (ADHD) in childhood	**Yes, but...** recommended as part of comprehensive programme for children with severe problems	£10,000–£15,000	+ £7 m upper limit
Tribavirin and interferon alpha for hepatitis C	**Yes, but...** recommended for patients with moderate to severe disease, depending on experience with other treatments	£3,000–£7,000 (first 6 months' treatment); £5,000–£36,000 second 6 months	+ £55 m spread over three years

The judgement, and influence, of individual doctors remains the key determinant of patients' access to treatment.

Tackling the 'big killers'

Outside the NICE appraisal system, the Government's other explicit approach towards priority-setting has been its decision to make the 'big killers' of cancer and heart disease the subject of many of its targets and directives. While this is well intentioned, it risks priority being diverted away from non-targeted areas that may nevertheless represent good value for money. Priorities relating to particular conditions are driven by 'the size of the problem' – a needs-based, epidemiological approach.[25] However, this does not take account of the degree to which those conditions are amenable to change, nor the effectiveness or costs of interventions with which to effect that change. As a result, whether these are the 'right' priorities – and what the opportunity cost is of focusing on them instead of other services, which have to be set aside as a result – remains unknown. Progress towards a 'whole systems' approach to rationing and priority-setting is still lacking.

Aside from the 'big killers', priority-setting in the NHS remains largely a local issue. Labour has made little impact on the processes by which decisions are made about what services the NHS will *not* fund in a particular locality. Thus, primary care trusts are implementing the Government's 'must-dos', and, as a consequence, there is no consistency about what they choose not to pay for. A resolution about whether or not this is how politicians and the public want the NHS to be managed is still a long way off.

Conclusions

Rationing decisions and trade-offs occur at *every* level of decision-making in the NHS. The decision about how much of taxpayers' monies are to be devoted to the NHS (as opposed to defence, education and so on) is a rationing decision. Once that budget is determined, more can be allocated to one part of the health system only by allocating less to another; and within that, more can be spent on some kinds of services or conditions only by sacrificing other types of services or conditions.

A lack of progress

The first five years of Labour Government have done little to make these rationing processes more explicit than they were before. While the total amount of money given to the NHS is a political matter, which is frequently the subject of public debate, before being decided by the Chancellor of the Exchequer, the allocation of resources *between* services remains largely implicit – apart from imperatives created by national-level clinical priorities, targets and directives, including those resulting from NICE guidance.

Implicit rationing processes

For patients on NHS waiting lists, there remains no coherent system for setting priorities according to the urgency of their need. The judgement, and influence, of individual doctors remains the key determinant of patients' access to treatment. This has allowed the perverse situation where patients with relatively low clinical priority sometimes get treated ahead of more severe cases who have waited less – so health authorities can avoid missing waiting times targets. There is also no way of knowing from waiting list or times data whether access to surgery by people of similar need is similar across the country. Clearly, the manner in which decisions are made about how long people have to wait is not as fair as it could be.

Labour's pledge was to remove the market mechanism from the NHS but retain the split between purchaser and provider that was the cornerstone of the previous Government's system.

Recruitment and retention of doctors was problematic, and there were many indications that a growing minority of GPs were seeking salaried or alternative employment options.[4] In response, ministers conducted a listening exercise among GPs across the country, to better understand their concerns and improve the conditions in which they were working. That exercise culminated in the publication of the White Paper *Choice and Opportunity,*[5] which promised to diversify the range of primary care services available to patients.

Opening up the primary care market

Before the 1997 election, the Conservative Government launched the Personal Medical Services (PMS) pilot schemes, marking the ending of GPs' monopoly of primary medical care, with new market entrants in the shape of NHS trusts and nurses.[6] With the development of alternative employment options to that of the independent contractor, the long-cherished national contract no longer to applied universally.

Labour inherited a divided medical profession. Having antagonised doctors in the early 1990s, successive Secretaries of State for Health had managed to placate them during the decade as fundholding became more popular and a series of improvements to their working lives were put in place. But inequities resulting from the Conservatives' handling of primary care remained.

The policy pledges

Abolishing GP fundholding

Labour's 1997 manifesto[7] promised that 'Primary care will play a lead role' in the party's rejuvenated NHS. While short on detail of how this would happen, the manifesto pledged to abolish GP fundholding. In its place, the manifesto said: 'GPs and nurses will take the lead in combining together locally to plan local health services more efficiently for all the patients in their area. This will enable all GPs in an area to bring their combined strength to bear upon individual hospitals to secure higher standards of patient provision. In making this change, we will build on the existing collaborative schemes which already serve 14 million people.' In addition, Labour pledged to remove the annual round of contracts between purchasers and providers, replacing them with longer-term 'agreements'.

Abolishing the internal market

The publication of Labour's 1998 White Paper *The New NHS: Modern, dependable*[8] formally announced the demise of GP fundholding. It underlined the role of the NHS in improving health, renewed an ideological commitment to equity in access and provision, and emphasised the need to ensure quality through clinical governance and accountability to local communities. Of fundamental importance was the move to loosen the restrictions of the NHS's old tripartite structure (of general practice, hospitals and community health services) by moving towards unified budgets and imposing a duty of partnership. Labour's pledge was to remove the market mechanism from the NHS but retain the split between purchaser and provider that was the cornerstone of the previous Government's system. The major structural change introduced to deliver these policy goals was the formation of primary care groups (PCGs) constituted from all the practices in a geographical area. PCGs were to be given responsibility for organising primary care services in their area,

The Government's actions

Reorganising primary care

PCGs began work in 1999, with three principal functions:[13]

- to improve the health of the population and address health inequalities
- to develop primary and community health services
- to commission a range of community and hospital services.

They brought together local providers of primary and community services under a board dominated by GPs, but also representing nurses, the local community, social services and the health authority. PCGs served populations averaging around 100,000 people and were expected to evolve over time into independent primary care trusts (PCTs). By April 2002, nearly all had made this transition. PCG/Ts were saddled with heavy expectations. In obvious respects they represented an evolutionary advance, giving all GPs the benefits of fundholding. But the creation of single budgets encompassing general medical services, prescribing, hospital and specialist care (rather than separating them, as previously) was revolutionary.

The duties of PCGs included clinical governance – using their new managerial structures to exert greater control over the quality of care provided by individual practices. Each PCG was required to ensure systems were put in place to monitor quality of care, to identify and tackle poor practice, to encourage the take-up of evidence-based procedures, and to ensure doctors underwent continuing professional development and education.

Though initially eclipsed by the creation of PCGs, the personal medical services (PMS) initiative was extended by Labour, as the pilot schemes proved unexpectedly popular. *The NHS Plan* enthusiastically supported the concept, and by April 2002 nearly one fifth of all GPs were working under PMS. Many of them are located in urban, more deprived areas, where the salaried option has been heavily taken up.

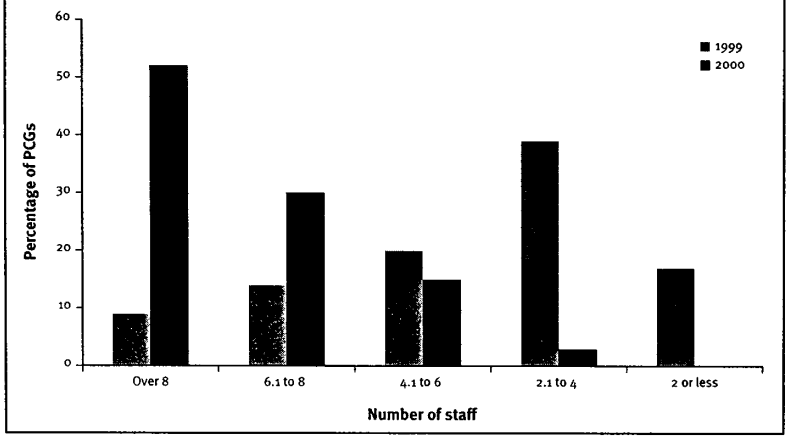
Improving access

NHS Direct was launched in three pilot sites in 1998, and rolled out rapidly thereafter. The service was available across the whole of England by the end of 2000 and now operates from 22 call centres, six of which serve the London area. A further three call centres are provided by NHS Direct Wales. A key development since the launch of NHS Direct is the adoption of a single, computerised decision-support system called CAS (clinical analysis software) in all call centres. This replaced the three different systems that were used by different centres until mid-2001 and will make it easier to ensure uniform standards of care across the country.

New roles for NHS Direct are under investigation – particularly in terms of integrating its triage function with access to out-of-hours medical care. There are 34 pilot sites for this development, of which 22 were launched in November 2001 and a further 12 started in March 2002. A typical pilot site exists in South London where access to the *Seldoc* out-of-hours GP co-operative is obtained through the South East London NHS Direct call centre. The centre employs 44 nurses and 26 call handlers, and receives approximately 500 calls per day.

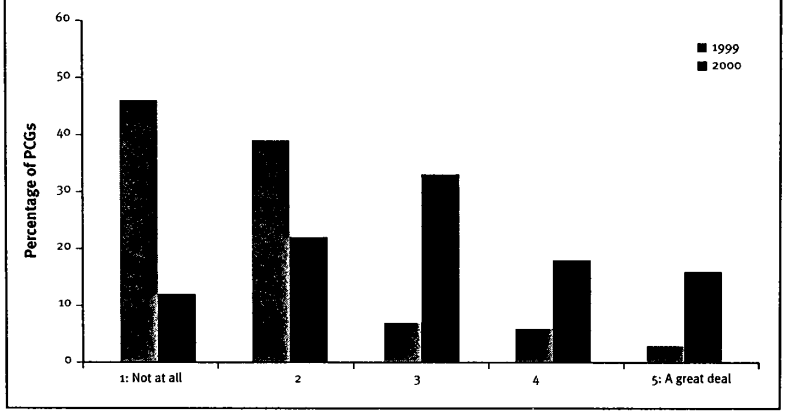
Forty NHS walk-in centres have been launched since January 2000, of which nine are in London. They provide a range of high-quality minor ailment/treatment services to

17 STAFF NUMBERS IN PCGS, 1999 AND 2000



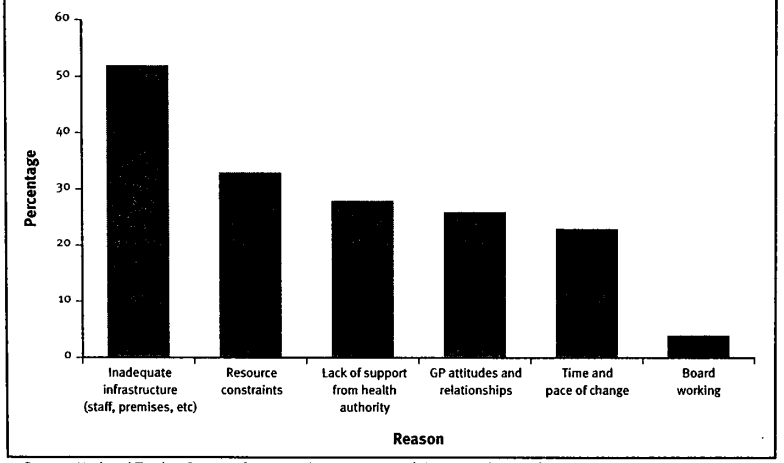
Source: National Tracker Survey of PCGs and PCTs. NPCRDC/King's Fund: 2000/2001

18 PCGS' PERCEPTIONS OF THEIR INFLUENCE ON HOSPITAL SERVICES, 1999 AND 2000



Source: National Tracker Survey of PCGs and PCTs. NPCRDC/King's Fund: 2000/2001

19 PCG CHIEF OFFICERS' PERCEPTIONS OF MAJOR OBSTACLES TO SUCCESS, 2000



Source: National Tracker Survey of PCGs and PCTs. NPCRDC/King's Fund: 2000/2001

which it benefits, for example, older people or minority ethnic populations remains contested.

Walk-in centres vary in the number and grades of nurses they employ in their level of provision of GP services and in the exact range of services they offer. [23] A recent study of walk-in centres [24] found the number of people attending them varied between 30 to 120 per day, with an average of 82 attendees. The average consultation length was 14 minutes, which is significantly longer than a general practice consultation. The most common presenting complaints were viral illnesses, unprotected sexual intercourse (to obtain emergency contraception), minor injuries, and dressings. Seventy-eight percent of consultations were managed entirely at the walk-in centres, without referral to any other health care provider.

NHS Direct and walk-in centres clearly illustrate the differences that diverse priority groups of people attach to access. The apparent popularity of these services with users contrasts with their reluctant acceptance by many health professionals. Concerns over their cost effectiveness remain but, both within and out of hours, numerous nurse-led providers – rather than the GP as the single gatekeeper – will increasingly form the first point of contact with NHS primary care services.

The Government's promised expansion in hospital beds and consultant numbers, with consequent reductions in waiting times, should ease the burden on primary care. Its plans to increase the number of GPs, however, are disappointing. An increase of 2,000 GPs represents only a modest increase in long-term trends. Even allowing for investment in other community-based services, GPs will not easily be able to improve access to their services or extend consultation lengths without a major expansion in their number.

Under *The NHS Plan*, patients who currently go to hospital will be able to have tests and treatment in one of 500 new primary care centres. Consultants who previously worked only in hospitals will be seeing outpatients in these new units, while 'GPs with special interests' will be taking referrals from their colleagues in fields such as ophthalmology, orthopaedics and dermatology. How these innovations will work in practice remains unclear.

Delegating power to the front line

Labour has repeatedly been criticised for its centralising tendencies at the expense of local experimentation. In *The NHS Plan*, trusts were promised considerable freedom from central supervision, and interference subject to satisfactory performance ('earned autonomy'). To monitor this, new accountability structures were created – many of them applying themselves to primary care organisations for the first time. The Modernisation Agency and numerous task forces are overseeing implementation of the Plan, and the capacity of the Commission for Health Improvement (CHI) has been extended. Though couched in a vocabulary suggesting local discretion, *The NHS Plan* thus tightens central control by limiting how trusts can use their new freedoms.[25] Whatever the Government's intentions, health professionals and managers fear they will be operating within an environment that is increasingly dominated by pre-determined clinical frameworks and an enhanced performance management system.

In April 2002, primary care trusts became the lead organisation for assessing needs, planning and securing all health services and improving health. Since 1 April 2002,

Today, primary care trusts are bowing under the weight of the Government's good intentions.

Improving people's health

If primary care organisations are to drive forward public health goals, they need to reinforce the culture of support for 'upstream' solutions. They are already investing in services that will improve access and reduce variations in quality of care. And there are signs that these new organisations may yet make something of their health improvement role, particularly in Health Action Zones.[28] Health Improvement and Modernisation Programme (HIMP) sub-groups are beginning to invest in health-promoting initiatives beyond the NHS that address social determinants of health. They are predominately led by GPs than by any other health professional.

There have always been plenty of GPs who understand the central role of primary care in addressing health inequalities.[29] But others are less supportive of Labour's elevation of social exclusion to the centre of health policy. They view it as fostering a dependency relationship between the state and recipients of welfare benefits. Many doctors eschew involvement in 'lifestyle modification'. They plead for a form of medical practice that treats illness rather than regulating behaviour, and puts the autonomy of the individual and the privacy of personal life before political objectives. Reactionary challenges to the 'tyranny of health' and withdrawal from a wider social role are powerfully appealing to a constituency under pressure.[30]

Understanding the 'forces of conservatism'

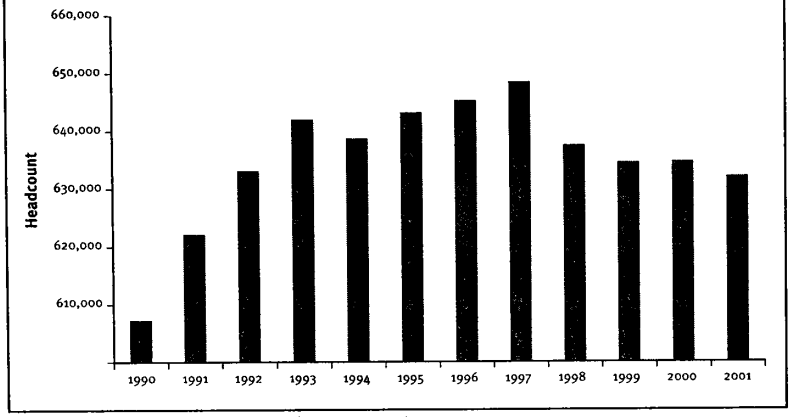
Doctors are easily portrayed as part of the problem as they grapple with their responsibilities for modernisation. Once more they have appeared to 'dig in' – to resist central control and to assert financial independence. Many have well-founded concerns. They fear that the emergence of many more salaried doctors on PMS contracts may create a new form of 'two-tierism', with less well-remunerated, peripatetic doctors providing more care in deprived areas.

The gap between doctors who are PCT committee members and those who are not, in terms of their grasp of the modernisation agenda, is large. The latter see PCTs as adding to their workload. They do not want to take further responsibility for the rationing of health services implied in PCTs' commissioning role. Many GPs show little enthusiasm for the opportunities these reforms undoubtedly offer. Much hinges on the outcome of new contract negotiations.

Under Labour, primary care is effectively being collectivised into locally managed units responsible for managing the care of their populations. The GP surgery will increasingly become the service outlet for larger primary care organisations. Some 'corner shops' may disappear. But practices are likely to remain the basic building block of the NHS for the time being. And – as more and more practices take on new PMS contracts – local enterprise, rather than central diktat, could still be deployed to deliver the sustained improvements to the NHS that patients increasingly demand.

Today, primary care trusts are bowing under the weight of the Government's good intentions. They are struggling under a weight of unrealistic expectations generated by the Government's performance anxiety. Fears that PCTs may 'fail' to deliver *The NHS Plan* may, ironically, bring the health service full circle. The emergence of 'foundation' PCTs, and of practice-based budgets, could bring many elements of the internal market back to the NHS. PCTs need more time to deliver Labour's ten-year project. They are unlikely to get it.

20 UKCC TOTAL REGISTRANTS: 1990–2001



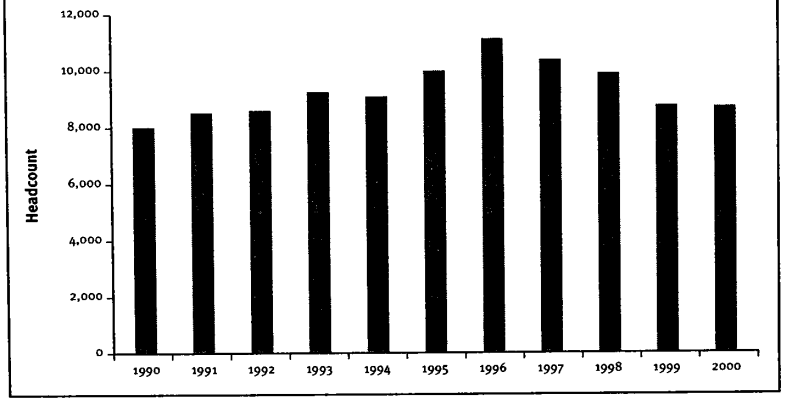
Source: UKCC Annual Statistics (Volume 1) 2000; Press release. 3 May 2001

Figure 20 shows that the overall number of registrants increased by almost 30,000 between 1990 and 2001, reaching a peak in 1997 and falling again thereafter. Since 1997, the number of people leaving the register has exceeded the number joining. In 1997/98, for example, 16,392 nurses and midwives joined the register while 27,173 left,[4] due, in part, to the earlier reduction in the number of pre-registration training places, which fell by 26 per cent between 1989/90 and 1994/95.[5] This fall may also be due to increasing numbers of nurses retiring, changes in post-registration education and training, and overseas nurses and midwives allowing their membership to lapse.

Doctors

The number of medical school places rose slightly during the mid- to late-1990s from 3,778 in 1994/95 to 3,804 by 1998/99. Figure 21 shows changes in the number of doctors registered with the General Medical Council since 1990.

21 GMC TOTAL REGISTRANTS: 1990–2000



Source: GMC

This figure shows that the overall number of registrants increased between 1990 and 2000. However, it does not show the decline in the number of doctors becoming GPs during the same period.

In *Improving Working Lives*, Labour made a commitment to make the working lives of NHS staff better suited to their needs.

The remaining workforce policy initiatives from Labour can be grouped under four broad promises: pay, working lives, workforce planning and staff numbers.

Pay

One of the key factors that influence a decision to leave a post is pay.[8] In 1999, the Government set out its plans for changing the NHS pay system.[9] It promised to develop a pay structure for the NHS workforce that would 'reward the actual responsibilities that staff take on rather than the job title they work under'.

The new pay system would be based on:

- new ways of working and breaking down traditional barriers
- principles of equal value and career progression through competence and satisfactory performance
- national core conditions but 'considerable' local flexibility.

There would be a single national negotiating council, a national job evaluation framework and a simplified pay spine with thresholds for key career stages.

As part of plans to assist with recruitment and retention, the Government promised a range of initiatives to ease the costs of living and accommodation, such as a national housing co-ordinator to assess accommodation problems and 2,000 more units for nurse accommodation in London by 2003.[10]

Working lives

In *Improving Working Lives*, Labour made a commitment to make the working lives of NHS staff better suited to their needs through family friendly working opportunities, support with childcare, tackling harassment, violence and discrimination, and giving staff more control over their working environments. There would be a national campaign to promote family friendly and flexible working practices; regional taskforces would be set up to share good practice; and targets would be agreed and set for all NHS employers.[11,12]

Workforce planning

In March 1999, widespread concern about current arrangements for workforce planning, education and training led the House of Commons Health Select Committee to recommend a major review of workforce planning in the NHS.[13] The Government accepted the findings of this report, which recognised many of the problems were longstanding and the result of failure by previous governments to tackle them.[14] In a detailed response to the report – the consultation document *A Health Service of all the Talents: Developing the NHS workforce* [15] – the Department of Health proposed new systems for workforce planning to include:

- merging education and training levies
- encouraging experimentation with skill-mix changes and new types of working within and between the professions
- establishing clearer lines of responsibility and accountability for workforce planning at local, regional and national level: in particular, new Workforce Development Confederations would replace the ETC. They would have a wider remit than the ETC, bringing together all employers of health care staff at a regional level to plan current and future staffing requirements, commission training

The Government's actions

Labour's promises were wide-ranging and ambitious. Progress on implementing them is detailed below.

Changing pay structures

The Government first set out its intention to change pay structures for the health professions in 1999. It reiterated this commitment in *The NHS Plan*. A further document reporting progress and setting out a timetable for implementing the new pay structures has long been promised but has not, as yet, been published.

During Labour's first five years, the health professions experienced year on year pay increases that barely kept up with inflation. In the latest round, however, which will take effect from 1 April 2002, nurses and midwives and doctors were awarded a 3.6 percent increase on their basic pay. Newly qualified physiotherapists, occupational therapists and radiographers would benefit from a 7.5 percent increase. In the previous round, doctors were awarded a 3.9 percent rise while nurses and midwives received a 3.7 percent increase. Senior nurses, on whom the Government depended to implement key aspects of *The NHS Plan*, were awarded a 5 percent rise. As a result, real pay has risen. Labour also ended the Conservatives' practice of staging pay increases – but only after its first pay settlement for nurses was staged, with the full rise not provided until December: eight months into the financial year.

In addition to basic pay award increases, a new type of 'bonus' award has been introduced in the form of 'golden hellos' and 'goodbyes' for doctors and nurses. Newly qualified GPs will receive a 'golden hello' of £5,000, with an extra £5,000 if they begin work in a deprived area. Family doctors who wait until they are 65 to retire will receive a £10,000 'golden goodbye'. Nurses, midwives and therapists who take a return to practice course will receive £1,000.[18]

To assist with pay and costs of living, Labour increased the London allowance for nurses by 3.7 percent in 2001, and boosted the inner-city and outer-city living allowances. A national housing co-ordinator was appointed in 2000 and a new scheme to help nurses and other public sector workers buy their first home was announced in September 2001.[19]

Working lives – setting up targets

The *Improving Working Lives Standard*,[20] which sets out the various targets all NHS employers are expected to meet, was issued in 2000.

Under the terms of the standard, by 2003, employers must prove that they:

- are committed to staff training and development
- are tackling harassment and discrimination
- are acting on the Government's zero-tolerance policy on violence against staff
- have a workforce that is representative of the local community
- and offer flexible and family-friendly working opportunities.

Workforce Development Confederations

The 24 Workforce Development Confederations (WDCs), promised in 2000, went live in April 2001. Education and training levies were merged and now fall under the

The Government has made a concerted effort to improve the working lives of staff. However, many of these policies are taking a long time to translate into tangible support for staff on the ground.

Working lives – slow progress

The Government has made a concerted effort to improve the working lives of staff. However, many of these policies, for example, flexible and family-friendly working and assistance with child care arrangements, are taking a long time to translate into tangible support for staff on the ground.[23] Furthermore, 'worrying' proportions of staff are unaware of the opportunities available to them.[24] Moreover, many of the targets, for example for 100 trusts to have on-site nurseries by 2004, are modest.

Despite the Government's efforts to make working lives better in the NHS, morale amongst health service staff appears to be at a low ebb. According to a recent King's Fund study, there are three key reasons for low morale amongst NHS staff:

- a feeling that they are not valued, that their work is not appreciated
- a working environment that frustrates and constrains staff, for example because of shortages
- pay levels that do not appear to reflect their skills and commitment.[25]

NHS and other public sector workers have received mixed messages about how far their work is valued by government ministers. Some of the rhetoric, for example about the 'forces of conservatism' in the public sector, has been positively harmful to morale. While ministers frequently tell NHS staff they are valued in set-piece speeches, their actions can suggest a distrust of public sector workers. The Government's apparent enthusiasm for using private sector providers as an alternative to NHS staff has been particularly controversial.

In addition, the organisational turbulence and pursuit of targets that has characterised the health service over the past decade, including before Labour came to power, has taken the attention of senior NHS managers away from staffing matters. The result has been that staff and managers feel unsupported, and both perceive that their concerns about poor working conditions are not being tackled.

Workforce planning – a short-term focus?

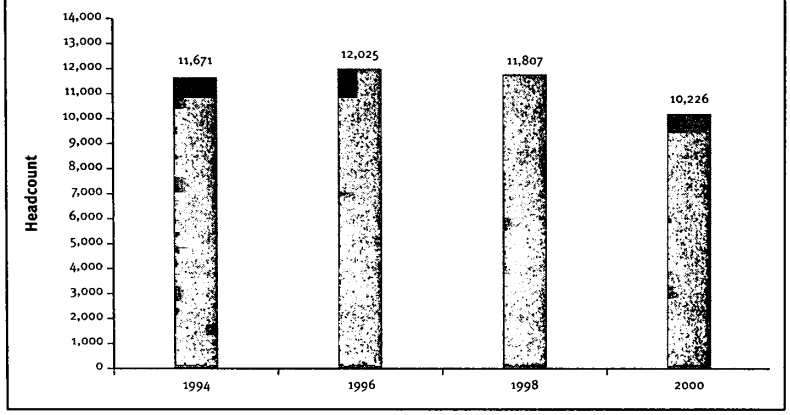
The Workforce Development Confederations are young organisations and it is too early to evaluate their impact. They have spent much of their first year establishing themselves and developing their agendas. There has been little time to experiment. Certainly, their potential to tackle recruitment and retention problems, and to develop the future health care workforce, is great. But there are several obstacles they will need to overcome, including a lack of adequate and reliable workforce data, and the fact that NHS workforce issues are not yet high enough on many NHS employers' agendas.[26] They will also need support from the centre, and should not have to worry that their second-year budgets are under threat, as they currently are.

The Government's own efforts to improve workforce planning have focused largely on the clinical professions, especially doctors and nurses. The other professional groups which comprise the NHS workforce have received less attention. Despite the organisational change that has characterised the past five years in the NHS, for example, the management requirements of the NHS have received little attention from ministers. The result is that, in many areas, primary care groups and trusts have struggled to meet the demands expected of them without the management capacity to achieve them.[27]

Managers themselves have been largely peripheral to discussions around the NHS workforce, except in the negative sense of a promise to reduce bureaucracy and re-divert any savings into patient care.

UCAS received 12,025 applications, but by 1998 applications dropped to 11,807, and by 2000, applications had dropped further to 10,226.[38]

23 UNIVERSITY AND COLLEGE ADMISSIONS SERVICE (UCAS) APPLICATIONS TO STUDY MEDICINE



Source: UCAS

Faced with a supply problem of UK-trained doctors, the Government has turned to other countries to recruit staff. But, in recent years, the favourable trend in overseas-trained doctors joining the register has tapered off. In 1996, for example, 7,150 doctors from overseas joined the register, of whom 2,435 trained in the European Economic Area. By 2000, that number had decreased to 4,244 of whom 1,380 were EEA-trained. Should this trend continue, it could significantly affect the Government's plans to recruit overseas doctors to plug gaps in the NHS.[39]

By September 2001, the number of allied health professionals had increased by 4 percent over the previous 12 months, to a total of 51,320.[40] But at the same time, vacancy rates among the allied health professions have been increasing. In March 2001, there were 1,820 vacancies for qualified allied health professionals[41] – 300 more than at the same time the previous year.

Conclusions

A high-enough priority?

Many of Labour's initiatives for addressing NHS workforce issues have been appropriately targeted at the deficiencies noted by staff, such as improving pay and working lives. But many are yet to make a real difference for staff, who are often unaware of the opportunities available to them. Recruitment and retention problems persist. In many trusts, workforce issues are yet to become a priority, as they compete for attention with the myriad other targets their chief executives have to meet. Managers themselves have been largely peripheral to discussions around the NHS workforce, except in the negative sense of a promise to reduce bureaucracy and re-divert any savings into patient care. This is despite the fact that managers are responsible for overseeing implementation of the workforce and wider NHS modernisation agendas.

The strategic focus on improving working lives and pay suggests that Labour recognises the value of the health care workforce. However, the Government treads a precarious line between such support and blame, leaving NHS staff and managers

From the first paragraph of Tony Blair's foreword to the Government's first White Paper on health, the emphasis was on delivering 'dependable, high-quality care'.

Performance measurement

Quantifying the performance of the NHS – primarily through performance indicators derived from routine data collection – has been common practice for many years. Previous Conservative administrations had developed performance indicators, mainly disseminated to the NHS as a comparative tool to prompt health authorities and trusts to improve their performance. While the internal market of the early 1990s assumed a greater role as a mechanism for improving performance, performance indicators continued to be produced for comparative purposes (not least to inform purchasers in the internal market). A key *composite* measure of efficiency – the purchaser efficiency index – was used not only to measure performance, but also as a basis for target setting for authorities. But this measure of efficiency led to perverse behaviour in the NHS.

The Conservative era provided Labour with a platform from which it could launch its more integrated approach to quality as well as giving many people in the NHS the practical experience necessary to turn new policy objectives into action.

The policy pledges

In its first two years of office, the Government's first White Paper [12] and subsequent policy documents laid out many aspirations, such as ensuring access to the same high level of care across the country. Only later did it turn its attention to more detailed plans that sought to ensure public protection from poor NHS performance and to put in place a systematic approach to spreading good practice across the service.

Like any government, Labour also had to develop policy in response to events – particularly past failures that had been subject to scrutiny or current failings that became the stuff of media sensation and political controversy. However, the Government launched a number of high-profile independent inquiries into the failings of the NHS. The inquiry into the scandal of children's deaths after cardiac surgery at Bristol Royal Infirmary was perhaps the most important, not just in terms of its scale, but in the scope of its recommendations.[13] Among the many other dissections of the past that occurred were the circumstances that allowed rogue individuals like the gynaecologist Rodney Ledward to continue unchecked,[14] or the collection of deceased children's organs without consent at Alder Hey Hospital in Liverpool,[15] as well as the murders of Harold Shipman.[16] These inquiries have provided the Government with a platform for more radical action to reform professional regulation,[17] develop more effective systems to regulate private health care,[18] and reform the legal and procedural systems for seeking consent.[19]

Grand blueprints: the New NHS

From the first paragraph of Tony Blair's foreword to the Government's first White Paper on health, the emphasis was on delivering 'dependable, high quality care'. New mechanisms were promised for assuring and improving quality. The White Paper promised that the new NHS 'will have quality at its heart'.[20] Labour offered no slick mantra for its definition of quality but it became clear that, at the heart of its approach, was the reduction of 'unacceptable' variation not only in the quality of care but in access to it.

To achieve this end, the 1997 White Paper promised new national standards and an organisation (the National Institute for Clinical Excellence) to take up the task of

The most striking feature of Government action has been the establishment of new central bodies to take on distinctive tasks.

To make this happen, the Government has proposed a variety of methods over the past five years, from 'loose learning networks' such as the NHS Beacon scheme, to the imposition of new managerial teams on failing trusts through 'NHS franchising'.[23,24] The Government promised to provide the systems and organisations to help identify best practice and make it accessible to others.[25] It promised central support (through the Clinical Governance Support Team) to enable local organisations to develop good systems of clinical governance [26] as well as help in redesigning priority services so that they could reach national targets, through the National Patient Access Team.[27] Measures were also proposed to develop the sort of leadership that could enable NHS organisations to foster innovation and improvement.[28]

Another aspect of organisational learning focused on the need to learn from error. The foreword to the Chief Medical Officer's report on learning from adverse events pointed out that 'advances in knowledge and technology... have immeasurably increased the complexity of the health care system... and with that complexity comes an inevitable risk'. The report recommended the creation of a new national system for reporting and analysing adverse health care events.[29] The Government promised to take the necessary action.

Performance assessment

Labour's revamp of the Purchaser efficiency index and the plethora of performance indicators introduced over the previous decade was first detailed in a consultation document.[30] This proposed a set of performance 'domains' that reflected the key objectives of the NHS (efficiency, effectiveness, equity, etc), supported by a limited set of performance measures. Given the criticisms of the purchaser efficiency index, no aggregation of these measures was proposed; rather, the performance assessment framework (PAF) was to be viewed as a 'balanced scorecard', reflecting performance changes across all the objectives of the NHS for all NHS organisations.

Not only were these new sets of performance measures to be disseminated in the NHS, they were also to serve as the baseline information for reporting changes in performance of the NHS to the public.[31,32]

The Government's actions

The most striking feature of Government action has been the establishment of new central bodies to take on distinctive tasks. The new bodies and their roles in delivering this ambitious agenda fall into three categories:

- those attempting to have an impact on the performance of NHS organisations *and* clinical professionals, through setting national standards, building clinical governance and assessing performance
- those with a remit specifically to address the performance of NHS organisations
- those with a particular remit to assure the performance of individual clinical professionals – particularly through the reform of the existing mechanisms for professional regulation.

Setting national standards

The National Institute for Clinical Excellence (NICE) was set up on 1 April 1999. Its role was to provide patients, health professionals and the public with authoritative, robust and reliable guidance on current 'best practice'. NICE has two main outputs: national guidance on the clinical management of specific conditions; and

To cover the private sector, the Government established the National Care Standards Commission (NCSC).[43] From 1 April 2002, it will regulate social care and private and voluntary health care in England, including care homes, children's homes, private and voluntary hospitals and clinics, and nursing agencies. The NCSC aims to regulate and inspect services against national minimum standards[44,45,46] and will have powers of enforcement to make sure that services meet required standards.

Assessing performance

Performance indicators on a wide range of NHS activities and objectives – based on the national performance assessment framework (PAF) – have been published annually for the past three years. In 2001, the Department of Health published a league table of acute trusts in England, with rankings based on a composite of a selected number of performance indicators (*see* box *below*).[47] Each trust was given a 'star rating' between zero and three.

Performance rating criteria

Organisations are assessed across four main areas:

1. Key targets
- Inpatient waiting
- Outpatient waiting
- Long inpatient waits
- Breast cancer waits
- Financial performance
- 12-hour + trolley waits
- Cancelled operations
- Treatment of staff
- Hospital cleanliness

2. Clinical focus
- Clinical negligence
- Emergency readmission
- Deaths in hospital

3. Patient focus
- Inpatient waiting (time)
- Outpatient waiting (time)
- 4-hour + trolley waits
- Complaints resolved

4. Staff focus
- Sickness/absence
- Junior doctor's hours
- Consultant vacancies
- Nurse vacancies
- Allied health professional vacancies

High performance on the star rating system (attaining three stars) has subsequently been rewarded not with extra money (a system that would be open to the accusation that to those that have most will be given more) but by a greater degree of freedom so called 'earned autonomy'.[48] This initially meant that a three-star trust had more freedom over how to spend its share of a national (and evenly divided) performance fund, although it has now been extended to possible new freedoms from regular inspection or the constraints of being a state-owned organisation.[49]

As well as incentives for those that performed well on the star system, the Government also introduced disincentives for those who did badly. Zero stars were to put the organisation on a last chance status with chief executives given three months before they and their management team were sacked and replaced – either from a more successful organisation within the NHS or even from the private sector in a process which (rather misleadingly) has been called franchising. The first round of star ratings produced 12 trusts with zero star ratings. Four have now been taken over by alternative NHS management teams.[50]

The Government's first action was to introduce new legislation, not directly to reform the professional regulators, but to make potential future Government reform of the statutory regulators of health care professionals easier to initiate and drive through Parliament.[55] The move was widely interpreted as laying the ground for more direct intervention if the professional regulators did not deliver an agenda for reform that matched Government objectives.

In 2000, the Government consulted on proposals and draft orders for just such a revamp of the structures for regulating nurses, midwives and health visitors, and for the organisation responsible for regulating thirteen other health care professional groupings.[56,57] These provided a clear model for the medical profession to follow. Broadly, the reforms followed the guidance later articulated in *The NHS Plan* that required the self-regulatory bodies to be smaller, with much greater patient and public representation, to have faster, more transparent procedures and to develop meaningful accountability to the public and the health service.

Council for the Regulation of Health Care Professionals

In addition, in 2001, the Government set out plans for an over-arching body to oversee the work of each of the professional regulatory bodies.[58] The Council for the Regulation of Health Care Professionals (CRHCP) is intended to co-ordinate the work of the different bodies, ensuring that they employ similar standards to judge their members' work and that their procedures are transparent to the public. It is proposed that the Council also has the powers to investigate maladministration and, in extreme circumstances, to refer individual cases to appeal where it believes the regulatory body may not have acted in the public interest. The establishment of the Council is part of the National Health Service Reform and Health Care Professions Bill currently before Parliament.

National Clinical Assessment Authority

In April 2001, the Government established the National Clinical Assessment Authority (NCAA). This new body will provide assessments of clinical performance when employers raise concerns about an individual's practice.[59] The NCAA is now testing its methodology. The intention is that on the basis of clinical data, discussion with the doctor and other staff, and a visit, the authority's team of medical and lay assessors will make a judgement about the doctor's performance and recommend a course of action. In the first instance, responsibility for dealing with problem doctors will rest with employers, who will be expected to act on the assessment authority's recommendations, although they are not bound by them. In serious cases, the NCAA is likely either to recommend that the employer refer the doctor to the GMC to see whether their licence to practise should be revoked, or to make a referral itself.[60]

The impact of policy

The impact of each theme in Labour's approach to health care quality is addressed separately. However, initiatives to develop quality assurance and improvement are not self-serving ends in themselves but multiple means to the same end. Indeed, it may be hard to ascribe cause and effect, let alone absolute impact.

The full range of institutions with a role in quality improvement in the NHS is illustrated in Figure 24.

The role brought with it massively increased paperwork, an over-reliance on locum cover, neglect of their own professional development, and strained relationships with colleagues, patients, spouses and children.

Building clinical governance – patchy progress

Evidence about the implementation of clinical governance fits a similarly mixed pattern. A three-year study of clinical governance in primary care showed that, by January 2002, the process was becoming embedded in the day-to-day working lives of the 24 practices that were participating in the study. Members of the primary care teams and the clinical governance leads were viewing clinical governance as 'part and parcel' of their job. Primary care clinical governance leads could identify benefits to their own surgeries (for example, regular clinical meetings, significant event auditing), as well as advantages for the primary care organisation (for example, sharing anonymised data, and networking across previously isolated primary care teams).[62]

However, these leads also identified some negative consequences for themselves and problems in achieving clinical governance objectives for the organisation. For example, the role brought with it massively increased paperwork, an over-reliance on locum cover, neglect of their own professional development, and strained relationships with colleagues, patients, spouses and children. For the organisation, this lack of perceived support led to a high risk of burn-out and resignation on behalf of clinical governance leads. Interviewees emphasised the challenge of trying to achieve implementation alongside substantial organisational change (the move to trust status in particular) and a paucity of ear-marked funding. Many reported that the clinical governance role still did not come with clear accountability, infrastructure, or adequate support funding.[63]

In hospital, mental health and community trusts, it is harder to find sound and timely research evidence through which to assess impact. However, it is clear from the first 80 or so CHI reports that progress on clinical governance is patchy. Earlier studies in London and the West Midlands reported significant progress on establishing systems and processes for clinical governance activity within trusts, but doubts over the degree to which the agenda had really reached the clinical frontline. Both studies found clinical governance to be well received and found progress in the supporting structures and processes necessary to undertake the work, as well as serious attention being given to the quality agenda by the board.[64,65] This mixed set of findings is unsurprising given the comprehensive ambition of the programme and the culture change needed to facilitate its wholesale implementation.

Assessing performance – can the PAF claim credit for improvements?

Commenting on the most recent set of performance indicators, published in February 2002, the Department of Health stated that:

> 'The data published here show real improvements across most indicators [when 'current year' 2000/01 is compared against previous year 1999/2000]... Taken together, the quantitative and qualitative data from these indicators and the NHS Modernisation Board Report show that the programme of investment and reform contained in *The NHS Plan* is bringing about measurable improvements to NHS performance.' [66]

However, improvements in performance as revealed by the performance indicators in the performance assessment framework need to be interpreted with care as:

- Performance could improve because of 'performance indicator creep'. For example, managers may focus on quality improvement, and direct their managerial energy

The Government has been active, even hyperactive, in its approach to quality improvement and assurance.

These approaches to reform have a sound basis in principles of good corporate governance and current statements of good regulatory practice in fields other than health care. Action on revalidation is the most radical. But a process for judging the revalidation of all doctors will not be in place until 2004.

Once implemented, changes in professional regulation could have significant impact the process for revalidating all doctors, for example, could, for the first time, bring effective scrutiny to bear on individual clinical performance, knowledge and behaviour. Alternatively, of course, the process could prove to be less meaningful based more on compliance with a paper exercise than on offering a robust challenge.

The new Council for the Regulation of Health Care Professionals (CRHCP) is still to be established, and the work of the National Clinical Assessment Authority is not yet in full flow. The Bristol Inquiry has already underscored the need for greater co-ordination between the multiple systems for professional regulation, redress and organisational learning.[73] Similarly, when addressing the regulation of health care organisations, the Inquiry called for greater co-ordination of organisations such as the National Care Standards Commission (which still has to start the work of inspection) and CHI (which is yet to initiate a proposed evaluation of the impact of its work).

If a modern system of regulation for health care professionals and organisations is to lead (rather than follow in the wake of) a new relationship between the public, professionals and the state, implementation needs to occur quickly. Given the current half-implemented nature of reform it is not possible to assess impact, although it is not too early to worry that the positive potential of proposed change might be tarnished by delay.

Conclusions

New organisations

The Government has been active, even hyperactive, in its approach to quality improvement and assurance. However, the focus of this energy has been on establishing quangos and giving them the responsibility for action. Putting these organisations in place takes time and money, and risks confusion as their new roles and responsibilities emerge. It is also an approach that delays real impact on those who work in the NHS and how they go about that work.

Developing a body of work

The more established organisations, such as NICE and CHI, have developed a body of work that is amenable to evaluation. They have been operational long enough to have developed a relationship with the NHS. Criticisms of NICE are developed in Chapter 4 but, in brief, the process used for the assessment of new treatments still lacks clear transparency in relation to the criteria for cost effectiveness.

Evaluation

CHI has also developed a body of work and has built a direct relationship with the organisations that it has inspected. It will soon be commenting indirectly on every organisation in the health service through the performance assessment system. However, like NICE, there is still no formal evaluation of the quality or usefulness of its work, or its impact on the organisation at the receiving end. The difficulty for CH and many other new or reformed organisations that seek to influence

It was entirely focused on the NHS: the private sector was not mentioned as a care provider.

Encouraging private provision through *The NHS Plan*

On assuming power, Labour did not try to 'claw back' privately provided services into the NHS: in effect, they were ignored or taken for granted. Nor was any positive incentive or instruction offered to encourage any further inroads by private providers into NHS services. Indeed, as late as 1999, the opposite was true. But from *The NHS Plan* onwards, a different policy emerged: for both elective and intermediate (including nursing home) care, the Government positively encouraged the use of private facilities and provided extra cash to buy operations from privately owned hospitals.

By 2002, the private sector was actively encouraged to extend its role in the provision of care as well as support services (for example, in early 2002 contracts for the supply of pathology services by the private sector were announced). In a speech given in January 2002, the Secretary of State, Alan Milburn, appeared to be opening up the provision of health care services to a wide range of public and private organisations, under the aegis of a 'values-based' NHS rather than a single 'nationalised industry'.[2]

When Labour took power, the need for a substantial hospital building programme was largely unchallenged. The NHS had suffered from cutbacks in capital spending since the mid-1970s when the International Monetary Fund visitation put paid to the implementation of the capital programme agreed in the previous decade.* Capital spending had fallen and, as a result, the condition of the stock worsened: an enormous backlog of repairs built up.[3]

But, while the need for extra spending appeared urgent, the case for using private finance was far from clear. In 1997, the Government was anxious to reduce its borrowing level to bring it into line with EU conditions for entry into the Euro. Using private finance enabled it to keep borrowing down while rapidly expanding the hospital building programme.

Over time, because of rapid improvement in public finances, that argument lost strength, leaving the case for the policy to be made in 'value-for-money terms': in short was procurement via the private sector more effective than the traditional method? In supporting the use of private finance in 1997, the then Secretary of State, Frank Dobson, poured scorn on the traditional method, citing massive overruns in terms of time and cost on (one or two) schemes.[4] Using private finance was expected to keep scheme costs under control and ensure that the new hospitals were built on schedule.

The Government's actions

Extending the Private Finance Initiative

To remove the logjam they inherited in the PFI, Labour passed the NHS 1997 Act, which allayed the fears of the private sector that contracts entered into with trusts might not be honoured. In June 1997, the then Health Minister, Alan Milburn, was

* The first major hospital building programme since the foundation of the NHS began with the 1962 Hospital Plan for England and Wales (revised 1966).

Using private clinical and nursing care

The *NHS Plan*[6] referred to a 'national framework for partnership between the private and voluntary sector and the NHS' bearing on elective, critical and intermediate care. In November 2000, the Government published the Concordat,[7] which set out what the framework would involve. This brief document set out in very general terms a broad brush agreement between the Government and the private and voluntary sectors. It pointed to the need to involve the private sector in capacity planning, staffing requirements and local service development. But it did not deal with these issues in a substantive way. In the following year, the Labour Manifesto stated that the private sector might be brought in to manage the 'specially built surgical units' which had been announced in *The NHS Plan* but did not specify precisely how and when this might be done.

The Government has not published any data and, at the time of writing at the time of writing is in the process of checking the extent to which individual trusts have made use of private facilities. It is clear, however, that the contribution of the private sector (including hospitals in other EU countries*) is tiny – a few tens of thousands of operations set against a total of some 5.5 million.*

In contrast, intermediate or nursing home care* is almost entirely in the hands of the private sector. In October 2001, the Government published a new Agreement, entitled *Building Capacity and Partnership in Care*[8] which, in the words of the Secretary of State's foreword, 'makes the beginning of a new and more positive partnership between the statutory and independent social and health care and housing sectors'. The Agreement argues that commissioning bodies should invest more ambitiously in private providers to help to shape the market for care services in their localities.

The impact of policy

Building new hospitals

Against the yardstick of speedy and efficient delivery, the use of private finance has been a success: schemes have generally been delivered on time and within budget.* As a result, the NHS and its patients are already experiencing the benefits of a number of new hospitals with the firm prospect of many more to come.

However, this comparison, good enough for Parliamentary debate, distorted the average experience of public sector procurement: the cited schemes were far from typical.[9] In most cases, overruns after final scheme costs had been agreed were less than 10 per cent. Furthermore, evidence to a Commons Health Committee inquiry showed that procurement by the public sector could be well managed even in very difficult circumstances.[10]

In addition, there is no doubt that the cost of negotiating the first wave of schemes was very high. Both those procuring new hospitals and those seeking to supply

* Following a decision by the European Court the Government supported the use of hospitals in other EU countries for patients on the waiting list: the first few went to France in January 2002.
* The NHS does more operations than this, but some are emergencies which would not be done in private facilities.
* The term 'intermediate care' is hard to define precisely. Here we use it to refer to services offered outside people's homes although, in some contexts, it may also be used to refer to home-based care.
* However, in some cases, eg, Norfolk and Norwich, scheme costs have risen substantially since the first estimates.

What is clear is that the NHS has rushed into a massive capital building programme without any collective or central reflection as to precisely what type of facilities it ought to be investing in.

If the merits of the policy rest on the long-term issues, other considerations come into play. Labour's hospital building programme was launched into a strategic vaccuum.[13] It was only in September 1998 that the National Beds Inquiry was commissioned by a Secretary of State worried about the NHS's capacity to cope with winter peaks of demand, and the results of this work were not published until February 2000,[14] when several billion pounds had already been committed.

The National Bed Inquiry attempted to estimate whether or not more acute hospital beds were needed. But it did not deal with most of the factors relating to changes in the type and size of hospital services we need, including changes to junior doctors' hours, increasing medical specialisation and concerns about the safety of smaller hospitals. Since the Inquiry was published, the Department of Health has not published a document responding to these issues.

In other words, whether the hospitals being built are the hospitals we are likely to need in 10, 20 or 30 years time is unclear, given the scope for shifting many services to other locations and the trend towards the centralisation of key functions such as emergency care.* This issue is especially pertinent to the PFI because NHS trusts are tied into deals with the companies who build and maintain their facilities for 30 years, which may reduce the flexibility they have to respond to change in need, or increase the costs of any alterations. So while the need for new investment may be clear, how it should be deployed is much less obvious. These uncertainties[16] cast doubt on the wisdom of entering into long-term contracts. The contracts under which hospitals are provided do allow for some degree of flexibility, but it remains unclear what costs a trust would incur if it had to close or restructure a significant part of its facilities – and whether those costs will represent a barrier to change in future.

What is clear is that the NHS has rushed into a massive capital building programme without any collective or central reflection as to precisely what type of facilities it ought to be investing in.

Using 'spare capacity'

The *NHS Plan* promised more staff and other necessary resources, but none could be provided quickly. Accordingly, the attractions of using spare capacity in the private sector were clear.

But 'spare capacity' is a short- rather than long-term notion. It does not provide the basis for the kind of relationship the Plan appeared to envisage. The Plan did, however, propose the development of a number of new elective care and diagnostic centres, in association with the private sector, which do imply a long-term commitment. By the time of writing, no agreements had been reached, but active negotiations were underway with BUPA to transform Redwood Hospital, in Redhill, Surrey, into a diagnostic and treatment centre.[17]

The Government's approach to private nursing care remains similarly vague. The Agreement does not have anything to say about the underlying economics of the private sector organisations to which it is to apply, in particular whether the public sector commissioners will be able to provide the long-term security to give the private sector the confidence to continue to invest in the market. Nor does it tackle

* In public, at least, the Department of Health has shown no interest in these issues; by contrast, the Foresight programme under the aegis of the Office of Science and Technology has done so.[15]

So far, at least, no reasons have been put forward justifying the view that the private sector may be better placed than the public to provide the expertise which a 'failing' hospital requires.

nursing homes, where the private sector is well established, recent developments do suggest the need for better 'market management'. But the Agreement does not provide a sufficient basis for that: it contains no analysis either of the way that the market works now, how it may work in future, nor of what is needed for its effective management in terms of national and local expertise.

In the case of elective care, the Government has published no data on the costs of producing more operations within the NHS compared to the private sector. It has specifically declined to publish the costs of using hospitals in other parts of the EU.[19] At the current level of purchasing from the private sector at home and abroad, this does not matter greatly: given the pressing need to reduce waiting times and the difficulty of rapidly increasing NHS capacity in the short term, it is hard to argue against what the Government is currently proposing.

But the longer-term policy remains to be defined. If the private sector were to become a major provider, issues that have been put to one side would come to the fore:

- How exactly should the staffing issues be dealt with?
- Would it possible to ensure that increases in private sector capacity were not at the expense of reductions in the NHS?
- Should private hospitals pay for their nurses' training and, if so, on what basis?[20]
- Does it matter what range of work is carried out in the private sector, and, in particular, what would the impact be on the quality of care offered by NHS hospitals if the private sector were to employ full time consultants (or equivalent) out of an effectively fixed labour supply?

In other words, while the Government has claimed that the purpose of the Concordat and the Agreement is to provide the basis of a long-term relationship, in fact neither have yet succeeded in doing so. Nevertheless, they do hint at fundamental change.

Moving towards a range of different providers

In a speech[21] given in January 2002, the Secretary of State referred to changing the NHS from 'a monolithic, centrally run, monopoly provider to a values-based system where different health care providers – in the public, private and voluntary sectors – provide comprehensive service to NHS patients within a common ethos'. He added that where a particular hospital was performing badly the so-called franchise for its management might go to some non-NHS body such as 'a university, or a charity or to some other external management team' – with the latter clearly opening the door to the private sector.

This speech, which aroused an unfavourable response within the ranks of Labour supporters, has yet to be reflected in specific policy proposals. So far, at least, no reasons have been put forward justifying the view that the private sector may be better placed than the public to provide the expertise which a 'failing' hospital requires.[22]

But the speech appears[23] to open the way for a radically different NHS, which maintains the current objectives of providing care free at the point of access on the basis of need and not ability to pay, but where provision lies with a range of different bodies.

would decide both about the need for a care home placement and an individual's ability to pay towards the cost of their care. More people than ever before found themselves being means tested. This included homeowners, some of whom had been encouraged to purchase their houses by a Conservative Government keen on creating a home-owning democracy. They found themselves having the value of their homes taken into account and the prospect of passing their assets to their children removed.

At the same time, many local authorities were charging for home care and other non- residential care services (as they were entitled to by law). They were compelled to do this as grants from central government were now calculated on the assumption that a proportion of local authorities' income would be raised through service charges. A complex system of charges emerged, with wide variations in charging policies and levels of fees.

The system was regarded as both complex and unfair. There was much talk of betrayal among older people and their carers, who felt they had paid taxes and National Insurance all their working lives and who expected the Welfare State to provide for them 'from the cradle to the grave'. This public outcry prompted John Major's Government to look seriously at insurance and equity release schemes that might protect people against the risk of needing long-term care.[1]

A fragmented system of care

Services for people with long-term illness and disability had long been provided by many different organisations, including the NHS, local authorities, voluntary organisations and private businesses. By 1997, the whole service system had become very fragmented, with serious turf wars breaking out between the NHS and local authorities about their responsibilities, and users and carers described as being caught in the crossfire.

The Conservative Government had attempted to clarify the respective responsibilities of the NHS and local authorities for the care of elderly and disabled people in the NHS and Community Care Act.[2] Local authorities were given lead responsibility for financing and arranging care, and the NHS was required to participate in the planning of local services. However, there was a grey area regarding people with 'continuing health care needs' who found themselves at the centre of disputes about who was responsible for their care.

With many hospitals having reduced their continuing care beds, the NHS was perceived as withdrawing from long-term care and shunting both patients and costs over to local authorities. Collaboration between the NHS and local authorities was weak and marred by cross boundary disputes. The Conservatives had to issue annual guidance on continuing care, spelling out what the NHS should provide and requiring both parties to agree on how they would deal with disputed cases.[3]

However, collaboration across boundaries was not made easier by a culture of competition that prevailed on both sides of the health and social care divide. On the one side, the NHS was operating an internal market, characterised by a separation of purchasers (health authorities) and providers (trusts). On the other side, local authorities were attempting to manage a mixed welfare economy, encouraging much greater use of independent providers. Unsurprisingly perhaps, it became more and more difficult to see how the whole system fitted together.

- extra money for the NHS to spend on community services, aimed at reducing the numbers of delayed discharges from hospital and emergency admissions.

He also announced the Government's intention to legislate 'to make it easier for the NHS and social services to work together' by pooling their resources. These early statements demonstrated the new Government's commitment to health and social care partnerships, and heralded plans for bolstering collaboration through legal and financial incentives.

Promoting better health and greater independence

Before its second term in office, the Labour Party's promises about long-term care had shifted from the financial concerns that had been evident four years earlier, to a new focus on promoting better health and greater independence.[9] More money was promised for intermediate care and related services to ensure that older people would have *alternatives* to long-term care services. Where long-term care was mentioned, the emphasis was on improving access to a wide range of community services. There was also a promise to extend more control and choice to older people and carers over the services used, through Direct Payments that could be used to buy the care and support they wanted. (This measure was already available for younger disabled people). And, finally, there was a promise of greater support for carers, through increased financial benefits and more social care services, such as respite care. These pledges repeated commitments made in *The NHS Plan*, drawn up by the Secretary of State for Health in July 2000.[10]

The Government's actions

Creating a fair funding system

The Government delivered on its promise to set up a Royal Commission. Under the chairmanship of Stewart Sutherland, the Commission worked throughout 1998, completed its work within a year and published its report in March 1999.[11] Its recommendations are summarised in the box below.

Key recommendations of the Royal Commission on Long-Term Care

- Making all personal and nursing care free and funded through taxation.
- Continuing to means test contributions towards living and housing costs.
- Disregarding the value of people's homes for up to three months after admission to a care home.
- Raising the capital limits used to determine whether and how much individuals should pay towards their care.
- Extending Direct Payments to people aged 65 and over.

Two members of the Commission, Joel Joffe and David Lipsey, issued a Note of Dissent, in which they argued that it would be better to spend the money required to fund free personal care on improving services such as home care, prevention and rehabilitation. They argued that providing free personal care would only transfer resources to the better off who were already paying for their care, and eventually to their children through inheritance.

The Government took some time to respond. Nine months after the Commission's report was published, the new Secretary of State, Alan Milburn, announced that

and social services by their achievements in improving mental health services and increasing the provision of rehabilitation services for older people. Both the NHS and social services departments became subject to star ratings, indicating the extent to which they were succeeding or failing to meet government targets.

The big test for health and social care partnerships always comes in the winter months, when demand for services increases. The Government soon instigated an annual process of winter pressures planning, involving health and social services at national level (through the Department of Health's Winter Emergency Services Team) and at regional and local level (through joint service initiatives designed to avoid long trolley waits in hospital A&E departments and to reduce delayed discharges from hospital). Large sums of money were injected into the system each winter to facilitate this process.

Improving the quality of care

The Government has set up a new range of institutions charged with inspecting and regulating care services. It has adopted a series of national standards regarding care services and applying to particular groups of people. And, finally, it has put in place a number of task forces and implementation groups charged with putting the standards into practice.

The Government's Long-term Care Charter, produced in December 1999, was one of Labour's earlier attempts to improve the quality of care by arming users and carers with information about the standards they could expect from health, housing and social services. The Charter was a national framework for the development of local charters. It was left to local authorities, working with their partners in housing and health, to set out what would be provided and when, and to specify the standards that would be met in, for instance, the length of time aids and equipment would be delivered following an assessment.

Later measures included the establishment of the National Care Standards Commission (NCSC) to regulate care homes, private and voluntary hospitals or clinics and home care services. The Government set up the Social Care Institute of Excellence to assist in the task of putting into practice evidence of service approaches known to result in good outcomes for users and carers. The General Social Care Council came into being, charged with registering the social care workforce, and raising professional and training standards.

These new bodies sat alongside health counterparts like the Commission for Health Improvement, the National Institute for Clinical Excellence and the longer established medical and nursing professional bodies. Few links were made between the respective organisations and the result was a somewhat overcrowded field that threatened to present a real burden to the local agencies expected to improve the quality of care. Thus, before the new social care institutions came into operation, there was talk of merging some of the bodies 'in due course'.

National standards were set for residential and home care services that care agencies would need to meet in order to be registered by the NCSC and allowed to carry on providing services.[17,18] And a series of National Service Frameworks were developed, setting standards to be achieved by the NHS and local authorities in mental health services and in services for older people.[19,20]

By the end of 2001, there were warnings of a looming crisis in the care sector, which could only be averted by substantially increased investment in social care – in line with the rate of increase already agreed for the NHS.

country, as some care owners left the market or decided not to take publicly funded clients any more. Care home owners in the private and voluntary sectors were struggling as prices were being held down while new quality standards had to be met and staff shortages addressed; realising valuable land assets was a more attractive option to many of them. In addition, local authorities complained that they had insufficient funds to provide fully for all the people who no longer needed to be in hospital. Instabilities in the care market were threatening to de-stabilise the entire service system. Furthermore, the old culture associated with the 'Berlin Wall' days was beginning to re-emerge, with health and social services blaming each other for blocked beds.

Labour moved quickly to try to stabilise the situation. First, an Agreement about the relationships between public and private care sectors was published. [30] This Agreement, drawn up in 2001, encouraged the use of longer-term contracts for private and voluntary sector care providers, allowing them greater certainty and security. It also encouraged greater capacity planning at local level, with representatives of both public and private sectors working together on commissioning strategies. Second, another infusion of cash was provided to deal with the 'bed blocking'. This time, the money – £300 million over two years – was given to social services, in recognition of their financial difficulties.

The Government claims that great progress has been made in developing and improving partnerships between the NHS and local government.[31] But the Secretary of State for Health clearly continues to be frustrated by the problem of delayed discharges and by the 'confusion and uncertainty about where the responsibilities of health and social care begin and end'.[32]

More protection for users?

Within five years, the Government succeeded in putting in place a complex regulatory framework – most of which was expected to come into operation in April 2002.

Early efforts to improve the way health and social care agencies delivered their services ran into difficulties. The Long-term Care Charter left authorities to specify standards, but, in practice, many preferred to describe the services they were providing rather than set specific service standards that users could rely upon.[33]

Although later measures, such as national regulation of the care sector, show more potential for safeguarding standards and improving the quality of care provided, they also inevitably drove up the costs of care, leading to difficulties for commissioners and providers of care alike. Some care home owners, and others who anticipated difficulties in meeting the standards for upgrading buildings and training staff, left the business. Local authorities claimed they had insufficient funds to pay for improved quality services. By the end of 2001, there were warnings of a looming crisis in the care sector, which could only be averted by substantially increased investment in social care – in line with the rate of increase already agreed for the NHS.[34]

Conclusions

New laws, institutions and funding commitments

Labour's record over the last five years has been a story of ambitious plans to tackle long running problems, responding to mounting public concern and recognising

The verdict

The Government has not succeeded in establishing a fair and sustainable system for funding long-term care. It has removed some anomalies from the system, but may well create new problems in their place. Integration between health and social services is improving, and both are now better regulated than before to protect users from poor quality care. Progress could still be seriously impeded by acute shortages of funds for social care.

The new Government pledged to open up public services to greater public scrutiny.

Community health councils

Finally, Labour inherited community health councils (CHCs), set up in 1974 to oversee local health services, and to compensate for the reduction in local accountability created by the unification of health services outside local government. The Conservatives had contemplated getting rid of CHCs but this proved a reform too far and CHCs survived where many public interest quangos fell by the wayside. By the end of the Conservatives' term of office, plans were in the pipeline to reform, though not abolish, CHCs.

The policy pledges

Opening up public services to scrutiny

Labour's 1997 manifesto promised to 'save and modernise the NHS'.[5] The public would be able to judge the quality of health services through new targets against which hospitals' performance would be monitored. A reformed Patient's Charter would help to make services more responsive to the public's needs by shifting from basic output measures to standards – focusing on the quality and success of treatment.

The new Government pledged to open up public services to greater public scrutiny. Trust boards – of which a third were chaired by Conservative councillors, former Tory MPs or people who had strong links with the Conservative Party [6] – were to become more representative of local communities, and board meetings were to be held in public.

Planning a radical restructure of the NHS

Within the Government's first term of office, two major White Papers – *The New NHS* and *The NHS Plan* – were produced, outlining plans for a radical restructuring of the NHS.[7] These promised greater public involvement in setting local health service priorities, a new set of principles for decision-making about planning major changes; new structures to give patients and the public more influence over local services; and more support when things went wrong, including an overhaul of the complaints system. They also promised greater transparency in the NHS, giving the public more information about their health and about the performance of local NHS organisations. Information would no longer be an end in itself but would be used to help patients choose, in limited circumstances, which services they would use.

Promising greater patient choice

The 2001 Labour manifesto[8] promised more responsive services and greater patient choice about treatment. Patients would be able to choose the time of their hospital appointment, which would be booked directly by their GP. Any hospital that cancelled an operation on the day of surgery for non-clinical reasons would have to offer a new date within 28 days or fund the patient's treatment at the time – and hospital – of their choice. Subsequent announcements stated that this could, in certain parts of the country, include receiving treatment abroad.[9]

The Government's actions

Increasing public access to information

The Government extended and refined the initiatives that the Conservatives had put in place to make services more responsive and more transparent to the public.

Involving communities in making difficult decisions about service reconfigurations – most contentiously, the closure or downgrading of hospitals – is an important area where little progress has been made since 1997.

months to be treated elsewhere.[12] New patient care advisers will be made available to help patients to choose between different options.

Increasing public involvement

One of the Government's earliest actions in 1997 was to implement its pledge to ensure that trust chairs and non-executive directors must live locally and use NHS services, and to make trusts hold board meetings in public. This policy provoked controversy from the outset over accusations that Labour Party members were being appointed to a disproportionate number of newly vacated seats on NHS boards.

Steps have also been taken to involve patients and the public in decision-making across the NHS. *The New NHS* introduced a new requirement on health authorities to involve the public in developing Health Improvement Programmes (or HIMPs), and to ensure that new primary care groups and trusts had suitable mechanisms to involve the public in shaping their services, for example, by including a lay member on the board of each PCG.

The NHS Plan, and subsequent policy documents on public involvement in the health service, were still more ambitious in scope (*see* box *below*). Although some of the measures announced in guidance leading on from the NHS Plan are not yet in place, local authorities now have powers to scrutinise health services, including the power to call chief executives and other senior staff before their new scrutiny committees. New patients' forums in all trusts, including PCTs, will have rights of inspection over NHS premises, including GP premises that had not been subject to CHC examination, and will also be able to nominate a member to the trust board. A new national Commission for Patient and Public Involvement will support public involvement activities locally. Patients have also been given a say on national regulatory bodies and on the new National Institute for Clinical Excellence.

Proposed structures for public and patient involvement, 2001

- Statutory *patients' forums* to inspect services at NHS trust level (including in each PCT) – functions to include electing a member to the board, monitoring service quality, overseeing Patient Advice and Liaison Services (PALS), making reports on trust activities, and inspecting services without notice.
- A national *Commission for Patient and Public Involvement in Health* (CPPIH)– to set standards for patient involvement, represent patients' views in NHS policy-making, commission research, report to the Commission for Health Improvement and provide training for public representatives in the NHS.
- Local networks, reporting to the CPPIH to support community involvement in health services and to work with local Patients' Forums.
- *Local authority overview and scrutiny committees* with a remit to scrutinise local health services.

Source: *Involving Patients and the Public in Health care: Response to the listening exercise*, London: Department of Health, 2002

Some key areas have still to be tackled. Involving communities in making difficult decisions about service reconfigurations – most contentiously, the closure or downgrading of hospitals – is an important area where little progress has been made since 1997. The Government made a commitment in *The New NHS* to issue guidance on how to work with local communities on reconfiguration. Although a new National Independent Panel has been set up to provide advice on contested plans, guidance to help trusts set up transparent processes to work with their local

Lay members have helped to bring a new perspective into the decision-making processes of PCGs.

Patient choice – are new services reaching those who need them most?

During the Government's first five years, increasing effort was put into extending patient choice and attempting to make services more responsive to local need. It is still too early to assess the full impact of these initiatives, scheduled to come on line within the ten-year period set out in *The NHS Plan*. Evaluations of schemes such as NHS Direct and walk-in centres are showing some early signs of success, offering greater flexibility in the way patients get access to advice and primary care services. Satisfaction rates with first-wave NHS Direct pilots have been high[14] and the service has helped to reduce anxiety about symptoms, as well as directing callers to the appropriate services.[15] Walk-in centres have given patients greater flexibility about when they are seen and longer consultations with staff. However, these early evaluations only reveal a limited picture of performance in certain parts of the country and do not necessarily reflect an accurate picture of the situation nationally.

Doubts remain about whether these new services are reaching people in greatest need. Although some walk-in centres are treating a high per centage of people who are not currently registered with GPs,[16] levels of awareness about NHS Direct may be lowest among groups most vulnerable to ill health. One study found that people over 65, from ethnic minorities or from less affluent areas were least likely to be aware of the service.[17]

The Government's promise to give patients greater choice over the location of their treatment has had some early results. Within a month of announcing that patients who had been waiting longer than 28 weeks could be treated at another hospital, 10 patients had made the trip to Lille in France for treatment, paid for by the NHS. But data about the costs of offering treatment abroad has not been made available and it is not clear whether the private sector and hospitals abroad are offering reduced-price treatment as a loss-leader to bring in higher volumes further down the line. The debate about choice over treatment has been largely divorced from a wider debate about the costs to the NHS as a whole of expanding choice.

Public involvement – involving lay members and patients in NHS decision-making

Significant steps have been taken to broaden the range of people taking up positions on NHS boards and to make these people more representative of local communities. New requirements for board members to live locally have been one important sign of progress, and, although the level of representation by women and ethnic minorities has only shifted slightly under Labour, there has been an increase in the proportion of both groups who chair NHS trusts.[18] The new independent NHS Appointments Commission, which sets out clear selection processes and uniform job criteria, may also help to tackle charges, confirmed by the Commissioner for Public Appointments, Dame Rennie Fritchie, that appointments were becoming politicised again under Labour.[19]

The introduction of formal mechanisms for public involvement within primary care groups and trusts has also had positive results in some parts of the country. Lay members, for example, have helped to bring a new perspective into the decision-making processes of PCGs. So while public involvement has fought for time and resources in the face of other priorities,[20] it has helped to deliver a range of service improvements for local people, including improving knowledge about health

The Government will have to consider how much real choice about different models of care should be offered to patients, and whether taxpayers will be prepared to fund this.

are treated. This is apparent in the introduction of Patients' Prospectuses, particularly in primary care – where the public will be able to use information about practice performance to select their GP – and also with the appointment of patient care advisors to help patients waiting beyond national targets times for heart surgery to assess different options.

But whether the public wants to exercise this degree of choice is unclear. In the case of secondary care, evidence from the first national survey of patients' views on general practice[23] showed that 75 percent were happy for their GPs to make a decision about where they should be referred to, and only 7 percent would like to have been given a choice. Although this may reflect low expectations among patients, it may also challenge the Government's assertions that, in a consumerist society, people expect a similar level of choice over their health care as over their car insurance or shopping.

Even the small proportion of patients who do want to make a choice over treatment are likely to find it hard to interpret the number of different systems for assessing and reviewing performance. United Bristol Health care – one of the so-called 'dirty dozen' trusts which failed to get a single star in September 2001 – was rated one of the highest performers for heart bypass surgery in a Dr Foster/*The Times* survey.[24] Simpler, standardised information will be needed if the public is able to use performance data in a meaningful way.

The rhetoric over choice has grown stronger during Labour's first five years in office. But whether ideology or pragmatism has motivated this is not clear. Many of the Government's initiatives in this area have focused on making existing services more responsive to people's needs (for example, extending opening times in primary care and the booked-admissions project). These initiatives give the public more choice over the time and, in some cases, the location of their treatment but do not offer any choice between different models of care. If initiatives to increase public involvement in local service planning work effectively, the Government is likely to come under increasing public pressure to offer real choice about alternative forms of service to patients. This is far from being a reality at the moment, except in limited areas, for example, maternity services.

Equally, the reasons for offering patients on long waiting lists the choice of treatment in another hospital, the private sector or abroad seems primarily to be pragmatic, motivated by the need to reduce waiting times. Again, these schemes offer limited choice: wait longer and be treated locally or travel for treatment and be dealt with more quickly.

The Government will have to face up to some key dilemmas over the extent to which choice will become a reality in the NHS. Treating patients abroad has raised the question of how much taxpayers are prepared to spend to reduce waiting lists and how to make the necessary trade-off between reducing waiting times and increased expenditure. In the longer term, the Government will also have to consider how much real choice about different models of care should be offered to patients, and whether taxpayers will be prepared to fund this.

Public involvement – reconciling local choice with national equity

Many of the measures that the Government has introduced to increase patient and public involvement are real steps forward. Patients' Forums will give patients greater

The bigger picture

Labour came to power promising a more open, accountable and responsive NHS in which the public had a greater say over the services they received. Throughout Labour's first five years, the political rhetoric around this principle has grown louder. The 1997 manifesto simply promised greater local representation on NHS trust boards. By 2001, individual patients were to be given more choice about services and more power in decision-making about their own treatment. They would be able to influence local service provision through representation on Patient's Forums and take part in consultation exercises about local service priorities. PALS would mean that where patients or their relatives were not satisfied with their care, problems would be resolved speedily. Finally, they could add their views about the effectiveness of local services by contributing to Commission for Health Improvement reviews, local Patients' Surveys and local council overview and scrutiny committees.

On the ground, the picture remains confused. Although the new structures are beginning to offer more opportunities for the public to influence local health services and to access services conveniently, it is uncertain how radical the Government is prepared to be and how much control they are prepared to cede.

Real patient choice over services remains marginal although more effort has gone into making services more responsive to local need. The full impact of these changes will not be clear for some time, and it also remains to be seen how far the Government is prepared to support (and the public to endorse) real choice over different models of care. The language of choice appears to be primarily targeted at increasing capacity to deliver against key targets rather than representing a more fundamental shift in ideology.

The verdict

Emerging policies on patient and public involvement suggest a significant change in the culture of the NHS. While the impact to date has been limited, the Government's promotion of enhanced patient choice may begin to knock down the paternalism that has characterised much of the NHS to date.

The Government promised a 'third way between the old extremes of individual victim-blaming on the one hand and nanny state social engineering on the other'.

The policy pledges

New goals for improving health

New Labour promised in its 1997 manifesto that a new minister for public health would 'attack the root causes of ill health, and so improve lives and save the NHS money'. It pledged to 'set new goals for improving the overall health of the nation' that would 'recognise the impact that poverty, poor housing, unemployment and a polluted environment have on health.' Additionally, to prevent illness, Labour pledged to ban tobacco advertising and to establish an independent Food Standards Agency.

Assessing health inequalities

Labour's first significant step in Government was to bring *The Black Report* up to date: in 1997, it commissioned an independent inquiry into health inequalities, chaired by former Chief Medical Officer Sir Donald Acheson. Its brief was to summarise evidence, spot trends, and identify priority areas for future developments likely to lead to 'beneficial, cost effective and affordable interventions to reduce health inequalities'. Acheson reported on the inquiry's findings in November 1998,[4] with 39 recommendations and four headline priorities:

- All policies likely to have a direct or indirect effect on health should be evaluated for their impact on health inequalities.
- All those policies should be formulated to favour the less well-off.
- Priority should be given to the health of women of child-bearing age, expectant mothers and young children.
- Further steps should be taken to reduce income inequalities and improve the living standards of poor households.

A 'third way' to health improvement

The Government's first public health Green Paper, *Our Healthier Nation* (1998),[5] pledged to 'improve the health of the population as a whole by increasing the length of people's lives and the number of years people spend free from illness' and to 'improve the health of the worst off in society and to narrow the health gap'. It acknowledged that there were sound economic reasons for improving health – citing days off work for illness and demands on the NHS – and promised a 'third way between the old extremes of individual victim-blaming on the one hand and nanny state social engineering on the other'. The Green Paper identified four targets to reduce premature deaths: cancer, coronary heart disease and stroke, accidents and mental health. Those targets would be met though a 'contract' between individuals, local communities and national government, working in three settings – healthy workplaces, healthy schools and healthy neighbourhoods.

Disease-based targets

The White Paper that followed in 1999, *Saving Lives: Our healthier nation,*[6] was much more narrowly focused on NHS-related measures intended to meet the four targets, with numbers (of deaths to be avoided) and dates specified. It claimed that the Government was addressing inequality 'with a range of initiatives on education, welfare-to-work, housing, neighbourhoods, transport and the environment which will help improve health.' This was fleshed out by the formal response to the Acheson Report, published on the same day.[7] Here it laid claim to 'the most

Health Action Zones

Twenty-six Health Action Zones were set up between 1998 and 2001, covering 13 million people in 34 health authorities and 73 local authorities. Health Action Zones, along with Education and Employment Action Zones, were early attempts by Labour to tackle disadvantage by loosening red tape and encouraging innovation. Investment in HAZs has been relatively modest, with £320 million made available for three years from 1999. HAZs are expected to come up with their own ideas and have the freedom to implement them. They are guided by seven principles, the first of which is 'reducing health inequalities, promoting equality of access to services and improving equity in resource allocation'. They are also intended to engage communities, work in partnership, engage frontline staff, and take a 'whole systems' approach that is evidence based and 'person-centred'.[10]

A wide range of innovative projects has been launched in designated Health Action Zones, with varying degrees of success. In Bury and Rochdale, for example, a new Action against Asthma campaign aims to achieve large reductions in the area's high rates of hospital re-admission and visits by children to A&E departments. It centres on home visits by a specialist asthma nurse and an environmental health officer, followed up by a health visitor, and backed by an efficient interpreting and translation support service. In Luton, Bedfordshire, a project to improve the quality of private sector housing for older and disabled people brings together health and housing professionals to identify needs and speed up renovations. In Hackney, East London, pregnant women and vulnerable mothers under 21 receive mentoring and support from other young mothers. Community participation and development, social inclusion, employment and child health are all themes that feature strongly in the HAZs' portfolio of activities.[11]

Healthy Living Centres

In a parallel move, £300 million was made available from the National Lottery's New Opportunities Fund to set up Healthy Living Centres in disadvantaged areas, charged with addressing inequalities, supporting local health aims and involving the community in measures to help improve health locally. Altogether, 136 grants had been awarded to Healthy Living Centres by the end of 2001.

Sure Start

Sure Start, another area-based initiative, was set up in 1998 under the auspices of the Minister for Public Health, to improve the life chances of very young children in deprived areas by making sure they are ready to learn when they reach school age. Up to 250 neighbourhood-level programmes, combining health, education and social services, are intended to support 18 per cent of poor children under four. Funds have increased from £184 million in 2000–01 to £499 million by 2003–04, to enable the programme to almost double its reach by 2004. Sure Start aims to reduce the numbers on the child protection register, the number of mothers smoking in pregnancy, the proportion of children with speech and language problems requiring specialist intervention. It also aims to help reduce the number of 0–3-year-olds living in households where no-one is employed, for example, by directing unemployed parents towards welfare-to-work programmes.

- For children under one year, to reduce the gap in mortality between manual groups and the population as a whole by at least 10 per cent by 2010.
- For health authorities, to reduce the gap between the fifth of areas with the lowest life expectancy and the population as a whole by at least 10 per cent by 2010.

The consultation document pointed out that three other existing targets also impacted on health inequalities:

- To reduce the number of children living in poverty by a quarter by 2004 and eradicate child poverty by 2010.
- To reduce smoking rates among manual groups from 32 per cent in 1998 to 26 per cent in 2010.
- To reduce under-18 conceptions by 15 per cent by 2004 and by 50 per cent by 2010, while reducing the gap in rates between the worst fifth of wards and the average by at least a quarter.

The key mechanisms for delivering on the inequalities targets were identified as primary care trusts (PCTs) and local strategic partnerships. An Inequalities and Public Health Task Force was set up at national level, as well as one in each region, as part of a new network of task forces to help implement *The NHS Plan*. The Treasury's cross-cutting review is expected to inform the way government departments contribute to reducing health inequalities. A delivery plan, setting out measures intended to meet the targets, is due out in the summer of 2002.

More specifically, the *National Service Framework for Coronary Heart Disease* (2000)[18] – designed to focus resources and prioritise action within the NHS – focused on reducing inequalities as a key theme, which involved 'ensuring that less well advanced organisations, including those which may face particular challenges or difficult circumstances, are able to learn from the experience of those which have made more rapid progress, and are given appropriate support'. *The Cancer Plan* (2000)[19] has four aims, one of which is 'to tackle the inequalities in health that mean unskilled workers are twice as likely to die from cancer as professionals'. Measures to achieve this include smoking cessation schemes aimed at low-income groups and schemes to improve nutrition – free fruit for primary school children, and a 'Five a Day' campaign to encourage people to eat more fruit and vegetables.

Improving access to health services

Health improvement, including reducing health inequalities, and 'fair access' to health services according to need, are among six goals defining the Performance Assessment Framework for the NHS. The framework is intended to ensure that universal standards are applied across the NHS and that low-income and socially-excluded groups and localities are not doubly disadvantaged by also having poorer quality health services. The National Service Frameworks (including those for coronary heart disease and cancer) help to set the parameters for performance assessment.

A review of NHS resource allocation was set up in 1998 with the main aim of contributing to 'a reduction in avoidable health inequalities'.[20] As a result, a new 'Health Inequalities Adjustment' has shifted the basis of allocation from securing equal opportunity of access to patients in equal need, towards positive action in favour of deprived areas. In 2001/2, the 47 health authorities judged to have the highest rates of 'avoidable mortality' received an additional £70 million, while a

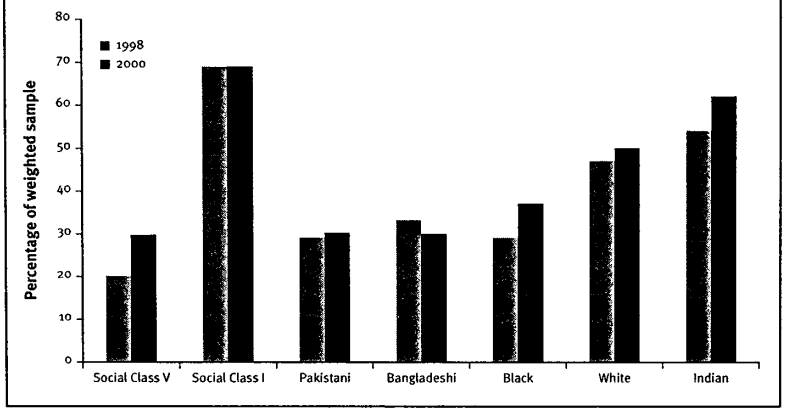
Unemployment among young adults remains high and has increased slightly: it now stands at 10 per cent.

children out of poverty by the end of the last Parliament (June 2001) – a figure said to include those who would have been in poverty had it not been for the policies introduced by Labour.[24]

Education

The number of 11-year-olds achieving level 4 at Key Stage 2 rose between 1996 and 2000: from 52 to 75 per cent for English and from 54 to 72 per cent for Maths. If this can be sustained, it will meet the target set for 2002. Progress is slower for GCSE grades, where there has been an increase in students getting five or more A* to C grades from 42.5 per cent in 1997 to 47 per cent in 2000 – well below the target of 75 per cent by 2004. Improvement has been much greater among manual groups than among non-manual groups.[25]

27 ATTAINMENT OF 5 OR MORE GCSE GRADES A* – C BY SOCIAL CLASS AND ETHNICITY 1998–2000



Source: Youth Cohort Study, ONS, 2001

Black and Indian students have improved their educational performance more than white and Pakistani students, while Bangladeshis' performance has declined. The gap between Inner and Outer London has widened slightly. The proportion of students achieving five or more A starred to C grades at GCSE increased between 1997 and 2000 by 5.1 per cent in Outer London and by 3.7 per cent in Inner London.[26]

Employment

Unemployment has fallen from 7.1 per cent in 1997 to 4.8 per cent in 2001. Currently there are 3.5 million adults who would like to have paid work but do not. Unemployment among young adults remains high and has increased slightly: it now stands at 10 per cent.[27] There has been no discernible improvement in rates of long-term employment, with 1.8 million out of work for three years or more in 1997 and 2001.[28]

Smoking, teenage pregnancy and obesity

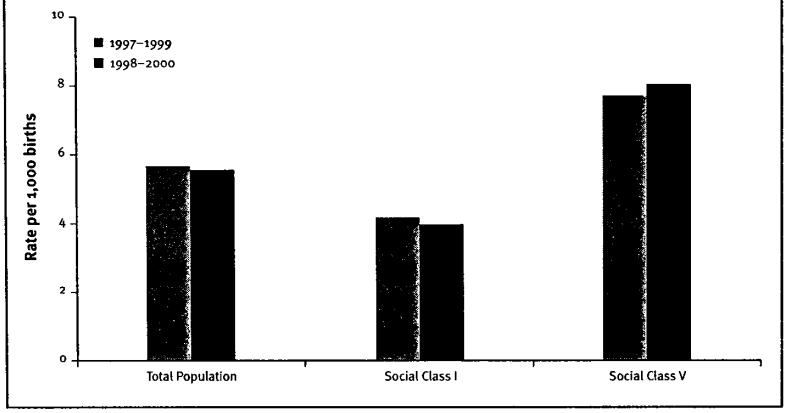
Self-reported smoking rates have declined since the mid-1970s, but have levelled off recently. Smoking rates remain much higher among manual than non-manual groups, although the gap is narrowing slightly. Between 1998 and 2000, smoking decreased among manual men and women (by 2 and 1 per cent respectively).

Infant mortality rates fell between 1997 and 2000, but the gap has widened between the lowest and highest social groups.

Infant mortality

Overall, infant mortality rates fell between 1997 and 2000, but the gap has widened between the lowest and highest social groups. Between 1997–9 and 1998–2000, there was a decline of 5.8 per cent in social class I and a rise of 2.9 per cent in social class V, so that the rate for the poorest is now double that for the wealthiest. Rates are higher for infants whose birth was recorded solely by the mother (38 per cent higher than the overall rate), for those born to mothers under 20 (50 per cent higher) and for those whose mothers were born in Pakistan and the Caribbean (more than double and 93 per cent respectively).[32]

30 INFANT MORTALITY RATES BY SOCIAL CLASS FOR ENGLAND AND WALES 1997–2000



Source: London Health Observatory, 2001

Life expectancy

Life expectancy in England and Wales has increased between 1996 and 1999 (by 1.1 years at birth for males and 0.4 years for females). The gap between the lowest and highest social groups has narrowed. But the picture is mixed: for example, men in social class II have improved their life expectancy by 1.6 years more than men in social class IV and men in the highest group can still expect to live seven years longer than men in the lowest group. There remain marked inequalities between ethnic groups, between men and women and between the north and south of the UK. Life expectancy in Scotland is 72.8 years for men compared with 75 years in England and Wales. The number of women dying at childbirth doubled in Scotland between 1997 and 2000, remaining steady in England and Wales.[33]

Death rates in England have decreased for heart disease, stroke and cancer, but not disproportionately for lower social groups. There has been no improvement in deaths caused by accidents, and suicide rates have increased.[34]

Conclusions

In 1997, New Labour stepped into a field where evidence and understanding of health inequalities were highly developed, where the case for intervention was strong, but where there were no recent precedents for Government action. Tackling health inequalities chimed well with New Labour's identity. Though the Labour Government sought to distance itself from traditional leftist redistribution and 'nanny statism', it needed to project a strong commitment to social justice and

Developing area-based initiatives

Area-based interventions are even more difficult to assess. Sure Start is almost universally regarded as a promising initiative, although it is too early to measure outcomes. It focuses on young children in disadvantaged areas and is based on evidence that positive pre-school experience can lead to improved health and opportunities later on. The Neighbourhood Renewal Strategy, with its recent emphasis on shifting mainstream budgets and programmes to deliver local change, marks a move away from unsustainable ad-hoc initiatives while addressing the immediate and longer-term needs of poor neighbourhoods.

Health improvement and modernisation plans (HIMPs) have received mixed notices. The idea of local cross-sectoral partnerships developing plans to improve health and reduce health inequalities was broadly welcomed on all sides. But several factors have conspired to limit their effectiveness. Reorganisation of the health sector at primary care level has absorbed time, energy and attention that might otherwise have been spent developing HIMPs. Forming useful partnerships is especially difficult while one partner is in a state of constant upheaval. The planning process has been confused by a lack of clarity over how HIMPs should relate to the local authorities' Community Plans. The centrally-imposed imperatives of cutting waiting lists and 'saving lives' threatened by the 'big killers' (heart disease, stroke and cancer) have limited the extent to which HIMPs can innovate to improve health, or identify and address the underlying causes of local health inequalities.

As for Health Action Zones, it took longer than anticipated for them to form productive local partnerships, to develop viable projects and to spend the money allocated. They were afflicted by – and contributed to – confusion caused by a plethora of area-based initiatives, many covering similar ground. The HAZs are due to be wound up earlier than originally planned, and it is expected that some of their activities will come under the auspices of local strategic partnerships.

Inequalities targets

Designing a health policy agenda around specific targets, to be measured in terms of health outcomes, is a risky business. Mortality statistics are harder to manipulate than figures on child poverty. On one hand, targets provide a strong sense of direction and purpose and can be easily understood. On the other, they can lead to over-simplification and even to distorted priorities. Actions whose impact cannot be measured by avoidable deaths may be sidelined, even if they are likely to improve health in the longer term. Resources may be focused too narrowly on areas where the Government feels confident of achieving measurable gains. Saving lives, especially by means of clinical treatment, is not the same as improving health so that treatment is not required. The 'big killer' targets are supposed to be supported by strategies to reduce inequalities, but it is the headline figures that dominate policy and practice, not the aim of reducing their unequal impact. It is too early to tell whether the revised resource allocation formula for the NHS will make any impact on health inequalities.

The introduction of national inequalities targets came late – more than two years after the announcement of disease-based targets. One effect has been to signal a kind of hierarchy. At the top are the disease-based targets for heart disease, stroke and cancer, backed up by detailed implementation plans and serious money. Next, mental health (suicides) and accidents, less well developed and resourced, but nevertheless part of the main 'saving lives' agenda. At the bottom are the health

ultimately bad news for the NHS as well. And it could prove embarrassing for a Government that pledged to improve the health of the poorest when it took office in 1997.

The verdict

The Government deserves credit for putting the 'health gap' on the policy map, but has allowed it to remain a second-order issue. It has instigated an impressive series of actions to improve health and health care for the poorest in society. To reduce health inequalities, however, it must reverse trends in the opposite direction. It is unrealistic to expect demonstrable progress at this stage. But without stronger political leadership and a higher priority given to measures aimed at reducing inequalities, the chances of significantly reducing health inequalities in the next decade are slim.

16 Mulligan, J, Appleby J, *op. cit.*
17 Appleby J, Boyle S, *op. cit.*

Chapter 3 – Waiting

1 Royal Commission on the NHS. Cmd 7615. London: The Stationery Office, 1979.
2 *The Patients' Charter: Raising the standard.* London: Department of Health, 1991.
3 Labour Party Manifesto. *New Labour: because Britain deserves better.* London: The Labour Party, 1997.
4 Department of Health. *The New NHS: Modern, dependable.* London: The Stationery Office, 1997.
5 Department of Health. *The NHS Plan: A plan for investment. A plan for reform,* London: The Stationery Office, 2000: Cmd 4818–I.
6 Department of Health. *The NHS Cancer Plan.* London: The Stationery Office, 2000.
7 National Audit Commission. *Inpatient and Outpatient Waiting in the NHS.* Report by the Comptroller and Auditor General. HC 221, Session 2001–2002. London: The Stationery Office, 2002.
8 *Ibid.*
9 Hospital Waiting Lists: April 2001. Health Statistics and Analysis Unit, NHS Wales. Press release (SDR 24/2001).
10 Modernisation Action Board. *Annual Report: The NHS Plan – a progress report.* London: NHS Executive, 2001.
11 *Review of National Findings: Accident and emergency.* Acute hospital portfolio No. 2. London: Audit Commission, 2001.
12 National Audit Commission. *Inappropriate adjustments to NHS waiting lists.* Report by the Comptroller and Auditor General. HC 452, Session 2001–2002. London: The Stationery Office, 2002.
13 Culyer AJ, Cullis JG. Some Economics of Hospital Waiting Lists in the NHS. *Journal of Social Policy* 1976; 5, 3, 239–64.
14 Luckman J, Mackenzie M, Stringer JC. *Management Policies for Large Ward Units.* Institute of Operational Research Health Report No. 1, 1969.
15 Baderman H *et al. Admission of Patients to Hospital.* London: King Edward's Hospital Fund, 1973.
16 Devlin N, Harrison A, Derrett S. Waiting in the NHS: Part 2: A change of prescription. *Journal of the Royal Society of Medicine,* 2002 (forthcoming).

Chapter 4 – Rationing

1 Hunter DJ. *Rationing dilemmas in health care.* NAHAT Research Paper No.8. Birmingham: National Association of Health Authorities and trusts, 1993.
2 Malone N, Rycroft-Malone J. Equity and rationing in the NHS: past to present. *Journal of Nursing Management* 1998; 6: 325–332.
3 Hunter, *op. cit.*
4 New B, Le Grand J. *Rationing in the NHS: Principles and pragmatism.* London: King's Fund, 1996.
5 New B. The rationing agenda in the NHS. In: New B, editor. *Rationing: talk and action.* London: King's Fund, 1997: Chapter 2.
6 Davies P. A conciliator putting his anxieties behind him. *Health Service Journal,* 28.02.91; p.15.
7 Doyal L. Rationing within the NHS should be explicit: the case for. In: New B, editor. *Rationing: talk and action.* London: King's Fund, 1997: Chapter 10.
8 Ham C, Coulter A. Introduction: international experience or rationing (or priority-setting). In: Coulter C, Ham C, editors. *The Global Challenge of Health Care Rationing.* Buckingham: Open University Press, Chapter 1.
9 *Ibid.*

14 Smith J, Regen E, Goodwin N *et al. Getting Into Their Stride. Interim report of a national evaluation of primary care groups.* Birmingham: University of Birmingham, Health Services Management Centre, 2000.
15 Wilkin D, Gillam S, Coleman A, editors. *The National Tracker Survey of Primary Care Groups and Trusts: Modernising the NHS. 2000/2001.* London: National Primary Care Research and Development Centre/King's Fund, 2001.
16 The National PMS Evaluation Team. *National Evaluation of First Wave NHS Personal Medical Services Pilots: Integrated interim report from four research projects.* Manchester: National Primary Care Research and Development Centre, 2000.
17 Steiner A, editor. *Does PMS Improve Quality of Care?* Final Report from the Quality of Care Project, National Evaluation of PMS. NPCRDC/University of Southampton, November 2001.
18 Department of Health. *A First Class Service: Quality in the new NHS.* London: The Stationery Office, 1998.
19 Hayward J, Rosen R, Dewar S. Thin on the ground. *Health Services Journal* 1999; 26.08.99: 6–27.
20 Department of Health. *Supporting Doctors, Protecting Patients.* London: The Stationery Office, 1999.
21 Wye L, Rosen R, Dewar S. *Clinical Governance in Primary Care: A review of baseline assessments.* London: King's Fund, 2000.
22 Munro J, Nicholl J, O'Cathain A, Knowles E. *Evaluation of NHS Direct First Wave Sites. Second interim report to the Department of Health.* Sheffield: Medical Care Research Unit, University of Sheffield, 2000.
23 Mountford L, Rosen R. *NHS Walk-in Centres in London.* London: King's Fund, 2001.
24 Salisbury C, Chalder M, Manku Scott T, Pope C, Moore, L. The role of walk-in centres in the NHS. *British Medical Journal* 2002; 324: 399–402.
25 Lewis R, Gillam S. The NHS Plan – further reform of the British health service. *International Journal of Health Services* 2001; 31: 111–18.
26 Tobin T. Called to account. *Health Services Journal* 2002; 17.01.02: 22–24.
27 Gillam S. Homeward bound? Just how far have we come in re-directing resources to primary care? *Health Management* 2000; November: 14–15.
28 Gillam S, Abbott S, Banks-Smith J. Can primary care groups and trusts improve the population's health? *British Medical Journal* 2001; 323: 89–92.
29 Skrabanek P. *The Death of Humane Medicine and the Rise of Coercive Healthism.* London: Social Affairs Unit, 1994.
30 Fitzpatrick M. *The Tyranny of Health – Doctors and the regulation of lifestyle.* London: Routledge, 2001.

Chapter 6 – Workforce

1 Davies C. *Gender and the Professional Predicament in Nursing.* Buckingham: Open University Press, 1995.
2 Beardshaw V, Robinson R. *New for Old? Prospects for nursing in the 1990s.* London: King's Fund Institute, 1990.
3 Finlayson B. The recruitment and retention challenge. *Health Care UK*: Winter 2001; 42–50.
4 UKCC. *Annual statistics. Volume 1.* London: UKCC, 2000.
5 *Making Up the Difference: A review of the UK nursing labour market in 2000.* London: Royal College of Nursing, 2000.
6 Department of Health. *The New NHS: Modern, dependable.* London: The Stationery Office, 1997.
7 Department of Health. *Working Together: Securing a quality workforce for the NHS.* London: The Stationery Office, 1998.

36 Taylor D, Esmail A. Retrospective analysis of census data on general practitioners who qualified in South Asia: who will replace them as they retire? *British Medical Journal* 1999; 318: 306–10.
37 Finlayson B. The recruitment and retention challenge, *op.cit.*
38 www.ucas.co.uk
39 Finlayson B. The recruitment and retention challenge, *op.cit.*
40 Department of Health. Statistical press notice, *op.cit.*
41 Department of Health. *Vacancies Survey, March 2001, op.cit.*
42 Audit Commission. *Review of national findings: Accident and Emergency.* London: Audit Commission, 2001.
43 Manley K, Garbett R. Paying Peter and Paul: Reconciling concepts of expertise with competency for a clinical career structure. *Journal of Clinical Nursing* 2000; 9,347–359.
44 Cochrane D, Conroy M, Crilly T, Rogers J. *The Future Healthcare Workforce: The second report.* Bournemouth: The University of Bournemouth, 1999.
45 Buchan J, Dal Poz M. *Role Definition, Skill Mix, Multi-Skilling and 'New' Workers.* http://www.who.int

Chapter 7 – Quality assurance

1 Kerrison S, Packwood T, Buxton M. Monitoring Medical Audit. In: Robinson R and Le Grand J, editors. *Evaluating the NHS Reforms.* London: King's Fund Institute, 1994.
2 The New Health Authorities and the Clinical Audit Initiative: outline of Planned Monitoring Arrangements. Department of Health, 1995 (Executive Letter: EL(95)103).
3 Improving Clinical Effectiveness. Department of Health, 1993 (Executive Letter: EL(93)115).
4 Improving the Effectiveness of the NHS. Department of Health, 1994 (Executive Letter: EL(94)74)
5 Improving the Effectiveness of Clinical Services. Department of Health, 1995 (Executive Letter: EL(95)105).
6 Humphris, D. *The Assisting Clinical Effectiveness (ACE) Programme.* ACE 1 Final Report Health Care Evaluation Unit. London: St George's Hospital Medical School, 1998.
7 Wye, L McClenahan, J. *Getting better with evidence: experiences of putting evidence into practice.* London: Kings Fund, 2000.
8 Evans D, Haines, A, editors. *Implementing Evidence-Based Changes in Healthcare.* Oxford: Radcliffe Medical Press, 2000.
9 Dunning, M. *Building on the Evidence: Learning from experience and evidence in everyday practice: the final report from the PACE programme.* London: King's Fund, 1999.
10 NHS centre for reviews and dissemination. Getting Evidence into practice. *Effective Health Care,* 5(1) 1999.
11 Department of Health. *Promoting Clinical Effectiveness – A framework for action in and through the NHS.* London: The Stationery Office, 1996.
12 Department of Health. *The New NHS: Modern, dependable.* London: The Stationery Office, 1997.
13 Bristol Royal Infirmary Public Inquiry. Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984–1995. In: *Learning from Bristol.* London: The Stationery Office, 2001 (Cmnd 5207).
14 Department of Health. *An Inquiry into Quality and Practice within the NHS Arising from the Actions of Rodney Ledward: The report.* London: The Stationery Office, 2000.

39 Department of Health. *A First Class Service – Quality in the new NHS, op.cit.*
40 Department of Health. Health Act 1999. London: The Stationery Office 1999.
41 Department of Health. *Primary Care Trusts – Establishing Better Services.* London: Department of Health, 2000.
42 The Commission for Health Improvement. See www.chi.nhs.uk
43 Department of Health. *The National Care Standards Act 2000.* London: The Stationery Office, 2000.
44 Department of Health. *The Care Homes Regulations 2001*: Statutory Instrument 2001 No 3965. London: The Stationery Office, 2001.
45 Department of Health. *Children's Homes Regulations 2001*: Statutory Instrument 2001 No 3967. London: The Stationery Office, 2001.
46 Department of Health. Private and Voluntary Health Care (England) Regulations 2001 No 3968. London: The Stationery Office, 2001.
47 Department of Health. *The NHS Plan – Implementing the Performance Improvement Agenda: A Policy Position Statement and Consultation Document.* London: The Stationery Office, 2000.
48 Department of Health. *NHS Performance Ratings: Acute Trusts 2000/01.* London: The Stationery Office, 2001.
49 Milburn A. Redefining the National Health Service. Speech given to New Health Network. 15.01.02.
50 All hospitals to become star performers. Department of Health. Press release, 11.02.02.
51 Department of Health. *The NHS Plan, op. cit.*
52 Department of Health. *Building a Safer NHS for Patients.* London: The Stationery Office, 2001.
53 *Protecting Patients: A summary consultative document.* London: General Medical Council, 2001.
54 Department of Health. *The NHS Plan, op. cit.*
55 Department of Health. *The National Care Standards Act 2000, op. cit.*
56 Department of Health. *Modernising Regulation: Establishing the new Nursing and Midwifery Council: a consultation document.* London: The Stationery Office, 2000.
57 Department of Health. *Modernising regulation: the new Health Professions Council: A consultation document.* London: The Stationery Office, 2000.
58 Department of Health. *Modernising Regulation in the Health Professions: consultation document.* London: The Stationery Office, 2001.
59 Department of Health. *Assuring the Quality of Medical Practice: Implementing supporting doctors protecting patients.* London: The Stationery Office, 2001.
60 *Interim protocol for contacts between the GMC and the NCAA.* General Medical Council, 2001.
61 *National Service Framework Assessments No.1: NHS Cancer Care in England and Wales.* Commission for Health Improvement and Audit Commission, 2001.
62 Sweeney G, Sweeny K, Greco M, Stead J. *Developing Clinical Governance in Primary Care: Briefing Paper 2:* Exploring the implementation and development of clinical governance within primary care in the South West. University of Exeter and Exeter and North Devon NHS Research and Development Support Unit, 2002.
63 Sweeney G, Sweeny K, Greco M, Stead J. *Developing Clinical Governance in Primary Care: Briefing Paper 1:* The experience of primary care clinical governance leads. University of Exeter and Exeter and North Devon NHS Research and Development Support Unit, 2002.
64 Department of Health. *Clinical Governance in London Trusts: Taking Stock: The 1999 London Regional stocktake of clinical governance: An overview of activities across all London trusts.* London: NHS London Regional Office, 2000.

14 Department of Health. *Shaping the Future NHS.* London: The Stationery Office, 2000.
15 Ferguson, M. *Progress through Partnership.* London: The Stationery Office, 1995.
16 These are brought out in Francis S, Glanville R. *Building a 2020 Vision: Future health care environments.* London: The Stationery Office, 2001.
17 *NHS and BUPA negotiate new public private relationship.* Department of Health Press release, 2001/0593. The intention is for the NHS to take over use of the hospital but for BUPA to continue to manage it under contract.
18 Coates P. Don't shoot the messenger. *Public Finance.* 25.08.00.
19 *Financial Times* 19.01.02, p.2.
20 This issue was raised 20 years ago in McLachlan G, Maynard A, editors. *The Public/Private Mix for Health.* The Nuffield Provincial Hospitals Trust, 2002. Alan Maynard pointed out that other sectors are now expected to pay for the training of those they employ. However, if purchasers were to be able to choose between private and public suppliers, then training costs would need to be paid for in a way that did not distort the choice between them.
21 Speech to New Health Network 15.01.02.
22 Timmins N, *Financial Times* 19.01. 02.
23 Timmins N, *Financial Times* 21.01.02.
24 Department of Health. *Working for Patients.*London: The Stationery Office, 1989.
25 *The Times,* 6.02.01, p. 1.

Chapter 9 – Long-term care

1 Department of Health. *A New Partnership for Care in Old Age.* London: The Stationery Office, 1996.
2 Department of Health. *NHS and Community Care.* London: The Stationery Office, 1990.
3 Department of Health. Community Care – September SSI / RHA Monitoring. EL (93) 119; CI (93) 35; Department of Health. Community Care Monitoring for 1994/5. EL (94) 57; CI (94) 57; Department of Health. NHS responsibilities for meeting continuing health care needs. HSG (95) 8; LAC (95) 5.
4 Winter cash boost for priority services. Department of Health. Press release 24.12.96.
5 UK Home Care Association. *Response to 'Moving Forward' and the Burgner Report.* Sowerby Bridge: UK Home Care Association, 1996.
6 Labour Party Manifesto. *New Labour: because Britain deserves better.* London: The Labour Party, 1997.
7 Frank Dobson issues NHS guidance on winter planning. Department of Health. Press release, 29.08.97.
8 Frank Dobson announces distribution of extra cash for the NHS this year. Department of Health. Press release, 22.10.97.
9 Labour Party Manifesto. *Ambitions for Britain.* London: The Labour Party, 2001.
10 Department of Health. *The NHS Plan: A plan for investment. A plan for reform.* London: The Stationery Office, 2000.
11 Royal Commission on Long-term Care. *With Respect to Old Age: Long-term care – rights and responsibilities.* London: The Stationery Office, 1999.
12 Health Secretary announces setting up of national care commission. Department of Health. Press release, 02.12.99.
13 Secretary of State for Health. *The NHS Plan – the Government's response to the Royal Commission on Long-term Care.* London: The Stationery Office, 2000.
14 Fairer home care charges to benefit thousands. Department of Health. Press release, 23.11.01.
15 Poxton, R. *Partnerships in Primary and Social Care – integrating services for vulnerable people.* London: King's Fund, 1999.

7 Department of Health. *The New NHS: Modern, dependable*. London: The Stationery Office, 1997.
Department of Health. *The NHS Plan: A plan for investment. A plan for reform*. London: The Stationery Office, 2000.
8 Labour Party Manifesto. *Ambitions for Britain*. London: The Labour Party, 2001.
9 More patients go ahead for treatment. Department of Health. Press release, 15.10.01.
10 Department of Health. NHS Performance Indicators (www.doh.gov.uk)
11 Department of Health. *Your Guide to the NHS*. London: The Stationery Office, 2001.
12 Department of Health. *Extending Patient Choice*. London: The Stationery Office, 2002.
13 Department of Health. *Reforming the Complaints Procedure: A listening document*. London: The Stationery Office, 2001.
14 O'Caithan O *et al*, How helpful is NHS Direct? Postal survey of callers. *British Medical Journal* 2000: 15.04.00. 320:1035
15 Munro J *et al. Evaluation of NHS Direct First Wave Sites: First interim report to the Department of Health, Medical Research Unit*. Sheffield: University of Sheffield, 1998.
16 Mountford L, Rosen R. *NHS Walk-in-Centres in London: An initial assessment*. London: King's Fund, 2001.
17 McInerney J *et al*. Impact of NHS Direct on intermediate care. *British Medical Journal* 28.10.00; 321: 1077.
18 Commissioner for Public Appointments, *Sixth Report, Office of the Commissioner for Public Appointments*, London: OPCA, 2001.
19 Commissioner for Public Appointments. *Public appointments to NHS Trusts and Health Authorities*, London: OPCA, March 2000.
20 Anderson W, Florin D. *Involving the Public – One of Many Priorities: A survey of public involvement in London's primary care groups*. London: King's Fund, 2000.
21 Anderson W, Florin D, Mountford L, Gillam S. *Every Voice Counts: Primary care organisations and public involvement*. London: King's Fund, 2002.
22 Department of Health. *Handling Complaints: Monitoring the NHS complaints procedures. England, financial year 2000/01*. London: The Stationery Office, 2001.
23 NHS Executive. *National Survey of NHS Patients: general practice*. London: NHS Executive, 1999.
24 Bell A. Dr Foster went to Coventry (and Bristol), *British Journal of Health Care Management* 2001; 7 (12): 403 (December 2001).
25 Department of Health. *Analysis of responses to the NHS Plan public consultation*. Accessed at www.doh.gov.uk/nhsplan/shiftinggearsanalysis.htm
26 Anderson W, Florin F. Consulting the public about the NHS, *British Medical Journal* 10.06.00; 320:1553–1554.

Chapter 11 – Health inequalities

1 Trends in life expectancy by social class 1972–1999, http://www.statistics.gov.uk/products/p8460.asp
2 Black D, Morris J, Smith C, Townsend P. *Inequalities in Health: Report of a Research Working Group*. London: Department of Health and Social Security, 1980.
3 *The Health of the Nation: A strategy for health in England*. London: The Stationery Office, July 1992.
4 *Independent inquiry into inequalities in health*: The Acheson report. London: The Stationery Office, 1998.
5 Department of Health. *Our Healthier Nation: A contract for health*. London: The Stationery Office, 1998.