



Building on the Best

Choice, Responsiveness
and Equity in the NHS

December 2003



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Presented to Parliament by
the Secretary of State for Health
by Command of Her Majesty
December 2003

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Foreword by the Secretary of State

“We will give patients more choice.” In 2001 the Government made that pledge in its Manifesto. That process has already started. Within the context of a much broader discussion aimed at the reform and improvement of our public services our preliminary consultation, with patient groups in particular, has been fruitful. It is time now to make another substantial step forward, aimed at providing patients with real choices inside the National Health Service.

That choice has to be real rather than just theoretical. It has to be available to the many not just the few. And it has to be the route to equity as well as excellence.

To make that choice real we have had to begin to create more capacity through massive investment and expansion. This investment allows us to honour the founding value of the NHS, that health care should be free at the point of delivery. Any introduction of personal finance into the direct relationship between doctor and patient would inevitably provide those with more money than others with an opportunity to jump the queue. That would mean that inequality of access to health care would mirror the inequality of access to wealth in the country. The richer you are the shorter wait you would have for your health care. Real choice would remain the privilege of the few.

We want choice, information and the power of personal preference extended to the many. To achieve the basic value of equity of access in the NHS we do need to improve the basic system created in the aftermath of World War II. The British people decided, at that difficult time, that the only way the health service could be fully and fairly provided for everyone was if we all decided to work together to pay for its provision.

If we did that, then it was felt we could – all of us – collectively pool all the risks that would have defeated us all individually. This was a grand social aim. Something that the public loved then and still hold in their affection. The White Paper on Health put this very clearly at the time:

“The Government want to ensure that in future every man, woman and child can rely on getting all the advice and treatment and care they may need in matters of personal health; that what they shall get shall be the best medical and other facilities available; that their getting these shall not depend on whether they can pay for them or any other factor irrelevant to the real need.”

(A National Health Service CMND 6502) 1944

That set of values remains central to our vision.

But, of course, values are meaningless unless they can be applied in practice. And that requires, above all, financial and human resources. No theoretical commitment to the underlying principles of the NHS is meaningful unless the person or persons making the commitment is prepared to make those resources available.

It is clear that the NHS has been starved of the necessary investment to build capacity for decades. We are beginning to put that right. That is why we have made the case for the most sustained and biggest ever increase in investment in the history of the NHS. It is why we have worked in the NHS to drive down waiting times and waiting lists, improve cancer and heart services, and rejuvenate primary care.

But we can only do that because we have put in the resources commensurate with the task. The 2002 Budget provided the largest ever sustained increase in NHS funding – an average annual increase in real terms of 7.4% between 2002/03 and 2007/08 taking total net NHS expenditure from £55.8 billion in 2002/03 to £90.2 billion in 2007/08. Our NHS today is no longer starved of cash. We may have a long way to go. But we have turned a corner.

This investment is buying the biggest ever capacity growth in the history of the NHS. There are over 55,000 more nurses than there were in 1997, 14,000 more doctors and 68 major new hospitals that have been completed, or are underway or approved. These extra staff and buildings, linked to reform and improvement in how we deliver healthcare, have already had an impact. Waiting lists are now more than 184,000 lower than in March 1997, and the number of patients waiting over 3 months, 6 months, 9 months and 12 months are now all substantially lower than those inherited in March 1997.

That is why the question of resources and capacity is inextricably linked to the question of choice. Without an increase in capacity in the NHS, we cannot deliver the degree of choice that we want for patients. And unless we give patients the power to make real choices, we will not maximise the effect of the increased capacity we are creating.

This is the crux of the improvements we are outlining in this paper. The development of choice for patients helps to ensure that capacity is actually taken up and used. At its simplest we know that if patients are involved in a discussion about the medicine they are prescribed they are more likely to take it. The result

is a healthier patient and a resource – the drugs – actually being used. We know from our pilots on choice in elective care that patient choice drives the efficient use of resources.

Furthermore, we argue that there is no contradiction between the increase in choice and the development of greater equity in the NHS. In fact we argue that, at the moment, the choice that exists within the NHS serves only relatively few people who can find their way through a difficult system. If we make these choices open to everyone, the ability to find their way through the system will belong not just to a few, but to the many. Overwhelmingly, the many people who joined in our consultation told us they wanted to see that wider choice in real practical terms.

In a modern health service, responsiveness to patients and the ability to offer them real choices goes hand in hand with the better use of capacity. These policies are a beginning of that development. Over the next few years the pace of this will quicken until it becomes the norm throughout the NHS.

We must meet the aspirations of the public. Tens of thousands of people have already taken the trouble to engage directly in our consultation process and to them, too, we must respond. The overall aim of all our reforms is to turn the NHS from a top down monolith into a responsive service that gives the patient the best possible experience. We need to develop an NHS that is both fair to all of us, and personal to each of us.

A handwritten signature in black ink that reads "John Reid". The signature is written in a cursive style with a long horizontal stroke underneath.

John Reid
Secretary of State for Health

Executive Summary

1. At the heart of the challenge for modern public services is the provision of a high quality service which meets the individual needs of an increasingly diverse population whilst also being underpinned by the values of fairness and equity we all hold in common. A service which feels personal to each and every individual within a framework of equity and good use of public money.
2. The NHS and the clinical skills of its staff are regarded very highly. But a service which was created to provide a uniform health service in the middle of the 20th century needs to adapt to a world where medical and other technological advances have revolutionised what a health system can offer. A world where there is a more diverse population whose ideas of quality and expectations of a convenient personal service have changed and grown. And where significant inequalities in health and health care still persist, despite the existence of a health care system founded on the principle of treatment according to need and free at the point of delivery.
3. To build an improved NHS requires significant investment to increase capacity. The Government has already started a major programme of investment. In addition, it requires systemic reform to maximise healthcare delivery at any given level of capacity. This process of reform is now underway. But it also demands a culture change to make services more responsive to people's needs, to treat people as whole persons rather than a collection of symptoms; a process of decentralisation to pass power outwards and downwards to put patients in control. Only then will the NHS deliver the best possible care to everyone. Central to this is the extension of patient information, power and choice.
4. The NHS has piloted offering choice to people awaiting some surgical procedures. That has been warmly welcomed and has encouraged all the hospitals involved to raise their game, benefiting all patients in the process. But elective surgery is just a small part of the business of the NHS and this culture of choice needs to be widened and deepened. People feel the service too often lacks the personal touch which is a key part of good care. And some still feel they lack a good service altogether.
5. We want to develop a patient-centred NHS which stays true to its founding principle of fairness to all. That is why we launched a national consultation with the simple aim of finding out how we could extend choices in a way which would create more personalised care whilst also promoting equity. The consultation consisted of four elements: national expert task groups; local consultations led by Strategic Health Authorities; a national Choice Consultation Survey, so that

members of the public and NHS staff could contribute views directly; and wide engagement with patient and professional groups, voluntary organisations and others. In total we estimate over 110,000 people were reached by the consultation.

6. There were several recurring themes in consultation responses:

- All of us – not just some among the affluent middle classes – want the opportunity to share in decisions about our health and health care, and to make choices about that care where appropriate;
- We want the right information, at the right time, as well suited to our personal needs as possible, to enable this – almost 90% of respondents to the Choice Consultation Survey stated that they needed more information in order to make decisions and choices about their treatment or care;
- Our health needs are personal, and we would like services to be shaped around our needs, instead of us being expected to fit the system.

And, on “what the NHS needs to do”

- Carry on building capacity; in particular, there is more to do to ensure that many people with long term conditions can be confident of getting their first choice – access to a good quality service that meets their needs;
- Maintain reform of healthcare delivery, including devolving more power to the frontline, strengthening local accountability, for example through NHS Foundation Trusts, and introducing new systems to underpin choice such as payment by results;
- Work at ensuring choices and services genuinely reach everyone, including the most disadvantaged and marginalised groups; and above all
- Listen to what patients and the public are telling us and then act.

7. Creating an NHS which delivers that kind of service every day, for everyone, requires a real culture change. People understand that it will take time, and that it must be done in a way which is fair and equitable for the whole population. But we are determined to set the direction. Nationally, we shall give priority to six main

changes to increase choice and responsiveness in the ways people told us would matter most. We shall give priority to action to:

- give people a bigger say in **how they are treated** – we will listen to people about how they wish to be treated and give them the opportunity to record their own information in their records. Everyone will have their own **HealthSpace** linked to their electronic health record allowing people to make their preferences known to the clinical team. Preferences might include, for example, how they wish to be helped at a time of mental health crisis. From next year patients will be able to record their own information securely on the internet. As facilities build up over time, **HealthSpace** will enable patients to access their own electronic health records and doctors to access information that the patient wants them to see.
- increase choice of **access to a wider range of services in primary care**, helping people get access to health care on their own terms. This will include not only developing traditional primary care services but also encouraging innovative new providers, particularly in deprived areas where primary care has traditionally been weak. It will also mean extending the ways in which people can get advice in other ways and new arrangements to help people access care away from home.
- increase choice of **where, when and how to get medicines**. We will continue to ease the bureaucracy around repeat prescribing, free up restrictions on the location of new pharmacies, expand the range of medicines pharmacies can provide without a prescription, promote minor ailments schemes where pharmacies can help patients manage conditions like coughs, hayfever and stomach upsets without involving their GP and increase the range of healthcare professionals who can prescribe.
- enable people to **book appointments** at a time that suits them, from a **choice of hospitals**. From August 2004 people waiting more than 6 months for surgery will be offered faster treatment at an alternative hospital. And by December 2005 patients requiring surgery will be offered a choice of 4-5 providers at the point of referral.
- widen choice of treatment and care, starting with greater **choice in maternity services** and greater **choice over care at the end of life**. We will ask local services to promote direct access to midwives, giving women quicker access to

specialist advice and support. We have commissioned local guides to maternity services. And, building on the strong tradition of end of life care in cancer and HIV/AIDS services, we will promote a training programme for staff working in primary care, in residential care and nursing homes and on hospital wards to ensure that in time all people at the end of life, regardless of their diagnosis, will be given a choice of where they wish to die and how they wish to be treated.

- ensure people have the right **information**, at the right time, with the support they need to use it so that this becomes central to how we care for people – an information partnership which is no less than an information revolution. Working with a range of partners we will embrace new technology such as digital TV, develop a programme of “kitemarking” information from a variety of sources so that patients know what to rely on and extend our range of local guides.

8. To achieve cultural change on this scale will require

- a clear vision and values, shared by local and national leaders;
- supported by continued investment and capacity growth;
- delivered by empowered staff, with support from peers and experts;
- backed up by high quality information systems;
- informed by a stronger patient voice; and
- underpinned by a coherent system of incentives, regulation and inspection.

9. This is just one further stage of a process. We will continue to work on a number of the other ideas which were suggested during the course of the consultation. A number will be fed into longer-term work such as the Children’s National Service Framework and the development of the forthcoming Priorities and Planning Framework, both to be published in 2004. There is more to do to improve access to NHS dentistry. But many others can be taken forward locally now as good practice. A nationwide programme in 2004, NHS Live, will spearhead the spread of good practice.

10. The steps outlined in this document set out the beginning of a journey towards an NHS which is easy to get to and has a wide range of services provided locally, where patients can choose how, when and where they get treated, on the basis of good information and a partnership of respect between them and their clinician. Already some patients for some of the time receive their health service from an NHS which has a wide range of choices and is responsive. Our vision is that this should be a reality for all patients all of the time.

Chapter 1:

Choice, health and the NHS

1. As individuals we make choices every day which affect our health and the health of our families. Decisions about what food to eat, whether to give up cigarettes and how much exercise to take may not always seem to us like choices about our health but that is what they are. The range of choice may differ according to our social circumstances, but we all make choices of one kind or another.

2. The media is full of health stories. Newspapers, magazines and TV schedules demonstrate the importance of health choices in people's lives. We read about health, listen to health advice and learn about health from soap operas and from friends and family. The second most frequently searched category on the internet is 'health'. Nearly everyone is interested in their own health and that of their family.

3. This daily experience means most people know something about the choices they have about their health. But if we are to look after our health and to make good use of health and social services we need to be able to choose well. All of us could make better choices, and we could all be better informed.

4. However, few people get to make many positive choices about the service they receive from the NHS. Depending where we live we might get to choose between different GP practices, although in some areas a lack of capacity severely limits this and for many the process of moving GPs is difficult and bureaucratic. If we have friends or family who work in the NHS we might know to ask for a referral to a particular hospital. If we can use the internet we might find out about different drugs and treatments that are available. For some these are choices they experience now, but, for most, they are not. By and large we register with the GP nearest our home, go to the hospital which our GP sends us to at a time given by the hospital and comply with the prescribed treatment without a proper discussion with the doctor or any information other than what we are given there and then.

“People living with long-term conditions make important health choices every day of their lives – and many would welcome a health service that started offering choice within the services they use – unfortunately the NHS has a long way to go before it has a culture of enabling and supporting responsible choices.”

(Long-term Medical Conditions Alliance)

5. The Government's ambition is to change that. In doing so we are seeking to reflect today's world.
6. In every generation, as people's standard of living rises and their expectations follow suit, they demand more control and flexibility over the manner in which they and their families are treated. In short, people want choice for themselves and their families. We should be as ambitious for them and their families as they are for themselves. The main question, therefore, is not whether people can and should exercise choice in healthcare, but whether we can ensure that choice can be exercised within the NHS, rather than only outside the NHS.
7. Choice is already central to the relationship between doctors and patients. Informed consent is the basis of treatment decisions and when someone makes a decision to accept or reject the doctor's advice they make a choice. There is a great deal of evidence to show that people who are more involved in their treatment, who understand the options available to them and who have taken responsibility and control of their own health care have better long term health outcomes. So involvement of patients in self management improves health.
8. We must ensure equity both in access to health services and in the choices that are available to people. We all know that buying healthcare outside the NHS can bestow a degree of privileged access to healthcare and choice. However, at present even *within* the NHS there is evidence of an unfair restriction of access to care, especially among the poor and other disadvantaged groups. At the moment some people are more equal than others – making more use of and benefiting more from the NHS. We need to do more to ensure equity of access to NHS services, and to ensure equity of access to knowledge about these services. And we must make certain that everyone has the same ability and resources to use that knowledge, and indeed to be able to access the services themselves. We must also ensure that the NHS itself does not intentionally or unintentionally discriminate against disadvantaged groups through its procedures or through the behaviour of the people who work within it. That is what we plan to do.
9. This means we must place real power – the power of making real choices about health care and exerting real influence over those choices – in the hands of all the users of services, especially the otherwise disadvantaged. Giving the power of choice to patients and users means they will have the opportunity to decide what is the appropriate health and social care for them, to choose what is convenient, where they want to be cared for, and to say how they wish be treated. By giving this power to patients we will give a powerful incentive to providers to raise their standards and by doing so improve healthcare for all.

10. Of course choice is not endless. In no walk of life can people choose without limits. There will be restrictions in healthcare choices too. So where individual choice is difficult, for example in emergency services, the Government is empowering patients collectively by increasing the accountability of local health services to local communities. That lies at the heart of the proposals for elected boards of NHS Foundation Trusts.

11. But wherever possible the NHS will empower patients individually by giving them personal choices – about where, when, how, and by whom they are treated, and about the treatment they receive.

12. These suggested improvements are based on what real people in the real world want. In the consultation people have told us the sorts of choices they want – these are not unrealistic or overly ambitious. The choice to see a nurse rather than a doctor in order to be seen more quickly and conveniently; the choice to get their prescriptions renewed without repeated visits to the GP; the choice to get urgent treatment and advice from different sources, not only Accident and Emergency departments.

“It is sometimes the smallest choice issues that matter most to patients – like is my doctor good at explaining this to me?”

(Patient)

13. And the people who work in the NHS have told us about choice too. About the choices they are already giving to patients in many ways and in many places. Those who work in the NHS have shown that choice *within* the NHS is possible. We must support all staff to build on that good practice, making it available to all.

14. The examples in this document of good practice show that excellence in choice is already available, whether it is making sure children and young people and their families can express their preferences, helping someone with chronic disease to manage their own life or making access to primary care easier. For too long equity has been an excuse for mediocre service on the grounds that it was fair. The NHS now aims for *equity of excellence*: to make the best available to all.

15. In July 2003 the Secretary of State for Health invited the nation’s patient groups, professional bodies and the staff of the NHS to work together over three months to create proposals on how best choice could be created, a responsive

NHS expanded and equity improved. Sir Nigel Crisp, Chief Executive of the NHS, launched a national consultation on choice, responsiveness and equity in the NHS and social care in August. The consultation process was led by Harry Cayton, Director for Patients and the Public at the Department of Health.

16. The consultation looked at all aspects of the patient experience. Convenient access and good information about your illness. Real choice of when and where and how you are treated. Attentive staff, a clean, comfortable, friendly place to be. Safe, high-quality, co-ordinated care. This is what staff want to provide, this is what patients want from their NHS. Details of how the consultation was conducted appear in Annex A.

17. The consultation has generated many ambitious ideas. Here we outline how they can be achieved over time and within the existing spending plans. We realise the importance of these issues to patients and the NHS. We intend to move forward step by step, testing all the time, to ensure the changes are delivering increased empowerment and the responsive and equitable services people have told us they want.

18. These proposals build upon and develop the principles on which the National Health Service was founded and has flourished. They deepen the commitment set out in the NHS Plan to a truly patient centred service and they respond to the wishes of modern people in a modern society.

19. When we started the consultation we acknowledged that in social care much progress has been made already in helping people to make choices about their own care. The primary focus of the consultation was not on social care. Our recommendations are therefore mainly for the NHS. However, there were issues about social care, in so far as it relates directly to people using the health service, that were highlighted. The Government is committed to continuing to encourage health and social care providers to work closely together in the interests of the people who use their services.

20. In the following chapters we set out our six core commitments to widen choice in the immediate future. These choices will be made available to everybody. Not just for the few with money who can buy the privilege. Not just for the few who know their way around the system. Not just for those who know someone who knows someone – but for everybody .

21. That is why increasing choice and increasing equity go hand in hand. We can only improve equity by equalising as far as possible the information and the ability to exercise choice. And we can only provide choices when we have increased the capacity of the NHS. But it is now within our grasp to rebuild a National Health Service for today's generations and for the generations to come. One which is truly fair to all of us and personal to each of us.

“The NHS Confederation believe that giving patients greater choice is a key priority for the health service. It holds out the prospect of a more responsive NHS, where services are tailored around the individual and patients are genuine partners in decisions about their care.”

(NHS Confederation)

Chapter 2: The consultation: what we asked, what we heard, what we will do

1. “What changes would do most to improve the experience of health care for patients, users and carers?” That was the simple question at the heart of this autumn’s consultation with patients, the public, voluntary organisations and NHS staff. A consultation on how to extend choice, not as an end itself, but as a means of improving patient and user experience; a means to deliver a service that is more responsive, and to tackle unfairness.

“Almost universally, people wanted choice: choice of where treatment should be provided, what treatment, when it should be provided and how care should be provided. Providing choice is seen as a means to addressing the perceived imbalance of power between patients and health professionals.”

(Cheshire & Merseyside Strategic Health Authority)

The consultation process

2. There were four main strands to the consultation: national expert task groups; local consultations led by Strategic Health Authorities; the Choice Consultation Survey conducted through MORI, and other opportunities for members of the public and NHS staff to contribute views directly; and wide engagement with patient and professional groups, voluntary organisations and others. Full details are in Annex A.

What we asked

3. All contributors were asked to consider the following questions:

- *what choices do patients/users/carers want?*
- *what information and support would patients/users/carers need to exercise their choices?*
- *what changes in the system, or how people work or communicate, would be needed to create these choices and make health and social care more responsive?*

4. The discussions had clear parameters. Proposals for change needed to meet test questions:

- *Is this really personal?*
- *Would giving people this choice be fair to everyone?*
- *Is there proof that it works?*

What we heard

5. We had over 750 replies – the largest response to a Department of Health consultation since we published the NHS Plan. And many of the responses were sent on behalf of members of an organisation, or to report back on views from local events. In total we estimate over 110,000 people were reached by the consultation.

6. Some people wrote to make a single telling point, drawing on their own or a relative's recent experience. Many wrote with suggestions to improve services for people with particular health problems. Some wrote on behalf of groups who struggle to find responsive services. We heard from all age groups and all parts of the country. We heard suggestions for radical reform, and for simple, local changes that could make a big difference.

“All too often, the individual needs and wishes are secondary to the convenience of the services that are available. This ‘one size fits all’ approach is neither responsive, equitable or person-centred.”

(Help the Aged)

7. Running through the replies were a small number of powerful, repeated messages. From patients, public, and NHS staff alike, we heard:

what people want

- All of us – not just some among the affluent middle classes – want the opportunity to share in decisions about our health and health care and to make choices about that care where appropriate

- We want the right information, at the right time, as well suited to our personal needs as possible, to enable this – almost 90% of respondents to the Choice Consultation Survey stated that they needed more information in order to make decisions and choices about their treatment or care
- Our health needs are personal, and we would like services to be shaped around our needs, instead of us being expected to fit the system

in response, the NHS needs to:

- Carry on building capacity; in particular, there is more to do to ensure that many people with long term conditions can be confident of getting their first choice – access to a good quality service that meets their needs;
- Maintain reform of how we deliver healthcare, including devolving more power to the frontline, strengthening local accountability, for example through NHS Foundation Trusts, and introducing new systems to underpin choice such as payment by results;
- Work at ensuring choices and services genuinely reach everyone, including the most disadvantaged and marginalised groups;

and above all

- Listen to what patients and the public are telling us and then act.

“Most people express a stronger desire for responsiveness to them as individuals, alongside a desire for a more human approach where people feel listened to, valued, and respected as individuals rather than simply diagnoses.”

(Mental Health Task Group)

8. There were also strong and consistent messages about what a responsive, personal service should feel like. Top quality clinical care is vital, but is not enough. “I want to be treated as a person, not a number”, was a frequent comment. Understanding, support, reassurance, care for emotional as well as physical needs, were all seen as important in a personal service – especially one with which we are as intimately involved as the NHS.

“We felt that there wasn’t a personal touch, he wasn’t really listening, just another name on a list that he has to see within that day.”

(Patient)

9. We asked patients and staff to describe the kind of patient experience they would like and this is what they said:

We want an NHS that meets not only our physical needs but our emotional ones too. This means:

- **getting good treatment in a comfortable, caring and safe environment, delivered in a calm and reassuring way;**
- **having information to make choices, to feel confident and to feel in control;**
- **being talked to and listened to as an equal;**
- **being treated with honesty, respect and dignity.**

10. Creating the kind of NHS which delivers that kind of service every day, for everyone, requires a real culture change. The consultation demonstrated a strong consensus that this is the right direction. But we also heard a strong vein of realism. People recognise that, only three years into a ten year strategy, there is a long way still to go. People realise too that there are limits to choice. Over 80% of the people who replied to the Choice Consultation Survey agree that their personal choices should be limited in whole or in part by the need to be fair to other NHS users and the wider community. Many recognise the existing pressures on staff. Ambition for change is matched by recognition that some changes will take time. People want real, achievable, steps in the right direction.

“For patients to have a true choice in the NHS there needs to be transparency and honesty about what is available and what is not. Patients need to know what exactly they have a choice about.”

(Arthritis Care)

What we will do

11. Nationally, we shall give priority to six main changes to increase choice and responsiveness in the ways people told us would matter most. We shall:

- give people a bigger say in **how they are treated** – we will listen to people about how they wish to be treated and give them the opportunity to record their own information. Everyone will have their own **HealthSpace** allowing

people to make their preferences known, which will in time link to the new electronic health records, which are being introduced from next year;

- increase choice of **access to a wider range of services in primary care**, helping people get access to health care on their own terms;
- increase choice of **where, when and how to get medicines**;
- enable people to **book appointments** at a time that suits them, from a **choice of hospitals**;
- widen choice of treatment and care, starting with greater **choice in maternity services** and greater **choice over care at the end of life**;
- ensure people have the right **information**, at the right time, with the support they need to use it, through work with the NHS and its partners so that this becomes central to how we care for people – an information partnership which is no less than an information revolution.

Chapter 3 describes these direction-setting changes.

12. The full response to the consultation will of course go far wider. We are looking at how we can continue to use the responses to the consultation in the future.

13. Many of the good ideas that came forward will need to be worked through locally. Local staff and communities are already working on some of the ideas from local events.

“Although this document [the local consultation response] has been prepared for the national consultation it has also been a useful local exercise and the issues raised within it will be acted upon by the local CHD implementation team.”

(Harrogate Health Care)

14. The national Task Groups also identified examples of good practice or ideas for local action that they hoped would be taken up more widely.

Examples:

- **Local arrangements to identify a key worker for the patient from within the clinical team who can help the patient navigate the healthcare system**
- **Local arrangements for patients to go directly to any member of the primary care team**
- **Local arrangements for patients to go back to a hospital specialist they have seen before, without needing a GP appointment first**
- **Local arrangements for young people to choose the age at which they transfer from children's to adult services**
- **Involvement of patients in choices about the detail of their care**
- **Local action to promote independence for older people**
- **Local arrangements for real time information in emergency care settings**

15. Other ideas from the Task Groups and others will need further exploration and development before they are ready for action. We shall bring forward proposals on these during 2004.

Examples:

- **Easier access to advice on options to get urgent care**
- **Developing a framework for access to complementary medicines**
- **Offering learning disabled people the option of taking up an annual health check**

16. Some of the ideas from the consultation will need extra capacity and therefore will be fed into longer term planning. Some of the proposals from the Maternity and Children's Task Groups, for example, will help shape the final version of the Children's National Service Framework (NSF), to be published in 2004. Several of the Task Groups pointed to the importance of improving access and choice in diagnostic services. The Mental Health Task Group produced a particularly comprehensive set of recommendations, which will help shape the next phase of action to implement the Mental Health National Service Framework and the work of the National Institute for Mental Health in England (NIMHE). NIMHE will

continue to build capacity in the system to support choice, and to ensure equity of access, particularly for those communities that commonly find it difficult, or whose needs are not currently met by services.

17. We shall build on all of these longer term proposals when in July 2004 we publish planning guidelines for the NHS for the period from 2005-06 to 2007-08. This will ensure that responsiveness and choice are to the fore in shaping the next critical phase of capacity building and NHS Plan implementation.

18. The consultation has confirmed that our vision should be of an NHS which is easy to get to, has a wide range of services provided locally, where patients of all ages can choose how, when and where they get treated based on good information and a partnership of respect between them and their clinician. The NHS already provides this for some patients sometimes. Our vision is that it should be a reality for all patients always.

Blackpool, Fylde & Wyre Hospitals

A Privacy and Dignity Policy has been developed to ensure that all patients receiving care within their hospitals feel that they are treated with respect, and that their right to privacy and dignity is upheld and actively promoted.

The policy is embedded through a whole range of initiatives including employee audits, user audits as well as communication and customer care training, and covers such key issues as:

- courtesy
- honesty
- respect
- communication
- confidentiality
- care and treatment
- cultural diversity
- accountability

Chapter 3: Expanding choice – the first steps

1. Patients have made it clear that they want a very wide range of extra choices within the NHS. This is not just a matter of where and when they are treated in hospital but reflects the full range of health service experiences from the cradle to the grave.

2. Here we outline the increase in choice that the NHS can make within the resources we have already allocated. In the summer of 2004 we will outline plans for increasing choice in all the other areas that have been mentioned to us. Below we set out six major areas that increase choice and responsiveness that we can address immediately. And we explain how these changes will promote equity.

1. More choice about how we are treated

3. Today's society expects any organisation in the business of customer service to take real care over how it treats its users. The NHS is a very special kind of service. The closeness of the relationship between NHS staff and the users of their services, sharing intimately in moments of deepest vulnerability, and in emotional heights and depths, calls for an exceptional level of understanding and empathy. Yet while the overwhelming majority of people trust the NHS to deliver clinical quality and the right outcome, they are far less confident in their total experience of health services.

4. We explained in Chapter Two that to make the culture change we are seeking will take time. But there is a simple change that we can make very quickly to add momentum to this deeper cultural change. A very common complaint from patients is that they have to give the same set of information to many different health care professionals. The new electronic NHS Care Record will improve this situation enormously as it will give health care professionals the information they need without the patient having to repeat it for their benefit.

5. But there is a further issue. Patients are not clusters of symptoms, but individuals with personal needs and wishes. How we are addressed. Religious and cultural needs. Diet. Issues around disability, which need to be taken into account. All the sorts of things which, if addressed, might make the difference between a responsive service and one where no account appears to be taken of our individual needs. Some trusts already make provision for these sorts of patient preferences to be recorded in their records. We were challenged as to why health records should not routinely record those sorts of issues.

“On all patient records not only should their disability or special need be recorded, but also the forms in which they choose to receive information, e.g. large print, Braille, audio tape or electronically on floppy disc or by E-mail.”

(Patient)

“All carers should have their caring role flagged up on all medical records.”

(Patient)

Hammersmith Hospitals NHS Trust “Expression of Wishes”

In every new set of patient notes, Hammersmith Hospitals includes a special section entitled ‘Expression of Wishes’. This section provides a place in the hospital records for information the patient wishes to be considered at the time of every consultation. Patients can place in this section any documentation they have identifying their wishes or choices. The Trust has been keen to ensure that those patients who outside the organisation have produced documents such as living wills, bring these documents to the Trust and place them in the Expression of Wishes section of the notes, so that the information contained in these documents is available to clinicians.

Having now created within the clinical records a specific place for holding documentation on patients’ wishes, the Trust is currently researching how best to help patients express and document their wishes and preferences, for example on care at the end of life.

6. We agree they should. We therefore intend that all NHS patients should be able to annotate their own personal health record, setting out their own preferences. From next year patients will have access to a new service called **HealthSpace**, a secure personal health organiser on the Internet, at www.nhs.uk/healthspace. As facilities build up over time, people will be able to record more personal information and preferences in **HealthSpace** and make decisions on sharing that information with the professionals who organise their care. Some places are already encouraging patients to record their preferences and personal information in their patient records; we would like to see this good practice more widely spread.

“I would like to see a centralised store of my medical records that can be accessed and appended by any health care professional, with my permission, whenever I interact with the NHS.”

(Patient)

HealthSpace will provide each patient who wishes with their own online account, accessible securely over the internet at www.nhs.uk/healthspace, which will allow them to record information about themselves, their health and the way they want be treated by the NHS. For example from 2004 people will be able to:

- keep addresses and telephone numbers (e.g. GP, dentist etc), dates and times of appointments, favourite weblinks
- register to receive e-mail reminders to attend appointments if they wish.
- store key health information about themselves, such as blood group, weight, allergies and medication.

The facilities in **HealthSpace** will build up over time enabling patients to see the information held about them in the NHS Care Record, check its accuracy and make choices about who can see this information. The sort of information it is possible to record will be expanded if there is a need and might include:

- faith and how it affects diet and the kind of spiritual support you would require
- wishes about organ donation
- birth plans
- information about disabilities
- advance directives
- communication and language preferences
- name of a relative or next of kin who can explain their wishes if they are not able to do so

with full implementation expected by the end of 2008.

7. This will ensure that whenever the clinical team consults the patient's record, they are reminded of these important points for the patient, without the patient having to repeat them. And this new arrangement will enable patients to express their wishes, and confirm that the NHS is committed to taking them seriously.

Birmingham Children's Hospital

Joe was three years old. He had been very ill since a few months of age with multiple problems that lead to him needing intravenous feeding via a central line. What food he did take was put into his stomach through a gastrostomy tube. He needed permanent oxygen to keep his oxygen levels into his blood at a satisfactory level. Joe also had problems that made communication with him more challenging. He had spent a long time in hospital over his short life and was now admitted for a full review of all his many problems in order to identify the key health issues and to discuss plans for the future.

Joe's mum, the Play Specialist and nursing team worked with him to draw up a list of 'preferences'. This list included:

- asking staff to give him a chance to help them
- what positions he liked to lie in to go to sleep
- his favourite songs and toys
- his bed time routine
- his favourite television programmes and the times they were on

These were his preferences and choices that we would do our best to meet.

Gill Brook

Head of Child and Family Centred Care, Birmingham Children's Hospital

8. We were also challenged by the Children's Task Group and others to see if we could go the extra mile and really put patients at the heart of the NHS by asking doctors to write to them directly. Patients already have a right of access to their medical records. The NHS Plan took this further by making the commitment that letters between clinicians about patients would be copied to the patient. This policy is now being extended across the NHS and has proved popular with patients. Patients put it to us that the next logical step was for clinicians to write direct to patients.

"... copying letters to me by the various health professionals writing to each other about me, was extraordinarily helpful. I had to ask for a copy in each case, but while somewhat surprised, none were hostile to the idea. I then felt part of the team, involved in my recovery in a way which I had never felt before. My view is that Copying Letters to Patients is an under-estimated tool in encouraging self-care and should speedily be properly adopted."

(Patient)

9. Clearly there are important issues to resolve with implementation. For example, it would not be helpful to send letters to patients that are full of specialist jargon, which means little or nothing to the patient. Some patients may prefer to receive information face to face, and bad news will need to be handled sensitively. But writing letters direct to patients is the right way to go. We will discuss this with the profession and encourage services to discuss taking this forward locally. Writing to children and their families should be a top priority for action.

Knowsley Child and Adolescent Mental Health Services

Knowsley Child and Adolescent Mental Health Services is committed to ensuring that service users and their families have routine copies of session notes and correspondence relating to them, written in a way that is as easy to understand as possible. It has positively challenged the way that professionals think, record and communicate with service users, their families and other professionals. And feedback from service users has also been very positive.

2. Freeing up access to primary care

Easier access to Primary Care

10. It was crystal clear from the consultation responses that one size does not fit all in primary care. Our individual needs and circumstances are complex. Primary care arrangements are becoming more flexible, but we must make the service itself more flexible and more convenient if we are to meet the challenges that have been put to us.

11. We want different things from primary care on different occasions. Many people, especially older people and people with long term conditions, place a high value on the traditional model of general practice, and on continuity of care and the personal relationship between patient and the GP or nurse. Research evidence reinforces the considerable benefits of continuity of care. So it is vital that continuity of care by clinical teams or individual care providers remains a choice for those that need it. But others attach more importance to being able to get quick help at a convenient time and place that fits with their other commitments – that choice, too, needs to be available.

12. So we shall:

- continue to expand capacity, with a particular focus on the areas where people have most trouble accessing primary care;
- develop a wider range of primary care providers, offering a wider range of services;
- explore easier options for people to get the care they need when away from home, including the scope to relax practice registration requirements; and
- promote easier access to diagnostic services, and better support for patients with long terms conditions, in a primary care setting.

And we shall ensure that information for patients, and incentives for practices and primary care trusts, support and promote this greater flexibility.

Expanding capacity – creating choice in areas of highest need

13. Too many people simply do not have proper choice of GP or primary care practice. Some estimates suggest that as many as 15% of the population live in areas where practice lists are closed to new patients. And under the previous arrangements for general medical services there has been too little investment and incentive available to support primary care expansion in deprived areas.

14. Capacity is now expanding. We are on track to deliver the NHS plan target for 2000 more GPs and these increases are set to continue into the future. Spending on primary care will increase by 33% from 2002-03 to 2005-06. The NHS LIFT programme is supporting wholesale redesign and refurbishment of the buildings used to provide primary care services across a third of the country. And across general practice, dentistry and pharmacy, new contracts are creating more scope for primary care trusts to shape local services to meet local needs.

15. So primary care trusts will have a key role in ensuring that communities which have lost out in the past begin to benefit from these new arrangements. They have responsibility for ensuring everyone in their local community has fast access to good quality primary care. And from April 2004 they will have both the mechanisms and the funding to enable them to begin building up provision,

especially for populations which have high health needs without the services to respond to them. So those primary care trusts will be able to test new ways to encourage new entrants to primary care delivery.

16. These new entrants could take a number of forms including providers offering:

- The full range of general practice services and specialist services (so called polyclinics);
- General practice services;
- Selected aspects of general practice services as determined by local needs (for example chronic disease monitoring).

17. As with general practice presently, these services could be delivered by a number of providers including nurse-led clinics, primary care trusts or private providers treating NHS patients within a framework that ensures value for money and safeguards the interests of the NHS (the latter are likely to be part of larger organisations with strong managerial support).

18. Progress in these areas would begin to tackle longstanding inequities, for example in parts of the North East where health need is high, but the number of GPs is low in relation to population numbers.

19. In dentistry too there are problems of access to overcome in some areas. The move towards local commissioning will enable primary care trusts to target the additional funds that have been made available for this to tackle local dental priorities: for example, commissioning extra dental sessions for local people, developing new employment models to attract dentists and helping NHS dentists develop and expand practices.

More flexible access for all – wider range of providers, wider range of services

20. For other patients, the problem is not that they have no choice of good quality general practices, but that they have practical difficulties over access. For instance, those working long hours, away from home, or who have no transport during the day, may find it difficult to access help at a time or place that suits them. For these people, the responsiveness of the NHS and the choice of services available must become far wider.

21. First there is a growing range of ways in which people can access care as an alternative to an appointment at their traditional general practice, all of which we are seeking to expand. These include:

- NHS Direct, NHS Direct Online, and from 2004 NHS Direct Digital TV as sources of 24/7 advice and information (these services have proved extremely popular, are safe, and can be of particular help in being available to patients at nights and weekends or for patients in rural areas);
- 42 Walk-in centres that offer immediate help for acute problems without an appointment (around 4m attendances since 2000);
- Improved access to their usual practice through telephone and e-mail consultations and other virtual techniques;
- A wider range of services being delivered by a broader range of staff, such as physiotherapists, phlebotomists and psychotherapists;
- Chronic disease monitoring (e.g. for asthma, blood pressure) at the pharmacy rather than the GP practice.

22. For many, this range of services will provide them with the choice and flexibility of care that meets their needs. But we also heard requests for more than this. In particular, people asked about the option of access to general practice close to their place of work, so that they can get easier access to primary care, at a time that suits them. There are a number of models we can now build on in response.

23. We can develop the role of NHS walk-in centres. As walk in centres have developed, so the proportion which include access to a GP as part of their service has increased. 31 out of the existing 42 centres have a GP on site, as do 9 of the 12 centres due to open in 2004. Primary care trusts will be able to tailor this model to respond to the needs of commuters by ensuring that GP cover is available and we anticipate further progress in delivering these services in the future.

24. Other options flow from the new arrangements for general practice, which mean that primary care trusts, rather than practices, provide “out of hours” care. This separation of responsibility for a daytime contract and a night time/weekend contract increases the flexibility around who provides care.

25. One consequence is that new “out of hours” providers will emerge, many with a centre that patients can visit, as part of their services. This creates a model and an infrastructure which might in some cases also be developed to offer a day time service, alongside walk-in centres and local practices. In urban areas these providers usually provide an out of hours service to more than one primary care trust, and a day time service might be planned and funded on the same basis, using a range of commissioning tools including personal medical services and primary care trust provider arrangements.

26. The changing responsibilities for out of hours care also mean we can look at changing the rules restricting where patients can register with a GP. In discussion with patients, the NHS and the profession, we intend to open up registration areas for GP practices in the future. The flexibility in personal medical services arrangements offers one potential way forward. Our aim would be to ensure continuity of care and access for local patients but also to allow commuters to register close to work, while their home primary care trust remained responsible for them at evenings and weekends. We envisage that this arrangement would grow over time, in parallel with wider capacity expansion, so as to respond both to the needs of local resident populations, and to those who need access to primary care when away from home.

27. Finally, responses to the consultation showed that it has sometimes been felt that practices choose which patients register with them, rather than the other way round. We will consult on amending the regulations. We want to ensure that patients can register with their preferred surgery unless, of course, the practice has agreed with its primary care trust that its patient list is already full. The right of practices to refuse to register violent patients would not be affected.

More services closer to home

28. People were keen to have the convenience of access to more services close to home. Already over a million specialist treatments, including diagnostic services, take place in community settings. There are more than 1250 GPs with special interests and now nurses and allied health professionals with special interests, providing outpatient care in primary and community settings. The new GP contract will also promote better and more comprehensive support for people with long term conditions such as diabetes or respiratory disease in a primary care setting.

29. Diagnostic and specialist services will also increasingly be in places that are more convenient to patients. For many patients, especially those with long-term conditions

such as diabetes, having to go to hospital for routine diagnostic tests, or to consult a specialist, can be very disruptive. Primary care trusts will develop a range of services previously only available in hospitals, by working with a variety of providers (including practices, community nurses, therapists) to build these new services. Further, developments in technology mean that an increasing number of diagnostic procedures and treatments will be possible in community settings. So people will be able to get Xrays and other imaging, blood tests, endoscopy and similar procedures, faster and more conveniently. We think the independent sector, as well as the NHS, will have a role to play in this, where it can deliver additional capacity and value for money; we therefore envisage a national procurement programme starting in 2004. This will build on the current independent sector treatment centre procurement programme which was launched in December 2002.

30. Increased choice in primary care must be supported by better public information if people are to make informed decisions on the growing range of options on offer. We plan to strengthen the information base for primary care by improving the quality and range, including making more use of e-communication, including NHS Direct. Practice leaflets will continue to develop, and alongside the existing primary care trust guides there will be an e-based Directory which will set out details of local providers, the services on offer and qualitative information derived from the new primary care contracts.

Southampton Walk-In Centre

A mother's experience

On Monday I received a call from my daughter's school. Sarah had been hit in the face with a hockey stick and would need treatment. I took Sarah to our GP surgery where the nurse advised us to attend the Winchester Accident & Emergency Department. The nurse said we would have hours to wait as the waiting room was extremely full. Luckily I remembered the Walk-in Centre at Southampton. We battled back through the traffic at about 6pm, parked, filled out a form and were seen within about 10 minutes. Sarah had anaesthetic injections and stitches between her eyes. What a fantastic service. The staff were smiling, friendly, un-stressed. The centre itself was great; it was clean with new furniture and equipment. But more importantly people had time for us and were very professional.

31. And we are aligning incentives to support choice and responsiveness. The new GMS contract includes incentives for practices who measure and take account of patients' views. For the first time, the patient experience will directly impact upon GP reward. We shall explore with the Commission for Healthcare Audit and Inspection the scope to reflect choice, responsiveness and equity within primary care trust star ratings.

3 Improving access to medicines- cutting the red tape

32. Easier access to medicines emerged as another very high priority during the consultation. For those millions of patients with long term conditions the existing arrangements for getting a repeat prescription, requiring the GP's signature on each occasion, frustrate patients and GPs alike. In the modern world they are absurd.

“My life is dogged on a weekly basis by nonsensical rules with unseen but significant repercussions, solvable by letting the patient choose where to obtain their prescription.”

(Patient)

33. We have made a start on changing that. In 30 areas of the country, patients can already get their medicines from a pharmacist of their choice for up to a year, before they go back to their GP, cutting out the bureaucratic hurdles. 14 more areas will be included in these repeat dispensing arrangements as part of new medicines management arrangements. With the implementation of the new community pharmacy contractual framework from next year, this choice will be available to patients across the country.

34. And by December 2007, the new national IT programme will mean patients using this new service will be able to pick up their medicines from any pharmacy in England.

35. We want to offer patients more choice in where they get their prescriptions dispensed – which in turn will mean more choice in where they can get medicines for self care, and access the range of services which pharmacies will be providing in the future. We propose to make it easier for new pharmacies to locate in areas where consumers already go, for example in large shopping developments, and to make it easier for new pharmacies to open if they intend to be open for more than 100 hours a week.

36. But choice goes beyond this. Some people want their medicines delivered to their home. Some pharmacies already provide this service. The new national IT

programme will mean that internet pharmacies will be able to offer dispensing services to NHS patients. Meantime, we shall be making it easier for mail order pharmacies to offer such services.

37. We are expanding the range of medicines which pharmacies can supply over the counter without a prescription. Since the NHS Plan was published some important treatments have become more widely available, including for example nicotine replacement therapies – supporting the Government’s targets on smoking cessation and coronary heart disease – allowing people to access products when they need them and to take control over their own treatment, backed by the expertise of the pharmacist. Another example is emergency hormonal contraception, where early access to treatment is essential. Hayfever treatments and painkillers are other important medicines that are now more widely available.

38. These developments promote self-care and give patients greater control of their treatment. But it is time to raise the pace of change and wherever it is safe to do so make it simpler for patients to get treatments over the counter for conditions which until now have been regarded as strictly the preserve of the prescriber. With this in mind we have recently announced a consultation on a proposal to allow simvastatin, a statin, which reduces cholesterol and hence the risk of heart disease, to be available through pharmacies without a prescription. If the application to switch legal status is successful it will be a world first and will mark a major step in the Government’s commitment to expand the range of medicines available for self-medication towards longer term, chronic conditions and preventative therapies.

39. In the ten years up to 2002 there were around 50 changes to legal status of medicines which made them easier for patients to access. In May 2002, marking the coming into force of fundamental changes to the law to enable wider availability of medicines, we announced a target of a doubling the number of changes to legal status to an average of ten a year.

40. We are on track to meet that target and we aim to increase the pace of change. As part of our ongoing strategy we will be looking to expand the range of treatments available over the counter for example in the prevention of heart disease – of which statins is the first – for the treatment of chronic migraine, gastro-intestinal conditions, skin conditions, asthma, pain management and eye infections. This approach, consistent with public safety, will give more people more direct control and responsibility for managing their own healthcare, something our consultation shows they want to do.

41. People who do not have to pay prescription charges, especially those whose income is low, often need to go to see their doctor for a prescription even though they are suffering from a minor ailment (such as coughs, hay fever, insect bites and stings, heartburn and stomach upsets) which they might prefer to treat themselves with a medicine which they could get from a pharmacy. This wastes patients', as well as doctors', time and can make people feel unnecessarily dependent, rather than helping them take control of their own lives.

42. Currently 28 primary care trusts have commissioned pharmacist-led minor ailment schemes locally where patients exempt from prescription charges have their minor ailments managed by a community pharmacist and can have their medicines on the NHS. Such schemes enable patients to go to their community pharmacist rather than their GP, mean GPs have more time to treat more serious conditions and so improve access to NHS services overall. Patients also welcome the convenience and it results in better use of the professional skills of pharmacists.

43. The existing schemes have demonstrated that all parties – patients, GPs and pharmacists – benefit. A survey of primary care trusts carried out in June 2003 showed that the number of primary care trusts developing pharmacy led minor ailment schemes continues to increase – 75% plan to or would like to have a scheme. We would expect all primary care trusts to consider carefully targeted schemes to meet the needs of patients who would otherwise go to their doctor for a prescription. As part of the implementation of the new community pharmacy contractual framework, model service specifications and benchmark prices will be developed, drawing on existing local schemes. Primary care trusts will be able to use these if they wish when commissioning minor ailment schemes.

44. Many nurses are now prescribing for patients – widening choice, enabling patients to get quicker access to the medicines they need and improving the quality of services provided. And in 2004, some pharmacists will also be able to prescribe medicines for patients. By 2005, we also want to improve patients' access to medicines further, by enabling optometrists and some allied health professionals to prescribe. This will improve the choice available to patients and make better use of the skills of professionals.

West Lincolnshire Primary Care Trust

A partnership in practice

West Lincolnshire Primary Care Trust is currently running a partnership scheme in one of its rural areas between two local pharmacies, one local GP practice and the patients of that GP practice. The scheme enables these patients to get advice on minor ailments from either of the two pharmacies together with the appropriate over the counter medication at the same cost as a prescription. Those people who are exempt from prescription charges will still receive their medicines free.

Ailments covered include coughs, colds, hay fever, conjunctivitis, head lice, ear ache, nasal congestion, vaginal thrush, diarrhoea, indigestion, temperature and heartburn.

The following benefits are already evident:

- patients' access to treatment is quicker and easier
- patients can manage their conditions better
- pharmacists can work in a more integrated way with other members of the primary healthcare team
- GPs can spend more time with other patients

This successful minor ailment scheme is due to be rolled out to another six GP surgeries over the next twelve months.

45. The services people can get from their community pharmacist are therefore widening well beyond the traditional roles of dispensing prescriptions and selling medicines. Pharmacists can provide easy access to emergency hormonal contraception and to smoking cessation services. They can provide advice on healthy eating, obesity, and the benefits of regular exercise particularly for patients at high risk of coronary heart disease. They can review the medicines patients are taking, and check whether patients are experiencing problems. This can give patients an opportunity to raise issues which they may think are too trivial to talk to their doctor about, and to be reassured or advised to talk to their doctor where appropriate. Community pharmacies may play a particularly important role in inner city areas where access to services may be poor. We will be encouraging developments in the role of pharmacy through the new contractual framework.

46. All these developments aim to make choice a reality for patients by cutting out the red tape and rules which insist on people following particular routes to get their medicines, however inconvenient and frustrating. The options need to be as diverse as the people using the service – the young person wanting emergency contraception, the mother needing a remedy quickly for a sick child, the terminally ill patient at home, or the patient with a long term condition like asthma, diabetes or hypertension.

4 Effective choice of time and place for planned operations

47. For too long, prolonged waits for appointments and operations have been symbolic of the NHS at its least responsive. Waiting times are falling now, and the programme of action already in train across the country will continue that improvement. The largest hospital building programme in the NHS's history has increased capacity and elective inpatient admissions have increased by almost a million a year since 1997, rising from just over 4.5m then to 5.5m last year.

48. Greater capacity has already resulted in more choice in planned care. In July 2002 we started a national pilot programme for patients experiencing long waits for heart surgery. Around 50% of patients chose to go elsewhere for faster treatment. In London some 70% of people chose to move for faster cataract surgery. This has meant that thousands of people have been provided with the opportunity not only to get earlier surgery but also to have that operation at a time and place that they have played a role in choosing.

49. Many people argued that by giving choice about place of treatment poorer patients would lose out and inequity thereby would increase. In fact, as the figures quoted above show, the national choice pilots have shown a huge appetite for choice amongst patients of all backgrounds. There is also some evidence that the pilots have helped reduce waiting times, benefiting all patients on the waiting list, whether they opt to move hospital or not. In addition a tighter focus on patient care pathways has promoted more consistent and better quality patient care. Choice for elective surgery is therefore a powerful tool for increasing responsiveness and consistency of high quality care, and for promoting equity.

50. We have already announced the extension of these choices so that from August 2004 people waiting more than 6 months for surgery will be offered faster treatment at an alternative hospital. The Government will meet its commitment that by December 2005, patients who may require surgery will be offered the choice of 4-5 hospitals at the point when their GP refers them to hospital. Patients will also be able to book their appointment for a time that suits them, using the electronic links between GP practices and hospitals that will be in place nationwide by 2005.

5 Extending choice in treatment and care

Shared decision-making

51. We already take responsibility for important elements of our own health care and the care of our families' health. We spend £1.4bn a year on over the counter pharmacy sales. We make choices about health care for our families and ourselves all the time. We provide care for ourselves and each other on a much greater scale than we receive from professionals.

52. We consult NHS professionals when we need help with managing health matters. But this does not mean we want to abdicate responsibility. 76% of those who replied to the Choice Consultation Survey identified greater involvement in decisions about their personal condition/illness and treatment as being important and 51% said this aspect of the NHS needed improvement. It is their health and it is understandable that people want to be involved in their treatment. People want to work in partnership with clinicians, to draw upon the essential knowledge, skills and experience of healthcare professionals, but they also want to be able to contribute their own knowledge about their condition and their own perspective on what matters most to them. They want the chance to reach shared decisions about their care and treatment. This is particularly true in relation to children and young people who wish health professionals to recognise that they have views and a contribution to make regarding their care. The hospital standard of the Children's National Service Framework recognised the need for child-centredness in all services provided to children and their families which includes the promotion of choice.

"The Royal College of Physicians welcomes the focus on shared decision-making between patients and clinicians as a confirmation of good practice. The College looks forward to helping to develop the ideas arising from the consultation and to putting them into practice."

(Royal College of Physicians)

"We believe it is important that patients and carers are consulted about what they want and choices are expanded because this strengthens services, enables informed patients to become empowered patients, and above all improves the patient's experience."

(Macmillan Cancer Relief)

Shared decision-making

Lara's story

“In my dark times, when I feel that I control little of what is happening in my mind, it has been essential to my fragile self-belief that my astute, caring, listening GP has offered me control of the ways forward.

As a full partner in my own healthcare, I have always been consulted about any use of anti-depressants, with reasons given to explain why a particular medication is his anti-depressant of choice.

His approach to mental wellness is holistic.

Rather than simply waiting for drugs to do their work, he often proposes that I talk to the Community Psychiatric Nurse about issues troubling me.”

53. Unsurprisingly, we already see increasingly well-informed patients, looking for a new form of dialogue. Of course not everyone wants the same degree of involvement, and we may want different kinds of involvement in different circumstances, but people want to have the opportunity for shared decision-making to be there.

54. Engaging and informing patients is at the heart of good clinical practice. The General Medical Council's guidance on good medical practice (*Good Medical Practice*, May 2001) makes clear that listening to and respecting the views of patients, giving them information in a way they can understand and respecting their right to be fully involved in decisions about their care represent the ethical bedrock of good clinical practice.

55. Involving patients also pays dividends in terms of outcomes. We know that almost half of patients with chronic conditions do not take their medication as recommended, resulting in huge personal and financial cost in avoidable continuing illness and premature death, as well as increased health expenditure. The traditional model of “compliance” (follow doctor's orders and take your medicine) does not work very well. It wastes everyone's time. By contrast, there is clear evidence that shared decision making, what is sometimes called concordance, in which patients understand and negotiate with clinicians the best course for themselves, can lead to higher follow through with the agreed course of treatment and better outcomes and satisfaction.

“Many hard-pressed health care professionals think they do not have time to devote to concordant consultations but, with evidence showing that many medicines are taken by fewer than half the patients to whom they are prescribed, the waste alone should make them think again. In addition, if a patient has symptoms that are not controlled and keeps on returning for further consultations and advice, then that is just as wasteful.”

(Editorial in Pharmaceutical Journal)

56. The Department is already working with patient organisations, the professions and other stakeholders to promote concordance through our Medicines Partnership programme. This is a national strategy to ensure that prescribing and medicine taking is based on partnership – in particular that patients have enough knowledge to participate as partners; that prescribing consultations involve patients as partners; and that they are empowered to take an active role in managing their own care. The Department also actively supported “Ask About Medicines Week” in October 2003, where people were encouraged to seek more information about their medicines. And we have two further proposals for promoting shared decision-making, the first centred upon care plans, the second on developing the Expert Patients programme.

Care Plans

57. Personalised care plans are a key part of a number of our national service frameworks which set out good practice standards across the major disease groups. Many responses highlighted the importance of care plans to ensure that there is a proper partnership between clinicians, patients and their families.

“We believe that all patients who want it should have a personal care plan jointly negotiated between the clinician, the individual patient and, where appropriate, the carer or family. This would outline the treatment that will be provided, but also set out what the individual could do to maximise their quality of life. For some people with chronic conditions, direct access to specialist advice could be agreed as part of their plan.”

(NHS Confederation)

58. Our programme of national service frameworks will over time increase the number of patients who have a personalised care plan which they have negotiated with their clinicians. Patients will be able to include their care plans in **HealthSpace** and ensure that this becomes part of the NHS care record which they may share with their clinical team.

Expert Patient Programme

59. There is already plentiful evidence that enhancing the patients' wider role in self-management of chronic diseases can produce real benefits. The Expert Patients programme has developed self-management training programmes for patients with chronic diseases within the NHS in England, giving patients advice, tools and techniques to look after themselves better and take more control over their lives. The experience here and abroad is that patients tend to see their condition become more stable or improve, they manage pain, complications and medication more effectively, they feel more confident in their relationship with services and they contribute their skills and insights towards improving health services. Our experience so far suggests that people with self-management skills will make around 40% fewer visits to their GP and 17% fewer visits to outpatients.

Blanche's Story

Blanche had suffered for many years from depression, diabetes and obesity amongst other ailments. She joined an Expert Patient Programme course in February 2003, after seeing an advertisement in the local paper. It has changed her life.

Blanche says:

"On the Expert Patient Programme I could talk openly and honestly with people who understood. Although the course was very short, I am left feeling stronger and able to cope with whatever life throws at me. I have stopped taking Prozac and am still totally amazed that six sessions of the Expert Patient Programme combined with the cognitive therapy I received in the past has changed my life so much for the better. I can honestly say that for the first time in 74 years I feel happy. I also feel able to manage my chronic illnesses."

60. The Expert Patient Programme demonstrates that creating a more responsive service pays real dividends for both patients and clinicians. The consultation has highlighted the need now to mainstream it into the NHS and ensure that it helps give all kinds of patients the skills and knowledge to make the best of their health, especially those who need the most support. Almost all primary care trusts have now either run some courses for patients locally or are preparing to do so. We will work with patient organisations and primary care trusts at local level so that the Expert Patient Programme becomes an integral part of supporting patient choice in every primary care trust, focusing support on patients who are most disadvantaged.

“Thank you for all your help on the course and for helping me to walk. You gave me the goals and the push to walk further every day. I have progressed so well with your help, I don’t think anything could stop me now. I know I will not be able to climb mountains but I hope I will be able to walk to the shops. I hope you will keep your good work up to help more people like me.”

(Expert Patient Programme participant)

Expanding treatment choices at the beginning and end of life

61. Patients want to be more involved in health care decisions and want their own preferences to be taken into account. But they also want more choices full-stop. The consultation and Task Groups identified some areas for early action to increase treatment choices, in maternity services and on end of life care.

Promoting choice in ante-natal care

62. Since at least the publication of *Changing Childbirth* in 1993 maternity services have been at the forefront of offering choice to women and their partners. Women for whom this has worked well told us just how important it had been for them. But others told of their disappointment when arrangements felt inflexible or impersonal. The consultation demonstrated that some of the impetus created by *Changing Childbirth* has been lost, and there remains more to do to meet the real appetite for better information, more choice in maternity services and better support for pregnant women.

63. The forthcoming Children’s National Service Framework, which we will publish next year, will set out a ten year strategy for improving services for children and young people, including maternity services. We will ensure that the views of the Maternity Services Task Group as well as other comments we received during the consultation are taken account of in the development of the framework. But we wish to highlight now several points which can be taken forward immediately, as well as action we are taking forward nationally.

(i) Direct access to midwives

64. Women can already go direct to a midwife rather than being referred by a GP. But most women are not aware of this option and go to their GP first before being passed on to a midwife or obstetrician. For many women this is an unnecessary step which can delay access to specialist advice. We will ask local services to publicise contact details for midwives so that all women know they have the option of direct access. This in turn should save some unnecessary GP appointments as well as bring women into contact with maternity services as early as possible.

(ii) Promoting birth plans

65. We have highlighted above the importance of care plans to promoting personalised care. In line with our commitment to promote the use of care plans, we will encourage local services to offer all women the option of having a birth plan. This birth plan should clearly set out what options are available, for example home or hospital birth, and record each woman's preferences for pain relief, food, movement and so on. A birth plan is not of course an end in itself. It needs to be discussed throughout pregnancy to the point of birth and beyond and amended to take account of any changes in a woman's choices or situation. Eventually this information will be included in **HealthSpace** so that the clinical team can easily refer to it through the pregnancy.

(iii) Building the capacity to offer real choice

66. The consultation highlighted the fact that in some areas, the numbers of midwives limit the choices that can be offered. We are tackling this problem in a variety of ways, by:

- increasing the numbers of training places for midwives. There are now 470 more training places than there were in 1996/97, an increase of 28%;
- contacting midwives not currently registered to encourage them to return to practice;
- offering a flexible "return to work" training module aimed at them;
- supporting work to identify and spread good practice on retention of midwives;

- encouraging local services to look creatively at their skill mix and to explore the scope for using support workers. This can improve the quality of support for women and their families and enable midwives to concentrate on providing the care, support and information that only they are able to offer; and
- developing midwife leaders to drive forward this agenda.

Together these steps should mean greater capacity to deliver the range of choices that women want and that local services are aiming to deliver.

(iv) Local guides

67. The Department will shortly publish local maternity guides, in association with Dr Foster, so that every woman and her partner or family can find out about the local range of services and think about the sorts of services they would like to use. The guides will be in a popular magazine format, designed to appeal to a wide readership.

End of life care

68. Some of the most powerful consultation responses came from people who were distressed and badly let down over the experience of relatives close to the end of life. There is a strong tradition and valuable experience of end of life care within cancer services and also in HIV/AIDS services. But too few people benefit from this. People whose conditions have become distressing and intractable should be able to choose appropriate services that can offer them relief. They may also want to make choices relating to the end of their life, such as where to die, whether treatment should be withdrawn and whether they wish to be resuscitated.

69. There is already work in hand to develop specialist palliative care services for cancer, as well as training programmes for district nurses. We wish to offer all adult patients nearing the end of life, regardless of their diagnosis, the same access to high quality palliative care so that they can choose if they wish to die at home. We will be taking forward training programmes for primary care teams and staff across a range of settings including hospital wards, care homes and nursing homes, working in partnership with Macmillan Cancer Relief, Marie Curie Cancer Care and other groups to draw on their expertise. This will widen the pool of staff who are experienced in the needs of people nearing the end of life and able to offer appropriate support in a range of settings of the patient's choice. We are also

working with the New Opportunities Fund to expand the range of services for children with palliative care needs. We have already seen the formation of new community teams allowing children and families more choice over place of care.

70. We shall also promote joint training between staff working on palliative care and cancer services and staff tackling other conditions commonly affecting people at the end of life such as renal problems, heart failure, chronic obstructive pulmonary disease and neurological conditions.

71. Choice at end of life means we must extend best clinical practice to ensure that all people have choices of where and how they are treated and in what way. The inclusion of patient preferences in medical records will help patients to set out their wishes and give them the opportunity to refer to an advance directive if they have one. The Government has published the draft Mental Incapacity Bill, designed to give greater choice to people who are mentally incapacitated. The draft Bill would allow people to appoint attorneys to represent their views in healthcare decisions should they lose capacity in the future and allow people to make advance decisions about treatment preferences if they should wish to do so. The Bill will be brought forward when Parliamentary time allows.

Maureen's story

Maureen was in hospital with advanced breast cancer. She had a number of different treatments to control her disease. Each of these gave some benefit, but the disease became active again – causing loss of appetite, breathlessness, fatigue and some bone pain.

She was aware that her disease was incurable and talked openly about dying – first with her breast cancer nurse specialist and then with her oncologist, as well as with her family. She decided she did not want any further anti-cancer treatment and wished to spend her last weeks at home.

The hospital palliative care team and the palliative care nurse specialist had been giving advice on her pain medication for some time and now liaised with her husband and primary care services to set up care so she could be safely discharged from hospital. Working together the GP, palliative care community team, district and Marie Curie nurses provided care and support for Maureen and her family. Maureen died peacefully at home.

6 Effective choice requires better information for patients

72. Information is absolutely fundamental to choice. Information which promotes understanding gives patients the power and confidence they need to act as partners with clinical staff. Information is key to building trusting relationships and is essential to enable individuals to stay healthy.

73. Time and time again during the consultation people told us that they need information before they can exercise choice. From information on the services available to them to information about medical conditions and how to deal with them. From information on treatment choices to information on healthier living.

74. They also told us that such information is not always available. Information is of variable quality and inconsistent. At the moment there is no sense that there is a national service of information that is available equitably to all – a value at the core of the NHS.

“Time and again we heard how difficult it is for patients to get good information once they are in the system – how long they will wait, why they are waiting, what will happen to them next, and so on.”

(Emergency Care Task Group)

75. People have access to health information from many sources; from newspapers, television and radio, the Internet, the NHS, health professionals, patient organisations, friends and family. Some of this information is of high quality, but some lacks balance, accuracy or evidence. It is not possible to regulate or control the flow of health information nor would it be right to do so. People have the right to multiple sources of information; that increases choice and enables people to choose information which suits them.

76. But information is two way. In order for the NHS to be patient centred and to provide personal and responsive care it needs to know much more about its patients as individuals and as a group. Systematic collection of information about individual patient preferences and about how patients use the NHS is an essential part of increasing choice and of improving patient experience.

77. Ensuring that the public and patients have the information they need and that the NHS has the information about them that it needs must become core

business for the NHS. We need an information partnership that is nothing less than an information revolution. This means the NHS must work with others rather than do everything itself and draw on the professional expertise of voluntary organisations, communications experts and the media. And it will mean developing a comprehensive view of the information people need and how these needs are best met. Sometimes this will be high quality national information produced directly by the NHS, for example through NHS Direct. At other times people value independent information – voluntary organisations have considerable expertise in producing such information. Often there will need to be a local dimension. The Department of Health will take responsibility for providing a framework to ensure that those different sources information are available.

“The NHS should offer people with long term conditions information about their condition and about the services available to help them manage it and live an independent life.”

(MS Society)

78. We will give people access to the information they need. We will draw on communications and marketing expertise on how best to reach the full range of NHS user communities. We will draw on best practice in the development of materials in different languages. And we will give people a choice in the information channel which is most convenient and accessible to them.

79. We are taking major steps which illustrate this new approach:

New information channels which fit the way people live

80. In summer 2004 we will be launching a national NHS Direct digital TV service. This will be the biggest dedicated public service on digital TV and will provide an innovative method for providing health information to the public. The service will include information on health conditions and treatments, healthy living, health advice for travellers, health and safety information and information on local NHS services. Using digital TV we will be able to reach less affluent groups of the population who are currently underserved by other information channels such as the Internet. For example 37% in socio-economic groups D and E have digital TV whilst only 25% use the Internet.

81. A new partnership between NHS Direct, the Department of Health and Thomson Local will mean that a specially developed version of the NHS Direct

Self Help Guide 'Not Feeling Well' will be featured in Thomson Local telephone directories. This guide will cover the main symptoms for which it is safe and appropriate to self-care, as well as a range of other information including smoking cessation, immunisation and how best to access local NHS services. The guide will be distributed as part of the directories, reaching 19 million homes in England by April 2005.

Helping people find the right information about treatment

82. We are committed to patients and doctors having access to the same high quality, evidence-based information, to support shared decision-making. As an important first step, the Department of Health will be working with the British Medical Journal to make available information about the best treatments for a range of conditions including how they work and what the options are. 'Best Treatments' will provide evidence-based information on over 60 conditions and treatments, including common surgical procedures, put into language and formats which are accessible to patients. In future, information will be translated into a range of minority community languages. To date this information has only been available to US patients, but an agreement has now been reached so that the information will be made available directly through NHS Direct Online and also to local NHS services to use as content for their local information products.

83. We are also taking major steps to work with other providers of health information, including the voluntary sector, drawing on their special expertise in this field. We will discuss with potential partners how the NHS brand might be applied to high quality health information resources, acting as a 'kitemark' which will reassure people of the integrity of the information. This material will again be made available to the NHS to help support patients. To begin with we are working with the Coalition for Cancer Information (a partnership between voluntary sector and NHS organisations involved in the development, dissemination and delivery of information to those affected by cancer) to make quality cancer information more readily available to patients. By March 2004, some of the best and most widely used cancer resources will be made available on the Internet via NHS Direct Online as part of the new NHS Information Partner accreditation system. A number will also be made available in print and leaflet form, including in minority community languages, 'kitemarked' NHS Approved to reassure patients and public that they can rely on these resources, and to help make them more easily available through the NHS. In addition we hope to pilot a central ordering system for the NHS so that local services can make these high quality and reliable resources available to patients.

Creating more localised information on NHS services, healthy living and treatment

84. We are also already taking a range of other actions to provide a framework for health information at a local level. A few examples include:

- 'Your Life' – a localised NHS led magazine produced in partnership with the independent health information provider Dr Foster targeting less affluent groups with healthy living information and how best to access NHS services;
- www.nhs.uk, the internet gateway to NHS organisations, providing details of local health care services, where to find them, and their performance;
- 'Your Guide to Local Health Services', now in its second year, is a short guide to local NHS services produced by primary care trusts and delivered annually to every household. As part of the routine evaluation process we shall test out the potential to extend the content to support choice.

85. Information alone is not enough. Many patients also want to discuss what it means for them and how it might affect their choices. Typically, this may happen in discussion with a GP, a hospital consultant, a specialist nurse, or someone from a patient organisation. There was a strong message from the consultation that patients value very much having someone to turn to, to help guide them through the choices available. There are a number of models for how this kind of support can be provided, including innovative examples from outside the health sector. We need to learn from these and existing arrangements within the NHS to see how best we can identify the key roles and competencies that matter most to patients and the ways in which clinical teams and others can build on these.

86. In parallel with ensuring high quality information is delivered, we need to support clinicians to develop the skills and techniques needed for shared decision making and to recognise this as a core part of their practice. The range of information resources we are making available will support clinicians as well as patients. We are already taking action in this area by working with the NHSU, who have commissioned Cancer Research UK and Marie Curie Cancer Care to pilot communication skills training for senior cancer clinicians. It is anticipated that, once evaluated, this programme will be rolled out by the NHSU.

Choice, responsiveness and equity

East Lancashire Hospitals

Mrs D's Story

Mrs D was born and raised in Pakistan and moved to Lancashire following her marriage. She was expecting her first baby and was unsure how she should feed him/her when born. Although she speaks Urdu, she does not read it, or speak English.

Her husband's family were putting pressure on her to bottle feed, so that they could assist with the care of the baby and permit Mrs D to rest.

A video describing the benefits of breastfeeding, made by local midwives, health visitors and women from the community was given to Mrs D to watch at home.

The video is in three languages including Urdu and is culturally sensitive.

Mrs D informed the link worker that the whole family watched the video, including her mother in law, and she was then encouraged to breastfeed her baby.

Mrs D went on to breastfeed for four months.

Brent Primary Care Trust

Brent Primary Care Trust is working closely with Brent Association of Disabled People to provide greater access to the local deaf community.

A Patient Advice Liaison Services Officer holds information and advice surgeries at the Association with the aid of a British Sign Language interpreter.

Feedback from the participants so far indicates that such outreach surgeries in the community setting are welcomed. So much so, monthly sessions are planned for 2004.

87. The Government is determined that widening choice should underpin and promote equity, rather than undermine it. We know from research that some existing services fail to deliver equity, with minority ethnic groups suffering from a number of areas of disadvantage in accessing health care. For example, a recent study looked at how black and South Asian patients experienced coronary heart disease services in London. These patients were nearly twice as likely as all patients to report that their appointment for first treatment had been postponed or cancelled and were less likely to understand their diagnosis completely. Studies on South Asian patients' experience of diabetes services again show less knowledge about the disease than other patients. Thus it is imperative that choice is a driver for reversing current inequities.

88. There is also a wide range of research evidence showing that lower socio-economic groups receive less by way of services relative to need. For instance, intervention rates for coronary artery bypass grafts or angiography following a heart attack were 30% lower in the lowest socio-economic group compared to the highest. Hip replacements were 20% lower among lower socio-economic groups despite roughly 30% greater need.

89. The consultation reinforced these results and gave the Department and the NHS some clear messages about equity. We heard the frustrations of groups who struggle to get access to good mainstream services. We heard about the need to communicate with everyone, on their terms. The need to focus on disadvantage. To draw on the strengths of community groups and patient groups to provide support and advocacy. To design services around people, creating flexible arrangements for accessing services that meet people where they are and respond to their needs in the round rather than isolating their health care needs. To listen and to keep on listening.

“Ethnic minority populations frequently have less access to information and commonly experience a sense of disempowerment in their interactions with statutory services and specific strategies are needed to change this.”

(Commission for Racial Equality)

90. The commitments in the chapter represent some important steps in the right direction. But they must form part of a more comprehensive approach, aimed at:

- good quality services directed towards the needs of all disadvantaged groups;
- tackling the specific issues about choice that these groups have raised with us; and
- rolling out wider health and health care initiatives in ways from which all can benefit.

“Choice is often seen as a prime example of inequity in healthcare. LMCA believes it is possible to use choice as a lever to improve equity, but only if this has been made a specific objective.”

(Long-term Medical Conditions Alliance)

91. We shall continue important strands of work which already focus on groups with special needs, including the Valuing People programme for people with learning disabilities; the women's mental health strategy; work to improve mental health services for black and minority ethnic communities; and other strands of national service framework implementation, such as action on age discrimination.

“There needs to be a change of attitude so that people who have a learning disability, or are very old, or have mental health problems, are not seen as being less ‘autonomous persons’ than those better able to assert their personhood and demand their rights.”

(MENCAP)

92. On choice, some of the strongest messages from disadvantaged groups were about their search for greater influence and control over decisions about their treatments and the impact on their lives. So it will be important to ensure that arrangements for supporting choice, including information and support for shared decision-making, respond to the full diversity of community needs. And we need to ensure that all groups are helped to articulate their preferences and needs, such as spiritual, cultural or linguistic needs, and to have these built into their NHS care records.

93. A key area of potential exclusion is access to transport. The Social Exclusion Unit's report "*Making the Connections: Final Report on Transport and Social Exclusion*" published in February 2003 examined aspects of transport as they relate to social inequalities, including access to health care. It recommended action and improvement in three areas relating to health: improving patient transport services, advice and information on transport options and accessibility of services. Ministers accepted the recommendations and work has begun to investigate the possibility of integrating the existing patient transport services and statutory Hospital Travel Costs Schemes into a framework that the local NHS will be able to use in developing their patient transport services. This is aimed at providing free transport to patients who qualify on the basis of social, health and financial criteria.

94. The NHS neither can nor should attempt to do everything itself. For some vulnerable groups, access to service will depend critically on trusted outreach, advocacy, and intermediary providers. Recognising and fostering the capacity of communities, patient groups, faith groups and others will be important. Her Majesty's Treasury's £125m *futurebuilders* fund will help to tackle the barriers to voluntary and community organisations engaging in effective service delivery, as

well as supporting the sector in developing and modernising capacity. As health and social care has been identified as a priority area for investment of the fund, this will be an important resource to support building capacity.

95. Finally, there are several key conditions to be met if disadvantaged groups are properly to share in the benefits of wider health and health care developments. We must:

- dismantle communications barriers;
- ensure that education and development equips the health care workforce to respond to the full diversity of patient and community needs;
- ensure the NHS's commissioning and procurement is sensitive to equity issues; and
- develop and use more rigorous frameworks for testing the impact of policy and action on equity.

96. Much of this is addressed within our proposals in chapters 3 and 4. In communications, following the commitment made in the NHS Plan, NHS Direct has initiated the procurement of a national interpreting and translation service, to be in place by March 2004. This will provide access for all NHS organisations to a telephone based interpretation service and a translation service. The framework contract will provide assured quality standards for both interpreting and translation, and a shared, centralised knowledge management system for translated materials.

NHS Direct is also working with the MENCAP Helpline service to respond to helpline users' enquiries about health topics. The services are working together to prepare health information factsheets (starting with one on healthy eating) in accessible format on the most frequently asked questions from users with learning difficulties and their carers.

97. An important task for 2004 will be to build a better understanding of the baseline position on equity, locally and nationally. NHS organisations are already working to guidance from the Commission for Racial Equality on carrying out race

equality impact assessments as part of their statutory duties. We are publishing guidance for primary care trusts this December on how to go about health equity audits, which will further assist understanding of the health needs of different groups and areas. We need similarly to continue to improve understanding of different groups' experience of access to services, and of their experience of choice. And we need to develop a framework to test for equity and to track the experience of different groups in benefiting from increased choice in health and health care.

98. Promoting equity is an issue for all public services and we need to learn from experience elsewhere. So to assist us with monitoring of progress in equity, we shall be working with local authorities, the voluntary sector and other organisations with experience of choice.

99. It is worth repeating that choice in itself is a means to an end – to better, more responsive services. We know that by introducing the dynamic of choice, combined with a relentless focus on tackling disadvantage the NHS, working in partnership with others, can deliver those high quality responsive services. This is the task the consultation has set us.

Chapter 4: Making choice happen

1. The six key changes set out in Chapter 3 will give focus to the drive for a more personal, more responsive service. But more is needed if the whole culture of the NHS is to be transformed so that patients feel they are not only at the centre, but in control. There is a good deal to build on – committed staff, the many examples of good practice, new structures now in place to ensure a stronger patient voice at every level in the NHS. Nonetheless, NHS staff, hospital trusts and primary care trusts all told us that there is a lot further to go. This chapter explains how we will approach the next stages.

2. It will not be easy. Change on the scale both patients and staff want never is. The centre certainly cannot do it alone. Real change will happen at the front line, with support from the centre, fuelled by encouragement and expectation from patients and drawing on the experience of partner organisations and other experts. Change will need:

- a clear shared vision and values, owned by national and local leaders;
- supported by continued investment and capacity growth;
- delivered by empowered staff, with support from peers and experts;
- backed up by high quality information systems;
- informed by a stronger patient voice; and
- underpinned by a coherent system of incentives, regulation and inspection.

“Meaningful choice for children and young people will depend on the extension of a culture of respect for and valuing of children across the NHS.”

(Children’s Task Group)

Leadership for change

3. The consultation and this document have confirmed the values on which the NHS was founded and set out a new shared vision of an NHS focused on delivering an excellent service that responds to the needs of each individual patient and recognises their diversity. This vision and its values will in turn help shape the Priorities and Planning Framework for the next phase of NHS Plan roll out, embedding them in NHS core business.

4. The local leadership of the NHS – managers and clinicians – will be critical in taking the changes forward locally. Many have already been active in local consultations, exploring what would make most difference locally and building new forms of dialogue with patients and public. As responsibility is increasingly devolved in the NHS, there will be more scope for local leaders to find the best ways of delivering a better experience for patients; and in turn, to enable frontline staff to do the same. The NHSU and Leadership Centre will pick up this challenge, designing their development interventions to help local leaders increase choice and offer more personalised care. An additional programme for senior and middle managers is being designed by NHSU and the Leadership Centre together with leading practitioners and business schools, to provide further support with a phased roll out across the country during 2004.

5. In addition, the new “NHS Live” year round programme of action will offer the opportunity for staff from NHS and social care organisations across the country, working with patients and stakeholder organisations, to identify the challenges and opportunities they face in taking forward the ideas in this document; to come together to share best practice and gain expertise; and to build this back into local action. There will be a national focal point event in July 2004 to bring local teams together. The programme will be designed to accelerate the pace of change, and will ensure local patients and staff are able to shape the next stages. Local teams may want, for example, to develop some of the ideas from the Task Groups and others, and find ways to put them into practice. Over time, the local role in shaping services both fair to all and personal to each, will continue to grow.

The International Pursuing Perfection Programme

Lambeth and Southwark Primary Care Trusts with King's College Hospital, sponsored by the Modernisation Agency

These organisations work together to improve services for patients across the whole system. Sites choose specific areas to focus on, then work with health care professionals, patients and carers to develop radical solutions to long standing difficulties.

One area of focus has been services for patients with chronic diseases such as lung disease. Staff delivering the service have worked with patients and local patients groups to look at how the service can be improved, agreeing the objectives and focus of the work at the outset.

Together, patients and staff have designed a wide choice of services that patients can access easily to keep themselves well – offering different options to suit different lifestyles.

Some of the changes have been very small but have had a large impact on patients. And as staff have become more used to working with patients, their confidence in asking patients for feedback has improved.

For example, a physiotherapist noticed that there were relatively high levels of drop out from a respiratory rehabilitation course she ran. So she asked patients why this was. They told her that the session finished at the same time as schools so they found it difficult to travel home on the full buses with their breathing difficulties.

A simple change in the time of the session has seen a significant increase in the number of people completing the course.

Investment and Capacity

6. The centre will continue to provide essential support, through sustained investment for capacity expansion. The next phase of the ten year NHS Plan programme will see increasing focus on capacity in primary care and the community, and on support for people with long term conditions. Replies to the consultation confirmed that there is further to go to put in place the models of service recommended in national service frameworks, and to address health inequalities, to ensure that all patients have the basic choice of a convenient, good quality service, delivered in line with national standards. Delivering this investment and capacity is a pre-requisite for other choices and will be a high priority for the NHS through to 2008. As numbers of staff continue to grow, and areas of shortage and pressure are eased, so there will be more opportunity for staff to offer the personal care which for so many was their reason for joining the NHS.

Support for staff

“It is crucial that staff are adequately trained and supported to facilitate the information seeking and decision making of a diverse range of service users. Nursing is a profession that works closely with patients, carers, service users and the general public on a day by day basis, and often over long periods of time. So we are ideally placed to help them access information, interpret it, evaluate it, make decisions, and follow through the choices made.”

(Royal College of Nursing)

7. Individual members of staff, teams, practices and hospital departments have been able to transform services, and shown what can be done. But expertise from other service industries renowned for their customer care confirms that relying on individual effort alone will not be enough. An unremitting concern for the user needs to permeate the whole organisation. We know that staff satisfaction has a direct impact on user satisfaction. Staff who feel that they are valued, empowered and offered choices themselves will feel better able to offer choice to patients. Staff want to feel that the systems with which they work and the incentives they are offered support their core motivation to give high quality, personalised care. They want training, learning and development opportunities and to be able to put what they learn into practice. And they need the freedom and flexibility to develop and put in place local solutions.

Good Practice

South Tyneside Health Care Trust

This Trust has developed its own customer care training programme which carries a well-adopted slogan of “My Customer, My Responsibility”

Learning is in multidisciplinary teams and includes employees from, amongst others, estates, finance, catering, domestic services and supplies department.

At the outset, it was determined that this training should be compulsory, stressing the importance attached to customer care training in a health care environment.

The purpose of the training programme is not only to emphasise good customer care technique but also to improve behaviour and attitude.

8. So we need high quality human resources practices which are seen to value and empower staff, educational programmes that support and reinforce customer care, and pay arrangements that recognise, value and reward those who live up to the values of the NHS. We have begun to put these in place. New contractual frameworks, covering medical and dental consultants, GPs, community pharmacists and general dental practitioners, and the Agenda for Change framework for most other NHS staff, create new opportunities to value and empower staff. So do strategies to transform learning and development for NHS staff, professionals and non-professionals alike. These initiatives also offer greater flexibility to match roles and services to local patient needs, and greater incentives to staff to provide high quality and responsive care.

“The provision of care for older people should focus on the individual, their circumstances and their needs. Staff throughout the NHS and social services should receive training enabling them to demonstrate the attitudes and behaviours that support this.”

(Older People Task Group)

9. Learning and development programmes will increasingly have customer service at their core.

NHSU

The NHSU will develop a School of Patient and Public Involvement, and expertise to ensure the whole of NHSU's activity is patient centred. Part of its early curriculum will focus on an induction programme (covering over 140,000 staff a year) and on communication skills programmes. These add to existing development programmes for "first point of contact" staff. NHSU will work closely with the NHS to support the development of effective joint learning between the public, service users and staff.

Agenda for Change will see the knowledge and skills needed to promote choice and responsiveness built into mainstream personal development and appraisal processes for all staff by 2006. This will be supported by further work with a range of partners to develop continuing professional development structures which will enable the effective planning of both personal and organisational learning needs.

The current fundamental reform of NHS-based medical training – Modernising Medical Careers – is designed not only to modernise training, but also to produce a medical workforce aimed at reflecting the needs of patients in the 21st century. Communications and responsiveness are at the centre of these reforms.

10. The Modernisation Agency has a significant role to play in developing a responsive service. It will work with Strategic Health Authorities and their health communities to explore their local development needs and will plan with them to meet these. It will also support local commissioners working with the voluntary sector and local users to develop service models that will improve choice for disadvantaged and vulnerable people, their carers and families. The Agency's changing workforce programme has already supported staff in redesigning jobs so that they can provide a more flexible and responsive service to patients. The Agency will also explore how best to use tested tools and techniques for the spread of good practice, to add impetus to the programme.

The Electronic NHS

11. The £2.3bn investment in the NHS Information Technology Programme will mean a radical change in the capacity of the NHS to respond to patient choice. It lies behind the six key changes in chapter 3. Patients and staff will both see the benefits.

Patient Access to Electronic Records System

Wells Park Practice, South East London

Wells Park Practice has offered patients access to their paper records for 17 years and continues to do this even though all records are now electronic.

Patients can look through their records in the waiting room via a PC that is situated in a private booth. Patients identify themselves by fingerprint which takes them immediately into their notes. They can then browse, using a touchscreen and print if necessary. Technical terms are explained by touching the relevant word which is also printable.

Safeguards are in place. For example, third party information cannot be accessed and sensitive information is restricted until it has been explained to the patient by a clinician face to face.

Research has proved that

- Access is safe
- Patients feel more confident in talking to their GP as they better understand medicine and the system
- Patients with cancer also value it. It helps them plan their future, reassures them that they will be treated with consistency and gives them confidence that what they've been told is what is actually happening.

12. Through better use of IT, access and convenience will improve. By December 2005, all patients will be able to choose and book hospital appointments through their GP's surgery. Electronic booking will enable this to happen. Electronic prescribing will mean faster and safer access to medicines. Test results will be available more quickly and all clinicians will be able to access core information from the (electronic) NHS Care Record when and where they need to. The delays and frustrations of 'lost' records will be a thing of the past.

13. The NHS care record will make it far easier to offer continuity of care, informed by the key information on a patient's medical history (and increasingly, by a record of the patient's own preferences) from a range of settings. This will free up options for patients to get health care at a time and place that fits best with other demands on their life, while remaining confident that relevant past events will be taken into account.

14. For patients and staff, prompt and easy access to the information they need will make a real difference to their ability to make good health decisions based on a common understanding of the patient's history, current condition and intended care pathway. Staff will be better able to offer a responsive service, built around the individual's needs. They will spend less time asking patients to repeat information already given and re-entering information that has already been entered into the patient's record by someone else. They will have the right information, at the right time, in the right place including, for example, prompt access to test results. They will also be able to keep up to date more easily on new evidence and developments in professional and clinical practice. This will be particularly significant as NHSU develops its online learning opportunities.

15. Better availability of information, held electronically, will improve choice for patients and allow staff to concentrate on providing better and more responsive care. But it is also important to make sure that proper safeguards are in place, and that any concerns about confidentiality are addressed. Well managed electronic records will be more secure (and more accurate) than paper records. Patients will be able to see the information which is held about them, check its accuracy and exercise more choice over who sees it.

Listening to patients

16. We need to listen to patients and the public to help shape personalised services for individuals and to inform the planning, development and commissioning of services. We know that patients are a diverse group and that feedback systems

need to work effectively not just at national level, but also at community and individual level. To support this we have passed legislation to give patients – and the public – new powers and more influence.

17. Local health services are now required to involve patients and the public in the overall modernisation of the NHS. In the past patients were only ever consulted at the last minute, when proposals for change were fully formulated. Today, patients, the public and their representatives must be fully involved in both the planning and development of services, and fully consulted on decisions that affect the operation of services. This represents a real shift in how the NHS is developed – changes to the NHS are a product of the views of those who use it. They are no longer just passive recipients.

18. In particular, we have set up the Commission for Patient and Public Involvement in Health to advise us on how the whole system of patient and public involvement is working. It will carry out national reviews of services from the patient's perspective and make recommendations to the Secretary of State and other bodies as it considers appropriate. The Commission is responsible for setting up and managing the performance of over 570 newly formed Patient and Public Involvement Forums, which will monitor the range and operation of local services from the patient's perspective, feed the views into decision-making and will review the effectiveness of trusts in responding to the patient's voice. In due course, the Commission will oversee the provision and commissioning of Independent Complaints and Advocacy Services (ICAS).

North of Tyne Patient Advice and Liaison Service

The Patient Advice and Liaison Service works with employees in the Trust to see things from the patients' perspective.

One concern involved a patient who was moved from one ward to another without any notice. The Patient Advice and Liaison Service was able to support staff to see the experience through the patient's eyes and understand the upset and stress caused by lack of communication. They then identified ways of improving communications in the future.

By representing the patients voice and addressing key issues like food and advocacy, the Patient Advice and Liaison Service is contributing to the developments the Trust is making towards a culture of person centred planning and putting the patient at the centre of their care.

“Patient and Public Involvement Forums will be a potent force for ensuring that the ideas behind Choice will be implemented in all areas. They will have the opportunity and responsibility to consult with stakeholders and health service practitioners on where Choice is working best, on sharing good practice and in developing the best ways in improving a service where it is falling short.”

(Commission for Patient and Public Involvement in Health)

19. We also have a comprehensive national survey programme, where individuals are able to rate their local services. At local level there are a variety of patient feedback systems. These include the Patient Advice and Liaison Service and complaints process that every trust and primary care trust should have. A further mechanism will exist when bedside comment cards are introduced early in 2004 for patients to provide immediate feedback to trusts and primary care trusts on their hospital experience.

20. Yet with all this, the Department and the NHS still lag behind world leaders in customer service, in terms of the vigour with which they seek out regular, real time feedback from their users, and act on it. In 2004, the Department of Health will establish a new Patient and Public Intelligence Unit, to provide better intelligence on patient and public concerns and enable a better informed response. And work will be commissioned on tools to help local health communities draw together the many sources of feedback now available to them, so that they can respond more quickly, tackling problems as they arise.

“Choice cannot be provided unless there is direct knowledge of user’s needs and preferences for health and social care services. Service users should be involved in planning, running and monitoring services and represented on all decision-making bodies.”

(MIND)

21. *The patient and public voice in commissioning.* Primary care trusts have a critical role in shaping local services so that these reflect the needs of local populations and offer the range of choices that patients most value. They will be able to draw on the messages from this autumn’s local consultations. They will also need to look at ways of tracking the choices local patients make (and the choices they may *wish* to make but which it proves difficult to deliver) so that this can influence future planning and commissioning. They will need to keep under review the extent to which choices are taken up by all parts of the population, and to work on this with Patient and Public Involvement Forums and others.

22. *The patient and public voice in NHS Foundation Trusts.* We have legislated to give NHS Trusts that become NHS Foundation Trusts more freedom to decide locally what needs to be done, in line with primary care trust commissioning, to improve the care they provide for NHS patients. The new governance arrangements for NHS Foundation Trusts mean that the local people, patients and staff have a real voice in determining how they do so.

23. Members of the public who live in the local area, patients of the hospital who live outside the area and their carers, and staff will be eligible for membership of an NHS Foundation Trust. A Board of Governors elected by the membership of the NHS Foundation Trust will represent their interests, and those of partner organisations, in the governance of NHS Foundation Trusts. These direct elections to the Board of Governors by local people and staff will get hospitals better focused on meeting the needs of the local communities they serve. NHS Foundation Trusts will be directly accountable to the local community through their Boards.

24. *A stronger voice for the voluntary sector.* We shall also build on the long history of collaboration between the voluntary and statutory sectors in public service provision, not least in health and social care. Community and voluntary groups already play important and valuable roles in supporting service users and carers, acting as advocates and providing specialist information and advice as well as providing a range of health and support services.

25. Voluntary organisations and local community groups are a vital source of expert knowledge in their own specialist areas. Their experience with specific client groups leads to a high level of understanding of needs and expectations. This combined with their flexibility and freedom to innovate, can be a powerful force in developing and influencing the delivery of services so that they are increasingly responsive to users and can truly reflect the diversity of need which exists.

26. “Making Partnership Work for Patients, Carers and Service Users – a proposed strategic partnership agreement between the Department of Health, the NHS and the Voluntary and Community Sector” – published for consultation on 28 August this year – signalled our joint commitment with voluntary sector leaders to work constructively together to optimise the voluntary sector contribution to a genuinely patient-centred health service where choice is the driving force for change. Through this strategic partnership, or concordat, we will strive to promote and

support joint working with the voluntary and community sector at local level leading, through progressive, dynamic and innovative partnership, to real improvements to choice, responsiveness and equity in health services.

Aligning Systems and Incentives to support choice

27. Progress towards a more personal service will be hindered if staff feel that incentives, systems and performance measures are pulling in different directions. So a key role for the Department of Health over the next period is to ensure a clear and coherent approach that supports and rewards delivery of the outcomes that patients say are important.

28. The new system of financial flows – *Payment by Results* – will be central. These arrangements are designed to ensure that the flow of funds to hospitals supports rather than dictates patient choices. The arrangements being rolled out to date focus on acute hospital treatment. The Task Groups, and other responses to the consultation, have put forward questions and ideas about ways in which *Payment by Results* could be developed further over time to help support choices in mental health services, in maternity services, and in diagnostic services. Maternity services and diagnostics will largely be commissioned on a tariff basis from April 2005. We are also actively considering working with a few sites to develop a system of *Payment by Results* for mental health services from 2008-9.

29. *Monitoring and Inspection*. It is important that systems of monitoring, inspection and regulation all have the patient's experience at their core. We will share the results of the consultation with the Commission for Patient and Public Involvement in Health and the Commission for Healthcare Audit and Inspection (CHAI). We shall discuss with each of them how best we can together support and encourage NHS staff and organisations to put patients at the centre.

“...we need to align the performance management regime with the requirements of choice. Outcomes and assessments of the patient experience of healthcare should form a much more significant part of the way that providers, commissioners and clinical staff are assessed.”

(NHS Confederation)

“CHAI intends to ensure that it assesses the involvement of patients and the public at every level in the health system. It will consult widely on the views and priorities of patients and providers.”

(Commission for Healthcare Audit and Inspection)

30. Together, these changes will help the NHS, local staff and local communities to shape services. They will promote and accelerate the spread of good practice, building on the best and making the best as widely available as possible.

Chapter 5: Rolling out the changes

1. The first six months of 2004 will be above all a time of preparation. Time to reflect on the consultation messages and what they mean, locally and nationally. Time for NHS staff and organisations to identify the support they will need to move forward. Time to test and develop proposals from the Task Groups and others. Time to identify where capacity expansion is needed.

2. There will be two initial strands:

Locally, the NHS Live programme will provide a focus for identifying the challenges and opportunities in developing personalised care, sharing good practice, and building momentum.

Nationally, we shall build choice and responsiveness into the new planning framework for the NHS for 2005-06 to 2007-08, to be issued in July 2004. This document will set the framework for the wider roll out of choice, as capacity continues to expand. Services will then develop plans to make a reality of the Government's priorities at the local level.

3. Both nationally and locally, there will be the same inclusive approach towards implementation as has characterised the consultation process.

4. *Milestones to come*

2004	● 'Kitemarked' cancer information available	March
	● new GMS contract enables improvements in primary care access	from April
	● NHSU Induction Programme launched	from April
	● NHS Direct Digital TV launched	Summer
	● NHS Live	July
	● 3 Year Planning Guidelines	July
	● choice of hospital for patients who have waited 6 months for hospital care	August
	● patients can pick up repeat medication direct from their chosen pharmacy	Dec

2005	● choice at point of referral for cataract patients	Jan
	● NHS Direct self care information included in Thomson Local telephone directories	April
	● NHS finalises 3 year plans	March
	● 4 or 5 choices at referral for all other elective surgery, and ability to book the choice	Dec
2006	● NHS Care Record allows for planning and recording the whole patient journey	June
	● HealthSpace links to NHS Care Record	June
2007	● Patients can pick up repeat medication direct from any pharmacy	Dec
	● Palliative care training programme complete	Dec
2008	● Full implementation of NHS Care Record	Dec

5. The milestones set out above are a framework for better information and increased choice. But the majority of changes set out in this document to create a more responsive NHS can be brought about by changes in practice and behaviour by staff, clinicians and managers of the health service. During the consultation we found examples everywhere of choices being given and extended and patients being supported in decision-making. Patients have told us time and time again that it is relationships and communication at every level which make the difference. The success of these changes is in the hands of every receptionist, every clinician, every medical secretary and hospital manager. The job of the NHS and the Department of Health is to support these staff at every level.

Annex A

The consultation process

1. In August 2003, Sir Nigel Crisp, Chief Executive of the NHS, launched a national consultation, entitled "Choice, Responsiveness and Equity in the NHS and Social Care". The consultation process was led by Harry Cayton, Director for Patients and the Public at the Department of Health.

2. There were four main strands to the consultation:

- A national consultation led by Expert Task Groups with a majority of service users, with clinicians and managers, exploring choice, responsiveness and equity across eight themes:
 - Maternity Care
 - Children's Health
 - Primary Care
 - Emergency Care
 - Planned Care
 - Mental Health
 - People with continuing, long term conditions
 - Older People
- Local consultations and events for the public and staff led by Strategic Health Authorities;
- A Choice Consultation Survey for the public, staff, patients, users and carers to contribute their individual ideas and views directly; and
- An opportunity for patient and professional organisations, the voluntary and independent sector, Modernisation Agency Associates and other stakeholders to contribute to the debate.

3. To engage as many people as possible in the consultation we listened through national events, including conferences for people with learning disabilities and for people from ethnic minorities, developed a dedicated website and made available a range of materials:

- A consultation resource pack for local consultation events;
- A video to set the scene for local engagement;
- A summary of the consultation questions for people to use at local events. This was available in other languages and formats;
- Copies of the Choice Consultation Survey in other languages;

4. All contributors were asked to consider the following questions:

- what choices do patients/users/carers want?
- what information and support would patients/users/carers need to exercise their choices?
- what changes in the system, or how people work, or communicate would be needed to create these choices and make health and social care more responsive?
- how could these choices be made fair for all?

5. The discussions had clear parameters. Proposals for change needed to meet test questions:

- Is this really personal?
- Would giving people this choice be fair to everyone?
- Is there proof that it works?

6. We contacted 7,500 organisations through direct engagement with 220 organisations and umbrella groups reaching over 80,000 people. These included bodies with national and regional branches, associations and alliances of voluntary organisations, leading institutes for people with learning disabilities, black and ethnic minority organisations, faith based communities and prison organisations.

7. The replies to the consultation were extensive. We heard from:

- The eight national Task Groups;
- 773 respondees including 314 NHS bodies, over 216 individuals, 123 local and national voluntary organisations, including 35 national organisations for long term conditions and 20 local groups of people with learning disabilities; 40 professional organisations and 80 other organisations;
- 2500 patients and staff who replied to the survey we conducted with MORI;
- National Consumer Council/MORI research/focus groups with disadvantaged groups.

8. To gather these views for us, the NHS and other organisations organised local consultation events. In their responses they told us that they had:

- Engaged 33,000 people;
- Used telephone surveys, public meetings, leaflets, the local media, focus groups, workshops, questionnaires and face-to-face interviews to gather views; and
- Included children, ethnic communities, people with learning disabilities and held events in the day and evenings to promote good coverage.

9. In total we estimate that over 110,000 people were engaged by the consultation. A list of organisations who have responded to the consultation is available at www.doh.gov.uk/choiceconsultation, or in writing from:

Room 533 Richmond House
79 Whitehall
London
SW1A 2NS.



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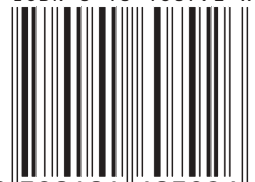
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