

ENGAGING PATIENTS IN THEIR HEALTH

How the NHS needs to change

Edited by Anna Dixon

Report from the Sir Roger Bannister Health Summit, Leeds
Castle, 17-18 May 2007

TheKingsFund>

LEEDS  CASTLE
KENT, ENGLAND

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Sir Roger Bannister was the first person to break the world record for running a mile in less than four minutes, an achievement that still fires the admiration and imagination of young athletes today. Sir Roger went on to become one of the leading neurologists of his generation, specialising in the autonomic nervous system about which he wrote several textbooks and many journal articles. He became Master of Pembroke College Oxford and the first Chair of the Sports Council.

Until 2007 he was a Trustee at the Leeds Castle Foundation, which has a commitment to supporting medical charities, and on his retirement, in recognition of his immense contribution to medicine and to the nation the Foundation decided to hold a summit in his honour. The King's Fund is grateful to the Trustees and staff of the Leeds Castle Foundation for their kindness and generosity in supporting the work of the summit, which we hope will help to shape a better understanding of the needs and expectations of the future patient.

Thanks also to Ben May, who helped behind the scenes with the organisation of the summit at Leeds Castle and Sarah Gregory, who provided assistance with the final editing of the report.

Contents

Introduction

Part 1 The patient of the future

1. Summary of themes	5
Background	5
Patient as consumer	6
Use of technology	8
Healthy behaviours	9
What needs to change	10
Recommendations from the summit	11
2. Next steps in patient and public engagement	14
<i>Anna Dixon and Niall Dickson</i>	

Part 2 Presentations

3. The patient of the future	21
<i>John Coulthard</i>	
4. Supporting patients to self-care	25
<i>Gopa Mitra</i>	
5. Making 'lifestyle' changes: changing behaviour to improve health	28
<i>Susan Michie</i>	
6. Patients as decision-makers	32
<i>Angela Coulter</i>	
7. Patients as entrepreneurs	36
<i>Harry Cayton</i>	
8. Patients as budget holders	41
<i>Peter Gilroy</i>	
9. The patient of the future – what needs to change?	43
<i>Alan W Hartley</i>	
10. What needs to change to meet the needs of future patients?	45
<i>Liz Kendall</i>	
Appendix 1 Delphi exercise	48
Appendix 2 Participants	49

Introduction

In his first report to the Treasury on how to secure good health (Wanless 2002), Sir Derek Wanless outlined three scenarios, in the most optimistic of which – the fully engaged scenario – individuals would be engaged in managing their own health, thereby reducing risk factors for ill health and the demands on professional services. This was followed, in 2004, by a second report in which the challenges involved in bringing about a healthier population were explored (Wanless 2004).

In May 2007 The King's Fund hosted a summit at Leeds Castle to raise awareness of the challenges for the NHS and the government in achieving the fully engaged scenario.

PART 1: THE PATIENT OF THE FUTURE

1 Summary of themes

Background

The Wanless reviews argued that engaging individuals in their own health and reducing the risk factors for ill health would reduce demands on professional services (Wanless 2002, 2004). The vision was of a world in which both healthy lifestyles and rates of self-care would increase, which in turn would reduce pressure on GP and outpatient services and slow the inevitable growth in NHS spending. At the same time, older people would take up opportunities for screening and prevention and, where it could be shown to be cost-effective, there would be increased spending on health promotion. The improvements in life expectancy would come from reduced rates of smoking, increased exercise and healthier diet.

A number of these issues have been addressed to a greater or lesser degree. Minor ailment schemes have been set up to allow people who are exempt from prescription charges to obtain their medicines direct from their pharmacist rather than having to go to their GP, and some medicines that were prescription-only are now available over the counter. NHS Direct, walk-in centres, minor injury units and a new pharmacy contract are all examples of measures designed to promote alternative access routes to health care and to self-care.

Similarly, in public health there have been a number of policy developments. There has been a significant effort to increase the take-up of smoking cessation services, and nicotine replacement therapy is available on prescription as well as over the counter. Perhaps even more significantly, the government has introduced a ban on smoking in public places. Other public health campaigns include the promotion of five portions of fresh fruit and vegetables a day and a reduction in salt intake. The Department of Health has announced a strategy to combat obesity and, in *Choosing Health* (Department of Health 2004), it set out a variety of measures including the introduction of health trainers and a multimedia service called Health Direct to provide people with information and advice to support health improvement.

There has been a major expansion of the Expert Patients Programme, the main generic self-management support programme for patients with long-term conditions. Other initiatives to support self-management include disease-specific interventions such as Dose Adjustment for Normal Eating (DAFNE) (NICE 2003), self-care training and tools for general practices (Working in Partnership Programme 2007).

The Commissioning Framework on Health and Well-being (Department of Health 2007a) sets out further detail about how improvements in health can be delivered by primary care trusts (PCTs) in partnership with others, including employers, the private and voluntary sector, and the more traditional partners in local government. Many of these policies are still being introduced and it is too early to assess their impact.

New technology, demographic change and changes in public attitudes are already transforming the way in which patients interact with health services and health professionals. Predicting how and how fast these and other emerging trends will evolve is

difficult. Yet, if the vision of a fully engaged health system is to be realised we do need to reflect on what has and has not been achieved thus far and the challenges that lie ahead.

The summit heard from experts in health, economics, government and patient relations (their presentations are set out in Part 2) and explored in more detail the concept of the patient as a consumer, the use of technology and promoting healthy citizenship.

Patient as consumer

- How might the way patients use and access services in future differ from the current situation? How will patients interact with clinicians in future? How much will patients be willing to do for themselves in future, that is, how much self-care? Do patients and clinicians need any extra support to help them take on these responsibilities?
- What would it mean to be a responsible consumer of health services in future? Will people want to be treated as consumers or patients in future? How will this affect the way they use health services?
- How do services need to be organised in future to maximise the role of consumers in co-production of health care? What is needed to facilitate this change?

The fact that we use the term ‘patient’ to describe the recipients of health care is perhaps significant. It suggests someone who is ‘ill’ in some way and has connotations of passivity – a patient is someone who has something done to them rather than someone who is an active participant in the process. Obviously it also suggests patience – someone who is willing to put up with whatever they are given.

At the summit a strong case was made for moving towards seeing the users of health care services less as inert patients and more as active consumers. A consumer is generally defined as someone who makes use of goods and services and who will obtain information about these goods and services and exercise choice in their use. If this model is applied to health, there are implications for both the relationship between patients and professionals and for the economy. For example, when users of public services act as ‘consumers’ (that is, with the right to take their custom elsewhere or ‘exit’), this can change the attitude of providers and the quality of the services they provide (Le Grand 2006). As these informed consumers take on more responsibility for managing their own health and health care it is likely that many more will develop a degree of expertise about their own health and condition. This is already changing the relationship between professionals and their patients and for some professionals it can be challenging as they are expected to use their own expertise in a different way. But professional attitudes are changing and resistance by some to innovations that, for example, put information in the hands of patients is much weaker now than it was 10 or 15 years ago. Moreover, the threat is not to professional expertise, which will remain as vital as ever, but to a model of care which relies on that alone to determine the relationship. There will always be circumstances in which patients wish the professionals to make choices for them, but, particularly in areas such as the management of long-term conditions or considering elective procedures, we are moving rapidly towards a partnership model of decision-making, where both the professional and the patient bring something to the encounter.

As technology enables more patients with chronic illnesses, such as diabetes, to self-monitor and self-treat, they are increasingly likely to want someone to advise them of the options available, rather than being told what to do or have the professional do something to them. Professionals will be consulted for assurance or confirmation of diagnosis, to discuss treatment options and care packages, and to educate patients about self-management techniques and strategies. A lot more of this will take place virtually on

the web or by telephone or text, but personal interaction will remain important: no-one is suggesting that it is possible or desirable to replace personal care with technology.

There are situations in which patients act as straightforward consumers without the need for professional consultation – for example, with a minor ailment or a recurring self-treatable condition such as hay fever – where they buy an over-the-counter remedy. On the whole we do not consider ourselves to be patients in these situations and if it does not work we might try something else next time. However, when we are faced with the prospect of more serious illness and the consequences of error are more likely to affect our health we will continue to seek professional guidance and support. To that extent health care, like other professionally driven services, will always be more complex than a simple market exchange between consumer and supplier.

Personal responsibility

It is generally assumed that the ideal patient of the future will be willing and able to take on more responsibility for their own health and health care. Such patients would feel more confident to self-care and would be more likely to seek professional advice and help only when they need it. That view underpins many of the current moves to encourage self-care, the assumption being that as they care more for themselves they will make less use of health services and thereby save NHS resources. Yet the NHS and other public services clearly have a responsibility themselves to support people to stay as healthy as possible and that is likely to require a more proactive and potentially a more expensive approach. We must also recognise that if individuals take on more responsibility for their health this may actually increase contact with the health service, as they seek more preventive health services.

Nevertheless, there may be ways in which overreliance on professional support can be reduced. It has been estimated that a significant proportion of GP consultations are for minor ailments that could be treated safely without professional care. There have been a number of schemes to reduce the number of these consultations, for example, through the minor ailments pharmacy schemes, and doctors themselves have shown that it is possible to encourage self-care through so-called self-care consultations, in which the GP establishes whether the patient has tried self-care and for how long, and advises whether it is appropriate to seek professional care and if so from whom.

Above all perhaps there is a need to ensure that interactions between professional and patient end up by empowering the patient and increasing their self-confidence and belief in their own ability to contribute to their own health and well-being.

In general patients are more confident when they are making decisions for themselves or experience something they have encountered before. When they have to make decisions on behalf of others, such as their children or adults with impaired capacity, they can be less confident and need reassurance. Not surprisingly then, the use of out-of-hours services is more common by those who are experiencing things for the first time (such as students away from home) and by parents and carers.

Information and how it is used is going to be key. There will increasingly be an expectation that professionals share information of all kinds and that they work alongside the patient to consider the implications whether it be in terms of different treatment options, self-management regimes or the performance of the service to which a referral might be made.

There is a reciprocal obligation for patients to engage with and use the information, but that should be handled with care. There will be some circumstances where the patient does not wish or feel able to be in control or where they do not want to have certain

information – that too should remain their right. In future individual professionals and those designing services will need to explore different ways of engaging patients to reflect this changing set of relationships.

Health care is and will remain a highly personalised service. However, in a publicly funded system such as the NHS there will always need to be a balance between the rights of the individual to a personalised and responsive service and the responsibilities associated with benefiting from a publicly funded service.

In practice this means achieving a balance between consumer demand and the need to work within a cash-limited system where some form of rationing is inevitable.

The drive towards personal responsibility for health will be largely motivated by self-interest – a desire to stay as healthy as possible – but there may be some scope too for encouraging a greater sense of social responsibility in the use of NHS services without making people feel guilty for accessing care and support when they need it. People already understand that their consumption of health services has an impact on the availability of services for others and that there are finite resources available for the NHS. It would be desirable if a way could be found to tap into this sense of responsibility rather just penalising those who misuse the system.

Use of technology

- How is information and communications technology (ICT) being used at present? What potential does ICT have for transforming how patients stay healthy and use health services? What are the barriers to ICT supporting these changes? What needs to happen?
- Are there other technologies that people use in everyday life that could be harnessed for health improvement and for engaging patients? How might these be used in future? What are the barriers to take-up of these technologies by the public and patients? What needs to happen?
- Are there specific health technologies (for example, telecare, monitoring devices) that could change the way patients care for themselves? What are the barriers to wider adoption of these technologies? What needs to happen?

The main uses of technology at present are to provide information and help monitor patient health, aid access to services and help shape personal behaviour.

Each of these areas is significantly under-developed. The internet has revolutionised access to information, transformed consumer behaviour and is rapidly changing the nature of social relationships as well. Although there is anecdotal evidence that access to general health information via the internet has influenced interactions between patients and doctors and changed the balance of power, there is as yet limited use of the internet for other health and health care transactions.

For example, as well as objective information about risks and clinical effectiveness there is scope for more personalised information to help patients understand and make decisions about their own situation. The Foundation for Informed Decision Making (in the United States) and Dipex (in the United Kingdom) have already introduced decision support tools that include a range of personal experiences. There is considerable scope for health information sites such as NHS Direct Online and NHS Choices to capitalise on emerging web technology (Web 2.0) to allow individuals to create their own content. Under such arrangements it would be possible for personal experiences to be modified by subsequent readers and adapted to accommodate a more representative range of experiences.

Health care organisations need to move much more quickly to enable patients to use email to book appointments, receive test results, view their medical records and have online consultations. The argument that this disadvantages those who do not have access to the internet or the skills and confidence to use it cannot be used as an excuse for failing to act. In some cases this can be addressed by retaining paper content for those who need it, in others by providing navigators or mediators who are available to assist.

Technology can also play a much greater role in identifying patients who would benefit from health interventions. At present risk stratification is largely focused on identifying high-intensity users of the health service but it could be developed to identify individuals at risk who might benefit from preventive strategies. This would probably require linking personal and health information, and that would raise ethical issues about data access and confidentiality. Given the level of public and professional scepticism about data confidentiality this is an area where the health system will have to proceed cautiously but it ought to be possible to introduce new data-sharing approaches in ways that conform to data protection requirements.

It is important not to forget other existing technologies, such as digital TV, community radio, DVDs, the telephone and email, and harness these for health. Digital TV and radio, for example, have a high penetration rate and enable information to be communicated in multiple languages and to niche groups. The telephone can be used to deliver personalised, targeted messaging; the use of automated voice technologies can enable patients to report vital health information from self-monitoring (such as weight) or complete structured screening tests. Email could be used in a variety of ways, with some responses able to be automated, while other responses would need clinical input. Thus far there has been a relatively slow take-up of some remote monitoring technologies whereas others such as personal alarms have proved popular. It is important to understand the receptiveness of patients to new technologies.

In general, information technologies are seen as ‘overlays’ or add-ons to current structures. It is rare for the NHS to rethink how available information technologies can help fundamentally to alter the way of working and to contribute to service redesign. This may be due to a lack of incentives in the health system to make better use of technology. For example, there is no incentive to establish direct email access for patients because GPs are not paid for it. And while there are funds for introducing new *medical* technologies in hospitals, there is limited support for technologies that support access and communications.

Although practice-based commissioning has increased the incentives for GPs to control demand for acute care, there has been no support or professional guidance on how to encourage self-management and how to use technology to achieve this.

Healthy behaviours

- To what extent are people choosing health today? Are people in the future more or less likely to lead healthy lives? What are the barriers to people living longer and healthier lives? What needs to happen to overcome these?
- What needs to happen to create a shift in healthy behaviours so that tomorrow’s generation does not adopt the bad habits of today? What will make people more likely to change their behaviours and take greater care of their health in future?

Attempts to influence individual behaviour and counteract unhealthy lifestyles have traditionally relied on negative commands – for example, ‘don’t smoke’, ‘don’t drink’, and ‘don’t eat’ this or that food and so on. Yet if the health care system is to encourage healthier lifestyles it is important to acknowledge that people derive pleasure from

unhealthy habits and that a different approach is needed to ensure that healthier behaviours are seen as the norm in all groups and communities.

There is extensive evidence that information alone does not change behaviour. To achieve change a number of different interventions and approaches may be needed and they will vary depending on the nature of the behaviour being tackled. There is a growing realisation that the health care system needs to learn from other industries, employing techniques such as segmentation and targeting to identify subgroups and tailoring messages and support for them. The aim must be to make healthy behaviours appealing, realistic and actionable.

Clinicians clearly have a role in supporting behaviour change. Although patients may see health care professionals for only short periods of time, it is important that those interactions support individuals to make changes. There is an argument that incentives should be offered to encourage people to adopt healthier behaviours.

Promoting behaviour change also requires the active involvement of other players such as local authorities and employers. There is a need to build a strong evidence base of what works in this area.

Finally, the government could restructure the incentives for local authorities and primary care trusts, rewarding those who demonstrate health improvements.

What needs to change?

Under the fully engaged scenario it was expected that the health services would respond effectively to the different needs of an engaged public. What changes are needed to the health service in order to meet the changing demands of patients and what impact will this have on the role of the professional in future?

Changes in health services

If patients are to be put at the centre of the health system, it needs to become predictive, preventive, personal and participatory, as John Coulthard of Microsoft Health Solutions Group vividly described (*see pp 25–28*). He argued that there is a need for a shift to a consumer-centric system, which recognises that to maximise quality of life, more care will be delivered closer to home or at home. It will be a system that supports each of us wherever we are on the spectrum from health to death, constantly trying to maximise health and quality of life.

At present patients tend to have an episodic relationship with the health care system; for the most part they seek help when they have a problem. Otherwise, quite reasonably, they want to get on with their lives. In future, though, they are more likely to have an ongoing relationship with a health care system that is also there to support them to keep as healthy as possible. This transformation will be challenging to achieve.

As yet it is not clear whether the current programme of reform will deliver this transformation. Some levers, such as patient choice, commissioning, and Payment by Results are designed to deliver a service that is much more responsive but these are early days and commissioning remains under-developed and aspects of primary and community care unreformed. The latest Darzi review suggests another move in the right direction with more emphasis on information to drive quality, including measures of patient experience and patient-reported outcomes that will affect the funding health providers receive. Liz Kendall, a former adviser to the Secretary of State for Health, spoke about how the NHS can encourage patients to start to drive the system (*see pp 49–51*).

Appropriate use of health services

There is currently a bewildering range of ways to access NHS care. Anyone seeking help can call NHS Direct or dial 999; visit a pharmacy, GP surgery or walk-in centre; attend accident and emergency, a minor injuries unit or an out-of-hours service or they could be directly referred for cataract surgery by optometrists. If patients are unable to assess their own problem they cannot determine the level or urgency of help required and may therefore make 'inappropriate' use of certain services.

There are a number of ways in which patients might be encouraged to make more appropriate use of health care. The proposed NHS constitution sets out broad rights and responsibilities for patients using NHS services in England, but it has also been suggested that the respective roles of the practitioner and patient could be set out in the form of a 'contract'. A patient-level contract could be a way of securing mutual agreement and would provide a framework for agreeing under what circumstances and how the patient could access services. In the medium term these ambitions will be realised through the roll-out of individual care plans for all patients with chronic diseases (Department of Health 2006b). These allow patients to set objectives and be more involved in decisions about their care.

Others have suggested that patients need to be made more aware of the costs of care if they are to make more frugal use of health services and reduce health care expenditure. This has given rise to ideas such as fining patients for not attending appointments or giving patients 'bills' detailing the costs of care. However, such ideas are based on the assumption that significant numbers of patients abuse or overuse health services, seeking care from which they cannot benefit, and that they can be made to be price-sensitive in their demand for health services which are provided free.

Allowing patients to book an appointment at the time and place of their choice is also seen as a means of reducing waste. Anecdotally, when patients are offered a greater choice about where and when to have an appointment it results in reduced did-not-attend rates. There also need to be improvements in the accessibility of services. Where services are being reconfigured and located further afield, it is essential that public transport is available and there is an integrated transport system.

The government is also pursuing a policy of increased choice of provider. From April 2008 patients have been able to choose from any accredited provider in the country, and the proposed NHS constitution enshrines this right to choose and places it at the heart of NHS care. This makes it all the more important that patients have the skills, confidence and support to navigate the complexity of the health system effectively.

Recommendations from the summit

Using a Delphi exercise participants produced five key recommendations (*see* Appendix 1, p 48, for an explanation of how the Delphi process works):

- greater availability of higher quality information on health and health care
- greater focus on people/patients, their lives and their personal goals
- professionals' roles and their relationships with patients to change
- doctors to support people rather than 'prescribe'
- NHS to understand its 'customers'/consumers and respond differently, eg, using marketing approaches.

In Section 2 The King's Fund sets out the next steps that are needed to help deliver the fully engaged scenario in terms of patient and public engagement in health and health care.

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2 Next steps in patient and public engagement

Anna Dixon and Niall Dickson

It is possible to overstate how much the behaviour of patients will change over the next 20 years. The predominant users of the health care system are older people, and the individuals now in their 50s and 60s are unlikely to change their attitudes in a radical way. Most of the professionals who will provide the service in 2028 are already at work or in training. As one of the speakers at the summit pointed out, 'the future is already here'.

Nevertheless, a number of factors are already changing the way patients behave, and these are likely to become stronger over the next two decades. This will provide a considerable challenge to the existing health care system and the way it currently operates, but it should also be seen as an opportunity to create services that are more effective, more efficient and more responsive.

The current model of health care is largely reactive. It is based on the assumption that while they feel fine individuals will want to live their lives with minimal contact with health care services. Only when they become ill are they expected to seek help from an expert, who will tell them what is wrong and provide them with the treatment to put it right or alternatively refer them to someone who can.

That model will not disappear, but alongside it we can expect a new set of relationships and interactions, ranging from regular screening and ongoing support for those with long-term conditions to health checks of various kinds for those who are asymptomatic.

Rising public expectations are often cited as one of the driving forces that will render the NHS unsustainable, along with an ageing population and new technologies. Ironically it may be the public's aspirations to live longer and in better health that enables the NHS to survive another 60 years – if individuals become more engaged in their own health and health care they will make fewer demands on the NHS (Wanless 2002) than would otherwise be the case.

However, to deliver such benefits the NHS and the professionals working in it will need to operate very differently, enabling patients to interact with the service in new and different ways. At the same time the health system will have to harness technology – especially information technology – and adapt its practices more than it appeared to do in the last 20 years of the 20th century.

The NHS must move from being a reactive service to one that is better placed to provide ongoing support, to predict the care that is needed and to help prevent ill health among those who are well and deterioration in those with a diagnosed condition.

The rising prevalence of chronic disease and in particular of dementia among older people is already challenging the existing model of health care – diagnose, treat, rehabilitate. Increasingly individuals are living with conditions that need active management over many years in order to maintain a reasonable quality of life and to prevent increased disability and dependence. It is not viable for that management to be undertaken solely by health care professionals, and those with long-term conditions

have to be supported to self-care. In many parts of the health system there are efforts to provide this greater level of support but a great deal more has to be done. That means encouraging self-management, building confidence and helping patients to understand when they can cope on their own and when they need help. The professional of the future will recognise that in many ways it is the patient who has the greatest expertise about him or herself.

The NHS needs to build and harness the patient's expertise so that the expensive and scarce resource of professional expertise can be deployed more effectively.

The concept of the expert patient is widely referred to but it is not clear all professionals accept this idea.

Health professionals' training should include discussion about the changing roles of patient and professional and should ensure they have the skills to support patients to keep as healthy as possible, which will include helping them to self-care and self-manage.

This more engaged patient is likely to want to be more involved in making decisions about their own care even when they need only a short episode of treatment. Technology has provided widespread access to information that was once confined to professionals and this means that patients are more likely to seek out details about symptoms, diagnosis, and possible treatments and that in turn makes it more likely that they will form their own opinions.

Given the uncertainty of medicine and the primacy of the patient's wishes (under informed consent rules), whether a course of action is followed will depend on the individual's understanding of the balance of risks and benefits. The traditional way of dealing with informed consent involves checking just before a procedure is carried out that the patient understands what is about to be done and the risks involved. In future such a presumptive and incidental approach will be regarded as too little too late.

The health system should be designed to give each patient as much decision-making responsibility as they want.

Information is likely to revolutionise the way patients interact with the system in other ways. The idea that hospitals should produce mortality rates would have been unthinkable a generation ago, now there is already comparative data available in a number of areas. This will grow significantly over the next few years incorporating performance on patient experience, clinical outcomes and patient-reported outcomes. Just as consumers routinely compare information and feedback on a whole variety of products and services, so patients will increasingly have access to validated information about the organisations and individuals who provide them with care. The Darzi review (Department of Health 2008b), which points the way forward for the next 10 years of health care in England, makes it clear that developing this information will be a key priority both to enable patients to choose and to encourage care providers to drive up the quality of what they do.

How far or how fast this will affect patients' behaviour is not entirely clear but even the introduction of performance and quality data to allow comparisons with other services represents a significant change.

The term health care consumer is sometimes rejected because it suggests that health is a commodity and because of its connotations of markets and over-consumption. Yet there are aspects of consumerism that should be encouraged in health care – to take control, to make informed choices, to expect high standards, to understand the impact of your consumption on others (as would an ethical or green consumer). Of course,

individualised consumption of health care may sometimes be at odds with a population perspective. Inevitably in a publicly funded system, there will have to be limits placed on the amount of resources spent on health care and some will not receive the care they believe they deserve. This is referred to in the draft constitution (Department of Health 2008c) on which the Department of Health is currently consulting and it should stimulate greater awareness of these issues.

The NHS will have to become more honest about the limits of care and encourage a wider debate about the limitations of the service and about the obligation on every citizen to use the resources of the publicly funded health service responsibly.

Advances in medical technology have been responsible for a significant part of the growth in health care expenditure world wide. This is partly because new technologies have often enabled previously untreatable diseases to be treated, or have improved techniques and results but at higher cost. There are, of course, plenty of examples of cost-reducing technologies – for example, the medical treatment of stomach ulcers replacing (ineffective) gastric surgery, keyhole surgery and improved anaesthesia. Nevertheless, the cumulative effect of technology has been to increase costs as well as effectiveness. As we move forward, a different approach might be needed to technology, not least by stopping the use of obsolescent technologies and giving greater priority to technologies that will improve health and reduce cost.

Until now interest has tended to focus on medical technologies – that is, developments that directly impact on clinical practice. However, information technologies that we use in everyday life could transform health care and the way it is delivered. We use technology to text our friends, to locate the nearest pub or restaurant, to book a train or flight, or to check our bank balance; we could use this technology to text or email a repeat prescription to the pharmacy, to book a GP or hospital appointment, or to check the results of a test. This would not require new technology, just changes in attitude and a transformation of care processes, so that services are designed around the needs of patients. As well as challenging current practice they have the potential to be cost saving and improve efficiency.

The NHS needs to focus as much on the development and adoption of information technologies as it does on the development and adoption of clinical technologies.

The King's Fund has commissioned a report to identify the barriers within the NHS to the adoption of technologies that have the potential to transform the consumer experience of health care (Liddell *et al* 2008).

Advances in medical technology will allow us to predict aspects of our future (ill) health; for example, genetic screening tests will map out our vulnerabilities and susceptibilities to disease. We will have choices, to heed the warnings that are hard-wired into our bodies and to modify other factors contributing to disease including lifestyle behaviours. By tracking our vital signs and monitoring our use of services, information systems will be able to predict a deterioration in our condition allowing early intervention to prevent the need for more intensive medical care. Such advances in medical technology will open up new possibilities, to enable the health system to become more proactive and put more energy into prevention.

It should be the ambition of government and all those within the NHS to create a health system that is proactive, accessible, and sensitive to the individual.

It is by no means certain that individuals will choose to take greater care of their health than in the past – in part that will depend on social attitudes, which both government and the health service can influence, in part on external factors and our ability to counteract trends such as more sedentary lifestyles. If individuals are not motivated to change or do

not have the skills and confidence to do so they will need support in order to build up the self-confidence to take a particular action or undertake a specific behaviour.

The NHS needs to implement evidence-based interventions that will help individuals change behaviour.

The King's Fund has produced a series of working papers on behaviour change as part of our programme of work on *Kicking Bad Habits* (www.kingsfund.org.uk/current_projects/kicking_bad_habits/index.html) and will be publishing a final report, which will set out what the NHS needs to do to support individuals to change their lifestyle behaviours.

To achieve a step change in people's health will also require strategies that reach beyond the health care system. Human behaviour is influenced by a complex array of factors, both internal and external. There is a comprehensive and multi-faceted approach to smoking, including the ban on smoking in public places and on advertising of tobacco products, labelling, taxes, advertising campaigns, telephone helpline, pharmacotherapy, and smoking cessation counselling. An equivalent comprehensive approach to obesity is not yet in place, though the government has begun to map out its strategy to prevent obesity in children (Department of Health 2008a) and has recently announced the setting up of a coalition of government, public and private organisations to begin to tackle it (Department of Health 2008b).

The NHS needs to work with other partners to create environments in which living healthily is fun, easy and realistic.

The future patient will be less patient, more expert and, probably, more engaged in their health care and in their health. The NHS and every professional within it will have to respond to this challenge and find ways to harness this if it is to adapt and survive to meet the needs of people in 2028.

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PART 2: PRESENTATIONS

3 The patient of the future

John Coulthard, Director, Microsoft UK Healthcare, Microsoft Limited

Often when people think of Microsoft they seem to associate it with the future. There's a joke in Microsoft that 'If we don't like the future we just go about changing it'. My first contact with the future started in 1982 when I was in the British Army and someone said 'John, you're just the chap for military intelligence'. I quickly realised that the future wasn't something that was in the future, it was in fact already here. William Gibson, in his book *Neuromancer*, said, 'The future already exists it is just badly distributed.' Another book written 15 years ago underlines the point. It highlights 15 or so trends and unsurprisingly many of things we see today: eco-warriors, the wellness agenda are all there. We all should have known about these things 15 years ago so none of it would have been a surprise (Popcorn and Marigold 1996).

There is a Copernican shift going on. We are moving from a system where institutions are at the core of the health care environment to one in which consumers are at the centre. By consumer I mean a patient that isn't ill. We must take the hospital out of the centre and put the consumer at the heart of things.

This means embracing things like marketing. I make no apologies for using this term but this can cause a reaction. At a recent presentation I said that I felt consumers/patients needed to be communicated to more effectively by the local health care providers. A person stood up quite angrily and said, 'I do not want my local health care organisation to communicate with me, how dare you.' At the same time another woman stood up and said her hospital had closed down and she knew nothing of it and she was furious. So I suggested they ought to discuss amongst themselves whether they felt it was a good idea or a bad idea for health care providers to communicate with people.

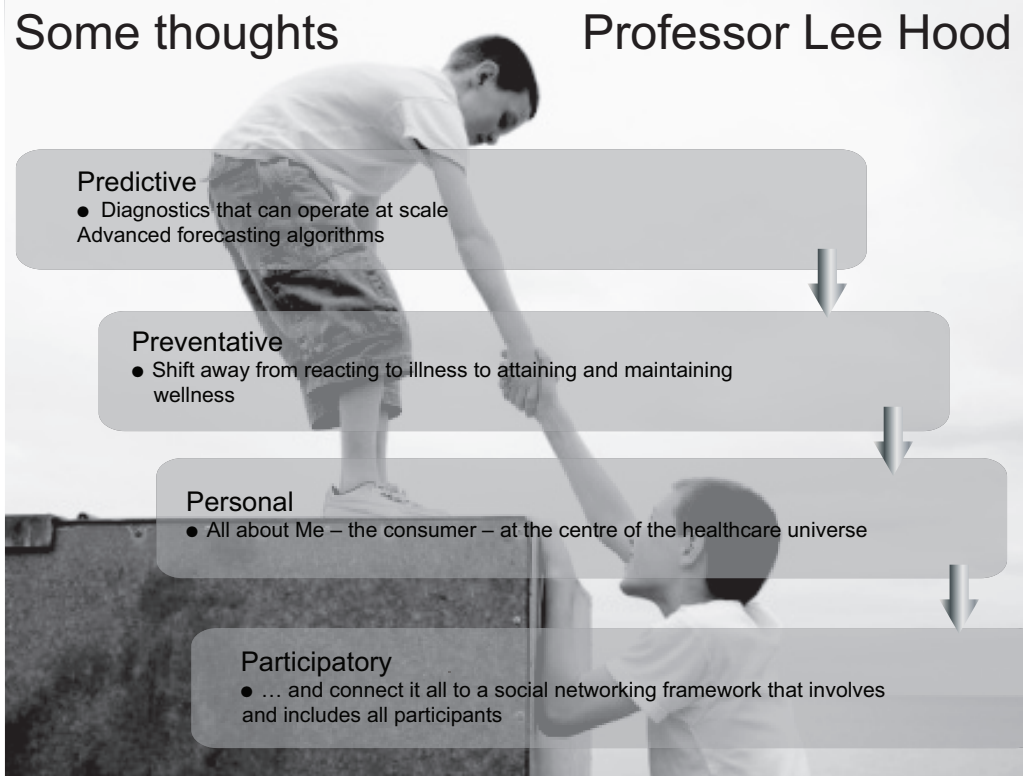
Now, the idea of making some product or services desirable is an interesting one. I suggest it would be inappropriate to make acute trauma emergency care a desirable place for anyone to spend time in. But I think it is a good idea in preventive or personalised or participative areas to make people more aware of what services are available.

The other thing that is needed is communication that is an exchange of information. Organisations that exchange information really well learn from this, poor ones just transmit information. So my thesis about the patient of the future is that they will be customers or consumers. The health system must therefore become much more consumer-centric and that, in my view, will bring considerable benefits.

Lee Hood talks about health care needing to be predictive, preventative, personal and participative. His is not a mantra that says it's all going to be preventative; of course it's going to be a mix. By personal he means the consumer at the centre of the health care universe. By participative he means what connects me with social networks. See Figure 1 overleaf.

What's causing this consumer-centric shift? Why are people feeling this way? People are beginning to realise that if they spend more time in good health with a better quality of life and less time in contact with the acute part of the health care system, their taxes will

Figure1 Health care needs



be lower as a result. As a result of the awareness of hospital-acquired infections people also realise they might be better off not going to hospital.

This brings benefits to government, to commissioners, to insurance companies and to employers as well as to the individual.

So who's going to lead the change? People themselves will lead the change. In many families change will be led by a 'family health care manager' that is typically a woman 25–55, with at least one child under the age of 18. Seventy per cent of users of a US health website – Medalink – fitted these criteria. The interesting thing is they're searching for symptoms, diagnoses, resolutions, they're looking for doctors, they're looking for local services. Interestingly they also want to store information, they want to keep their knowledge, they want to create a bank of knowledge about health care and they also want to connect to other doctors, and to other people. *See box opposite.*

The challenge for the patient of the future is the web. Searching is not the answer. If you search for something like diabetes on the web you will typically get about 14 million hits, and probably have no idea what most of it means. What you actually want is to discover something, you want to read about it, you want to learn about it and you want to act upon it.

The other dimension of web information is consumer-created health care content. Four out of five people who looked at consumer-created content changed their behaviours, which is extraordinarily powerful (*see Figure 2 opposite*).

The challenge is that access will not be equal. Because the government didn't make it a utility it's actually very difficult to get access. It also varies by age. If you're under 30 years of age you are classed as a digital native. If you're over 30 and you don't fear technology

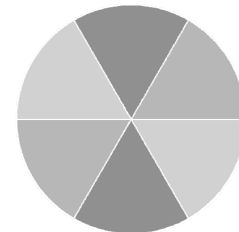
Functional needs

Family Healthcare Manager



Women 25 to 55, with at least one child <18

"Seventy percent of our users are women storing information about kids, spouses, aging parents and themselves," says Fotsch, who runs Medem Inc., an online business that links the needs of patients and doctors through the Web at iHealthRecord.com. (Source: USA Today – Saturday, January 6, 2006)



FUNCTIONAL NEEDS

DISCOVERY	STORAGE	CONNECTING
Information on:	Confidential	Doctors
• a symptom	Secure	Devices
• a diagnosis	Controlled	Plans
• a resolution	Share	Employers
Hospitals		Applications
Doctors		Facilities
Local Services		

EMOTIONAL PAIR STATES

Ignorance	Awareness
Confused	Knowledgeable
Avoidance	Prevention
Denial	Action
Despair	Hope
Helpless	Control
Fear	Security
Uncertainty	Knowledge
Anger	Acceptance
Suffering	Relief

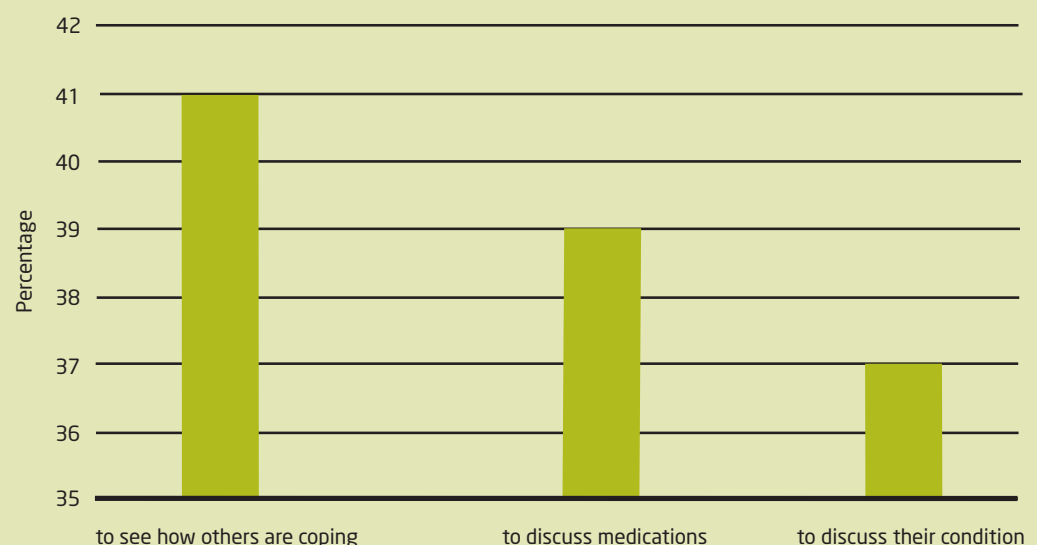
Microsoft | Health Solutions Group

Microsoft Corporation
Confidential and Privileged

you're a digital immigrant and if you're over 30 and you fear technology you're an analogist.

I'm not sure that at the moment the patient of the future, the consumer, is actually well served by the health service. My thesis would be that actually they're going everywhere else other than the NHS, and the NHS has got to put itself between them and all of the

Figure 2 Reasons people look at consumer-created health care content



other organisations that are out there without fear that they're going to drive a lot of additional business into the direction of local health care services. Because if we don't do this we never get into the preventative element of this; the risk is if we're not saying 'learn this – act in this way' somebody else is and we will lose control of them.

The future patient is our patient. The NHS needs to get into a position where it can provide people with relevant information and interact with them in a way that means the patient/consumer of the future is our patient and not somebody else's more commercial patient.

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4 Supporting patients to self-care

Gopa Mitra, MBE, Director of Health Policy and Public Affairs, PAGB (The Proprietary Association of Great Britain)

Whilst people's innate desire to self-care has been present for centuries, their ability and confidence in doing so has slowly been lost during the relatively short years of the NHS. During this period the UK population has moved towards reliance on others, in particular doctors, to 'cure' their problems. Consequently, self-care was introduced as an integral level of care in the NHS Plan in 2000. A strategic 10-year blueprint for the NHS, it formalised the role of people to look after their own and their families' health as well as the importance of ensuring that health professionals are trained with much more of an emphasis on self-care. In the Wanless Treasury review of the future of the NHS in 2002 (Wanless 2002) it was stated that 'self care is one of the best examples of how partnership between the public and the health service can work'. The impact of this was noted: 'Increased self care, and the more aware and engaged public associated with it, could result in useful cost benefits for the health service both in terms of levels and effectiveness of resources, arising from more appropriate use of health social care services'.

Translating the policy into reality has proved a challenge and it was not until 2006 that the 'blueprint' for delivery appeared in the White Paper *Our Health, Our Care, Our Say* (Department of Health 2006), which included the following aims for self-care:

- maintenance of good health and lifestyle, and prevention of ill health
- minor ailments
- acute illness
- long-term conditions
- support including patient education and information, self-care skills training, peer support networks, and a care plan approach
- engagement and training of professionals to support self-care.

It can be argued that people are already involved in self-care to the extent that these aims should be easy to deliver. Research shows that:

- more than three-quarters of people (77 per cent) say they often lead a healthy lifestyle
- nearly 9 out of 10 people often treat minor ailments themselves – 42 per cent do it all the time
- of people with a long-term illness 82 per cent actively take a role in caring for it
- of those who have been to hospital 64 per cent take an active role in monitoring the illness they went to hospital for.

(Department of Health 2005a)

The same research confirms people are confident about leading a healthy lifestyle and not seeing their GP for a minor ailment and yet:

- for minor ailments there are 300,000 GP consultations a day (Whittington *et al* 2001)
- forty per cent of GP time is spent dealing with minor ailments (Department of Health 2005b)
- around 80 per cent of GP consultations relate to long-term conditions (Department of Health 2005b)
- around 75 per cent of accident and emergency attendances are for minor illness and injury (Department of Health 2005b)
- only 50 per cent of prescribed medicines are used after collection (Department of Health 2005b)
- people with diabetes spend three hours a year interacting with a health professional; the remaining time they are making their own decisions (Pringle 2006).

These various data underline the fact that when asked about the source of their information about health, 85 per cent cited the doctor as the main source (Everyday Healthcare 2005). Interestingly, however, it must be noted that while 69 per cent of respondents have visited the doctor to discuss general health (Everyday Healthcare 2005), on average this is about twice a year, which means that the interaction is likely to be just 20 minutes a year. Further, when people saw their GP, 44 per cent felt their doctor did not encourage them to play a more active role themselves in staying healthy or in long-term health conditions (Department of Health 2005a). It is clear that the NHS response must be to support patients to self-care, but the greater challenge will be to change people's overall behaviour towards increased independent action from dependency on the NHS, and this cannot be done only at the time that people interact with the service and their health care professionals.

Habits are formed long before the NHS comes into people's lives and so these influences need to be considered for behavioural change. As part of the study *Self Care Aware: Joining Up Self Care in the NHS: The outcome of an action research project in Erewash PCT* completed in October 2006 (PAGB *et al* 2006), respondents were asked about their heart health information. If breakfast cereals are included then 56 per cent of awareness for health promotion was concerned with diet; however, wheat at 20 per cent accounted for the main diet association with heart health. A number of branded products were mentioned including, among others, Actimel, Cheerios, Shredded Wheat, Special K, Flora and Benecol. Typical information gleaned from the advertising of these products and television programmes included 'Foods that cause arteries to clog up with fatty foods, stop eating beef burgers, stop eating fast foods'; 'Less fat going into foods, better for heart'; 'Eat vegetables'; 'Junk foods store up fatty tissue, blocks your arteries'.

For the NHS to be considered as a place for health information it must compete at this level and be 'on air' almost all day and every day. One example of the NHS tackling such an approach is the anti-smoking campaign, which has been running for some seven years. It has taken the shape of national advertising in paper and broadcast media, new technology, face-to-face in clinics with GPs, nurses and pharmacists, with a 'new news' element so that the messages don't become over-familiar and discarded. At the peak of the campaign in 2003–4, it was on air 11 out of 12 months and the messages were presented in advertisements with another voice, heart charities, for added effect. In addition, tobacco regulation was introduced. The campaign was supported by manufacturers of nicotine replacement therapies and their brand advertising so that the national campaigns

presented why smoking is bad, the face-to-face interactions presented what to do and the brands provided how to quit smoking. This multi-layered and multi-faceted approach showed that advertising has increased the number of prompts to quit smoking to 32 per cent from 21 per cent for prompts from the GP (BMRB Tobacco Education Campaign Tracking Study, commissioned by Department of Health 2004).

If the Wanless 'fully engaged' scenario and the White Paper aims are to be achieved there needs to be a recognition that the NHS alone cannot deliver these but that people need to be engaged as they go about their everyday lives. Perhaps we need a 'self-care movement' that allows all parties, individuals, private, public and voluntary sectors as well as civil society to come together at multi-layered, multi-faceted levels to shape the 'fully engaged consumer' who:

- is confident looking after their own and their family's health and illness
- knows when to use GPs and other health professionals effectively
- prevents illness as well as self-treats minor ailments and self-manages recurrent and long-term conditions
- acts on messages about self-care and self-medication
- uses information and technology resources
- challenges health care professionals on what they want for support
- is educated from school age about self-care and effective use of the NHS and health care professionals.

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5 Making 'lifestyle' changes: changing behaviour to improve health

Susan Michie, Professor of Health Psychology, University College London

'Lifestyle' behaviours are a major cause of illness and premature death. For example, a recent US study found that 48 per cent of deaths were due to the behaviours of smoking, alcohol use, poor diet, low physical activity, unsafe sex, driving habits and violence (Mokdad *et al* 2004). Improving health depends on behaviour change – amongst the general population, patients and those providing health care services. In his 2004 report, Wanless outlined the ways in which realising the 'fully engaged scenario' depends on greater public engagement, both to manage their own behaviours in relation to health and to develop the health care system to support the self-management approach. Health professional behaviour impacts on patients' health in several ways, for example, in the extent to which they implement evidence-based practice. Research shows that implementation is often poor (Haines and Donald 1998), with potentially adverse consequences (Grol 2001). Interventions to change health professional behaviour have had only modest results (Grimshaw *et al* 2004). Effective interventions to improve both public and professional behaviour change will depend on understanding principles of behaviour change, including the self-management of behaviour. Interventions should draw on the evidence and theories of behavioural science, rather than be guided by 'common sense' (Michie and Abraham 2004). In the wake of the increasing problem of HIV, a group of leading behavioural science theoreticians met in the 1990s to try to identify the key constructs associated with behaviour change (Fishbein *et al* 2001). There were encouraging similarities with a more recent consensus project conducted in the United Kingdom, involving health psychologists and implementation scientists (Michie *et al* 2005). This provided an interview tool for understanding problems of behaviour, with a view to developing theory-based behaviour change interventions.

'Self-management... is good medicine. Indeed, if the huge benefits of a few key lifestyle habits were put into a pill, it would be declared a spectacular breakthrough in the field of medicine' (Bandura 2000). Self-management requires interventions at several levels, for example, learning individual techniques of behaviour change, changing the social and material environment to support the desired changes, and working at a societal level, for example, teaching self-management in schools, workplaces, neighbourhoods (Stokols *et al* 1996).

We know that providing information about people's risks and what they should do to reduce them is rarely, on their own, effective in changing behaviour. Five meta-analyses have found that interventions that increase people's perceptions that their health is at risk have only small effects (Brewer *et al* 2007). A recent meta-analysis of interventions aimed at increasing condom use found that information influenced behaviour *only* when accompanied by active, behavioural strategies (Albarracin *et al* 2005). We also know that trying to get people to change their behaviour by frightening them ('fear appeals') is only slightly effective. In a meta-analysis, Witte and Allen (2000) found a small effect of fear

appeals, particularly if combined with efficacy messages; Albarracin *et al*, however, found no effect and, in some instances, a harmful effect.

To successfully manage behaviour, people need to:

- interpret risk in a way that leads them to perceive a problem they want to address
- find a way of translating their intention to change into action
- maintain the changes they bring about over time.

Although the 'stages of change' theory has not received empirical support (eg, Littell and Girvin 2002; West 2006), influences on behaviour change vary over the behaviour change process (Rothman 2000; Rothman *et al* 2004). Initiating behaviour change depends on expecting favourable outcomes of changing and feeling confident about performing the new behaviour. Whether behaviour is maintained over time depends less on these thoughts about the future, and more about what has happened since they changed their behaviour. Those who feel satisfied with the changes and can maintain their positive expectations in the face of their experience will be more likely to continue the new behaviours. Long-term maintenance depends on managing lapses so that they don't become relapses (Marlatt and George 1998), and in building the new behaviours into habits. Behaviours become habits when they are maintained by context rather than by self-regulatory effort. Each of the influences on behaviour is associated with techniques to change behaviour. For example, building confidence to change ('self-efficacy') can be achieved by breaking down change into small, achievable steps and building on success; relapses can be prevented by helping people anticipate the situations in which they may lapse and developing coping strategies to avoid or change these situations and recover from any lapses that may occur. A comprehensive list of techniques to change physical activity and healthy eating has been produced which can be used in designing interventions and in reliably reporting interventions to facilitate their replication (Abraham and Michie, 2008).

Two theories of behaviour change that can be drawn on in developing interventions to change behaviour are self-regulation theory (Carver and Scheier 1999) and operant learning theory (Skinner 1953). Self-regulation theory describes how people set goals for themselves, monitor their behaviour, assess the extent to which they are achieving their goals, and implement strategies to reduce any discrepancies between their goals and current behaviour. Operant learning theory describes how the likelihood of behaviour is influenced by contingent reinforcers and environmental cues that signal the likely future occurrence of such reinforcement. These principles can be used by people to manage their own behaviour (Michie *et al* in preparation).

The evidence-based principles described above underpin the NHS Health Trainer service, and the new NHS LifeCheck programme. Both aim to provide people with an understanding of behaviour change principles, techniques to initiate and maintain change, and the support to do it for themselves. Some of these techniques are summarised in the *NHS Health Trainer Handbook* (Michie *et al* 2006). For any of these techniques to be effective, they need to be tailored to people's own concerns and their personal characteristics and circumstances (Skinner *et al* 1999). This is especially important for interventions such as Health Trainers and LifeCheck that aim to engage those traditionally 'hard to reach', with the goal of reducing health inequalities.

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6 Patients as decision-makers

Angela Coulter, Chief Executive, Picker Institute

Co-producers of health

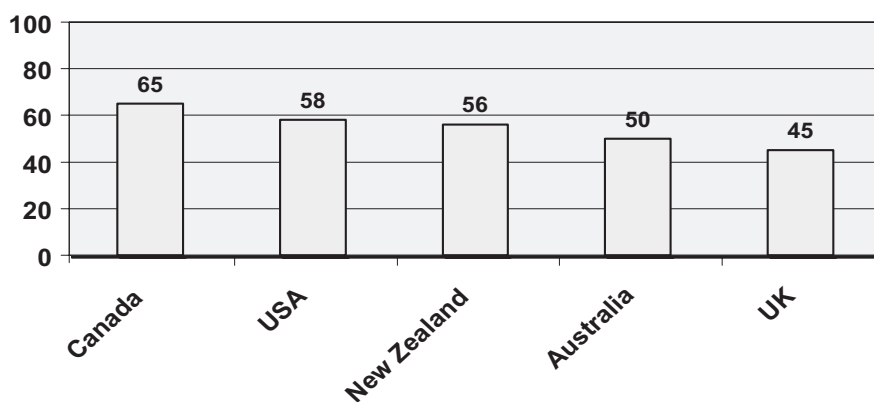
Patients nowadays have to make many decisions. First, they must interpret their symptoms and decide whether or not to seek professional help. If they decide they need to seek professional advice they must then decide who to consult and when. They must listen to any advice they receive and decide whether or not to follow it, and, if a treatment is recommended, they should consider the alternatives and choose which is the most appropriate for them. If they have a chronic condition they must decide how to cope with it, how to monitor their condition and what they can do to ameliorate the effects of any symptoms or disabilities. And if they wish to avoid future ill health or exacerbation of existing conditions they need to think about screening, health checks and lifestyle changes.

The patient's role as a key player in producing health, coping with acute episodes of ill health and managing chronic disease, tends to be ignored in discussions about health policy. Policy debate often proceeds on the assumption that the actions of health professionals are the sole determinants of health outcomes. Yet direct contact with health professionals constitutes only a small part of any disease episode. The fact is that patients themselves and their carers provide the majority of health care. In this role they require education and decision support just like other members of the health care workforce. Yet such support is often not forthcoming.

Support for patient engagement

The Picker Institute analysed data from two population surveys carried out in 2004 and 2005 in five countries – Australia, Canada, New Zealand, the United States and the United Kingdom. Our analysis focused on six indicators of the extent to which patients are engaged in their own care (Coulter 2006a). The United Kingdom performed worse than the other countries on almost all the indicators. Fewer patients in the United Kingdom were involved in treatment decisions and they were less likely to have been invited to take part in a review of their medicines or to have been given information about medicine side-effects than patients in other countries. British patients were given less help to cope with recovery and rehabilitation and fewer than one in five patients with chronic conditions had been given a self-management plan (*see* Figure 1 opposite). Even more alarmingly, the United Kingdom had the highest smoking rates of the five countries, the heaviest alcohol consumption, and the second worst record on obesity (after the United States). Yet British patients were the least likely to report that their doctor had given them advice on preventing ill health (*see* Figure 2 opposite).

None of the countries in the study, which involved telephone interviews with more than 15,000 people, excels in promoting patient-centred care, but it appears that British patients receive even less support for engagement in their health care than those elsewhere. Findings from the national patient surveys confirm that while there

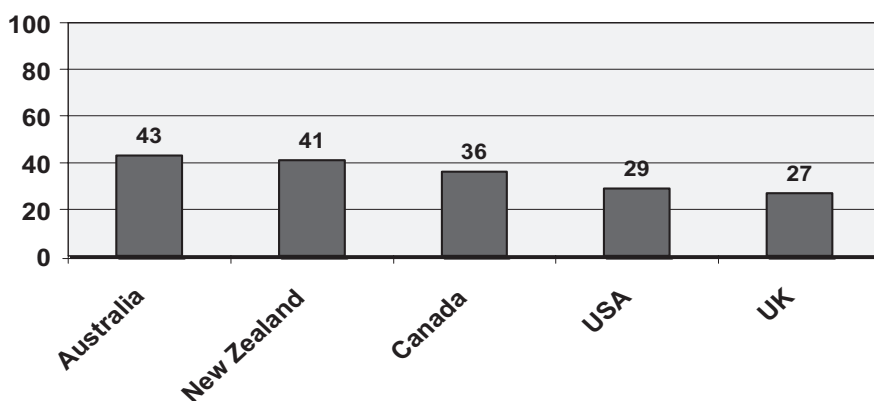
Figure 1 Percentage of patients with chronic conditions given self-management plans

Source: Commonwealth Fund survey 2005

have been improvements in waiting times and in the quality of care provided to patients with priority conditions such as cancer and heart disease, there has been little or no improvement in the everyday interactions that most patients have with health professionals (Coulter 2006b). Information provision, involvement in decisions and support for self-care are still at a low level for many patients.

What do patients want?

How do we know that patients want to play a more active role? There is plenty of evidence that most patients want more information than they are currently given and that many want to participate in decision-making (Coulter and Magee 2003). A survey carried out in England in 2005 of patients with long-term conditions found that 90 per cent of respondents were keen to play a greater role in treating minor ailments and 87

Figure 2 Percentage of patients given information about treatment choices and asked for their preferences

Source: Commonwealth Fund survey 2005

per cent were interested in more actively managing their chronic condition (Department of Health 2005). However, there is considerable variation between subgroups in terms of knowledge, confidence and skills for self-management (Ellins and Coulter 2005).

Some have argued that the desire for greater involvement is restricted to a minority group of young, white, middle-class patients, but the evidence does not support this. The desire for participation has been found to vary according to age, educational status and disease severity, but these factors explain only part of the variance (Coulter and Ellins 2006). For example, despite the association between age and decision-making preferences, age on its own is not a reliable predictor of a patient's preferred role. People's preferences may vary according to the stage in the course of a disease episode and the severity of their condition and there may also be important cultural differences, but the only way to find out patients' preferred role is to ask them. Clinicians' assumptions about what their patients want have often turned out to be wrong.

What works?

There is a substantial evidence base on the effects of interventions designed to engage patients more actively in their care (Coulter and Ellins 2006, 2007). Interventions to involve patients as active decision-makers include:

- strategies for informing and educating patients to build health literacy, such as patient leaflets, web-based and interactive computer packages
- targeted mass media campaigns
- decision aids to help patients facing significant treatment choices, coupled with coaching and question prompts for patients
- strategies for improving self-care, including educational programmes, patient-held records, and telecare
- communication skills training for professionals.

There are, of course, many gaps in the evidence and many questions that remain unanswered, but the foundation for moving forward in this area is much firmer than is often assumed. Yet despite the insights provided by the Wanless report (2002), which called for a new focus on moderating demand by promoting patient engagement, investing in health promotion and supporting self-care, progress has been very slow. Factors that may be important in explaining the disappointing UK performance include shortcomings in professional education, a low level of expectation from the regulatory bodies, and a failure on the part of government to offer incentives to clinicians to engage their patients.

Moving forward

Moving forward must involve engaging clinicians as well as patients, encouraging them to see patients as their partners in the process of treatment and care, and recognising and supporting their role as decision-makers. Outdated professional attitudes are currently preventing patients from playing the active role that most want. Overcoming this barrier must become a much higher priority if we are serious about increasing the efficiency and effectiveness of health care.

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7 Patients as entrepreneurs

Harry Cayton, Chief Executive, Council for Healthcare Regulatory Excellence

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Introduction: 'The equity of the mediocre'

The organisation of health services is predicated on the passivity of patients.

This is particularly so in the United Kingdom. Until the publication of *The NHS Plan* (Department of Health 2000), our publicly funded and provider-managed system had concentrated on command and control, on demand management, on the restriction of choice and the restraint of supply.

To a great extent this was possible because patients and the public have long accepted their role as grateful beneficiaries of a paternalistic National Health Service. Within recent memory the British Medical Association was able without irony to run an advertising campaign asking patients to 'Be patient'. Doctors were busy doing their best, we were told, and waiting was inevitable. And we believed it. We tolerated lost notes and long delays and waiting lists of a year or more because we accepted that if we had to wait it was because the NHS was busy looking after someone else. The Health Service justified this to us on the grounds that it was fair. I have called this the 'equity of the mediocre' and it remains a strong element in the arguments of those who resist the opening up of choice in the NHS because they fear that choice and equity are incompatible (Cayton 2006).

The argument seems to be that the NHS is good enough and that at least we have an equitable share in its inadequacies. This counsel of inertia ignores the fact that health inequalities continue to grow and that the rich and the well-connected have always been able to jump the queue.

A comparative study by the Picker Institute (Coulter 2006), covered in more detail in Angela Coulter's chapter (pp 32–35), highlights how ingrained this culture of passivity and paternalism is in the NHS. Despite higher levels of expenditure per head on health in Northern Ireland, Scotland and Wales, and an explicit policy commitment to patient and user involvement in England, the Picker study found no significant difference between the four home countries. This underlines how strong the prevailing attitude is and how difficult it is to shift.

The NHS Plan and the subsequent Wanless reports envisaged a patient-centred NHS in which people both as patients and as citizens were actively engaged in their own health and well-being and in helping to shape the quality and structure of health services through public participation and some limited forms of consumer choice (Wanless 2002). A series of policy papers, *Building on the Best* (Department of Health 2003), *Choosing Health* (Department of Health 2004), and *Our Health, Our Care, Our Say* (Department of Health 2006b) have aimed to put these ideas into practice. Alongside policy there has

been great effort put in locally in the NHS to service redesign, improved information for patients, better patient experience, choice of provider, support for self-management and for people with long-term conditions. And yet little has really changed.

Sir Derek Wanless himself has warned that movement towards the ‘fully engaged’ public he described in his 2002 report as essential for the future of health and the health service has been slow. He highlighted obesity in particular as getting worse rather than better (Wanless 2006).

A new role for patients

This is disappointing for those of us who seek an NHS which works more effectively for the people who pay for it and use it. However, many of the mechanisms we need to bring about change are in place. What we need now is to recognise that for the first time patients really can be active partners in the system and to allow them to be so. We need to have the courage of our convictions and turn a ‘patient-led’ NHS from idea to action.

‘Social entrepreneurs’ are people who bring about change and innovation not to make money but to improve society. Entrepreneurs are active, decision-making, and self-motivated. These are the very qualities that as citizens we need to apply to our health care. Patients must become the entrepreneurial force for change using the opportunities available to them and creating the social energy for more. Having put the mechanisms in place in the NHS, we need to start believing in patients as agents of change.

If you travel from Whitehall to Newham in east London, you lose a year of life expectancy for every Underground station you pass. Newham is the most diverse borough in Britain but that very diversity is being turned into a strength by a remarkable programme called ‘Communities of Health’ which starts with the reality of local communities and supports and encourages them to create their own health and well-being (personal communication, Ian Mcdowell, Newham PCT 2006). Concerned about diabetes in the south Asian population, Newham’s NHS trusts launched a programme offering tests in public places such as markets and shopping centres. High levels of diabetes were found and the people tested were advised to see their GP as a matter of urgency. There was no real increase in people seeking help. It seemed that people were powerless to act on the information they were given. Medically defined, professionally delivered public health information was not meaningful to them, so they could not use the knowledge to change their behaviour. The Newham Trusts adopted a different approach. They went to talk to the communities, to faith groups, housing associations, day centres, schools and workplaces. They went where people were and found in those settings the motivation to improve health and the community leaders who could do it.

Communities of Health is the opposite of the usual approach: traditional public health interventions are professionally provided, knowledge-based and structured. Communities of Health promotes variety, culturally specific and citizen-led action. It has clinical involvement but it is not clinically led, its strength and direction comes from the leaders of community groups and activities.

The Expert Patients Programme is another model of patient-led change created in this case by people with long-term conditions for people with long-term conditions. Supported self-management programmes, such as the Expert Patients Programme, focus on personal motivation, decision-making, goal setting, dealing with pain and fatigue and getting the best out of health professionals. They can produce measurable health improvements but primarily they increase self-efficacy and thus well-being and quality of life (www.expertpatients.nhs.uk). The tutors who run Expert Patients Programme courses are volunteers who have long-term conditions themselves and this is central to its success.

Tutors model behaviours that participants aspire to and demonstrate in their lives that health is achievable. They are the epitome of 'do as I do, not do as I say'.

The Expert Patients Programme has become a community interest company. It is now a not-for-profit business, liberated from the restrictions of government accounting and Department of Health bureaucracy. It will seek new markets with employers and in social care, and it will escape from the illness-centred NHS to promote well-being.

A culture in need of change

Professionals are often uncertain about the Expert Patients Programme. They fear 'expert' patients as a challenge to their own expertise. But the programme doesn't attempt to impart professional knowledge. It seeks to enhance the person's expertise in their own life. Professionals often continue to behave towards self-managing patients by directing them. They undermine rather than reinforce their autonomy. Or they want to take the programme over, suggesting it would be better delivered by clinical professionals who would 'know what they were doing'. Of course, this misses the point entirely.

And we are still missing the point entirely in much of the implementation of a 'patient-led' NHS. If 'patient-led' means anything it means that the way people using the NHS choose and act should shape the service. Some rudimentary tools have been provided: there is choice of provider, some information to help make those choices and payment by results to provide incentives for providers.

In social care we have direct payments and soon will have personal budgets. Early reports suggest that choice of provider is popular and that it is working (Department of Health 2006a). Even if only small numbers of patients change their provider the payment system has a significant effect. However, doctors' organisations remain mainly resistant to choice for patients, though doctors have always exercised it for themselves and their families. GPs remain the gatekeepers to the system controlling access to choice. And most of the clinical specialties continue to resist the publication of information on quality or comparative data. The Society for Cardio-thoracic Surgery is an admirable exception. Individual surgeons' outcome data, adjusted for case mix, is now published by the Healthcare Commission on its website (www.healthcarecommission.org.uk).

So there are real examples of change but these are small scale – as social entrepreneurial activity often is – and they are as yet peripheral to the vast majority of activity in the NHS. Patient engagement, patient choice, self-management are not seen as the radical revolution they could be. Instead they are perceived as yet another intervention to be imposed on patients. When patient choices do start to have an impact under the new arrangements, the instinct of the service is to resist and not to follow where patients lead.

After the introduction of the new GP contract and the introduction of waiting time targets for accident and emergency (A&E), attendance increased by 27 per cent between 2001/2 and 2004/5 (Hansard 2006). This was not what was meant to happen. It was seen as a problem; discussions were had about how people could be stopped from going to A&E. But isn't this exactly what patient-led should mean? GPs had abandoned their patients by ceasing to provide out of hours services. The alternatives were mistrusted. Accident and emergency had improved: it was available 24 hours a day and no matter how minor or serious your problem you knew you'd get treated eventually. Instead of trying to stop people attending A&E, a patient-led health service would be investing in new forms of urgent care services which meet the needs and preferences of patients.

Embracing patient initiatives

Instead of constantly resisting their impact, we ought to welcome patients as agents of change. A cultural change is needed. This is demonstrated by people with chronic obstructive pulmonary disease, or long-term breathing problems in plain English, who took part in an innovative project with the Meteorological Office and their provider trusts. Chronic obstructive pulmonary disease is directly affected by the weather: the colder and damper, the more severe the symptoms. Trusts knew that cold, damp weather meant an increase in inpatients and they wanted to plan their availability of services around this. Ninety-four per cent of patients knew that the weather affected them. The Meteorological Office provided weather forecasts to help providers. But the patients affected took control. Give us the information you have on the weather and we will use it to manage our own illness, planning our shopping so we can stay indoors, taking our drugs at the right time, turning up the heating. By allowing the service to be patient-led the effect was better for everyone. Providers no longer had to prepare for an influx of seriously ill patients: the patients by their actions, with the support of clinical professionals in the community, kept themselves out of hospital. Hospital admissions were reduced by over 20 per cent.

From Canada comes a powerful example in the field of mental health (Cunningham 2005). At McMasters University in Hamilton, families with children needing mental health services faced long waits of six months or more. During that time children's mental health deteriorated and family stress increased. Some of the more assertive parents asked the clinicians, 'What can we do to help ourselves and our children? We are wasting this waiting time.' Working with the families in a systematic study of their information needs and the barriers to their effective use of information they designed a self-managed, home-based programme providing step by step solutions for parents to use. This was backed up by a telephone helpline and coaching service. The results were dramatic. At the end of the six-month waiting time for professional help 87 per cent of families had solved their own problems and no longer met the referral criteria for the service. This was better than clinically based interventions where the recovery rate was 63 per cent.

The entrepreneurial patient

These examples illustrate what I mean by patients as entrepreneurs. This is why it is so important that we stop thinking of patient and public engagement as a new way of getting people to do what the NHS wants. We should understand it as a real force for getting the NHS to deliver what patients and the public want. In particular, we need to stop managing patient behaviours at every level and start responding to patient choices. We need to do less of some things and more of others. Policy-makers need to give up trying to control the system rather than just saying that they have. Everyone needs to recognise patients and service users as a new force in the system and we need to continue to bring health and social care closer together.

The opportunities that people have to be entrepreneurial about their own health care are still inadequate. Choice is still mostly dependent on exit. That is, it depends on leaving a GP or leaving a hospital and going elsewhere. Such choices may be difficult and inconvenient and therefore not real choices at all. So choice must be matched with voice; with effective, influential consumer involvement and real community engagement. We also need to think over time about new mechanisms for entrepreneurial patients such as personal budgets in health or choice of commissioner.

As patients and citizens we need to seize the opportunities given to us to shape health care, small though they are, and become entrepreneurs for change in our own interests and those of our fellow citizens.

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8 Patients as budget holders

Peter Gilroy OBE, Chief Executive, Kent County Council

My overall theme is promoting independence. In that context one of our key aims is the personalisation of services. The two conflicting issues which concern citizens and care professionals are how, in a qualitative sense, to help people maintain independence while at the same time reducing public costs, at a time when we face additional challenges from demographic trends. As citizens, we are becoming more articulate, more demanding as to the services we use and expect, and increasingly we like to handle things ourselves. This is reflected in public policy which is moving us all towards services that give more choice and control and which increase quality of life.

I want to use two examples of the innovative approaches that we are using in Kent County Council to illustrate the journey that we are undertaking to modernise and personalise services and shift power from practitioners to service users and carers. My first example is telehealth. Our pilot scheme has been aimed at people with chronic conditions who require a high level of health and social care. A touch screen monitor and sensors enable people to monitor their conditions and transmit the information to health care professionals. This gives people a better understanding of their conditions and greater confidence in their ability to manage them themselves. It reduces the need for hospital visits and admissions and enables the health care professional to make much more timely interventions and changes to medication. This is a key preventive tool and the increased confidence and control that it brings is a major factor in improving the health and quality of life of the individual and their carers, and in promoting their independence. There is undoubted potential for extending the use of telehealth into the education economy for children with special needs, and for people with mental health needs, for example. Currently the equipment is located in people's homes but there is scope for monitoring in kiosks in public access points such as Gateways,¹ libraries, leisure centres and schools.

My second example is the Kent Card. This is a fully automated system for handling regular payments – the first of its kind in the United Kingdom. It gives people using care services the flexibility to tailor their own support and use the providers they choose, while at the same time reducing back-office costs for the County Council. The card has been developed with the Royal Bank of Scotland for the use of people who have chosen direct payments to meet their care needs. The card is pre-loaded with an agreed amount which can then be spent with a range of care providers or used to employ carers. This gives people the freedom, control and choice of a credit card without the need to apply for a card or manage a bank account. It has enabled the County Council to streamline its own processes with considerable back-office saving while at the same time improving the quality of life of people using it. Again the card has been developed for use in social care but the range of possible applications right across the Council is potentially huge. The technology offers the opportunity to deliver the whole range of welfare benefits through

1 Gateways - a development led by Kent County Council incorporating a customer-focused, large-scale, cross-agency service in a modern retail setting. In contrast to traditional one-stop shops, Gateways offers citizens convenient physical access to frontline customer advisers and staff from multiple agencies/delivery partners covering central and local government and the voluntary sector, uniting services under a neutral brand.

one card, putting the customer firmly at the centre as well as making massive savings in back-office transactional costs.

By using technology in this way Kent County Council is providing a new kind of person-centred service designed to meet people's needs in a much more personalised way. It enables people to remain independent in their own homes for longer, reduces anxiety and improves well-being and peace of mind for people using services, for their carers and for professionals. Both these examples represent additional tools to transform our relationship with people and enable them to take control of their lives. Both examples work best when fully integrated into local service delivery.

In summary, this is not about restructuring – it is about transformation. It is about retaining and promoting independence and a level of choice. Alongside other developments such as telecare and self-assessment this is a journey that is making a very significant contribution to the future of Kent. It has fundamental implications for the social and health care economy over the next decade, nationally and internationally, for remote care and clinical management. Technology is just a tool and will continue to change but we must not underestimate the massive shift in all areas of our lives with regard to applied technology. As I said at the beginning, this also marks a significant shift in power from the professional to the service user. Ironically, there is little doubt that the public will not only accept these changes but in time demand them. The real challenge is not whether the public will want the service – we know they will – but whether professionals in all disciplines are prepared to let go and embrace the change.

9 The patient of the future – what needs to change?

Alan W Hartley, Chair, General Medical Council Patient and Public Reference Group

What the patient wants in primary care settings

Most (if not all) GP surgeries now only open Monday to Friday; why not Saturday morning and afternoon appointments? Many people have full-time employment so cannot attend midweek, and those who live in rural areas often have to take time off work to visit the doctor.

Patients want more treatment locally, which could be improved by more use of minor injuries clinics; that said, in a number of rural areas these too now open only during normal working hours. Once again, why don't they open Saturdays? Many minor treatments could be carried out locally (GP surgeries, local clinics, cottage-type hospitals). The system and thereby the patient would benefit if better use was made of other health professionals such as nurses and even pharmacists for procedures such as blood taking, normal health checks, reviews for patients with long-term illnesses.

There should be more flexible clinic hours (such as support for those attempting to give up smoking); in many rural areas these only operate on midweek daytime hours. They should operate evenings and weekends. Day surgery should be available within local health centres and also be available at weekends.

Patients want more walk-in centres and better use of NHS Direct. These are available only in very large towns or cities; there should be more available locally. Likewise NHS Direct should be publicised more often and using television and radio.

The Expert Patients Programme should be extended and better publicised. Many patients have benefited from this programme but again it is not widely publicised. Primary care trusts should make better use and give more support to voluntary self-help groups.

Appointments at both outpatients and GP surgeries should take into account carers' needs. Often receptionists time appointments for carers and their patient at different times and days. This puts carers under a lot of stress and increases their workload. More respite care should be available and training courses for carers to help them understand the health problems of those they care for. There should be a dedicated telephone service that carers can use for help, advice and support.

What the patient wants in secondary care settings

Surprising though it may seem, more patients are fearful of hospital-acquired infections while an inpatient than of operations going wrong. Confidence in doctors and nursing staff is extremely high and the vast majority of patients believe that doctors and nurses are highly skilled professionals; the fears and concerns are about dirty hospitals. Therefore a real effort should be made to greatly improve hospital cleanliness and reduce incidents. Patients and visitors should be encouraged to report dirty hospital wards. There should

be a dedicated senior manager to whom patients and visitors can report dirty hospitals and there should be a return to in-house cleaning teams. The use of a dedicated telephone service where complaints could be made anonymously would greatly improve confidence and identification of problems.

In many small towns and rural areas, access to hospitals (and walk-in centres) is very difficult due to poor public transport links (Selby to York an example); no trains after 7pm and very poor bus services from rural areas. Car park charges and disabled parking is expensive, in short supply and in many cases disabled parking spaces are of a poor design.

One of the major complaints is that of waiting lists: real steps should be made to improve these, especially those waiting times between first and second appointments. The practice of requesting too many patients to attend at the same time (the famous 10am appointment) should be abolished. This causes frustration and anger in both patients and carers. Real efforts should be made to reduce the waiting time between the first appointment and tests, and after tests the waiting time for a follow-up appointment.

10 What needs to change to meet the needs of future patients?

Liz Kendall, former Special Adviser to the Health Secretary, Department of Health

The NHS faces three main challenges in meeting the needs of future patients. First, patients are more demanding than ever before. They want more convenient and accessible services that are personalised to meet their individual needs. Second, the burden of disease is shifting: the population is ageing, medical advances mean more people with disabilities are living longer, and chronic conditions like obesity and heart disease are on the rise. Third, persistent and unacceptable inequalities in health remain. Sixty years after the NHS was created to provide free health care for all, based on need not ability to pay, the poorest and most disadvantaged sections of society are still more likely to get ill and to die earlier, and less likely to access good quality care.

Meeting these challenges means giving people more choice and a greater say over their health and care, both as individual patients and as members of the public. It means delivering a fundamental shift in services into the community and more towards prevention, and making the long-held goal of joined-up health and social care a reality. It means transforming our understanding of the health needs of all sections of the community, targeting effort and resources more effectively towards those in greatest need. Above all, it means changing the relationship between the NHS and patients, and between the NHS and other public services, so that they work in genuine partnership with one another.

The framework for delivering these objectives is already in place. Patients have a choice over when and where to have their operation. The White Paper *Our Health, Our Care, Our Say* (Department of Health 2006) shows how patients can be given more choice about their local GP and primary care services. And more information is being provided for patients, including through the new NHS Choices website (www.nhs.uk).

The Department of Health has made strengthening commissioning a key priority for primary care trusts (PCTs) and established a new framework for bringing in support where PCTs lack the necessary skills to fulfil this role, including from the private sector. Joined-up commissioning with local government is being developed, made easier now that four out of five PCTs have the same boundaries as local councils. Practice-based commissioning, where groups of GPs come together to commission services, is providing real incentives to shift care into the community, improving patient care and releasing resources to invest in new types of care.

Opening up services to new providers – including from the private and voluntary sectors – is giving patients and commissioners greater choice. New providers provide extra capacity and innovation to the NHS and can help challenge under-performing parts of the system. For example, mobile independent sector treatment centres and one-stop-shops, which allow patients to have their inpatient appointments and diagnostic tests on the same day, are helping to bring down waiting lists. New providers are also being used to tackle health inequalities. For example, Barking PCT is using the private sector

to provide GP and other primary care services in one of the most deprived, and poorly served, parts of east London.

Payment by Results, the national tariff for services, will underpin these changes. Understanding the true costs of care at every stage of the patient's journey – in primary as well as secondary care – will support the shift towards more preventive and community services. And the new regulatory framework will help ensure national standards and more joined-up health and social care.

But although the basic framework is in place, there is still a long way to go before patients' needs genuinely drive the system.

Patients must be involved in every stage of their care, in the way they want. This means giving patients who want it greater choice, not only over when and where they have their diagnostic tests and operations, but also in which drugs, treatments and services they use in primary, community and mental health services, and in self-care and preventive care. The goal must be to fundamentally reshape services so they fit around patients' needs and preferences, rather than making patients fit the system.

While more choice and a greater say are vital, so too is encouraging patients to take on a bigger role in their own health and care. Evidence from the Expert Patients Programme – where patients take on more responsibility for their medicines, treatment options, diet and exercise – shows that greater patient involvement can improve health outcomes and lead to less frequent use of health services. This approach must be adopted throughout the NHS. People are far more likely to make healthier choices, and take more responsibility for their own health, if information and services are provided in a way that fits in with their daily lives. Information technology has a crucial role to play here. Getting information on the internet and accessing services via mobile phone is the norm for many people today – something the NHS must recognise if it is to keep up with public expectations.

Patients need a stronger collective voice as well as individual choice, particularly as more power and responsibility is devolved to the front line. Decisions about reshaping services must have legitimacy at the local level if they are to gain public support. Despite efforts to increase patient and public involvement, most people still do not know what a primary care trust is, let alone feel able to influence its decisions. The democratic deficit in the NHS contrasts starkly with other public services. For example, in education, parents have long been involved in local schools – through parent–teacher associations or as school governors – and can have a say in local education authority decisions by voting in local council elections.

An urgent debate is now required about how best to give patients a genuine say in their local NHS. This could be through traditional methods, such as greater involvement of local councillors on PCT boards or direct elections of patients and members of the public, or through more innovative methods such as citizens' juries and people's panels – or a combination of the two.

Perhaps the most urgent issue is to strengthen commissioning. This is critical for tackling inequalities and for shifting services and resources into the community and more towards prevention. While there are examples of good practice, the NHS still too often fails to understand the health needs of local communities, let alone commission appropriate services. Groups whose needs cross traditional service boundaries, for example, people who suffer from mental health problems and drug and alcohol addiction, are particularly poorly served. Far better information about, and better engagement of, communities whose needs are not being met is vital. Commissioners must also be more willing to

commission different types of service, not simply 'more of the same'. There is much that could be learnt from the voluntary sector here.

An important priority for commissioning should be children's early years. The NHS frequently fails to prioritise children's services, yet all the evidence suggests the earliest years of a child's life are critical in shaping later physical, social and emotional development. The most effective programmes tend to start during pregnancy, are regular and intense, take account of multiple factors, develop alliances with parents, target the most needy and use well-trained support. Children's centres – which bring together a wide range of professionals in local communities – provide the perfect vehicle for delivering this new type of support. PCTs and practice-based commissioners must be fully engaged in their development.

These challenges are considerable. But perhaps the most difficult issue is that of delivering cultural change. The relationship between patients and professionals must be transformed, so that they work in partnership, sharing information and responsibility every step of the way. The relationship between professionals within the NHS, and between the NHS and other public services, such as those working in social care, must also change. The old attitude that hospitals, and hospital consultants, always know best and should take up the lion's share of resources, must end if we are to meet the needs of future patients.

Too often lip service is paid to these issues. Most professional bodies at the national level support the need for greater patient and public involvement, a shift towards prevention, and for greater co-operation between primary, community and social care. Yet the difficulties involved in the day-to-day running of the NHS mean the experience on the ground is often very different. Leadership from medical and other professionals at every level – national, regional and local – is urgently required, so that these changes are seen as a top priority, not an optional extra.

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Appendix 1

Delphi exercise

Participants were asked the question: 'What key changes will make the difference to how patients use health care and manage their health in the future?' They then wrote down five answers in no particular order.

The answers were collated into a list of the most popular/frequent themes that emerged, again in no particular order:

- changing professionals' roles and their relationships with patients
- NHS need to understand its 'customers'/consumers and respond differently, use marketing approaches
- doctors to support people rather than 'prescribe'
- financial incentives
- availability of more and higher quality information on health and health care
- changes in society – education, housing, financial equality
- changes in expectations of different generations
- more use of health professionals other than doctors
- teaching of evidence-based self-management skills for all life stages
- use of information technology and personalised technology
- changes in attitudes of patients to doctors
- changes to the health system – funding, commissioning, provision
- focus on people/patients, their lives and their personal goals.

Participants were then asked to choose five answers from the list that they felt were the key changes needed, and list them in order of importance. The 'top 5' answers from all the participants were collected and then graded and formed into a final list of what the delegates felt, in order of importance, were the five key changes that would make the difference to how patients use health care and manage their health in the future.

Appendix 2

Participants¹

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Sir Roger Bannister, Trustee, Leeds Castle Foundation

Dame Carol Black, Chairman, Nuffield Trust

Frances Blunden, Principal Policy Adviser, *Which?*

Harry Cayton, National Director for Patients and the Public, Department of Health

Professor Angela Coulter, Chief Executive, Picker Institute Europe

John Coulthard, Director, Microsoft UK Healthcare, Microsoft Limited

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Niall Dickson, Chief Executive, The King's Fund

Anna Dixon, Deputy Director of Policy, The King's Fund

Peter Gilroy OBE, Chief Executive, Kent County Council

Fiona Godlee, Editor, *British Medical Journal*

Mark Goldman, Chief Executive, Heart of England

Margaret Goose OBE, Chair of Patient and Carer Involvement Steering Group, Royal College of Physicians

Christine Hancock, European Director, Oxford Health Alliance

Graham Harries, Chief Executive, CHKS

Alan Hartley, Chairman, General Medical Council Patient and Public Reference Group – Patients Association

Liz Kendall, Special Adviser to the Health Secretary, Department of Health

Geraint Lewis, Policy Advisor, Cabinet Office; Visiting Fellow, The King's Fund

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¹ Job titles as at the summit.

David Pink, Chief Executive, LTCA

Rebecca Rosen, Humana

Hilary Rowell, Head of Strategy, Dr Foster Intelligence

Stephen Shortt, PEC Chairman, Nottingham County Teaching Primary Care Trust

Richard Smith, Chief Executive, UnitedHealth Europe

David Stout, Director, PCT Network, NHS Confederation

Matt Tee, Director General, Communications, Department of Health

Anna Walker, Chief Executive, Healthcare Commission