

an uneasy consensus: patients, citizens and the NHS

February 2012 Paper 1

Paper 1

Personal experiences, public value: changing relationships in the NHS

Key points

- The model of a consumer is problematic within free-at-point-of-use health services.
- 'Baby boomers' and their children have higher expectations of public services than their parents.
- The digital revolution provides access to knowledge, new styles of services and the opportunity for people and patients to communicate to mobilise support through social networks.
- The NHS must demonstrate value in exchange for its share of tax revenue.
- Engaging people at all levels of the service will increase productivity, improve outcomes and put service quality on display.

The relationship between individual patients and the health service has been remarkably consistent since the establishment of the NHS in 1948. However, during this time, expectations, technology, patterns of disease and demography have all changed significantly. There remains great attachment to the idea of the NHS as a public service, but public expectations of the service and assumed safety and willingness to bear an ever increasing tax burden are now very different. This paper explores aspects of these changes and what this may mean for the future leadership and sustainability of the NHS.

Intended to stimulate discussion, this paper is the first in a series looking at interactions between the NHS, individuals and communities. A further four papers in the run up to the **2012 NHS Confederation annual conference and exhibition** will explore:

- putting people first through shared decision-making
- information and the power paradigm
- micro-enterprises and building community assets
- building social value within the system and society.

How did we get here?

In order to understand the relationship we currently have with the NHS, we need to look at how these relationships have developed over time. Prior to 1948, most

British citizens' relationship to the state was characterised largely through their obligations to it – of being available for military service and participating in and being regulated by a judicial system

An uneasy consensus series

These papers are intended to stimulate debate with members and others, culminating in a panel discussion with the authors during the NHS Confederation's Annual Conference and Exhibition in June 2012. To find out more, go to www.nhsconfed.org/2012

grounded in the protection of the person and property. 1923 brought the privilege of a vote for almost everyone* and, with the introduction of the welfare state, most of the population became beneficiaries of state services for the first time. They started to experience free education, universal child benefit, pensions in old age, income support for periods of unemployment and, of course, a health service funded out of general taxation and largely free at the point of delivery.

The generation which created this system of collective support were mostly born between 1877 and 1921 and had experienced, to their cost, the reality of a society which required everyone to 'stand

Citizenship

Marshall's classic model of citizenship has three elements:

- a civil dimension, largely relating to the judicial system
- a political dimension, vested in the right to participate in representative democracy
- a social dimension, as part of a collective funder and user of state services.

on their own two feet' regardless of circumstances. They were deeply appreciative of the new public services and became the prototype 'patient' – grateful recipients of whatever the NHS chose to make available. This was the generation who were the basis of Marshall's classic definition of citizenship.¹

Their children, however – the 'baby boomers' – were those who had "never had it so good". The first generation to benefit from the grammar school system, they took part in the student unrest of 1968, which marked a shift from class politics to a counter-culture, and raised issues of individual identity and rights, rather than class action. Beneficiaries of the collectivist approach of their parents and grandparents, they exemplified a new form of citizenship. They were sceptical of the role of the state, willing to exercise more direct forms of political participation in protests against what they saw as the failures of 'traditional' politics, and active on issues of the individual rights of marginalised groups (women, Black and Minority Ethnic groups, or of different sexual orientation). For the first time, people with disabilities began to both celebrate their differences and demand the same rights of participation in society as other citizens.

From the beginning, the boom in population happened simultaneously with increases in economic opportunity. By 2007, over a third of all identified personal wealth in the country was held by people over 65 years of age.² If their parents and grandparents had a relationship

with the state marked by an exchange of obligation for benefits, then the baby boomers were the new consumers. Through the choices they made – in clothes, music, household goods and design – they began to express their individualism through the High Street, rather than protest on the street. Over the next decade they will replace the founders of the welfare state as the most regular users of the NHS.

Consumerism, rights and the NHS

Consumption has become the process which characterises life in mature capitalist societies. Shopping is the most popular leisure pursuit and, typically, our purchases are disposable or have short lifecycles and satisfy desire as much as need. This generates a strong sense of entitlement and high expectations. From the 1980s onwards, there has been a growing realisation that the NHS cannot just go on treating patients as passive beneficiaries of service, when in all other aspects of life they are people who make active choices which define who they are or aspire to be.

The idea of the patient as consumer is an uncomfortable fit within a health service established to be national, consistent and free at the point of delivery. The public dislikes the 'postcode lottery' of local priorities, but is disappointed with the personal experience of inflexible, 'one size fits all' services still largely designed for the convenience of providers rather than users. We are rightly intolerant of unsafe or uncaring services but concerned to preserve local access as an important

* Women aged between 21 and 29 didn't get the vote until 1929; and adulthood did not begin until the age of 21.

symbol of health service availability, even where services may be unresponsive or less effective than others. In this context, our rights as citizens become important, but are compromised by the professional power dynamic in which clinicians or other professionals have an unequal amount of knowledge and expertise in comparison to service users. Knowledge and skill sit with the health professional and, when we are ill, we are at our most vulnerable and least assertive.

What is the public value of the NHS?

The relationship between a state and its citizens is dependent on a consensus about relative roles and responsibilities and about the proper value citizens should experience in exchange for regulation and taxation. Moore describes public value as arising from the interaction of three areas of activity³:

- **Outcomes** – there are clearly defined goals and expected outcomes of tax-funded activity, which are recognised as legitimate by the public.
- **Trust** – services are open about their activity and expenditure and experienced as accountable
- **Service quality** – services are demonstrably effective, responsive and appropriate.

In each of these areas we can see that both public expectations and the nature of provision has changed significantly over the lifetime of the NHS, at times creating dissonance between loving the idea of the service being available and the reality of the experience of what it offers.

The new citizenship – from paternalism to partnership

Some see paternalism as a downside of the well-meaning assumptions on which the NHS was founded – that we must design for a lack of competence in all to ensure we support those least able to help themselves. Insights from psychology have identified the importance of working with people to enable them to change behaviour and attitude, without which medicines and surgery will have little lasting impact. A new model of the medical consultation has developed, in which the patient's personal insight is considered alongside the professional knowledge of the clinicians to develop shared decision-making on services or treatments required.⁴ In many cases, patients' relationship with healthcare professionals now has a more mature basis which encourages patients to take responsibility for their own health in exchange for access to services.

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It is an approach which seems to improve individual health outcomes and, by building self-confidence, reduce unnecessary use of services. This approach is increasingly appropriate as chronic disease rather than the acute event is becoming the paradigm of the service. Because each consultation respects the individual circumstances, values and capabilities of those involved, it works to tackle inequalities. It has been adopted in a range of services based in disadvantaged communities with great success.⁵

The electronic citizen

Digital developments have given rise to 'the electronic citizen'. In adults aged between 15 and 65, 83 per cent of men and 76 per cent of women use the internet. There are, of course, those who remain outside the 'virtual

What services should the NHS provide?

Once commissioners begin to consider return on investment for public money, there are questions about what is legitimate for the taxpayer to fund. Recent discussions in the media have focused on whether the NHS should bear the cost of removing possibly faulty implants from women who chose to buy cosmetic breast surgery, and the appropriateness of allowing patients undergoing NHS cancer treatment to buy 'top up' drugs of yet unproven value, which may in turn trigger the need for greater NHS support.

This debate becomes heated when it relates to investing in preventive activity, which is not always seen by some as a legitimate area for the NHS, even though we know investing adequately in this part of the pathway will reduce costs at the more expensive end of healthcare. The public wants the security of knowing they will be looked after once they are ill, but many would prefer not to have advice from the 'nanny state' on how to stay well in the first place.

world', but even in the most disadvantaged groups of older people, over a quarter access the web.⁶ Not only are they able to access a wealth of information, they can also 'like' an initiative, sign a petition, or share good or bad practice with thousands of others at the touch of a button.

Social networks form around shared issues and interests and can be maintained over large distances. This enables patients to take some of the power traditionally reserved for consumers: to comment on services, choose alternative providers or mobilise support for change and improvement in local services. A number of companies now provide TripAdvisor-like opportunities to review and rate health services, which benefits both new users and the provider, who now have insight into what is being said about them and the opportunity to tackle problems which may previously have been hidden.

This visibility of information and activities makes public organisations and government more accountable, and the influence of rapidly assembled topic-specific interest groups more powerful, than ever before.

"Traditional hierarchies can no longer apply and traditional authority figures are no longer in control. The power rests with the people".⁷

The digital world is social. It enables individual participation in a dialogue, with social networks crossing borders and enabling real-time action and reporting, as in the Arab Spring or English summer riots of 2011. There are well-rehearsed limitations to the

use of digital technology for service and information delivery,⁸ but there is no longer any doubt about its general reach and contribution to engaging groups, such as young people or working parents of young children, who have traditionally sat outside face-to-face methods. It can enable 'patients like us' to network, share and act. This may be to support each other in self-management, provide advice or mobilise action for access to particular services which may not reflect professional views of what is 'right'. Recent examples include the Alzheimer's Society's campaign for NICE to approve new drug treatments, or the mobilisation of support against changes to the Disability Living Allowance. Many mental health organisations are already using social media to provide support on a range of issues such as depression, alcohol and drug dependency and anxiety disorders, often to patients and services users who were reluctant to participate in more traditional services.⁹

Personal contacts and local acts

An emerging body of evidence suggests that active participation contributes to both individual health and stronger, more cohesive communities. Recent government attempts to measure wellbeing have been responses to emerging insights that support Burke's 18th-Century thesis that personal contacts and local acts build a positive sense of belonging to a larger whole, and that helping others makes us happier ourselves.¹⁰

Greater personalisation may, paradoxically, be the basis for more social action and the possibility of developing competent and well-informed

communities of interest. Doherty and colleagues have moved beyond individual interaction, to work with patients and their families, as well as their communities, so that they are more involved and 'co-produce' how services are developed and how they can improve their own health and the health of others. This moves beyond the 'activated patient' to the 'activated community', with professionals learning community mobilising skills and working with individuals and families who see themselves as citizens of healthcare rather than consumers of clinical services.¹¹

The consumerist model of individuals choosing from a market of differentiated provision has driven concerns about those who will be left behind and the abandonment of public services by those with disposable income. With the public more in control of improving their own health, individual rights to safe and responsive services are felt more keenly and play to collective concern that the plight of others could affect us all. This kind of self-interested 'sympathy' has underpinned the social justice role of the NHS since its inception and reducing health inequalities remains a key priority for both the NHS itself and for all government departments.

Personal interest, public value

We are all part of the NHS as staff, users and funders of services. Much of our passion for the NHS comes from our personal and family experiences as much as from our professional pride. The NHS Institute for Innovation and

Improvement is tapping into this passion and personal commitment to provide a powerful resource for change.¹² It is adopting community mobilisation in Quality, Innovation, Productivity and Prevention (QIPP) initiatives to build a sense of shared purpose and community between professionals, voluntary organisations and the public.¹³ Examples include initiatives aimed at improving end-of-life care and minimising inappropriate medication for people with Alzheimer's disease. The mobilisation approach acknowledges the NHS as part of a wider community of citizens and challenges the boundaries between expert and beneficiary, which have characterised the relationship for much of the life of the service.

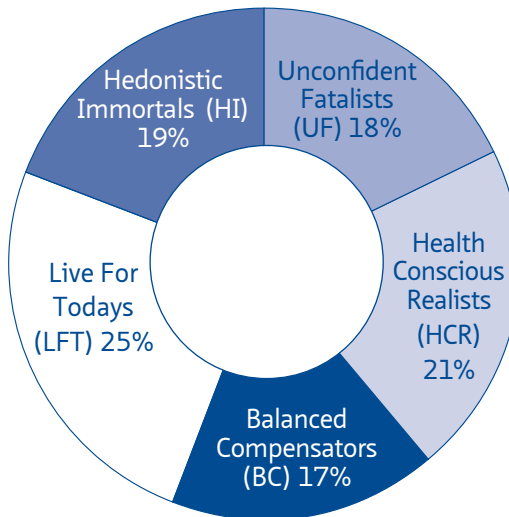
Outcomes and equality

At a population level, the NHS has done well on outcomes. It has contributed to significantly increasing average life expectancy, and intervenes daily with lasting impact for patients, their families and friends. However, international comparisons suggest significant room for improvement in both safety and mortality.¹⁴ In general, patient satisfaction is high, but 26 per cent of survey respondents would not recommend their local trust – a discontent caused by perceptions of lack of involvement in decisions and a lack of respect for patients.¹⁵

In order to understand how being a consumer results in a different experience of the health service for different groups, we need to look at how patients and the public choose to access health services. A growing, articulate, educated and assertive proportion of the population has emerged, better

Figure 1. Preference profiling – what makes us tick?

The five core motivational segments:



Source: DH Healthy Foundations Life Stage Segmentation Model Toolkit

- HCRs and BCs – generally motivated, with positive health behaviours, tend to be less deprived and working.
- LFTs and UFs – different drivers but similar high-risk behaviours and resistance to change; more disadvantaged.
- HIs – younger segment, enjoy taking risks.

placed to access the state's universal services than those intended as the original 'safety net' recipients. This is starkly apparent in health, manifesting in persistent inequalities in life expectancy and life chances following an established socio-economic pattern of low income and employment. In England, 37 per cent of men aged 45 to 54, and skilled in routine and manual work, have limiting long-term illness, compared to 12 per cent of women of the same age and in senior managerial positions. People living in the poorest neighbourhoods will, on average, die seven years earlier than people living in the richest neighbourhoods.¹⁶

The notion of citizenship is grounded in a concept of equality of access, but the sort of 'preference profiling' (see Figure 1) associated with the differentiation of consumerism may be better placed to tackle health inequalities. The diversification and targeting of a service offer is more likely to

reach vulnerable communities than a one-size-fits-all service. Tackling inequalities will require greater diversity in our service offer and giving more attention to some than others. The Department of Health's Healthy Foundations model reveals five distinct groups, all requiring different approaches and types of service. This can be applied to reach out to particular at-risk populations and design different services to appeal to different groups.

Trust and quality

The NHS is well loved by the public, and doctors are the most trusted profession,¹⁷ but there is discomfort with the failure of the NHS to have changed life chances. Opinion polls indicate that people tend to exercise choice on the basis of safety and cleanliness and then they go to their local hospital on the basis of convenience.¹⁸ This suggests there is not yet general public understanding of the wide variations which exist in service delivery and

'Leadership in the NHS over the next decade will be on public display more than ever. Leaders' decisions will be more visible'

effectiveness. Scandals, such as at Mid Staffordshire trust or the Winterbourne View care home, erode public faith in the safety of all services. The importance of this public perception of service standards has been emphasised;¹⁹ taxpayers are not tolerant of funding services which are unsafe, ineffectual or unresponsive. If they choose to pay privately as an alternative, they are even less tolerant of funding 'universal' services from which they no longer benefit personally.

Sustainability

Post 1948 and the launch of the welfare state, general government expenditure rose steadily, from circa £75 billion in 1950 to £300 billion by the year 2000 (at 1995 prices). As a proportion of GDP it peaked in 1975, at nearly 50 per cent, and has remained above 40 per cent since.²⁰ As in the rest of the Western world, healthcare has become a significant and growing proportion of GDP and a growing burden on the British taxpayer. In the current economic and political context, the NHS is unsustainable without significant increases in productivity, adopting innovations in service delivery from other sectors and giving greater attention to prevention – the ethos behind the QIPP challenge, which requires the NHS to reduce recurring costs by £20 billion by 2014.

The 'passive patient', with ever increasing expectations of rescue, has been an expensive model of delivery. Shared decision-making

and self-care can stabilise conditions and reduce unnecessary utilisation. Preference profiling can engage vulnerable populations with services earlier and be the foundation for effective health promotion. Digital technologies can connect communities of interest and support independence through remote surveillance and virtual conversations. There are significant opportunities in a service which is dominated by individual and face-to-face interventions by expensive professionals to optimise phone and digital technology for service delivery and peer support.²¹ 'Citizen healthcare' is actively engaging with communities to promote health and build the resilience to cope well with illness. There is a business case for a different relationship with patients and the public.

What sort of relationship do we need now?

The relationships between individuals and the state and patients and the health service have expressed themselves differently over time and between different generations and groups. The main users of the health service are the generation following the founders of the welfare state, and their families, who have an increasing sense of entitlement for self and for self-reliance in others. Subsequent generations are unlikely to tolerate much of what we have provided historically. Being part of society today requires the NHS to become much better at understanding preferences, differentiating services and responding to a 'whole' person. Being a public service requires the NHS to

maintain consistent, high standards and develop a core offer which respects and empowers individuals.

The challenge for the NHS of being comprehensive and available to the vulnerable in times of need, but still responsive to the rights of the individual and promoting self-reliance, is an ongoing social policy conundrum.

The relationship between citizen and state is founded on an implicit contract. That is, that we allow our income to be top-sliced and delegate the decisions about how it is used to people who spend their working lives providing a comprehensive set of services to keep us safe and society functioning. The NHS commissioning system now needs to understand both current dominant beliefs about what is an appropriate mix of health services, and to be in touch with how those services are being experienced on the ground; and providers need to take seriously patient and family feedback and commentary as critical intelligence on how well their service is performing and as being integral to their brand and reputation.

Leadership in the NHS over the next decade will be on public display more than ever. Leaders' decisions will be more visible, and commentary on our activity will likely be immediate, more widespread and less open to being managed through a few selected groups of patients. As leaders, it is incumbent on us to actively engage in it and to tap into the passion and commitment for a national health service, largely free at the point of delivery.

What does this mean for your organisation?

- How are the key issues raised in this paper relevant to you?
- How do you see the NHS changing in the future in the way that it interacts with patients and the public?
- Have we made the most of technology in redesigning services for convenience, choice and affordability?
- How honest are we about our service quality and sustainability? Could we do more to develop a dialogue with people about how services should develop and change to meet new challenges and remain affordable?

We want to hear your views. Send your comments to nicola.stevenson@nhsconfed.org and we will collate feedback for discussion during our annual conference and exhibition.

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Come and meet Sophia and the other authors of the *An uneasy consensus* series at the 2012 NHS Confederation annual conference and exhibition.

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