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# Towards NHS 2.0

A discussion document

## A need for balance

Letting people be the authoritative and decisive masters of their own health takes nothing away from doctors, nurses or therapists. In fact, the reorientation of the system that we envisage should be as emancipating for clinicians as it will be for patients.

Clinicians will have more objective data, better prepared patients, and a culture of engagement, sharing and co-production working on their side. We can expect better communication, better informed decisions, more sensitive reflections of personal preferences for care, better adherence to care pathways and recommended treatment, and with all of these, better results.

Health 2.0 does not mean that people won't sometimes be patients or that patients won't need clinical expertise. But it does place that expertise into a different relationship balance, and also seeks to strike a different balance in resources. Health 2.0 is focused more on community-based care that reaches out to people where they live and helps them create their own health.

The nuclear chain reaction that accompanied the delivery of the Beveridge Report may lend us another useful metaphor. Imagine the patient as the nucleus of the system surrounded by several orbiting electrons, each representing a community that supports them, such as personal, social, medical, and technological. It is an implicit acknowledgement that people seek and use healthcare services for lots of reasons. One of the challenges of the next generation health system will be to get these support systems to work harmoniously around the patient.

## A need for boldness and innovation

Health 2.0 is not as far-fetched as it may sound. Much of the technology underpinning it is already under development. But it will take bold commitment to the vision and deliberate investment in people, technology, experimentation and innovation to create it.

This last point is a true challenge for the NHS. Bold innovation is a challenge for any government programme, because to innovate is to take risks, to avoid being bounded by our current experience and reach beyond it to try something new. Yet this is exactly what Beveridge challenged us to do. To be guided by our experience but not to be limited by it. Are we up to that challenge?

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The NHS is the envy of the world – a triumph of western 20th century healthcare. It gives all citizens access to essential services based on their level of need, free at the point of care. And the care is always there.

The NHS was born out of a belief that social progress demanded a public response to what Sir William Beveridge called “the five giants” that were the scourge of human happiness: “want (or as we would call it today, poverty), disease, squalor, ignorance and idleness”.

In drafting the report that gave birth to the NHS, in November 1942, Beveridge suggested three very modern admonitions about how such a system should be created:

1. The need to see beyond current experience – in particular beyond entrenched “secular interests” that resist change – and not letting fear of change get in the way of creating something new.
2. That health does not exist in a vacuum: social progress depends on our addressing all the other great social “giants” at the same time – each of which influences the others.
3. That the state must work with individuals, and that the safety net created through social programmes should encourage, not stifle, individual control and personal responsibility.

These amazingly far-seeing concepts are still relevant today. We continue to struggle with mental models that prevent us from imagining a future healthcare system fundamentally different from the one we have now. It’s a kind of “healthcare exceptionalism,” that treats healthcare as if it is unique and separate from other aspects of our lives, rather than being seamlessly integrated with every part of them. And that conflicts with finding the balance of independence and dependence required by a state that wants to provide for its citizens, without depriving them of their autonomy and individual initiative.

# A century of change

At almost exactly the same time as the NHS was being born, another revolution was taking place. This time in science. In early December 1942, a few weeks after the Beveridge Report was published, the first sustained nuclear chain reaction was observed in an underground laboratory at the University of Chicago. This experiment ushered in the nuclear age and with it, the transformation of every branch of science under the sun – every branch, that is, except the science of management.

Think about how the world has changed since the launch of the NHS in 1948. The industrial post-war world is so fundamentally different to the highly technological world we live in today.

Advances in clinical medicine, medical technology, and pharmaceuticals have made far more conditions treatable in 2008 than were possible in 1948. And the initial NHS focus on a regulated system of hospitals, to standardise quality and ensure universal access, has given way to a desire to move care out of hospitals and take it closer to community and home.

In 1948 it was believed that the public health measures taken to reduce population mortality had already achieved their impact, and that any future improvements would depend upon developments in medical treatment. In 2008, we know that while improvements in medical treatment have achieved stunning success, the causes of mortality today are overwhelmingly associated with diseases that are non-communicable and largely preventable. We are plagued by chronic illnesses such as obesity, diabetes and forms of cancer, caused by lifestyle factors such as drinking, smoking, diet and lack of activity. Today, we know that future improvements in mortality depend on efforts to improve the healthiness of lifestyles.

So much has changed since the inception of the NHS. Today's England is more affluent, more technology enabled, more diverse, and more consumerist than could have been conceived in 1948. Citizen expectations about every element of our lives, including service, choice, and convenience, are very different today. How we spend our time, how we entertain ourselves, how we learn and how we communicate are all undergoing radical change.

So what kind of NHS would we create if we were starting from scratch today?

# From rational hierarchy to governance by network

In 1948, an industrial model of social organisation prevailed. The system was rational and hierarchic, with centralised decision-making and a pyramidal operational structure that placed policy-makers at the top and the people receiving services at the bottom.

The industrial organisational models of the past were based on standardisation, hierarchy, rule-making, and formal divisions of power and labour. They have made way for more fluid organisational designs, based on looser networks of teams working harmoniously in matrixed organisations, with highly decentralised decision-making.

The NHS reforms introduced ten years ago called for shaping services around the needs of patients, ensuring continuity between health and social services, focusing on health and not just on treating illness, and creating more transparency in the system to help people make informed health decisions.

These reforms have the potential to transform the NHS. But they cannot work if we continue to think about organisations, management and governance in 20th century terms. As Beveridge told us, we have to get beyond our experience – use it, but reach beyond it – to achieve our goals. But we need to use the technology, attitudes, know-how, and organisational structures that exist today rather than those that prevailed in 1948.

## The Web as metaphor

21st century thinking is about personal engagement. Changes in the nature of technology, demographics, and the global economy are giving rise to new models of production based on community, collaboration, and self-organisation rather than on hierarchy and control.

In the last ten years, a revolution in thinking about the relationships between individuals and complex systems has emerged as a result of the evolution of the world-wide web. Indeed, the web is itself the most compelling metaphor.

The first generation of the world-wide web – known as Web 1.0 – was all pull and no push. The web was “host” to content that

would be accessed and drawn down by the user. Distribution was centralised and communication was one-to-one or one-to-many. Knowledge was organised into pre-defined categories. Expertise was a property of the host and content was judged and accredited by experts in respective fields.

Web 2.0 is the second generation of web organisation that has transformed the web – not only as a learning and communication tool but also as a model of social organisation. Web 2.0 is highly interactive and extremely personalised. Targeted content is pushed to users based on their preferences. Users determine how much information to get and in what form. These developments in the web have caused many people to rethink how to share information, how to communicate, how to create, how to innovate, and how to effect change in organisations and wider society.

Web 2.0 embodies a new model of social organisation and communication in which the opportunity for co-creating knowledge in self-organised networks can become a model for co-creating health. Just as Web 1.0 has transformed into Web 2.0, so the NHS needs to transform from Health 1.0 to Health 2.0 in order to meet the needs of healthcare in the 21st century.

Web 2.0 is all about communities and co-production. Social network sites make it possible, easy in fact, to find like-minded people with similar interests. Communication can be one-to-one or many-to-many. The open-source movement democratises knowledge and fosters mass collaboration, whether on software development (the Linux operating system) or the world's largest encyclopaedia (Wikipedia). Self-regulating social networks are the dominant organisational model, and everyone can contribute content.

■ ■ WEB 2.0 IS THE BUSINESS REVOLUTION IN THE COMPUTER INDUSTRY CAUSED BY THE MOVE TO THE INTERNET AS PLATFORM, AND AN ATTEMPT TO UNDERSTAND THE RULES FOR SUCCESS ON THAT PLATFORM. ■ ■

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Most importantly, Web 2.0 is anti-hierarchical – the system is fundamentally networked and enables relationships between and among people. Enormous resources – more than can be contained in any textbook let alone any single brain – are available and reachable. Information is searchable, organised by users and added to by users, from minute to minute. Knowledge is contributed by users, and expertise is an emergent property of the community, residing in the networks themselves – conferred

by the collective judgements of the many rather than the personal judgements of a few.

Ever advancing technology is enabling new ways of collective thinking, learning, deciding, behaving, sharing, organising, and acting. But the web is only one of many technologies that will make Health 2.0 pervasive and persuasive. By the time we catch up to the opportunities created by Web 2.0, it will have passed on to its next generation – Web 3.0 – breaking out of the computer box and extending freely into our everyday lives: from mobile phones to everyday appliances, even the clothes we wear.

We have already reached the next frontier for web access through mobile phones and handheld devices. These devices will mobilise much of the functionality of the web. The level of functionality of these devices will continue to grow, and as it does the digital divide that many feared would separate the middle classes from deprived populations will begin to be breached. In Britain over 65% of people currently have access to mobile phones, and one in nine have web mobile access.

That divide will become erased with the advent of ubiquitous, pervasive, and persuasive technologies. Ubiquitous computers are small, networked devices embedded in everyday objects capable of capturing and sharing information and generally designed to support everyday activities. Futurists have imagined smart refrigerators that can catalogue electronically labelled contents and compute nutritionally specific menus depending on their contents. Or biometric sensors woven into clothing that can connect to environmental controls and regulate interior spaces to your specifications. Pervasive technologies deliver spontaneous services through ad hoc connections to other devices. And persuasive technologies include sensing and communicating technologies developed specifically to influence personal behaviour.

These technologies will be computer-driven, but not computer dependent. And the computers will not be in boxes, as we know them today. Instead they will be wireless, mobile, deeply contextual. Their ability to penetrate the context of everyday life will make them exquisitely attuned to and adaptable to us as individuals.

The web is not only personal and democratic, it is egalitarian. Speakers from the web can be old or young, black or white, male or female, right or left. Their voices speak for themselves, and they are filter-free. That is, free of the judgements that typically colour our interactions with other people, and that often lead us to make unwarranted assumptions. The web is a colour-blind tabula rasa. It waits for you to declare and define yourself. The web itself doesn't judge you and it makes it hard for others to pre-judge you – two of its most seductive characteristics.

Personalisation, independence and equality, conjoined with communication, participation, and engagement. The social

implications of these technologies are profound – and, paradoxically – profoundly individualising and socialising at the same time.

## Web 1.0 to Web 2.0

Web 1.0	Web 2.0
Centralised	Distributed
Individual	Social
Content	Services
Made, packaged, and sold	Created through use
Expert-generated content	Person-generated content
Readable	Writable
Deliberate	Spontaneous, emergent
Static	Dynamic
Rigid	Loosely coupled
Knowledge organised in pre-defined categories in a taxonomy	Knowledge organised by "tags" into a "folksonomy"
One-way communication	Many-ways communication

# The potential of Health 2.0

## So what would it mean if the advances of the web were applied to health?

Of course this is not fundamentally about the web – we are using the web as a metaphor. But it is about technology and how advances in technology have enabled changes in the way we connect, learn, and organise ourselves, and could help us create better health. Key elements of the change are:

- Personalisation (including personal engagement, mass customisation, and individualisation)
- Community (including obligations of both participation and collaboration)
- Co-production (including person-generated content and person-to-person support)
- Openness (including notions of honesty, transparency, freedom, flexibility, disciplinary boundary crossing, and expansiveness)
- Ubiquity (implying mobility, context-sensitive monitoring and context-sensitive messaging)
- Emergence (organisation is not imposed, it emerges as the result of sharing, networking, and self-organising)

Technologies are already developing that will support a more personal level of healthcare, that is more conveniently delivered, and more integrated with everyday life. For instance, personal blood glucose monitoring enables diabetics to monitor themselves at home, allowing patients to integrate their care into their lives, and reducing dependency on the health system. Most importantly, it provides immediate feedback on glycemic control based on personal eating, sleeping, and activity patterns, rather than a one-time snapshot in a lab. The patient is better informed, therefore there can be a better conversation between patient and doctor, and better informed decision-making by both.

The first generation of these technologies decentralises care, gives patients more control, and permeates the boundaries between the care system and the community. In this first phase of change, the focus of care shifts to home, but is not yet supported by systems or communities.

But imagine a health system that centres around the individual. A system that is well informed about a person's health risk, their attitudes and behaviours, how they prefer to receive information, their linguistic preferences, and behavioural influences. A health system such as this could sense a change in a person's health risk or need and deliver context sensitive messages to help them

to adhere to their care plan, take their medicine, or talk to their clinician. Imagine the benefits of a home glucometer which can transmit its results via computer to be analysed and monitored, so that any changes in personal health risk can trigger messages, coaching, or other clinical support. And imagine being able to capture that data onto a computer, and being able to connect the person to a community of other patients with similar conditions, who can give each other tips and support in order to develop better strategies for coping with their disease.

### Sharing personal experience

Community interaction takes the fundamentals of the Expert Patient Programme to a new level. By understanding and managing their conditions, people can take more control over their health. By being able to talk to fellow sufferers, people new to chronic disease get to tap into the experience of people like them who have learned to live with and manage the disease effectively. They can share personal experiences about their conditions and how to manage them, their treatments and how they react to them, and how they cope with family and home lives.

Technologies already exist that can support community interaction. PatientsLikeMe (PLM) is an online community of people with ALS, MS, AIDS and mood disorders who share information about their condition and their treatment and use online tracking tools to monitor and share their experience in concrete, measurable terms.

PLM links to a whole community. And unlike the Expert Patient Programme, which relies on the individual experience of a single patient, PLM exposes people to a collective experience. It also provides patients with tools to track their treatments and experiences, creating a real-time experimental environment generating real-time data in a real-life context.

Communities like this will not only provide better support to patients, they will generate better data for clinicians to learn about the impact of clinical treatment outside of the controlled environment of the clinical trials. Google (GoogleHealth), Microsoft (HealthVault), and others are scrambling to provide a secure personal health record where people can maintain a comprehensive treatment history that can be made accessible, with the patient's permission, to doctors, clinics, hospitals or emergency services. Reliefindsite.com allows patients and doctors to work collaboratively to map, monitor, analyse, and treat chronic pain.

### Sharing professional knowledge

And indeed there will be communities of doctors as well as communities of patients. SERMO is an existing community of doctors that captures their observations about clinical treatment and gives them an opportunity to share observations and clinical insights and review clinical cases with other clinicians. Unlike social

networking sites, which allow users to connect with each other and share personal information, SERMO encourages frank clinical reporting and tries to leverage the “wisdom of crowds” to identify trends in clinical practice and effectiveness of clinical interventions.

These communities should not exist independently of the healthcare system and clinicians. The health system needs to support them, inform them, analyse them, and learn from them. And in order to do this it will need to be a data-rich, technology-driven knowledge management system that will help individuals find the most appropriate care.

The use of distributed pervasive technologies, embedded in context, will allow the capture of information and enable the health system to deliver context-appropriate support. Working in the background will be a system of data analysis and messaging that is regularly analysing an individual’s health data, making judgements about their health trajectory, and intervening to provide information and guidance that is tailored to their personal context.

Health 2.0 is thus as social as it is personal; as technologically sophisticated in the background as it is simple to the user in the foreground. It will create an entirely different experience for the patient. And it will radically democratise healthcare:

- It democratises medical knowledge putting it equally in the hands of patients
- It personalises needs assessment, with a rich understanding (to the extent the patient desires and allows), of personal health risk and personal health trajectory
- It individualises health communication, with patient control over when, where, and how
- It creates an opportunity for every individual to express their health priorities and personal preferences
- It strives, above all, to engage people in their own health

NHS 2.0 comes closer to Sir William Beveridge’s vision than the system that exists today. It envisages a patient experience unencumbered by the bricks and mortar that preoccupy us. It envisages a health system that is deeply integrated with all aspects of the way we live. And it envisages a health system that liberates people to independence and self-sufficiency through a combination of personal and social responsibility.

Some will argue that a system such as this will be more expensive than the system we have today. But there are good reasons to suspect that much of the investment in technology and resources required to support it would be offset by the savings made through a reduction of inappropriate care, the substitution of low-cost community for high-cost hospital care, increases in patient compliance and adherence to recommended care paths, and increases in patient safety and its consequent reductions in error and waste.

Some will say that although these technologies will be well-used by the middle classes, they may not be accessible to or embraced

by the poor and underserved. Evidence suggests the opposite. In the mid-1990s, researchers in the US created a programme called CHES – the Comprehensive Health Enhancement Support System. Even though web technology was in its infancy at the time, CHES embraced many of the features of Web 2.0. The innovative programme connected individuals by computer and included modules for managing stress, AIDS, heart disease and breast cancer. Participants had access to a bulletin board, where they could post questions to doctors at the National Institutes of Health, read personal narratives of other patients like themselves, take part in discussion groups about their personal challenges and stories, access a library of information about their conditions and use tools to help measure and manage their care.

Sceptics suggested that this sort of programme would not be used by the elderly and could not be used by the poor. So the researchers took the system to an elderly population and a population of poor, African-American women with a positive diagnosis of breast cancer at the public Cook County Hospital in Chicago. These women had an average reading level of 8th grade (about age 14) upon entering the programme. Despite this, they became some of the most active users of the programme. They were especially active in the social networking and patient narrative features (as opposed to the ask an expert and library features), and generally improved their self-reported health status more than any other group.

## Health 1.0 to Health 2.0

Health 1.0	Health 2.0
Focused on the system	Focused on people
Healthcare to fight disease	Focused on creating health, not on healthcare
Top down regulation, planning, and budgeting,	Bottom up risk management through personalisation, engagement, activation
Process engineering	System thinking
Waits for you to come to it	Anticipates your needs and reaches out to you
Draws on economics, medicine, engineering sciences	Draws on psychology, sociology, anthropology, ecology
Driven by science: evidence-based care	Driven by personal preference: choice, independence, transparency
Standards are imposed	Standards emerge as a necessary pre-requisite to collaboration and sharing
Oriented to the average patient	Targeted and tailored to the individual
Opaque and expert-dominated	Fully transparent and democratic
Medical expertise is valued	Patient expertise is valued
Technology resides in the system; patients must come to it	Ubiquitous technology resides with patients and the system reaches out to them