

AN NHS INFORMATION REVOLUTION TO SAVE LIVES

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Summary

Conservatives are proposing to transform information services in the NHS to raise standards radically and help prevent tragic events like those that took place at Stafford Hospital from ever happening again.

Alongside a breakdown in management, there were two fundamental failures at the heart of the Stafford Hospital tragedy. The first was Labour's imposition of top-down targets which occurs throughout the NHS. This system forced staff at the hospital to follow rules which actively caused harm to patients. As the investigation into the tragedy concluded, it became clear that government targets contributed to hundreds of deaths at Stafford.

The second failure was the closed culture in the hospital. There was too little information available to the public about the problems that were taking place and, while management knew about many of the failings, they did not take action. In fact, they tried to hush them up. This closed culture problem has been behind too many hospital failures.

Conservatives believe patients have a right to know what is going on in the hospitals in which they are treated and what quality of care they can expect from staff. So we will put, for the first time, key information on care standards and patient safety fully in the hands of the public. This puts no extra burden on NHS staff – they already have to supply huge amounts of data to the Department of Health, but this is geared towards meeting bureaucratic targets. We will channel it to suit the needs of patients.

Along with more accessible and meaningful information, we will give people improved means of reporting bad practice as it occurs and checking on a hospital or GP's care record before they are treated. Low standards will be fully exposed and people will never again be left in the dark about poor practice or left powerless to do anything when they receive poor treatment.

Our information revolution will also involve developing new ways of tackling health inequalities, including ensuring people are not excluded from the improved system because they do not have internet access. Independent organisations will be allowed to compete for NHS contracts and develop innovative information strategies to help people better understand key health risks and diseases like cancer, and make informed choices over their treatment options. This will improve public health and help cut the costs to the NHS of late diagnosis and treatment.

By shifting accountability in the NHS away from politicians and firmly towards patients, our information revolution will genuinely empower people to shape the kind of care the NHS delivers, raising standards of both healthcare and safety throughout the service.

What's wrong with the current system

Labour's regime of controlling the NHS through top-down government targets and bureaucratic reporting was supposed to ensure higher standards. But after twelve years, the actual outcomes of NHS care (e.g. survival rates for cancer) are now amongst the worst in Europe. The problem is that NHS activity is measured according to various targets set by politicians and bureaucrats, while too little is geared towards actual care results and safety standards – this drastically limits the patient choice and service innovation needed to improve the NHS, and leaves too much bad practice unchallenged. Furthermore, data is often rendered meaningless as it is published too long after it was collected. For example, the deadline for returning surveys for the National NHS Staff Survey 2008, was 8 December 2008, but the information was not published until 25 March 2009, by which time it is out of date.

Stafford Hospital failings. The Healthcare Commission's report into the failings at Stafford Hospital clearly identified its 'closed culture' as a major problem that prevented people from accessing even the most basic information about safety. It gave the example of data on infection rates: 'A former member of the patient and public involvement forum (PPIF) commented that it was difficult to obtain information from the trust on *C. difficile*. He felt this should be in the public domain. He obtained a copy of the infection control minutes for the meeting on 21 September 2006, which recorded that there had been 341 cases in total, of which 285 were inpatients, averaging 36 per month between January and September 2006. The minutes were not marked as confidential. When this information was released by him to a newspaper, he was expelled from the forum for breaching the code of conduct of the PPIF. He told us that the chair of the trust met with the chair of the PPIF and said that confidential documents would not go to the PPIF any more' (p.89).

Information produced for managers not patients. A lot of information is collected in the NHS, but it is inaccessible and indecipherable to most patients as it is geared towards the detailed requirements of regulators and managers. Simple, trustworthy information is needed to help patients get the care they want and to help providers raise their standards. Yet, despite the reams of information out there, it is still incredibly difficult to find an answer to a simple question like: 'How can my mother best be treated for Alzheimer's in Somerset?'

NHS choices website inadequate. The NHS choices website, which the Government launched to help people navigate their way through the NHS, does not address the problems described above: it is not sufficiently independent, as it is controlled by the Department of Health; it does not break information down by individual hospital let alone by member of staff; it is not simple enough for patients; and it is inaccessible to the 29 per cent of people who are not internet users (Office of National Statistics, 26 August 2008).

Too many numbers, not enough real-life information. There is a chronic lack of reliable information about the results of treatments at local hospitals that has real-life relevance to patients. For example, it matters little to a patient how many people went to an A&E unit in the last quarter and what proportion were seen in a four-hour time target, which is the kind of data the Government currently compiles. What matters is whether they got good treatment or not, with their condition correctly diagnosed and addressed. While the Government is attempting to collect some data on how good patients' care was ('Patient-Reported Outcome Measures'), these are far too narrow as they only refer to four procedures. The health regulator conducts surveys of patients' views, but too few patients respond - in some areas only one per cent (Healthcare Commission Patient Survey 2007).

Political manipulation of information. At present, it is too easy for politically inconvenient questions simply to be removed from surveys of patients and staff. For example, the Healthcare Commission used to ask staff whether they agreed with the following statement: 'If I were a patient of this Trust, I would be happy with the standard of care provided' but this was removed from their most recent staff survey, published in March 2009. The importance of this question is demonstrated by the fact that it was a key indicator of the poor performance of Stafford Hospital. The Healthcare Commission's report on Stafford found that: 'the majority of doctors we interviewed would not have been happy for a relative to be treated at the trust. In a 2006 survey, only 27 per cent of staff said they would be happy to be cared for at the trust, compared with 42 per cent nationally' (p.8).

AN INFORMATION REVOLUTION

Our plan for an information revolution will spark a major shift in NHS accountability away from politicians and towards patients, making care standards and safety records fully available to the public, including NHS staff. This will allow the NHS to at last become genuinely patient-led. People can check on care results before they choose a care provider and also receive key information on major health risks and how to prevent them. Bad practice will be fully exposed and people can report it as it occurs, while best practice can be shared and spread.

What information will patients be able to get?

Care and safety standards. Patients need simple, independent information about standards of care and safety in the NHS that is relevant to their healthcare needs. There are kinds of questions we believe people want answers to:

Where can I find the best GP in my area? If I need out of community care, which practices are good at providing care for someone with my condition? What is the quality of local community services to support me? How will my local GP practices help me get the best local services?

If my GP thinks I may have, for example, heart problems, which hospitals provide treatment for heart problems? What are the arrangements for access to those services? What kind of support do they provide? How long would I have to wait for treatment?

Of the hospitals that treat, for example, heart problems, which have the best results? What percentage of their patients recover? Are patients happy with the service? Would staff use that hospital if they or their family needed treatment?

Are there any other factors I need to consider about the hospital? How does it do on issues like infections, on single-sex accommodation and the availability of single rooms?

What happens after my initial hospital treatment? Does this hospital do well at following up patients and making sure their treatment was successful? If something is wrong or if I have any feedback on the service how well would I be listened to?

A patient-centred service. This kind of data, provided in an accessible and meaningful way, will empower patients and drive up standards in NHS care, both in hospitals and in the community. Under our proposals, the NHS Board will publish commissioning guidelines with help from NICE, to provide evidence-based standards of treatment which patients have a right to expect. Within these standards, there will be critical quality measures (some of which are included above). The Care Quality Commission will be given responsibility to combine this data with outcomes data and service standards, in order to assess overall performance of hospitals and other healthcare providers. This will in turn provide patients with an improved level of information relevant to their referral and treatment. And it will also provide a validated base of information from which information brokers will be able to provide a range of information sources for the public and patients.

The right level of detail. Most current information on the NHS is too general to be useful, such as the performance of large NHS trusts. We will provide information at the level of individual hospitals and, in some cases, on individual departments within them. On infections, for example, a patient with heart problems needs to know, not just whether the hospital has a high MRSA rate, but whether there have been problems in a particular department e.g. cardiology, in which he or she will be treated. This information could be easily collected by Trusts and published to inform patient choice.

Information will give people more control over their care

Offering real choice. Having access to the information we describe here will give patients a genuinely empowered choice about where they go for their treatment, in a way that is not currently possible. Hospitals should be in a position to offer patients and GPs choice of referral to a named consultant or a generic referral to the hospital, recognising that patients may themselves have to decide whether they want faster treatment or access to a named consultant.

Patient-reported assessments of care. To make the NHS fully responsive to patients' needs, we will develop 'patient-reported outcome measures', or PROMs, which collect patients' views on outcomes via a simple questionnaire. PROMs will be used alongside patient experience data to help inform our healthcare performance assessments. We will ensure questions are specific enough to capture the things we know matter to people, such as ward cleanliness and whether nurses treated them with dignity and respect. A new and independent national patient voice, Healthwatch, will approve the questions we use and no questions will be able to be removed without their say so.

Identifying problems before they become tragedies: immediate patient feedback. As well as publishing information on PROMs and patient outcomes for public use, we will allow patients to give immediate feedback to hospitals about problems they encountered – as well as good experiences – which should flow freely from hospitals to the regulator. This would help give early warning if things are going wrong at a particular hospital, and help hospitals continuously monitor their performance so that problems like those in Stafford can be identified before they get out of hand. Patients could also provide feedback on GPs.

Encouraging innovation through a new information marketplace

A new era of competition: ending the monopoly of NHS choices. Because private and third sector providers have clearly shown they are far better at providing and disseminating information than the public sector, we will end the dominance of NHS Choices and open up the market for the provision of information to any willing provider. Information providers will be able to compete on a level playing field for any government funding and will have equal access to all NHS information that the NHS Board decides should be collected. NHS Choices will no longer be run from the Department of Health and will have to compete on the same terms as all other providers.

Information driving greater innovation in the NHS. As well as allowing different providers to compete to manage NHS information, we will drive greater innovation by allowing them to develop new ways of using information to provide better services to patients. For example, we want to see a system where people could download an NHS application with real time updates on their i-phone and where online internet forums like 'facebook' provide a powerful way for patients to group together and share their views.

Examples of the kinds of innovation we want to encourage:

DVD information packs for patients. In the US, the independent 'Foundation for Medical Decision-Making' has developed a series of DVD information packs which they proactively send out to patients who might be lacking information about the different treatment options available and their implications. For example, surgery for prostate cancer can have side effects and some patients will prefer other options like chemotherapy or brachytherapy, others may even prefer 'watchful waiting', as not all indicators of prostate cancer are of an aggressive form. The DVD takes patients through their options in a simple way.

Real-time patient feedback. The organisation “iWantGreatCare” has developed a product allowing GPs or hospitals to get real-time feedback from patients on their experience of their care. This information is fed into a computer dashboard so that the GP or hospital can monitor patients’ satisfaction with their treatment as it happens.

Taking information to people who need it. The charity Starthere has been experimenting with innovative ways to get information to people who would otherwise struggle to access it. They provide simple, colourful information screens which people can navigate through to answer questions like ‘Where can my mother get treatment for Alzheimer’s in Somerset’. These screens are available in places such as BT phone boxes, GP surgeries, libraries and Citizen’s Advice centres and on Teletext and mobile phones.

Reaching excluded groups

The power and reach of information. We recognise that health inequalities often follow the same patterns as other social inequalities, like poverty and disability. Not-for-profit groups and charities can often reach these groups far more effectively than government can, which is why we will open up the contract money that currently goes to the NHS Choices web information service to competition from charities and other providers. In addition to disseminating information about health services, they can also provide links to local support groups and other sources of advice and assistance.

People that don’t or can’t use the internet. There are still many people in the UK who never use the internet (often called the ‘digitally excluded’) and these are often the same people who suffer the greatest health inequalities or are elderly people who rely on health services more than most. A proportion of the NHS Choices money we are freeing up will become available for providers that work to reach digitally excluded patients.

Trial of information outreach centres. Some healthcare providers in the US very successfully use nurses in call centres to proactively telephone people with information about their healthcare and the options available to them. We could use this approach to provide target audiences with information about key health risks – for example, informing women about the availability of local screening for breast cancer. This innovation can help save many lives, as well as large amounts of NHS money, because it means illnesses can be prevented or those that need treatment receive it before it is too late. We will use some of the NHS Choices funding to trial this approach in areas with the greatest health inequalities.

Other benefits for the NHS

Slashing unnecessary bureaucracy. We will slash NHS bureaucracy by rooting out unnecessary data collection. We will ensure data collection is channelled towards improving patient care and ensuring standards in hospitals and community services are up to scratch. Bureaucracy linked solely towards meeting arbitrary Government targets will be slashed.

A modern IT system in support. The NHS needs a modern, efficient IT system to support the collection and publication of this information. Our review of NHS IT, to be published later in the year, will set out how this will happen.

