

**NEWSTATESMAN**



# Towards a blueprint for a **healthily informed** patient



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# Telling patients what they want and need to know

Over the past 15 years, advances in technology have meant that more information has been available more widely to many more people than ever before. In terms of our own health, this availability of information has made it possible for patients to find out a vast amount of information on all types of conditions and their diagnosis, treatment and prognosis.

Our appetite for this information stems from our desire to have control over our bodies and our lives and the fear that we experience, particularly when we are given a diagnosis that has serious implications for our health.

However, quantity does not equal good quality and patients are now in the position of having to consider how to filter out the quackery from sound judgement. While there may appear to be a surfeit of information, at the same time, this information may also be incomplete. For example, we may read of a new drug treatment that might save lives, but not find out about the likelihood of it working for us as an individual or the side effects and caveats that accompany it. The result can be confusion and an unwillingness to trust the healthcare professionals that we have always had confidence in, in the past, to tell us the best course to follow.

Even our doctors and consultants may feel bombarded with information and need assistance in unravelling the truth, when much of what they read may be published by a pharmaceutical company that developed the therapy and may underplay certain side effects of medication.

Following recent calls by many for a scheme for identifying good quality

information, Department of Health research revealed that 77 per cent of us had looked up some form of health information in the previous 12 months, and 75 per cent of us had found it difficult to establish the trustworthiness of the information that we found. It has started to address some of the variability in quality of information with its Information Standard (see: [www.dh.gov.uk/en/Healthcare/PatientChoice/BetterInformationChoicesHealth/Informationstandard/DH\\_098427](http://www.dh.gov.uk/en/Healthcare/PatientChoice/BetterInformationChoicesHealth/Informationstandard/DH_098427)).

This scheme aims to improve the patient experience by certifying reliable producers of health and social care information with a quality mark so that consumers can easily identify it as coming from a reliable and trustworthy source.

As patients find out more information independently, perhaps a new relationship will need to develop between them and their healthcare providers – a more collaborative and supportive relationship where neither party feels challenged by the other as they are working together towards the same goals. This interaction might include more of the patients' experiences of therapies, both in terms of outcomes and experience of the therapy.

If a treatment is very unpleasant but very effective, patients may need support from their doctor to comply with treatment and understand that persisting with it will yield results. Conversely they might be supported to decide that the therapy is not for them if the time spent enduring the treatment outweighs the benefits that it will bestow on them, perhaps for a limited amount of time and with side effects that may seriously affect their quality of life.

# Baby boomers will be experts on their own health

They know their rights and they have more knowledge available to them than ever before, writes *Paul Rodgers*

Preparing to see the GP makes me feel like a mediaeval knight girding himself for a joust. First, I don a chain mail of facts gleaned from the web. Then I take up a psychological shield against dismissive suggestions that I “stop worrying” and trust the professionals. And finally, my lance, the pointed belief that I have the power to decide matters concerning my body.

Fortunately, my current doctor is not so much the Black Knight as a maiden dispensing favours. At our last appointment, I listed my symptoms, offered my analysis and requested a specific treatment. She confirmed my lay diagnosis, checked her Pharmacopeia and wrote me a prescription.

It’s not always so easy. Before surgery at the Middlesex Hospital a few years ago, I asked the anaesthetist what she was going to give me. “Are you a doctor?” she asked, before telling me the sesquipedalian names of the gases she planned to pump into my lungs. I asked what they did. In a tone reserved for addressing four-year-olds, she said: “One will take the pain away and the other will make you very sleepy.” In her world, the gulf between doctor and idiot was unbridgeable. Yet, she was the patient-friendly member of the team. The surgeon was so supercilious he made the stereotype for his profession look self-effacing.

The relationship between doctors and patients is changing rapidly as a result of three forces. First is the sense of assertiveness that the baby-boom generation has demonstrated since the Sixties. Unlike their

parents, they’ve never been inclined to ovine docility. When they bleat, they expect the shepherd to come running, no matter what field he’s in. As they enter retirement-prime years for consuming healthcare services – their demands will become harder to ignore. And the cohorts behind them are no less insistent on their rights.

Second, patients are now equipped with far more knowledge than ever before. Google, Wikipedia, NHS Direct and specialist medical websites have made it easier for us to figure out what we are suffering from and the treatment options available. Some 70 per cent of British patients now consult the internet before they consult their doctors. It is hard to maintain the arrogance of a high priest of health when anyone can study the temple’s innermost secrets online.

Third, a new generation of medical professionals has realised that patients who understand what ails them are more likely to stick to treatment regimes, whether it be a course of drugs or a set of lifestyle changes. And the questions they raise help doctors conform more closely to emerging best practice.

Realising these benefits, the government, the NHS, trusts, hospitals, consultants, clinics, patient groups and pharmaceutical companies have been pouring information on to the internet, as well as into more traditional posters, pamphlets and television adverts. However, their impact varies widely. Compare the bureaucratic leaflets stuffed inside drug packets and routinely discarded,

unread, by patients with the “act FAST” stroke campaign, with its simple, clear message. Suppliers of information should seek the middle ground between “2,2,2-trifluoro-1-fluoroethyl-difluoromethyl ether” and “it makes you very sleepy”.

Combined properly, these forces lead to the concept of the expert patient, someone living with a long-term illness who is well informed about their condition and can manage it themselves. Research by Professor Julie Barlow at Coventry University found that expert patients had less severe symptoms, a significant decrease in pain and improved “life control”, activity, resourcefulness and satisfaction. Importantly for the cash-strapped NHS, they went to their GPs 7 per cent less often, had 10 per cent fewer outpatient visits and 16 per cent fewer visits to A&E departments. Better-informed patients could also lead to better reporting of symptoms, leading to faster and more accurate diagnosis and to more comprehensive feedback on drug side-effects.

Yet this tectonic shift is not without its problems. A Google search for “cancer” returns 178 million results; “breast cancer” gets 35 million hits. Even a rare cancer such as a “placental site trophoblastic tumour” generates 2,250 links. Wading through such a wealth of information is a daunting task. Since most people are unlikely to look much beyond the first few pages of results, they become dependent on the ordering done by the search engine.

Then there's reliability. Some sites, abandoned by their authors, present out-of-date advice. Poorly maintained ones may have errors that lead the reader astray. Even good websites could have information inappropriate for treating a patient's specific illness. Some, such as those selling quack cures, may be wilfully misleading. At best, these will waste time as health professionals labour to correct the false impressions left with patients; at worst they can lead to people turning from potentially life-saving therapies to unproven alternatives. You might think that books are a better bet, since the barriers to publication are so much higher. But publishers are under no obligation to ensure their authors are qualified or get their facts right. A sensational title can be counted on to trump experiment, reason and peer review in the sales charts.

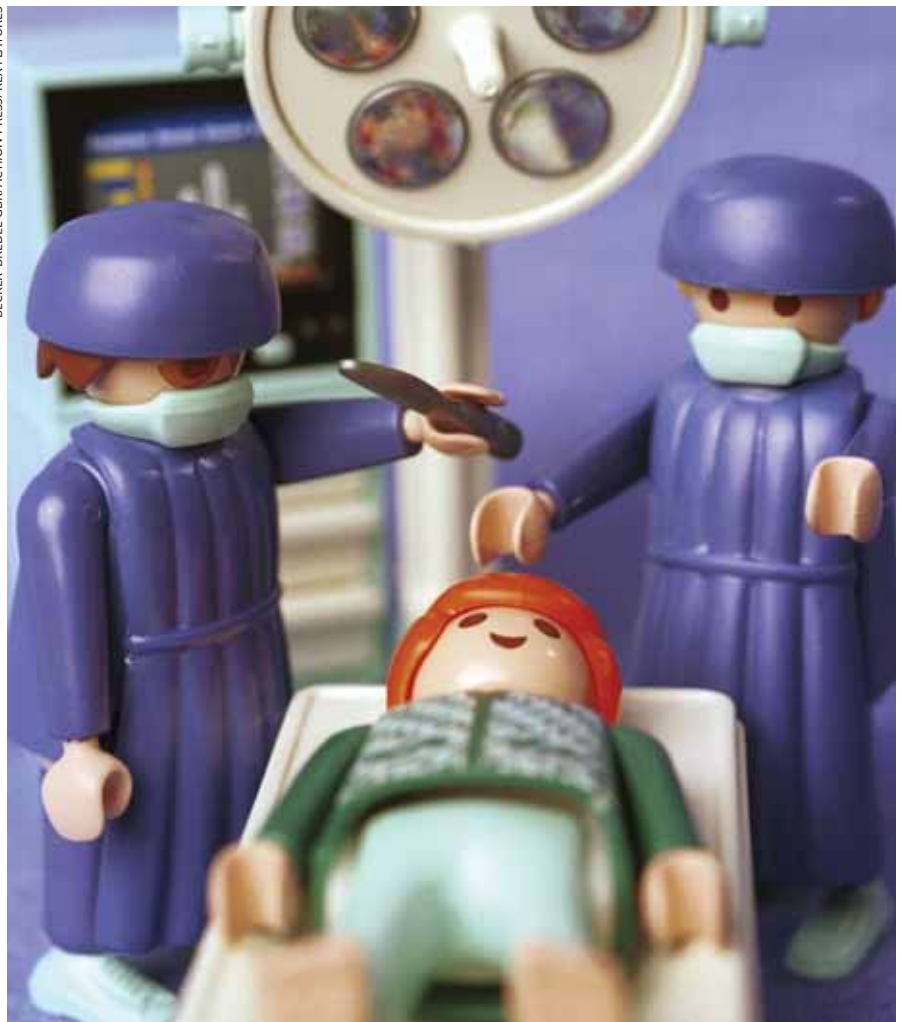
Journalists pride themselves on filtering information for their readers, but they too can be sucked in, particularly if a source looks credible. Consider the MMR vaccine. Andrew Wakefield's claim in 1998 of a causal link between the vaccine, bowel disorders and autism led to a fall in inoculation rates below the 95 per cent needed for herd immunity. In 2005, more than 1,000 cases of measles were reported, the highest level in decades. Although comprehensively debunked, the myth continues to circulate, and every so often a reporter will give it credence by calling it a "controversy" rather than an established falsehood.

Even when there is a real danger, information reaching patients often fails to put the risk into context. People are not good at judging risk intuitively, generally because they give more weight to a rare but dramatic outcome than they do to a common but less serious one. Statistical presentation can add to confusion. If the danger of catching a disease rises from one in a million to two in a million, patients have little to fear, but when this change is described as a "doubling" of risk, they will almost invariably worry. Novelty also distorts perceptions. So far, swine flu has shown itself to be less deadly than seasonal flu, yet it has the nation on the verge of panic.

As patients become better informed, it is not enough that a scattering of doctors and institutions respond enthusiastically. If the problems of patient awareness are to be addressed at the same time as the benefits are enjoyed, the entire healthcare system must realign itself with a world of patient power. We are not sheep, but knights.

*Paul Rodgers is a science, medicine and technology journalist*

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**Suppliers of information should seek the middle ground between “2,2,2-trifluoro-1-fluoroethyl-difluoromethyl ether” and “it makes you very sleepy”**

## Call to action

- Make patient information easily accessible, evidence-based and up-to-date, encompassing both the clinical and service aspects and supported by an effective and understood approval system. Information should also cater for the requirements and preferences of individual patients.
- To overcome the morass of information currently available, make the approach of patient information providers more joined up, engaging those groups best placed to supply high-quality, reliable information on medicines and treatments.
- Ensure information to patients complements, rather than supplants advice issued to patients by clinicians, with access to prescription drugs remaining subject to professional judgement.
- Facilitate improved health literacy to address the disparities between population groups in understanding services and treatment options, and enable more effective dialogue with clinicians.
- Continue to establish systems that create a more evidence-based approach to information. Encourage ways that enable patients to communicate their experiences of treatment, as well as its outcomes to improve clinical understanding.
- Improve clinicians' training to encompass “soft” skills to facilitate collaborative communication with patients.

*These points are just some of the suggestions and comments made by participants in the round-table discussion that follows on page 6*

# Round table: giving targeted information

**Jenni Russell** I am not sure if you saw the London *Evening Standard*, but there is a story in there involving the parents of an eight-year-old girl who is dying of a rare disease. They have discovered that a drug company is running trials on a drug that may save her life. This drug costs £44,000 per month. Having raised £860,000, the parents are demanding that the drug company provides them with the drug. The company has said it cannot because trials are incomplete.

To me, this story summarises the pitfalls about informing patients. On one hand, you have parents who are sure that there is a chance and on the other hand you have drug companies thinking, "We may be sued. This is not safe. You cannot let this stuff out. You cannot allow rumour to drive health policy." I want to ask the minister, Mike O'Brien, what he considered the pitfalls and benefits of attempting to inform patients.

**Mike O'Brien** Patients want to be informed in order to have control of their lives, their illness and their medication. Measures are being introduced in order to deal with some of the fear and loneliness that results from being diagnosed with a life-threatening disease or a long-term condition. These can change the way in which a patient leads his or her life. Such a diagnosis can be traumatic, especially when the patient has to find out for themselves the implications of the diagnosis and the nature of the drugs they will be prescribed. This period can be very worrying for people.

In the past, we have been in a situation where we



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have needed to search around for information in order to know what was happening; one would rely on nurses, doctors, or consultants to provide the information. The reliance was a result of trust. Today, through the internet, patients can be overloaded with information regarding the nature of a drug, opinions about its effectiveness and its side effects. There can be a vast amount of information and a variety of alternatives.

There are 50,000 organisations that provide information on health and social care in the UK and many are located abroad. Their reliability varies. Having the ability to sift through that information, through a mass of, sometimes conflicting, opinion, and to genuinely empower people to make those choices, and to know who they can and cannot trust, is one of the key problems that we face today. Information overload in healthcare is something that needs to be dealt with.

However, information overload is not the only problem. With new illnesses and new drugs, there can be a lack of information. Jenni identified, at the start of this discussion, a scenario where we have a new drug, which might deal with a particular condition. Where there is a new drug, it needs to be tested and to come through the relevant procedures.

Even after this, a lack of information may remain as to what the drug will do and whether or not it will be reliable. Despite the changes and the increase in the availability of information, we have found that patients still trust their healthcare professionals, doctors and consultants to give them the best judgement.

The difficulty is that doctors and consultants can also rely on a wealth of information that can come at them with regard to a particular condition. Occasionally, they may need help to identify the quality information that should be passed on to the people they care for.

The pharmaceutical industry, in particular, is often able to provide a wealth of research and data because the cost of producing a new drug for the market, I am told by some of the large companies, is in excess of £1bn at the moment. Through this process, they will accumulate a wealth of knowledge about their product. Of course, because it is their product, they want to be able to sell it and ensure it is properly marketed. So, there may be a question about the reliability of the information. Often, pharmaceutical companies are the best source of information and, providing the research is verified and cross checked by peers, it might well be that their research provides us with reliable information for the public.

**Jenni Russell** Mark Duman, as the national Patient Information Forum representative, what do you think should be happening to ensure that patients are getting the best quality information? What are the pitfalls?

**Mark Duman** The Department of Health (DH) has launched the “Information Standard”. The related documentation suggests that there are somewhere between 60,000 and 120,000 information producers in the UK. One of the objectives of the Information Standard is to raise the bar for information providers. Information producers, such as Macmillan Cancer Support, Diabetes UK, and pharmaceutical companies, can, if they wish, receive an Information Standard quality mark from the DH. This indicates that the process that they have been through reaches certain accreditation standards.

**Jenni Russell** Is this a quality mark for being readable, understandable and correct?

**Mark Duman** It focuses on the process and not on the actual product. It focuses on whether or not their offering systems have been established correctly.

**Jenni Russell** So, it is not related to readability or comprehensibility. The role for the journalist remains.

**Mark Duman** At least, there is a role for a few journalists. We need to get patient groups involved but we also need to involve real patients. Many patients are not members of patient groups.

**Jenni Russell** Do you feel a lot of information in circulation is not understood?

**Mark Duman** That is interesting. There is an agency, represented at this table, which I shall not name, that tested the information it produced. It found that patients did not change their behaviour as a result of the information. The agency was told, but went ahead and printed the information anyway. In the case of a drug or a surgical intervention, this would be considered negligent. A significant current issue is that information is not considered a therapy; it is a luxury.

**Mark Platt** To follow up on the issues raised by Mark, the Information Standard is about assessing an organisation’s ability to produce information that reaches certain standards: is it produced with peer-group reference? With peer-group reference, the information included with regard to specific medical products has been checked with the relevant people: professors and those involved in the clinical trial. It ensures the information is accurate, understandable, and that reference has been made to the relevant areas significant to patients. The DH has produced the Information Standard. The National Institute for Health and Clinical Excellence (Nice) has produced another standard, which is concerned with evidence.

I am from an organisation called National Voices. Until October 2008, we were called the Long-Term

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Conditions Alliance. We spent 20 years supporting organisations that provide support to people with long-term conditions. We never had too little information; it was often that the information was inaccurate, confusing, complicated or provided a limited picture that did not give an impression of what it was like to live with the condition.

The government has taken some impressive steps: the Information Standard and information prescriptions. The latter is a codified way of making sure that patients are given the information in a timely fashion and in a manner that is appropriate to them, when they are ready. It will enable them to choose what kind of information and when they would wish to get it. There was a disparity in the information provided; some patients were not given any, while others were diagnosed and informed of the terminal nature of their condition at diagnosis. There was confusion, rather than consistency.

In addition to information prescriptions, we are moving into a codified way of providing care, which encompasses information, as well as treatment. Information is about all the aspects you need to know to live your life as well as possible with a certain condition. It is about the services available, self-care, self-management, advice lines and support groups. It is about the whole range of services. There are many people providing information. A study carried out two years ago found that there was too much information and it was confusing. The mechanisms being discussed are attempts to make it simpler.

I like the idea of the “informed patient” but I question for whose purposes we are providing the information: the patient’s or ours, in order to allow us to tick boxes. We have to make sure that the patient gets what he or she wants in order to make the decisions they have to make, as opposed to providing a leaflet, a care plan and a prescription and leaving them alone.

**Nick Bosanquet** What the two Marks have said, points in the direction of a positive agenda. We suffer from having too much information. Within this amount of junk, irrelevant, or meaningless

information, there is a key area, where evidence-based information could improve both the process and the outcome. There remains scope for pharmaceutical companies to work with the NHS, as has been done with diabetes in Birmingham, to improve the uptake, motivation and outcome for patients.

There should be two-way communication that uses independent evidence to find solutions to particular problems. We should be willing to face negatives as well as positives. The great propagandist, Lloyd George, said the only effective propaganda was the truth. I hope the companies can learn that, too. We also need to focus on increasing motivation, particularly with regard to intractable lifestyle options.

I feel there is a huge opportunity for evidence-based information to improve process and outcomes.

**Jenni Russell** There is a dual agenda here; one is about getting people more control, while the other is about saving the NHS money, in order to avoid the micromanagement of doctor/patient relationships.

**Nick Bosanquet** It should save some money. The problem with the current system is that people wait until they have something respectable to report to hospital authorities, rather than seeking an answer immediately. Somebody from BT said, "If someone sees a doctor quickly, the problem halves; if they have to wait, the problem doubles."

**Mark Platt** We have also seen that patients who are given the level of information that they want are less likely to turn up in A&E as a result of being unaware of how to manage their condition. It will require investment. Investment has been made in the Information Standard and information prescriptions; these are purchases for the future because they will help to create citizens who are better able to manage their conditions themselves, with a degree of support.

At some point in the near future, while the NHS IT system will be expensive, the benefits will allow people to be more comfortable with the information that they receive.



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**Nick Bruce**

**Mike O'Brien** Empowering patients means that they have the ability to make decisions themselves. There remains a question as to whether they will make the right clinical decisions for their long-term care, or whether they will make decisions, for example, to use certain drugs because the information they have accessed was not reliable, leading to an exacerbation of their condition.

**Nick Bosanquet** The step towards empowering patients would require professionals to be adequately informed as well. This would allow them to communicate and to develop these evidence-based solutions with the patient.

To provide a glaring example of poor evidence being provided to patients, I would cite the National Radiotherapy Advisory Group. This group recommended a 90 per cent increase in fractions, without mentioning, in the whole 60-page report, the issue of side effects or access to radiotherapy. These are both huge problems.

**Jonathan Michael** It is important that we start with the principles. One of these is, "How much information should patients or society have?" The principle has to be, "They must have as much information as they want."

In moving towards a consumer-focused approach to healthcare, where healthcare is working as a service, whether public or private, people will want information. Using the internet, you look at reviews of hotels, destinations and soon you will be able to look at healthcare options. The principle of maintaining open access to information remains an important key principle.

However, when managing healthcare, one needs to remember that not everybody wants to have the information or to make the decision; some will say, "Please clinician, you have the information, please make the decision for me." We need to respect that. We need to manage the complexity and accuracy of the information. With such a volume of information, a lot of it is misleading, incomplete and inaccurate.

For me, this does not alter the principle of people having a fundamental right to information. We try to control the amount of information available at our peril. I have spent most of my life in the NHS working with patients. Few have complained about receiving too much information but many have raised concerns about not getting enough.

**Nick Bruce** Building on previous points, at the heart of this is understanding what it is that patients want and need, as well as understanding how and when to provide that information to them. Something that we have identified in the research that we have done with patients is that they want quite different things. We really have to understand that variability in order to develop a pluralistic approach to sharing information, rather than assuming that we can define the one way in which people receive information.

We have done some work looking at the

relationship between breast cancer and weight gain. Something that came through very clearly was that patients want their clinical services provided in a clinic, but the diet and exercise piece somewhere else and at a different point in time. Understanding what patients want, and when, is key.

**Jenni Russell** Do breast cancer patients necessarily get fat?

**Nick Bruce** It is a concern for some patients. It is partly physiological and partly emotional.

**Martin Fletcher** I want to emphasise the point that Jonathan raised about the importance of openness. We have to look back only a few years to see that we are in a very different environment in terms of the availability of information. We are in an exciting place and we should be very positive about the possibilities of information as a driver for changing the system in a way that was inconceivable, even a few years ago.

In our own work remit, which is patient safety, there is no doubt that, the more informed patients and their carers are about their care, the more likely they are to act as agents of their own safety. We see that very powerfully in terms of medication. Put simply, a person who knows the medication that they are on and is given something that they are not normally given is able to ask questions about that and, in some cases, avert a problem. The work that we need to do is to ensure that the health professionals do not feel threatened by that, but rather see it as a partnership with the patient and their family around care.

My third point is around the huge potential of the web. We have barely scratched the surface of what we can do to address issues of customising, targeting and personalising information in a way that meets the needs of people across a range of perspectives.

**Peter Barron** The first thing to say about Google's involvement in this is that we are not a healthcare company and have no aspirations to be one. Our interest in this is to do with the mission of the company, which is to try to organise the world's information and, most importantly, to make it useful to people. We are constantly working on improving people's search experience to make searches relevant so that they can find what they are looking for among the morass of information.

**Jenni Russell** Does that imply that what they find is more likely to be other people's trusted sources?

**Peter Barron** Indeed; the entire basis of Google's mission was based on finding trusted sources. It started off as an academic exercise, so it was linked to by the most trusted other sources. We are very much bound up with the idea of the most relevant search being based on authoritative and valuable material.

The second area that we have done a lot of work on recently, and something that is extremely topical, is

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flu trends – the idea of collating a huge amount of search information from around the world and trying to predict where a flu epidemic might strike next. We have done this officially in the US, in conjunction with the Centres for Disease Control and Prevention (CDC), to attempt to predict, based on search patterns, where an epidemic is going to strike. For example, people search for symptoms or for remedies before they would ever contact a doctor and enter the official records. There is a value there in seeing patterns of anonymised, aggregated searches. It works extremely well in the US, and maps the official data. In fact, it is two weeks ahead of the official data. While we have done nothing official in the UK, we did an experiment around the Mexican flu outbreak, but that requires a lot of filtering, because the story is very much in the news and people are searching for it, whether or not they are ill.

The third area is Google Health, which has been in the news over the last week or so and which the Conservative Party has been looking at. That is to do with people being in control of their own health data, having access to it; being able to share it, for example, with members of their own family; and being able to carry it around with them, so that, if they move house, they do not have to start from scratch with a different health authority. That facility is up and running in the US; clearly, the culture of health provision in this country is very different from what is in the US.

We are at an early stage in terms of talking about it, but we would say that, where people have more access to and control over their personal health information, that is a good thing.

**Jenni Russell** Having spent some time in the US, you can see the bombardment of pharmaceutical company advertising, with the effect that people think, "This must be the remedy for my illness," and then turn up at their surgery demanding it. You see a very direct relationship between advertising and the drugs being prescribed, which we have, so far, rather avoided here.

**Mike O'Brien** In relation to the advertising of prescription drugs, we do not propose to change to a situation like that in the US. Prescription drugs should be subject to professional judgement being exercised as to whether or not people should have them. This has the benefit that, by and large, there is some professional judgement before these drugs are issued but it does make it a little more difficult for a patient to challenge the professional judgement of the consultant or doctor issuing the drug.

**Mark Duman** Nick raised an interesting point: in terms of information, we have to remember that one size does not fit all. Even in terms of the package insert – the leaflet included with the medication – we are one size fits all and, indeed, it fits many people speaking multiple languages.

However, if we compare the north-east and south-east of England, there are huge differentials in health literacy, by which I mean even the basic ability for people to understand how to access services. Mark touched on the idea of A&E versus GP services. We need to address some of the literacy and numeracy issues even before we start discussing the internet and introducing health inequalities.

My third point is around health-communication skills. I did my clinical training many years ago as a pharmacist and, although I have been registered for 20 years, I have had very little information about how to improve communication skills. It has all been around clinical and disease topics, but with very little around conformance or compliance, how to elicit patient references or how to break bad news.

A paper was produced in December 2004 and the DH committed to look at health communications. However, five years later, neither of those topics has been addressed. I urge the minister and others to ask what the DH is doing about health communication skills. It is not enough for the royal colleges to look at that, so I would suggest that Patricia Hamilton [the director of medical education for England] and others within the same area begin to look at the health communications and soft skills of clinicians. Without



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that, it does not matter how good the information is – people trust the advice of their clinicians.

**Jenni Russell** A friend of mine’s daughter was diagnosed with cerebral palsy at 10 months. The doctor came into the room and said, “Yes, we have run tests and this is definitely a baby with cerebral palsy. Don’t look like that – they are not all like Daniel Day-Lewis in *My Left Foot*. See you in three months.” That was the sum total of the information that she was given. This was only seven years ago – not in the 1950s.

**Mark Platt** I would like to add a point to Mark’s, which is about people’s ability to understand the concept of risk. As we move into pharmaceuticals that are more tailored to individuals, people are going to have to start making decisions that require them to have a certain grasp of the likely benefits and possible risks of taking one prescription over another. That feeds into health literacy because we have a populace that is not very good at analysing risks. People go completely mad when we talk about things like genetically modified organisms (GMOs), but they are quite happy to dash across the road in front of an approaching car.

**Jenni Russell** Are you talking about genetic-based medicine, which presumably tells you that you are more likely to respond to one drug over another?

**Mark Platt** It is about drugs that are more tailored to smaller groups of people, but which might also have differences in terms of their likely outcomes for certain people. It is about the way in which medicine is going. It is going to be much more focused on individuals or groups, but will require more thought before someone decides whether or not to take it.

**Jenni Russell** Can you explain why that is so? At the moment, you are just given a drug and told that very few people have side effects. Why will this require more participation by the patient?

**Mark Platt** We are moving into a world where more people will have more illnesses. More people will have the potential to be able to take more different medications. There is a chance that more people will be faced with the possibility of side effects. We have not really had conversations about this. Most people are given a drug by the clinician and they put up with the side effects. If we move towards having more informed patients, we will need to say, “There is a potential for this to have a side effect, and this is what it might be like.” If we want to move towards having more informed patients who can make more rational decisions, we have to support them in that.

**Jenni Russell** What about the information flow from patients to doctors? I know that many people have spent many years saying, “These drugs make me feel this way or that way,” but doctors just ignore them. It is only the advent of the internet that has enabled them to discover that masses of people also have the

same experience, yet it is very difficult to convey that information to the health system, because doctors tend to go blank.

**Mark Duman** There is a formal yellow-card reporting scheme that is now open to patients, but how many people know about it? You can do it online. I do not know if it is possible to include something at the bottom of every patient information leaflet. We need to get these mechanisms out there.

**Mark Platt** The yellow card is for serious side effects or complications. However, under the Medicine Use Review (MUR), everyone on therapy or treatment should be given an opportunity, once a year, to talk to their clinician about the medication they are on, how it is working, and whether or not there is something else that could replace it if it is better, cheaper or smarter. These reviews are things that can be carried out by pharmacists as well as by GPs, but they are being undertaken only in certain areas. We have done some work around how we can improve the MUR system. Quite often, medication does not cause major side effects, but causes something relatively minor. Often, rather than tell their GP that they have stopped taking their medication due to nasty side effects, elderly people will just say that they are taking it and stockpile it, which is a cost to the NHS.

**Nicola Perrin** Going back to the points about the introduction of genomic medicine and advertising to customers, we are already seeing far more in the way of direct-to-consumer tests, where people send off a DNA sample to a private laboratory over the internet, which is tested for their risk for Alzheimer's, heart disease or glaucoma, for example. A number of different companies are offering these services.

Because it is very early in the science and the diseases are multifactorial, the results that people are being given are inconsistent. This raises a lot of questions about how one vets the quality of the information, how the public knows what information they are being given, and how the GP deals with it when the patient goes along and says, "I have been given this," when often there is no medical treatment. There are questions around the clinical validity and utility of this information at the moment. The House of Lords science and technology committee last week joined a number of people calling for better regulation of this key area.

**Mike O'Brien** You are quite right. People are not just going to be affected by wanting to go along to their GP and say, "I have been told I might have this genetic outcome." They may not realise, when they respond to suggestions that they should have these tests done, that it has all sorts of implications on their lives in terms of life insurance and mortgages. So much is going on now across a whole range of medicine but this is just one area where we need to monitor it with care and identify where we need to intervene.

There is the view that you should not regulate too

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**Nicola Perrin**



much but sometimes, when you see the development of a new area that can cause potential problems that the consumer does not immediately understand, governments have to look at that and start questioning whether or not there is a need for some regulation.

**Jenni Russell** Currently, does the consumer have to say that they have had such a test?

**Mike O'Brien** If they are applying for an insurance policy and have had a test done, it is a contract *uberrimae fidei*, so they are supposed to disclose it.

**Nicola Perrin** There is currently a moratorium on the use of genetic information, apart from a few conditions, such as Huntington's. It is due to expire in 2013.

**Jonathan Michael** Is that not an example where more information should be made available about the disadvantages of doing this? I accept that there is a responsibility in terms of regulation. In a way, we need to come back to the business of both the healthcare professional and the general public increasing their understanding of probability. People understand the probability of winning the National Lottery but they still go off and buy tickets. However, if you put something in relation to healthcare in those sorts of terms, they begin to understand that the probability risk ratio becomes very complicated.

**Mike O'Brien** If you find out that you have a predisposition towards a disease you did not realise you had, that may produce depression and all sorts of clinical outcomes that you had not previously been at risk for. There are some quite significant implications of doing this that we still have to work through.

**Nicola Perrin** There is also the opposite of a false negative when you are given a sense of security, in that you think that you are fine and you do not need to make changes that you really should make.

Some tests are accurate in their science but not in their clinical implications. In some cases, the

laboratories are not validated; it depends on the companies. One journalist took his sample and sent it to a number of different companies, and received very different results because they were using slightly different tests. Each test was correct in its own right, but the information given was contradictory.

**Mark Platt** Key here is the fact that we are not really consumers of healthcare; we are patients, because so many complex decisions are involved. Things such as genetic tests treat healthcare as a consumable, without the peripheral that our healthcare system provides. People want to find quicker ways of receiving information about conditions or something they think they might have, but that is where our state system has to find ways of making that easier to access within that supportive environment.

**Nick Bosanquet** I would like to accentuate the positive and say that, while I agree with Jonathan, as on everything, that more information is a good thing, we also need to identify some priority areas where, currently, the information is poor, where the patients may be in a very vulnerable and exposed position and where there are long-term consequences from wrong decisions. There are two areas in which there is a clear need for better information, partly to back up professional standards and quality.

The first is drugs for severe mental illness, where, for example, the company that produces olanzapine was widely alleged to have played down information on weight gain. On average, more than 50 per cent of patients on olanzapine gain 10kg in a year. It is used to treat schizophrenia and bipolar disorder. That is a very serious development for the patient, and one that was not made plain to them. That is one area where information is very important.

Another area where there has been a detailed study showing that information is very poor is chemotherapy for late-stage cancer patients. I do not know whether the minister is aware that the National Confidential Enquiry into chemotherapy standards, which was published a few years ago, showed that only



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35 per cent of chemotherapy courses were being given to acceptable standards in terms of information, patient communication and choice of drug. That is appalling. It is not just a general issue about improving information, but is absolutely vital for some groups of patients.

**Mark Duman** I would like to throw in a non-clinical perspective. What is the communication to patients like in terms of turning up for their appointment or having a map to find their way around the hospital? Many people look at A&E and GP services as the main point of contact, without thinking about NHS Direct, walk-in centres or community pharmacies. This means that we are not really communicating very clearly all the different channels and ways in which we can interact with the service. With a huge push in efficiency and productivity, would it not make a lot of sense that the letters we send out are clear in terms of simple things like where to park. While we are very focused on the clinical side, information covers the service side too.

Touching on the point about risk, we need to take this much further back. Something that I am trying to teach my three young children is critical appraisal. While that may sound crazy, there is something here about “why are we waiting for the department’s Information Standard or for Google to tell us what is trusted or not?” If we begin to start talking about authorship and timeliness, whether you are allowed a second opinion, and whether it is financial or healthcare information, and if we can begin to build some sort of critical appraisal into citizenship, we will be a much more empowered nation. Some of the issues around wheat and chaff will come through the population rather than always having us telling them what to do.

**Peter Barron** Like it or not, 70 per cent of people already search online for health information. That level will only go up, particularly as part of the Digital Britain drive to put more of the country online. There really is a huge opportunity here. People are searching for information, so the onus is on government and other institutions to provide information that is valuable and useful and to give people the tools to make sense of the information and control the outcomes. As part of the broader digital inclusion drive, while NHS Direct is a fantastic start, there is a huge and new opportunity to give people more information and more control over their healthcare.

**Mark Platt** However, many people will not have access or do not know how to search properly, so we must not forget those people for whom IT is not a means to get information about their health; otherwise, we marginalise them even further.

**Peter Barron** That is a fair point, although the digital media inclusion strategy tries to address that point on a wider basis.

**Jenni Russell** I would like to return to the issue of people being unaware of the side effects of drugs, either because patients are not reporting them or

because the drug companies are not making them known. A couple of my childhood friends have been prescribed drugs because they were schizophrenic or psychotic but gave up, having been enormously distressed at having put on massive amounts of weight. I am shocked to know that they were not told about this side effect. What can we do about this? Perhaps we can hear from Pfizer and Wellcome about drug companies' obvious desire not to make their products look less attractive.

**Nick Bruce** There is no excuse for not providing that information – it is as simple as that. The regulations and expectations are that that information is provided and put into the public domain. It is the same as efficacy within a clinical trial setting. That information should be made available routinely. What we have seen in recent years is a move towards more disclosure of clinical trials, which has been a positive development.

Part of the challenge on the safety side goes back to the point that Nick raised: to a degree, you are reliant on those who have suffered the side effects to report them in order for them to enter into the system. However, as soon as they are known to the company, they need to be registered. If there are a number of serious events, or events that happen on a very regular basis, it would trigger a response from the regulatory authority, so it should not happen.

**Jenni Russell** Is there an obligation on a doctor to report something if a patient says, "I am having these symptoms" and the doctor thinks, "So what"?

**Nick Bruce** Yes, they should report that.

**Nick Bosanquet** They should, but it is highly variable. In Jonathan's specialty, which is renal, three months after the end of the year there is good information on what is happening to patients at every unit in the country. It is collected in an annual report. In cardiac surgery there is also very good information. However, in cancer, the metrics are absolutely woeful. There is no information on local process or outcome.

**Jenni Russell** Why is there that difference? Is there not a culture of thinking that this information is important and needs to be collected?

**Jonathan Michael** You need to achieve professional engagement and understanding about the correctness of sharing information. You then have to allow people to make a judgement about what is significant information, and that is one of the difficulties. If you go along to a doctor and say, "I am taking this drug and I am feeling this way," someone has to make a judgement call about whether or not it is a side effect that needs to be reported or something that is unrelated and just happens to be coincidental.

Somewhere along the line, then, you are back to the business of having to train the healthcare system and professionals to understand the importance of information. That needs to be done without dumping

**You need to achieve professional engagement and understanding about the correctness of sharing information**  
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the responsibility on the patient, given that one of the dangers of empowering them is that you discourage clinicians from making a judgement call.

**Jenni Russell** Our health is something that affects every bit of us. Often, when you see a doctor, they may only be interested in how the drug interacts with the particular problem that you have presented. They do not care if you end up with tremendous fatigue, for example, as a side effect of the drug, because, as far as they are concerned, they have cured the symptom.

**Mark Platt** It goes back to clinicians explaining more fully to patients the consequences of taking pharmaceuticals but having that conversation in a way that means something to the individual patient so that they can relate it to themselves. They then need to make judgements about whether or not fatigue is something they are willing to put up with if the drug works.

The Health Foundation is running a wonderful project called Co-creating Health, which is about putting patients and clinicians in the same space and recognising that clinicians need to have patients on side if they are to achieve good outcomes for the patients. They have to be able to feel that it is an important part of the process of getting better or maintaining their health. It is about sharing equality in terms of those discussions.

**Mark Duman** Instead of looking at drugs and identifying how blood pressure is being lowered and blood sugar levels are being controlled, we should use patient-reported outcome measures (Proms) to see whether the drug made the patient feel better. We need to move away from always just focusing on drugs. Potentially, information could be a therapy. Surgical interventions are a therapy, but if I asked the average primary care trust how much it spent on commissioning information, it would not have a clue. How much do pharmaceutical companies spend on information provision, compared to the £1bn quoted earlier? It is an absolute fraction, and yet they complain about compliance issues.

We need to begin to step up to the plate and ask, “Is information a therapy or not? If it is, are there outcomes that we can measure from that?” NHS Choices had 5.2 million hits in May last year, which is fantastic. We are investing £60m in Choices over the next three years, which is also fantastic. However, in terms of the Treasury, how do we know that that made a difference to the nation’s health? Did 5.2 million hits increase smoking cessation uptake, reduce cardiovascular risk or improve cancer detection? Rather than focus on the number of hits received or leaflets sent out, the big question is, “What difference did it make?”

**Mike O’Brien** In terms of the approach of GPs and doctors more generally, it requires quite a big change in the way in which they deal with patients. Until recently, patients accepted the judgement of a doctor. Increasingly, now, it is being challenged, so doctors and medical practitioners have had to change the way in which they deal with people.

People can now access not only NHS Choices, which we are investing in and which provides a wealth of information, but also the information prescriptions and information standards that we are developing. Those will, we hope, provide some reliable sources of information, which means that patients can be better informed and can say to their doctor, “There are some sources of information here that you cannot readily challenge. You might describe an opinion by somebody on Google as being quack information, but this is not. It has been verified and checked and you are giving me different advice to what I am being given here.”

So, doctors are now finding that they have to engage with patients in a much more collaborative way. Mark Duman is quite right that we need to look at the way in which that affects not only the relationship but also the ability of the health service to see whether that produces better patient outcomes. If they are better informed, have better choices, and are more in control of their own lives and health, and of the interaction that they have with their GP or consultant, will it improve



**There is a move towards an evidence-based approach to information, as there has been for other forms of clinical care**  
**Mark Platt**

health outcomes? We do not know enough about that yet. We will have to look at that in the future. I am conscious that all of this has a regulatory cost but finding out whether information helps the progress of a patient’s condition is something that we need to look at.

**Jenni Russell** I am interested in Mark’s point, given that doing such research will cost money. We are in an environment in which everyone wants to spend less, yet it seems absolutely critical. Does this make a difference to people? Can you see yourself running specific research projects to look at this?

**Mark Duman** We started one on 26 June. We gathered together the National Audit Office, the *British Medical Journal*, Novartis Pharmaceuticals and the Stroke Association to discuss whether information is a therapy and to pool our information on this. We are all trying to prove the case for information. In our own little way, we are trying to pull together the grey and non-existing literature, and if there is some central support to do that, we would love to know about it.

**Mark Platt** There is a move towards an evidence-based approach to information, as there has been for other forms of clinical care. As well as Proms, there are also patient-reported experience measures, which talk more about how the patient felt about the treatment or therapy, rather than whether the outcome was right.

**Nick Bosanquet** In our reform reports, we stress the importance of more evidence-based research on the prevention area. Prevention could be a very powerful thing. For example, my daughter recently visited a new dental centre and the dentist said to her, “If you do not stop smoking, your teeth will rot.” She has not been near a cigarette since. Obviously, that is a particularly favourable example, but we need more evidence on how to really get this prevention message across, since prevention is the key challenge for the health system in the longer term, together with the treatment of severe illnesses.

**Nicola Perrin** One of the best sources of evidence is going to come from the research uses of Connecting for Health – the idea around having everybody’s patient records online through the National Programme for IT. That will give information about side effects that do not need to be reported as side effects of drugs. You will begin to make the links if you look across the whole population instead of just across individual practices or people who you know have taken the drugs. There has been increasing recognition of the research uses of that information, so the DH currently has a research capability programme module as part of the secondary uses service of Connecting for Health.

**Mike O’Brien** I would emphasise that it is anonymised.

**Nicola Perrin** There are some uses of identifiable information, provided the right processes are in place.

**Mark Platt** It is still under discussion.

**Mike O'Brien** There are still concerns about that.

**Jonathan Michael** The NHS IT programme began with the concept of using this enormous potential database for these purposes. The IT programme came out of the NHS R&D programme, when it was headed by John Pattison. The potential is enormous; the complexity of dealing with it is significant.

**Nick Bruce** I want to pick up on some points that Mark made about collaboration and health promotion and prevention. Because we cannot advertise directly to consumers about medicines in the UK, most of our current focus is around the wellness agenda and how we can help patients lead healthier lives. Virtually all of the programmes that we have been involved in over recent years are with other sectors, such as the Medicines and Healthcare products Regulatory Agency (MHRA) or the Patient Information Forum (PIF). There is something here about doing things in a joined-up fashion. My sense is that much of what is going on is very fragmented, and there could be opportunities to pool resources in the future.

**Nick Bosanquet** Nick is quite right to stress the widening role of pharmaceutical companies, both in diagnostics and targeting these expensive new drugs that are entering the market and in measuring outcomes and side effects in a much more timely way than is the case currently. The evidence on the use of the drugs when used in much larger populations has often been quite different from what comes out in clinical trials.

**Peter Barron** In terms of scaling those preventative measures, the Leicester NHS Trust advertisement about teenage pregnancy a couple of months ago was an extremely shocking, “lo-fi” viral video. When it first appeared on YouTube, people thought that it was real and it was taken down for breaking the guidelines.

It showed a fight in a playground. It looked like a happy-slapping video. When the camera reached the scene, everyone was screaming and shouting, and a girl was giving birth in the playground. It was extremely shocking. At first, a lot of users thought it was real and complained about it. It was duly taken down but when it was put into context, it became clear that it was a health message. However, it was viewed by millions of people in Britain, and got the message across.

**Martin Fletcher** Returning to the issue of pathways for consumers to raise concerns or issues, this is still an area that is largely underdone, not just in terms of medicines but more broadly in healthcare. That is still a question around, beyond formal complaint, how people raise a concern about something or obtain information about an experience that is not what they expected.

In terms of evidence around impact, I would restate that safety is a very good domain to look at, where informed patients are able to play a very active role in reducing risk around their own care.

**Safety is a very good domain to look at, where informed patients are able to play a very active role in reducing risk around their own care**

**Martin Fletcher**

Finally, in terms of the wider culture in which all of this works, we have talked a lot about working with patients and consumers, but we should not forget about the professionals. We have mentioned the point around the environment in which they work, and I would use the example of hygiene. We still see that, when patients and carers ask questions around the hygiene associated with their care, it is often still seen in a very negative and threatening way by healthcare professionals.

**Jenni Russell** Do you mean, “Have you washed your hands before you examine me?”

**Martin Fletcher** Yes; it is about people feeling empowered to ask that as well as that being seen as part of a partnership approach to healthcare, rather than an attack on the skills of the person involved.

**Mark Platt** We have a background document to better information for patients, which is the NHS Constitution. This gives people a right to information and rights to make choices. However, it needs to be better embedded within the NHS and the staff system. They need to have more support around being able to make use of it. People will make use of it at their individual consultations, when they are going through the healthcare system and having to challenge every so often. There is, then, something that underpins this idea of a better-informed patient.

**Mike O'Brien** The NHS Constitution is currently being taken through parliament in a new health bill and should become law relatively shortly. We already have a copy of the document, in any event. It will mean that, for the first time, the NHS will have very clear objectives and a constitutional structure, and will, we hope, make patient-focused medicine a key objective. Ensuring patients are properly informed and have the information that they need to know, rather than all the information that may be thrown at them, is a key part of that.

**Jenni Russell** Do you think that there is going to be real change on that, however gradual?

**Mike O'Brien** Everything in the NHS is gradual. It is like turning a supertanker around: it takes time but, once it is turned, it goes in the right direction. You started off by saying that this was about not just having informed patients but also saving money; in fact, it is not. The primary objective for the NHS has to be looking after patients. There is always a question about quality and ensuring that the quality of what we deliver is good, that funding goes into that and that we use that funding in the best way possible. However, the NHS is based on values more than anything, and it has to be about ensuring that patients have the ability to make choices and decisions in an informed way about their future health and their life.

**Jenni Russell** Thank you, everyone, for coming.

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