

the talking
cure why
conversation
is the future
of healthcare

Jack Stilgoe
Faizal Farook

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Jack Stilgoe
Faizal Farook
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1 Dr Finlay's Facebook

A doctor is no longer at his intellectual peak just because he knows the best new methods... he must also have a talent for conversation that must adapt to every individual.

Friedrich Nietzsche, 1878¹

A trip to the doctor is the start of a conversation that provides the link between our everyday lives and the medical profession. Each day in the UK more than a million conversations take place between doctors and patients.² When governments, policy makers and others talk about healthcare, these conversations often fade into the background. But conversations are the foundation for our health, with enormous potential impact.

Health conversations can be narrow, starting with the assumption that medicine has all the answers and ending with a diagnosis. Or they can be something more – a genuine exchange of values, interests and knowledge. These broader conversations, as we will see, are far more productive but harder to control. For healthcare, conversations and the information behind them matter. But with all the noise of healthcare reform, the small conversations that matter most have been drowned out.

This pamphlet takes conversations as its focus. It asks how they are starting to change, what's stopping them from changing and how they need to change in order to make us healthier. It looks at the information, illnesses and relationships that shape conversations. And it offers conclusions for healthcare innovation. Our argument is that, given all the changes around us and the challenges ahead, conversations need to be broad and ambitious, not just in the doctor's surgery, but in the way policies and services are designed. Conversation is more than just talk.³ It has implications for the future of the NHS and it has implications for the future of doctors and other health professionals.

Restaging the medical drama

All public services follow some sort of script.⁴ As users of a service, we know pretty well what sort of script professionals will be reading from, and we play our own part in the unfolding drama. In 1951, the sociologist Talcott Parsons described how illness makes us play a 'sick role'.⁵ We are given time off from normal responsibilities, but we know what is expected of us as patients. So we play along while the kindly doctor reads his lines and makes us better. For most of the NHS's history, policy has followed a script based on these two characters – the caring doctor and the compliant patient. For all sorts of reasons, this traditional script is undergoing some pretty radical editing by patients, professionals and policy makers.

The stage has been set by Derek Wanless. Following decades of success in treating acute illnesses and failure in enabling healthy lifestyles, the major challenge faced by the NHS, according to Wanless, is the spread of chronic illness. To address this challenge, and meet rising public expectations, Wanless demanded increased spending, and gave Gordon Brown a Hobson's choice: change the way that we think about health or pay the crippling costs of growing demand for treatment. The model he advocated was one in which the public were 'fully engaged' in their own health. The challenge of chronic illness will be met only with the active cooperation of patients and the public.

Wanless's NHS requires rethinking some old assumptions and it requires new relationships – between public health, chronic care and acute treatment; between health services and the public; and between patients and professionals. This is not just a task for politicians, policy makers or professionals. It asks everyone to play new roles and to take on new responsibilities. Indeed Wanless argued that the big challenge was 'not the way in which the service responds over the next 20 years, but the way in which the public and patients do'.⁶ The script that shapes our healthcare relationships needs to change.

If you know what's good for you

More than in other public services, healthcare professionals possess arcane expertise. Traditionally, we have relied on a 'doctor knows best' model of medicine. But expert authority is questioned increasingly. Traditional deference has gone, along with blind faith

in experts.⁷ Doctors must now earn their authority, which demands a new sort of relationship.

When an illness is chronic or rare or both, patients now commonly find themselves knowing more about many aspects of their illness than general practitioners (GPs).⁸ While this reversal of the expert–lay relationship is still the exception rather than the norm, it tells us something about the new importance of information and the possibilities for new relationships at the heart of health. With a new gateway to information, more and more patients are playing doctors at their own game. On the internet, health comes second only to pornography as the most searched topic. So where patients once turned up at their GP’s surgery unarmed, with nothing but questions, they now often bring their own answers.

The medical profession insists that it has moved beyond paternalism – ‘Dr Finlay is dead’, they cry – to a model of partnership.⁹ But patient advocates and others remind them that they still have some way to go.¹⁰ The standard conversation between expert and layperson is a hard script to rewrite. One study of over 1,500 consultations found that patients routinely possessed some relevant knowledge about their condition, but that doctors found it difficult, if not impossible, to fit untidy patient experiences into their professional frames of reference. Worryingly, the harder patients tried to express their expertise, the more evasive doctors became.¹¹

The paternalistic reflex is to see informed patients as an annoyance rather than a resource. But as paternalism starts to fade, new possibilities emerge. There is no great competition for information. An informed patient does not mean a less well-informed doctor. Most of the medical profession has now got past diagnosing internet-enabled patients as ‘cyberchondriacs’ and realised that it must deal with this new conversational reality.¹² Many doctors acknowledge that they learn from their patients as well as from other doctors. But there is a clear ambivalence in how doctors see informed patients. As part of our research, we asked a group of young GPs what they thought of the internet:

A1: For doctors?

A2: Fantastic. I’m on Google all day. Any medical questions I have, just type them in it and up it comes, before you see a patient...

Q: And what about for patients?

*A1: We'd rather the internet didn't exist. They look up some really scary stuff.*¹³

According to one study, 71 per cent of doctors said that the internet had changed how they relate to patients. But there was little consensus on whether this change was positive or negative. Thirty-seven per cent thought it enhanced the relationship and 27 per cent thought it undermined it, with the rest unsure. Eighty-five per cent thought it challenged their professional knowledge while 70 per cent thought it allowed for shared care. There is, according to the study's conclusion, 'uncertainty as to whether this impact will enhance or damage the doctor–patient relationship'.¹⁴ But we can be sure that it is not going away. Debates about the benefits and risks of the internet in healthcare point to a new politics of information.

Expert professionals often worry about whether the information to which lay people now have access is *correct* or not. Just as they would love for their patients to obey all the instructions on their medicines, they also want their patients' online exploration to be unambitious and firewalled according to certified knowledge. But people are unlikely to comply. Patients don't see the need to separate the science from the broader *narratives* of illness. On myriad blogs, people with illnesses are reading and writing about what illnesses mean, both scientifically and personally.¹⁵ Patients are relating their experiences of diabetes, bipolar disorder or any other chronic condition to anyone who will listen. They are talking about new research and new treatments. They are comparing their symptoms with what the books tell them. And they are complaining about their last visit to the doctor. Just as when they speak to their friends and families, when they go online, they are not just looking for facts. They are looking to make sense of health and illness and they are looking for like-minded others. Doctors, according to one commentator, 'don't get the wisdom of crowds'.¹⁶ While the temptation is to wish the internet didn't exist, the new challenge is to add it to the conversations at the heart of healthcare, to take advantage of all this feedback.

Health 2.0

The modern history of healthcare has been defined by what Roy Porter calls a ‘war between disease and doctors fought out on the battleground of the flesh’.¹⁷ The weapons of choice have been increasingly accurate science and increasingly sophisticated medicines, therapies and surgical techniques. But medicine will always be a victim of its successes. New treatments answer old problems but create new ones. As acute illness becomes more and more soluble, chronic illness becomes a bigger problem. Porter goes on to say that this war ‘has a beginning and a middle but no end’.¹⁸

Chronic illness and the growing necessity of prevention expose the limitations of current treatments. Medicine now needs to add to its arsenal. Given all the treatments currently available, the most important new weapon in future healthcare battles will be information. Government is starting to realise this. In early 2007 the Department of Health began piloting a policy that will see information prescribed in much the same way as drugs currently are. Initial findings from the pilots, conducted across various settings, diseases and groups, tell us about the practicalities and politics of information. The first lesson is that information in itself means very little. We know from the failure of countless public health campaigns that generic information has little effect. Without some element of specificity, an information prescription becomes just another leaflet. This sharpens the need to personalise healthcare. Information needs to make sense to people from diverse backgrounds with different illnesses and different needs.

So the next lesson is that professionals need to be involved in the conversations that shape and make sense of information. This does not mean that an information prescription should be a download of what doctors, nurses or pharmacists know. It means that professionals need also to talk about what they don’t know, signposting people to other sources of relevant information.

This leads to a third lesson, which speaks to a wider tension within healthcare. Information resists central control. So while the language of information prescriptions has been transferred from medicines prescription, the crucial difference is that we can get information anywhere. Stewart Brand explained how ‘information wants to be free’, which makes it hard to control, but also that information is more and more valuable, because ‘the right information in the right place just changes your life’.¹⁹ If specific

information is going to make a difference, it needs to be more credible and more relevant than the alternatives.

The challenge for information prescriptions will be scaling them up and out to other illnesses and new types of patients. As with so many healthcare initiatives, this will require relaxing control more than government would instinctively like to. Centralised information creates bureaucracy without benefits. Information schemes have tended to work when they are in genuine partnership – between health and social care, between different parts of the health system and between the NHS and the voluntary and private sectors. Information in the hands of patients – about access to resources as well as illness – can provide a new glue to connect parts of services together.²⁰

The politics of health information reflect recent discussions about the new shape of the internet. Web 2.0 has become a fashionable way to describe a nebulous set of changes to the way that online services benefit from the power of networks. Web 2.0 is built on the realisation that information contained in and organised by networks is far more powerful and personalisable than centrally stored and accredited information.²¹ So, much to the annoyance of traditional publishers, Wikipedia has become a more useful source of information than its hardbound equivalents.²² Facebook, which provides nothing in the way of content, only a means to connect with others, has become one of the world's most popular websites within two years. If health services want to benefit from Web 2.0 and learn from its lessons, they must resist the temptation to centralise and control. Their role instead needs to be linking and guiding people, helping them on their own journeys.

Information prescriptions have made visible a tension between government and those in the voluntary sector who have traditionally filled information and support gaps, particularly with chronic illnesses. These groups are concerned that government attempts to centralise information will be at best not particularly credible and at worst counterproductive. Paul Hodgkin is a GP who has started Patient Opinion (www.patientopinion.org), a web resource designed to let people give feedback on their experience of services to healthcare managers. Writing in the *Guardian*, he was critical of the emerging NHS Choices website, which aims to be a one-stop shop for healthcare information:

Running Patient Opinion has convinced us that the state or public sector providers themselves are likely to be poor hosts for these conversations. Citizens are likely to instinctively distrust government websites, suspecting them – rightly or wrongly – of spin.²³

For Patient Opinion, as for many patient and support groups in the voluntary sector, the issue is not information per se – it's what we do with it that counts. Patient Opinion exists as much to listen to people as it does to tell them about health services. Just as doctors need to recognise patients' questions and concerns, healthcare needs to learn one of the lessons of Web 2.0, that participation is more important than publishing.²⁴ Information is just one part of the bigger challenge of conversational healthcare.

Building conversational healthcare

There is no shortage of talk about patients and the public in health policy. Their opinions and desires are constantly invoked to justify initiatives and interventions, whether increased GP access or the rollout of polyclinics.²⁵ But there is little negotiation and little recognition of the trade-offs that need to temper public demands. It is easier to assume their interests than explore their needs. Real conversations are starting to take place, but they are sporadic. Across a range of policy areas, the need for new forms of dialogue and participation is coming to the fore. There is a new recognition that, especially in areas involving a degree of expertise, the public voice is a vital way of making policy more socially robust.²⁶

In health, we are seeing experimental conversational systems at various levels.²⁷ NHS trusts have patient and public involvement forums. In medical research, where patients used to be regarded as guinea pigs, researchers and patient groups are increasingly working together to ask new questions.²⁸ Even those organisations that are designed to standardise and regulate healthcare are now recognising the value of social intelligence and public input. The National Institute of Health and Clinical Excellence (NICE), for example, now listens to the views of patients and carers as it considers the cost-effectiveness of treatments. These new conversations are rarely transformative, but they question assumptions and reveal some important tensions. In the last decade, for example, NICE has found it difficult to reconcile this open conversation with its narrow focus

on scientific evidence, leading to political challenge of its decisions.²⁹ Real democracy within healthcare is still hard to come by.³⁰

Emerging schemes for patient and public involvement supplement the conversation that has always sat at the heart of healthcare – between doctor and patient. Such conversations have traditionally served a direct function, reaching a diagnosis, and a broader one ('bedside manner') of building trust and ensuring compliance with treatment. The conversation has tended to involve patients talking about their bodies and doctors talking about diseases. GPs are taught not to interrupt patients when they are explaining their concerns, but they usually do, after about 20 seconds according to one study.³¹ Time pressures force doctors to tightly control conversation. As Harry Cayton told us, doctors are 'under such pressure to get from patients the information that they need that they are driving the dialogue rather than having a conversation'.³²

One way of opening up conversations is transparency. By giving patients and the public access to previously protected information, we might expect richer, if more challenging, conversations with professionals. One GP, Brian Fisher, has pioneered transparency in the use of electronic patient records by giving patients online access. He is an evangelist for the benefits this brings to conversations with his patients. He told us that it makes his practice more efficient: 'Things can get messy in the NHS. This can help make things neater.' But it has also created new sorts of relationships, especially where patients have long-term conditions:

*They've become partners in new ways. They can see test results, look at their histories, spot new patterns and talk to us in more detail about how things fit together. This is a very different sort of partnership from someone just bringing sheaves of internet printouts to the consultation, although that also has a value of its own.*³³

Sharing patient records is one way of inviting patients into a new sort of conversation. Elsewhere, the NHS has experimented with giving patients access to some parts of the care pathways that doctors use to recommend treatments. A patient with a recent diagnosis of prostate cancer can now visit the NHS Choices website and follow the flow chart of options suggested by the current best evidence.³⁴

These schemes are still in their infancy and their potential is still limited by institutional nervousness. But such experiments will soon start to have real impacts. The most important conversations will still have to take place in the gaps of the flow chart and the subtext of patient records, but if it is used wisely, transparency gives doctors and patients a head start on their consultations.

Conversations with doctors provide memorable punctuation to people's experiences of illness, but they are by no means the only conversations that matter. Our research suggests that doctors and patients both sit in a wider network of conversations. The consultation is only a central point, surrounded by wider 'circles of care', all of which have the potential to contribute to health.³⁵ We need to consider how to get benefit from all the conversations that take place outside the doctor's surgery, with other professionals, friends, family, support groups, patient groups, internet resources and more. Current policies, however, are throttling conversational healthcare.

Making choices, taking care

In its efforts to change relationships and improve performance, the Blair government invested in the idea of 'choice'. Patients have been asked to choose services, the idea being that this drives efficiency through bottom-up demand. The rhetoric has suggested that more choice is self-evidently a good thing. In the last ten years there has been an undercurrent of criticism of the idea of choice, most of it focusing on its practicalities and its effect on professionals. Our argument in this pamphlet is bigger, and it echoes the conclusion of a recent book that describes the widespread effects of a 'logic of choice'. Annemarie Mol, through close observation of a diabetes clinic, contrasts this logic of choice with a more productive 'logic of care', which fits what professionals and active patients do most of the time.³⁶ In medicine, where the question so often is not what people want but what they need, choice is a real problem. The alternative need not be paternalism. Too often in the past, needs have been assumed. In a democratic logic of care, needs are explored and negotiated, inviting the patient into a real discussion.

Choice has delivered real changes to healthcare systems, but from the perspective of patients, it is the most desiccated possible form of participation. Aside from the fact that 'almost nobody (ill or

healthy) is any good at it',³⁷ 'choice' has the unintended consequence of limiting patient action. The logic of choice asks people to make decisions that they are not very interested in, for the benefit of the system. In the long term, we don't know the prognosis. These 'aggregated choices may not necessarily add up to the public good'.³⁸ In the short term, the logic of choice forces patients and professionals into limited roles, driving them apart rather than encouraging conversation. Professionals retreat to matters of contract and core skills, as we have seen recently with the British Medical Association and the Royal College of Nursing.³⁹ And on the other side, patients are imagined as consumers, not active participants.

In medical science, care often takes a back seat to the more glamorous questions of causes and cures. In policy, care is either assumed to be a by-product of systemic efficiency or it is atomised and incentivised in its constituent parts. The government has made clear its intention to deliver a 'clinically led, patient-centred and locally accountable' NHS but, as the Picker Institute has described, it is failing.⁴⁰ In the last ten years, for all the financial commitment to the NHS, policy has lost its connection to the conversations that matter. The logic of care, by refocusing on the people at the heart of healthcare, provides an alternative vision.

Signs are appearing that, as the language of choice cools, Gordon Brown is warming to the idea of care, not just as a friendly way of talking about public service, but as a coherent story to tell about health and the clinical benefits of partnership between patients and professionals:

The NHS of the future will do more than just provide the best technologies to cure: it will also – as our population ages and long-term conditions become more prevalent – be an NHS that emphasises care too... a more personal and preventative health service... to give people the choice of taking a more active role in managing their own care. Patients benefit from being treated as informed users and choice will help deliver this – so we will continue to make it more widely available. But this third stage of reform involves moving beyond people being seen as simply consumers and empowering them to become genuine partners in care – not just making choices but knowing more about their condition and taking more responsibility for their health and their lives.⁴¹

Good care takes seriously the idea of empowerment, which is often talked about but rarely practised. In our everyday lives, we

feel increasingly disempowered by and alienated from the things that matter to us.⁴² This is exacerbated when we become ill or are at risk of becoming ill, at exactly the time when we need to be able to contribute to our own health. This pamphlet focuses on ways to empower and the assumptions that stand in the way of empowered people. We focus on the relationships that need to change to make this possible. These relationships are often assumed, ignored or instrumentalised as part of a drive for efficiency. By turning our attention back to the everyday context of healthcare, we can get a new view of the system that indicates effective innovation rather than top-down reform.

Most health policy analysis starts with the system. Our project started with people. This pamphlet is about health policy, but more importantly it is also about the practice of medicine, which is often left out of policy debates. Our intention was to see how new relationships are impacting on and being impacted by policy. We have spoken to doctors, pharmacists and other experts of all descriptions. At our project seminar, we heard discussion and insights from leading thinkers in this area and have tried to feed this into our own work. In partnership with Diabetes UK and Rethink, two of the UK's leading patient groups, we have looked in depth at two illness contexts. The next two chapters trace these case studies and offer wider lessons for healthcare. Chapter 2 takes a look at diabetes, often cited as a growing problem for the NHS. Our conclusion is that, while diabetes presents some huge challenges, the way arguments about treatment and in particular self-management have played out provide useful lessons for other chronic diseases. The problem of diabetes lets us zoom in on a wider social malaise – of chronic, treatable but often preventable ill health.

Chapter 3 focuses on mental health, offering a further clinical rationale for richer conversations in health. But it also colours in our picture of conversational healthcare. It asks how conversations are punctuated and enabled by access to information and patient records. We also look at the complications and opportunities presented by the involvement of carers. Chapter 4 asks what healthy conversations might mean for professionals. We look at how doctors, pharmacists and others are developing new relationships and ask what role professionals need to play in developing new models of healthcare. Our final chapter offers some conclusions and recommendations for policy makers.

2 The drugs don't work (on their own)

The delegates at the 2007 Primary Care Diabetes Society conference are upbeat. Insofar as a complex illness like diabetes can be reduced to a set of numbers, the numbers are heading in the right direction. The percentage of patients who are in control of their blood sugar is increasing.⁴³ This is good news for patients, as it reduces their risk of complications, and good news for their doctors, a slice of whose pay now depends on hitting diabetes targets.⁴⁴

The conference is full of professionals – GPs, some with a special interest in diabetes, nurses, nurse practitioners and more. They attend masterclasses from innovative service providers, exchange notes on the latest clinical trials and wander past exhibits from drug companies claiming to have found new answers to old problems. But for all the excitement about new techniques, new treatments and new technologies, the difficulty with diabetes is that most of what needs to happen lies beyond the control of the people at the conference. Diabetes patients spend an average of three hours per year talking to a doctor, alongside other short conversations with nurses. The rest of the time they are taking care of themselves.⁴⁵ Doctors cannot force patients' glucose levels beneath the guideline suggested by NICE. Companies cannot make drugs that will suit everyone all the time. Between them, they can provide the tools and the advice, but it is ultimately patients who will determine their own health. With diabetes, being an active, informed patient is vital. Diabetes presents an enormous challenge for healthcare, but it also shows the way forward.

The promise of insulin

The history of diabetes as we know it begins with what was supposed to be a miracle cure. Before the discovery of insulin in 1921 treatments that did exist, such as starvation diets, delayed death only briefly. People diagnosed in childhood with what we now call type 1 diabetes – a failure of the pancreas to produce insulin – were

expected to live no more than three years.⁴⁶ The discovery of insulin was a triumph of modern medicine – once the illness was understood, the treatment was obvious. As scientists learnt to produce insulin, the story should have been ‘happy ever after’. The *New York Times* in 1923 celebrated the conquest of diabetes: ‘One by one, the implacable enemies of man, the diseases which seek his destruction, are overcome by science.’⁴⁷

But the discovery of insulin is only the beginning of the story. Insulin turned diabetes from a death sentence into something that people now live with – a chronic illness. A person with diabetes can remain healthy while being officially ill. But the illness is still deeply serious. Even with all the treatments available, if it is not well managed diabetes causes serious complications such as blindness, kidney failure, amputations and heart disease. Estimates suggest that up to 5 per cent of the UK population has diabetes – diagnosed or undiagnosed. Derek Wanless, in his hard-nosed analysis of NHS economics, reckoned that diabetes accounted for about £1.3 billion of the NHS budget.⁴⁸ Keeping people with diabetes well is incredibly complicated, and it’s not getting much easier.

Box 1. **Diabetes definitions**

Type 1

Type 1 diabetes develops if the body is unable to produce any insulin. This type of diabetes usually appears before the age of 40. Type 1 diabetes is the least common of the two main types and accounts for between 5 per cent and 15 per cent of all people with diabetes.

Type 2

Type 2 diabetes develops when the body can still make some insulin, but not enough, or when the insulin that is produced does not work properly (known as insulin resistance).

Source: Diabetes UK

Until the invention of a faultless artificial pancreas, people with type 1 diabetes must take over the pancreas’s job of balancing

levels of glucose and insulin. Even with huge numbers of patients and decades of investigation, the science of diabetes is not clear. Uncertainties about ‘cause, cure and care’ fuel billions of pounds’ worth of research around the world. But for sufferers, the illness is more complex still. Like other chronic illnesses, diabetes is impossible to forget and it comes to define a part of the person who has it. People with diabetes need to talk about their illness, and they need to find out about it. So treating diabetes becomes more than just a narrow clinical issue. It means understanding the place of the illness in people’s everyday lives. In the last decade, the normally private personal experiences of diabetes have become increasingly broadcast.

A growing number of people with diabetes are using blogs to talk about and share their experiences of the illness. They describe their everyday lives and how diabetes fits into or clashes with them. They ask questions and they support others. And they make sense of diabetes in a very personal way. This is one patient’s description:

The longer I have diabetes the more I feel like I live somewhere in between. In between how the world defines sickness and health... It seems the world sees people as either sick or well and what I’m realising is that I’m neither, and both... Good days and bad ones. In control and not. Up and down. With diabetes it’s never static and so the usual definitions of health don’t really describe my life.⁴⁹

Diabetes is a mechanical failure in the body, but its impacts are personal, psychological and emotional.⁵⁰ When bodies are working well, we take them for granted. They do what we tell them to do and they fade into the background. It is only when they malfunction that they make themselves known again.⁵¹ People with diabetes have to play a constantly active part in dealing with their illness. Their bodies are constantly apparent and their health can never be taken for granted. Even if everything is going well, treatment is working and things appear normal from the outside, a person with diabetes is, as one told us, ‘thinking about it all the time... it looms over you’.⁵²

Insulin is a difficult medicine to take. It cuts the risks of long-term complications from diabetes, but brings with it a short-term risk of hypoglycaemia. Too much insulin will make blood sugar levels fall and increase the likelihood of a ‘hypo’, characterised by

dizziness, tiredness and, if it is serious, coma. To the outside world, a hypo can be mistaken for drunkenness, making it less likely that sufferers will receive the help they need. The balancing act required to keep blood sugar levels low, but not too low, is familiar to all people with type 1 diabetes.

Two decades ago, a person with type 1 diabetes would expect to give themselves an insulin injection and then keep a close eye on what they ate. They would have their blood glucose measured in a lab a few times a year. Now, patients are likely to eat what they like, within reason, check their blood glucose levels through the day and give themselves insulin as they need it. For many patients this has been a revelation. One told us that it is a change from 'the insulin controlling us to us controlling the insulin'.⁵³ This change has been possible because of the dual development of new, fast-acting insulin and blood monitors that allow people to prick their fingers and calculate their blood glucose levels. Since 1991, the amount the NHS spends on glucose monitors for people with diabetes has increased tenfold.⁵⁴ But changing diabetes treatment has required more than new technologies. It has also demanded a new relationship between patients and professionals.

In 1993, an American trial seemed to provide irrefutable evidence of the benefits of this new treatment – glucose monitoring and multiple daily insulin injections. Over 10 years, doctors compared more than 2,000 people on different diabetes treatments. The trial found that the group who controlled their insulin and closely monitored their blood glucose levels were overwhelmingly better off – the risk of major complications was cut by more than half.⁵⁵ This trial persuaded the UK that it made sense to fit insulin treatment into people's lives rather than vice versa, leading to the widespread adoption of multiple insulin injections.

Education vs medication

Back at the conference, Sue Cradock has taken the stage. She is a nurse specialising in diabetes and she's keen to bring us all down to earth. She is interested in why the everyday reality of British diabetes treatment doesn't reflect the results in the American trial. Her explanation is that we've learnt only half the lesson. People in the UK who changed to new diabetes treatments tended to get

better for a bit and then get worse again. People, it seemed, were taking care of themselves for a short while, but slipping back into bad habits as support faded. A closer look at the study tells us that the most important aspect of the new treatment was not just technological. It also involved healthy doses of ‘that complex intervention called education’.⁵⁶

At the level of policy, structured education is now recognised as a cornerstone of treating diabetes. People with the condition need to be told what it is, what the risks are and how to manage them. All the evidence suggests that people who are in education programmes are healthier. But despite recommendations from NICE and commands from the National Service Framework, people are often still unable to access education programmes. It seems that primary care trusts (PCTs) are much slower to adopt softer but more effective interventions such as education than they would be to adopt new drugs. According to a recent audit 26 per cent of people with diabetes said that they wanted structured education, but only 11 per cent had taken part in a course.⁵⁷ Contrasting this with the optimism of professionals, it seems as though diabetes patients have a very different picture of the quality of care.

One structured education programme is known as ‘DAFNE’ – ‘Dose Adjustment for Normal Eating’. Copying a long-running initiative in Germany, DAFNE is a five-day course for people with type 1 diabetes, where they are taught to administer variable amounts of insulin depending on what they have been eating, counting the carbohydrates as they go.⁵⁸ A study of the programme in the *British Medical Journal* suggested that not only did the programme show objective improvements to the sorts of things health systems like to measure – risk of complications and average blood glucose levels – it also improved people’s subjective quality of life.⁵⁹ Education made people feel more satisfied with their treatment and more able to cope with the illness. For people who are drawing blood from their fingers, doing the sums and injecting themselves four or five times a day, these subjective benefits are very real.

Crucially, education is not just about information. Indeed one study in the *American Journal of Cardiology* claimed that patients who know more about diabetes do not necessarily manage their illness any better. The conclusion was that education must also aim to ‘activate, motivate and empower’ people to take charge.⁶⁰ If they do

not take ownership of the disease, they are unlikely to be able to manage it. So professionals must change how they interact with patients. The next step in diabetes treatment requires empowerment and then handing a degree of control back to the patient, which in turn asks professionals to radically rethink their role. Sue Cradock realises that this is a challenge. At the end of her presentation she asks the doctors in the audience whether they have access to education programmes for their patients. Most raise their hands and the offending PCTs of those who don't are publicly shamed. She goes on: 'And how many of you are thinking that you might change the way you work in your surgery?' From an audience of hundreds, eight brave hands go up.

The challenge of type 2

With type 1 diabetes, the case for structured education and self-management is pretty clear. Patients tend to have been diagnosed when they are young and the disease is not likely to be caused by or connected to other pathologies. Type 2 diabetes accounts for a huge and growing majority of diabetes diagnoses and it is far messier. 'Maturity-onset diabetes' as it is sometimes called is a breakdown in the body's insulin system production, normally in people over 40. It is strongly associated with obesity, inactivity and age. With type 2 diabetes, professionals are often faced with what they call 'co-morbidity': patients with a range of symptoms and more than one chronic illness. With an ageing population it will be more and more common to see patients coming to the doctor with, for example, arthritis, diabetes and heart disease. Doctors are faced with understanding and sorting out the best solution to these myriad illnesses.

So while we can transfer the lessons of type 1 diabetes across to type 2 and beyond, we are met with a reality that can be far more complex. We are reminded of the limits of self-management and conversational healthcare. In 1998, a huge 20-year clinical trial demonstrated that type 2 diabetes can be controlled by tighter management.⁶¹ The complications around type 2 diabetes mean that professionals are less likely to immediately grasp the value of self-management. But the logic behind getting people to take care of their diabetes is the same logic that shows us new ways to prevent it from occurring.

Type 2 diabetes is often termed a lifestyle disease, but it is not that simple. It has a partial genetic basis, and it is this that attracts much of the scientific interest. Pima Indians in the USA and Nauruans in the South Pacific have rates of diabetes that approach 50 per cent of the population.⁶² But its growth reflects more complex changes in society – linked to unhealthy lifestyles. According to one study, middle-aged Americans were twice as likely as British people to have diabetes, across all socioeconomic groups.⁶³ The authors of the study could not explain their findings with obesity alone, but the message is clear: despite the messy causality of type 2 diabetes, it is in part a social condition and a modern condition.

Combating type 2 diabetes means detecting it early, finding drugs that work for individuals, and finding ways for those individuals to take better care of themselves with diet and exercise. All these steps are complicated. As with other lifestyle-dependent chronic illnesses, people could well be in denial. They may not want to know whether they have diabetes, or they may pretend that they don't even after diagnosis. A member of Diabetes UK's team told us about running a roadshow, testing people who may be at risk of diabetes. One obese individual refused the test, claiming that, with a child who had special educational needs, there was enough to worry about already.

Because type 2 diabetes is often tangled up in a set of other symptoms, it is often diagnosed late. Half of people diagnosed with type 2 diabetes already have the complications coming from the illness lying undetected. So attempts to help people develop healthier lifestyles are even more difficult. Again, the focus needs to be on self-care, behaviour change and prevention, and here the challenge is the broader one of helping people to lead healthier lives.

At one conference session, a doctor gives a presentation on new medicines for type 2 diabetes, beginning with the caveat that 'it's difficult to know how these things fit into my life as a GP'. He goes on to talk about the value of primary care in personalisation. Looking down a daunting flow chart of treatment options, he concludes that 'algorithms are one thing, patients are another'.⁶⁴ Diabetes makes tailored care vital, so it can teach the rest of healthcare about the possibilities of personalisation. Good care for both types of diabetes looks the same as good care in general.

A balancing act

For GPs, diabetes is a growing problem. Many of the doctors at the conference had no special intellectual interest in diabetes. They were there simply because more and more of their patients are developing type 2 diabetes. As the responsibility for diabetes moves from secondary to primary care, it is an unavoidable issue for GPs and the challenges for the doctor–patient relationship are enormous. A group of people with type 1 diabetes described to us the importance of long-term relationships with health professionals. They have all grown up with diabetes and have acquired a degree of expertise. Some of them are frustrated when they encounter a new GP and find themselves having to teach the professionals about their illness. But all agreed that a long-term relationship was vital. Meeting a new GP, as one told us, was ‘like being adopted’.⁶⁵

Their relationship with professionals is ambivalent. They rely on health services while realising that responsibility for their health is largely their own. They benefit from personal contact and personalised care while being frustrated by the limited conversations they are able to have in the time available. And while there is an underlying frustration with professionals going through the motions, there is a real appreciation of the majority of professionals who make a difference to their lives. There is a sense of a culture shift. Doctors are slowly becoming more willing to share responsibility and provide information to increasingly demanding patients.

The type 1 diabetes story is one of the power of self-management. The tools for this are technological, but the challenge is social and psychological. We now know that structured education works, but it is more complicated and less glamorous than a new drug, and so isn't currently given the attention that it demands. We also know that education on its own doesn't do the job. Teaching people to do things in a new way only gives them another option. While some people with diabetes embrace the flexibility of insulin that fits into their lives, for others, this means more uncertainty and more cause for concern. As with any other aspect of life, different people have different approaches to routines, and they have wildly varying everyday circumstances.

Diabetes education and self-management are about more than getting patients to do the professionals' jobs for them. Patients need to be able to read and respond to their blood glucose monitor, but they also need to be able to respond to their body's signals and deal

with the unpredictability of everyday life in a way that makes sense to them. One woman with diabetes told us that after 30 years she was still learning to adjust to the ups and downs and control her insulin accordingly: ‘For me, it took years to be able to do that, and I don’t get it right by any means.’⁶⁶

Inevitably, many of the conversations that do take place about diabetes, whether at professional conferences or on patient blogs, are about the prospect of a cure. Technology promises to provide a closed loop between insulin monitors and insulin pumps, inching towards an artificial pancreas. At the same time, stem cell research and islet transplants suggest a way to kickstart the body’s own insulin production. These developments, while welcome, should not distract us from the reality that, for most people with diabetes, in the short term, it will remain a chronic illness. Lessons from the past suggest that magic bullets are rare. Patients’ relationship with technology will be more complicated and more ambivalent. Companies at the clinical end of diabetes research now know that chronic illness technologies need to pass a hard test. They need to make sense in the everyday context of people’s lives.

Diabetes highlights the importance of getting patients involved, in a productive way, in personalised healthcare. For patients, diabetes is a sort of negotiation between illness and everyday life. For professionals, this demands new sorts of conversations. It means not just asking patients questions or just telling patients more about their disease when they ask. It also means helping patients to ask the right sorts of questions, or encouraging them to find out more. One diabetes patient told us that, while doctors were on the whole good at answering his closed questions, they rarely opened up the conversation, explored new avenues or encouraged further research.

Policy has moved a long way on diabetes in a relatively short period of time. Following a National Service Framework in 2001, which put self-management and individuals’ care plans at the heart of treatment, we have had NICE guidelines, and more to follow in the near future.⁶⁷ The policy message reflects the evidence that health is related to the extent to which patients contribute to managing their illness, but this conceals as much as it reveals. Making self-management work in practice for individuals is very different from judging its benefits according to generalised clinical trials. There is a feeling that not only are the recommendations

of policy makers and patient groups failing to filter through, they are also coming up against health systems that interrupt conversational care.

Diabetes does not fit well into a logic of choice. The everyday experience of a person with diabetes will not map onto a flow chart care pathway, and it cannot be reduced to a set of decisions. Dealing with diabetes demands a logic of care. As we described in our introduction, this means relaxing assumptions about ideal treatments or techniques and instead starting with people's everyday lives. A patient's view of successful treatment may look very different from the numbers on a GP's Quality and Outcomes Framework. While a doctor is aiming for a low HbA1c (a proxy for average blood glucose levels), a diabetes patient may well be just looking forward to taking their grandchildren out for a pizza.⁶⁸ Finding an achievable goal is vital to quality care. But a quarter of patients still say that they have never talked to a professional about what they are aiming for.⁶⁹ For diabetes, treatment is a learning process and an exploration, working towards solutions that work in the long run.

Talking to people with diabetes, the word *balance* often crops up: *balance* between blood sugar levels and insulin levels, *balance* between risks of various kinds or *balance* between letting an illness control you and getting on with life. When things are balanced they work well, and when the balance is upset ('things fall apart' as one put it) the illness reveals itself again in all its seriousness. Listening to this talk of balance, it is clear that the language of *choice*, *care packages* and *evidence-based medicine* fails to capture the care that is necessary for people with diabetes to stay well. Diabetes UK and the National Service Framework agree that personalised care plans are vital, but fewer than half of people with diabetes have one.⁷⁰

Diabetes lets us see what good care might look like and it lets us see the scale of the challenge across other chronic illnesses. Good care asks patients to be active, but it does not blame them when things go wrong. Instead, responsibility is shared, strengthening the link between patient and professional. Once this link is established, it is enormously valuable. One young woman with diabetes we spoke to told us about the various relationships she had been through with professionals. She has built up momentum with a series of GPs around the UK, often teaching them about the nuances of type 1 diabetes, recounting her history and explaining

her circumstances. Having settled in London and having got to know a new set of professionals, her advice to other people with diabetes was, half-seriously: ‘Don’t move. Live in the same area for ever.’⁷¹ Diabetes UK and the Department of Health have recently joined forces in emphasising the importance of long-term care planning for diabetes. Their Year of Care project is ongoing.⁷² This experiment will provide some valuable new lessons for the management of chronic illness, testing how care planning can be used to give people with diabetes genuine choice and individualised care.

Looking at diabetes, we are also forced to consider how different professionals play different roles and relate to one another. We have seen that diabetes demands new skills of doctors. But it also asks more of nurses who are more likely to be on the other side of patient conversations. Recent studies have suggested that, because they have richer conversations with nurses, patients in nurse-led care are more active, happier and healthier.⁷³

The logic of care casts new light on the treatment of chronic illness. But it also forces us to confront the bigger challenge of prevention. A logic of choice divorces treatment from prevention – prevention becomes an apparently straightforward task of telling people what’s good for them.⁷⁴ And we know this doesn’t work. The logic of care, focusing on the relationship between patients and professionals, embraces and personalises prevention, making it more likely to make sense to people and make a difference to them.

3 More than words

If you were to walk into your GP's surgery with symptoms of heart disease, a series of physical checks would identify the illness you were suffering from and the degree to which it had progressed. If you had suffered from your first disorienting episode of a serious mental illness (SMI), a diagnosis wouldn't be as clear. Unlike physical illness, SMI isn't definitive and it often has a complicated relationship with the history and lifestyle of the patient. In mental health, conversation has always been a vital part of care. However, a close look at mental health medicine also illustrates that it is important not to mistake talking for genuine conversation.

Box 2. What is severe mental illness?

There is no universal understanding of what severe mental illness is, because it tends to be seen differently by the person experiencing it, their family and friends and doctors. The National Service Framework for Mental Health (1999) differentiates between severe mental illness and common mental health problems. Examples of severe mental illness include schizophrenia, bipolar affective disorder (manic depression), organic mental disorder (dementia), severe anxiety disorders, severe eating disorders, severe depression and severe panic disorder.

Source: Rethink⁷⁵

Conversations about mental health aren't easy. They can involve dealing with strongly held views, powerful emotions and profound disagreements. Navigating this requires listening, understanding and open-mindedness. It is tempting for health services to substitute this difficult process for a proscribed approach, relying on a restricted, narrow dialogue or over-relying on medication.

Mental health is unique in healthcare, however, in that conversation isn't just part of a diagnostic interaction, it is recognised as a treatment in its own right. Government has recently acknowledged the value of conversation as a clinical response. Following the success of a number of pilot schemes, government has pledged to increase NHS spending on psychological therapies to £170 million by 2010/11 so that within six years all GPs in England can offer their patients psychological therapies.⁷⁶ This is a positive development, moving away from a reliance on medication despite patients' preference for 'talking therapies'.⁷⁷

But mental health conversations are complex and multifaceted. The government's view of therapeutic conversations relies on a narrow focus on cognitive behaviour therapy, which is only one of a number of different talking therapies. Likewise, a focus on the patient side of the conversation suggests that patients need much broader spaces within which to talk and interact. More than any other area of medicine, mental health is emotive and highly contested. Patients' needs and values aren't as clear as is often assumed, and the responses can't be neat, one-size-fits-all solutions. Context is an inherent part of illness, which means treatment won't work without an intimate understanding of patients and their interactions with their symptoms. Processes of treatment contain myriad assumptions (on both sides), many of which need to be explored as part of vital conversations with patients.⁷⁸

From medication to conversation

With mental illness there can be a gulf between a health professional's perceptions and values and those of a patient. Professionals bring their own assumptions to interactions, which, if they remain hidden, can shape treatments in a way that doesn't align with the patients' own aims and goals. Health professionals often see patients in the context of their illness, while patients see their illness in the context of their lives. Inevitably, this leads to differences in what both parties see as valuable and desirable when it comes to treatment. Health professionals will instinctively view a mental health condition as negative, but for many patients with SMI, their relationship with their illness is multifaceted.⁷⁹ On one mental health blog a contributor writes:

As someone with bipolar disorder, I'm very familiar with the misery of some symptoms, and the seductiveness of other symptoms. I don't know why anyone would want the miserable symptoms; however, other symptoms are, like I said, quite seductive. The euphoria, endless energy, creativity, inflated self-esteem – I can completely understand why someone would want them.⁸⁰

Mental health service users come to consultations with a variety of feelings about their condition, intimately related to their everyday experiences. A list of symptoms from a medical textbook looks very different through a patient's eyes. For patients, diagnosis is more than a straightforward medical categorisation – it defines treatments and shapes the possibilities of their lives. It is understood both cognitively and emotionally. A personalised response is therefore both vital and complicated.

For both sides of the health conversation, medical information is intensely political. In our previous chapters we discussed the positive effect of increased access to medical information. For some patients with SMI it can also be seen as a threat, because of the way it shapes what is seen as possible or acceptable. Members of Rethink's national advice team told us how some patients feel that discovering more information about their mental illness will mean subconsciously conforming to a predetermined definition or pathologising otherwise normal behaviour.⁸¹ Likewise, some doctors avoid labelling mental illnesses in particular circumstances, mindful of the associated stigmas and the implications for a patient's future care or employment prospects. While some patients may welcome this, others may feel disempowered by the ambiguity.⁸² They may also be hampered practically by being unable to claim benefits or take time off work. What is clear is that there is no right or wrong approach, only better and worse approaches for the particular patient.

The gap between patients' and professionals' perceptions can be seen in their respective views of mental illness in general. While health professionals tend to see serious mental illness as chronic, to be managed rather than cured, many patients value the more optimistic outlook – that they may one day recover.⁸³ Patients often prefer treatment that recognises recovery, in the broadest sense of recovering one's life, as a possibility.⁸⁴ This divergence has important implications for how conversations around long-term care are framed, whether agreeing achievable treatment goals,

obtaining patient commitment to treatment programmes or adopting flexible attitudes to new treatments. Without positive engagement to clearly agree the possibilities of care, these discrepancies can foster misunderstanding and frustrate patients and professionals.

It is only through spending time in open, respectful conversation that professionals can discover how a patient interacts with their SMI, what aspects of their experience they value and how they wish to live their lives. This dialogue and understanding is a vital element in helping a patient to try to live the life they want and in making them a full partner in their own care. And it has to happen across the range of health professionals, GPs, psychiatrists, nurses and more, that an individual with a long-term mental health condition will be dealing with.

As with diabetes, there are clear clinical benefits to conversational care. With mental illness, patients use conversation to understand their own experiences as well as to get answers.⁸⁵ Service users, who often feel their voices are ignored, get huge value from being listened to. Bearing witness without necessarily offering a solution lets patients articulate and give value to their narrative. The act of conversation helps service users and professionals express themselves as individuals and make sense of a condition, which medication cannot. This process of reconstructing a sense of self, regaining agency and creating a coherent life narrative are integral to recovery.⁸⁶

The importance of a deep relationship between health professionals and service users is often overlooked. Mutually beneficial interactions between service users and doctors depend on subtle interpersonal dynamics. Healthcare in general can learn from particular ‘talking therapies’ in mental health. There are numerous schools of thought within talking therapy, each with its own approach, process and techniques. But the technicalities of the various methods are not the most important factor in achieving positive patient outcomes. Instead, we now know that most importantly across all methods are the personal qualities of the therapist and the quality and nature of the patient–therapist relationship.⁸⁷ The quality of the professional–patient relationship has practical implications for professionals too. As Malcolm Gladwell describes, American research shows that it isn’t poorly performing doctors who are likely to be sued for

malpractice, it is doctors with a poor relationship with their patients.⁸⁸

So what does a good relationship look like? In Gladwell's analysis, what differentiated the doctors who weren't sued from those who were wasn't the amount or quality of information they gave their patients but *how* they talked to their patients. They spent more time in consultation, made clear its purpose and goal, listened actively and were more likely to laugh.⁸⁹ Patients were most comfortable and satisfied when they were interacting with their doctor as a person rather than as a patient. Psychotherapist Martin Seager explains the need to connect to people rather than medicalise them:

*A conditions-based approach divides people into 'us and them', 'crazy and normal' whereas a relationship-based approach focused on the human condition enables us to empathise and connect with people in distress from our own related experience.*⁹⁰

It is this need to be treated as an individual rather than a patient or a collection of symptoms that underpins many of the difficulties faced by mental health service users, and presents some of the challenges that need to be overcome in creating a conversational model of healthcare. Patients can often feel that they are seen in the light of existing assumptions and conditions.⁹¹ Without health professionals taking the time to respect and understand patients' subjective experience, it is impossible to offer personalised and engaged care.

Three's a crowd?

The relationship becomes more complicated when it widens to include formal and informal carers, as is often the case for patients with SMI. Carer involvement can be empowering, but it can also sideline patients, reducing them to passive recipients as others make decisions about their healthcare. Managing these tensions asks a lot of doctors, especially when it comes to patient confidentiality. The degrees of involvement, disclosure and consent are dynamic. They change not just from patient to patient, but also within a particular doctor–patient relationship. Some service users don't want to involve carers at all, while others may wish to share, for example,

information about medication but not about sexual health or involve carers only when they themselves are present. Despite widespread reservations, only 12 per cent of service users reported that they are routinely asked by professionals for consent to share information, according to research by Rethink.⁹² The implication is that health professionals need to engage in deeper conversations with service users to fully understand their wishes rather than adopt blanket approaches, or assume that consent to one disclosure is consent to total disclosure.

As with patients, carers needs are often assumed or overlooked. Although their role is crucial to the health and wellbeing of patients, the same Rethink research showed that a third of carers felt they weren't given enough information to play their part.⁹³ This has serious implications for patients' care but also for the wellbeing of the carer. Even where consent hasn't been given by patients, there is still the opportunity to offer carers generalised information about treatments, conditions and the intricacies of the health system. One Rethink member talked about her experience:

I need to know what you are trying to achieve for my son and how you are planning to do it. I need to understand the treatment that he is receiving so that I can play my part in his recovery programme. What I do not need to know are the personal details of what takes place between him and the professionals concerned.⁹⁴

The role of the carer, like that of the patient, is highly personal. Carers need time and space to discuss their thoughts and worries. But lack of time is the reason most psychiatrists give for not sharing information.⁹⁵ Finding the time to develop a collaborative, conversational approach helps build a shared understanding and agree a way forward. As the president of the Royal College of Psychiatrists says, 'Good practice is built on partnerships – not only between doctor and patient, but between patient and carer and between carer and doctor.'⁹⁶

Setting records

As we have discussed in earlier chapters, the conversations we have about our health are enormously varied, whether face-to-face or

online. But when we talk to professionals the discussions continue long after we leave the consulting room through the information added to our patient records. While it is clearly vital to keep a written record in any conversation-based approach, we risk losing the nuances and subtleties of the discussions. Records protect patient safety, but they can harden the terms of reference for future interactions as patients move through the system.

This is a concern in all areas of medicine, but especially so in mental health where subjective judgements are an inherent part of assessment⁹⁷ and therefore patient records. Patients and doctors can often disagree considerably. One service user we spoke to wondered, ‘Am I in a different world or are they?’ as she related how records sometimes contain derogatory comments or even misinterpretations of normal behaviour: ‘I laughed at what I thought was a joke and the doctor had recorded it in the notes as “inappropriate laughter”.’

The disconnect between understandings shows us why patient access and control of records is such an important turning point. While the Data Protection Act guarantees patients access to their records (often for a fee), few take advantage of it. Access will become easier, more sophisticated and more routine as the rollout of the NHS Care Records Service continues over the next few years. The Care Record Development Board, a working group of service users, health and social care professionals and members of the public, has developed the Care Record Guarantee, that gives patients the right not only to freely access their records but also to limit who can access their records and how much they can see.⁹⁸ The risks with this form of centralisation and transparency have been agonised over.⁹⁹ But we are only starting to think through the opportunities for improved care. Within a joined-up NHS, access to and amendment of patient records by different specialties and services requires a change in the locus of control and continuity, from hospitals and GP surgeries to the one common factor in all interactions: the patient.

This new relationship between patients and information will inevitably entail a change in the way professionals view and use notes and records. The presumption of openness means that doctors will need to ensure that the process of note making is transparent, accessible and engaged. As the Care Record Guarantee points out:

It is good practice for people in the NHS who provide your care to:

- *discuss and agree with you what they are going to record about you*
- *give you a copy of letters they are writing about you*
- *show you what they have recorded about you, if you ask*¹⁰⁰

As we outlined in the first chapter, transparent patient records are disruptive, which makes them a useful tool for innovation. They can change conversational assumptions and build new relationships. Professionals will still need a place to share interim thoughts, diagnostic discussions and other information that may prejudice a patient relationship if made transparent. There may also be genuine worries about patient safety, third-party involvement or even child protection that doctors may wish to flag up for further investigation. However, the rebalancing of the relationship between patients and their records means that health professionals must view the records not just as historical reference but as an active and crucial part of a live doctor–patient dialogue. The same rules that apply to live conversations – openness, transparency and clarity – should also apply to medical records.

Where records are viewed as part of an ongoing conversation, they can even help to speak for patients when they aren't able to do so for themselves. From time to time patients with SMI may not be able to participate in conversations with professionals. Acute episodes of their illness may make them temporarily incapable of making informed choices about their care or of consenting to particular treatments. In such circumstances, the doctor–patient partnership can be maintained, with the patient's voice being heard through advance agreements or directives.¹⁰¹ Patients can state how they wish to be treated in particular circumstances, whether refusing electro-convulsive therapy or specifying medicine choices.

Drafting an advance agreement can be complicated and time consuming. Although some professionals view advance agreements with suspicion, patients see them as an opportunity to clarify their voice and improve the quality of their care.¹⁰² If viewed constructively such statements can be another opportunity to extend a healthy conversation. According to one study, a collaborative approach to advance statements improves health outcomes for some patients, by reducing compulsory admission and treatment.¹⁰³ And collaborative statements provide professionals

with two key opportunities. First, they can clarify a patient's values and choices. As Rethink's national advice centre often finds, these values may not be to do with medical treatment at all. Patients may be more concerned about who is caring for their children in their absence. Second, advance statements can be an opportunity to educate and inform patients about available options.

Time to talk

With mental health, conversations both reflect and shape patient–professional relationships, from questioning assumptions and providing emotional support to understanding values and aims. If the space for conversation is to be enlarged and developed, then professionals and patients will need greater capacity and new skills. Professionals need to be able to accommodate active patients, while also helping and empowering patients who are less keen to get involved. Their roles will have to broaden to include increasing patients' health literacy and capacity. Facilitating and empowering patients into shared ownership will require a different outlook and a different approach.

Even though the system divides patients into discrete categories, doctors pride themselves on understanding the complexity of health issues as they relate to each other and to wider social and lifestyle factors. Healthy conversations are needed to explore these interconnections, especially within a healthcare system that prioritises prevention and early intervention. Patients with SMI are more likely to suffer from long-term chronic conditions such as diabetes and coronary heart disease,¹⁰⁴ sometimes triggered or exacerbated by their psychiatric medication. Patients with mental illnesses can find that they are viewed through 'mental health tinted glasses',¹⁰⁵ which means their physical health concerns may not be taken seriously and their interaction with the different sides of the health system may be confused.¹⁰⁶ Similarly, patients with long-term physical conditions are vulnerable to mental health problems such as depression.¹⁰⁷ In these blurred spaces, conversation is vital in creating a joined-up service, which is crucial to early diagnosis and preventative wellbeing.

4 The professionals

The mechanic and the hairdresser

Both of our case studies illustrate that, especially when health problems are complicated, long term and preventable, information and conversation are key. But they also reveal new tensions – about control, about responsibility and about who knows what’s good for us. A conversational model of healthcare, with active, fully engaged patients, means rethinking a traditional model of expertise and reconstructing professionalism. With diabetes, as we have seen, a degree of patient expertise is a necessity. With mental health, patient expertise is far more complicated, and likely to be more contested. As patient expertise grows, professional expertise becomes less well defined.

Expertise is often defined defensively, by experts who see their profession or status under threat. It is a perceived challenge to medical expertise that makes Ray Tallis, among others, worry that ‘medicine may be reaching the end of its course as a profession’.¹⁰⁸ Other doctors worry that, with the influx of new sorts of health professional and changes to education, medicine, underpinned by expertise, is ‘dumbing down’. What has become clear is that there are many different types of expertise, and many different types of expert. In their recent book on the sociology of medical science, Harry Collins and Trevor Pinch suggest two types of experts, through which we can understand changes to the medical profession: the *mechanic* and the *hairdresser*.

Pulling into a garage forecourt, we might have a vague sense of what might be wrong with our car. The exchange as we hand over the keys might involve pointing to the part of the car that we think is ill. The mechanic will then suck his teeth and take away the car to make a real diagnosis, administer the solution, tell us what he has done and present a bill. The mechanic unilaterally decides both what the problem is and what a successful outcome is, leading Collins and Pinch to call the interaction ‘among the most powerless in modern life’.¹⁰⁹

A visit to the hairdresser on the other hand begins with a conversation (one which often continues throughout the consultation whether we like it or not). The conversation elucidates the nature of the problem and what a reasonable solution might look like, but the conversation is led by the client. Delivery of the service is then in the hands and the scissors of the professional, possibly guided through further conversation. But the outcome is assessed by the person in the chair – do they like the haircut they've been given?

For most of medicine's history, doctors were like hairdressers – they worked at the whim of patients – 'he who paid the piper called the tune'.¹¹⁰ The growth of scientific medicine in the twentieth century gave doctors a better mechanical understanding of bodies and new diagnostic tools. Especially in areas such as surgery, doctors morphed into mechanics. For GPs and other health professionals, especially around chronic illness, the role they play is still closer to the hairdresser. Symptoms, causes, cures and care plans are complex and constantly under negotiation. GPs, though they might not shout about it, are experts not in science, but in understanding the distinct needs of patients.

So being an expert is about more than just what you know. Experts are more than encyclopaedias – bodies of detached knowledge. Given the democratisation of information, the encyclopaedia model of expertise is the most fragile. Information is now available, on the whole, to all. The role of the expert in modern societies is more complicated. The expert acts as a guide for the rest of us, helping us to navigate areas of uncertainty and think through the implications of what we know.¹¹¹ Prevention and self-care, driven by public behaviour, are becoming more and more important for health, but, as one of the professionals at the Primary Care Diabetes Society conference put it: 'To get our patients to behave differently, we have to get ourselves to behave differently.'

Towards a 'democratic oath'

The last year has seen a vicious and narrow argument about doctors' financial contracts. More important for the long-term health of the NHS, however, will be the new social contract that doctors negotiate with patients and the public. For all the changing public expectations of healthcare, patients want above all else for

their doctors to know their stuff and be able to practise medicine. But as we have seen, there are many ways to be an expert doctor. Realising that doctors of the future need to be a bit more hairdresser and a bit less mechanic, the medical community has begun rethinking aspects of professionalism and education.

Medicine's public statements of professionalism begin with the Hippocratic Oath. The public purpose of the Hippocratic Oath is to engender trust, to tell the world what it means to, in the words of one doctor/author, 'be good at something where failure is so easy, so effortless'.¹¹² But, as Roy Porter points out: 'The oath was intended to protect doctors, through a guild-like closed shop, no less than to safeguard patients.'¹¹³ Public statements of professionalism also have a private dimension.

As with any expert system, the relationship between doctors and patients relies on some element of trust.¹¹⁴ We cannot know about or worry about everything that is wrong with us, so we rely on experts. Among health professionals, this means a system combining generalist (GPs, nurses, pharmacists) and specialist expertise. Between professionals and the public, the asymmetry of expertise is more marked. Surveys tell us that, more than any other profession, people trust doctors to tell them the truth, and that this trust is pretty stable over time.¹¹⁵ But this conceals as much as it reveals. Trust is not a fixed quantity, it is a product of a relationship, in this case underpinned by a sense of professionalism. The other determinant of trust is a sense that professionals, and the system of which they are a part, are acting in our best interests.¹¹⁶ Doctors have conversations as people, but they are also the public face of a system that is trying, behind doctors' backs, to have its own conversations with the public. The doctors we spoke to as part of our research feel that while patients trust them as people, they are propping up an increasingly untrustworthy system.

If we are serious about involving patients in their own care, a certain sort of trust may be unhelpful. In the USA, patients' trust in doctors is, according to some measures, lower – a product of a different sort of relationship. But this means that medical literacy among the public is higher.¹¹⁷ They find out more, self-diagnose and negotiate choices with doctors. In his search for a new professional relationship, Richard Horton concludes that 'less trust is actually a good thing, for it suggests greater transparency regarding the reality of medical practice'.¹¹⁸ Rather than thinking about trust in terms of

‘how much?’), it might be more helpful to ask ‘what sort?’ Blind faith reinforces paternalism and disempowers patients. In some areas of policy, we see a situation of ‘critical trust’, in which high general trust runs alongside deep scepticism.¹¹⁹ The positive aspect of critical trust is a public feeling that experts will acknowledge non-expert questions. So, rather than asking how much patients trust doctors, the key question for the coming years will be how much doctors trust patients.

Authority now needs to be earned. It is the endpoint of a process of negotiation rather than the start. This negotiation defines what it means to be a professional. In all areas of public life, professionalism is under question.¹²⁰ Professions are both extroverted and introverted. The walls that professions erect around themselves mean that they can be cast, at worst, as a ‘conspiracy against the laity’ in George Bernard Shaw’s words.¹²¹ At best, professionalism has benefits that extend far beyond the roles and responsibilities that can be captured in a contract. Previous Demos work has explored professionalism and used the analogy of sportspeople. Professionals are participants in a game that relies on players’ shared understanding. They develop a feel for the game that transcends rational decision making. And their engagement with their work typically involves some element of ‘emotional labour’. They are personally invested in their profession.¹²² For Ray Tallis, this has been traditionally visible among doctors in their long hours and ‘going the extra mile’.¹²³

The last few years have seen a number of high-level attempts to find a new professional settlement in healthcare – a *democratic oath* to build on the Hippocratic one. The ‘Medical professionalism project’, a combined USA/Europe initiative, has produced a ‘physicians’ charter’. This charter recognises that *professional* autonomy has already been eroded, which may be no bad thing. So it emphasises *patient* autonomy, asking physicians to ‘be honest with their patients and empower them to make informed decisions about their treatment’.¹²⁴ In the UK, the King’s Fund, the British Medical Association and the Royal College of Physicians have all taken up the challenge of renewing professionalism.¹²⁵ Uniting these efforts is a sense that doctors have found themselves on the defensive in the last few years. Richard Horton, who wrote the Royal College of Physicians’ report,¹²⁶ turned up on Radio 4’s *Today* programme exasperated by posturing from the British Medical Association. The

social contract, he argued, is more important than the immediate financial one. Doctors needed to change ‘the public image of the profession... we know what it’s *against*, but we don’t know what it’s *for*’.¹²⁷

The Royal College of Physicians swept aside what it considered outdated themes such as *mastery*, *autonomy*, *privilege* (and with it *self-regulation*). It held onto ideas of *knowledge*, *skill*, *integrity* and *judgement*. But it realised that the context of knowledge was changing. In an era of instantly accessible information, the most important quality is the ability to navigate what we do and don’t know and judge accordingly. Talking to the working group, Harry Cayton explained the importance of judgement:

*I think mastery is an archaic concept. Indeed it comes from late Middle English and is linked to the mysteries of the Guilds; the idea that members were in possession of secret knowledge withheld from others. So while a body of knowledge is clearly essential, it is the interpretation of knowledge, the engagement with new knowledge, the acknowledgement of uncertainty about knowledge, the sharing of knowledge, not the holding of knowledge, that are characteristics of modern medicine.*¹²⁸

So the doctor-as-expert becomes a wise guide through the thickets of information both inside and outside medicine. Cayton went on to emphasise the importance of *empathy* and *mutuality* in addition to expertise, which suggests that professionalism, rather than being a quality possessed by professionals, only exists in relation to others. It is a way of defining and building a partnership.

Doctor Who?

More than in any other area, healthcare professionals are viewed by modernisers as roadblocks. Nye Bevan famously had to ‘stuff doctors’ mouths with gold’ to enable the creation of the NHS 60 years ago.¹²⁹ Doctors are still seen as protecting their own interests to the detriment of a functional health system. Following the new GP contract – which some would consider to be a new round of mouth stuffing – we were keen to find out about the new expectations from professionals and the impact on the care they provide. Speaking to eight young London doctors, we began by asking them to draw their relationship with their patients and

describe their ‘rich pictures’. Their pictures represented both the multitude of roles they were expected to play and rapidly changing public and political expectations. (These pictures and the doctors’ own descriptions of them form this pamphlet’s appendix.)

One doctor saw her role as a gatekeeper, the friendly face of an increasingly faceless healthcare system. Another said that his role was to make medical sense of the mass of patients’ knowledge and concerns. As well as talking to patients, he found himself more and more dealing with the expectations and opinions of patients’ friends and families. One doctor drew her conversations as a series of seesaws, representing the balance of power and knowledge and the distances that separate her from her patients. And one drew a relationship mediated by, and often interrupted by, her computer, representing the various procedures and technologies that she feels narrow the conversation she is able to have with her patients. In all cases, our doctors felt that, as ever, there were countless different types of patient, and countless correct ways of responding to them. But there was also a perception that things were changing.

Among our young doctors there was a strong sense of professionalism, but it was seen as malleable in response to changing public expectations. One compared her experience of medicine with her father’s:

F1: In my father’s generation, it was much more of a paternalistic attitude – ‘I’m the doctor, this is the patient and this is my advice.’ I say to my patients ‘what do you think is wrong with you?’ or, ‘given these options, what would you rather do?’ My dad often says to me, ‘You are the doctor, why are you giving them the choice?’ It is a very different way of looking at things.¹³⁰

M1: There used to be the ‘doctor knows best’ mentality and I think that’s what has disappeared.

F1: But I think that’s not necessarily a bad thing.

M1: No, no, I don’t think it’s necessarily a bad thing.

For these doctors, moving beyond paternalism is not just a necessity, it’s an opportunity to give patients more power and more responsibility for their own care. But they worry that this isn’t happening. In the minds of many professionals, paternalism has given way to ‘choice’ – doctors now ask patients to take decisions

that were once taken on their behalf. Paternalism, for all its limitations, embodies a clear and rich description of what it means to be a professional. The disingenuous rhetoric of ‘choice’ strips this away and does not provide an adequate replacement. For doctors, the language of ‘choice’ fails to capture the most important parts of their relationship with patients:

So we give them a lot of choice now. Maybe some of the time we give them too much choice. On the one hand you want your patients to be involved in the decision. But on the other hand, it depends very much on the patient. You have to gear it towards who the patient is and whether or not they are okay with making that choice.

For some, ‘choice’ was seen as a smokescreen for a systemic paternalism that was proving harder to shift:

I think that the way we communicate with patients on a one-to-one basis has definitely become very different. In some ways we’re getting less paternalistic, but in other ways, it is more paternalistic because we are becoming more target-driven... In some ways, we do offer more choice but there is a bit more pressure not to give people the choice and still to come out with what you as the doctor want.

The tone throughout was of being burdened by a set of expectations, boosted by policies, that didn’t reflect the complexity of healthcare and the need for partnership:

People now, because they have a choice, come with all these wants and we have to sort out what they need and what they want.

Our doctors saw the benefits to the system in telling patients that they should be exercising choice. Standards are raised and professionals get a better sense of the system of which they are a part. But the problem is that the idea of choice imagines a consumer who, through choosing, shapes the system rather than their own health. So choice does not create active patients, engaged in partnership. According to this group of doctors it has the unintended consequence of raising expectations among the public, who then outsource their health to the NHS:

With choice should come patient responsibility, and it doesn't.

If we are serious about engaging patients in their own care, we need to recognise that current structures of choice inhibit responsibility. Top-down control of choices and structures means that people have less bottom-up desire to get relevant information, self-diagnose and self-manage their health. This is why it is so important that patients and the public are allowed to make choices about the things that matter to them rather than the things that matter to the NHS. It requires a genuine negotiation, a conversation between patient and doctor, and a shift in logic.

Choice, as it is currently imagined, is a deeply flawed basis for a healthy conversation. If the logic of choice defines patients and the choices they want to make from the top down then the logic of care asks what matters to them.¹³¹ In the logic of care, choice is the start of the conversation rather than the end. The conversation that needs to take place is necessarily open-minded and open-ended. A number of initiatives, introduced in the name of quality, efficiency and equity, now stand between professionals and their patients. Doctors told us how their computers narrow conversation by putting patients and illnesses into fixed categories. Further discussion revealed how the computer acts as a metaphor for all sorts of procedures and policies that constrain professional judgement and patient agency.

Medicine is increasingly talked about in terms of evidence. Evidence-based medicine is seen as a way of assessing technologies and techniques and spreading best practice. Advocates claim that it redresses the balance between doctor and patient: 'Authority is devolved from expertise to the data and thus, ultimately, to the patient.'¹³² But the rhetoric of evidence narrows down conversations. It presupposes a sequence in which we – professionals or patients – collect all the value-free evidence and then make our choice based on this and what we value. In an era of choice, this means that patients are making the decisions.

But evidence does not speak for itself and choices are not that easy. In reality, as Annemarie Mol describes, evidence, uncertainty and decision making are all bound up together.¹³³ Healthy conversations demand that we talk about all of them at once, not assume that there is a body of relevant and universally applicable evidence out there. The logic of care means relaxing the constraints

of a narrow view of evidence and re-introducing elements of professional and public judgement. The public image of scientific medicine depends on it knowing the right answer. But professionals know that often there is no single answer, there are just better and worse ways to proceed. Conversations need to start with what is known and then explore what really matters. As it is currently imagined, evidence-based medicine provides a thin veneer of technocracy over an NHS that is still deeply political.

Conversational healthcare means talking about these politics rather than trying to pretend that there are easy answers. Giving patients simplistic or irrelevant choices is disingenuous. The logic of care demands a new sort of openness:

Q: What do you have to do now to earn trust?

A1: I think admitting, definitely, being fallible.

A2: They're often surprised if I don't have an answer. I say, 'I don't know, I'll call you later.' Then I'll call people at home and they'll say, thank you so much. It's almost like they're more impressed by you saying you don't know but you've gone and looked it up for them.

Doctors are struggling to find new ways to build trust in a complex system. So we also need to think about how people relate to systems. Here, the picture looks bleak. We asked our doctors to think about whether people can trust the system:

A1: Trust is eroded and I think that's inevitable and there's little that you can do, but ultimately it's getting to know them and build up your personal relationship with each patient that will rebuild that trust. It's the only way.

Q: So is it linked to continuity of care then?

A2: I think so, I really think it's fundamental, the relationship and trust and that's why everything can't be taken to polyclinics or out of hours...

Q: Could I though, as an active patient, trust the system?

A2: I don't think individuals can. I wouldn't.

These doctors are picking up on a wider breakdown in trust that is slowly seeping into their surgeries. They know that the trust relationship is changing, and some of them welcome a new

scepticism on the part of patients. But they worry that, for all their efforts, patients increasingly think that the system is not working in their best interests. There is a struggle for conversations to take place and relationships are suffering.

Pharmacists – filling the conversational void?

Doctors in their various guises are only part of increasingly diverse healthcare teams. As we saw with diabetes, people often prefer the conversational care they get from nurses.¹³⁴ We need to open up conversations with doctors, but we cannot expect them to do all the talking. More and more, it falls to pharmacists to fill in some of the blanks.

We gathered a mix of community and hospital pharmacists to talk about their role in modern healthcare. The picture they painted was one of change. Their position in conversational healthcare is in flux. For many people, the pharmacist is the first point of call, preceding or replacing the GP, and the site of a very different sort of conversation. One pharmacist told us that the reason people like talking to him is that the conversations are, metaphorically and literally, ‘a bit more *off the record*’.¹³⁵ The power relationship is less well established than with a doctor so conversations can be more exploratory. And according to one community pharmacist ‘the conversations with customers are getting longer’.

The complaints of pharmacists reflect those of doctors. They have responsibilities both to their businesses and to broader society. According to a survey by the King’s Fund, they have a sense of professionalism that sees them often working long hours and doing jobs not captured in their contracts.¹³⁶ Pharmacists too see the effects of a networked public. ‘The internet, that’s changed everything,’ one said. Where once they would be the source of information about medicines, pharmacists are now increasingly arbiters of conversation with an informed public.

Pharmacists’ relationships with other professionals are changing too. Rather than acting as a dispensing machine for GPs and hospitals, they are now answering back. According to one survey, pharmacists are keen to take on a more active professional role, to use their expertise to help people manage increasingly complicated treatment regimes.¹³⁷ And policy makers are listening to their demands. So in hospitals pharmacists are now part of the

ongoing conversation with patients, likely to be seen wandering wards and engaging patients in conversations that, according to our group, are more open and honest than those that people feel they should be having with doctors.

On the high street, pharmacists have been asked to prescribe for minor illnesses and to talk to patients about the drugs they are taking. A ‘medicines use review’ is a conversation that takes place between pharmacist and patient and can produce recommendations to be taken back to the doctor. Like patients, pharmacists find that old habits are hard to break. They know that their contributions to this new conversation are not always welcome: ‘A lot of the recommendations end up in the bin,’ one told us.¹³⁸ But they are also helping the patient towards a better conversation with the doctor at their next encounter.

The art of conversation

Doctors and pharmacists have in the past agonised about *compliance* – patients taking their prescribed medicines in the prescribed way. In an era in which doctors had authority and their judgement was deferred to, they could expect that a sufficiently intelligent person would follow their orders to get better. The aim of the conversation was therefore to engender trust and understanding and make compliance more likely. Now, as we have seen in our case studies, patients are likely to have their own opinions about treatment and we can’t assume that professional and patient will agree on what counts as a success. Following a realisation that as many as half of all patients weren’t doing what they were told, pharmacists began looking for alternative ways of understanding and building relationships. They concluded that we needed a new way of talking about people’s relationship with medicines – one emerging from a model of partnership rather than paternalism, appreciating that the professionals no longer monopolise expertise.¹³⁹ While compliance starts from a position of hubris, *concordance* starts from one of humility. It aims at negotiated and shared understandings of both illness and treatment.

As with any change in nomenclature, the replacement of compliance with concordance could be interpreted by professionals as political correctness. But those recommending the change demand a fundamental rethink. Concordance involves recognising patients’ expertise rather than just finding medicines to fit their

chaotic lives. It asks professionals to agree goals with patients rather than assume them. It asks that the role of the patient in decisions and ongoing care is brought to the fore. And it gives debates about choice real traction by suggesting that patients should be intimately involved in choosing the things that matter to them – treatments and care plans – as well as the things that don't. Our diabetes case study illustrates how the promise of technology can fall short if it doesn't make sense to the people who must find a place for it in their lives. With chronic illness, people will not live their lives as technology or medicine tells them to. What works for one person will be incomprehensible to another.

For health services and pharmaceutical companies, a turn to concordance changes the definition of innovation. Rather than looking for increasingly powerful drugs, or increasingly effective ways of delivering drugs, the challenge of concordance is one of empowerment, helping people to take part in decisions. Emerging innovations in patient information and decision aids for patients is a key area of growth.

One understandable reaction to the embedding of patient choice in treatment is a fear that patients may choose things that are ineffective or dangerous. But concordance does not ask for patients to take over doctors' decisions. Surveys suggest that patients do not want doctors to monopolise decisions; nor do they want to take decisions in isolation. Instead, the majority of patients want treatment decisions to be negotiated and shared.¹⁴⁰

Medicine has always been laden with expertise and specialist knowledge. But it has always been about more than science and technology. It translates scientific understanding and technological promise into something that makes sense to people's lives. As the power of science and technology increases, the need for translation becomes greater and conversations about concordance become more vital. A *BMJ* editorial explained that 'concordance doesn't come easily'.¹⁴¹ But given that compliance, coercion and other approaches have routinely failed, it is worth working out how to make concordance work.

Learning to listen

As part of the re-imagining of what a good doctor should look like, the medical profession is also considering how to

create future doctors in this image. Organisational failures in recruitment and training systems have received a huge amount of attention in 2007, but they have had the effect of opening up a new debate on the content of training. The Tooke report published in early 2008 conducted a post mortem on the recent failures of medical recruitment and training, finding a disturbing mass of conflicting motives and confusion about the role of the doctor in future healthcare.¹⁴² The lesson is that doctors' future professionalism needs to intertwine with changes to the ways that doctors are educated.

The Postgraduate Medical Education and Training Board, which deals with all the education that takes place after medical school, is currently reviewing medical training. It realises that it is impossible to talk about a curriculum without thinking through bigger questions of culture and practice that make medicine what it is. Training doctors to work in partnership, and to engage in the sorts of conversations that lead to good care, requires a radically new approach.

Medical education now places less emphasis on learning facts and more on making sense of problems and patients. Following advice from the General Medical Council, doctors are starting to be taught to anticipate and answer the new questions that patients might ask.¹⁴³ The Royal College of Physicians has provided a set of questions that patients should ask professionals in order to stretch, deepen and get the most from healthy conversations.¹⁴⁴ At the level of the profession, this represents an admission of the importance of conversation, but the next step is to transfer this to practice. During a consultation, patients often have little idea what questions are relevant and important. A brave doctor therefore needs, in the interests of productive conversation, to tell patients the difficult questions that they should be putting to professionals.

In the future, conversation will be an increasingly important part of what health professionals do and it will become increasingly difficult. With global migration, professionals will need to talk across cultures and, often through interpreters, across language barriers. They will need to find new ways to talk and listen to children, people with different educational backgrounds, learning disabilities and mental health problems. And the substance of medical conversations will become more complicated. As social science and genetic testing provides a clearer picture of people's

future health risks, professionals will have to engage in new conversations about preventative treatment. We now know, for example, that women with faulty BRCA genes have a massively increased risk of breast cancer, but the conversation raising the possibility of a prophylactic mastectomy is a very hard one to begin.

As medicine becomes more scientific and more complex, conversation has paradoxically gone from being an optional extra to a core part of healthcare and a core skill of professionals. We should therefore look for ways in which the system can adapt to value conversation in its own right.

5 From the personal to the political

The challenges for the NHS in the twenty-first century are well documented. We need not repeat them here, except to point out that the solutions to rising public expectations and growing chronic illness are less about technology or treatment and more about people and behaviour. Health policy makers increasingly recognise that the shift to a preventative, early intervention model can't be imposed or delivered unilaterally. People need to participate in their own treatment, collaborate with professionals and change the way they live their lives. But that means we have to put relationships at the heart of healthcare and move beyond a policy debate focused on structural fixes. Our analysis has started with people, not systems. In this pamphlet we have focused on an area that has been ignored and unwittingly narrowed through top-down reform – the conversations between professionals and patients. As we have seen, these conversations are vital to good care and a new source of innovation.¹⁴⁵ So how should the system respond?

A glance back at the catalogue of healthcare reforms since 1997 shows an overwhelming enthusiasm for top-down structural change. Modernisation of the system has been necessary, but there has been little thought given to people's behaviour within these new structures. Patients and professionals have been cast as agents of change, but not the sorts of change that they want, nor the sort that needs to happen to realise the Wanless vision of a new relationship between people and healthcare. Where the system should be encouraging empowerment and participation it has instead created a dependency. Despite a shared recognition among patients and professionals of the need to move beyond paternalism, systems of healthcare still medicalise people's lives and strip away responsibility.

Our project has explored in depth two cases in which conversation is working to change healthcare. The stories within these case studies hopefully speak to the communities of interest –

patients, patient groups, doctors, nurses and others – that congregate around diabetes or mental health. Medicine, which advances along lines defined by particular conditions, is pretty good at taking these lessons on board. Health policy is less good at learning from the bigger lessons. Current debates about treating and preventing diabetes and mental illness have much to teach healthcare in general. We can extract lessons about what is required from patients, professionals and their relationships to improve outcomes. These lessons are particularly applicable to the management of other chronic illnesses – Alzheimer’s, arthritis, asthma and more. But conversational healthcare also speaks to the broader challenge of prevention. Everyone agrees that prevention is more important than cure, but the system stubbornly still finds it easier to deal with the certainties of diagnosed illness than the uncertainties of preventable ones. Our argument is that rethinking healthcare provides a coherent and joined-up approach to both treatment and prevention – a *logic of care*.

An engaged population cannot be engineered through organisational change. It depends primarily on the personal relationships between healthcare professionals and the public. Partnership demands personalised healthcare, with a strong doctor–patient relationship at its heart. In 2007 the idea of personalisation came to prominence. Gordon Brown spoke of healthcare moving from universal to personal.¹⁴⁶ David Colin-Thome, the National Director for Primary Care, published *Keeping It Personal*.¹⁴⁷ And Lord Darzi’s interim report *Our NHS, Our Future* featured an entire chapter devoted to ‘a personalised NHS’.¹⁴⁸ But both Darzi and Colin-Thome focus more on bringing structures closer to people than personalising care. Personalisation for them is about local services and greater access.

Healthy conversation won’t happen as a by-product of structural change. Moving healthcare closer to people’s everyday lives may give people opportunities to interact more closely with professionals, but it doesn’t answer other important questions: What do we want these interactions to look like? What do we want them to achieve?

Truly personalised healthcare allows patients to articulate their experiences, express their values, set their priorities, be aware of their options, exercise their preferences and be educated in managing their health. This means an end to paternalism. Professional

cultures, communication skills and conversational styles will need to adapt and evolve. Personalisation also requires a change in the way success is judged, widening beyond biomedical indicators to look at the degree to which patients are able to lead the life they wish.

One strong message from our research is that doctor–patient relationships are necessarily individual. It is not possible to say what all patients want relationships to look like or what they want from them. That is part of the process of negotiation. Some patients will prefer to remain passive, others will want to have more say, or may take different approaches at different stages of treatment. But policy makers need to be concerned about the foundations of these relationships – the expectations of patients, the way doctors view patients, the assumptions the system makes about patient capacity, the potential role of the patients in their own care and the amount of time and space dedicated to cultivating a productive relationship.

A strong constitution

While requiring professionals to work in new ways, personalised healthcare also requires patients to respect professionals, and to understand that the collective nature of the NHS requires cooperation and compromise. Gordon Brown’s New Year message to the NHS outlined ‘a new constitution of the NHS setting out for the first time the rights and responsibilities associated with an entitlement to NHS care’.¹⁴⁹ A constitution represents a valuable opportunity to clear away some of the ambiguity surrounding the public’s relationship with the NHS. As the King’s Fund has pointed out, a constitution is an opportunity to reconnect public and professional understandings of the NHS.¹⁵⁰ It is a chance to start new conversations about values rather than rehearse arguments about systems.

But if the doctor–patient relationship is going to be set in stone, we need to consider carefully what we want. The duplicity of the rhetoric of ‘choice’ has muddied this relationship, creating confused expectations and unintended dependency. An NHS constitution provides an opportunity to move from choice to care, to recast people as citizens rather than consumers. A citizen-based approach recognises the collectivist foundation of the NHS. Unlike a consumer, a citizen has responsibilities towards the provider of

services. A constitution can empower open and productive conversations. If the NHS constitution is going to urge us to take more responsibility for our health and contribute more to our own care, then it must also recognise that the NHS has a duty to support us to do so. An NHS constitution should explicitly recognise the value of the doctor–patient relationship and underline a patient’s right to information. But it must not ossify the dynamic, individualised relationship between patients and professionals.

Building the NHS imagined by Wanless means abandoning the conception of the patient as consumer. So we need to ask what we want from patients as citizens. While a logic of choice has had the positive effect of creating more assertive patients and redistributing power, it has also skewed the doctor–patient relationship. By over-emphasising the conflict of interest between professionals and service users it undermined the idea of a relationship based on cooperation and partnership, pitting patient against professional. A citizen-based approach, drawing on the logic of care, also requires professionals to relinquish power. But in return it asks patients to play a larger part in achieving their own health outcomes, where they are able.

Conversations and relationships provide a new focus. We should take seriously the idea of patient experience. While policy makers have so far overlooked the importance of relationships, others haven’t. The private healthcare company BUPA sells itself on the length and quality of conversation between the doctor and the patient. And we can learn a wider lesson from shifts in advertising, away from seeing people simply as consumers of products. Advertisers are increasingly concerned with people’s experiential relationships to brands. Advertising guru Kevin Roberts has written of the importance to brands of emotional connections, what he calls ‘lovemarks’.¹⁵¹ For the NHS, the lessons are enlightening. Policy makers should not underestimate the importance of personal experiences, emotions and relationships. A personalised NHS that engenders loyalty, self-management, contribution and cooperation needs space for conversation, and it needs to ensure that the system values it.

An instinctive response might be that all of this demands more of the NHS’s scarcest resource – time. But healthy conversation does not necessarily mean that the doctors at the centre of health need to spend more time listening to patients. As we have seen,

valuable conversations are often diverse, decentralised and take place far beyond a doctor's gaze. The challenge is to take advantage of these rather than try to control them. Healthy conversation asks professionals to talk differently, not talk more. As we have seen from our case studies and close inspection of changing professionalism, in certain areas, these conversations are moving in the right direction. We need to ensure that in the future they are supported by the system rather than happening despite it. Policy makers and politicians too must develop a more honest conversation with the public, rather than hiding their politics behind a veneer of managerialism. This will in turn encourage patients and professionals towards better relationships.

We end by offering some recommendations to help the NHS benefit from the power of conversations in healthcare.

Recommendations

Wikirecords – patients as authors of their own health information

As we have described in this report, patient records punctuate and connect conversations. Patient record transparency can positively disrupt and improve doctor–patient conversations. The last year has seen a race between Microsoft and Google to corner what is likely to be a lucrative American market for the provision of online electronic patient records. The UK, despite its problems with the construction of a centralised health data system, has a chance to be a world leader in the provision of trustworthy, transparent, conversational patient records. For all the concerns about making this work in practice, it is clear that the major barriers will be cultural rather than technological. As patient records open up, policy makers should take inspiration from Wikipedia and allow patients to contribute to and comment on (though perhaps not *edit*) professional information. This will have clinical benefits while also sending the clear signal that information should be owned by and be under the control of patients.

Getting engaged – a pilot

If we are serious about realising Wanless's vision of 'fully engaged' patients, we need to appreciate the effort involved. Policy makers should take advantage of the groups that are struggling to make this

happen for the benefit of their members. Patient groups such as Diabetes UK and Rethink should lead pilot programmes of full engagement, linked to innovative service providers. These programmes should be designed from the bottom up and given the space to illustrate to the NHS what it would take to accommodate this new model of patient action.

Personal budgets

We have seen with diabetes care that available services are out of step with people's needs. Within diabetes care, groups are starting to advocate what they call 'micro-level commissioning'.¹⁵² But the nuances of the decisions patients make at the micro level risk being erased when they are aggregated. We need a genuinely bottom-up model of empowerment. The concept of personal budgets and self-directed services is gaining ground within social care,¹⁵³ and there are signs that personal budgets will be a key plank of further healthcare reform.¹⁵⁴ Following the *Putting People First* concordat,¹⁵⁵ patients with long-term conditions should be allocated a budget for services allowing them to access and build education, support and self-management programmes. But these cannot just become an extension of the existing logic of choice. Within healthcare, there will be resistance because of old paternalistic assumptions about who knows what's good for us. As we have seen, in many cases patients know more about their illness than doctors. The NHS needs to learn from them. For personal budgets to empower patients, patients must be able to define their own choices and create new options. They must be able to question, improve and build services from the bottom up.¹⁵⁶ If patients get to choose from only a limited menu of options, personal healthcare budgets will fail.

Outcome statements

As we have seen, patients and professionals often disagree on what counts as a good outcome. An outcome statement would be an agreed set of goals, forming part of the patient record, towards which the patient and doctor can work. The statement would help patients and professionals clarify each other's priorities and values. The statement would be voluntary and malleable, providing a starting point for a more productive conversation.

Information provision

The NHS needs to stop seeing information as a health supplement. It now forms an integral part of health interactions. In an internet-enabled population, the ability to find, understand and critique health information has a profound influence on the way patients approach their treatments and consultations. Health professionals have a role in building patients' capacity to do this. The Information Prescriptions pilots need to be extended to look at capacity building. Information provision should be encouraged through inclusion in the Quality and Outcomes Framework.

Conversational regulation

The lessons of conversational healthcare also apply to institutions. Regulators in healthcare, from the General Medical Council and National Institute for Health and Clinical Excellence up to the Council for Healthcare and Regulatory Excellence, need to ensure that they are having genuine dialogue with patients and the public. This can provide a new source of innovation and new forms of leadership.¹⁵⁷ Experiments such as the NICE Citizens' Council expose a real tension between participation and expert evidence. Public conversation throughout healthcare demands a new openness and a new honesty about values and interests.

The 'patient pack'

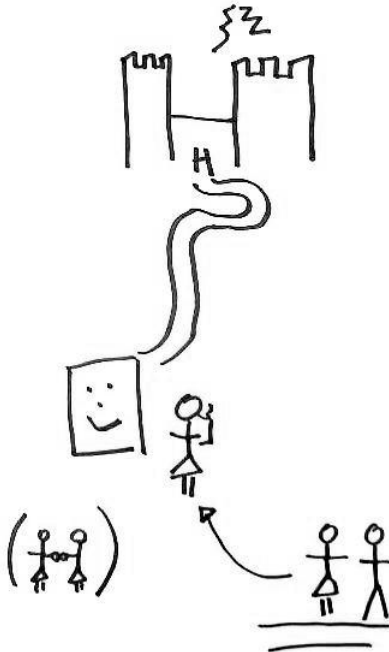
Finally, patients with or at risk of chronic illness should be provided with a 'patient pack'. This pack would provide information on what to expect from consultations and treatments, how to get the most out of meetings with professionals, what the important questions are and what a patient's rights and responsibilities are. The pack should challenge professionals to respond to new sorts of conversations and start care planning early.

Appendix: Rich pictures from primary care

Beginning a group discussion with eight young GPs, we asked them to draw their relationships with patients. Here are their pictures, along with their descriptions:

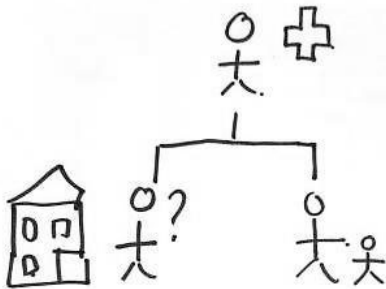
1 The gatekeeper

'That is me as a friendly GP, working in partnership, holding hands. There's the scary building called the hospital. I am here to help you get from there to there.'



2 The family doctor

'I drew it as a family tree so this is probably the doctor at the top with the patients in the house, at the bottom, and they might come and ask anything. Half the time, it could be things that could be dealt with by other family members or peers or friends, whatever.'



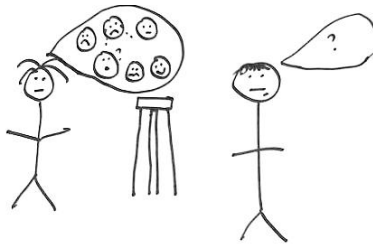
3 Making sense

'This is the doctor on the left hand side and the patient on the right hand side. These are what the patient brings the doctor – ideas or concerns. And hopefully, I can recognize them. So I kind of assimilate all those and come up with my ideas and feed them back to the patient so he or she can think about them and then maybe generate some more stuff or maybe go away. I increasingly find these days that there is the person in the room but there are all these other people outside who are usually family members who are pushing and putting things into the patient's head or making them come to the doctor with certain expectations.'



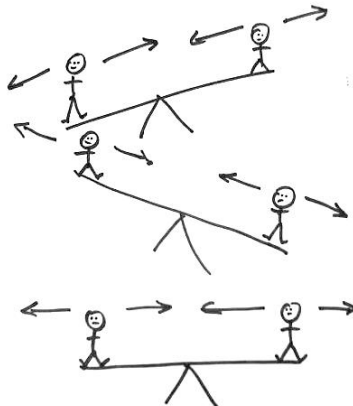
4 The hurdle

'The patient has got many different guises of emotions, concerns, expectations, happiness, sadness, and comes with their own impression of what is going to happen. This is the doctor [on the right] and he does not know what they [the patients] are going to expect when they come in. This is a hurdle that they have to break down to develop their relationship, for the doctor to find out what is going on and hopefully help the patient in some way and for the patient to leave slightly healthier than when they came in.'



5 A balancing act

'I've got a seesaw picture of different ways that we communicate with patients. The doctor could have the upper hand, be the parent if you like, or you can be looked down on by the patient, or be on an equal footing. Whichever scenario you are in, you could be a certain distance away or close to the patient depending on the relationship with that particular person.'



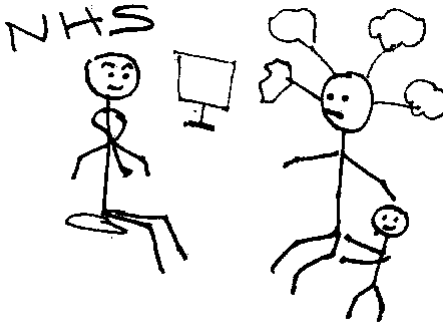
6 Talking jargon

'This is not me by the way – the doctor looking very knackered, talking in a language that the patient does not understand.'



7 Through a computer

'I was trying to see the doctor as NHS doctor. There is the strong relationship with the computer which the GP has today and is meant to obey, which is a barrier between the GP and the patient.'



8 The different faces of different patients

'The first one, the patient here [top left] has shown his dark side, the sadness, and is keeping the bright side away from the doctor. So they are asking for help. Then there are the patients with a shopping list [top right], telling the doctor "get me what I want", which is really annoying. The third picture [bottom] shows that the patient can be a teacher for us.'



Notes

- 1 Nietzsche, 'Menschlich, all zu Menschlich'.
- 2 There are more than 290 million consultations with GPs each year. 'General practitioners figures FAQs', British Medical Association, see www.bma.org.uk/ap.nsf/Content/gpfiguresfaqs (accessed 24 Apr 2008).
- 3 Jones, *Talk Us Into It*.
- 4 Leadbeater, *Personalisation Through Participation*.
- 5 Parsons, *The Social System*.
- 6 Wanless, *Securing Our Future Health*, interim report.
- 7 Stilgoe et al, *The Received Wisdom*.
- 8 School of Health and Related Research, 'Expert patients and non-expert doctors'.
- 9 Dixon, 'Best of both worlds'.
- 10 Richards and Coulter, *Is the NHS Becoming More Patient-centred?*
- 11 Tuckett et al, *Meetings Between Experts*.
- 12 Powell et al, 'The doctor, the patient and the worldwide web'; see also Bee, 'How the internet ruined my health'.
- 13 GP's focus group, 26 Nov 2007.
- 14 Cox, 'The impact of the internet on the GP-patient relationship'.

- 15 Some examples that we have found particularly illuminating: 'aiming for grace', see dearada.typepad.com/grace; 'Diabetes Mine', see www.diabetesmine.com; 'A shot in the dark', see artistmom2two.blogspot.com (all accessed 24 Apr 2008). Interestingly, more and more, often aggrieved, doctors and other professionals are also contributing their and their patients' stories to blogs.
- 16 'Health 2.0', *Economist*.
- 17 Porter, *Blood and Guts*.
- 18 Ibid.
- 19 Brand, 'Keep designing'.
- 20 See Information Prescription Project, 'Interim report on the information prescriptions pilot project'; for more on the broader debate about information, see Bradwell and Gallagher, *FYT*.
- 21 O'Reilly, 'What is Web 2.0?'.
- 22 J Giles, 'Internet encyclopaedias go head to head'; see also Leadbeater, *Wethink*.
- 23 Hodgkin and Munro, 'Conversation peace'.
- 24 O'Reilly, 'What is Web 2.0?'.
- 25 Ipsos MORI, *The GP Patient Survey 2006/2007*.
- 26 Wilsdon and Willis, *See Through Science*.
- 27 Andersson et al (eds), *Healthy Democracy*.
- 28 See, for example, Epstein, *Impure Science*; see also Wilsdon et al, *The Public Value of Science*.
- 29 Davies et al, *Citizens at the Centre*.

- 30 Stilgoe and Farook, 'Doctor, the patient will see you now'.
- 31 Rabinowitz et al, 'Length of patient's monologue, rate of completion, and relation to other components of the clinical encounter: observational intervention study in primary care'.
- 32 Taken from the podcast 'One healthy conversation' (Demos).
- 33 Interview with B Fisher GP, 7 Feb 2008.
- 34 See 'Map of medicine healthguides'.
- 35 Tulusan, *Circles of Care*.
- 36 Mol, *The Logic of Care*.
- 37 Ibid.
- 38 Public Administration Select Committee, 'Choice, voice and public services'.
- 39 'BMA team "stunned by GP contract"', *BBC News*; 'Nurses ready for fight over NHS', *BBC News*.
- 40 Mulholland, 'Johnson vows to heed concerns over NHS reforms'; see also Richards and Coulter, *Is the NHS Becoming More Patient-centred?*
- 41 Brown, 'Speech on the National Health Service'.
- 42 Bentley, *Everyday Democracy*.
- 43 See National Diabetes Audit, *Key Findings about the Quality of Care for People with Diabetes in England and Wales*.
- 44 See British Medical Association, 'Quality and outcomes framework'.
- 45 Cottam and Leadbeater, *Health*.
- 46 Feudtner, *Bittersweet*.

- 47 Quoted in *Ibid.*
- 48 Wanless, *Securing our Future Health*, final report.
- 49 'Healthy in between', at the 'aiming for grace' blog.
- 50 Diabetes UK, 'Emotional and psychological support'.
- 51 Leder, *The Absent Body*.
- 52 Group interview at Diabetes UK, 22 Oct 2007.
- 53 *Ibid.*
- 54 Patel et al, 'Trends in the prescription and cost of diabetic medications and monitoring equipment in England 1991–2004'.
- 55 The Diabetes Control and Complications Trial Research Group, 'The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus'.
- 56 S Cradock, speaking at the Primary Care Diabetes Society conference, 16 Nov 2007.
- 57 Healthcare Commission, *Diabetes*.
- 58 See www.dafne.uk.com (accessed 19 Mar 2008).
- 59 DAFNE Study Group, 'Training in flexible, intensive insulin management to enable dietary freedom in people with type 1 diabetes: dose adjustment for normal eating (DAFNE) randomised controlled trial'.
- 60 Sánchez et al, 'Diabetes-related knowledge, atherosclerotic risk factor control, and outcomes in acute coronary syndromes'.
- 61 See the website of the UK Prospective Diabetes Study, www.dtu.ox.ac.uk/index.php?maindoc=/ukpds/ (accessed 28 Jan 2008).

- 62 Spero, *Diabetes*; Orchard, 'Diabetes: a time for excitement – and concern'.
- 63 Banks et al, 'Disease and disadvantage in the United States and in England'.
- 64 Notes from the Primary Care Diabetes Society conference, 16 Nov 2007.
- 65 Group interview at Diabetes UK, 22 Oct 2007.
- 66 Ibid.
- 67 Department of Health, *National Service Framework for Diabetes*; National Collaborating Centre for Women's and Children's Health and the National Collaborating Centre for Chronic Conditions, *Type 1 Diabetes*.
- 68 This example is borrowed from P Streets, former head of Diabetes UK.
- 69 Healthcare Commission, *Diabetes*.
- 70 Darzi, *Our NHS, Our Future*.
- 71 Group interview at Diabetes UK, 22 Oct 2007.
- 72 National Diabetes Support Team, 'Year of Care'.
- 73 Bodenheimer et al, 'Nurses as leaders in chronic care'; see also Diabetes UK, 'Specialist nurses could save NHS £100 million'.
- 74 Mol, *The Logic of Care*.
- 75 Serious mental illnesses are generally said to be those in which psychosis occurs, eg schizophrenia or bipolar disorder; see Rethink, 'What is severe mental illness?'.
- 76 Department of Health, 'Johnson announces £170 million boost to mental health therapies'.

- 77 Mental Health Foundation, 'Exercise and depression: results of 2005 online survey'.
- 78 Singer, 'The social origins and expressions of illness'.
- 79 Thornicroft, *Shunned*.
- 80 Sparks, 'Would anyone want your mental illness?'.
- 81 Mind, *Putting the Soul Back into Psychiatry*.
- 82 Sokratis et al, 'Stigma'.
- 83 Recognition of recovery in mental health is still in its infancy, though a growing evidence base suggests that about half of those with a diagnosis of psychotic illness recover to some extent. See Harrison et al, 'Recovery from psychotic illness'.
- 84 Lester et al, 'Patients' and health professionals' views on primary care for people with serious mental illness'.
- 85 Mental Health Foundation, *Strategies for Living*.
- 86 Roe and Davidson, 'Self and narrative in schizophrenia'.
- 87 See Seager, 'Getting personal'.
- 88 Gladwell, *Blink*.
- 89 Ibid.
- 90 Seager, 'Getting personal'.
- 91 Hinshelwood, 'The difficult patient'.
- 92 Pinfold et al, *Positive and Inclusive?*
- 93 Ibid.

- 94 Royal College of Psychiatrists, *Carers and Confidentiality in Mental Health*.
- 95 Rethink, 'Sharing mental health information with carers'.
- 96 Royal College of Psychiatrists, *Carers and Confidentiality in Mental Health*.
- 97 Stanghellini, 'The puzzle of the psychiatric interview'.
- 98 NHS Connecting for Health, *The Care Record Guarantee*.
- 99 See Bradwell and Gallagher, *FYI*.
- 100 NHS Connecting for Health, *The Care Record Guarantee*.
- 101 Mental Health Foundation, 'Advance statements in mental health'.
- 102 Amering et al, 'Psychiatric advance directives'; British Medical Association, 'Advance statements: BMA views'.
- 103 Henderson et al, 'Effect of joint crisis plans on use of compulsory treatment in psychiatry'.
- 104 Disability Rights Commission, 'Equal treatment'.
- 105 Rethink, 'Physical health and mental health'.
- 106 Ibid.
- 107 Lau, 'The case for inclusion'; see also Royal College of Psychiatrists, 'Physical illness and mental health'.
- 108 Tallis, *Hippocratic Oaths*.
- 109 Collins and Pinch, *Dr Golem*.
- 110 Porter, *Blood and Guts*.
- 111 Stilgoe et al, *The Received Wisdom*.

- 112 Gawande, *Better*.
- 113 Porter, *Blood and Guts*.
- 114 Giddens, *The Consequences of Modernity*.
- 115 Worcester, 'Public attitudes to science'.
- 116 Poortinga and Pidgeon, 'Exploring the dimensionality of trust in risk regulation'; Scholefield, *A Guide to Trust*.
- 117 Collins and Pinch, *Dr Golem*.
- 118 Horton, *Second Opinion*.
- 119 Poortinga and Pidgeon, 'Exploring the dimensionality of trust in risk regulation'.
- 120 Craig, 'Building shared autonomy'.
- 121 As quoted by Harry Cayton at the Association for the Study of Medical Education conference, Defining and Developing Professionalism, London, 28 Apr 2005.
- 122 Craig, 'Building shared autonomy'.
- 123 Tallis, *Hippocratic Oaths*.
- 124 Medical Professionalism Project, 'Medical professionalism in the new millennium: a physicians' charter'; see also Coulter, *The Autonomous Patient*.
- 125 Rosen and Dewar, *On Being a Doctor*; British Medical Association, *Shaping Tomorrow*; Royal College of Physicians, *Doctors in Society*.
- 126 Royal College of Physicians, *Doctors in Society*.
- 127 R Horton, speaking on the *Today* programme, BBC, 6 Feb 2008.

- 128 Royal College of Physicians, *Doctors in Society*; see also Cayton, 'Some thoughts on medical professionalism and regulation'.
- 129 Greener, 'Where are the medical voices raised in protest?'
- 130 Quotes taken from GP's focus group, 26 Nov 2007.
- 131 Mol, *The Logic of Care*.
- 132 Patterson, 'What doctors don't know (almost everything)'.
- 133 Mol, *The Logic of Care*.
- 134 Bodenheimer et al, 'Nurses as leaders in chronic care'.
- 135 Quotes taken from focus group with hospital and community pharmacists, 28 Nov 2007.
- 136 Lewis and Jenkins, *Developing Community Pharmacy*.
- 137 Ibid.
- 138 See also Wilcock and Harding, 'General practitioners' perceptions of medicines use reviews by pharmacists'.
- 139 Marinker, *From Compliance to Concordance*.
- 140 Coulter and Magee (eds), *The European Patient of the Future*; see also Sihota and Lennard, *Health Literacy*.
- 141 Smith, 'An extreme failure of concordance'.
- 142 Tooke et al, *Aspiring to Excellence*.
- 143 General Medical Council, 'Good medical practice'.
- 144 Royal College of Physicians, 'Choosing the right treatment'.
- 145 See also Parker and Parker (eds), *Unlocking Innovation*.

- 146 Daly, 'Gordon Brown plays down an independent NHS'.
- 147 Colin-Thome, *Keeping It Personal*.
- 148 Darzi, *Our NHS, Our Future*.
- 149 Brown, 'PM's New Year message to NHS staff'.
- 150 Dixon and Alvarez-Rosete, *Governing the NHS*.
- 151 Roberts, *Lovemarks*.
- 152 Diabetes UK, 'Year of Care for Diabetes project newsletter'.
- 153 Leadbeater et al, *Making It Personal*.
- 154 Donnelly, 'Health "voucher" for NHS patients'.
- 155 Department of Health, *Putting People First*.
- 156 For an example of personal budgets as a source of innovation, see Leadbeater et al, *Making It Personal*.
- 157 Stilgoe, *The Nanodialogues*.

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Approaching its sixtieth birthday, the NHS faces some tough challenges. Success in treating acute illness and failure in prevention mean that medicine will have to manage a flood of chronic illness. This means rethinking relationships between patients, professionals and the public. Every day in the UK, more than a million conversations take place between doctors and patients. But in the noise of healthcare reform, the small conversations that matter most have been drowned out.

This pamphlet eavesdrops on the conversations that are taking place between doctors and patients, in particular around diabetes and mental illness. Here, professionals are learning to talk and listen to increasingly assertive patients. Improving the quality of conversations is key to empowerment and innovation. For professionals and policy makers, this means letting go of some old assumptions about expertise and professionalism. The future of healthcare depends not only on new technologies and treatments but also on giving people the space to talk.

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