A long and winding road

Improving communication with patients in the NHS

IN PARTNERSHIP WITH



Author: Andrew McDonald

Principal researcher: Joseph Sherlock

Acknowledgements

With thanks to Mark Anderson, Dr Emran Mian, Dr Bill Noble, Prof Finbar O'Callaghan, Dr Adrian Tookman, Prof Sir Mike Richards and Dr Nicholas van As.

February 2016

Contents

Executive summary	4
Section One: introduction	6
Section Two: a short history lesson	8
Section Three: the problem and why it matters	15
Section Four: the scale and cost of the problem	18
Section Five: making things better	22
Section Six: reaching for the prize	29
References	33

Executive summary

Look at any of the NHS reform plans of the last quarter of a century and somewhere you will find a commitment to better communication between healthcare professionals and patients. Whereas this was once put forward as a good which was self-evident, it is now proposed as an objective which can save costs, improve health outcomes and enhance the quality of patients' experience of healthcare.

This paper argues that the evidence underpinning these claims is compelling. Focussing on serious illness, particularly cancer, and on end-of-life care, it acknowledges that substantive progress has been made in the last 20 years, but it identifies the distance still to be travelled.

It might be tempting to regard the issue as desirable, but of the second rank. This would be mistaken. It has never mattered more. We do not know the full extent of waste generated through poor communications but this report argues that it is in excess of £1 billion. This waste is evident in poor adherence to medication regimes, repeat visits to clinics, disputes and, ultimately, litigation.

And the bar which healthcare professionals must meet is going up: patients increasingly want and expect to be engaged in shared decision-making. This approach offers great benefits for the patient if done well, but it demands more refined communication skills from the professional. These reasons alone add urgency to the challenge. But beyond that we should be spurred into renewed effort by the consistent message from patients that this is an issue that they care about profoundly.

The report demonstrates that we already have to hand the tools we need to make measurable improvements in communication: through training; the deployment of more Clinical Nurse Specialists; and the use of simple decision aids and prompts.

What is more, these solutions have been shown to be cost effective: they offer the prospect of recouping the initial investment over subsequent years as waste is eroded.

NHS England is currently considering its response to the training recommendations in the Cancer Taskforce Report of September last year. This paper is supportive of that work, but it urges the NHS to go further – developing a comprehensive business case for improved communication

to support curative and palliative care. That programme should have clear, defined leadership, dedicated resources and, above all, it should be followed through with determination. We will only realise the improved health outcomes and efficiencies if we stay the course.

We do not underestimate the challenges ahead. We are talking about executing far-reaching cultural change in the largest institution in the UK. That will ask much of doctors' willingness to value 'soft skills' and it will require NHS leaders to provide healthcare professionals with the time and context to conduct some of the most difficult conversations any of us will ever have.

This issue goes to the heart of what sort of health service we want. This is a first order issue, not one that can wait for the next passing health white paper. It is urgent.

This report is a call to action.

Section One: introduction

Good communication is critical to good healthcare.

Countless official reports and plans have opened with a sentence much like the one you have just read. Clinicians and patients alike now believe that excellent communication improves the prospects of patients and enriches the quality of life for those whose prognosis is terminal. This is common ground. The NHS and government ministers have repeatedly expressed such sentiments over the last three decades. We have, mercifully, moved on from the era where the doctor's authority was unquestioned and the patient was in thrall to the medic's expertise. We live at a time of informed choice.

And yet, we also know that deep-seated problems remain. Patients tell us as much in surveys. Campaigners press the message home, leaving us with uncomfortable accounts of their treatment that are hard to ignore.

Two contrasting examples suggest something of the scale and variety of the problem that remains.

The first is the stuff of anecdote. Last year a medical undergraduate sought advice from friends on the curriculum module about communicating with patients. They laughed. She was told not to bother: nobody took it seriously.

Second, turn to the ground-breaking NHS *Cancer Plan* of 2000 and the text is clear about the problem and its

solution. It makes the now familiar acknowledgement of the importance of communication and recognises the priority attached by patients to 'a willingness to listen and explain'. It further accepts that many complaints stem from 'a perceived failure of the doctors and health care professionals to communicate adequately or to show they care.' The plan is clear that communication skills can be taught and can improve practice - and that there is a need for training to make good a deficiency. And by 2002, it argues, it should be a pre-condition of qualification that the requisite skills in communication should be demonstrated.¹ Follow-up action was taken. In particular, a training programme for clinical staff was put in place. But 16 years on, central funding for the training initiatives has dried up. The problem has not disappeared, but the means to solve it have.

Progress has unquestionably been made. The medical profession and those who lead the NHS regard the acquisition and practice of better communication skills as desirable. But when push comes to shove, other things seem to matter more. Communication is a 'soft skill' (a term pregnant with hidden meaning).

Nobody would claim the problem has been solved. Most importantly, patients say the shortcomings remain, and that they matter to them. This paper argues that inadequacies in communication are still damaging medical care and wasting muchneeded NHS resources. More than that, it argues that we already have many of the tools we need to make inroads into the problem. And to do so without adding to NHS costs. What we have lacked is the will to stay the course in driving through the cultural change. And there is evidence to suggest that patients' expectations are rising: many are seeking participation in decisionmaking, not just a better-informed dialogue with doctors.

A determined assault on poor communication would make a difference to patients, whether they have the prospect of a cure or they have had a terminal diagnosis. This paper does not claim to have all the answers and it recognises the need for further research, but the course it offers is pragmatic and achievable. Hitherto, the journey might have been tortuous and circuitous. We seek to understand why. And we suggest that the road ahead need not be.

The paper begins by reviewing the efforts of those who have travelled this way before us and it considers the progress they have made (Section Two). It then defines the problem to be solved and explains how unsatisfactory communication influences the experience of patients (Section Three). Next it reminds us of the importance patients attach to the issue and estimates the scale of the task ahead (Section Four). Turning to solutions, Section Five evaluates possible interventions. Our concluding thoughts on the route we have travelled and the way ahead are in Section Six.

Before we address these questions, a brief word on scope. The messages in this report have relevance to the treatment of most serious illnesses. but our principal reference point is cancer. Equally, we maintain that our analysis holds good for palliative care as it does for curative care. Many of the examples we cite relate to doctors, but again we would argue that the analysis and recommendations are of relevance to all healthcare professionals. We are not considering the effectiveness of information systems more generally: that is a topic worthy of discrete treatment. Our priority here is the interaction between patient and professional, not on technology. Our survey of developments in this field cover the last three decades, during which period healthcare in the UK was devolved. Our principal focus here is England, and costings are for NHS England, unless we state otherwise.

Section Two: a short history lesson

Those who cannot remember the past are doomed to repeat it.

George Santayana^{1a}

Interest in communication in healthcare was relatively unusual amongst the medical profession until the last guarter of the 20th century. Since then, we have seen burgeoning research by academics, a recognition of the potential by some medics and a repeated insistence by decisionmakers that there is a problem, a problem which will be cracked. These developments have run in parallel to, and have been informed by, broader societal changes. In particular, we have seen recognition that citizens are more than consumers of public services: they have rights to participate in decision-making, especially where those decisions directly bear on their own future.

This section reviews the growing interest in the topic over the last 30 years or so and discusses the way in which the terms of the debate have changed in recent years. It concludes with a brief assessment of progress in recent years.

Communication in healthcare: from the Patients' Charter to shared decision-making

The 1993 Audit Commission report on communication within the NHS is as good a place to start as any, not least because it reflects some of the themes which brought the question to the fore.² The report is notable for three reasons. First, there is a strong sense that this is new ground, not fully understood or researched. Second, there is recognition that there are deep-seated organisational and cultural factors causing deficiencies in communication and these will be difficult and expensive to fix. Instead, it opted for an assault on low-hanging fruit. Third, the report conceives of communication in transactional terms. It concerns itself with the delivery of information to patients, with the quantity of information and with complaint mechanisms. Conceptually, it is a market-oriented diagnosis. It credits consumerism and the Patients' Charter with the issue's rise to prominence. When it comes to enumerate the benefits of action, it does begin by pointing up the possible improvements

to patients' experience but it goes on to list other advantages, arguing that progress on this front can:

- improve clinical outcomes;
- increase efficiency; and
- strengthen the hospital's market position.

Few would argue that this is a patient-centred approach to the problem.²

The Audit Commission's work was implicitly influenced by the growing interest among academics in the role of communication in healthcare. The topic, of course, was not a new discovery in the 1990s. This field of enquiry had originally been opened up by Michael Balint at the Tavistock Clinic and by Elisabeth Kübler-Ross, the Swiss-American psychiatrist. In the 1960s Balint had applied psychoanalytic thinking to the understanding of the dialogue between doctor and patient. In her celebrated taxonomy of the five stages of dying, Kübler-Ross emphasised the significance of the doctor's own attitude to death when it came to communicating with dying patients. Research by Peter Maguire, a Manchester psychiatrist, demonstrated that communication skills could be taught. And he inspired others to follow his lead. It is no coincidence that the University of Manchester's communication training for medical students today provides a benchmark for others to meet. Nor, indeed, that three of Maguire's associates – Lesley Fallowfield, Susie Wilkinson and Cathy Heaven – each went on to influence the design of communication training across the NHS. From the 1980s onwards, Maguire and others began,

step-by-cautious-step, to build the evidence base that communication training could make an appreciable difference (see, for example, Maguire, 1990³). The field continues to be characterised by formidable methodological obstacles concerning the measurement of improvement; the duration of any training benefit; and the significance, or otherwise, of self-reporting of the merits of training. But it is beyond question that Maguire and those who followed him have won ground for the argument that communication training for medics is an intervention which merits investment.

If we turn on to the publication of the NHS Cancer Plan in 2000, we see that the tone of its treatment of communication is already different from that adopted by the Audit Commission seven years before. The assessment of the state of play is equally bleak. But communication is discussed in less narrowly transactional terms and there is a stronger and more confident emphasis on training as a way forward: the ambition is no longer to be restricted to the easier targets. In his foreword to the plan, the then Secretary of State for Health⁴ wrote that, 'perhaps most important of all, it puts the patient at the centre of cancer care' (p.3). Rhetorically, at least, patient-centred care had arrived.

The 2000 Plan gave rise to tangible change in many aspects of cancer care. Work began on the design and testing of a national training initiative. In parallel, the National Institute for Health and Care Excellence published its Guidelines for Supportive and Palliative

Care in respect of cancer. These pressed home the need for action and catalogued the growing body of evidence in favour of communication training interventions.⁵

In 2005, the National Audit Office, in a series of reports, took stock of progress since the launch of the NHS Cancer Plan in 2000. One of the reports focussed on the patient's journey, a shift which further emphasised the move towards a patient-centric view of healthcare. On communication, there was the now-familiar stern conclusion that the pupil must do better, but the detail of the report card showed clear signs for encouragement. Comparing a 2004 patient survey with 2000 baseline data, the report demonstrated that across a range of indicators patients reported improvements. But the distance to be travelled remained clear: just 68% of respondents found doctors' explanation of a patient's condition, treatment or tests were very easy to understand.6

The report was less than illuminating on how the improvements in communication had been achieved. They did not arise from the national training programme, because this was still under development. Indeed, the stern but reasonable report⁶ concluded:

the advanced communication skills programme currently being developed by the Cancer Action Team and the NHSU (the corporate university for the NHS), intended to improve communication between health professionals and cancer patients, their

families and carers, should be rolled out to healthcare professionals across England as soon as possible. (p. 7)

Two questions might be asked about this recommendation. If the NHS thought this topic was a priority, why was there no training programme in the field after five years? And if the report's authors thought it was a problem, why was this the penultimate recommendation, squeaking in only just above the call for a standard assessment of 'patients' physical, psychological, social and spiritual needs.' Patient-centric philosophy still had a way to go.

The full training programme was finally to be rolled out in 2008. But this was not before another in the wearyingly long sequence of official commitments to the importance of communication and training. The programme, branded as Connected.^{6a} was the fruit of a collaboration with Marie Curie and Cancer Research UK. It was a three-day course in advanced communication skills training for senior clinical staff. Local delivery of the programme was to be approved by a national team so as to maintain standards. Funding was to be provided centrally. Before this dried up in 2012, the programme was shortened to two days. An evaluation of the impact of a pilot of the two-day programme gave some modest grounds for optimism, but, as with most studies of this sort, it relied heavily on selfassessment by course participants. It would be hard to argue that that this was necessarily the most reliable source of data.

Our last stopping point on this brief survey is the 2015 strategy prepared by the Cancer Taskforce, and accepted by the Government. The overall assessment of the state of communication might have been lifted from one of the predecessor reports: progress made, but still not good enough. The Taskforce is particularly blunt about the need to improve the patient's experience, arguing that it is simply not valued sufficiently. Having acknowledged that most cancer patients do receive good, compassionate care, it goes on to declare: T

there are still too many people with cancer who do not have a good experience of their care, treatment and support. For example, a quarter of all cancer patients will have treatment-related long term effects. But only two thirds of cancer patients will have treatment-related long term effects... Improving people's experience needs to be prioritised across the [cancer] pathway, including at the end of life. Often patient experience is not viewed as being on a par with the other elements of high-quality care (clinical effectiveness and safety).' (p.48, p.50).

This cultural explanation is novel and interesting, but it is not pursued by the Taskforce. Instead, the authors fall back on a managerialist solution, recommending that incentives be introduced to make the enhancement of the patient's experience more valued.

When it came to communication training, the Taskforce called on Health Education England to review current provision and to 'work with Medical Royal Colleges and other

bodies to ensure that all new and, where appropriate, existing staff have mandatory communications skills training' (emphasis added; p.52). But it was more guarded as to funding – as was the Government in its response.

Another novel aspect of the Taskforce was its interest in sharing data more readily with patients. For example, it recommended that by 2020 patients should have online access to their test results. This is of interest in its own terms, but it is also indicative of a more profound shift in philosophy, a philosophy apparent in the Taskforce report and in NHS England's Five Year Forward View which was published at about the same time. In short, the patient-centred approach had won the day - in policy terms - by 2015. This perspective, championed successfully by the National Voices, an alliance of health and social care charities in England, may be summarised thus: patients are to be seen as partners in the decisions which affect them; this is essential to improvements in quality and it will, over time, develop the capacity patients need if they are to retain independence and to live a rich life. The same thinking was apparent in the vision for palliative care published in September 2015.8 And it is explicit in the Five Year Forward View, which assumes that patients will effectively be enlisted in a common drive to improve quality. National Voices is one of the key partners in implementing this reform agenda.

Before we discuss shared decisionmaking in more detail, it is worth saying that this approach, and the thinking behind it, are not unique to healthcare. Prompted by the failure of public services satisfactorily to meet the needs of citizens, advocates in the US and in the UK began to argue for service design which was tailored to the needs of the individual. Self-evidently, successful personalisation could not be delivered if a public authority decided on its own what would suit its citizens. Nor would consultation alone suffice. Reformers began to argue that a more radical solution was required: public authorities had to cede power to those they sought to serve. Citizens were to be drawn into decision-making from the design of services through to their delivery. Austerity has given added impetus to this approach since it allows cash-strapped authorities to mobilise the energy and insight of their own communities. Done badly, it can become window-dressing for cuts in health and social care. Done well, it has the potential to reshape public services. The approach remains contested territory but it is no longer a theoretical debate: there is now fieldwork to allow us to evaluate its merits.

Shared decision-making in healthcare refers to a way of approaching the conversation between a patient and the healthcare professional to inform the patient about all the risks and benefits of available treatments. The patient is engaged as a participant in a process to reach collaborative decisions.9 Analysis suggests that this approach has benefits not only for the patients but also for the professionals and for the healthcare system as a whole. This is achieved by increasing patient knowledge, fostering patient autonomy, reducing anxiety, improving health outcomes and reducing unwarranted variation in care and costs. 10

To examine the effectiveness of shared decision-making in improving communication, a review of 86 randomised controlled trial studies. was conducted for the Cochrane Collaborative Review (2011). Compared to patients who received standard care, those who used decision aids demonstrated greater knowledge, more accurate appreciation of risk and, ultimately, had a greater likelihood of having a care plan that aligned with their specified needs and values. 11 There is also reason to believe that shared decision-making might be cost effective. In one study, 20% of the patients participating in this approach opted for less invasive surgery than would otherwise have been the case. The Lewin Group (2008), working on US healthcare, estimated that implementing shared decision-making for just 11 procedures would yield more than \$9 billion in savings nationally over a 10-year period.11

For reasons that are perhaps obvious, shared decision-making is not yet well established in oncology. 12, 13, 14, 15 Research has suggested that clinicians ask for patient preferences with regard to medical decisions in no more than half of cases. 16, 17 But patients report they would like to be more actively engaged. Between 60% and 90% say that they prefer either an active, shared or collaborative role in decisions. Clinicians frequently underestimate this desire. 18 The views of patients, the growing body of research evidence and the prospect of savings all help to explain the growing interest in shared decision-making.

What does this all mean for communication? Quite simply it raises the bar. Advocates of this approach are at pains to point out that it is for the patient to decide the extent to which he or she wants to participate in decision-making. But there can be no doubt that successful engagement requires the patient to become an active collaborator in treatment. It is axiomatic that this demands that healthcare professionals have the skills needed to engage the patient in participation. Collaboration between healthcare professional and patient over decisions, which, at their starkest, might be matters of life and death, is not an enterprise undertaken lightly. We have travelled a long way from the Audit Commission's emphasis on transactional communications. As the Taskforce⁷ spelt out, communication training now needs to include 'empathetic listening skills, shared decision-making, empowering patients to self-manage, and how to deliver difficult news' (p.52).

This approach is now entrenched in policy and law. The Health and Social Care Act 2012 requires clinical commissioning groups to adopt shared decision-making. The General Medical Council's Good Medical Practice guidelines implicitly draw on the same model. And the National Institute for Health and Care Excellence. 19 in its quality standard on end-of-life care, makes a clear commitment to one of the underpinnings of the model: the holistic needs assessment. This does much as its name suggests: it requires healthcare professionals to take into account all of the needs of the patient, whether they are physical, psychological or spiritual. If they matter to the patient, they should matter to the professional. Again, the communication and skills implications will be as obvious as they are daunting.

Are we there yet?

Before we leave this necessarily brief survey of changes in approaches to communication in the last 30 years, we should reach some conclusions as to whether progress has been made in improving the quality of communication with patients. One preliminary point before we attempt an answer to that question. Any response is necessarily a generalisation which will obscure the experience of many. The quality and availability of survey data have improved significantly in the last 16 years and the statistics do show demonstrable progress in communication. But how does one weigh those data against the searing evidence of neglect and abuse of patients chronicled in the Francis Report²⁰ on the Mid-Staffs scandal?

Allowing for these caveats, it would be churlish to deny the signs of improved communication as experienced by patients. It is true that the starting point was not necessarily high. In the 1999 national survey of cancer patients, just half were given written guidance at the point of diagnosis. And no more than 61% of respondents reported that they had had a proper discussion of possible side-effects. Patients over 65 clearly found their experience particularly confusing.²¹

Turn forward to the National Cancer Patient Experience Surveys of 2010-14 and there is clear evidence of movement in the right direction. More than that, many of the indicators which have a bearing on communication have shown incremental progress over that period and some are now impressive in absolute terms. By 2014, 84% of respondents were reporting that they had been told their diagnosis with sensitivity and 91% said they got understandable answers to important questions most or all of the time.

It would be tempting, but mistaken, to take these figures to mean that the job is done, Some indicators remain stubbornly low: just 56% say that they were definitely briefed on the side effects of treatment. Some results are simply shocking: just 22% say they have a care and assessment plan.²² The National Inpatient Survey of 2014 tells much the same story. The accompanying report urges a renewed emphasis on communication skills. Perhaps the most noteworthy result is that just 56% felt that they had been involved as much as they wanted to be in their care and treatment.²³ Read that result in the light of the ambitions underpinning the 2015 Taskforce Report and the Five Year Forward View^{23a} and one has good reason to be cautious about our determination to meet the challenges ahead. Not only have we not arrived at our destination yet, but the thinking behind patient-centred care means that our target has become more demanding to attain.

Section Three: the problem and why it matters

Communication makes a difference in how I feel about myself and whether I have the courage to go on. If I have a negative experience, I withdraw and close up and that's very harmful, mentally and physically. [Quote from qualitative research]

Thorne, Hislop, Armstrong and Oglov²⁴

This section considers how communication bears on health outcomes and it then examines the research evidence that these outcomes might be improved through richer interactions between healthcare professionals and patients.

Cognitive mechanisms

Ong, Visser, Lammes and De Haes²⁵ have demonstrated that clear and understandable information is especially important in the treatment and care of cancer patients. Yet it is evident that healthcare professionals all too often fail to impart the necessary information satisfactorily. Adler and Page¹⁸ conclude that the majority of patients simply want more information from their doctor, a finding supported by Guadagnoli and Ward;²⁶ Wong et al;²⁷ Gaston and Mitchell;²⁸ Kiesler and Auerbach.²⁹ But in practice the need is not just for more information: it is for information that is more easily understood. At their best, doctors can play a critical role in translating complex biomedical terminology into language that a

patient can understand. But all too often they fail to meet this standard (see, for example, Kerr et al;³⁰ Epstein & Street).³¹ Ong et al²⁵ found that doctors treating cancer patients were relatively good at delivering descriptive information (type of disease, its stage, type of treatment) but they were found wanting when it came to evaluative information of direct relevance to the patient. Too often, he or she was left unclear as to how painful the disease would be or even whether recovery was feasible.

Information received *from* patients is crucial in allowing the doctor to make accurate and effective decisions about the course of treatment.³² Patients do not always disclose relevant information about their symptoms or concerns³¹ leading to unsatisfactory decisionmaking.³³ The challenge for doctors is easy to imagine.

Behavioural mechanisms

Perhaps the most powerful mechanism through which communication influences health

outcomes is the impact it can have on patient behaviours. Effective communication supports positive self-management on the part of the patient¹⁸. With good understanding and motivation, a patient will be better able to manage diet, exercise, drinking and smoking behaviours.

Of particular significance here is the influence that can be brought to bear on a patient's adherence to medication. Many drugs are less potent or even potentially harmful when not taken as prescribed. 34, 35, 36 Poor adherence is not explained exclusively by shortcomings in the relationship between healthcare professionals and patients, but it is the cause for which the evidence is most powerful. Put simply, a patient who receives poor communication from their GP is less likely to follow their treatment plan than one who receives clear advice.37 This has substantive implications for the patient's health outcomes. Thorough reviews from Haynes et al³⁸ and from Andersson et al³⁹ have identified improved doctorpatient communication as critical to improved adherence to drug regimes, with consequent benefits in health outcomes.

Emotional mechanisms

The diagnosis and treatment of cancer can, of course, be immensely stressful. 40 One third of cancer patients are considered to be at high risk of developing a psychological disorder in their first year of treatment. 41, 42 Good quality communication is capable of positively influencing a patient's emotional state, which, in turn, may have a positive impact on his or her health outcomes. The contrary also

holds good: poor communication can lead to heightened anxiety and depression, which may then have a deleterious impact on the patient's health.^{24, 43, 44}

Emotional support from a doctor may be comforting for the patient, but can any more substantive claims be made for it? Fogarty et al⁴⁴ demonstrate a link between compassionate doctor behaviour - providing reassurance, touching the patient's hand, expressing support – and reduced patient anxiety. Redelmeier, Molin and Tibshirani⁴⁵ go further, showing how patients in receipt of 'compassionate care' had fewer repeat visits and higher satisfaction than those who did not have the benefit of the same empathetic and sensitive regime. In short, compassionate, emotionally supportive care can positively impact patient's experiences and reduce the need for extra contact.

Communication and health outcomes

Having identified the pathways through which communication has an effect on health outcomes, we now turn directly to the question as to whether we know how to use those pathways to good effect. Can better communication improve health outcomes?

There is a growing literature on this topic. Some of it, it might be argued, labours hard to bring forward a mouse. The definition of terms is undoubtedly a worthwhile discipline, but do we need to agonise, as some have done, over the characteristics of the communication of bad news? Mercifully, other researchers have focused more directly on our question and there is

a weight of evidence that confirms that better communication is capable of having a positive impact on health outcomes (see for example, Kaplan, Greenfield & Ware; 46 Del Piccolo, Saltini, Zimmermann & Dunn;⁴⁷ Heisler et al;⁴⁸ Engel et al;49 Kerr et al;30 Schofield et al;50 Maliski et al;51 Di Blasi52). Stewart, for example, reviewed 21 studies and concluded that good communication skills were linked to better health outcomes. The evidence was apparent in patients' emotional health, the resolution of their symptoms, pain control and in physiological indicators, such as blood pressure and blood sugar concentration.³² Beach, Keruly, and Moore⁵³ studied 1,743 patients and found that patient-centred communication was a strong predictor of improvement in the treatment of HIV.

What, then, are the interventions which have been seen to improve these outcomes? Benefits have been claimed for a variety of measures. At the more prosaic end of the spectrum, improved outcomes have been seen to arise from a more disciplined approach to communication based on simple and intuitive safety checklists, a point to which we return in Section Five.⁵⁴ Towards the other end of the spectrum, researchers have argued that the creation of an enhanced patient experience leads to better outcomes. Better communication is, of course, a prerequisite for a richer patient experience. Proponents of this approach⁵⁵ have even gone as far to arque, 'that better patient experiences, even more than adherence to clinical guidelines, are associated with better outcomes' (p.201).

And what of the evidence of the impact of shared decision-making on health outcomes? In their review of research in this field. Hibbard and Greene⁵⁶ conclude that more engaged patients have better health outcomes and better care experiences than those who are more passive. These results hold across a variety of health conditions, including bowel disease,⁵⁷ asthma⁵⁸ and multiple sclerosis.⁵⁹ A number of studies reach similar conclusions in respect of cancer care. For instance, research demonstrates that breast cancer patients, who are offered a choice in their treatment by the doctor, show reduced anxiety and depression and improved physical functioning.^{60,61} This result is supported by similar findings from Fallowfield et al⁶² and Deadman et al.⁶³

It is safe to conclude that a clear link has been established between better quality communication and positive health outcomes. This link is evident across a variety of conditions and settings.

Section Four: the scale and cost of the problem

Talk is the main ingredient in medical care and it is the fundamental instrument by which the doctor-patient relationship is crafted and by which therapeutic goals are achieved.

Roter and Hall⁶⁴

Efforts to sustain an improvement in communication with patients have fallen short of their objectives, not for want of goodwill but because, ultimately, other initiatives have been found to be more attractive or urgent by decision-makers in the NHS. With this in mind, we would do well to consider the cost of the problem and of its solution. At a time of the muchdiscussed NHS spending crunch, it would be fanciful to do otherwise. Evidence exists to demonstrate patients benefit from improved communication. But to succeed, we need to clear a higher bar: we need to show that determined, sustained action on this front is cost effective.

This is no easy task. Surprisingly, the cost of poor communication has attracted limited attention from NHS leaders and researchers. Thorne, Bultz and Baile⁶⁵ sum up the challenge we face:

It is increasingly accepted that communication plays a significant role in many aspects of the care experience, and that poor communication can have a significantly negative influence on the patient's psychosocial experience, symptom management, treatment decisions, and quality of life. However, scant attention has been given to the idea that poor communication may also have an economic impact worthy of attention (p.875).

This gap in the research is beyond the scope of this paper, but what we can do here is to explore a number of different perspectives to get some sense of the order of costs arising from poor communication.

NHS litigation

The NHS in England has a dedicated agency dealing with claims made against the service for failures of one sort of another. This is no small matter. In just one year, the NHS Litigation Authority (NHSLA)⁶⁶ paid out £1.1 billion to complainants and their lawyers and that figure is expected to rise to £1.4 billion in the current year. It has set aside the sum of £28 billion for future liabilities.

What is driving these costs? The Authority places a heavy emphasis on learning from experience but it has not, in recent years, attempted a systematic analysis of the underlying causes of these daunting figures. Its most recent report has some suggestive case studies, not least of medical negligence. But it does not provide the thorough analysis we need.

One eminent medical expert witness suggests that the search for those clues is worthwhile. Professor Finbar O'Callaghan, a paediatric neurologist at University College London, comments, 'I cannot think of a single case I have reviewed where poor communication is not a factor leading to poor health outcomes and subsequent disputes: poor communications between patients and health professionals and among health professionals' (Interview with the author. December 2015).

Our search for clues might begin with the parallel dispute resolution process run by the Parliamentary and Health Service Ombudsman. In her report on end-of-life care in May 2015, she argued that almost all the cases studied highlighted failings in communication between health professionals on the one hand and patients, clinicians and families on the other; clinicians and their teams; clinicians and other teams; and between hospitals and care providers in the community.⁶⁷ The ombudsman suggests that poor communication results in uncertainty, unrealistic expectations, and that these failings in communication can contribute to inadequate palliative and active care. This can then lead many patients to feel they have not been told

the truth about a lapse in safety and it can generate disputes.

The handling of some those disputes which generated official complaints was the subject of a 2013 review by Ann Clwyd and Professor Tricia Hart. Although its focus was on what happened after a problem had arisen, the themes will be familiar to us: inadequate information provision, poor communication to complainants and unsatisfactory training. Each case, in its turn, contributed to distress and delay, but also to inefficiency and waste.⁶⁸

Adherence to medication

Non-adherence to drug programmes is one of the more easily quantifiable costs of poor communication. A study in the US, put the cost there as high as US\$100 billion per year as early as 1997.69 In Canada in 1998 it was thought to be in the region of C\$8 billion a year. 70 The disparity may be attributed in part to the differences in their respective health systems and to the near tenfold difference in population between the US (320 million people) and Canada (35 million). In the UK meanwhile, 6.5% of adult hospital admissions are thought to be medicine-related and 30% of these arise from non-adherence to drug regimes.⁷¹ More recently, Cappemini Consulting⁷² estimated that the cost of unused medicine in the US is close to \$310 billion. In a report by the York Health Economics Consortium and the School of Pharmacy, University of London, Trueman et al⁷³ investigated the cost to NHS England of nonadherence in specific conditions and found the following:

- **statins**: Increasing compliance to 80% of patients complying with 80% of their medicines, would realise savings of some £9 million per year to the NHS;
- hypertension: Achieving 80% compliance would lead to savings in the region of £100 million per year for the NHS; and
- schizophrenia: Securing 80% adherence would generate a saving of over £113 million per year for the NHS.

Clearly, non-adherence is a costly problem. Of course a host of practical and socio-cultural factors are likely to influence its size, but research has demonstrated that poor communication is one of the primary causes. Vermeire, Hearnshaw, Van Royen and Denekens³⁷ conducted a systematic survey of the available evidence, concluding that improved doctor-patient communication could have a significant impact on adherence. Cegala, Marinelli and Post⁷⁴ go further, suggesting that action on this front is also financially cost effective. In other words, the cost of implementing an intervention is at least recouped in the money that is directly saved. Experimental evidence to that end has been supplied by Elliott et al.⁷⁵

Mental health

There is growing support for the link between cost and psychological distress. For instance, a meta-analysis of 91 medical-cost-offset studies investigating psychological interventions concluded that 90% were able to reduce significantly the use of medical services. ⁷⁶ One US study has demonstrated a 23.5% reduction in health plan billings over a two-year

period from breast cancer patients who were offered cognitive-behavioural therapy as against those who were not.⁷⁷ This study is believed to be the first to demonstrate how mental health interventions can reduce costs in cancer care.⁷⁸ From their review, Chiles *et al*⁷⁶ concluded that significant cost savings are likely to be found by concentrating on improving the mental health of patients undergoing medical treatment.

The cost of unnecessary treatment

Discussion around prognosis and the transition to palliative care is, of course, notoriously difficult. Page 80 Research by The et al 10 n patients suffering from lung cancer suggests that doctors frequently avoid discussing difficult disease information and offering realistic recovery estimates and treatment plans. A large survey conducted by Higginson and Costantini suggests that poor communication occurs in as many as 40% of late-stage cancer treatments.

Poor doctor-patient communication can lead to extra or unnecessary and even futile treatment in late-stage cancer.83 One study of patients with lung cancer indicates that third and fourth line chemotherapies have the potential to double the overall cost of an individual's treatment costs but they yield almost no improvement in survival rates.84 Almost 25% of lung cancer patients receive chemotherapy in the last six months of life.85 We do not offer an opinion on the wisdom of this course of treatment so late in life. We merely flag it as an example of a choice which can only be resolved by the clearest and most informed dialogue between patient and professional.

The proposition here is simple: that better doctor-patient communication will lead to better decision-making.

Effect on healthcare professionals

The suffering in cancer care is not the exclusive domain of patients and their families. Healthcare professionals in cancer experience psychological wear and tear, including stress and burnout. Shortcomings in communication with patients have been shown to contribute to these conditions. 86, 87, 88, 89 Leaving aside the impact on the individuals concerned, these ailments generate direct costs as new staff have to be drafted in as replacements. Beyond that, there are intangible costs in the loss of experience and expertise acquired by senior doctors. Ask senior clinicians in cancer care to explain burnout and they offer, as one reason, the inadequacy of their own training in communication skills. 90,91 The explanation is revealing: burnout, and its associated costs, might be mitigated, in part, through early investment in training.

Adding up the cost

In the absence of a comprehensive study of poor communication in the NHS, we are unable to put an overall price tag on the bill to the taxpayer. All we can say with confidence is that it is significant and that the same may be said of the adverse impact on health outcomes. To give some hint of its scale, we might consider just two of the factors we have discussed.

First, look at the litigation costs incurred by NHS England in the present year. If we were to attribute just one fifth of the outlay to inadequate communication – an extremely conservative figure – then this alone would have cost more than £200 million last year, rising in the present financial year to close on £300 million.

Second, look at the waste generated by non-adherence to drugs for two common conditions: hypertension and schizophrenia. It runs to more than £200 million. Not all of it, of course, is caused by inadequate communication but poor interactions with the patient have been identified as a primary cause of failure to follow drug regimes. Another perspective on the costs of non-adherence is provided by the comparative data from the US and Canada. If we take the second of these (a publicly funded health service) and update the 1998 figure for inflation and convert it to sterling, one arrives at a figure of £5.6 billion. Even if we make no adjustment for population size, we are contemplating a huge cost to the NHS for non-adherence. And we know that poor communication has been shown to have a significant influence on nonadherence.

On the basis of the discussion of these two factors, we can be confident that the total cost of poor communication is likely to be measured in ten figures. And we know that those failures are damaging to the patient's experience and, at its simplest, to health outcomes. That alone is a reason to act.

Section Five: making things better

Attending to psychosocial needs should be an integral part of quality cancer care. All components of the health care system that are involved in cancer care should explicitly incorporate attention to psychosocial needs into their policies, practices, and standards addressing clinical health care.

Adler and Page¹⁸

We turn now to examine ways of further improving the quality of communication in healthcare. We first discuss training to develop relevant skills, before highlighting the opportunity that exists through employing more Clinical Nurse Specialists. Finally, we consider the potential of approaches informed by the behavioural sciences.

Training healthcare professionals in communication

Some form of communication training is now mandatory in all UK medical schools. This is all to the good, but what of the existing cohort? This question is particularly pressing because of the higher premium placed on communication skills by shared decision-making and because we know that communication skills do not reliably improve with clinical experience.⁹²

We have noted that central funding for the Connect programme has come to an end and that Health Education England has yet to determine its

training response to the Cancer Taskforce. Now might be as good a time as any to consider the efficacy of established training interventions.

One review of empirical evidence suggests there are some courses that can improve the *objective* performance of clinicians as well as their subjective ratings of their own communication skills.93 A 2013 Cochrane Review analysed 15 randomised controlled trials; 11 studies which were not subject to the same methodology; the communication skills of 1,147 healthcare professionals; and 2,105 cancer patient encounters. It found that training significantly improved some of the communication skills used by healthcare professionals. Improvements were particularly registered in the use of open questions to gather information and in a willingness to demonstrate empathy as a way of supporting patients.93

And we know that certain interventions have been shown to have promising

outcomes which are statistically significant. These include:

- a two and a half day workshop with six bi-monthly, three hour consolidation workshops;⁹⁴
- a one hour lecture followed by a computerised training intervention based on social cognitive theory to improve oncologist responses to patient expressions of negative emotion:⁹⁵
- a one day training course teaching physicians to deliver bad news;⁹⁶ and
- an intensive three day learnercentred training course incorporating cognitive, experiential, and behavioural components which entailed trainees' working in small groups led by an experienced facilitator. They were supported by a team of six patient simulators skilled in providing constructive feedback.⁹⁷

We may draw some comfort from these examples. But before we conclude that we have found the necessary remedies, we should note two shortcomings in our evidence and one obstacle in management practice.

We have research to demonstrate that some training interventions work in the short-term, but we do not have a longitudinal study to tell us whether the trainees ultimately fall back into old habits. In addition, research seeks to identify changed professional behaviour to demonstrate the effectiveness of training, but we do not know whether this translates into an improved experience for patients.

The obstacle for managers is how to ensure healthcare professionals

put their communication skills into practice. Some encouragement may be taken from a randomised controlled trial that found that clinical nurse specialist trainees, who were assigned a suitable clinical supervisor after attending a communication course, were more likely to use open questions, negotiation and psychological exploration. There was clear evidence that the supervised trainees demonstrated greater sensitivity to the psycho-social cues from patients than those in the control group (unsupervised trainees). Hence we learn that appropriate support structures can embed training more effectively.98 But does this hold good for other professional groups, not least doctors?

Training – and re-training – healthcare professionals undoubtedly has a part to play in the quest for better communication. But the evidence reviewed here suggests that this is not sufficient. And we should be alive to the possibility that the barriers to success may be as much a matter of professional culture and institutional process as of pedagogy. We will return to this point in Section Six.

Clinical Nurse Specialists

Clinical Nurse Specialists (CNSs) are registered nurses with a graduate degree in nursing who have expertise in a clinical specialty and perform an advanced nursing role that includes practice, consultation, collaboration, education, research, and leadership. 99 They play an important role in facilitating communication between professionals and patients. Aside from delivering direct patient care, they provide emotional support to patients

and families. Beyond that, they may co-ordinate a wider multi-disciplinary team to ensure patient care is managed effectively.

Perhaps the first observation to make about CNSs is that they secure positive feedback from patients. For instance, the 2014 National Cancer Patient Survey¹⁰⁰ recorded that 91% of patients assigned a CNS felt they were 'listened to'. Those with a CNS responded more positively to information, choice and care than those without a CNS. 100 Indeed, the 2014 survey found that the single most important factor associated with high patient scores was being given the name of a CNS in charge of care.7 Evidence of this sort led Keenan to conclude that the CNS model has significant benefits for patient and carer well-being, by reducing stress and anxiety levels while enabling better decision-making.¹⁰¹

There is also compelling evidence that CNSs help patients navigate through what might otherwise be a bewildering information landscape. For example, 74% of patients with a CNS felt they were given information about their cancer diagnosis that was easy to understand. The figure for those without a CNS was just 47%. Similarly, 74% of patients with a CNS felt they had been directly involved in their treatment plan compared to 57% of those without a CNS.

Further evidence may be found in endof-life care. Most of us would rather die at home: in the Social Attitudes Survey (2013) 67% of those questioned gave this as their preference. Consider now the preferences as exercised by lung cancer patients: 40% who were assigned a CNS chose to die at home rather than in a hospital or hospice. Just 23% of those without a CNS did the same. 102 The primary point here is that CNSs are helping individuals to exercise their preferences at a time of particular vulnerability. A secondary point is that the outcome results in a saving. In a retrospective cohort study on deaths of all people known to a hospice in a two-and-a-half-year period, Abel, Pring and Rich¹⁰³ found that those who died in hospital spent on average six days more in care (26.5 days) compared to those who died at home (20.5 days). As a result, the cost of hospital care in the last year of life for those who died in hospital was estimated at £11,298 compared with £7,730 for those who died at home.

The suggested saving in end-oflife care is not the purpose of the exercise: the CNS is not introduced into the system with a view to realising efficiencies. What of their record as a means of reducing costs through better communication? Let us begin by considering how they help the interface with patients operate more efficiently. Patients often need contact with medical staff to ask simple, or at least non-specialist, questions about their plan or situation. All too often the only options are to wait to see their specialist or for the questions to go unanswered. The CNS can remedy this by providing telephone consultations. Leary and Oliver¹⁰⁴ found that CNSs produce savings of £72,588 per nurse per year by reducing the number of appointments in this way.

Broadening out this analysis, the Department of Health commissioned an economic analysis of the costs and benefits associated with providing a one-to-one support worker in cancer care (ie a CNS and support staff). The report concluded that, 'aside from the workforce costs associated with this proposal, the analysis suggested that the annual bill of £60 million would be offset by savings of £89 million per year'. 104a

The effectiveness of the CNS model has now been demonstrated across a range of illnesses. Case studies in NHS trusts have highlighted the cost effectiveness of multiple sclerosis specialist nurses (MSN). Based on an economic evaluation, a new MSN post could yield net cash-releasing savings in the region of £54,000 by preventing 300 outpatient appointments and 40 emergency admissions. 105 Research on Parkinson's specialist nurses suggest that each can save, on average, £147,021 per year in bed days; £43,812 in avoided consultation appointments; and £80,000 in unplanned admission to hospitals (Parkinson's UK). 105a Epilepsy Action 105b has identified the value of epilepsy specialist nurses in reducing consultants' workloads. A review of 76 heart failure specialist nurses in 26 NHS primary care trusts showed an average estimated saving of £1,826 per patient; a 43% reduction in hospital admissions; and total savings of £8 million for the NHS across the UK over a 12 month period.^{105c} A study commissioned by the Royal College of Nursing (2010) found that outpatient work done by rheumatology nurse specialists is worth on average £72,128 per nurse per year, and saves £175,168 per nurse by

freeing up consultant appointments.¹⁰⁶ Here we have a model which is reliably effective across a wide range of illnesses.

What is not to like about the CNS model? Well, the nurses themselves do not give an altogether happy account of their experience, expressing concern about their workload and long hours. And there is no standard professional training for the post: recruits are expected to learn on the job. This might go some way to explaining their low retention rates compared with other nurses.¹⁰⁷ This, in turn, prompts important questions as to how to balance supply and demand: the number of referrals between 2005 and 2010 to specialist nurse clinics has risen from 115,000 to 650,000.¹⁰⁸ This represents an average increase of some 40% per year, an increase which dwarfs the rise in the number of CNSs over the same period.

The CNS model is undoubtedly part of the solution we are seeking, and they might, at first blush, seem to offer a swifter route to improvement than that offered by re-training of doctors. But more CNSs would have to be drawn from the existing cadre of nurses: this policy option is not available overnight.

Behavioural interventions

The approach to be considered next draws on the insights offered by behavioural science. Our approach will be to look at the challenge through a psychological lens and to examine small, low cost, behaviourally-informed innovations to current practice. They do not constitute a solution in themselves: they improve the context in which

communication takes place. There is a good evidence to suggest that such changes can have significant effects, producing encouraging results (e.g. see Thaler & Sunstein, 109 Martin, Goldstein & Cialdini, 110 Thaler 111). In this passage we will consider a number of examples which reflect this thinking.

Prompted question sheets

Communication between healthcare professionals and patients is bidirectional: both parties have to be actively engaged. Communication from the professional to the patient is, of course, essential but it is also necessary for the patient to engage in the discussion and ask relevant questions. One way this challenge might be addressed from a behavioural perspective is simply to make it easier for individuals to ask relevant questions by providing them with prompted question sheets. 112 A systematic review¹¹³ of 199 articles on the use of prompted question lists concluded that such interventions, 'increase patient question asking in consultations, and may lead to more information being provided by the doctor in these consultations' (pii).

The sheet could be simple, containing a list of the types of questions that an individual might benefit from asking and a section for notes so that individuals can record their own questions and the answers they receive (see Epstein & Street).³¹ The prompt would be given to a patient when they check in for an appointment so they have time to read it and select the relevant questions while in the waiting room (Sansoni *et al*).¹¹³ The sheet is not simply a mechanism to prompt a

dialogue but it might help to open up a wider conversation. In this way, it might be of particular benefit to those who are less health literate.¹¹⁴

A Cochrane Collaborative Review (2011) found that, as compared to patients who received standard care, those who used decision aids demonstrated increased knowledge, had more accurate risk perceptions, less internal conflict about decisions and a greater likelihood of having a care plan that aligned with their specified needs and values.¹¹

Recording conversations

Even when patients ask the relevant questions, it is not always easy for them to understand and remember the answer, especially when they are being presented with a large amount of new information in a short time period. This problem is often compounded by complex medical terminology unfamiliar to the patient.

One solution is to allow the patient to record the conversation. Most smart 'phones now offer this facility. The necessary intervention is simply to prompt and encourage the patient to do so. This message could be delivered by a receptionist, in the waiting area or from a specialist at the beginning of the session. The key benefit is that patients can play back the recording to themselves in their own time. This allows them to focus on the conversation with the specialist without worrying about taking accurate notes.

But there are, of course, complications. Elwyn¹¹⁶ has argued that doctors would show lower levels of trust once faced with a recorder. If untrusted, the

intervention may even backfire with specialists reluctant to say anything that may subsequently prove to be problematic. An innovation designed to free up conversation may end up constraining it. This idea evidently requires careful trialling before it could be advocated more widely.

Doctor pre-commitment

One way to ensure that healthcare professionals regard communication as a top priority might be to encourage doctors to commit to communicating in an effective way with their patients. There is evidence that getting people to pre-commit to do something significantly increases the likelihood that they will do so (e.g. see Ladouceur, Blaszczynski & Lalande;117 Kast, Meier & Pomeranz). 118 Meeker et al 119 have shown the concept to be effective within healthcare. In their study, a poster-sized pledge was displayed in the clinic waiting room. It was signed by the clinicians, pledging their commitment to avoid inappropriate antibiotic prescribing. It led to a 19.7% absolute percentage reduction in inappropriate antibiotic prescribing, relative to a control group. It seems worth exploring a similar approach to communication: a poster in a clinic might, for example, articulate the standard patients have a right to expect from their healthcare professionals.

Prompts on clinical screens

A less public prompt might be included within a clinic's IT system. Healthcare professionals would be reminded of the need to meet communication standards when, for example, they are making an entry on a patient's record. This would increase the salience of

the issue (see Dolan *et al*). ¹²⁰ There is good evidence to suggest that prompts do work to encourage other desired behaviours from healthcare staff. They have been shown to be effective, for example, in improving the quality of decision-making and aligning prescribing practice with recommended guidelines (see Shojania *et al*; ¹²¹ Moxey *et al* ¹²²).

To improve communication, the prompts might simply offer a reminder of the importance of communication or they might prompt specific behaviour. Going further, the IT system might display the prompt only for patients for whom clarity in communication was imperative. This type of directed communication approach is well supported in the literature (see Adler & Page; 18 Trice & Prigerson 123).

Increasing adherence to medication

In Section Three we discussed the chronic problem of inadequate adherence to prescribed drugs. A number of interventions shaped by behavioural insights have been shown to be effective. These include shorterterm regimens; fewer doses per day; easy-to-use packaging; reminders; tailoring; patient education; and patient satisfaction measurement (see reviews from Haynes et al³⁸ and Andersson et al³⁹). One idea to ensure individuals finish their regime is to make the final few pills in different colours to the rest and to state that these needed to be taken last (Kesselheim et al¹²⁴). All of these ideas might be supplemented by enlisting patients to devise their own plan as to when they will take their medicines.

The ideas explored here recognise that we have a mismatch between policies and aspirations on the one hand and behaviours on the other. It argues that we should seek to learn from the insights offered to us by behavioural science. These interventions are cheap, quick and scalable and they potentially offer cost effective solutions. Some are already used in practice; others merit further investigation as one option amongst many in our quest for improved communication.

Sadly, we have to accept that there is no silver-bullet solution which will remedy each and every deficiency in healthcare communication. And even though many of the options reviewed here are cost effective, they do involve up-front expenditure before savings can be recouped. Some are logistically challenging. Others will not bear fruit for some years.

All of this is fair, but this section has demonstrated that we do have viable tools to hand. This is not a policy domain where we find ourselves searching for new solutions. What we need is a viable, pragmatic plan – and the will to see it through. Section Six considers what we might do next and asks why we haven't gone further faster.

Section Six: reaching for the prize

A good interpersonal relationship can be regarded as a prerequisite for optimal medical care.

Ong, Visser, Lammes and De Haes²⁵

This paper has reviewed the attempts made over the last quarter of a century to improve the quality of communication in healthcare. It has noted the significant progress made but has also argued that there is much still to do, not least because the demands of shared decision-making ask more of the healthcare professional. But the prize is of great value. Not only will improved communication eliminate waste the NHS can ill afford, but it will, as we have shown, improve health outcomes for patients and improve the quality of life for those with a terminal diagnosis.

This is a prize which is within our grasp. We have shown that we do have to hand solutions which are fit for the purpose and, crucially, are cost effective. And feedback from patients on these solutions is encouraging.

In the light of this, perhaps we should ask ourselves quite different questions. Why have we not made progress more quickly? Why have we not stayed the course on the initiatives we have launched? Why has central funding for

training programmes been dropped? Why, in short, are we now at risk of going backwards rather than forwards?

With these questions in mind, we would do well to consider how major change is successfully delivered. Typically, one has a compelling case for reform – the burning platform in the project manager's cliché. One has strong, defined leadership and a determination to stay the course. Costs and benefits are tabulated; resources are allocated; risks and obstacles identified. Change champions are identified; teams are assembled; and stakeholders engaged. And there has to be a plan.

The NHS may operate on a quite different scale to any other institution in this country, but these disciplines are as relevant to it as they are to the local GPs' clinic.

If we look now at the challenge of delivering improved communication across the NHS, it is perhaps easier to understand why the prize has remained elusive. For a moment, let us run the rule over what we know of the latest initiative – the communications project which has come from the Cancer Taskforce. We don't lack a burning platform, it is safe to say. Indeed, the wonder is that there is any timber still to burn. As for leadership, things are less clear: implementation of the Taskforce's report is to be overseen by an advisory board and development work on communication has been delegated to Health Education England. On costings, our position is Rumsfeldian: we know what we don't know. It is surely telling that nobody has yet sought to commission the research to put a price tag on the money wasted through poor communication and nobody has articulated the comprehensive spendto-save case to justify a determined assault on the prize.

As for a plan, we will have to see what emerges. And as for funding, it is not yet clear how much funding has been allocated to secure the Taskforce's communication objectives. We should acknowledge that some of the necessary preparations may be under way away from public view. That does raise some questions about the mobilisation of allies, but we should be grateful for the increasing prominence of National Voices in NHS planning.

None of these observations is made to dismiss the work under way on cancer communication. On the contrary, it is deserving of our support and encouragement. But those charged with delivering these critical changes would do well to have a clear line of sight to how fundamental cultural change is customarily delivered and embedded. In particular, we would urge clarity of leadership, engagement

of stakeholders and the allocation of a dedicated budget. All of this must rest on a business case which articulates the resources currently being wasted and the benefits to be derived in savings, health outcomes and demonstrably improved patient experience of healthcare. Let us be clear: we are not asking for an additional burden to the NHS's longterm budget. Our proposition is that the evidence is sufficiently rich to allow a case to be formulated which articulates a programme of costed inputs and a stream of outcomes which will withstand rigorous scrutiny. And to make our ask somewhat greater, we look for similar initiatives for other curative treatments and for palliative care. One further point: we need to see decision-makers in the NHS show the determination to stay the course this time.

Nobody is suggesting this is easy. But it is achievable. Indeed, much has already been achieved.

It is worth our pausing for a moment to consider what we are asking of our doctors every day in out-patient clinics up and down the country. Picture the scene. A patient is called to a cubicle, accompanied by his wife. They have prepared by an extensive session with Dr Google, which has inspired fear and confusion in equal measure. The clinic is over-booked and running late. The consultant arrives with test results. She has never met the couple before. She has, some years before, had a course on communicating with patients, but nobody has guided her on how to cope with a triangular conversation involving a spouse. The news is bad. Somehow

she has to land it sensitively, effect a hand-off to a colleague (if available) and be out of the cubicle within as short a time as is reasonable, all the while hoping that the patient and his wife will suspend disbelief and pretend that the curtains around the cubicle afford a measure of privacy.

Few of us would envy the doctor her task. But its savage difficulty prompts us to ask one, final question about the obstacles which might lie ahead. How easily do the reforms we have discussed sit with the medical profession itself? How easily do they sit with a profession which renews itself by recruiting those who have a record of academic excellence and promotes on the basis of clinical expertise?

The profession has, late in the day, begun to train its own in managerial skill. It has, again belatedly, identified communication skills as a required component of the undergraduate curriculum and it requires competence in communication to be demonstrated in the professional examinations set by all the Royal Colleges. It does now even have annual appraisals and reaccreditation of consultants. It has devised tests of 'soft skills' and mandates patient feedback as part of the appraisals. But few would claim that these measures provide reliable incentives or sanctions. This is a profession where many in hospitals now work in multi-disciplinary teams with other professionals, but could one claim with conviction that these are genuine teams, with a common purpose, shared values and an equal opportunity for all to have their voice heard?

The central factor in the quality of communication in healthcare is the relationship between clinician on the one hand and patient and family on the other. Steps have been taken to facilitate patients' contact with CNSs. But clinic slot lengths, duty rotas, discontinuity of care and heavy case loads have become barriers to doctors' spending time with their patients. What price 'soft skills' in this context? Does the medical profession value them sufficiently? And is it minded to argue for the infrastructure needed if patients and their families are to be treated with the sensitivity and respect they have a right to expect?

These must remain questions for now, because they go beyond the scope of this paper, but NHS leaders would do well to focus on the cultural and organisational obstacles to better communication.

Imagine this scene five years from now. The Secretary of State for Health has determined that there should be a new reform plan for the NHS. Working parties have worked. Consultation groups have consulted. And the strategy has been strategised.

A Department of Health official is preparing the executive summary to the White Paper. There is a bold series of pledges on reorganisation, on the health of the nation and on investment in technology. The task is almost done. But she needs a couple of additional commitments to round the plan out. She reaches wearily for her dog-eared copies of earlier plans and strategies. And she has it. Just

above the commitment to learn from international experience, she types the penultimate bullet point:

We will launch a new initiative to drive up the quality of communication in the NHS

Fanciful? Perhaps. But it is all too easy to imagine.

We cannot let it happen. The prize is too valuable. For the NHS. For taxpayers. For patients.

References

- 1. Cancer Reform Strategy. The NHS Cancer Plan. A plan for investment. A plan for reform. NHS. 2000.
- 1a. Santanya G, The Life of Reason. Prometheus Books, 1998.
- 2. Audit Commission. What seems to be the matter? Communications between hospitals and patients, 1993.
- 3. Maguire P. Can communication skills be taught? *British Journal of Hospital Medicine*, 1990; (43): pp215-216.
- 4. Department of Health, 2000, National Surveys of NHS Patients. Cancer. National Overview 1999/2000.
- 5. National Institute for Care and Health Excellence, 2004, Improving the quality of palliative and supportive care for adults with cancer.
- 6. National Audit Office (2005). Executive Summary. Tackling cancer: improving the patient journey.
- 6a. Rabiee F, Bibila S. Communication in Cancer Care: Evaluating the Connected© 2-day Advanced Communication Skills Training Programme. Centre for Health and Social Care Research, University of Birmingham, 2012.
- 7. Independent Cancer Taskforce, 2015, Achieving World-Class Cancer Outcomes. A Strategy for England, 2015-20.
- 8. National Palliative and End of Life Care Partnership, 2015, Ambitions for Palliative and End of Life Care).
- 9. Veroff D, Marr A, Wennberg DE. Enhanced support for shared decision-making reduced costs of care for patients with preference-sensitive conditions. *Health Affairs*. 2003; *32*(2): pp.285-293.
- 10. Oshima Lee E, Emanuel EJ. Shared decision making to improve care and reduce costs. *New England Journal of Medicine*. 2013; 368(1): pp.6-8.
- 11. O'Connor AM, Bennett CL, Stacey D, Barry M, Col NF, Eden K B et al. Decision aids for people facing health treatment or screening decisions. *The Cochrane Library*. 2009.
- 12. Aiello Bowles EJ, Tuzzio L, Wiese CJ, Kirlin B, Greene SM, Clauser SB, et al. Understanding high quality cancer care. *Cancer.* 2008; 112(4): pp.934-942.
- 13. Ayanian JZ, Zaslavsky AM, Guadagnoli E, Fuchs CS, Yost KJ, Creech CM et al. Patients' perceptions of quality of care for colorectal cancer by race, ethnicity, and language. *Journal of Clinical Oncology.* 2005; 23(27): pp.6576-6586.
- 14. Ayanian JZ, Zaslavsky AM, Arora NK, Kahn KL, Malin JL, Ganz PA, et al. Patients' experiences with care for lung cancer and colorectal cancer: findings from the Cancer Care Outcomes Research and Surveillance Consortium. *Journal of Clinical Oncology.* 2010.
- 15. Wagner EH, Bowles EJA, Greene SM, Tuzzio L, Wiese CJ, Kirlin, B, et al. The quality of cancer patient experience: perspectives of patients, family members, providers and experts. *Quality and Safety in Health Care.* 2010; 19(6): pp.484-489.
- 16. Lee CN, Chang Y, Adimorah N, Belkora JK, Moy B, Partridge AH et al. Decision making about surgery for early-stage breast cancer. *Journal of the American College of Surgeons*; 2012; 214(1): pp.1-10.
- 17. Zikmund-Fisher BJ, Couper MP, Singer E, Ubel PA, Ziniel S, Fowler FJ, et al. Deficits and variations in patients' experience with making 9 common medical decisions: the DECISIONS survey. *Medical Decision Making*. 2010: 30(5 suppl); 85S-95S.
- 18. Adler NE, Page AE (eds). Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs. National Academies Press; 2008.
- 19. National Institute for Care and Health Excellence, *End of life care for adults*, 2011.
- 20. The Mid-Staffordshire NHS Trust Public Inquiry, Report of the Mid-Staffordshire NHS Trust Public Inquiry, 2013.

- 21. Department of Health, 2000, National Surveys of NHS Patients. Cancer. National Overview 1999/2000.
- 22. NHS England, 2014, Cancer Patient Experience Survey 2014. National Report.
- 23. Care Quality Commission and NHS, 2015, National NHS patient survey programme. National results from the 2014 Inpatient Survey.
- 23a. NHS. Five Year Forward View. 2015.
- 24. Thorne SE, Hislop TG, Armstrong EA, Oglov V. Cancer care communication: The power to harm and the power to heal? *Patient Education and Counseling*. 2008; 71(1): pp.34-40.
- 25. Ong LM, Visser MR, Lammes FB, De Haes JC. Doctor–patient communication and cancer patients' quality of life and satisfaction. Patient education and counselling. 2000: 41(2); pp.145–156.
- 26. Guadagnoli E, Ward P. Patient participation in decision-making. *Social science & medicine*. 1998; 47(3): pp.329-339.
- 27. Wong F, Stewart DE, Dancey J, Meana M, McAndrews MP, Bunston T. Men with prostate cancer: influence of psychological factors on informational needs and decision making. *Journal of psychosomatic research*. 2000; 49(1): pp.13-19.
- 28. Gaston CM, Mitchell G. Information giving and decision-making in patients with advanced cancer: a systematic review. *Social science & medicine*. 2005; 61(10): pp.2252-2264.
- 29. Kiesler DJ, Auerbach SM. Optimal matches of patient preferences for information, decision-making and interpersonal behavior: evidence, models and interventions. *Patient education and counselling*. 2006; 61(3): pp.319-341.
- 30. Kerr J, Engel J, Schlesinger-Raab A, Sauer H, Hölzel D. Communication, quality of life and age: results of a 5-year prospective study in breast cancer patients. *Annals of Oncology*. 2003; 14(3): pp. 421-427.
- 31. Epstein RM, Street Jr RL. Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. National Cancer Institute, NIH Publication (07-6225), 2007.
- 32. Stewart MA. Effective physician-patient communication and health outcomes: a review. *CMAJ: Canadian Medical Association Journal*. 1995: 152(9); p.1423.
- 33. Begum T. Doctor Patient Communication: A Review. Official Journal of the Bangladesh College of Physicians and Surgeons BCPS Bhaban. 2014; 32(2): p.84.
- 34. Horne R. (1997) Representation of medication and treatment: advances in theory and measurements. In: Petrie R, Weinlan J, eds. (1907)
- 35. Haynes R, Nieuwlaat R, Wilczynski N, Navarro T, Hobson N, Jeffery R, et al. Ways to help people follow prescribed medicines. *Cochrane*. 2014.
- 36. World Health Organization. *Antimicrobial resistance: global report on surveillance.* World Health Organization, 2014.
- 37. Vermeire E, Hearnshaw H, Van Royen P, Denekens J. Patient adherence to treatment: three decades of research. A comprehensive review. *Journal of clinical pharmacy and therapeutics*, 2001: 26(5); pp.331-342.
- 38. Haynes R, Ackloo E, Sahota N, McDonald H, Yao X. Interventions for enhancing medication adherence. *Cochrane Database Systematic Review*. 2008; (2).
- 39. Andersson M, Garfield S, Eliasson L, Jackson C & Raynor DK. Delivery of patient adherence support: a systematic review of the role of pharmacists and doctors. *Patient Intelligence*.2014; 6.
- 40. Schofield NG, Green C, Creed F. Communication skills of health-care professionals working in oncology—Can they be improved? European Journal of Oncology Nursing. 2008; 12(1): pp.4-13.

- 41. Burgess C, Cornelius V, Love S, Graham J, Richards M, Ramirez A. Depression and anxiety in women with early breast cancer: five year observational cohort study. *British Medical Journal*. 2005; 330(7493): 702.
- 42. Kissane DW, Grabsch B, Love A, Clarke DM, Bloch S, Smith GC. Psychiatric disorder in women with early stage and advanced breast cancer: a comparative analysis. *Australian and New Zealand Journal of Psychiatry*. 2004; 38(5): pp.320-326.
- 43. Ellis PM, Tattersall MH. How should doctors communicate the diagnosis of cancer to patients? *Annals of medicine*. 1999; 31(5): pp.336-341.
- 44. Fogarty LA, Curbow BA, Wingard JR, McDonnell K, Somerfield MR. Can 40 seconds of compassion reduce patient anxiety? *Journal of Clinical Oncology*, 1999: 17(1); p.371.
- 45. Redelmeier DA, Molin JP, Tibshirani RJ. A randomised trial of compassionate care for the homeless in an emergency department. *The Lancet.* 1995; 345(8958): 1131-1134.
- 46. Kaplan SH, Greenfield S, Ware Jr JE. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Medical care.* 1989; 27(3): S110-S127.
- 47. Del Piccolo L, Saltini A, Zimmermann C, Dunn G. Differences in verbal behaviours of patients with and without emotional distress during primary care consultations. *Psychological Medicine*. 2000; 30(03): pp.629-643.
- 48. Heisler M, Bouknight RR, Hayward RA, Smith DM, Kerr EA. The Relative Importance of Physician Communication, Participatory Decision Making, and Patient Understanding in Diabetes Selfmanagement. *Journal of general internal medicine*. 2002; 17(4): pp.243-252.
- 49. Engel J, Kerr J, Schlesinger-Raab A, Eckel R, Sauer H., Hölzel D. Predictors of quality of life of breast cancer patients. *Acta Oncologica*. 2003; 42(7): pp.710-718.
- 50. Schofield PE, Butow PN, Thompson JF, Tattersall MHN, Beeney LJ, Dunn SM. Psychological responses of patients receiving a diagnosis of cancer. *Annals of Oncology*, 2003; 14(1): pp.48-56.
- 51. Maliski SL, Kwan L, Krupski T, Fink A, Orecklin JR, Litwin MS. Confidence in the ability to communicate with physicians among low-income patients with prostate cancer. *Urology*. 2004; 64(2): pp.329-334.
- 52. Di Blasi Z, Harkness E, Ernst E, Georgiou A, Kleijnen J. Influence of context effects on health outcomes: a systematic review. *The Lancet*. 2001; 357 (9258): pp.757-762.
- 53. Beach MC, Keruly J, Moore RD. Is the Quality of the Patient-Provider Relationship Associated with Better Adherence and Health Outcomes for Patients with HIV? *Journal of general internal medicine*. 2006; 2 (6); pp.661-665.
- 54. Walker IA, Reshamwalla S, Wilson IH. Surgical safety checklists: do they improve outcomes? *British journal of anaesthesia*. 2012; aes175.
- 55. Manary MP, Boulding W, Staelin R, Glickman SW. The patient experience and health outcomes. *New England Journal of Medicine*. 2013; 368(3): pp.201-203.
- 56. Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health affairs*. 2013; 32(2): pp.207-214.
- 57. Munson GW, Wallston KA, Dittus RS, Speroff T, Roumie CL. Activation and perceived expectancies: correlations with health outcomes among veterans with inflammatory bowel disease. *Journal of general internal medicine*. 2009; 24(7): pp.809-815.
- 58. Saft HL, Kilaru S, Moore E, Enriquez M, Gross R. The impact of a patient activation measure on asthma outcomes: A pilot study. *CHEST Journal*. 2008; 134(4_Meeting Abstracts): s2004-s2004.
- 59. Stepleman L, Rutter MC, Hibbard J, Johns L, Wright D, Hughes M. Validation of the patient activation measure in a multiple sclerosis clinic sample and implications for care. Disability and rehabilitation. 2010; 32(19): pp.1558-1567.
- 60. Morris J, Royle GT. Offering patients a choice of surgery for early breast cancer: a reduction in anxiety and depression in patients and their husbands. *Social Science and Medicine*. 1988; 26(6): pp. 583-585.

- 61. Morris J, Ingham R. Choice of surgery for early breast cancer: Psychosocial considerations. *Social Science and Medicine*. 1988; 27(11): pp.1257-62.
- 62. Fallowfield LJ, Hall A, Maguire P, Baurn M, A'Hern RP. Psychological effects of being offered choice of surgery for breast cancer. *British Medical Journal*.1994;309.
- 63. Deadman JM, Leinster SJ, Owens RG, Dewey ME, Slade PD. Taking responsibility for cancer treatment. *Social Science and Medicine*. 2001; 53(5): pp.669-77.
- 64. Roter D, Hall JA. Doctors talking with patients/patients talking with doctors: improving communication in medical visits. 2006, Greenwood.
- 65. Thorne SE, Bultz BD, Baile WF. Is there a cost to poor communication in cancer care?: a critical review of the literature. *Psycho-Oncology*. 2005; 14(10): pp.875-884.
- 66. NHS Litigation Authority, Report and accounts, 2014/15: p4.
- 67. Parliamentary and Health Service Ombudsman. May, 2015. Dying without dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care. http://www.ombudsman.org.uk/reports-and-consultations/reports/health/dying-without-dignity/4
- 68. Clywd A, Hart T. A review of the NHS Hospitals Complaints System. Putting patients back in the picture. 2013.
- 69. Lewis A. Noncompliance: A \$100 billion problem. *Remington Report*. 1997: 5: pp.14–5.
- 70. Coambs RB, Jarry JL, Jensen P, Her MH, Porter J, Ferguson BS. Prescription non-compliance and inappropriate prescribing in Canada: causes, consequences and costs. 1998. Toronto, Canada: Health Canada Publications.
- 71. Howard RL, Avery AJ, Howard PD, Partridge M. Investigation into the reasons for preventable drug related admissions to a medical admissions unit: observational study. *Quality and Safety in Health Care*. 2003: 12(4): pp.280-285.
- 72. Capgemini Consulting. Patient Adherence: The Next Frontier in Patient Care; Vision and Reality. 2011 9th ed. Paris.
- 73. Trueman P, Taylor DG, Lowson K, Bligh A, Meszaros A, Wright D, et al. Evaluation of the scale, causes and costs of waste medicines.
- 74. Cegala DJ, Marinelli T, Post D. The effects of patient communication skills training on compliance. *Archives of Family Medicine*. 2000; 9(1): p.57.
- 75. Elliott RA, Barber N, Clifford S, Horne R, Hartley E. The cost effectiveness of a telephone-based pharmacy advisory service to improve adherence to newly prescribed medicines. *Pharmacy World & Science*. 2008; 30(1): pp.17-23.
- 76. Chiles JA, Lambert MJ, Hatch AL. The Impact of Psychological Interventions on Medical Cost Offset: A Meta-analytic Review. Clinical Psychology: Science and Practice. 1999; 6(2): pp.204-220.
- 77. Simpson JSA, Carlson LE, Trew ME. Effect of group therapy for breast cancer on healthcare utilization. *Cancer practice*. 2001; 9(1): pp.19-26.
- 78. Salmon P. Is there a cost to poor communication in cancer care? A critical review of the literature. *Psycho-Oncology*. 2005; 14(10): pp.885-886.
- 79. Back AL, Arnold RM, Tulsky JA, Baile WF, & Fryer-Edwards KA. Teaching communication skills to medical oncology fellows. *Journal of clinical oncology.* 2003; 21(12): pp.2433-2436.
- 80. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, & Kudelka AP. SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer. *The oncologist*. 2000; 5(4): pp.302-311.
- 81. The AM, Hak T, Koëter G, van der Wal G. Collusion in doctorpatient communication about imminent death: an ethnographic study. *Western Journal of Medicine*. 2001; 174(4): p.247.
- 82. Higginson IJ, Costantini M. Communication in end-of-life cancer care: a comparison of team assessments in three European countries. *Journal of clinical oncology*. 2002; 20(17): pp.3674-3682.
- 83. de Haes H, Koedoot N. Patient centered decision-making in palliative cancer treatment: a world of paradoxes. *Patient education and counselling*. 2003; 50 (1): pp.43-49.

- 84. Hoverman JR, Robertson SM. Lung cancer: a cost and outcome study based on physician practice patterns. *Disease Management*. 2004; 7(2): pp.112-123.
- 85. Emanuel EJ, Young-Xu Y, Levinsky NG, Gazelle G, Saynina O, Ash AS. Chemotherapy use among Medicare beneficiaries at the end of life. *Annals of Internal Medicine*. 2003; 138(8); pp.639-643.
- 86. Armstrong J, Holland J. Surviving the stresses of clinical oncology by improving communication. *Oncology.* 2004; 18(3): pp.363-368.
- 87. Gordon GH. Care not cure: dialogues at the transition. *Patient Education and Counseling*. 2003: 50(1): pp.95-98.
- 88. Ramirez AJ, Graham J, Richards MA, Cull A, Gregory WM, Leaning MS et al. Burnout and psychiatric disorder among cancer clinicians. *British Journal of cancer*. 1995; 71(6): p.1263.
- 89. Razavi D, Delvaux N. Communication skills and psychological training in oncology. European Journal of Cancer. 1997; 33: S15-S21.
- 90. Fallowfield L, Jenkins V. Effective communication skills are they key to good cancer care? *European Journal of Cancer.* 1999; 35(11): pp.1592-7.
- 91. Maguire P, Pitceathly C. Key communication skills and how to acquire them. *British Medical Journal*; 325: pp.697-700.
- 92. Bernhard J, Butow P, Aldridge J, Juraskova I, Ribi K, Brown R. Communication about standard treatment options and clinical trials: can we teach doctors new skills to improve patient outcomes? *Psycho-Oncology*. 2012; 21(12): pp.1265-1274.
- 93. Moore PM, Rivera Mercado S, Grez Artigues M, Lawrie TA. Communication skills training for healthcare professionals working with people who have cancer. *The Cochrane Library*. 2013.
- 94. Razavi D, Merckaert I, Marchal S, Libert Y, Conradt S, Boniver J, et al. How to optimize physicians' communication skills in cancer care: results of a randomized study assessing the usefulness of post-training consolidation workshops. *Journal of Clinical Oncology*, 21(16), pp.3141-3149.
- 95. Tulsky JA, Arnold RM, Alexander SC, Olsen MK, Jeffreys AS, Rodriguez KL, et al. Enhancing communication between oncologists and patients with a computer-based training program: a randomized trial. *Annals of internal medicine*. 2011;155(9): pp.593-601.
- 96. Fujimori M, Oba A, Koike M, Okamura M, Akizuki N, Kamiya M. et al. Communication skills training for Japanese oncologists on how to break bad news. *Journal of Cancer Education*. 2003; 18(4): pp.194-201.
- 97. Fallowfield L, Jenkins V, Farewell V, Saul J, Duffy A, Eves R. Efficacy of a Cancer Research UK communication skills training model for oncologists: a randomised controlled trial. *The Lancet*. 2002; 359(9307): pp.650-656.
- 98. Heaven CM, Clegg J, Maguire P. Transfer of communication skills training from workshop to workplace: the impact of clinical supervision. *Patient Education and Counselling*. 2006; 60(3): pp.313-325
- 99. Affara F. ICN Framework of Competencies for the Nurse Specialist, International Council of Nurses. European Parkinson's disease Association. 2009.
- 100. National Cancer Patient Experience Survey 2013.
- 101. Keenan E, Eaton K, Adam S. Using a database to demonstrate the clinical nurse specialist's contribution to patient care. *Nursing times*. 2010; 106(22): pp.14-17.
- 102. NHS Information Centre, National Lung Cancer Audit. 2010.
- 103. Abel J, Pring A, Rich A, Malik T, & Verne J. The impact of advance care planning of place of death, a hospice retrospective cohort study. *British Medical Journal Supportive & Palliative Care*. 2013; 3(2): pp.168-173.
- 104. Oliver S, Leary A. The value of the nurse specialists' role: Pandora initial findings. *Musculoskeletal Care.* 2010; 8(3): pp.175-177.
- 104a. Frontier Economics. One to one support for cancer patients. A report prepared for the Department of Health, 2010.

- 105. Myners G, Perman S, Morse M. Defining the value of MS Specialist nurses. *Multiple Sclerosis Trust*. 2012. Accessed at: http://www.mstrust.org.uk/downloads/defining-the-value-of-ms-specialist-nurses-2012.pdf
- 105a. Epilepsy Action. Best care: the value of epilepsy specialist nurse, 2010.
- 105b. Parkinson's UK. Parkinson's nurses- affordable, local, accessible and expert care: a guide for commissioners, 2011.
- 105c. Price, A. Specialist nurses improve outcomes in heart failure patients. *Nursing Times*; 108: 40; pp.22-24.
- 106. Hughes RA, Carr ME, Huggett A, Thwaites CEA. Review of the function of a telephone helpline in the treatment of outpatients with rheumatoid arthritis. *Annals of the rheumatic diseases*. 2002; 61(4): pp.341-345.
- 107. Doran D, Duffield C, Rizk P, Nahm S, Chu CH. A descriptive study of employment patterns and work environment outcomes of specialist nurses in Canada. *Clinical Nurse Specialist*. 2004; 28(2): pp.105-114.
- 108. MacMillan Cancer Support. Cancer clinical nurse specialists: an evidence review. 2011. Accessed at: https://www.macmillan.org.uk/Documents/AboutUs/Research/ImpactBriefs/ImpactBriefs-ClinicalNurseSpecialists2014.pdf
- 109. Thaler R, Sunstein C. Nudge: Improving decisions about health, wealth, and happiness. Yale University Press, 2008.
- 110. Martin SJ, Goldstein N, Cialdini R. *The small BIG: small changes that spark big influence*. Grand Central Publishing, 2014.
- $111.\,Thaler\,RH.\,\textit{Misbehaving: The Making of Behavioral Economics.}\\$ WW Norton & Company, 2015.
- 112. Behavioural Insights Team. EAST: Four simple ways to apply behavioural insights. Cabinet Office, 2014.
- 113. Sansoni J, Grootemaat P, Duncan C, Samsa P, Eagar K. A Systematic Literature Review on Question Prompt Lists in Health Care (Final Report). Centre for Health Service Development, University of Wollongong, 2014.
- 114. Protheroe J, Nutbeam D, Rowlands G. Health literacy: a necessity for increasing participation in health care. British Journal of General Practice. 2009; 59(567): pp.721-723.
- 115. Flocke SA, Stange KC. Direct observation and patient recall of health behavior advice. *Preventive medicine*. 2004; 38(3): pp.343-349
- 116. Elwyn G, "Patientgate"—digital recordings change everything. *British Medical Journal*. 2014; p.348. Accessed at: http://dx.doi.org/10.1136/bmj.g2078
- 117. Ladouceur R, Blaszczynski A, Lalande DR. Pre-commitment in gambling: a review of the empirical evidence. *International Gambling Studies*, 2012; 12(2): pp.215-230.
- 118. Kast F, Meier S, Pomeranz D. *Under-savers anonymous: Evidence on self-help groups and peer pressure as a savings commitment device* (No. w18417). National Bureau of Economic Research, 2012.
- 119. Meeker D, Knight TK, Friedberg MW, Linder JA, Goldstein NJ, Fox CR et al. Nudging guideline-concordant antibiotic prescribing: a randomized clinical trial. *JAMA internal medicine*. 2014;174 (3): pp.425-431.
- 120. Dolan P, Hallsworth M, Halpern D, King D, Metcalfe R, Vlaev I. Influencing behaviour: The mindspace way. *Journal of Economic Psychology*. 2012; 33 (1): pp.264-277.
- 121. Shojania KG, Jennings A, Mayhew A, Ramsay C, Eccles M, Grimshaw J. Effect of point-of-care computer reminders on physician behaviour: a systematic review. *CMAJ.* 2010; 182 (5).
- 122. Moxey A, Robertson J, Newby D, Hains I, Williamson M, Pearson SA. Computerized clinical decision support for prescribing: provision does not quarantee uptake. JAMA. 2010; 17: pp.25-33.
- 123. Trice ED, Prigerson HG. Communication in end-stage cancer: review of the literature and future research. *Journal of health communication*. 2009; 14 (S1): pp.95-108.
- 124. Kesselheim AS, Misono AS, Shrank WH, Greene JA, Doherty M, Avorn J et al. Variations in pill appearance of antiepileptic drugs and the risk of nonadherence. *JAMA internal medicine*. 2013; 173(3): pp.202-208.

We're here for people living with any terminal illness, and their families. We offer expert care, guidance and support to help them get the most from the time they have left.

mariecurie.org.uk



MarieCurieUK



@mariecurieuk

IN PARTNERSHIP WITH

