A dog's life

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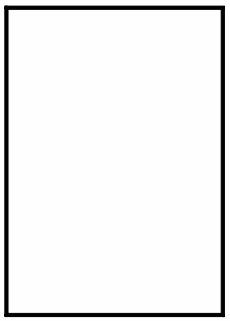

Introduction

IT'S a dog's life to be 'harried from pillar to post, to be nagged constantly and never left in peace'.[1] While this may sound like a description of a general practitioner's (GP's) day, it may also be a description of how it feels to be a patient in the modern National Health Service (NHS).

The normal relationship between a dog and a human has, from the dog's perspective, two positives — continuity and trust — and two negatives — passivity and powerlessness. Well cared for, loved dogs have a great life; abused dogs are suspicious and unpredictable. Some doctors have been abused by the NHS and patients, and have become uncooperative and angry. And we all know patients whose experience of medicine has tarnished their relationships with doctors long-term.

In the modern NHS, doctors and patients are on a continuum between trust and suspicion, and they often share a common feeling of powerlessness. This leads to a sense of their locus of control moving away from them or, as Seligman postulated, to learned helplessness.[2]

First let us consider patients. Many experience a long-term supportive relationship in which their doctor advocates for them in the complexities of the health service, calls and recalls them, and delivers clinical care that ranges from competent to excellent. Yet many experience disconnected episodes of care with no real relationship or continuity, appointment systems that restrict access, and an expectation that they should be 'grateful for what they get'. Very few patients would see themselves as true partners in their care.

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One theme of this lecture is therefore a 'patient-centred NHS', a concept recently espoused as policy in the Kennedy report on the paediatric heart surgery scandal[3] and in *The NHS Plan*.[4] I will explore what this means for us in general practice and in the wider NHS.

Now let us consider doctors. All too often we feel that things happen to us, not with us. We experience constant change but seldom understand the rationale for it. We feel that so many people are looking over our shoulder that the consulting room is getting crowded — and we feel that nobody trusts us to get on and do our job well. We yearn to be loved and appreciated but seldom feel so.

So, the second theme, with which I start, is a 'primary care-centred NHS'. How can we learn the lessons from the best of general practice for the NHS as a whole? Before I start into my two themes, I will give a framework within which I will assess the current NHS and any future changes.

What is a 'good' health service?

In his book, *Bowling alone*, Robert Putnam reflects on the glue that makes communities work, which he calls social capital.[5] Although he did reflect on implications for health care ('Of all the domains in which I have traced the consequences of social capital, in none is the importance of social connectedness so well established as in the case of health and wellbeing'), he did not extrapolate the concept to companies, industries or organisations such as the NHS, but his ideas do translate effectively.[6]

Social capital is one of the three forms of capital: physical, human, and social. In the NHS, the *physical capital* encompasses the buildings, equipment, the drugs prescribed and the information technology. This has clearly suffered from under-investment. *Human capital* is not just numbers of doctors, nurses and other staff — and there is a recognised need to build capacity — but also the skills and competencies of the workforce. But *social capital* is the foundation. When Marks and Spencers suffered a loss of profits and share price in 2000, the underlying malaise was that the shops were no longer seen as acceptable. From being a source of national pride, in the space of a year, they became a national embarrassment. An organisation can lose social capital overnight, but building it takes years.

So what is social capital? For Putnam it consists of:

- Values: the organisation is tied to its workers and its customers by shared values that are uplifting and worthy. In the NHS, these values include 'free at the point of delivery', 'respect and dignity', 'high quality of care for individuals and communities', 'reduction in inequalities', and 'good access'.

- Trust and mutual obligation: patients and carers must trust the NHS to be there when it is needed

and perceive the potential benefits in supporting the NHS for them and their community. For doctors and nurses, they need to trust the NHS to support them in delivering the values on which it is founded.

- Shared ownership: communities need to feel a sense of ownership of the organisation. People must not just feel that the NHS is 'our NHS', but the hospital is 'our hospital' and the general practice is 'my practice'.

- Empowerment: while 'empowerment' has been devalued as a word through overuse, the meaning is still fresh; decisions need to be taken as close to the consumer as possible, often by the consumer themselves. In general practice we often see it as enablement.[7] The service must be flexible and responsive, and workers and customers must feel that they can influence the way the service is delivered. In the NHS, this means that there must be local flexibility in determining services, and a feeling that services can be improved through local partnerships. Individual patients must feel that they can influence important decisions that affect their care.

Being a doctor in the NHS

NHS doctors have exceptional job security. As GPs, we get remarkable affection and loyalty from our patients and we enjoy a very high level of reputation. In the *People's Panel* in 2000, general practitioner services were rated highest with a 90% satisfaction rating.[8]

We certainly haven't experienced continuity of management structures. Many of us have lived and worked through so many re-organisations that we expect all reforms to be temporary. Who among us can forget the promise of reward for extra work in the 1990 new GP contract, leading to clawbacks because we responded as we had been asked? Many doctors feel that the NHS fails to meet its obligations to them. It fails in delivering each of Putnam's 'capitals'.

Firstly, the physical capital of the NHS is poor. This is not just about buildings, although many of our hospitals and practices are inadequate. More importantly, it is the low level of availability of CT scanners, effective but expensive drugs, intensive care beds, and operating theatres. The current government has committed itself to correcting this lack of investment, both directly and through public finance initiatives. However, the new money has yet to become apparent on the ground.

In terms of human capital the shortfall is, perhaps, worse. The Royal College of General Practitioners and the General Practitioner's Committee have argued that we need 10 000 more GPs to maintain the service.[9] However, the expansion of medical school places will take another 5 years to materialise beyond registration, and many of the extra doctors will be required in hospitals to support the reduction in junior doctor's hours and the creation of a consultant-delivered service.

There is, however, another reason for needing more hospital doctors — a stark decline in productivity. Julian le Grand's productivity index show a pronounced decline in recent years,[10] and data from John Yates at the Health Services Management Centre in Birmingham has charted the decline in surgical productivity; for example, in the past 13 years there has been a 26% drop in the number of operations undertaken by each orthopaedic surgeon (J Yates, personal communication, 2002). (There may be many explanations for this fall in productivity, some positive and some negative. It is not my task to comment on those here, merely to observe that falling productivity in the face of increasing demand calls for increased capacity.)

Table 1. Collingham practice consulting rates 1999–2002.

	1999	2000	2001	2002
Total number of contacts with PHCT	28 581	29 220	29 696	33 581
Contacts with PHCT per patient	4.9	5.0	5.0	5.5
Contacts with GP per patient	2.7	2.9	2.7	2.7

PHCT = primary healthcare team.

Table 2. Median days of duration of clinical journey for cancer patients in one general practice.

	Before guidelines (days) (n = 16)	After guidelines (days) (n = 16)
GP referral to first OPD	17	7
GP referral to decision to treat or palliate	45	65

OPD = outpatient department.

GPs are, by contrast, becoming more productive, using their training and skills more than ever. Practices are coping with the expansion of demand with new roles (especially for GPs and practice nurses) and larger primary care teams. In my practice, in Collingham on the Nottinghamshire–Lincolnshire border, the total number of patient consultations is rising, but not consultations with doctors. The main expansion is in practice nurse consultations. A family of four members will average 22 contacts a year with GPs, practice nurses or community nurses — about 4 hours face-to-face (Table 1).

In community clinical support services the story is one of long-term decline. Many people have no access to NHS dentistry, community chiropody or dietetics. Psychology and psychotherapy services are grossly understaffed.

One response from the NHS is to encourage more and better care through performance management. This carries potential risks, not least that inappropriate target setting can distort clinical behaviour.[11] By illustration, Dr Julia Hippisley-Cox and I have audited delays in the treatment of new cases of cancer in one large practice in the East Midlands before and after the '2-week wait' for first appointment for suspected cancer was introduced.[12] We did this by looking back into the records of all patients newly diagnosed with cancer in the two time periods. Admittedly with small numbers, there was a reduction from 17 days to 7 days in the mean wait from referral to first consultation (Table 2). For the 'worried well' and cancer patients alike, this was a considerable improvement in quality. However, the time from referral to the instigation of treatment, operation or a decision on palliation

Total patient list size	6200
Number of consulations by GP	16 317
Number of consultations with whole primary healthcare team	33 581
Acute admissions	116
Referrals to NHS outpatients	960

Box 1. Consultation pattern for people in Collingham in 2001.

Figure 1. The Hotel Dieu, Beaune, France.

had extended from a mean of 45 days to 65 days. For patients with cancer this is the crucial measure and it had extended by 20 days. Yet it is not the chosen performance measure and its deterioration is not, therefore, apparent to the commissioners of care, clinicians or patients.

If the physical and human capital is poor and NHS management responses are inadequate, what of the social capital of the NHS in relation to the doctors who work in it? The social capital for GPs is being steadily depleted. We feel that our values are being eroded, that our contribution is being devalued. The 2002 Labour party conference in Blackpool had a slogan of 'schools and hospitals' on its backcloth[13] — hardly a recognition of the work of primary care. GPs, the doctors who most understand the needs and concerns of patients — dare I say, their patients — do not feel particularly empowered by their primary care organisations to create a better health service. Many are keeping their heads down and hoping for a smooth run through to an early retirement.

So what's to be done?

If that is the diagnosis, the prescription for some issues is clear:

- Increased physical capital to develop buildings, supply technologies and the ability to use both effectively. The promised increased investment in the NHS is a good start, however we must ensure that it is best applied, including the ready availability of investigations and treatments that other Western countries take for granted.

- Increased human capital, with expansion particularly of the range and intensity of services in primary care, increased numbers of GPs and practice nurses, and through investment in skills development; for example, through GPs with a special interest.[14]

- Increased social capital. A devolved health service with local decision-making and responsibility. If one believes that *Shifting the balance of power in the NHS*[15] is about devolved decision-making — in effect the de-politicisation of the health service — then you would say that this is already happening. Others, more cynical, might say that the blame is being devolved while the real decisions are being kept centrally.

I referred to changes to make doctor's lives better under the banner of a 'primary care-centred NHS'. This hackneyed phrase is code for increasing the resources and responsibility for general practice and community services, valuing those services, and identifying the strengths of primary care and applying them more widely.

In recent months, I have been considering whether the substantial problems with secondary care cannot be addressed by revisiting the 1948 NHS settlement — by applying general practice partnership to routine care in NHS hospitals. I have already referred to the falling productivity in hospitals. Access is poor, not only as I have shown, with cancer care, but across the board. For routine surgery, many people opt for private care because that is the only way they can get quick access and be treated with respect.

The solution does not lie in abolishing private care. There will always be those who wish to, and will pay for, private care. If you have visited Beaune in the Rhone Valley you will, no doubt, have toured the Hotel Dieu — one of the oldest hospitals in Europe, built in 1443 (Figure 1). In the main hall there were cubicles along the wall and a chapel at the end. Just around the corner, however, was a smaller room with larger cubicles, storage space, paintings, and a jewelled altar. This was the 15th century private wing.

Rather, I wish to see the incentives to productivity and quality in the new GP contract extended into routine care in the hospital sector. When delivering routine care, members of the consultant-led teams would be profit-sharing partners or salaried employees. Their team would be rewarded by volume and quality. The ethos of the private sector would be used to enhance care in the NHS, but without privatisation. It would be simply the application of general practice principles to another health sector.

We, in general practice, recognise that we are the engine of the NHS. Box 1 shows the consultation, admission, and referral rates for my practice in the year 2001. We have a predominant effect on the health outcomes for the population. Yet we are seldom, if ever, congratulated on our care. We retire without a word of thanks. We seldom believe that the NHS knows we exist. Building on *A health service of all the talents*,[16] we need a new charter that sets out the obligations of the NHS to us as our employer.

When general practice works well, it does so because the GPs, as partners in their practice, have a high level of control over the care delivered, the policies implemented,

Total patient list size	6200
Number of patients with diabetes	217 (3.5%)
Number of consultations by patients with diabetes in 2001	33 581
Number seen in hospital diabetic clinic	35 (16%)

Box 2. Consultation pattern for people with diabetes in Collingham.

the wellbeing of their staff, and their own income. We don't close-up shop if there are patients to be seen.

At the end of the day, the best argument for a primary care-led NHS lies in Barbara Starfield's work. She has shown that those countries that have strong primary health care have the best outcomes at the lowest cost.[17]

Being a patient in the NHS

One of the most pleasurable, but disturbing experiences in preparing the Diabetes National Service Framework (NSF) was meeting with and listening to patient groups. People with diabetes always began by praising the positive, and many could tell of some excellent care for their diabetes. However, after a few minutes their accounts turned negative. The same story was told in the Audit Commission's survey of people with diabetes *Testing times*[18]:

- People with diabetes do not perceive the health service as treating them with care, respect, and dignity. They see us as stressed, remote, uncaring, and impersonal.

- Access is not just about appointments and surgical waits, although those are important. It is also about access to information, advice, and support. Many criticise the information they are given about diabetes. It is often given in one rush at the beginning of treatment, but is not available when they need it, or in different reading ages, languages, and media. And when things go wrong, many people with diabetes feel exposed and unsupported.

- A key element of building trust and mutual obligation is through relationships. This is no surprise to GPs — this is our stock in trade. We offer a long-term continuing relationship, in which mutual respect and trust can grow, and in which our obligation to act in the patient's and community's best interests is matched by the patient's obligation to assist us in doing so. However, people with diabetes often report poor continuity. Several people with diabetes expressed a belief that there was a positive conspiracy to ensure they saw a different — and usually more ignorant — junior doctor on every visit to the diabetes clinic. If people are to trust us, they need to believe that we 'know them' and their care.

- However this 'knowing them' is eroded because we don't communicate well between ourselves. And when we speak to patients, they get confused and receive mixed messages.

- Many feel that their care is not a partnership. One person memorably described to me visiting a doctor, putting down his book full of blood tests taken since the last visit, only to be handed the book back unopened. Many say that they are not respected by doctors and nurses as partners in their care, with an expertise in both diabetes in general, and their diabetes in particular.[19]

For people with diabetes, and they express the generic truth, the social capital of the NHS has almost been exhausted. They do not expect much, but their expectations are repeatedly not met. They do not trust the health service and they do not feel empowered or supported.

This is not only, or predominantly, a problem for primary care. But we do deliver most of the care to those with diabetes — in my practice in Collingham our patients with diabetes consulted an average of ten times each, with only one in six attending a hospital diabetes clinic (Box 2). We are, therefore, in the best position to make a difference.

So what can we do?

The solution is simply said — indeed it is said regularly by managers and politicians — and it is for a 'patient-centred NHS'; an NHS in which patients are empowered, should they wish, to become true partners in their care. We are witnessing the next part of a changing relationship between doctors and their patients, from the deity–believer relationship of previous centuries, through the expert–supplicant relationship of the 20th century, into the adviser–decider relationship of modern medicine.[20]

If we are to empower our patients, we must give them the respect that we would expect from a colleague. We must trust their judgement, but we must ensure that their judgement is informed. We must nurture and support 'the resourceful patient' as Muir Gray has so effectively written about recently.[21]

In an echo of my earlier statements on performance indicators, we must provide patients with information, and the understanding to change information into knowledge and then informed choices. To achieve this, each patient needs:

- Information
- Education
- Advice and support
- Respect

Patients need the information in ways that they can access it, in a language that they understand, and at the time of their choosing. They need advice at all hours of the day or night because pain, dysfunction, and crises do not follow working hours. And they do not just need information about their own care. They also need information on which they can base informed choices about which services they access. They need to compare hospitals, practices, doctors, and nurses; for example, I am working with Dr Foster to increase access to comparative data on primary care.

The strongest argument that I know for patient empowerment is this: the average person with Type 2 diabetes loses an average of 10 years of life expectancy and those with Type 1 lose an average of 20 years. We know that good glycaemic

control can make a major difference. The average person with diabetes spends less than 3 hours a year face-to-face with a health professional. However good the care they receive in those 3 hours, it is the decisions that they make in the other 8757 hours in the year that will really make the difference.

In writing the NSF for diabetes, we were well aware of the need to change the culture of the health service. The recommendations were not about ACE inhibitors and creatinine monitoring, although those are important. They are about giving people with diabetes information, helping them through education and support to use that information, and valuing their expertise.

Other NSF recommendations concern Managed Diabetes Networks; patient involvement in service design, delivery and monitoring; a named person to act as a source of advice; and patient-held records.

I want to look at that last proposal in a bit more detail. *The NHS Plan* spoke of the aspiration for all letters about patients to be copied to them.[4] I would go further and would hope that all letters will be addressed to them and copied to relevant health professionals with their knowledge and consent.

While I envisage, for very good reasons, primary care teams retaining their electronic patient record, and hospital teams doing likewise, it would seem to me ideal if the synthesis of these electronic patient records — the electronic health record — was controlled by the person to whom it related.

We already have sensitive interchanges with websites — my credit card details are held by several web-based organisations, for example. Web access to their electronic health record, by all patients who wish it, would allow them to recall previous events, to challenge the accuracy of their record, add comments on their care, and enter readings such as blood sugar levels, blood pressure and cholesterol levels. And we could access the electronic health record during the consultation, integrating patient-generated entries in our electronic health record.

In this scenario, decision support can be embedded throughout the record. If a patient clicked on their beta-blocker, they would be able to access information about that drug relevant to their specific context, allowing them to become truly informed consumers.

To make good decisions, patients need both information and the skills to use that information. Those skills will only come through education, and this transformation calls for an educationalist in every practice. Only 10 years ago, the idea of a counsellor in every practice was challenging.[22] I think that the next development should be a person with an educational background, skilled at helping people turn information into knowledge, and skilled at helping behavioural change, such as smoking cessation, healthy eating, and safe sex.

We will need an investment in our physical and human capital to achieve our potential. But mostly we will need a rebuilding of the social capital of the NHS around the concept of the empowered patient.

Conclusions

This journey started from a negative perception — that both doctors and patients are leading a dog's life. I have given an analysis of why that might be, using Putnam's three capitals — physical, human and social — as the framework.

I am not, however, pessimistic. There are two old, tired, and tarnished concepts that I believe we need to revitalise in order to offer the route to improvement:

- A patient-centred NHS
- A primary care-centred NHS

They are but two dimensions of one concept — the empowerment of those closest to the problem. The patient has the problem and cannot avoid owning it. Primary care is their first carer, their long-term carer, and their advocate.

Empowering patients will not be easy for us. None of us relish discovering that a patient knows more about their condition and its management than we do. However, that will become more and more commonplace. General practice, in its key place as the cornerstone of primary care, is the great NHS success story. We are not perfect, but we are the service that delivers. We need to build on our strengths by trusting our patients more; and to demand and take control of local healthcare.

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