PRINCIPLES AND PARADOXES IN MODERN HEALTHCARE

A CHALLENGE TO PROFESSIONALISM?

Deirdre Hine

The Nuffield Trust
FOR RESEARCH AND POLICY
STUDIES IN HEALTH SERVICES

To my mother in her 91st year
with gratitude for a lifetime of support and encouragement

About the Author

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INTRODUCTION

"In matters of principle stand like a rock"

<div align="right">Thomas Jefferson</div>

"A paradox, a paradox, a most ingenious paradox"

<div align="right">W S Gilbert</div>

It is a truism to say that the UK healthcare system, in all its dimensions, is going through a period of significant and disturbing change. Many of the policies, if not the fundamental philosophy, underlying the delivery of healthcare are being turned upside down. The government has deemed it necessary to unleash a process of wholesale system reform to achieve a radical and substantial improvement in the effectiveness and cost-effectiveness of the service to patients.

When organisations are forced into rapid or radical change – and when groups of professionals are asked to change or coerced into changing – there is an instinctive recourse to the solace and protection of restating fundamental principles that the organisation, or group, believes underlie its practice.

This phenomenon is also experienced by those charged with establishing an organisation, or a methodology, to meet a new demand or accomplish a new task. The ideas and observations contained in this monograph have their origin in over 45 years of experience working in the United Kingdom's National Health Service. However, they only crystallised some years after my retirement from full-time work when, with others, I was tasked with establishing such a new organisation, the Commission for Health Improvement. An experience, which though extremely satisfying and enjoyable, was demanding and eventually frustrating. This then is a commentary, a critique, and a search for answers borne of that and other experiences in a professional career of over 40 years. This is in no way a comprehensive review. Nor is it an academic treatise, a form which, by skills and inclination, I am totally unqualified to produce.

In the early summer of 1999, the department of health began to implement the government's announced intention[1] to establish an "arm's length" body to inspect and review the quality of clinical governance in the health service in England and Wales. The objective was to improve the standard and quality of care that patients were receiving.

The first meeting of the Commission took place in late November, with a requirement to have a programme of clinical governance reviews and investigations up and running by 1st April 2000. This was a demanding timetable since methodologies for each of our programmes of work had to be devised and tested, staff recruited and trained, within five months. That we met the deadline for beginning the reviews is a tribute to the hard work and competence of the relatively small team that comprised the staff of the new commission. On the very day we became operational we were able to respond to requests made by the department of health and the Welsh assembly to undertake two major investigations into serious deficiencies of care.

The need for haste in beginning to put together methodologies, and the means of implementing them, perhaps meant that it was surprising that the members of the commission spent much of their first few meetings devising a set of fundamental principles that would shape and guide the work of the new body.

It was, however, a use of time that proved its worth again and again during the lifetime of the commission. These principles became the template against which we judged all our decisions as a body, and to which we returned frequently when faced with a dilemma or a choice about how to fulfil our obligations.

Principles

I cannot recall that the Commission ever debated what was meant by principles. The dictionaries consulted in preparation of this monograph give several similar but differing definitions. In what follows I am interpreting the word principle to mean a standard or rule providing a motive or reason for action. This is a hybrid of the definitions in the Shorter Oxford and Collins dictionaries.

A relatively short list of principles or qualities emerged from our discussions to be incorporated in all of the commission's work. We aspired to make the new body and its judgements:

- Patient-centred
- Supportive of professionals rather than punitive
- Independent of government and other vested interests
- Collaborative, recognising and using the skills and knowledge of others
- Evidence based, though recognising that evidence may be sparse or difficult to pin down
- Fair
- Rigorous
- Developmental
- Consistent.

Desirable though each of the principles were individually, some of them were, or could be seen to be, in conflict or at the very least in tension with each another. For example, we aspired to be patient centred but supportive and understanding of the problems of the staff of the service. We needed to achieve credibility by being independent of vested interests but at the same time to fully utilise the skills and knowledge present within many other organisations in healthcare. It was important that our methodologies were applied fairly and consistently to the healthcare organisations that we reviewed. Yet since we devised them to achieve a task that had not previously been attempted – that of coming to an independent judgement on the quality of clinical governance and thus of the care given by an organisation – it was equally important that they should be developed, modified, and amended as experience was gained in both the process and outcome of the work. So consistency and development were at odds with one another. The same could be said of the principles of patient-centredness and professional support.

Paradoxes

Thus the adoption of a list of principles created a series of paradoxes for the Commission. Though this was implicitly recognised, to my recollection, it was never widely articulated in our meetings. For the sake of clarity the definition of *paradox* as used in the title of this work is that of the Shorter OED and Collins: "Something exhibiting apparently contradictory characteristics," or "a statement seemingly self contradictory or absurd, though possibly well-founded and essentially true." Here *characteristics* can be replaced by *principles.*

Since that time, my recognition of the problem of conflicting principles has caused me to reassess many of those traditionally promoted within the healthcare professions as desirable or essential principles in the practice of healthcare, and to discern in them the same phenomenon of paradox. Paradoxes that have become more evident, and more widely recognised and debated, in the context of rapid technological advances that have implications for the way modern healthcare is delivered. In particular, the radical changes proposed for the UK's healthcare system, which, though most dramatic and well publicised in England, are also evident to some extent in the devolved administrations of the UK. While many within healthcare may find some of these changes unwelcome, or even unacceptable, it is inevitable that change will be necessary to make the rightly prized NHS fit for the "modern" healthcare of my title.

Modern healthcare

This adjective encompasses the enormous technological, economic, and social changes that have occurred both within healthcare and the wider world since the inception of the NHS in the aftermath of the Second World War. Globalisation, the IT revolution, increasing UK affluence, consumerism, and the diminution of deference – indeed the growing challenge to the professions – are a backdrop against which the service cannot continue to operate unchanged. The changing relationships between the professions and society engendered by these external forces is well described by Newton[2], quoting Klein[3], as the transformation of a "status" society based on human capital created by education and enforced by the exclusion of the unqualified, with corporatism, authority, autonomy, self regulation, and trust among it characteristics, into one based on "contract," with individualism, performance, accountability, and review as its features.

Many of us may regret the loss of a more innocent and amenable context in which to work as professionals. It seems inevitable, however, that if the essential principles of universal and comprehensive healthcare – free at the point of use and funded by taxation and underpinned by professional values – are to survive, it may be necessary to examine other principles to ensure that they are appropriate in their traditional form or else can be adapted and "modernised" so that their essence is not lost.

In what follows I will attempt to discuss some of these principles, selecting those that seem to be particularly relevant, at risk, or topical, in the context of the "system reform" to which the NHS is currently being subjected. I hope that it will become apparent that what might be seen as a personal, philosophical, or semantic preoccupation has the potential for practical, and indeed serious, impact on how healthcare in this country is organised and, most importantly, on the quality of care that patients receive.

The selection is idiosyncratic to some extent. Discussion of all the possible candidates for inclusion would require a very lengthy document and possibly lead to more confusion. For this reason I have jettisoned some issues close to my heart, especially the tensions between equity and efficiency and between collaboration and competition. I have tried to focus on those that, at the time of writing, appear to be the most topical or potentially problematical, even though much has already been written about them. I hope that coming as they do so late in my professional career as a doctor, and so increasingly close to a probable new role as a patient, these insights may be of some value.

In this context I apologise in advance if the work seems overly medico-centric. I am forced by experience to comment mainly from that standpoint. Many of the dilemmas faced by doctors, however, are also experienced by other professionals within healthcare, and this commentary may therefore be of relevance to other colleagues.

The sets of principles I have selected for discussion are:

- Trust and accountability, with discussion of the role of regulation and touching on issues of risk and consent
- Confidentiality and the possible danger to it from the collection and use of data obtained from personal health records, in the context of the potential offered by computerisation of medical records and the department of health's initiative to create a common database across the NHS in England
- Leadership and team working in the context of blurring of professional boundaries and the calls for clearer clinical leadership.

I aim to demonstrate that the paradoxes are more apparent than real. Although several appear to be a challenge – even an attack on healthcare professions – it is in the redefinition of professionalism, and an acceptance of a more appropriate relationship between healthcare staff, between them and those for whom they care, that can provide the key to overcoming the apparent paradoxes and allow us, even in this modern healthcare system, to obey the Jeffersonian injunction of standing like a rock in matters of principle.

TRUST AND ACCOUNTABILITY

"Trust is like a vase…once it's broken you can fix it but the vase will never be the same again"

Anon

"Accountability breeds reponse-ablility"

Stephen R Covey

Trust as a principle

There is an enormous and highly erudite literature on the subject of trust that I am not competent to evaluate in any detail. However there is universal agreement that trust is an essential factor in maintaining a successful and productive relationship between individuals or groups in which there is an imbalance either of knowledge, skill, or power; trust by the less knowledgeable, skilled, or less powerful in the good intentions, competence, and capacity of those they perceive as having these attributes in greater measure. This is particularly true in circumstances in which individuals perceive themselves to be at risk. Trust in our financial advisers is a pre-requisite for allowing them to manipulate our money. Trust in an airline pilot is essential if we are to travel confidently by plane.

The importance of trust, in a world in which the complexity of every day life is increasing as a result of developments in technology, has led to much philosophical, academic, and journalistic exploration of the factors that underlie its achievement. In healthcare relationships there is growing interest in factors that contribute to maintenance or diminution of trust. Robb and Greenhalgh[4] record how, in the context of healthcare, within Greener's[5] taxonomy, such trust is described mainly as "coercive trust," since the care seeker has no choice but to trust the system or the individual having the skill and knowledge that they do not themselves possess.

For some patients Greener postulates that "coercive" trust may be present alongside "voluntary" trust, in which confidence in the institution or the professional reputation of an individual – sometimes accompanied by confidence derived from continuity of relationship – are present. It seems likely that many of the changes that have occurred in the NHS over the last decade, notably the series of healthcare "scandals," and the move to large group-practices based in primary-care centres together with the withdrawal of out-of-hours cover by most family doctors, may significantly alter the balance between these two forms of trust.

However, there can be another version of trust, one that I will call "informed trust," a concept that I regard as an essential development of the traditional understanding of trust and one that will be increasingly important in the context of modern health care.

As the US Institute of Medicine[6] observes:

> *"Health care is not just another service industry. Its fundamental nature is characterised by people taking care of other people in times of need and stress. Patients are ill, families are worried, and the ultimate outcome may be uncertain. Stable trusting relationships between a patient and the people providing care can be critical to healing or managing an illness."*

It is widely recognised by those who provide healthcare that since the well being, freedom from distress, and at times the very survival of those they care for is at stake, trust and trustworthiness are important fundamental principles to be observed in all that they do.

In a less dramatic way also, maintaining trust in the healthcare system is important since without it patients are unlikely to comply with the advice they are given, may fail to keep their appointments, or may resort to practices and remedies that are at best ineffective and at worst dangerous.

There can be little doubt that in modern healthcare both the characteristics of trust and the way in which trust in institutions and individuals is achieved are already undergoing change, and will continue to do so as the social and technological changes that characterise life in the 21st century impact on relationships between patients and healthcare staff. A change perhaps most clearly described and discernible in the relationship between patients and doctors. It seems increasingly inevitable that rationalisation,[7] a process whereby society moves from a traditional to a modern state by abandoning subjective values in favour of more objective ones, will occur. This is a process that I hope and anticipate will lead to *informed trust.*

A similar observation[8] of the transition in relationships that is occurring in healthcare identifies the key cultural change as a shift away from an attitude of paternalism to one of partnership, which is seen as leading to the establishment of "enlightened trust." This in many ways is identical to my own concept, though I prefer the adjective "informed" as having fewer overtones of passivity in those called upon to exercise trust.

A crisis of trust?

In June 1998, Richard Smith, then editor of the *British Medical Journal*, commenting in a leader[9] on the fallout from the serious deficiencies that had been revealed in the surgical care of infants undergoing cardiac surgery at the Bristol Royal Infirmary, quoted WB Yeats, saying: "All changed, changed utterly." Similar well-publicised scandals have involved the nursing and other healthcare professions. It is more than possible to suggest that these may have eroded the trust of the public in all the healthcare professions. And, indeed, to many commentators on health care, these medical scandals, culminating in the identification of the medical multiple-murderer Harold Shipman, did seem to represent a watershed in the traditional relationship of trust between patients and the health service in general, and within that, the medical profession.

But did it? It is at least doubtful if the degree and scope of trust in doctors was ever as complete as some contemporary writers would like to have us think. Authors from Voltaire to Shaw have expressed in their writings a certain scepticism about the beneficence of the profession. Voltaire famously described

doctors as "men who prescribe medicines of which they know little, to cure diseases of which they know less, in human beings of whom they know nothing."

This was, perhaps, a reasonable view of medicine in the 18th century. However, Shaw in the 20th century voiced the view that all professions are a conspiracy against the laity. While Hilaire Belloc expressed it humorously in his poem on the sad tale of "Henry King who chewed bits of string and was early cut off in dreadful agonies," reporting how "Physicians of the utmost fame were called at once, but when they came, they answered as they took their fees, there is no Cure for this Disease."

More recently Phil Hammond, presenter of a TV programme called *Trust Me I'm a Doctor* reports[10] that a friend suggested that he should rename his programme, *Trust Me, You Have No Choice*. And Donald Gould[11] in what New Society called his uncompromising tract, *The Medical Mafia*, asserts that society asks too much of the medical profession, and that they often fail to meet these expectations and pretend to powers and wisdoms they do not possess in a vain attempt to do so.

On the other hand, the evidence from repeated polls[12] even those conducted soon after the conviction of Dr Shipman, in which the public were asked to rank various professions and occupations in order of trustworthiness, seems to demonstrate that people still trust doctors above almost every other group to tell them the truth, and that they are convinced that doctors and nurses do a good job. Over the period 1983 to 2005 the percentage of those polled who said that they trusted doctors to tell the truth rose from 82% to 91%, making doctors the most trusted of any professional group. And in 2004, 92% of those polled were fairly or very satisfied by the way doctors did their jobs, a record surpassed only by that of nurses at 95%.

In the report of her inquiry into the Shipman affair, Dame Janet Smith observes that for much of the last century "the profession was held in such deference that people were unwilling to question the actions of a doctor."[13]

Trust in what?

The evidence for the existence of universal trust in doctors in the past, and any recent change in the extent of that trust, is at best equivocal. Is the apparent crisis of trust then merely a media generated mirage? The poll results indicate that the postulated reduction in trust is indeed a media phenomenon based on a wholly unrepresentative set of relatively rare disasters and instances of failure of care. However, it is important to note the narrowness of the questions asked in the polls. Being trusted to tell the truth is important but is not the whole spectrum of trust that is required for a successful therapeutic relationship.

That spectrum has to encompass a wide breadth of trust in healthcare advisers, particularly doctors. Trust in their competence, trust that their knowledge is up to date, trust that they are independent of other interests in their thoughts, decisions and actions, and ultimately trust in their compassion and humanity. Quite a tall order, and one that is not explored adequately by the simplistic questions used in polls. Indeed, in the context of system reform it is possible to speculate that trust in the independence of health professionals will be reduced by the introduction of multiple provider organisations into UK healthcare. This change has been presented as commercialisation of the NHS and may carry with it a fear that professionals within the new system will be motivated more by commercial rather than professional values and principles.

Dangers of trust

There is some reason to argue, on the other hand, that an excessive degree of trust, especially that described by Greener as "hegemonic trust" based almost entirely on social deference, can be, and has been, extremely damaging to patient-doctor relationships in individual cases and as a whole. Where trust is thought to have been betrayed, the bitterness that ensues is well exemplified by the feelings of the parents of the babies in the Bristol cardiac surgery case, and those of parents of children whose organs were harvested without consent at Alder Hey. Indeed, the ferocity of the reactions in both cases may be explained to some extent by the pre-existing excessive veneration of, and trust in, the children's doctors exhibited by parents. At the time, these parents believed they had no reason not to trust doctors to act solely for the welfare of their children. The ferocity of the reaction was transmitted to the public by the print and broadcast media, who scented stories "with legs" that allowed them to indulge in a feeding frenzy at the expense of the medical profession. As Rob Innes observes in his chapter on Alder Hey in *Rebuilding Trust in Healthcare*,[14] when blind trust is betrayed, the resulting anger is intense.

Reith Lectures: A Question of Trust

In the 2002 Reith Lectures entitled *A Question of Trust*, O'Neill[15] examined what she described as the "supposed crisis of (public) trust" and the "supposed remedies". Though she was examining the phenomenon of trust in a wider context, much of the content of those lectures is germane to the paradox of trust and accountability within healthcare. O'Neill made it clear that she was discussing both the breakdown in public trust and the current remedies as "an outsider" and from a philosophical point of view, while hoping that this also had practical relevance.

Essentially her message was that claims of loss of trust in major areas of public life are not entirely supported by evidence. Although journalists highlight the

results of public opinion polls that purport to demonstrate a lack of trust, the complexity of the true position cannot be accurately determined through the simplistic questions on which these polls are based – an argument similar to that used above but, interestingly, pointing in the opposite direction. Indeed, she maintained that stronger evidence for the existence and maintenance of trust lies in our actions rather than our words, and we constantly demonstrate trust in both individuals and institutions by the way in which we interact with them.

However, it can be questioned whether, in the case of healthcare services and doctors, these actions are the result of a rational assessment of the validity of that trust or are dictated solely by the necessity of clinging, at a time of extreme need, to the hope that competent and compassionate help will be forthcoming. Emotion may well always play a part in such transactions, but in modern healthcare it is surely appropriate that rationality rather than emotion should be the dominant basis for trust. If so, is such a rebalancing desirable and how can it be achieved?

Accountability

The evidence, however equivocal, supporting a perception of diminishing trust in the health service as a whole has been sufficient in the past to stimulate government action. In December 1997, the newly elected Labour Government issued the white paper entitled *The New NHS. Modern, Dependable.*[16] This document contains the first public reference by government to the need for the NHS to be accountable to the public. One of the six principles of the paper is: "To rebuild public confidence in the NHS as a public service accountable to patients, open to the public and shaped by their views."

In the foreword to the white paper, the prime minister describes his government's approach to ensuring the modernisation and dependability of the NHS:

> "This White Paper marks a turning point for the NHS… replaces the internal market with integrated care…saving £1 billion of red tape and putting that money into frontline patient care. For the first time the need to ensure that high quality patient care is spread throughout the service will be taken seriously. National standards of care will be guaranteed. Our approach combines efficiency and quality with a belief in fairness and partnership…. I want the NHS to take a big step forward and become a modern and **dependable** service that is once more the envy of the world."

This passage may now seem somewhat ironic to a service undergoing a whole system reform designed to enshrine, for good or ill, a market approach that is more explicit, more commercial, and more fragmented by design than the internal market devised by the Conservative administration.

Dependable may be a term that is more user friendly than accountable, but it is clear that the two are used synonymously in the white paper. Given the scandals of the previous decade, together with the demonstrated variability of the quality of healthcare in the UK, the incoming administration could claim to have been entirely justified in setting up a structure designed to produce equity of quality and prevent abuses. That framework consisted of three new initiatives: establishment of a national institute for clinical excellence, NICE; production of a set of standards for treatment of major disease categories or patient groups, the National Service Frameworks; and an independent regulator, the Commission for Health Improvement. The latter is widely recognised as being misnamed since it was given the task of health service improvement not health improvement. It appears that in an effort to produce the memorable acronym, CHIMP, ministers were prepared to sacrifice accuracy for spin!

So the NHS was and is now explicitly required to be accountable for the quality of the service it provides, a word that the Shorter Oxford English Dictionary defines as "to be counted on." This definition justifies its substitution for "dependable," the word used by the authors of the white paper. Interestingly, the ultimate responsibility for this accountability for quality was, for the first time, vested in the chief executives of institutions, particularly hospitals, that comprise the NHS. Was this a tacit recognition that accountability of clinicians to the public, and to the government, was more difficult to achieve and would be more vigorously resisted, especially since the medical profession held that doctors were already and solely accountable to individual patients? And was this new accountability regime capable of achieving the objective of the white paper, that of "rebuilding public confidence" in other words, trust in the service, assuming that public confidence had been demolished or at least eroded in the first place?

Problems of accountability

O'Neill argued that the complex and expensive panoply of measures introduced to remedy any general loss of trust – transparency, audit, accountability and regulation – have **not** been shown to work. She posed the question of whether "the revolution in accountability" may not indeed have undermined trust. Much of the argument developed by O'Neill is also discussed by Michael Power in his book, *The Audit Society*, though he acknowledges in the preface to the paperback edition[17] that:

> "*There is something unavoidable about audit and related practices and something irresistible about the demands for accountability and transparency which they serve, even when the consequences are perverse.*"

As applied to the health service, and perhaps in particular to the medical profession, such philosophical questions and critical observations are as

important as they are disturbing. Especially to one who has spent part of a professional lifetime endeavouring to devise, and implement, ways of ensuring adherence to a high standard of quality in patient care and thus demonstrable accountability. A pre-occupation that has required involvement over time with the development of clinical audit, quality assessment, quality control, evidence-based medicine, clinical effectiveness, clinical governance, medical regulation, health service inspection, and other initiatives both professionally and government led.

Initiatives intended to ensure a firm basis for trust

Such initiatives have been characterised by many in the medical profession as politically driven, ephemeral, irritating obsessions of the moment. Indeed, like other colleagues whose professional practice has had to absorb and adapt to them I have, at times, viewed them with irritation, if not distaste. However, mature reflection from the lofty heights and tranquil waters of retirement – possibly even more influenced by an increasing recognition of the greater likelihood of future patient, rather than doctor, status – allows them to be seen, perhaps more clearly, as important and admirable, if fumbling, efforts to meet and allay the anxieties experienced by those who are in the position of having to put their trust in doctors, and in the health service as a whole, and to increase the rationality of such trust.

My interest in these matters was initially stimulated by a teacher in my undergraduate and postgraduate education in Wales, Professor Archie Cochrane, long before the publication of what, somewhat to his dismay, turned out to be his most famous publication, *Effectiveness and Efficiency*.[18] His then, almost heretical, idea that much of medical practice could not be justified by evidence was indeed a wake-up call, akin to a douche of cold water, to a young idealistic doctor in the making. Perhaps his monograph, incidentally first published by the Nuffield Trust, was a crack in the wall of the general climate of professional complacency and hubris engendered by the undoubted massive strides in the capacity to treat disease that characterised practice in the years following the Second World War. The hostile reception given at the time by his colleagues to many of Archie's ideas and research results certainly gives some colour to this perception.

I have suggested elsewhere[19] that failure to follow Archie's lead was, and still is, a factor in the financial and capacity crisis that has beset the NHS in recent years. But his ideas may also have marked the beginning of a reluctant intellectual recognition within the profession that there was a degree of misplaced trust in doctors, a recognition that became more widespread and resulted in what Graeme Catto has called the "shift in tectonic plates"[20] that took place in the wake of Bristol and Shipman.

Intra-professional trust and accountability

One aspect of the overall question of trust that is not covered in O'Neill's otherwise very comprehensive treatment of the subject is that of trust in oneself and one's own and one's colleagues' professional competence and performance. Efforts to produce evidence to justify such trust have arguably been greater within the medical profession than many others, for example lawyers and teachers, who also serve the public. The collection of data on the result of treatment regimes, the analysis of these data, and the exploration of what they reveal in terms of outcomes for patients, has a long and honourable tradition in medical research. The Confidential Enquiries into Maternal Deaths (CEMD) and Peri-Operative Deaths (CEPOD) are notable and noble examples of medical audit.

However, for most of our history such activities were the preserve of enthusiasts rather than being universal practice, and it was not until around 1990 that the concept of "audit" as applied to everyday, every doctor, medical practice became widespread. A series of articles [21] in the *British Medical Journal* was the vehicle that first brought the subject to the attention of large parts of the profession and a later government initiative[22] to introduce this throughout the NHS ensured that it became, slowly and somewhat grudgingly, part of weekly or monthly, rather than everyday, practice in the NHS.

The development of medical audit can be seen as the beginning of explicit accountability for its practices by the medical profession, but only to itself. Both the process and outcome were kept strictly confidential to those taking part in these activities, and were seldom shared outside a very restricted group from which other professionals, and certainly managers and patients, were rigidly excluded. As Power observes in the section of his book[23] that covers audit in clinical practice: "Audit often does not coincide with information release, especially where practitioners control the process." Moreover, he points out: "Medical audit was never initially intended as a public accountability device and practitioners have worked hard to maintain its status as a heuristic tool to improve practice."

This exclusion of "outsiders" was ironically a provision adopted to establish trust in the process for those taking part. Trust that audit would not result in damaging or humiliating exposure of their deficiencies and those of the treatments they were applying to their patients. It was an attitude that may have been more damaging than protective, since it engendered suspicion and resentment among other health care professionals, particularly managers who were required to provide resources to support the activity. Such resistance to openness still prevails to some extent among some parts of the profession, though the pioneering work of the cardiac surgeons of the UK led by Sir Bruce Keogh[24] in beginning to publish openly the outcomes of surgery by consultant

is the exception that proves the rule, and the entrepreneurial approach of Dr Foster Ltd has begun to make both institutional and individual outcome information more widely available.

A similar defensiveness characterised the reaction of much of the medical profession to the introduction of the concept and practice of evidence-based medicine (EBM)[25] to the UK and to the resultant production of "guidelines" and "protocols." EBM was aimed at ensuring that doctors could demonstrate, to their peers and their patients, a scientific rationale behind their proposed remedies, but was denigrated by some doctors as "cook book medicine."

Allegations that the concept devalued clinical experience and "merely synthesised fool's gold out of the base metal of medical publications" were published in the correspondence columns of at least one respected medical journal,[26] together with an editorial that "deplore(d) attempts to foist evidence-based medicine on the profession as a discipline in itself."[27] I remember well the difficult experience of attempting to introduce colleagues in hospital practice in Wales to a clinical effectiveness initiative based on EBM. This was despite it being designed to address criticisms of EBM by helping staff to access the evidence themselves, and determine its applicability to their personal practice, rather than follow protocols produced by others. I was met, in at least one hospital postgraduate centre, by indignation and the claim that such evidence-based practice was already, and always had been, the norm in the hospital – despite ample evidence from the outcomes of care in that establishment, as in much of the NHS at the time, that this was far from the truth.

Other initiatives designed to support trust

The introduction of a completely new service within the NHS provided me with a personal opportunity to experience how to embed in a clinical though admittedly narrowly-based service, the principles and practices of evidence-based medicine, quality control, clinical audit, benchmarking and clinical governance – though the latter concept had yet to be clearly articulated.[28]

Breast cancer screening services were established throughout the UK as a direct result of the report[29] of a group chaired by Professor Patrick Forrest that was accepted by the government in November 1986. The evidence base was the Swedish experience of screening women for the condition using X-ray mammography at set intervals. The introduction of the service was supervised by a UK-wide steering committee that, with the support and encouragement of epidemiologists, clinicians, and, in particular, the Royal Colleges of Surgery and Radiology, set and monitored clear national standards for every facet of the process to be adopted.

In Wales, we recognised that we were inviting apparently healthy women to undergo a procedure that, while not painful in most cases, was far from free of

discomfort. At best, we gave only limited and temporary reassurance to them. At worst, they could find out months or even years before their condition became life threatening. They had no guarantee that this would confer any individual advantage in outcome. This gave rise to a determination that the whole exercise should be as rigorously quality controlled as possible, that every stage in the process should be audited to ensure that such quality control was effective. To ensure this, an "All-Wales" service was established, with ultimate responsibility for quality vested in one individual, the director. Such a regime was seen as an ethical imperative, but also to be essential in maintaining sufficient trust within the population to ensure maximum uptake, and thus the best possible chance that the programme would achieve its stated aims.

The careful analysis of each stage of the process against the standards, and the recording and storage of data made possible by computerised patient records, gave both clinicians and managers the information to convince themselves, and thus the clientele, that they were achieving the required standards. This undoubtedly led to a degree of professional trust in the process that was essential in gaining its widespread acceptance within health care and ultimately within the population as a whole.

The place of such quality control and audit, and their importance in maintaining confidence and trust in screening programmes, has been amply shown by the cases in which such programmes have been found to be defective (an outcome notable for its absence in the Welsh screening programme). While these have been distressing both for the women involved, and for those running the service, it could be argued that it was only the collection of computerised data on the details of each individual transaction in the process, together with critical analysis of them, that enabled problems to be detected and any necessary call back of patients to be done. This in turn has led to improvements in the competence of both the programme and the professionals involved. Short-term anxiety has been expressed by the media on each occasion that problems have been detected, but the programme is still widely accepted as safe and effective. The success of rigorous quality control to ensure a safe and effective service, and thus a trustworthy one, has been demonstrated.

Risk and trust

One criticism of the breast cancer screening programme that is justified to a certain extent is that the trust that women had in it, whatever its technical excellence, was achieved by overemphasis of the benefits that it offered and the failure to emphasise the risks that it entailed. The risk that a false positive result could lead to unnecessary anxiety at best, and unnecessary surgery at worst. Or the risk that a false negative result could produce a delay of weeks or months in establishing a correct diagnosis, and thus a delay in appropriate treatment.

The connection between risk and trust is an important one. It is perfectly possible to argue that in seeking to shield the parents in both Bristol and Alder Hey from the truth about some unpalatable, distressing, unacceptable risks – specifically in the Bristol case, the true level of the risk that the operations they proposed to undertake could lead to death or damage to the children – the doctors concerned were, as they saw it, acting in the interests of the families as a whole. Such an attitude of extreme paternalism was not unusual in paediatric practice as I observed it in the 1960s and 1970s, and was to some extent a feature of the early years of breast cancer screening. But as we have seen, underplaying risk can have disastrous consequences for trust.

Medical care is not unique in this context. It has been widely observed that the public perception of risk is an important factor in the level of trust that the public places in scientists and in government. The difficulties in assessing the risk that bovine spongiform encephalopathy posed to health, and the subsequent false reassurance offered by scientists to the government, and the government to the public, have probably damaged public trust in both.

And in what might be called an own goal, scored by a medical researcher aided by medical and national journalism, the large-scale loss of trust by UK parents of young children in the measles mumps and rubella (MMR) vaccine followed the publication of flawed research[30] that purported to show a causal relationship between administration of the vaccine and bowel disease and autism. An unnecessary, and falsely based, claim of risk resulted in a loss of trust that has had serious consequences in setting back efforts to reduce or eliminate the serious damage to children caused by these diseases.

Expectations and trust

Definitions of public trust in the literature differ but all embody the notion of expectations. In terms of healthcare services, these are expectations by the public that providers will demonstrate knowledge, skill, and competence. Raymond Tallis,[31] in his passionately written and highly readable book, *Hippocratic Oaths*. draws attention to the "curious dissociation between what medicine has achieved and the way in which it is perceived." That perception, says Tallis, is less favourable than the facts would justify, a dissociation that I first heard enunciated many years ago by Sir Michael Peckham. Tallis' purpose in writing the book was to make "invisible medicine truly visible." He thereby strove to overcome this paradox of perception, ascribing it to the fact that although medicine is continuously improving it has not kept pace with the expectations of patients, expectations that reflect the changes in the world at large.

It is possible, however, to propose an alternative, though one understandably less attractive to doctors. This is that the medical profession has over-sold its capabilities, or allowed the media to do so, on the tide of hubris I referred to

earlier. I have indicated elsewhere[32] that the expectations the population has of the health service are based on a false perception of the risks of failure and of complications of medical and surgical treatment. These are fuelled in part by factual, though over optimistic, media reporting of wonder drugs and breakthroughs in treatment, together with the effect of medical soap operas that have a requirement for a happy ending in less than thirty minutes. This phenomenon was recently identified in the public's unrealistic expectation of survival rates for those undergoing intensive treatment as a result of the portrayal of such cases in programmes such as *Holby City*.

The fundamental difficulty may well be that the profession has been unwilling or unable, for reasons of either *amour propre* or misplaced paternalism, to help patients and the public to recognise and understand the levels of uncertainty of medical practice. Patient representatives and lay commentators, in particular, have repeatedly challenged this benevolent arrogance over the past decade. While there have been major advances in medical understanding of its inappropriateness in present day practice, it is disheartening to frequently read hostile medical reactions to efforts to reduce it from inside and outside the profession. Critics of benevolent arrogance have been characterised as: "The unthinking voices of those who have a shallow understanding (and an even shallower appreciation of) the achievements of medicine."[33]

Informed consent enables understanding of risk

One of the ways devised to enable recognition by patients of the risks of treatment, and thus give them a solid basis for their trust in those who provide care, has been an improvement in the process of obtaining consent from patients. This aims to make them aware of the extent of the probable, if not of the myriad of possible, risks that a course of action, whether an investigation or a therapeutic procedure, will entail. The problems of obtaining full and accurate understanding of such risks by patients, some of whose age or condition makes the absorption of information problematic, are not thought to absolve clinician from their duty to attempt it. Some may feel, though, that informed consent is impossible to achieve given the disparity of understanding that exists between clinician and patient, and so amounts more to a ritual than a valid process that could, if not sensibly applied, interfere with emergency or urgent treatment.

Such views are common among the medical profession, and it may well be that doctors routinely underestimate the capability of patients to understand and cope with the uncertainty that much of medical practice entails. On a personal level, I have observed the process at its most effective and benign when a consultant anaesthetist explained fully, but with sensitivity and carefully chosen words, the risks that the proposed surgery and the required anaesthetic entailed for my then almost 90-year old mother. Having the trust in her healthcare

advisers characteristic of her generation, she would have been ready to consent even without such a careful explanation. But it turned out to be a powerful factor in grounding her expectations as well as recognising her dignity as a person capable of taking her own decisions – an important factor not always well acknowledged in the health service.

There is a huge literature on the subject. Lloyd reviews this well[34] in his article in *Quality in Health Care*, "The extent of patients' understanding of the risk of treatments." In this he quotes research by Gattellari *et al*,[35] who identified an intriguing obstacle to patients' understanding and retention of the risks of their condition.

They found that:

- 80% of cancer patients who had been told by their doctor that there was no chance of a cure reported that there was actually some chance of a cure.
- 15% reported that this chance was at least 75%
- 40% of them did not understand whether the goal of treatment was curative or palliative
- 44% overestimated the probability of treatment prolonging life.

Regression analyses in the study revealed that misunderstanding was predicted by denial rather than poor understanding or communication, with patients actively avoiding information about their disease, thus reducing the emotional impact of such information.

If such barriers to risk perception do indeed exist, unmet expectations of a favourable outcome of treatment will almost inevitably impact seriously on trust in the doctor. If we accept the view of the Institute of Medicine, this might lead us to the conclusion that the movement to achieve transparent accountability may indeed be fraught with difficulty with the danger of perverse results. Equally it might be far more important to achieve and maintain *informed trust* in healthcare than in other contexts.

The burden of accountability

However, if we accept some of O'Neill's arguments, such explicit accountability may not only be more damaging than helpful but, even if marginally helpful, may be unacceptably expensive on the resources of an overstretched service. There is no doubt that the accountability mechanisms and the regulatory organisations that currently exist in the health service, including those of longstanding, those introduced by the White Paper, and those proposed since, constitute a significant burden on the NHS and on individual practitioners.

Tallis[36] describes vividly "at least five different ways in which a consultant is accountable," and more extremely relates a communication from a consultant surgeon, who is also an academic, listing the twenty-two regular reports he is required to make on his practice.

Harrison and Innes, in their concluding chapter of *Rebuilding Trust in Healthcare*[37] draw the distinction between accountability that encourages trust through monitoring and openness, and hyper-accountability that, by distorting the aims of professional practice, may be counter-productive for all concerned. Clearly, an accountability regime that is so onerous that it impedes the proper, indeed essential, professional activities of doctors and nurses, or the efficient running of healthcare institutions cannot be defended. This was a major concern of those responsible for CHI. Indeed, the concern of many of the regulatory organisations themselves over the past few years and has led to attempts, including the concordat negotiated by the Healthcare Commission, to lessen the burden of the production of numerous similar, but not identical, sets of data and an endless uncoordinated round of hospital visits. It is a welcome sign of maturity in the government that the Healthcare Commission was given a mandate to co-ordinate the activities of the various regulators in the health field. It should not be beyond the ingenuity of the Healthcare Commission, together with the professions, to develop at least a menu of datasets, which allow routinely available information to be shared by regulators to meet their various individual responsibilities for accountability. The need for multiple visits, for the purpose among others of reality checks on data, is a more difficult problem to solve. These may indeed be disruptive for management, but the disruption might be balanced by the learning achieved by both the visited professionals and their visitors. The peer-review professionals used by CHI reported that they were able to obtain valuable insights as a result of their involvement in visits, insights that they were able to use to good effect in their own Trust setting.

It had long been my personal theory that a methodology based almost completely on data could meet the requirements of accountability without the need for visits by individual or teams of clinicians to one another's hospitals. However, I now think that I was wrong because it was the experience of CHI that reliance on data alone, without the addition of peer review on the ground, could not reliably identify poor care or, more importantly, the reasons for it and the remedies necessary. In this, I agree with O'Neill that:

> *"Much that has to be accounted for is not easily measured, it cannot be boiled down to a set of stock performance indicators. Those who are called to account should give account of what they have done to and of their successes and failures to others who have sufficient time and experience to assess the evidence and report on it. Real accountability provides substantive and knowledgeable independent judgement of an institution's or professional's work."[38]*

A significant proportion of the serious deficiencies, identified by CHI investigations and clinical governance reviews, related to factors such as poor relationships between members of clinical teams, or between clinicians and managers. These matters are all too easily brushed under a carpet of apparently

favourable statistical reporting based on targets. I now regard judicious use of on-the-ground inspection by peers, and even devices such as mystery shoppers, as essential to uncover problems, intrusive and expensive though they may be felt to be.

Tallis, in a characteristically sweeping assertion, alleged that CHI:

> *"Visited a large number of hospitals taking up time, disrupting management, prompting switches of priorities, and bringing considerable opprobrium on some hospitals,"* with *"no evidence that it has produced any benefit."*

He chose to ignore the many testimonials from healthcare staff, including doctors, that CHI was the agent that, more than any other, stimulated adoption of well-established improvements in patient care in some hospitals. This was also the view of the experienced researcher Sheila Leatherman,[39] and the National Audit Office – a body not normally easily persuaded to approval – also fully supported this verdict.[40]

Medical regulation after Shipman

One inevitable consequence of the knock that the several medical scandals of the late 1990s gave to patient trust in doctors was a call for something to be done to ensure that doctors were both competent and beneficent in their relationship with patients. The report of the Shipman Inquiry,[41] while acknowledging that the regulatory machinery operated by the GMC could not have identified a multiple murderer of his cunning, still found that the GMC "Had not always safeguarded patients as it should have done," and that "there had not yet been the change of culture within the GMC that will ensure that patient protection is given the priority that it deserves."

Dame Janet Smith, who chaired the inquiry, foresaw that clinical governance would:

> *"In time provide a comprehensive framework for the detection of poor or aberrant practice, as well as the improvement of clinical practice generally."*

However, she concluded that it was not yet sufficiently well, or universally, developed to be sufficient for the purpose and that:

> *"Revalidation could make a major contribution to the identification of incompetent and poorly performing doctors and thus to patient safety … Present proposals for revalidation of GPs do not provide an evaluation of every doctor's fitness to practise."*

The message of the Shipman Inquiry could be summarised as that trust in doctors must be supported by effective regulation, transparently undertaken by a body that can be seen clearly to be independent of the interests of the profession, to have as its priority the safeguarding of patients. In short, a body to which doctors are accountable and which is itself accountable to the public.

This confirms vividly the view that trust is enhanced rather than undermined by accountability, an accountability that has in this instance been recognised in the review undertaken by England's Chief Medical Officer Sir Liam Donaldson, to require more rigour and more transparency of medical regulation.

His report *Good Doctors, Safer Patients*[42] recommended changes to almost every aspect of the working of the GMC. It is significant that many of these recommendations, including abolition of the medical majority on the council, were welcomed by the council itself albeit with some modifications outlined in their counter-proposals. Recommended changes to the council's role in medical education for the transfer of its power of adjudication to a separate tribunal, however, were not supported by the council. The BMA was predictably more hostile, in particular to the proposal to replace the current criminal level of proof of beyond reasonable doubt with the civil level of on the balance of probability. However, the response of the profession to the review did seem to indicate its recognition that, in the 21st century, the standing of the profession is not a matter that can be allowed to decline through a failure to adopt "medical regulation that puts patient safety first, is fair to doctors and is practicable and affordable."[43]

> *"Public and professional opinion has moved from a position in which trust alone was sufficient guarantee of fitness to practice, to one where that trust needs to be underpinned by objective assurance."*

This direct quotation is from the White Paper, interestingly entitled *Trust, Assurance and Safety*, published in early 2007, that constitutes the government's long awaited response to the Shipman Enquiry and the CMO's report. It echoes much of the argument developed in this section of the monograph.

The White Paper adopts many, though not all, of the recommendations of both the Smith and Donaldson reports. Radical changes to the role of the GMC, especially that which removes its adjudication function, are aimed at demonstrating greater transparency and assured independence of vested medical interests together with public accountability of the regulator through reporting direct to Parliament. The decision to adopt the controversial change to the sliding civil level of proof indicates a determination to ensure that the adjudicators are not hampered by legal technicalities in reaching an appropriate judgement. Both the change in the balance of membership of the GMC with the appointment of its membership replacing an elected element and the establishment of a new adjudicating body, also with appointed membership are aimed at enhancing the trust of patients and the public in the integrity and absence of bias in the system.

The publication makes clear that much of the detail of the new arrangements is still to be worked out but perhaps the most striking feature of the White Paper is that, far from making doctors a special case it places medical regulation firmly

in the context of regulation of the healthcare professions as a whole, recognising explicitly that healthcare in the 21st century is dependent on multi-professional teams and that to assure the public that their care will be safe and of high quality it is necessary to ensure proportionate regulation of all the professions involved. And it recognises that professional regulation is one element within a system of assurance that also includes both clinical audit and clinical governance.

Conclusions

The relationship between trust and accountability, as two necessary and desirable principles in healthcare, remains a controversy over which two opposing sets of philosophies seem destined to continue to fight for the moral high ground, and thus the support of government, the professions, and the public.

On the one hand there are those, often but not exclusively, older doctors, implacably wedded to the world as it was when they first qualified, and opposed to any further developments in what they see as the destruction of professional autonomy. They predict a future in which managers, if not politicians, will take all the important decisions about patient care, and the medical profession will be reduced to an army of box-ticking automatons carrying out their orders.

On the other side are the arch accountability freaks in politics, the media and, sad to say, some academic departments of health policy, as well as some patient organisations, who because of concern about demonstrating value for money, bad personal experiences at the hands of doctors or the NHS, or envy of what they perceive as the unwarranted status and power of the medical profession, wish to curtail what they see as its ability to bury its mistakes.

Radical fundamentalists are never the best of guides to the making of public policy. The answer must lie in moderation, in idealism mediated by rationality. In today's world, no professional group can avoid being accountable to those it serves. Furthermore, in a healthcare system such as the UK's, where the vast majority of care is funded and the salaries of the staff are paid out of general taxation, the public, as represented primarily by parliament, has a right to expect transparency and accountability at an appropriate level of detail. As one commentator observes:[44]

> *"Public trust acts as a backdrop against which the more clear cut features of accountability arrangements are displayed. It tends only to become an explicit consideration when concerns are raised that it is being abused or when attempts are made to construct stable and fruitful relationships in its absence. Because trust is such a pervasive and largely unconsidered feature, a certain carelessness with its sustenance is to be expected. This would be a mistake. The extent of public trust may, for example, define which policies on organisational accountability and control are politically and practically sustainable. We need a much clearer idea of whether and how too much trust shields the incompetent."*

And O'Neill in her third Reith lecture,[45] dealing explicitly with accountability in the health service pleaded for "intelligent accountability" to avoid damaging professional performance. She maintained that this requires more attention to good governance and less to fantasies about total control.

There are signs that the medical profession is coming to terms with accountability requirements where they can be made less burdensome by the use of information technology to capture the evidence necessary, albeit partly in response to the carrot of extra earnings as a reward for compliance. The Quality of Outcomes Framework (QOF) for family doctors requires highly detailed accounting, through electronic data collection, of the way in which doctors and practices have organised and delivered care to their patients. Some GPs have expressed fears that this is leading to a "tick box" approach to the patient consultation. A BMA press release on 26th September 2006 marking the publication of the second year of results of this scheme in England, which offers practices up to 1050 remunerable points if they deliver on a range of services, however disagreed. The chairman of the BMA's general practitioners committee claimed:

> *"This is great news for patients…[it] means that more patients than ever before are being diagnosed promptly and getting the treatment they need."*

Reporting that, although participation in the scheme is voluntary, the overwhelming majority of practices do take part, he said:

> *"The UK leads the world in having a national system which encourages and rewards general practice teams for providing top quality care, looking after patients in ways that reflect the best medical evidence of what actually works."*

As yet, no research has shown whether the QOF has resulted in greater public trust, let alone greater individual confidence and satisfaction with the family doctor service, or even whether the general public is aware if it. These will be interesting questions for researchers, in respect of which, I have no doubt applications for funding are already in the pipeline. However, it does point to the way in which, if appropriately involved in their design and appropriately remunerated for the burden of their implementation, accountability regimes that are quite powerful in their potential impact can be devised to the satisfaction of accountants and account holders in healthcare.

As O'Neill wisely observes in her final Reith lecture: "A crisis of trust cannot be overcome by a blind rush to place more trust." It is here that Tallis' concept of increasing the visibility of medicine is proper and germane. As the old English proverb has it: "It is an equal failing to trust everybody and to trust nobody."

Intelligent accountability is necessary, but it is not sufficient to ensure the development of "informed trust." Such trust must be based on the availability to the public, and the individual patient, of information that is comprehensive,

accurate, and timely. Informed trust requires information that has been competently and independently produced as a result of the collection of data integrated with and based on routine clinical activity, and that is presented in an accessible and understandable format.

Truly informed trust could be built on such hard evidence. But there is one important proviso. It requires intelligent effort on the part of the public, no less than that of the service and its staff: effort to access the evidence, effort to understand it, and effort to apply it in the face of pre-conceptions, wishes, anxieties, or fears. An emotional element, especially in trust in an individual, may exist alongside the rational. And this is probably an important element in the relationship between patients and their carers. However, if this were allied with the provision of the evidence derived from intelligent accountability, and a will on the part of patients to access and understand such evidence, the imbalance between emotional and rational trust could be remedied. Informed trust could become the norm and the apparent paradox between trust and accountability in healthcare would become a false one.

To what extent then will the technological developments of the post-modern world contribute to the achievement of informed trust supported by intelligent accountability?

CONFIDENTIALITY AND THE USE OF INFORMATION

"Whoever deliberately attempts to ensure confidentiality with another person is usually in doubt as to whether he inspires that person's confidence in him. One who is sure that he inspires confidence attaches little importance in confidentiality"

<div align="right">Friedrich Nietzsche</div>

"As a rule he or she who has the most information will have the greatest success in life"

<div align="right">Benjamin Disraeli</div>

If modern healthcare is indeed to be based on informed, rather than blind, trust between patients, their doctors, and the healthcare services generally, and if that trust is to be based, at least in some part, on intelligent accountability, the success of this relationship will depend on the availability of accurate, complete, and up-to-date information. Indeed, informed trust based on intelligent accountability is not possible without such information. While others have used the term intelligent information, I would prefer to describe what is needed as *intelligent use* of information.

But the role of information in healthcare services, though vital to accountability, is very much wider. At the most basic level, patients cannot access services without the information necessary to do so. Doctors and other healthcare professionals cannot diagnose and treat patients without easy and, in an emergency, fast access to information about patients and the diagnostic and therapeutic measures best suited to treat them. It would seem, therefore, a self-evident truth that the availability of the most complete up-to-date information and the most full, rapid, and effective communication of this information, are important principles for healthcare. The functioning of the NHS, as a first class service, has been handicapped by inadequate information systems.[46]

So information is required:

- by patients and the public to enable them to play an appropriate part in the decisions that they have to make in accessing care and in understanding and agreeing to individual clinical options for their treatment
- by individual practitioners to enable them to practice effectively and safely,
- to assess the health needs of the population
- to plan and manage the healthcare system effectively and efficiently
- to allow research into the causes of diseases and the development of effective means to prevent and treat them.

In order to achieve intelligent use, suitably collected and analysed information has to be accessible to or communicated to those who need to use it in a form and at a time that will allow, encourage, and maximise its use.

The confidentiality paradox

Much of the information required to inform the requirements of healthcare professions, patients, and the public can be derived only from the records of individual patients and groups of patients. However, the principle of observing the strictest confidentiality in the use of personal health information is also important in healthcare. This principle has been observed since the time of Hippocrates and, moreover, it is one that is enshrined in law and protected by professional regulation.

So within any system of collection of the data necessary to ensure intelligent use of information, in the analysis of that data, and in its storage and access – even by those who have a legitimate use for it – privacy and confidentiality must be safeguarded as rigorously as in face-to-face patient to practitioner interactions.

This simultaneous adherence to the principles of the fullest possible use of information on the one hand, and rigorous confidentiality on the other, poses a paradox, especially for the modern healthcare service in which the possibilities of fast and wide dispersal of information are greater than ever before.

As commentators too numerous to reference have pointed out, the information technology revolution of the past decade has provided the means to allow, as never before, the effective provision of health information to patients and the public; the exchange of information about patients within and between the caring professions; and the use of patient-derived information in planning and managing services, in protecting public health, and in research. Simultaneously, it has fuelled a debate on the ethical issues involved in retaining the confidentiality of personal information, especially that which individual patients do not want shared beyond their immediate principal health adviser, commonly their general practitioner.

Public expectations following the IT revolution

These are tensions that have emerged within the context of a paradigm shift[47] that has occurred as the internet has contributed, along with other social developments, to a fundamental change in the relationship between providers and consumers of healthcare.

What Tony Blair has called the Google generation will increasingly expect to be able to access the information about its health or ill health, and about the services available to protect and treat it, in terms of both location and quality. However, it is likely that the Google generation will also expect the healthcare system to store and utilise data derived from its records to manage both the individual clinical and wider administrative aspects of its care, in the same way that banks and airlines currently operate their services. Indeed, many patients are under the illusion that this is already the case.

The US Institute of Medicine[48] identified the potential of IT solutions to improve the quality of care for patients through:

- Ensuring safety
- Improving effectiveness
- Making care more patient-centred
- Increasing timeliness
- Improving efficiency
- And enhancing equity.

However, the road to realising that potential is a long and difficult one. Morris Collen,[49] writing on the history of medical informatics in the United States, described the development of a comprehensive medical information system as a more complex task than putting a man on the moon. One aspect of that complexity was acknowledged by the IOM to be the need to capture patient-specific clinical information through an automated medical record against the challenge of concerns about privacy and confidentiality that this entailed.

These concerns are currently one of the fiercest areas of contention within the healthcare system in the UK, and the paradox apparent in the desire of both patients and professionals for full and effective use of information, to improve both service and individual care with the simultaneous determination to safeguard confidentiality, has been highlighted as never before.

Connecting for Health

The battleground in England is *Connecting for Health*, the initiative that is the world's largest information technology programme. It is designed to provide, through the National Programme for Information Technology (NPFiT), a comprehensive health records system, which is based on an individual Electronic Health Record (EHR). Data are captured at the point of care, stored in summarised form on a central electronic spine, and available to authorised users, while safeguarding confidentiality by a series of security measures that allow information to be accessed in identifiable, completely anonymous, or reversibly anonymous (pseudonymised) form, as appropriate.

It was inevitable that such a major programme would encounter difficulties along the road of its implementation. All similar large scale IT programmes have done so, and few have covered such sensitive ground or had such huge potential for changing the way in which the users of the system would have to work. This programme demonstrates well the claim by one international medical informatics expert[50] that:

> *"Getting such technologies to work in practice appears to be a politically textured process of organisational change in which users have to be put center stage."*

It is clear that at the start such advice was not followed by those who initially worked on its implementation. The medical press is full of complaints by doctors that they were ignored in the early stages of development of the software to support the programme, and that their concerns have not yet been fully met. And, despite the endeavours of the Care Records Development Board (CRDB) and its ethics advisory group, both professional and public anxieties about the way in which personal records will be uploaded on to the central spine and the mechanisms to ensure confidentiality, continue to be expressed.

The government established those bodies with professional and lay representation to progress the clinical records service and to ensure, among other

objectives, that the programme retains, and even enhances, the security of personal data. To this end, a detailed commitment, called the Care Records Guarantee (CRG)[51] was produced, covering 12 points of concern. Despite these efforts, the programme is seen by some within the healthcare professions, notably doctors, but also by journalists and some representatives of patients and the public, especially those with sensitive conditions, as recklessly and irretrievably endangering the confidentiality of personal health information. A view most widely articulated by some general practitioners, and taken up as a crusade by a national newspaper.[52]

This, together with scepticism based on the failure of so many large-scale computerisation projects, within and outside the healthcare field both nationally and internationally, understandably colours the opinion of many of those involved as subjects or as users of the new system.

Confidentiality and the electronic health record

It may be, however, that the apparent commonality of concern of sections of the public, patients, and the medical profession about the dangers to confidentiality posed by IT is based on rather differing perceptions and perspectives, on incomplete understanding, or even on differing interests.

To illustrate this most starkly, the belief of some doctors that confidentiality is safe in our hands and only in our hands is not entirely shared by some patients. In a discussion about possible dangers to confidentiality in the context of the electronic patient record, a mental health user described the current confidentiality of paper records to me as:

> *"There is no real confidentiality now. Nobody trusts the system. Information is left lying around. There is loose talk in coffee shops etc. That's how people feel now. It is better not to use the term confidentiality."*

This opinion is given more colour in a striking account[53] by a doctor and patient of her experience of confidentiality on a gynaecology ward of a London hospital:

> *"It was impossible to avoid overhearing bedside consultations and inter-professional discussions at the nursing station... The curtains seemed to provide some false sense of confidentiality. The nurses' handover also rang out around the ward: an audible summary of every patient, updated daily. I then realised that everyone must have heard all about me."*

I still recall a heated discussion in the GMC some years ago on the subject of the access by health authorities to operating lists for administrative purposes, in which one of the lay members of the council expressed greater concern that information on their care was easily accessible by the GP's receptionist – who they might have to meet frequently in future, who might indeed be a close

neighbour – than that it might be accessed by members of the staff of a remote health authority, who merely abstracted some of the details and who were unlikely to know them and they would never meet face to face.

Indeed, the view has been expressed[54] by the chief executive of the Terence Higgins Trust, an organisation with more reason for concern than many others, that the proposed electronic record system provides a greater degree of security than the current paper-based one since it will be possible to identify all those accessing an individual record, the time of access, their status, and to pursue and discipline any inappropriate access.

The possibilities for unorthodox, indeed unlawful, storage of the existing paper-based patient records and their vulnerability to alteration is also a problem, as was revealed by the finding of multiple records packed in old cereal boxes in the garage of Dr Shipman in the course of the inquiry into the mass murder of numbers of his patients, to the consternation of relatives of his victims. That inquiry also demonstrated that it was possible to detect alterations and falsifications in computerised records in a way that is often difficult or impossible when paper records are altered.

However, there is no doubt that public anxiety about the misuse of personal details about individuals derived from computerised databases has increased in proportion to the amount of such information held on innumerable such databases. The extent to which personal information is being traded unlawfully is described in the publication, *What Price Privacy?*,[55] issued by the information commissioner's office. Richard Thomas describes the buyers of such information, including journalists, and cites one investigation that uncovered evidence of information records supplied to 305 named journalists working for a range of newspapers. He notes that: "Journalists have a voracious demand for personal information."

It is interesting, then, that it was *Guardian* newspaper journalists who headlined: "Warning over the privacy of 50m patient files." On 1st November 2006, they reported a "call for boycott of medical database accessible by up to 250,000 NHS staff." The article[56] describes the fierce opposition of civil liberties critics to what they sensationally labelled data rape, together with the more reasonable concern of the BMA about the need for explicit consent before records are transferred to the central database and its worry that the scheme is going ahead in the face of problems with the vital software that could ensure high levels of security.

The spread of articles on the subject in that edition of the paper included the provision of a cut-out letter for those concerned to send to the secretary of state for health, requiring no processing of the sender's sensitive personal data to the central spine, giving 10 different reasons, some difficult to deny but others unsubstantiated.

Opt in versus opt out

Against a background of broad consensus on the benefits of a national, electronic, care records service the arguments are focused on the question of consent from each individual to the automatic uploading of their personal details, both demographic and clinical. It is clear that seeking individual explicit consent from every man, woman, and child registered for healthcare with the NHS would be a massive, impractical task. The alternative to such an opt-in approach is one that uses consent implied by the fact of registration, together with provision for those who object to the use of their record in this way to voice that objection and to opt-out. The arguments for expediting the availability of the system: reducing potential workload on GPs, cutting bureaucracy, and greater utility of a total population database for purposes, such as service planning and management, public heath information and protection, and medical research, have been well aired in editorials and correspondence columns of both the professional and the lay press.

These arguments are however not assisted by a serious lack of clarity on the legal basis of peoples' rights over their medical records. A statement was made at a recent conference[57] that: "The NHS is not a set of personal private contracts." Some respected academics, however, believe that patients do have legal rights over their medical records. It was emphasised at the same conference that while the record itself may be owned by the NHS, the information on it is the property of the patient, and work is currently in hand that will allow any individual with an EHR to access that record online, and to add to or correct information held on it through the *My Health Space* personalised electronic portal. A prospect understandably, but perhaps paternalistically, greeted with some concern by doctors.

Patient representatives at meetings I have attended over the past year have expressed the view that trust in the security of their personal health information, and the retention of confidentiality and thus their acceptance of the new system, will rely heavily on knowing that data are protected by a system:

- that has clear rules and standards
- that has been developed in consultation with representatives of patients and the public
- that is audited and regulated by an independent body
- that carries strong penalties for breaching the rule.

In other words, in this context at least, regulation and accountability are essential to underpin trust. An essential feature of the public engagement campaign envisaged for the early part of 2007 must be a clear factual exposition of the extent to which the new system is able to meet these criteria together with an explanation of the major benefits to both the individual and the community.

Elements in the opposition to the electronic record

It is possible that at least part of the hostility expressed by both doctors and patients to the greater availability and use of information that IT systems will allow is related to the perception that this improved accessibility is designed primarily to enable professionally unpopular government system reforms, such as payment by results and choose and book – initiatives hardly known and much less understood by significant numbers of patients and the public. The EHR might well have had much greater acceptability if it had been established primarily as a freestanding initiative independent of government requirements. Less suspicion would have been engendered if it had been seen as solely aimed at improving patients' understanding of their own health, the services available to them, and assisting healthcare professionals' ability to treat and to advise their patients. As it is, even relatively neutral commentators have identified a perception among NHS staff that will have to use the system that it was a "technologically determined vision foisted on the NHS by outsiders with little understanding of the service, or even of health care in general." [58]

Many of us who have long recognised and espoused the need for better systems of data capture to allow exactly the potential improvements in healthcare that the programme will offer, may wish fervently that the IT revolution, and all that it will allow in this respect, had taken place long before and preferably completely divorced from the current system reform of the NHS.

One interesting alternative reason for medical reluctance to embrace what might seem to be an unequivocally beneficial tool, in the context of the ability to improve the quality of care, is a recognition that doctors will have to radically alter the way in which they record their work. They will require the cognitive ability and skills needed to organise and document clinical facts to a level of detail and accuracy that has hitherto been uncommon.[59] A view most cogently expressed as:

> *"The adoption of an electronic patient record changes the position of the physician from an entrepreneurial gentleman to a methodical member of a team and changes record keeping from a private affair to a matter of co-operation with colleagues. Shifting from paper-based records to electronic record keeping makes work practices (and especially record-creating activities themselves) more visible, more respectable and manageable."*

This, though it may be a steep learning curve for some hospital staff, must surely be less of a challenge for general practitioners who have been widely recognised as the early adopters of IT within the health service. The majority of general practices were computerised in the late 1980s and early 1990s, and in some this included, by the end of the 1990s, the development of electronic patient records. However, it was a GP writing a letter to the *BMJ*,[60] who pointed

out that many clinicians, himself among them, are two-finger typists, and the time correcting the mistakes made by such amateurs will take away precious minutes from patient care. He pleads for the end product of the electronic record programme to be as similar in format to the current paper record as possible, and to include the ability to operate the system without keyboards.

Guidance, issued by the BMA in November 2006, confirms this and warns doctors that:

> *"Navigating and entering details on to a multi-contributory record will present a new challenge for NHS staff and each contributor will have a role in ensuring that their entry is accurate within the content of that record."*

The guidance offers the comforting information that training will be available and required before any staff are allowed access to the new system.

The early general practitioner systems, though well in advance of the ones elsewhere in the NHS, were limited by being idiosyncratic and isolated, unable to communicate with one another, let alone to those of the hospital service. I have vivid memories of a forlorn attempt I made over 30 years ago to persuade all the GPs in one family practitioner committee area to adopt the same software for use on the NHS-funded computers we were providing to practices. Despite having the support of the chairman of the local medical committee, generous financial support for the change, and despite my glowing accounts of the benefits such a move would bring, I was defeated by the wish of individual doctors to determine the choice of their individual software.

Younger members of the profession will probably have no such hang-ups, brought up from schooldays on computer-generated data and skilled from their earliest years in the use of electronic equipment to a degree that astounds and shames their parents and grandparents.

Yet another strand in this antipathy, on the part of the medical profession, may be fear of losing control of patient information, and with that control the power and status that has so long attended their monopoly[61] of personal health data. This is a point that surfaced in the correspondence columns of *The Times* at the end of last year. If this is true, it is likely that any attempt to retain such exclusive rights is doomed to failure.

Information technology and continuity of care

Modern healthcare requires that patients, even in primary care, are treated by clinical teams rather than one individual, and thus information has to be shared for the patient's benefit. In the UK, the alteration in the working patterns of doctors brought about partly by the European Working Time Directive, and by the renegotiation by the profession of its terms and conditions of service – notably the withdrawal of GPs from out-of-hours cover – has made the availability of

patient notes to those who provide alternative cover the only way in which continuity of care, a principle itself long espoused as essential in discussions about the gatekeeper and family physician roles of GPs, can be assured.

Whatever the concerns – and some are legitimate and appropriate – about the security of the electronic health record and its use within the teams of professionals involved in an episode or series of episodes of individual patient care, it is increasingly accepted that the present record systems fail to meet the primary purpose of documenting details of history and care that will be of use in the immediate or long-term future.

> *"The current concept of the patient record as a provider, speciality – and episode-based journal is (also) flawed preventing the easy generation of a clear longitudinal picture of patients' illness or health"*[62]

This is a description given greater colour by evidence from clinicians themselves as, for example, the prize letter published in *BMA News* on 29 July 2006[63] entitled "Midnight ride of patient's notes: For the record, let's improve this mess", in which a junior doctor questions the complacency with which the delay in obtaining old notes of patients admitted as emergencies seem to be viewed in UK hospitals.

He says:

> *"In this age where documentation is so important and litigation increasingly common, it seems unbelievable that it is still acceptable to make daily management plans without complete medical records. Perhaps with computerised record keeping things will change…"*

And in a personal view article[64] entitled, "That's all I got handed over", in the *British Medical Journal* of 25th February 2006, describing the serious limitations of the current methods of handover between hospital doctors working on full or partial shift patterns, an orthopaedic senior house officer identifies the deficiencies in information that could quite clearly be met in future by the EHR. Indeed, the further potential of the electronic record to act as the organiser of the whole of a patient's pathway of care and of the activities of the individuals who make up the clinical team and the wider clinical network in delivering seamless, rapid, high-quality care to patients has also been recognised.[65]

The recognition that continuity of care now must rely on arrangements beyond those of personal contact in hospital as well as in primary care is a concept that has received attention in other countries than the UK. Krogstad *et al* writing from Norway[66] on continuity of care in hospital settings refer to the fact that "hospital care is an organised, multi-disciplinary, and interpersonal service." In developing their arguments about how continuity can be provided they differentiate:

> *"Front stage continuity – in which the patient sees the same doctor or nurse day after day, a popular but unachievable pattern – (differs) from "backstage" continuity which is part of the organisational system and which relies heavily on accurate and accessible information to ensure that all staff members know the plans for a patient's stay, the patient is not asked to repeat information to different staff members, observations made by someone the previous day are followed up and the information received by and from staff members is consistent."*

A picture that would seem an unrealisable dream to many patients and staff in the current state of medical records in the UK, but could be readily achievable with electronic patient records combined with access from hand held devices. And it is likely that both the professions and the public will, if they have not already done so, soon come to recognise that this is the only way in which continuity can be achieved in the modern health service.

Special cases

The concern of patients is that of improper disclosure from inadequate security. This concern is not surprising since as we have seen already some of these patients have experienced sloppy security for their existing paper-based information. Moreover, it is not surprising that the knowledge that databases of banks, commercial companies, and even the Pentagon, have been broken into by hackers engenders anxiety in people whose health status could compromise their chances of employment, securing a mortgage, or life insurance.

There must be concern that the combination of professional and patient unease about the project could lead to patients not being open with their doctors, thus jeopardising their care. Or alternatively, doctors might omit important facts from the patient record, thus creating a situation in which information vital to care is lost to other members of the clinical team and to future, possibly emergency, health needs of the patient. The plans for allowing the most sensitive information to be kept in a sealed envelope within the overall record, an envelope that can be opened only with the current and express permission of the subject of the record, is an attempt to deal with these fears. However, the current state of development of this system is incomplete and fraught with problems, including discussion of whether an equivalent sealed envelope might contain information that the professional wished for legitimate reasons to keep from access by the record subject.

Secondary uses of the electronic patient record

While many, probably a majority, of doctors welcome the improvements that the EHR offers in the immediate clinical care of the individual, there is more controversy over the use of even anonymous or encrypted data in the

management of the health service itself or in research outside the control of the medical profession. In the case of the first of these, there is some recognition that, in a system in which the financing of healthcare is met from general taxation, both the most effective distribution and proper accountability of funds can be served by the use of data generated initially by the EHR. Indeed, if patient records were to play no part in determining the flow of money throughout the service the funding streams would quickly dry up. And as previously noted, many patients believe that such uses of information derived from collective datasets are already used for this purpose. This perception is heightened by the increasing knowledge that use of data is routine in other walks of life.

Much of the current controversy arises from two extensions of the use of information derived ultimately from patient records, neither of which is entirely new but both of which will be greatly assisted and expedited by the use of EHRs. These are the sharing of individual identifiable records beyond the NHS itself to other public services, mainly the social services. And the access to data derived from records by management, including the department of health, to govern the NHS, by epidemiologists and public health practitioners to protect and promote public health, and by academics and others for medical and health services research. All these would be greatly facilitated by the provision of a proposed Secondary Uses Service (SUS).

The unease of doctors with the suggestion that information about an individual could be shared as a matter of routine with staff of social services, is understandable since they need evidence that social work professionals have the same absolute adherence to the standards of confidentiality espoused by the medical and other healthcare professions. However, the need to share some information to enable appropriate social care to be provided to, for example, a frail elderly individual or handicapped patient could hardly be contested, though it must always rest on the informed consent of the patient.

Far more controversial, though increasingly highlighted by tragedies, is the need for information to be shared appropriately and effectively in circumstances where a patient poses a risk to themselves or to others. Repeated cases of fatal child abuse from Maria Colwell[67] to Victoria Climbié[68] have generated reports that exposed the failure of the health and other public services to communicate effectively in cases where the result was a tragedy for both victims and perpetrators. I was depressed to have to record in my introduction to the CHI report on the Climbié case that more progress had not been made in this respect since I chaired, in the wake of the 1974 Maria Colwell Report, the first cross-agency group in Wales to establish a protocol of communication and action to be taken in cases of suspected child abuse.

More recently, several cases of homicide, for example the murder of Lin and Megan Russell by Michael Stone, have also generated criticism of the extent to

which the well documented mental illness of individual patients in the care of the health service, with symptoms that indicated a serious risk of harm to others, were not communicated to agencies that had responsibilities to ensure their protection and that of the public.[69] The potential for an electronic patient record to allow improved prevention of such cases is an important benefit to be weighed in the balance against the serious possibility that there could be inappropriate leakage of such information or its misuse.

Perhaps easier to contemplate is the sharing of data and information with academics and others involved in clinical or epidemiological research. Easier for the medical profession, at least, since doctors both understand the methodologies used in such research and the benefits it can bring. They also have more confidence in the professional values of researchers, though this is sometimes moderated in the case of Big Pharma researchers, no doubt influenced to some extent by fictional accounts such as John LeCarré's book, *The Constant Gardener.*

The Academy of Medical Sciences[70] has been active in presenting the benefits that result from the secondary use of medical records, the problems that currently arise when confidentiality or privacy protection is overly restrictive, and the enormous improvement in terms of time and money required to undertake research that enables advances in knowledge that is potentially available from a fully populated central database. Their enthusiasm is understandable and laudable, but could be seen as special pleading for privileged access that may not meet the strictest interpretation of the confidentiality principle or the Data Protection Act.

Here again it is likely that the full support of the public will be forthcoming only if the system of information governance and regulation that controls such access is transparent, independent, audited, and accountable.

Conclusions

The tension between the use of information derived from patients' records and the necessity to maintain confidentiality may not be a new paradox for the healthcare services. It has been thrown into greater relief by the potential of computerisation and the National Programme for Information Technologoy initiative of the Department of Health. And, almost as starkly by the realisation that the way in which healthcare is delivered has moved increasingly away from individual patient/professional interactions, to complex care given by a range of different disciplines and professions, all contributing from their specialised skills and knowledge. Thus confidentiality, and the means to ensure it, in the face of the necessity to communicate information in order to provide proper patient care, must evolve using the technology now available.

The exploration of the issues that these developments have required; the discussion of the impact they will have on the care of patients; the availability of information to the public; the knowledge of health needs of the population; the planning and management of services; and the expediting of research, all within a recognition of the ethical principle of maintaining confidentiality, amply demonstrate the complexity of the paradox.

However, these discussions have also provided the opportunity to review the extent to which the health service currently protects privacy and confidentiality; the difficulties experienced by NHS staff in maintaining, storing and accessing patient records, and the potential offered by an electronic record, suitably safeguarded, to overcome barriers to effective care of individual patients, benefit planning and management of the NHS, including achieving both greater equity and greater efficiency, and to promote public health and advance medical research.

Furthermore, information sharing is a powerful tool that both clinicians and patients have only begun to use effectively. It is a tool that can empower patients allowing them to take part in decisions that affect their health and healthcare, and it drives the doctor-patient relationship away from paternalism towards a more equal partnership.[71] I would add only that this equal partnership, engendered by appropriate information sharing, must also extend to the other members of the healthcare team. The *Health Service Journal* reports that Dr Gillian Braunald, one of the two clinical leads appointed by the NPfIT, has compared the opposition to the development of a national electronic records system to that which attended another innovation, the introduction of the stethoscope in 1834. The *London Times* then commented:

> *"That it will ever come into general use, notwithstanding its value, is extremely doubtful because its beneficial application requires much time and gives a good bit of trouble, both to the patient and the practitioner because its hue and character are foreign and opposed to all our habits and associations."*

However in this modern world it must surely be recognised that "the ability to integrate data from different sources resulting in the richest source of data anywhere in the world"[72] is a prize that makes finding a way forward an essential responsibility for the professions, the government and the public.

This paradox is real, and to some extent the solution to it is still work in progress. It requires a new vision of how to balance confidentiality and use of information, and thus to ensure that in an era of team-delivered care essential information is available for the benefit of patients.

LEADERSHIP & TEAM-WORKING

"When the best leaders' work is done the people say 'we did it ourselves'"

<div align="right">Lao Tzu</div>

"Teamwork divides the task and doubles the success"

<div align="right">Anon</div>

In the same way that the chapter on trust and accountability led appropriately into a discussion of the confidentiality and information use paradox, the discussion of the reason that new clinical information systems are needed leads equally well into the third paradox that I identified: that represented by the tension between the requirement to achieve truly effective team-working, that maximises the contribution of a range of different individual professions in the care of patients, and the recognition that strong committed leadership in both the clinical and management aspects of this care is still – and possibly more than ever – necessary. As Jenny Simpson, chief executive of the British Association of Medical Managers, says: "The national rhetoric is clearly focused on clinical leadership."[73] The dilemma inherent in meeting expectations in what appear to be two conflicting roles is experienced by all of the main professional groups within the service but perhaps most acutely by doctors. And it is to their problem that most of these observations are addressed.

Medical leadership

Traditional medical education, of the pattern experienced by the majority of doctors now in practice, was based implicitly, and often explicitly, on a concept of the primacy of the medical role in the diagnostic and decision-making aspects of patient care. It recognised alongside this primacy, the role of the nursing profession in the provision of daily care and comfort of patients, and the leadership of senior nurses in ensuring that this care and comfort was of the highest possible standard. Indeed, for many of us, our training left us in no doubt that it was the ward sisters who made and enforced the rules about such matters as the timing of ward rounds, access to the wards and behaviour on them. For the most part, certainly in my training years, the other healthcare professions were seen as and labelled "professions supplementary to medicine," a title that denoted their subsidiary role, and managers, represented at that time by the remote and scarcely glimpsed figure of the hospital secretary, were not even part of the picture.

The example set by our seniors, though rarely as blatant as that portrayed by the figure of Sir Lancelot Spratt in the *Doctor in the House* films, gave the impression to generations of doctors that they were being trained to be the leaders of the service. An impression reinforced by the experience of junior hospital posts, with their incessant requirement for the doctor to be bleeped to the ward when even minor decisions were to be made on varying patients' treatment, and certainly when a patient's condition worsened. The terrifying sense of responsibility, for the lives of up to a hundred very sick patients, that was the commonly felt emotion of most newly appointed pre-registration house officers has stayed with me to this day. It was a common reaction, thereafter, for young doctors to cover their perceived inadequacy with a veneer of competence

and capacity that would allow them to assume a mantle of leadership, particularly in crisis situations, and for this to grow with years in practice into an assumption that they were the most important arbiters of all that went on in both the clinical and management aspects of hospital and primary care.

These experiences inevitably produced and reinforced the sense of elitism and tribalism that some have detected as the predominant culture of doctors. Sir Bruce Keogh,[74] speaking at a conference of the New Health Network with the title, "The shape of things to come," and discussing the role of clinicians in creating a patient-led NHS, recognised the tribal nature of clinicians saying that their first loyalty is to the profession, their second to their specialty, their third to their own hospital department and only their final loyalty, if it exists, to their Trust and the NHS as a whole.

As Olsen and Neale wrote in a *British Medical Journal* editorial:[75]

"Traditionally junior doctors absorb hierarchical leadership skills "by osmosis" from their chiefs, a model that is no longer appropriate for the effective working of multidisciplinary teams."

A point they note that is reinforced by the evidence of the National Confidential Enquiry into Patient Outcome and Death, that both leadership and team-working among consultants was deficient.

The impact of general management

This assumption of a professional right to the leadership role of the healthcare service received a setback in at least one aspect for many senior doctors, in the early 1980s, with the introduction of general management in hospitals following the Griffiths Report,[76] although Griffiths himself was convinced that:

"The nearer the management processes get to the patient the more important it is for doctors to be seen as the natural managers."

And, although he encouraged greater involvement of clinicians in resource management, the report also quite clearly removed them, at least in the higher levels of management of the NHS, from a position of primacy. A demotion arguably further confirmed by the 1997 White Paper[77] and the consequent legislation that made chief executives of NHS Trusts accountable for the first time not only for the financial management but also the clinical performance of their hospitals.

So the previously inculcated sense of a right of leadership by the medical profession seemed no longer to have any relevance in the organisation of modern healthcare. Finance directors, directors of nursing, ward managers, business managers, practice managers, and others might legitimately claim to lead on developments and decisions within their field of competence but also in a more general sense, making decisions that directly affected the way in which clinicians

worked. And, indeed, I have experienced attempts by some of these players, often finance directors, to lead in areas in which extensive medical knowledge was required.

The emphasis on the portrayal of managers as leaders and what came to be called the cult of the chief executive led inexorably to the identification of the leadership role with that of management. This has had two consequences. On the one hand, it allows those clinicians who have neither the appetite nor the talent for leadership to abdicate the responsibility for a difficult and time-consuming duty. On the other hand, it places serious obstacles in the way of genuinely interested and motivated doctors who understand the importance of clinical contribution to leadership – as distinct from management – of the complex organisation that is modern healthcare. Many of these, understanding the need to retain a seat at the table of management in order to have their leadership recognised, became medical or clinical directors. But their qualities were not always accepted or valued by management. I recall well a committed and talented medical director of a major NHS trust, one who had been appointed in the wake of a major upheaval in its management following a loss of confidence by the consultant medical staff, complaining to me that all the important discussions and decisions "still pass my door on the way to the offices of the finance director and the chief executive." The exercise of leadership requires at least involvement in the current problems of an organisation, as well as an input to the solutions, if it is to be exercised effectively.

Like many medical and clinical directors, this doctor had been appointed under terms that gave him totally insufficient time to make a proper contribution to such decision-making, let alone to act in a leadership role within the overall management of the Trust. In this practice, I detected an unspoken collusion between chief executives jealous of their own primacy, and doctors fearful of losing credibility with clinical colleagues – or in some cases their time for private practice – if they gave up more than the occasional session of clinical practice. This led to such clear absurdities as the medical director of a major acute trust being allocated a single session a week to undertake his/her management role. There was, then, little incentive for clinicians to attempt to lead, when their contribution was likely to be neither recognised nor welcomed by their medical or management colleagues.

The response of the profession to the conflation of leadership with management seems to have been to interpret leadership as a purely intra-professional concept. And even further, for a majority of the profession, to see it in almost exclusively trade-union terms, with the most commonly acknowledged leaders of the profession being the leaders of the council, the craft committees, and the negotiators of the BMA. Many of these doctors have indeed displayed significant leadership appetite and qualities but usually exercised them

over a narrower field than that of the health service as a whole. Notable individual examples of leadership have also been demonstrated by recent presidents of the GMC in seeking to identify and act on the need for reform of medical regulation, though these have too often resulted in opprobrium rather than recognition by their colleagues. Indeed, the medical profession has, to my mind, displayed a suspicion of attempts to aspire to its leadership, even by its own members, that has amounted at times to clear hostility and has led me on at least one occasion to make public my feeling that doctors don't do leadership, though it may be more accurate to say that doctors don't do followership. It was certainly the case that when at one point, during my tenure as chief medical officer at the Welsh Office, the four chief medical officers of the UK discussed who we would see as the overall leader of the profession nationally, we were unable to confidently identify an individual who would be recognised as such by a majority of our clinical colleagues.

Donald Irvine[78] describes leadership in the medical profession as having been essentially reactive and badly coordinated, and notes that as in all walks of life it is a critical ingredient in managing change successfully. However, he singles out two groups of doctors as displaying such leadership: clinical teachers over many years and the members of the Academy of Royal Medical Colleges more recently.

It has to be said in addition, that the confusion of doctors about their responsibility, and capacity, for leadership has not been helped by the ambivalence of health service policy makers, apparent in the progression of descriptions of the hospital service from "consultant-led" through "consultant-based" to "consultant-delivered."[79]

The reluctance of many doctors to assume the responsibility for leadership, both within the profession and in whole of the healthcare field, is one that must be of concern since the potential contribution they make, to the development of sound professional practice and to both policy and practice in organisation and innovation in the health service, is currently significantly less than their abilities and experience should allow.

Team-working

Against this background, the increasing realisation that the complexity of modern clinical care is such that it requires a team approach with contributions from a range of professionals, each having particular training, knowledge, and skills, has presented doctors with a real sensation of paradox. Those who had overcome the difficulty of adopting a leadership role are now expected to share it and become good team players. And by team I mean a group of individuals with differing but complementary skills, who share a common purpose for which they are mutually and collectively accountable.

Some doctors and other health professionals have risen with enthusiasm to the challenge posed by such a definition, but others within the medical profession have found such an egalitarian way of working inimical to the hierarchical and competitive system in which they were trained. With a sense of relief, they have sometimes abdicated leadership, particularly at the level of the organisation and even, in some instances, at the clinical team level. They have withdrawn to a safe distance from the team itself, justify this with the narrowest interpretation of their responsibilities and limiting their role to diagnosing and prescribing.

I have long been a convinced and enthusiastic promoter of the vital importance of team-working in healthcare, and of the benefits to patient care at both the clinical and the organisational level that effective team-working can bring, borne originally out of my own early clinical experience. No doctor who has experienced the frontline of emergency healthcare as a casualty officer in an emergency department could possibly doubt the vital importance of the operation of a competent, integrated, and committed team. A team composed of medical, surgical, nursing, administrative, and portering professions allied to para-medical and technical staff. In this at least the TV medical soaps *Casualty* and *ER* portray a fairly accurate picture, even if their preoccupation with the off-duty relationships of the team members is hopefully far from a general reality.

I was unfortunate in that my experience of general practice pre-dated the advent of the team concept in primary care, because it is here that it has been most widely and enthusiastically developed and practised. However, when I was briefly a GP in the South Wales valleys in the early 1960s, we worked in splendid – and as I now recognise, dangerous – isolation, frequently without even a receptionist, especially at the branch surgery. I once again experienced the value of good team-working in the different, and in some ways even more challenging, setting of clinical public health. Here highly competent health visitors were more than capable of providing insights and answers to assist me in solving the problems of patients. Local authority staff, from teachers to social workers, housing officers, and environmental heath officers, worked with me willingly across agency boundaries to ensure that the needs of both individual patients and groups were met.

Later, my continuing contacts with clinical colleagues, particularly the work I did with paediatricians, psychiatrists, and geriatricians, further confirmed for me the effectiveness and satisfaction to be gained from working with other disciplines across specialty, professional, and agency boundaries. In the hospital sector these were the specialties that had realised the essential value of the team approach and of holistic care of patients.

These experiences ensured that I fully supported the emphasis on the importance of the multi-disciplinary team in the treatment of serious and

complex conditions contained in another report with which I was associated, that of the Expert Advisory Group on Cancer Services,[80] now widely recognised as a turning point in the organisation of cancer services in England and Wales and the fore-runner of the National Service Frameworks.

Teamwork works

Only later did I become aware of the ample research evidence that had begun to accumulate, that teamwork works. In 1999, I was invited to chair a forum established jointly by the Royal Pharmaceutical Society of Great Britain and the BMA to explore the practical aspects of team-working in primary care and to make recommendations on how the primary care team concept could be developed and strengthened by the relevant professional associations. The forum was broadly based with, in addition to the sponsors, representation from the Royal College of Nursing, the Royal College of General Practitioners, the Patients Association, the British Dental Association, the Institute of Healthcare Management, the Association of Directors of Social Services, Association of Community Health Councils, the Doctor Patient Partnership, and the Community Practitioners and Health Visitors Association.

Our report, *Realising Shared Aims in Primary Care*,[81] published in 2000, did not attract great attention even within the organisations that had established the group. Maybe its 11 recommendations (looking back a modest number considering the breadth of the membership of the group) were too challenging, or maybe many of them were already becoming accepted practice, and we were somewhat behind the times. However, the report is still a valuable repository of the evidence for the benefits of teamwork in primary care, benefits that accrue to both the recipients of care and the providers.

- a more responsive and patient-sensitive service
- a more clinically effective and/or cost effective service
- more satisfying roles and career paths for primary healthcare professionals.

We also found clear evidence for advantages of team care over the traditional pattern of individual professional care.

- improved organisation and planning
- avoiding duplication and fragmentation
- developing more comprehensive databases leading to better identification of health problems (and solutions) leading to
- the development of better and more comprehensive healthcare plans.

The report included numerous examples of such benefits resulting from innovative team-working practices across England and Wales, but perhaps the most valuable messages it contained were the definition of team-working that it

adopted; its recognition that the membership of the clinical team was not fixed but was a variable combination of personnel drawn from a wider alliance of professionals; tailored to the needs of the individual patient; and that the patient was always a vital and essential full member of the team.

Team-working, good and bad

Why then has the development of team-working been so slow and so patchy? And why is it not embraced with more enthusiasm by doctors? This is the more disappointing in that efforts are now being made within the educational setting to inculcate team-working behaviours by introducing an element of inter-disciplinary education in the curricula of the medical and other professional training. Whether such efforts can succeed in overcoming what has been described (private communication) as the apparent inability of medical students to engage in any meaningful way with other students in such ventures is a subject that needs urgent research.

Having declared my conviction that team-working is both beneficial to the patient and the most effective and satisfying way of working for the individual professional, I now have to express my concern that the establishment of this principle has not, however, in some cases, yet resulted in better care. Where team care exists in theory, but not in practice, the care of the individual patient may well be less co-ordinated and less effective than that given by individuals, each working in relative isolation but adhering strictly to the standards and using the authority of their various professions. I have had recent personal experience, and have received reports from others, of clinical teams where the care given, particularly to elderly patients in both primary and secondary care is fragmented, communication between the members of the team is almost non-existent, responsibility is difficult to discern, and where a patient or a relative is quite unable to identify who to turn to for a holistic account of progress and prognosis. In some cases, the team concept has even been used as an excuse to duck responsibility on the part of healthcare staff.

Much of this disappointing state of affairs may be explained by shortages of staffing and/or supportive resources for such teams. For many doctors, the disappearance of the firm as the structural unit of medical staffing in hospitals, a structure that provided both the identity and the leadership opportunity necessary for a medical team, has also made the practice of the principle more difficult to realise. Certainly, the pressures of increased through-put, together with high staff turnover, make the ideal of team-working difficult to achieve. However, others have argued that much of the difficulty in achieving effective team-working derives from a failure to identify and provide appropriate leadership.[82]

Conclusions

I have come to realise that, far from being a paradox, the principles of leadership and team-working are, for doctors as for other health care professionals, entirely complementary.

The apparent difficulty in reconciling these two important principles may lie in the commonly held view of leadership as directive, a view that is the result of the previously noted misinterpretation of leadership as management. I would argue that leadership, though requiring recognition and assent from the members of the team, does not necessarily or optimally require to be exercised through a line management role.

In the preparation of this section of the monograph I have come across numerous definitions and descriptions of what constitutes leadership. The distinction between transactional leadership based on contract and translational leadership[83] based on negotiation, persuasion, and influence, is perhaps the most relevant in the context of team-working. Clearly, in a team of professionals, each of whom has a natural authority based on their individual skills and knowledge, the latter is more likely to achieve results.

But it was in a seminar organised by the Nuffield Trust to assist me in this work, that the definitions advanced of a leader as one who walks in front of the team in some important respect (with all the personal danger that this may entail) and one who makes sense of what they are trying to achieve, were ones that I found most attractive. From my experience of attempting to achieve change in various roles and areas of healthcare I have observed these attributes of leadership as being the most effective.

In my post of chief medical officer at the Welsh Office I had the privilege of working with a chief nursing officer, who was herself an impressive combination of an expert and compassionate nurse and a leader of her profession, who never forgot her primary purpose of serving patients. In discussion of the dilemma of the potential of teamwork to afford better care for patients, together with the recognition we both shared of the need for leadership, we evolved a vision of a team of healthcare staff as one in which all of the roles, including that of leader, were determined solely by the aptitude, ability, skill, and knowledge of the individuals that contained it rather than their status. This concept would allow, by consensus among the members, roles to vary from time to time as the mix of staff or the needs of patients dictated.

Since that time, the boundaries between health professions have become more and more blurred. Within medicine itself specialities like radiology have broadened. Once purely diagnostic, it now encompasses both interventional and imaging elements. Nurse practitioners have a fully accepted role, at least in primary and community care, and nurses now prescribe within their field of capability. Recently the employment of surgeon's and physician's assistants has

becoming a reality in some part of the UK. The potential dangers of this change and the possible confusion it may cause for patients are matters that have been well aired in the medical press, but the momentum for such developments seems inexorable and the new roles are increasingly accepted and valued by patients.

All this seems to point to an urgent need to develop clearer concepts of both team-working and of leadership within the health service and to ensure that these are inculcated into the training of the professions involved from the beginning. Indeed it may be that the selection of trainees in medicine, nursing, and the other healthcare professions should pay more attention than previously to the attitude and aptitude of those selected to embrace both team-working and the responsibility for both leadership and followership as important aspects of their professionalism.

The challenges facing the NHS, both those imposed by government and those resulting from sociological and technological change, call for a transformation of the systems and processes of the service that will impact on the working practices of many of its professional staff. There is a popular opinion that these changes will require strong clinical leadership, and in many of the institutions of the NHS efforts are being made, often by reorganising the management structure to encourage and promote individuals who can provide such leadership. However, there has also been recognition[84] that structural variables are insufficient to integrate clinicians into these processes and that a more genuine clinical leadership is needed. There is also evidence[85] that change does not depend solely on clinical leadership and that this needs to be accompanied by administrative leadership. Indeed, that a constellation of clinical, administrative, and political leaders at different levels of the healthcare system offers more promise of positive change. The answer it seems is the establishment at the clinical, unit, and national level of teams of leaders.

PROFESSIONALISM

"Professionalism has contributed a great deal to modern healthcare but has inhibited the ability to achieve cross boundary solutions based on team work"

Braithwaite J *et al.*[86]

The subtitle of this monograph is "A challenge to professionalism?" This question represents my solution to the problem of the paradoxes, whether actual or perceived, that have been discussed in the previous three chapters. It indicates my conviction that ensuring recognition of the falsity of the paradox in each case requires the exercise of professionalism. That statement may itself appear to be paradoxical since some of the principles involved in my construct have been widely seen as attacking professionalism. There is no shortage of writers, both medical and lay, who see the exercise of accountability as intrinsically damaging to professional status. The wide availability of information to the public on the nature of their diseases and the publication of detailed assessments of the quality of care given by institutions, and even individual consultants, is seen as intrusive and undermining the reality and exclusivity of the professional body of knowledge. And the advent of the clinical team is considered to erode and diminish professional authority. Such views are confirmed for many by what they see, with some cause, as a concerted attempt by recent UK governments, of both political parties, to reduce the power and influence and undermine the status of all the professions.

There is little doubt that some of these principles do challenge professionalism, as it has traditionally been understood. However, the response of true professionalism to such challenges is to analyse the reasons for that challenge and, where necessary, to respond by redefining its principles and adapting its practice, to ensure that it continues to utilise all appropriate means of meeting the needs of those it serves.

So the challenge that my three selected paradoxes, and the many others that I have not described, pose to professionalism in the health service lies less in an attack on professionalism and more in stimulating a determination to resolve the paradoxes in a way that will advance the care and welfare of patients. It is my hypothesis that it is possible for professionalism to meet such a challenge, but that it will not be the professionalism that Braithwaite and his colleagues were describing in their article from Australia in 1995. I am distinguishing what I define as professionalism from mere tribalism, and in doing so I have found it necessary to use the term three-dimensional professionalism to express my vision.

Throughout my career of over forty years, on numerous occasions I have experienced situations in which the inhibition of rational and practicable solutions to healthcare problems has resulted from the unwillingness of members of the medical profession to accept solutions that they see as damaging the interests of the profession as a whole, or on occasions the interests of groups, the crafts, or specialties within it. It has often seemed that the profession is happier with old problems rather than new solutions, particularly if the latter involve some loss of influence, area of practice, or status. This is a tribalism that is not, however, confined to the medical element within health care.

Since Braithwaite's article appeared in 1995 numerous authors have reviewed what professionalism means and ten years later the Royal College of Physicians led by Professor Dame Carol Black published its report[86] of a working party chaired by Baroness Julia Cumberledge, *Doctors in society; Medical professionalism in a changing world*. This was a courageous move by the college and one that filled a long overdue need for the medical profession to review some sacred cows against the changing social, technological, economic, and clinical context within which healthcare is now delivered. It has provided a definition of medical professionalism as "a set of values, behaviours and relationships that underpin the trust the public has in doctors," and further expands this with a description and a list of values "which underpin the science and practice of medicine."

Perhaps predictably, the college's redefinition of the content, scope, and role of professionalism has not been received with universal acclaim. Despite the central role it envisages for the patient, an indissoluble partnership between patient and doctor in a radically new social context, it has drawn expressions of concern from at least one respected patient advocate,[87] and has received remarkably little attention from the profession as a whole.

While some of those, both medical and non-medical, whom I consulted in the course of preparation of this monograph have seen the RCP report as an effective expression of what they understand professionalism to mean, others have regarded it as an important first step but also found it disappointingly inward looking. Some of this reaction can be ascribed to the not-invented-here school of thought, but there is a sense in which, despite the declaration that the report is not for the profession and its institutions alone, its wish to achieve the responsible engagement of a well informed public, and its impressive range of consultants, the report still concentrates on what might be described as vertical professionalism. The very act of defining medical professionalism as being realised through a partnership between patient and doctor could be seen as perpetuating a separateness, and an elitism, that diminishes the professionalism of other members of the health care team.

The absence of any discussion in it of professionalism as a more general concept, indeed a reality, shared by other professions and disciplines underlines this tendency. Innes [88] identifies "the taking of responsibility" as the essence of professional life and conduct, and it is this acceptance of the burden of responsibility, and all that it entails, allied to the knowledge and skills derived from medical training, that is the underlying element of doctors' professionalism. But it is a burden that the medical profession shares with, but all too often overlooks in, other healthcare professions.

However, the report does go further than any other exposition of the subject I have read towards what I would advocate. That is a three-dimensional view in

which the professionalism of doctors involves the recognition of the professionalism of others within the healthcare field, and in its emphasis on a partnership with patients, the recognition of the professionalism that is represented by their unique knowledge. Knowledge of themselves, what their health or illness means to them – including their own individual coping skills – and thus their responsibility as part of the team. In moving in this direction, the report acknowledges the current pressure from both non-medical colleagues and patients for more shared decision-making and a new era of enlightened or informed trust that requires a change in professional attitudes and the development of new skills.

My personal definition of medical professionalism is:

- the acceptance of the responsibility to exercise the skills and utilise the knowledge that result from medical training and experience to the highest degree of excellence
- the acknowledgement, with honesty, of the limitations of these attributes and the recognition and utilisation of the contribution of the different skills and knowledge of allied professions
- the inclusion in this partnership of the self-knowledge and coping skills of the patient.

It is this three-dimensional professionalism that would seem to be the way to resolve the conflicts that have been presented in the foregoing chapters as paradoxes. Integral to it is the exercise of judgement in the face of uncertainty, an element widely recognised as a vital skill in the healthcare professions and perhaps most frequently exercised by doctors.

Three-dimensional professionalism acknowledges accountability in the healthcare professions as an essential element in building and maintaining trust in both individuals and institutions of the service. It learns from other industries, notably the airline industry where airline pilots see their regular and rigorous performance appraisal as an integral element of their own professionalism rather than an assault upon it. But farther than that it takes the lead in, rather than having to be coerced into, developing the systems of audit, appraisal, reflective, and evidence-based practice, governance and regulation that is required by the complex and wide-ranging healthcare service, in order to be truly accountable. It also, however, provides judgement on the limits of the value of accountability, since while there can be no doubt that its absence can, and has, resulted in events that have seriously damaged trust, an accountability regime that is either overly burdensome or lacking in validity will be rightly rejected by both the professions and the public. Its ultimate aim will be to replace blind, or even partially sighted, trust with rational *informed* trust.

Three-dimensional professionalism will provide clear-sighted appreciation of the enormous potential of the IT revolution, and its many applications in the

field of healthcare, without losing sight of the ethical and legal obligations of confidentiality. It will define and take a judgement on the balance of the risks and advantages that appropriately available and accessible electronic patient records, backed by rigorous systems of governance and accountability, offer to individual care and to service management and research. Similarly, it will establish where intelligent use of information ends and assault on confidentiality begins. Some leaders, in the drive to harness these systems, have already shown in pilot studies that there are solutions to the paradox that are capable of ensuring such a balance.

Three-dimensional professionalism acknowledges both the responsibility of leadership, especially in areas where the particular skills and knowledge of a profession are integral to that leadership, at all levels within the health care system. But it also recognises and enthusiastically embraces the effectiveness and enjoyment of team working, especially at the clinical level. It explores and develops ways in which the various professions can adopt appropriate roles, which will vary from time to time, between leading, contributing, and supporting. It accepts that these judgements require the insights of both the professions and the public. There is no monopoly on wisdom in such matters, and three-dimensional professionalism sees no shame in exercising followership in appropriate circumstances. And, further, it champions the establishment of teams composed of all the necessary skills and knowledge to serve the interests of individual patients and the population, together with the resources that will allow these teams and networks of teams to deliver excellence in healthcare.

This new *three-dimensional medical professionalism* should evolve from the lead signalled by the RCP report. It could, if developed to embrace the rest of the healthcare system, allow truly shared decision-making between healthcare professions and the public, and is in that sense the key to unlock the paradoxes. In the modern healthcare system, the recognition that such a brand of professionalism is needed is urgent if the *informed trust* of the public is to be retained against the backdrop of the changes induced in healthcare systems by social, economic, and technological developments in today's society.

Postscript

This monograph was written as part of the Queen Elizabeth the Queen Mother Fellowship of the Nuffield Trust for 2006, and in ending it I would like to draw an analogy between the new three-dimensional professionalism that I hope will maintain the institution of a universal free healthcare service in the UK and the professionalism that the great lady who is commemorated by this Fellowship demonstrated; a professionalism that arguably saved the institution of the monarchy when that was threatened.

Though, unlike most healthcare professionals, she had never had an overt programme of training, and indeed could have had no expectation of filling the role that she was called upon to fill, Queen Elizabeth the Queen Mother was a true professional. She took up the role of Queen alongside her husband at a time when the monarchy had been battered by the storm of the abdication and there were serious moves to sweep it away. By her sheer professionalism in the role, a professionalism that involved much difficult and delicate judgement – a quality that her daughter recognised, learned and in her turn has perfected – she ensured a return and enhancement of the respect and affection of the British public for the institution.

In the NHS, the professions have the chance to achieve the rescue of an institution that is similarly in need of such a restoration if they are willing to rise to the challenge. This may well entail recourse to the principles that underpin the health service and their examination and, if necessary, redefinition to meet the demands of a world that has greatly changed since its inception. The new professionalism with its wider appreciation of what that concept constitutes, a concept whose redefinition has been begun by the RCP report but needs to be further developed by discussion among the professions – and a discussion that I hope this monograph may play a part in stimulating – is the key not only to resolving the paradoxes that I have described but also to making sense of the current series of healthcare reforms. We must ensure that the ideals of a healthcare system, battered by events that have called into question its fundamental principles, survives and thrives in a modern world by fully utilising the benefits of technology but standing like a rock upon its principles.

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