



**The advocates of private practice promote an agenda of choice, but this is only a choice for the wealthy**  
**Des Spence, p 49**

**PERSONAL VIEW** **Mohammad Al-Ubaydli**

# Patients must have control of their medical records

Imagine an elderly patient with heart disease, arthritis, and a history of depression who needs social care at home. These are the patients who generate most of the work and cost in today's developed world health systems, and usually their care is fragmented. Our hypothetical patient sees two specialist nurses as well as different general practitioners at her local practice. She sees three sets of specialists, two of them at different hospitals, and she is to have a cataract removed at a third hospital. A carer comes every day, and she depends heavily on her three sons who share her care and live in different parts of the country.

Everybody accepts that this patient will have better care, and that costs to the health system will be lower, if her care can be integrated. But how can that be done? Well, one way—and perhaps the only way—is through the patient having electronic records that she controls herself: a personal health record.

A personal health record is different from an electronic patient record in that the patient controls it rather than an institution. The beauty of this is that our hypothetical patient can share the record with whomever she wants, including her carer and her sons if she so chooses. By contrast, an electronic health record is designed for employees of an institution to work together. It is logistically, technically, and legally difficult to connect such records.

The number of connections in a network necessary for integrated care goes up exponentially if the connections are institution to institution, but only linearly if they go through the patient (a hub). In other words, only the latter approach can cope with the networks of care of modern medicine. Furthermore, each institution may have its own system, incompatible with others. Clinicians will rightly hesitate to share data with non-clinical staff like social workers, teachers, charities, and relatives, but these parties may be important for the patient's health. There are also formidable legal difficulties with institutions sharing data about patients. Patients, by contrast, can quickly and usefully consent for data sharing if they are in control. Our hypothetical patient may well want her sons to help her make decisions about her health, and if she develops dementia and the sons have power of attorney then they can seamlessly take over control of her records and care.

Just as everybody is for integrated systems, so every clinician and health system wants their care to be patient centred—but it is hard to see how care can truly be patient centred when patients' records are scattered and not under their control.

Building integrated systems with patients controlling their records is not just a theoretical dream. It is happening now in the NHS. As a doctor with a lifelong medical condition I have always believed passionately that the best care results from patients not only sharing their care with clinicians and others but also having ultimate control. That's why I founded Patients Know Best, a business that uses information technology to improve the relationship between patients and clinicians.

One of our first projects has been with the gastroenterology department at Great Ormond Street Hospital. The department looks after children throughout the country with intestinal failure. These children need parenteral feeding, and their care is highly complex and involves many parties. The parents of the children and, as they get older, the children themselves control the records and share them with local hospitals, general practitioners, community nurses, home healthcare companies, teachers, and sometimes social workers. It's no accident that patient controlled records begin with such complex patients because, as Susan Hill, consultant gastroenterologist at Great Ormond Street, says, it was becoming impossible to cope with paper records. One benefit has been that as the children become adults and their care transfers to adult specialist centres it is easy to share the records. Hill also believes that teenagers who control their own records are less likely to rebel against their treatment, because they can't resist electronic communication.

Some patients—for example, pregnant women—have long controlled their paper records, and patients have a legal right to access their records, but many clinicians and institutions are understandably nervous about moving to electronic records held by patients. It seems inevitable that patients will eventually

control their own records as they control much else in their lives, but three moves could hasten the process and encourage integration of systems.

Firstly, the government might require all institutions providing care to provide its patients with a machine readable copy of their data. Machine readable means that it can be stored in patient controlled record software outside of the institution's control. Secondly, clinicians must learn, with support, how to write records with the expectation that patients will read every word. Social workers went through this change decades ago. Thirdly, the law for machine readable records should exclude written notes up to two years

after the passing of the law. These notes will remain legally accessible as they are now, but the mass availability of these records frightens clinicians because they wrote the notes under different rules.

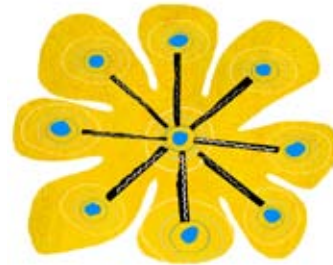
Ultimately, all of society, including clinicians, will win from the transition to patient controlled records with its resulting integration, but the biggest winners will be those patients, such as our hypothetical patient, with complex conditions.

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Competing interests: I am a founder, employee, and shareholder at Patients Know Best, a company that sells patient controlled medical records software.

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● FEATURE, p 24



ROB WHITE

**The number of connections in a network necessary for integrated care goes up exponentially if the connections are institution to institution, but only linearly if they go through the patient (a hub)**

## BETWEEN THE LINES Theodore Dalrymple

## The scourge of ulcers

In the middle of the last century there was a genre of books (I will not dignify it with the name of literature) with titles such as *How to Live with Your Ulcer* and *How I Cured My Duodenal Ulcer*. The lettering on the spine of the latter work, by John Parr, was in silver, except for the word “cured,” which was in diabolic red for emphasis. A cure for ulcer then was regarded as of almost supernatural occurrence.

Parr, who wrote the book in 1951, had an ulcer from 1919 until 1946, which gives him a kind of authority. We find it now as difficult to remember the miserable chronicity of peptic ulceration as to remember life before the internet. With a little effort, however, I can remember the household smell of ulceration—namely, that of boiled fish, peppermint water added to aluminium hydroxide, and various extracts of liquorice; a combination that was, aesthetically if not therapeutically, unpleasing.

Parr recounts his search for a cure. Before the war, for example, he went to a surgeon who declined to operate and whom the author calls “Old Bedsocks,” because the wearing of bedsocks was his suggestion for the alleviation, if not cure, of ulcer.

Then there was the Sippy diet, named after its inventor, or deviser, in 1915, Bertram W Sippy. I remember this from my childhood, when my father tried it before the operation that nearly killed him. The patient went to bed for six weeks and ate a disgustingly bland diet that, if nothing else, gave him psychological reasons to get better (and at the time, there was deemed to be an “ulcer type” of personality).

Injections of histidine and various extracts of various animals’ stomach linings were tried in the treatment of ulcer, all with initial success and enthusiasm, all with ultimate failure. The gastric juice of people was infused, presumably by nasogastric tube, into the stomachs of ulcer sufferers. Then there were the operations: all those Billroth gastrectomies whose names were

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once such a torture for medical students to learn. The surgeon, Sir Heneage Ogilvie, objected to the use of eponyms for the operations: “If we must have names let credit be properly attributed and call the operation the high posterior Finsterer-Lake-Lahey modification of the Mikulicz-Krönlein-Hofmeister-Reichel-Polya improvement of the Billroth II gastrectomy.”

Unintentionally, no doubt, Parr’s book illustrates the limitations of epidemiology. He quotes from a paper published in 1949, titled *The Peptic Ulcer Problem*, by none other than Richard Doll, who was soon to strike epidemiological gold with the causation of lung cancer. Doll writes:

*Four reasons suggest that environmental factors are of importance in the aetiology of peptic ulcer. First, there has been a great increase in peptic ulcer during the past thirty years; secondly, there are curious geographical differences in the incidence of ulcer and in the ration between gastric and duodenal ulcer; thirdly, there are differences in the incidence between social classes; fourthly, differences have been reported in the risk of developing ulcer in different types of occupation.*

In the end, Doll plumps for the stresses and strains of modern life; because, as Parr says, ulcer is a scourge of civilisation, though it is unclear whether he means by this that civilisation causes ulceration, or ulceration undermines civilisation. Incidentally, the cure of the book’s title is a low fat diet; the author mentions the infective theory of ulceration, only to reject it.

Theodore Dalrymple is a writer and retired doctor

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## MEDICAL CLASSICS

## Holding on to Humanity: the Message of Holocaust Survivors: the Shamai Davidson Papers

Edited by Israel W Charny; first published in 1992

When Shamai Davidson (1926-1986) began his groundbreaking work towards understanding the psychological traumas of holocaust survivors in Israel in 1955 he was appalled by the silence and seeming indifference of his psychiatric colleagues. Davidson was born in Dublin but grew up in Scotland, completing his medical studies at the University of Glasgow in 1950. Though living in the security of wartime Glasgow he was acutely aware of the fate of European Jewry and in particular that of his father’s two sisters and all their children, who were to perish at the Treblinka death camp in Nazi occupied Poland.

Davidson was described by colleagues as an astute clinical observer who was exquisitely sensitive to human hurt. He completed his psychiatric training at Oxford and then moved to Jerusalem, where he began his clinical practice caring for holocaust survivors. There he completed his training in psychoanalysis and began a distinguished career in which he obsessed about alleviating his patients’ problems through bringing their suffering into the open. Indeed, it was only after the trial of the Nazi leader Adolf Eichmann in 1961 that society became more sympathetic to the continuing distress of survivors. Davidson was also the first to understand the second generation pain in survivors’ children, with their particular psychological needs.

By 1979 Davidson held the Elie Wiesel chair in psychosocial trauma of the holocaust at Bar-Ilan University. He was working on *Holding on to Humanity*, which encapsulates so much of his life’s work, when he died in 1986, just before his 60th birthday. The book is a tribute to his career and describes much of his pioneering thought, which has subsequently become mainstream practice.

Although most survivors did not become patients, Davidson notes abnormalities in their behaviour, their coping mechanisms, and their often rigid personalities. He instituted counselling services to take care of the long term effects of dealing with repressed feelings. He devotes one chapter to how the therapist should relate to patients who have lived through extreme trauma, often in a hostile post-trauma environment. People who lived for years constantly alert to danger continued to experience heightened awareness, and many needed help in integrating into society.

Davidson indicates how survivors often owed their lives to the ability to bond with other prisoners. He describes how in his centre at Bar-Ilan University they achieved their aim of providing a suitable framework for survivors to articulate their experiences while speaking of previously suppressed trauma.

This book, posthumously published by a colleague, is a moving account of dealing with all the aspects of severe trauma and serves as a memorial to a farsighted physician who moved on from his own family’s loss, still deeply felt in post-war Scotland, to provide a framework for all survivors of genocide.

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**Only after the trial of the Nazi leader Adolf Eichmann in 1961 did society become sympathetic to Holocaust survivors**

## FROM THE FRONTLINE

## Bad medicine: private practice

In private practice, financial incentives can lead to unnecessary treatments; in socialised state healthcare, advice and interventions are not tainted by temptation. The poison of profit spawned the inefficient and chaotic system that is US healthcare. The US Fortune 500 includes 11 healthcare providers and insurers that have enormous financial interest in blocking reform.<sup>1</sup>

Private practice sees patients as a raw material churned at the mill for profit; it has vested interest in making us all patients. In the developing world, private practice diverts scarce resources from the needy to the wealthy—who in turn are made dependent on doctors, for profit. And the pursuit of profit in healthcare explains the wide variation in health seeking behaviour around the world.

These problems arise in UK private practice too. Search the internet and up pop allergy tests, screening medicals, computed tomography, colonic irrigation, nutritional supplements,



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References are in the version on [bmj.com](http://bmj.com).

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gastric banding, nose jobs, and all the other cosmetic surgeries aimed at the vulnerable. If you can't afford it, there is the option of credit. Private practice is bad for patients, who often get what they want not what they need. In medicine the customer is not always right, and we have a professional duty to sometimes refuse treatment.

Some private patients are overinvestigated and sent on a tour of internal private referrals, which pour petrol on the flames of health anxiety. The gin and tonic veneer of quality in private practice seeks to imply that NHS care is inferior. So many people of influence opt out of the NHS, and lose any vested interest in making it work better, which is bad for us all.

There runs a dubious argument that private practice relieves pressure on the NHS. But many treatments offered privately are not available on the NHS because they lack evidence of benefit. The General Medical Council may regulate doctors, but private practice

lacks the scrutiny and quality oversight of the NHS. Some even question whether working for the NHS and also working in private practice is a potential conflict of interest, because a poor NHS forces more patients into private care.

The advocates of private practice promote an agenda of choice, but this is only a choice for the wealthy. No person is more or less deserving in health: we are in it together. And if choice is so important, more can be done to expand choice within the NHS.

Lastly, private practice is bad for doctors: excessive fees reflect badly on the profession and are a divisive matter between colleagues. But even to question the quality of private care causes defensive, pinstriped, white hot fury. Doctors may work to the highest ethical standards, but the private system and pursuit of profit is bad medicine.

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THE BIGGER PICTURE **Mary E Black**

## What Olympic legacy for couch potatoes?

I am happily imbued with Olympic spirit, enthralled, uplifted, and privileged to have been in London this summer. I was involved, as many others were, in the NHS planning; I met a few athletes; and I even managed to get tickets to some events. Despite the gloom mongering the Central Line ran better than usual, and total strangers conversed on the tube.

The loudest call to action around exercise after the games is for support, funding, and detailed planning for elite (read Olympic) sports. Gold medals aside, the pyramid of population engagement (athletes, sports clubs, coaches, health professionals) in these sports is extensive, and the wider impact of such funding on population health is bigger than you might think. Raising the profile of sports medicine is essential, and may the Faculty

of Sport and Exercise Medicine, established in 2006, and the National Sports and Exercise Medicine Centre of Excellence, established this year, flourish.

The next loudest call is for more school sports. Confining teenagers to desks for much of the day is physically abnormal, so offering them the option of moving around for a couple of hours a week is a pretty sensible investment. We are evolutionarily engineered to hunt and gather, not to complete multiple choice questions, travel in cars, or play war games online. The choice is either to increase school sports or to supersize every chair and hospital bed in the land by 2050.

But surely the loudest call to action should be to get everyone moving more, including all of us who sit these days at meetings and press conferences discussing the health



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legacy of the Olympic and Paralympic games. There is hope for all of us who will never break a world record: the greatest benefits of increased activity are in elderly people and people with longstanding conditions such as stroke, diabetes, chronic obstructive pulmonary disease, heart disease, and depression.

The 2012 London Paralympics will round off our national immersion in sports nicely. One of Team GB told an entranced audience recently, "I have transformed myself. I am an elite athlete, 38 years old, and a mother of two. I also happen to have cerebral palsy in both legs and one arm."

Paralympians have the inspirational firepower to lift us all, hopefully out of our seats.

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