Foreword

As doctor-driven medicine sinks into disreputable old age, user-driven medicine is the hope of the future. This transition is already taking place across the world, and doctors and other health professionals should welcome it and play a creative role in shaping it. This book is a beginning in that process: a collecting together of materials, of stories, of insights, of ways of thinking, of problems and potential solutions, from users (“patients” - a word which needs to disappear) and from health professionals. A new kind of shared health care will emerge out of the current chaos not by the imposition of a single will, but through the shaping that emerges spontaneously from the creative efforts of many individuals and many different forces. The unprecedented privilege of our time is that we can each participate in this on a global scale, and this book is one illustration of how this process can get started.

Medicine in our time has become alienated from its users, and even from its practitioners. We are all, to a varying extent, pawns in a global business which is only incidentally related to helping ill people. And yet our individual efforts are well motivated and overwhelmingly successful compared to those of previous generations. I write as a doctor who has practised for 35 years, and when I look back I can be proud of many things achieved, but also frustrated: not just by personal shortcomings, which all of us have, but by the restraints of systems we all have to work in and which could be far more effective and creative than they ever seem capable of becoming. It is to liberation of this creativity, of organic development through shared aims between users and professionals, that this book is directed.

Doctors for the main part lead crowded and emotionally demanding lives. I am told that when doctors go on narrative medicine courses and are asked to write stories from their lives, the commonest subject is the patient they killed (or blame themselves for killing). By contrast, the weekly medical magazines which are sent to general practitioners throughout the UK always include columns about silly things that patients do and say and the ways they find to annoy us. Between confessional anguish and shared world-weariness, we manage to survive and protect ourselves. This may be necessary, but we need to move well beyond it. If personal continuous care by doctors for individual sick people is to be transformed into user-driven health care, delivered by genuinely integrated health professional teams. There is a need to share values as well as effective systems of operation.

For doctors, to be “user-driven” means an increase in the vulnerability which we already find so stressful. It means opening up to the demands of people with physical and mental problems, whether or not these bear any relation to the diagnostic categories that appear in medical school courses and textbooks. It means that the traditional defence mechanisms of doctors - ranging from carefully limited consulting times to shared rote-learning from “expert” lecturers - need to be replaced by far more open and interactive forms of shared communication and learning with sick individuals, or users.
I find this model of user-driven medicine quite frightening. I don't know if I have the required mental flexibility or the right repertoire of skills. It may be that nobody has, but that these will simply develop as we open up to new ways of helping users in need of our services. They are almost always be in a position of disadvantage in relation to us - they will be ill, or worried, or distressed, and may lack the resources to assess what they need - just as we often do, the moment we become sick. We can fall back on our usual defensive armoury, including emblems of authority like the white coat, ways of speaking which are more elevated and technical than the patient can follow, the ordering of batteries of investigations, etc, for which they may respond with a seeming gratitude which reinforces our bad habits. We can really listen to their needs and adopt a much wider repertoire of genuine empathy and help. It is our failure to do this that drives patients so often to seek “complementary” therapies with a proven lack of physical benefit. We need to widen the debate about these forms of user-professional interaction, both remote and face-to-face. Both users and health professionals have hurdles of vulnerability to overcome before they can align themselves more closely.

Medicine only became effective when it ceased to be based on transmitted authority and aligned itself with science, which is a truth-seeking activity. The “truth” of medicine was sought first of all in the physical realities of how the body functions and how disease arises, and it continues to be sought this way, with spectacular success. Most people go into medicine with the idea of putting this success into practice, and actually succeed to the extent of doing much more good than harm throughout their working lives. Additionally we now seek “truth” by constantly assessing that balance of good versus harm in the wide range of scientifically plausible treatments that we use. This has come to be called evidence-based medicine. We discover that many treatments which have a good basis in scientific logic do not in fact benefit the majority of people. We also discover the frayed edges of seemingly objective truth as we struggle for precise definitions of such conditions as “heart failure” or “major depression”, and then look at outcomes from interventions in populations which bear little resemblance to the patients who most often come to see us.

User-driven health care must include the aligning of our understanding of the truth with that of the patient. By this I do not mean trying to explain the full science of every situation as we understand it. On the contrary, it means recognising that our understanding of the situation is usually critically dependent on what the user can tell us, and our management is always aimed at making the user better, not simply at discovering or ruling out disease. We want to know above all what the person before us is experiencing and how this affects them. This concordance of understanding can then lead to a concordance of aims. Without such concordance, we can act as effective technicians in certain circumstances, but we can never provide any deeper help to a person facing the distress of illness, loss or death. Without it we cannot begin to develop a research agenda that deals with real causes of distress, rather than the things that are convenient or lucrative to write papers about.

If we limit ourselves to the technical, the user will be free to leave us and seek a different practitioner, perhaps non-medical, and we are thus relieved of further responsibility. If this is the future of “user-driven” health care, then I want no part in it. It is not that I am opposed to the principle of free choice among users - far from it - but rather that I believe that such a take-it-or-leave-it system degrades health professionals and exploits sick people, and ultimately makes health care unaffordable for those who need it most. To me, an encounter between a sick person and a professional involves an assumption of responsibility, above all the responsibility of understanding and helping.

We will know when we have arrived at a proper model of user-driven medicine when there is a free dialogue between patient experience and evidence-based medicine. Above all we will know it when
every person (user) in the world has access to health professionals whom they can trust to listen to them and help them, and a health system which will provide them with the best available care. If only a small percentage of health professionals in the world united behind this aim, it could be realised within the lifetime of most of us.

Richard Lehman
Oxford University, UK
7th March 2010

Richard Lehman is a Senior Research Fellow in the Department of Primary Care at Oxford University. He is perhaps best known for his individual weekly reviews of the principal general medical journals, maintained for the last 12 years and posted worldwide by the Centre for Evidence Based Medicine and on the BMJ website. His clinical interests are wide and in 2006 he was responsible for the first book on Palliative Care for Heart Failure. Following retirement this year from clinical practice R has been acting as medical adviser to the Health Experiences Research Group at Oxford and their groundbreaking website of patient interviews covering 70 clinical areas on www.healthtalkonline.org. His current main interest is in combining qualitative and quantitative research methods to identify patient-important outcome measures, especially in chronic illnesses as exemplified by type 2 diabetes.

CONVERSATIONS

Physician, Ireland:

Strongly agree with the need to discontinue the use of the word 'patient,' but the word 'user' does also have some fairly significant negative and pejorative connotations. Could we simply refer to 'people centred,' 'people,' and 'individuals,' or even 'individualised.'

In this profound reorientation of our personal practices in healing and caring, it is important we do not throw out any babies with the bathwater. As with any revolution, overtly political or merely within the infinities of the mind, it is important to retain carefully the good of the older while bringing on the new. As a younger Doctor, I was vividly taught by Dr. Manne Berber, a Dublin based Jewish Family Doctor, the art of positive unconditional regard when in the presence of any individual consulting me professionally. At the core of this manoeuvre was the effective ability to ruthlessly exclude any other concern or distraction other than the issues of importance for this individual at this moment in time. Thus taught, it has informed many of my own consultations, and though it originates from well within the twentieth century, it is well deserving of a place in the twenty first.

Editors:

Just to add to our official perspective (also detailed on our journal web page) on the term “user”: The term “user” includes health professionals as well as patients and anyone who uses the web with a user name. These “users” generate an information flow that “drives” the system's workflow (hence the choice of the term “driven”). “User driven healthcare” aims at improved healthcare through clinical problem solving utilizing concerted experiential learning in conversations between multiple users and
stakeholders, primarily patients, health professionals, and other actors in a care giving collaborative network across a Web interface. 

User driven health care is actually Patient/People centred but it is as much about health professionals as much as it is about patients.

Physician, Dublin, Ireland: 
I think 'we' know what we mean by the word 'user,' which is fine. Its a practical and utilitarian term. It is strictly accurate. But all of this still does not make it the best choice as a successor to the word 'patient.'
This is, I believe, because it has negative connotations as in 'bloody users,' 'friendly user,' and even 'user friendly,' which in itself is nowadays more often used ironically and sarcastically than in its original sense where it started off life as part of the marketing jargon of peddlers of computer consumables...

Anyway, I'll get over it!!

Editors: 
Yes it is not a successor to the word patient because there is a 'patient user' as well as a 'health professional user.' I guess as of now it is a successor to the word 'humans' perhaps.

Asst Prof, Marketing, Eastern Kentucky University, USA: 
It was important for me to learn about the thoughts or feelings of a physician about user-generated healthcare, since physicians now become more conscious of their expertise and of course become vulnerable with shared decision-making and active involvement from patients. Quick question though, at the very end, the author talks about a free dialogue between patient experience and evidence based medicine? What does he exactly mean by free? Also, is there a clear cut between patient experience and evidence based medicine?

Dr Lehman, Oxford, UK: 
What I mean is that in future research questions should be generated by users on the basis of their experiences and answered by the methods of EBM, and that people generally should be much better informed of how medical decisions are made, how evidence is generated, and what the shortcomings are.

Epidemiologist and Associate Professor, Dublin, Ireland: 
Quoting from Dr Lehman, “Medicine in our time has become alienated from its users, and even from its practitioners”

This equates medicine with Medicine - I would see the alienation of users from Medicine as indexed by the huge profitability of alternative medicine(s). The demand on behalf of users to define their own problems (rather than the typical Doctor retort of “Let me be the judge of that”) and to decide on their own treatment has led to an explosion of spending on medicine outside the professional sphere of Medicine.

Quoting from Dr Lehman, “Medicine only became effective when it ceased to be based on transmitted authority and aligned itself with science, which is a truth-seeking activity”

Yes but...
Yes but the whole enterprise of scientific medicine has been hijacked by the vast commercial interest involved. The ten highest earning companies in the Fortune 500 are ALL pharma companies. And furthermore, these ten companies together earn more than the other 490 companies put together. At these high stakes, of course the dice are loaded.

Psychology Researcher, Copenhagen, Denmark
Quoting from Dr Lehman, “We want to know above all what the person before us is experiencing and how this affects them. This concordance of understanding can then lead to a concordance of aims.”

But a preliminary concordance of understanding between doctor and patient necessary to develop a research agenda that deals with the real causes of distress may—at least in chronic cases—have to involve an assumption of patient responsibility as an empiricist. The focus on the brief (and expensive) face-to-face encounters between patient and doctor (and patients’ on the spot recollection and condensed narrative of selected distresses) tends to distract from the data resources available through long-term involvement of the patient in documentation.

To reach a free dialogue between patient experience and evidence based medicine, patients—in an age where the 200 dollars laptop is globally available—must be provided free tools to collect their own evidences of what they—when they are not before us—have been experiencing, and how this has and now affects them around the clock and along the weeks, months and years, before, between and after their encounters with health-providers.

“An abundance of unrealised potential that is waiting to be unleashed”…yes indeed. And this is also a question of acknowledging the more or less global access to Internet 2.0, and creating a user-driven approach to the presence and future of medicine.

Sociologist, Liverpool, UK:
I can’t really comment on the vulnerabilities experienced by practitioners but as a regular user of healthcare and a social scientist, however, I am concerned with other ‘vulnerabilities’. Indeed, my main concern is with what goes on ‘outside’ the medical encounter: the lived experience of patients, the barriers (and resources) they must daily negotiate within wider structures of inequality.

Patients are not just disadvantaged because of illness and loss but also because of the alienation they experience when encountering health professionals. The institutions of medicine are, like it or not, constructed and designed by a privileged few for the (greater) benefit of a privileged few and utilized most ‘effectively’ by such. My concern then is that it is the latter who become the focus of user-driven healthcare and, consequently, health inequalities may become even more pronounced. These are also the same people who have generally enjoyed the unprecedented ‘successes’ of medicine in the past—which is easily evidenced today in, for example, in the enduring (and unacceptable) differences in rates of mortality and morbidity both within and between different societies across the globe.

This not, of course, to take anything away from the achievements of medicine but, clearly, as the author of the foreword intimates there remains an abundance of unrealized potential that is waiting to be unleashed.
It is a connected point but I do wonder, also, if we all understand the term ‘user’ (the best term we have, I think). Does it designate anyone who comes into contact with a health professional, only those who have a health ‘condition’ (which could include all of us) or those undergoing some kind of ‘treatment’? I think Rakesh uses the term (in this book and elsewhere) in relation to all ‘stakeholders’ whereas the author of the foreward seems to confine it (as I generally do) to ‘patients’ as opposed to health professionals (paras 1 & 5) or practitioners (para 2) or doctors (para 4). I wonder if this may cause some confusion to readers.

Like much of the emerging debates in ‘user-driven healthcare’ we need to get beyond semantics and listen to what ‘users’ actually say and do not just in medical encounters but in everyday life for the latter is the real ‘test’ of what drives them. User-driven healthcare can I hope contribute to the on-going dialogue that is needed to address these issues (and others) but we must never lose sight of the multiple disadvantages experienced by many and we cannot presume to speak on their behalf.