

# PERSONAL HEALTH RECORDS

A GUIDE FOR CLINICIANS

MOHAMMAD AL-UBAYDLI MD





# **Personal Health Records**

A Guide for Clinicians

To Anisa and Buthaina

# Personal Health Records

A Guide for Clinicians

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# About the author

**Mohammad Al-Ubaydli, MD**, is founder of Patients Know Best ([www.patientsknowbest.com](http://www.patientsknowbest.com)) and has over 15 years of experience in medical software. He trained as a physician at the University of Cambridge; worked as a staff scientist at the US National Institutes of Health; and ran the hospital chief information officer consulting practice for US hospitals at the Advisory Board Company.

Dr. Al-Ubaydli wrote six books about the use of IT in health care, including *Handheld Computers for Doctors* and *Streamlining Hospital–Patient Communication: Developing High Impact Patient Portals*. He is an honorary researcher in personal health records at University College London’s Centre for Health Informatics and Multiprofessional Education, and the University of Cambridge’s Addenbrooke’s Hospital.

## About Patients Know Best

In 2008, Dr. Al-Ubaydli founded Patients Know Best, Ltd, a personal health record company, serving clients in the United States, the UK, and Middle East. These include Great Ormond Street Hospital, the UK’s largest children’s hospital, Bupa, the UK’s largest private health care provider, and Thalidomide Trust, providing care to all thalidomide patients in the UK.

The company has been highlighted for its innovation by several organizations, including Seedcamp, who chose them as one of the top 6 start-ups from across Europe in 2009; BusinessWeek, which named them one of the world’s 25 most intriguing start-ups; and the Institution of Engineering and Technology, which highlighted the platform’s innovation (Figure 1).



**Figure 1** [www.patientsknowbest.com](http://www.patientsknowbest.com).

# Acknowledgments

My parents always taught me that if I see something that needs to be improved, I should step forward and do what I can. This is hard but my parents led by example, living a life of service to their country.

What they did not tell me, and I had to learn by myself, is that when you step forward, hundreds steps forward with you. All of them want to help and none of them expects anything in return. Some were already friends, others became friends, and all are filled with kindness.

I am grateful for the help I received from these hundreds even as space forbids me from thanking them all.

First is my mother, Buthaina, who kept my medical records as we traveled between different countries and received care from different doctors and nurses. It was she who, long before my rare genetic immune deficiency was diagnosed, spotted how prone I was to infections and boiled all water before I could drink it. Were it not for her precautions, it is unlikely that I would be alive today, and certain that I would have lost all my hearing to the ear infections of my childhood.

I am also grateful to all these clinicians that helped her and helped me. Not only did they provide the care that I needed, they cared about what I needed and they taught me how to take care of my own needs. I still remember the doctor who stabbed himself with a needle to help me overcome my needle phobia, and the nurse who patiently taught me how to inject myself as I struggled through my fears. The doctors and nurses of Addenbrooke's Hospital tolerated my childhood sulks, provided me with the independence I needed for medical school, and coached me through the risks of being a doctor on the wards.

It has been a pleasure and an honor to work with my cofounders at Patients Know Best over the past years. When I returned to England from the United States, my priority was to find the best people with whom to create the best company. Ian, Jon, and Richard: I do not know how I managed to find you, but I am so pleased that I did.

Finally, a thank you to my wife, Laura, the secret of my happiness. As a physician and author of medical textbooks, she was the first to utter the words "patients know best." During the 2 years that it took to write this book, she named our company, spelled out its mission, supported me with her salary, and brought two beautiful girls into our lives.

Mohammad Al-Ubaydli  
December 2010

# Foreword

Records can seem very boring. I do not think that anybody taught me anything about medical records in my 6 years at medical school. They had the status of a chair: something you used but never thought about. This was a serious omission because good medical records are fundamental to good health care. They may not be so important when tending to a man who has just lost his leg under a train, but very little medicine is that acute. Most of medicine is working with patients who have long-term conditions, often more than one. With this type of medicine, which is 99% of medicine, records are essential. Poor records are likely to mean poor care.

Unfortunately, poor records are common. I have been in hospitals about five times in my life, all different hospitals. Somewhere in the bowels of those hospitals, there will be five different records of what happened during my admissions. Quite probably, they are lost and could not be found if I were to turn up with a complication of one of my operations. I might well anyway be admitted to a different hospital, and I would either have been fixed or died by the time my records were located. Then, there will be other scattered records of when I have given blood and had the occasional diagnostic test. My general practice has an electronic record for me, but it contains almost no information and some of what it does contain is wrong. The practice may also have an extinct paper record, a small folder stuffed with letters, test results, and probably illegible accounts of consultations going back 50 years. So my medical records, like those of most of us, are fragmented, incomplete, scattered, and little use.

This does not matter too much because I do not yet have a long-term condition (or at least one I know about), but if I am run over tomorrow in Edinburgh, 400 miles from my home, and rendered unconscious, the doctors who see me will know little about me. Many patients with long-term conditions have highly complex medical histories, multiple test results, and are taking many drugs. It is essential for anybody caring for these patients (and it is likely to be several doctors, nurses, various kinds of therapists, and social workers) to be able to quickly know something about the patients, their medical history, and their current status. This can be very hard because of multiple different records and bulging, disorganized, and often inaccessible ones.

We have to do better and electronic personal health records controlled by the patient would be an important step toward doing better. Mohammad Al-Ubaydli has done an excellent job in writing this very clear book about what personal records are, what benefits they can bring, what snags must be avoided, and how they can be used practically.

On reflection, I find it very odd that we have not made much more progress toward personal health records being universal.

Why then it has not happened? As usual, I suspect that it is a combination of factors that has blocked what seems an obvious, but nevertheless, radical change. Some doctors may be resistant with worries about distressing patients and other anxieties, but increasingly doctors recognize the importance of working in partnership with patients. If they could be confident of easy access to well-organized personal health records, I think that most doctors would not stand in the way. Indeed, most will recognize that such a system could be much superior to what we have now.

Other health workers would, I think, be equally comfortable, although each group may be interested to keep its own records—so undermining the value of a single, patient-controlled record. More prosaic but ultimately more important may be the political, logistic, and cultural problems of getting the health system to build a system of personal health records. Perhaps, one of the biggest blocks has been us, the patients. We have not shown that we want a better system.

I have tried getting online access to my records. Although it is supposed to be technically easy—“simply the flick of a switch”—it took me 6 months, and neither the GP nor the practice managers were against it. When I did finally get access to my records, it was a horrible disappointment. They said almost nothing about me: only fragments of my medical history were there, and some important information was missing. I longed to be able to edit the records, add what was missing, state my values, give any possible users a sense of me. But I cannot do that. These records are about me, but they are not mine. A personal health record would be mine.

We are moving from what the American thinker Tom Ferguson called “industrial age health care” to “information age health care.” This takes us from a world dominated by hospitals where doctors are authorities to a world where there is more emphasis on the ability of patients and their friends, families, and online communities to take charge of their health care. Doctors are now navigators, facilitators, and when necessary agents of action. Considerable evidence has accumulated to show that when doctors and patients take decisions together rather than taking decisions for patients then outcomes are better; patients are more satisfied, and costs are lower. Personal health records are an essential step in moving to information age health care and fostering the doctor–patient partnership.

Another step we need to take is to move from disease-based care to person-based care. Patients with multiple chronic conditions are passed from cardiologist to diabetologist to chest physician to rheumatologist with each concentrating on his or her body system and disease. The values and goals of the patient are too easily forgotten, but personal records could include statements on values and very importantly wishes of the patient that will guide the patient’s inevitable death. All the time we hear the shibboleth of

“patient-centered care,” and surely personal health records are central to care truly becoming patient centered.

Dr. Richard Smith

Director of the UnitedHealth Chronic Disease Initiative

Honorary professor at the University of Warwick

Chair, Patients Know Best

Former editor, BMJ

# Introduction

Modern medicine is wonderful. In 1799, George Washington's clinicians treated his throat infection by bleeding, and this contributed to his death (Morens 1999). In 1981 his 39th successor, President Ronald Reagan, was shot in the lung. Prompt treatment by his clinicians saved his life and allowed him 8 more years of public service and a long retirement after that.

Every year, obstetric care saves the lives of tens of thousands of mothers and children. Vaccinations have drastically reduced infant mortality all over the world. Heart attacks are no longer fatal, cancer is curable, and diabetics live for decades. When all else fails, hospices allow a dignified death.

And yet the most commonest complaint I hear from clinicians is a lack of time: they have too little time to spend with their patients, and too many patients to care for. Their frustration is because most clinicians entered health care because they wanted to help other people. They feel time-starved because they are not able to help as much as they would like to.

But the irony is that clinicians are providing more help to more patients than ever before in human history. If you are reading this book, you are one of the people making a difference.

## **Victims of your own success?**

The problem is that you have solutions. The reason you have more patients than ever before is that you are actually able to help them more than ever before. This is wonderful news.

In the next few years, however, you will have to be even more helpful. In most societies, citizens are getting older and gaining weight, so more of them will be patients. Even those who are not sick can still become healthier with some medical attention. Those who are sick will have chronic and often multiple diseases, requiring coordination of care between multiple clinicians.

You will not have more resources. You will have more and better technology; of course, we can take that for granted for the next 10 years. But during those same years, most countries are unable to spend more money on health care than they already are. And more dangerously, we cannot count on expanding the workforce. In many countries, more nurses are retiring than are joining the profession.

So how can you continue to help more patients?