Patients Know Best

By Mohammad Al-Ubaydli

It was not until the 18th century that scientists accepted the existence of queen bees. Until that point they insisted that only a “king bee” could be in control. But the queen had always been in control, it just took us a while to believe and understand this. Similarly, around the world, patients are already in control. As more people believe and understand this, they design the health care system differently. This is the reason that hospitals, patient charities, pharmaceutical companies, insurance companies and government payers around the world are adopting Patients Know Best, a patient-controlled medical records system.

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The march of specialisation

There is no consumer movement or campaign behind this shift to patient control — rather the steady march of progress towards ever increasing levels of medical specialisation. Specialisation has allowed for miracles of modern medicine, overcoming the natural limitations of how much knowledge any single human can have. Health professionals today have an increasingly deeper knowledge about an increasingly smaller area of medicine and the human body.

These specialists pool their knowledge: nurses, doctors, pharmacists and surgeons are all becoming specialists in their particular fields. GPs have the broadest knowledge of all but they have become specialists at identifying a complaint or set of conditions and referring a patient to the most appropriate expert – that is also a specialisation. Specialisation happened quickly and massively over the last 100 years, and over the next 100 it will be faster and bigger still.

So who knows about the whole patient? The patient and their carers: they are the only ones who have been to all the appointments, the only ones who know what different teams are prescribing, the only ones who are able to join the dots. Handing back control to the patient is not about passing the buck, it’s about handing back control to the person who is best equipped and best placed to manage his or her own care.

So what does this mean in practice? I have a rare genetic medical condition that means that I receive help from multiple specialist clinical teams in a range of clinical settings. If I get an infection and see a GP out of hours – who will not know me or understand my condition – the GP is often worried about how best to treat me. So, to help him and myself, I tell him what drugs I am currently prescribed, which antibiotics work best, and which doses to use. I can tell him – not because I am a doctor – but because I am the patient, the one who knows my condition the best. I am the one who knows what all the different experts treating me have said. It is around this principle that we developed Patients Know Best – an online medical records system which puts the patient back at the heart of their own healthcare management.

Patients Know Best

Patients Know Best is the world’s first patient-controlled medical records system. It is a fully secure online tool which enables patients to better organise, manage and control their own health care provision – it also saves the time of physicians through allowing secure, online consultations. Founded by Dr. Mohammad Al-Ubaydli, a Cambridge-trained physician, programmer and author of seven books in IT in healthcare, Patients Know Best has won awards for its focus on patient care. Patients Know Best’s first customers include Great Ormond Street Hospital, St Mark’s Hospital, NHS South Devon, Novartis and Thalidomide Trust. Patients Know Best integrates fully into the NHS secure network and is available for use by any patient with any clinician anywhere in the world. Patients Know Best complies fully with UK NHS and data protection requirements as well as the EU data protection act and US HIPAA legislation for dealing with medical data. Patients Know Best is a social enterprise business and Dr. Al-Ubaydli is an Ashoka Fellow.
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Shifting relationships

So we know that patients like myself are already at the centre of managing their own healthcare – even if they do not know it yet – but like the scientific community studying the beehives back in the 1800s, this fact is not formalised or recognised in our healthcare service or wider healthcare establishment.

This has to change – but two things must happen first. Initially, the medical establishment needs to alter its attitude towards patient care. Doctors must admit that going to medical school does not give them all the answers. They must get much better at involving patients in their own healthcare and actively listen to them if they come to them with internet research or information.

Secondly, patients must get better at taking responsibility for their own healthcare. 69% of health care spending is on long terms conditions, ones for which there are no simple cures. Asthma, diabetes and heart disease are some examples. These are not conditions that the doctors can ‘treat’ without the cooperation and action of the patient themselves. Managing conditions like asthma require the patient to take an active role. Asthma treatments can be confusing but patients must remember to take their inhalers wherever they go. They must remember which inhaler is used for which kind of attack – patients have to get better at listening too.

Unfortunately, the system that we have does not encourage doctors to hand over control to patients or patients to take responsibility. It remains based in an old fashioned ‘paternalistic’ style of medicine where the doctor hands out a cure to a grateful, unquestioning patient. This style of medicine does not lead to patients taking responsibility – it leads to patients becoming disempowered. We must move towards a more participatory style of medicine where the patient and the doctor come together to decide on a course of action. We must move towards a more equal and collaborative relationship where doctor and patient come together with information – to reach a mutual decision.

The informed patient

New technologies are enabling patients to be far more informed and knowledgeable about their condition than ever before. Patients are becoming experts in their specific illnesses – and doctors must listen to these people. No longer can the clinician believe that she is the smartest person in the room just because she’s attended medical school.

20 years ago, if a patient wanted to know more about his or her condition, the options were pretty limited. He or she would have either had to ask their doctor or spent time finding a book written in patient-friendly language. Today, the same patient would most likely just ask Google – and receive more reliable results, instantly.

Also, there are now many online tools available to help patients not just define and understand their condition but translate and interpret complex medical data – making what was impenetrable medical data available to all. Indeed, through our own Patients Know Best platform, our software explains to patients what their test results mean. Each patient can read this information at home, with their family, and prepare their questions in time for the doctor’s appointment.

There are other platforms that help patients to learn from each other such as peer-to-peer support networks Health Unlocked, Patients Like Me, and Crohnology. Sites like these enable patients to share details of their medical conditions with people who have similar conditions, and compare and contrast different treatments and outcomes anywhere in the world. Not only does this make the patient more informed about his or her condition, it means that he or she can go into consultations asking very specific questions. Questions like: Why am I taking this combination of drugs when that doctor in that country is prescribing something different? Why is that patient with the same condition as me getting better taking that medication when I’m not? Why are those 100 people improving with that drug – and why aren’t I being prescribed it? Questions like these are hard to brush off. They also lead to a radical reconfiguring of the doctor-patient relationship. The health professional can be challenged. No longer is he the only source of information – and this means relationships become more equal and collaborative.

Saving money, making money

To treat my condition, I have to have regular injections of antibodies. Until a few years ago, I had to spend a whole day in hospital each time I needed another boost. However, after receiving training from my hospital team, I inject myself at home. I gained enough independence to go to medical school, have a job and travel on holiday. But it was only while writing a book about giving patients access to their medical records that I learned that my hospital had saved money. Through putting me in charge of managing this area of my health, the NHS has made an immediate cost saving. And there are thousands of examples like this.

One of the functions of our Patients Know Best system is to give patients the facility to securely message their doctors should they have a question. Whilst initially, some hospitals were wary of this facility – they thought they would be bombarded with questions – now they find that messaging often saves them time as quick questions can be cleared up without the need for a hospital visits or phone
**Patients Know Best and St Mark’s**

St Marks Hospital, Northwick Park, London is one of the leading hospitals in the world treating intestinal failure. Patients often come to the hospital with highly complex and hard to treat cases – normally involving multiple conditions. A patient might have a serious gut problem, alongside also having asthma, diabetes or an immune problem – all of which mean treating the patient can be very complicated. Normally, such patients are highly dependent on their clinical teams and have high levels of trust in them. Many do not like to stray far from their area in case they have an emergency. However, St Marks now use Patients Know Best which means that anyone treating a complex St Mark’s Hospital gut patient can see that patient’s medical history – what drugs they are on and their entire treatment plan. Indeed, this year, one St Mark’s patient and PKB user with a serious and rare gut problem felt confident enough to leave the London area and fly to Australia for their first ever holiday – safe in the knowledge that if anything happens to them abroad through PKB, an Australian doctor would be able to see that patient’s entire medical history and treatment plan.

**Thalidomide Trust**

Based on Patient Know Best’s system, The Thalidomide Trust has developed a new e-health platform that records and captures the often highly complex nature of a Thalidomide patient’s medical history and makes it far simpler for attending clinicians to quickly understand the interrelated nature of a patient’s health problems. In 2006 The Thalidomide Trust found that the overall health of its members was deteriorating fast. Many were living with increasingly high levels of ‘co-morbidity’ – multiple, and often interrelated health problems. The organisation knew that it had to find a way to help its members help themselves and to help GPs and clinicians understand and better diagnose their conditions – which can be very complex and specific to Thalidomide patients. Through using Patients Know Best as the platform for its new e-health platform, the Trust now has an all-embracing system that enables users to receive better treatment and improve both their health and wellbeing. It also has a system that will be adapted in the future and one which gives them the flexibility to add new features for users over time.

**Great Ormond Street Hospital**

Great Ormond Street Hospital is one of the leading children’s hospitals in the world. In 2011, Patients Know Best was used to enable the first fully online transition of patients’ medical histories between Great Ormond Street (GOSH) and St Marks. PKB is currently being used in GOSH’s gastroenterology unit.

The GOSH patients in the PKB group are all using the software to manage their own treatment. This involves having online consultations, having full online access to their patient notes and clinical letters and taking a more active role in their treatment. The complex nature of the condition means that a patient’s treatment is normally delivered by several multidisciplinary teams such as specialist nurses, dieticians, pharmacists, home care companies, GPs, administrators and the doctors themselves. It is important in any shared care process that all these different people act as ‘a joined up’ group to ensure consistency of care – something often difficult to achieve with the current system. PKB allows the patient, or the patient’s existing healthcare team, to ‘invite’ individual members of their new care team to be their PKB ‘friends’ – as familiar process for teenagers from social media sites such as Facebook. Once they accept, new members have full access to their medical history. By taking a patient-centred approach, PKB gives the patient more control of their treatment and more control of their lives – something especially important for teenagers reaching adulthood.

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**Innovative providers began using our Patients Know Best system to reach more people and offer better customer service – opening up new markets to them and generating more revenue.**

**The future**

For me, the entire health care system would be organised differently – and more efficiently – if we believed and understood that patients are in control. It is in everyone’s interest to trust patients and to give them the responsibility for managing their own healthcare.

As a first step, this would mean handing over medical records and medical histories back to patients. It would involve handing back responsibility to the patient – or the patient’s chosen carers – for managing their own care. This already happens successfully within UK maternity services and in hospitals such as Great Ormond Street Hospital and in Torbay Hospital that use Patients Know Best. By giving copies of the records to patients, each patient could enter his or her own data, combined with those of local GPs and hospitals, public and private health care providers, teachers and social workers. Now a complete, citizen-centred record is possible.

For their part, to encourage a participatory style of medicine, health professionals must become health coaches. In this new world, clinicians and doctors will be ever more valuable, but their relationship to the patient will become more equal. In the future, patient and doctor will combine their knowledge and expertise with the patient’s knowledge and come together to help the patient get better – and improve the healthcare system.