

Basically the Draft is far too general, leaving the possibility of very loose interpretation. e.g. “Access” to health services needs to be defined, and be provided in a specified time frame. However, I intend to focus on the core issues related to patients being involved in decision making in their own health care. I will focus on the following Rights:

- 4. Communication
- 5. Information
- 6. Participation

Clear Communication. Information. Participation

As a health professional (Psychologist) and Educator, throughout my career I have made considerable effort assisting people in making choices and ensuring that they understand the issues, and have relevant information.

It is not enough to provide Interpreters for non English speakers. The doctor has to appreciate the ability of the individual patient to comprehend the issues. As about half of the Australian population has difficulty reading and writing, patients need an explanation that explains their condition and options – in basic English. Diagrams are also helpful.

Many patients leave medical appointments only with a prescription – and no clear understanding of what they are being treated for, or the importance of other aspects of treatment – e.g. exercise, rest etc. They rarely can pronounce or spell the name of their disease or condition. Thus, they are hardly in a position to participate in making choices or decision making.

Some doctors already provide computerised reports of each consultation at the time of the consultation. It takes very little time, and the patient can go away and review any concerns and issues.

Research in USA has shown that 60 percent of patients look up information about their health on the Internet. Many change their behaviour on the basis of what they read. Much of the information they access is in Basic English, and often provides explanations of various treatment options. My focus has been on areas of my expertise, and of my own conditions: specifically ADHD, Depression, Dementia, Arthritis, Diabetes, Breast Cancer, and programs that I run e.g. Stop Smoking, Weight Loss, to mention just a few, and several others. I also participate in Continuing Medical Education Programs, and read research papers on the internet and extract pertinent information to pass on to others.

There are also websites where patients can check on details – including side effects – of their medications. E.g. www.rxlist.com Modern medicine i.e. health professionals should recognise and embrace this desire of patients to have timely and relevant information. They can share information, and direct patient to “good” websites.

Personally, I have been involved with several internet groups for a number of years, and time and time again people report learning more about their difficulties through the groups than from their doctors. Obviously there is a wide range of understanding. It is not difficult to find groups focused on research based information. One Diabetes group I am involved with is owned by a Harvard Endocrinologist – and he does not allow discussion of unscientifically proven treatments. We have authors of books on diabetes and various health professionals in the group.

One of the talks I give to community groups is about “Taking Control of Your Health”. Very few people have a list of the various medical conditions, operations etc. that they have had. I talk about ways to make and keep such records. Clearly we are handicapped by rarely if ever being given copies of our test results, or reports.

This is especially important for a number of reasons. If we move, or change doctors our medical records should be immediately available to share with the new doctor. A couple of years ago my GP moved from one group to another because the first group closed the rooms in my suburb. She chose to stay in the suburb. It took 9 months for any of our medical records to be released to her. Obviously, if we had our own summaries and reports of tests etc. there would not have been this gap.

Several years ago I realised that it was up to me to provide my medical history when I see a new doctor/specialist. Last year I was referred to a heart surgeon and presented him with an A4 Excel sheet with my history, operations, medications, allergies, adverse reactions, surgical errors, and other relevant matters. He was thrilled, and said everyone should do this. The referral letter from my GP included a list of medications prescribed. As I have had severe bleeding problems with aspirin over many years I do not take any aspirin. I have advised her to take this off the list – but it's still there. I also advise carrying a Medical ID including this information with one's Drivers Licence, and also to show new doctors. This way we are empowered to correct errors in our medical records.

As I said earlier– I teach people different ways to compile a medical record. Some use hand written notebooks, others can use computers to maintain their records in various formats. Obviously, our records will be continue to severely limited as long as we are not given our test results, diagnoses and reports. We must have the right to copies of our medical records.

Thus, the current version of Patient Rights is too general and vague. Although I have only addressed the Rights of Clear Communication, Information and Participation this criticism applies to all of the Rights. Specific details need to be stated otherwise doctors, and others managing health services can settle for woefully inadequate levels of communication and thus limit the participation of patients in decision making. Most doctors think it is enough to prescribe medications for Diabetes, and advise patients to lose weight, watch what they eat, and exercise more. In fact Self Management is an everyday activity – patients need to have insight into the effects of particular carbohydrates, they need to understand portion control, and dozens of other topics. Some patients may go to dieticians, Diabetes Educators or others – but the bottom line is that each patient needs information in a form that he/she can understand, and also needs to be encouraged to participate in own their health care.

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