

Michele, I just feel this is a case of an academic research project that will not make an iota of difference on the ground. I have thought about the adage that you have to start somewhere but then dismissed this as not being acceptable in 2008. The start has already been made because loads of health consumer and health provider organisations has one. It's not new or innovative and it is stated it is based on the charter of rights of others.

Cheers

Ann

## ANSWERS TO CONSULTATION QUESTIONS

1. I think that the development of rights and principles is cumbersome and not useful unless you are having a theoretical, analytical, academic review. If the rights were more than just one word that could be taken in many contexts then you wouldn't need the explanatory principles. I believe the rights need to stand alone so they can be printed out and circulated, who is going to circulate the rights AND the principles - yet one will be no good without the other. Patients need to have a document they can refer to easily and understand not a set of rights then having to read through another document to explain them. I would suggest each of the rights be a sentence that makes sense, that people can understand and importantly the meaning is unambiguous.

I thought the wording under the blue My Rights column is very clear and easy to understand – it is once I got to the What This Means column where the jargon and non-words creep in that make the meaning complicated.

I think a one-pager with the rights as listed in the blue column on page 5 would be easily downloadable from the web, easy for organisations to have as handouts to their patients, easy for patients to carry around with them. They can be made to look attractive but not big blocks of colour as in the draft document because it does not fax or photocopy well and uses a lot of ink when printing.

2. The Introduction on page 4 states the eight rights are statements about what patients are entitled to expect from the health system. I would have thought the whole point of using the health system was receiving quality of care, to expect a certain quality standard of care, to expect to get better or have the injury or disease managed under quality initiatives. In Australia quality would have to be relatively high/good compared with, say, a third world country. I'm disappointed therefore that there is nothing in the rights about quality of care. There is a "right" based around Safety that includes competent care, skill and competence but the word quality does not appear and it isn't the same thing. It makes a nonsense of all the quality programs run by various professional organisations not to include quality as something a patient has a right to expect. I think that above all

else we do expect a certain quality and standard of treatment and care, that when we agree to a treatment it is going to be administered/managed by health workers who are suitably qualified within a framework of quality programs and standards in place at the establishment where we receive the care. On page 5 it further states the rights in the Charter are essential to the provision of quality and safe health care and treatment. Where is quality of treatment dealt with in the set of rights. I realise this is a tricky one because not all people in Australia have quality of care but surely this Charter has the opportunity to raise the bar or is it that quality of care is not achievable in the current Australian environment. I have looked at a number of patient "charters" and similarly I can not find anything that equates to quality of care or treatment so possibly it is an intangible and unenforceable element of patient rights. The words safety and quality appear throughout the paper and therefore have an accepted different meaning to each other. One does not replace the other – they are different. To me it is not sufficient that it is implied, it needs to be stated. If safety also meant quality there wouldn't be an Australian Commission on Safety and Quality in Health Care, it would be the Australian Commission on Safety in Health Care.

There is nothing in the Charter about choice. This is another area where, with the increase in awareness of all things medical by patients, choice is an important part of treatment and care. Patients have a right to choose which medical establishment they want to be treated at, the choice of which treatments to accept and not accept, etc.

There is also nothing in the Charter about the right to know how much the medical treatment is going to cost because this will have an impact on a patient's choice, despite the statement under Access that public health care is based on clinical need. There are many examples where cost affects choice.

Access – I believe this needs to include race and background, not just monetary considerations.

Respect – while I agree that mutual respect between patient and provider/carer is the desirable outcome, this is a Patient Charter of Rights so in my opinion the mutual respect should be changed to state that the patient is entitled to respect, dignity and consideration.

Communication – it states "adequate" communication. Adequate is very pedestrian, I would like to see it changed to appropriate communication because communication needs will change and need to be appropriate to the circumstances. I would also like the word honest to be included because this is too often lacking. It also states, particularly when plans change... I believe this needs to be changed to, including when plans change... As it reads now, the emphasis is on changed plans rather than communication about health care and treatment in a language that can be understood. I would also like to see the words "and format" included after

language because it is a combination of presentation and language that makes information consumer friendly.

Information – it states what happens next which is unclear as to meaning. What happens next in what context. What about what happens next after next. I think I would like to know the planned care path at the beginning rather than keep waiting to find out about what happens next and next and next. Patients need information as well in advance as possible.

Participation – I would like to see the word treatment added so that it reads decision making about treatment and care.

Redress – the word properly is one of those meaningless, very subjective words (although many words in documents such as this are) and I don't know what it means in this instance. It needs to be clearer.

3. In the preamble on page 6 it states the word patient includes, as appropriate, families, carers and other nominated support people. This means that not only are the rights not stand alone and require explanation but also the principles are not stand alone, they will always need an explanation to go with them to explain the principles which explain the rights... A lot of explaining...

I'm not sure who the principles are designed for, who is the audience? I am certain these explanations are not going to assist in understanding the rights because no one is going to read them, cross reference them with the rights and then find this of assistance. The wording of the rights, explanation of rights and principles are slightly different which is confusing.

4. Principles: Respect – the first paragraph needs to go. This is supposed to be a patient charter of rights yet it is giving patients an edict. There must be...how condescending. I have no argument that mutual respect is paramount but this is not the forum.

Principles: Information – the two paragraphs at the end need to go. Again, this is a patient rights charter. I absolutely agree that patients have an obligation to do certain things but if this is a charter of patient rights, then these condescending "you must" and "are expected" have no place in it. Rights and obligations are different things and need to be shown differently.

There should be no emphasis on patient responsibilities unless these are shown as a separate set of edicts in another time or place. Interspersing them in patient rights is confusing. The emphasis here is on patient rights and it diminishes the impact of this message if it includes provider rights as well.

5. The rights are so general that they would fit into any existing charters and there is no harm at all in organisations reviewing their charters in the light of the release of a national charter. Here the Commission has the

opportunity to bring the health system up a notch which is in the interest of patients and providers rather than being hesitant and apologetic about what this might mean to individual charters.

Whether the national charter overlaps with other charters is neither here nor there. If extensive research and consultation result in an agreed set of rights then other less overarching charters need to adjust. In any event, the rights are not a surprise or innovative, they are the rights everyone would expect to see.

6. The only way the charter will be used is if there is an imperative for it to be used such as legislation. These are basic human rights and if the Commission is serious about making a difference then they need to do more than just have a nice set of rights that sit on a website to show how hard everyone has worked or in dusty documents on a shelf to be looked at years ahead and quoted in yet another research project about patient rights.

Again, they are so very general and there is no indication even in the principles of the level at which any organisation or individual has to apply them. At best the rights are an indication of what the government expects from the health service and at worst, any one of them could be weaseled out of, even given the addition of meanings and principles if they are not legally enforceable. It will depend entirely on how individual health organisations/providers do business as to the uptake of the rights.

7. I didn't think there was any doubt these broad rights are applicable in practice because they are basic to the needs and expectations of the Australian community. As above, they are very broad in nature and I can not foresee any difficulty in adapting them to community needs. The difficulties will appear when providers do not believe it desirable to give patients these rights. There are examples of providers complying with accreditations and audits yet at the same time denying basic patient rights.

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