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AUSTRALIA

VIA AIR MAIL

Dear Cheryl

Draft Code of Health Rights and Responsibilities

Thank you for asking me to comment on the Draft Code of Health Rights and Responsibilities (the Draft Code). Congratulations on drafting a comprehensive document, which no doubt has attracted some healthy debate. I acknowledge the magnitude of the task of drafting such a document and of this consultation process.

As New Zealand Health and Disability Commissioner, one of my functions is to make public statements in relation to any matter affecting the rights of health or disability services consumers.¹ I hope that you find my observations useful in developing a Code that affirms and promotes health rights.

New Zealand's experience

I note that, in Section 1 of the consultation paper, you have referred to the fact that the HQCC drew heavily on the experiences of the Northern Territory and New Zealand. I have therefore set out below a brief outline of the New Zealand Code of Health and Disability Services Consumers' Rights (the New Zealand Code) and a comparison of the similarities and differences between the Draft Code and the New Zealand Code.

New Zealand's Code

The Health and Disability Commissioner Act 1994 (the New Zealand Act) established the Office of the Health and Disability Commissioner. The purpose of the Act is "to promote and protect the rights of consumers of health and disability services and, to that end, to facilitate the fair, simple, speedy and efficient resolution of complaints relating to infringements of those rights" (section 6). This objective is achieved through the implementation of the New Zealand Code, the establishment of a complaints process to ensure enforcement of those rights, and the ongoing education of providers and consumers.

¹ Health and Disability Commissioner Act 1994, section 14(d).

The Act lists a number of matters that are to be covered by the New Zealand Code, which came into force in July 1996 as a regulation under the Act. The Code creates legal rights for consumers and imposes corresponding duties on providers of health and disability services in New Zealand. The New Zealand Code applies to health consumers and disability services consumers as they are defined by the Act (see sections 2-3). Under section 3 of the Act a “health care provider” includes a number of persons and includes any other person who provides, or holds himself/herself out as providing health services to the public or to any section of the public. Consumers of health and disability services have ten rights under the New Zealand Code, which focus on the quality of health and disability service delivery.

Comparison with the Draft Code

Both the Health Quality and Complaints Commission Act 2006 (HQCCA) and the New Zealand Act include in their purposes the promotion and preservation (or protection) of rights. Whereas the New Zealand Act refers to the specifically to the rights of consumers, the HQCCA refers more generally in section 3(2)(e) to “health rights”. Furthermore the HQCAA contains a specific provider entitlement (in section 34(d)), whereas New Zealand Code enunciates that consumers have rights and providers have duties. In New Zealand, while user behaviour is relevant to assessing whether a provider has fulfilled his or her duty, the statutory responsibilities lie with the provider.

I also acknowledge that the HQCCA covers users of health services (but not users of disability services, who are covered under the New Zealand Act), and health information privacy (which is covered by the Privacy Commissioner in New Zealand).

Finally, I note that there is no provision for access to remedies for breaches of the Code in the HQCCA, such as that granted by sections 50-58 of the New Zealand Act (which empowers the Human Rights Review Tribunal to grant remedies for breaches of the New Zealand Code).

General Observations on the Draft Code

Rights, entitlements, responsibilities, and guidance

It seems that the Draft Code affirms pre-existing and recognised fundamental user rights (with corresponding absolute provider obligations), creates some user and provider entitlements, and also includes other matters which might be considered advice or guidance. The risk of including the range of basic rights along with some merely desirable entitlements is the dilution of strong rights. Furthermore, the lesser entitlements that have been specifically singled out may also take on a greater significance than some equally important ones that have been excluded or taken as read.

Referring to both user and provider responsibilities being conduct that each “should” engage in implies that users and providers have equal obligations in relation to the provision of health services. This is concerning, given that providers clearly have a number of mandatory responsibilities. I therefore recommend that these mandatory responsibilities are distinguished from those that are merely desirable actions. It may therefore be desirable to alter some of the language accordingly, and I elaborate on this later.

I note that the consultation paper explains that “health service provision should not be contingent *solely* on the health service user fulfilling their responsibilities” (Section 1, paragraph 7 – italics added). Given the extensive responsibilities place on users in the Draft Code, I suggest that there should be an explicit statement that the provision of health services **should not be** dependent on users complying with the responsibilities set out in the Code.

User responsibilities

In developing the content of the Code, the Queensland Commission was required under section 34 of HQCCA to have regard to a number of entitlements for users. However, also included is one entitlement for providers, being:

(d) *an individual who provides –*

(i) *a health service; or*

(ii) *care for another individual receiving a health service;*

is entitled to consideration and recognition for the contribution the individual makes to health care;

I have previously written on the issue of patient responsibilities and provider rights.² I acknowledge the relevance of patient responsibilities, such as those set out in the Northern Territory Code of Health and Community Rights and Responsibilities (NT Code). I have a great deal of sympathy for the situations many providers face, such as the Emergency Department worker who is subjected to abusive and even violent behaviour. It would seem that this type of situation was contemplated by section 34(d) of the HQCAA. However, I query the apparent shift of responsibility from the provider to the user in relation to a number of areas, such as communication and provision of information.

It should be borne in mind that one key reason for patients to participate fully in their care, by asking questions and seeking clarification, etc. is that patient involvement promotes good health outcomes.

Before turning to the specifics of the Draft Code, it is useful to consider further the nature of the therapeutic relationship.

Therapeutic relationship

My primary concern with the Draft Code is that a sense of patient autonomy and partnership between user and provider does not emerge. Rather than enabling or empowering users to participate fully and make choices regarding their healthcare, the tenor of the Code leans towards dictating to users how they must behave. I suspect this is the opposite effect of what was intended.

² Ron Paterson, “Rights and Responsibilities – a two-way street” *NZ GP* 16 October 2002: available at www.hdc.org.nz/publications/articles.

As you know, community expectations have moved a long way from a time where it was felt “Doctor knows best” and the patient never questioned professional advice. The relationship today is one of partnership between the health practitioner and the patient.³ This partnership model is emphasised in Section 1 (Background and Information) of the consultation paper (Paragraph 7), where it is acknowledged that partnership is required to assist “in the journey toward a culture of empowerment of health service users, and optimisation of health”. It is also recognised by a number of healthcare professions in Australia, for example, the Australian Medical Association Code of Ethics (2006) refers to the doctor-patient relationship as “a partnership based on mutual respect and collaboration” (Preamble).

However, the user is reliant on the provider’s training and expertise, and therefore the relationship is not an equal one. The power imbalance inherent in the health practitioner-patient relationship is acknowledged in the *Statement on Sexual Relationships Between Health Practitioners and their Patients*, endorsed by 12 Queensland health provider boards:

“1.3 The relationship between a health practitioner and a patient is not one of equality, because the patient is seeking assistance and guidance, and may need to reveal intimate physical and emotional details.”

Professor Ian Kennedy provides a comprehensive statement on the nature of the doctor/patient relationship in his essay “Patients, Doctors and Human Rights”:⁴

“As between the doctor and the patient there is an inevitable imbalance or disequilibrium of power. The doctor has information and skill which the patient, who lacks these wishes to employ for his benefit. When it is remembered that among the powers possessed by the doctor is the privilege to touch and even invade the body of another and as a consequence exercise control to a greater or lesser extent over that person, it will be clear that, with the best will in the world, and conceding the good faith of the doctors, such powers must be subject to control and scrutiny, from an abundance of caution. This is the role of patients’ rights, whereby the permissive limits are set by ethics and law to the exercise of the doctor’s power.”

The factors he outlines apply in varying degrees to all therapeutic relationships, whether or not the provider is a registered practitioner. I believe these factors are useful to remember when discussing health rights and responsibilities.

Size and format

You have prepared a very comprehensive Draft Code. However, I draw your attention to the advantages of a simple document that can be referred to quickly and easily navigated. Both the Northern Territories Code and the New Zealand Code fit easily on two sides of an A3 size piece of paper which can then be folded into a brochure. The headings for each of the rights are readily identifiable. The language used to describe the rights and responsibilities is comprehensible to laypersons. In my view, a simpler document is more accessible to users and providers, and is therefore more effective. I recommend that this is considered when finalising the Code.

³ For an excellent overview of the components of the therapeutic relationship, see College of Nurses of Ontario *Practice Standard: Therapeutic Nurse-Client Relationship* (2006, Pub. No. 41033): available at www.cno.org.

⁴ Ian Kennedy, *Treat Me Right: Essays in Medical Law and Ethics* (Oxford University Press, 1988), p 384.

I note that, in the Draft Code, each main heading and sub-heading refers to a right to which a user is entitled, but the detail in each paragraph sets out responsibilities of both users and providers. A clearer format would be to set out the right of either the user or provider with the sub-rights articulated below. With the current format, a user reads of the existence of a particular right, but then goes on to read about a number of user responsibilities, rather than the sub-rights expected. This might be remedied by a change in the language as suggested below.

The obligations that are currently then set out do not always relate very clearly to the heading above. For example Right 1, which is directed at users, advises of the right to timely and accurate information about health services. Right 1.1 (Health service users are entitled to information regarding health care) is consistent with that, but Right 1.1.1 refers to the user providing information (to the provider). Because it is on the left hand side of the page, and precedes the provider's obligations in 1.3, it has more impact than 1.3. Since the main headings of the rights refer to users' rights, I recommend that you set out the rights of the user on the left or the responsibilities of the provider on the left. Another option would be to outline user responsibilities (and provider rights) in a separate document that would provide guidance to users on how they can contribute to their own care.

Use of certain language

In my opinion, on the provider side of the document, the use of the word "should" is not strong enough on some occasions. If the user has a right to information, for example, then the providers "must" provide users with the appropriate information. These provider responsibilities are absolute obligations, rather than merely optional or moral obligations (as is indicated by the term "should").

A number of user rights also seem to be expressed as responsibilities, particularly under Right 1. I suggest that the word "should" be replaced by "may" or "have a right to" or "are entitled to", in most instances throughout the document. It may be that some commentary could follow, for example that by providing as much information as possible the user is helping the provider to provide a better service.

It may be a useful exercise to differentiate between those matters which you consider to be absolute rights or responsibilities, and those which are desirable actions or helpful advice. The language and format should then reflect the appropriate category.

Right 1. You have a right to timely and accurate information about health services.

I have already commented on certain aspects of this above. The suggested change from "should" (to "may") is particularly relevant for paragraphs 1.1.1 and 1.1.2. I note that 1.1.3 refers to information to enable a reasonably informed decision to be made. I query this for two reasons. First, I suggest that information covers more than just what is required for decision-making (for example, the outcome of expected waiting times, costs, and tests). Having made a decision to undergo a course of treatment there may still be a great deal of information to which the user is entitled, such as cost, duration, recovery time, and so on. Secondly, the issue of informed consent is dealt with under Right 3, and so there appears to be some overlap between 1.1.3 and Right 3.

I was a little confused by the footnote reference to section 22 Civil Liability Act 2003, which covers peer professional opinion. I presume the reference is specifically referring to the exclusion under section 22(5), which makes it clear that peer professional opinion is not determinative of the information required to be provided to users. I wonder whether this footnote is necessary as it may serve to confuse rather than elucidate.

I thought that the second footnote contained some very pertinent guidance, which would be helpful to have within the body of the Code. I refer to this again under Right 3.

Paragraph 1.3.1 seems to put an onus on the user to ask the provider for information about the safety and appropriateness of a service that is recommended or has been received. The provision of such information would seem to be squarely the responsibility of the provider. Of course, if “should” was changed to “may” then this concern would be addressed. Likewise, I was concerned that there is an onus on the user to inform the provider if an interpreter is required (1.4.1). This could pose a significant obstacle if the user has a language difficulty.

I suggest that “may” is substituted for “should” in 1.3.2 and 1.5.1, as both these subparagraphs appear to refer to options that the user may wish to utilise to improve the quality of care provided (rather than obligations on the user). Alternatively, this guidance could be included into a commentary. I also note that the use of the word “relevant” in 1.3.2 (second sentence) presupposes that the user knows what is relevant, so seems to put an unreasonable obligation onto the user.

Right 2. – You have a right to take an active role and engage in a successful working relationship with your health service provider/s.

Because the Draft Code includes a number of user responsibilities, it would seem appropriate to have this right as the first right. This would set the scene for a successful working relationship in which users and providers appreciate the value of the user asking questions and actively participating in their care.

I was surprised that there is an obligation on the users to acknowledge the need for mutual respect and consideration (2.1.1), but there is no corresponding obligation on the providers included. I do not understand the reference to the “rights” of health service providers to deliver treatment plans (which would appear to be a basic duty of providers rather than a liberty), and therefore recommend removal of that phrase.

I appreciate that 2.1.1, 2.1.2 and 2.1.3 have arisen from situations where certain health service users have behaved in an extremely abusive or aggressive manner, as I noted above. However, I would be surprised if that is the norm. As drafted, these items tend to assume greater significance than is desirable. Most users conduct themselves in an appropriate manner. Of course, there are other users who, present with challenging behaviour, but with the exercise of appropriate skills by the provider the situation can generally be defused and managed. The difficulty with these items as drafted is that one gains the impression that users are “lucky” to be treated by providers, which may serve to alienate the parties rather than enhance the working relationship. My concern is that some providers themselves may inadvertently inflame situations and the tone of the current Draft Code supports that happening.

Accordingly, I suggest starting with the user's right to be treated with respect and moving on to their acknowledgement of the need to treat the provider with respect and that failure to do so will impede the provider's ability to provide the service. This might be an appropriate place to include the provider right as statutorily mandated in section 34(d) of the HQCCA (and currently framed as a user responsibility in 5.3.1). Finally, the right of a provider to restrict or withdraw treatment if the behaviour becomes intolerable could then be set out. I note that the NT Code specifically requires the provider to set out the standards of behaviour that are acceptable and make clear the circumstances in which a service may be withdrawn.

I also thought that this might be an appropriate place to include some of the matters contained in footnote 2, such as being culturally sensitive (which is not the same as the obligation to provide services that are free from discrimination in 2.2.3), and the use of an environment that provides for effective communication. These matters are key to a successful working relationship. I note that communication as a fundamental principle is covered in paragraph 7 of Section 1 (Background and Information), and yet this does not emerge with any force in the Draft Code.

I was surprised to see that the responsibility for identification of the user rests with the user (2.4). This is a particularly onerous responsibility where language and competence issues arise, and does not acknowledge that there may be situations where a user should be allowed to remain anonymous when receiving services.

Right 3. You have a right to take part in decisions about your health and informed consent.

I suggest that you add the words "to give" before "informed consent", and make similar amendments to 3.1, as a "right to informed consent" does not seem to make sense. It is useful to remind ourselves of the basis upon which the phrase "informed consent" has been coined.

As you know, the right to receive adequate information is a prerequisite to the giving of proper consent. It is helpful to remember that the primary obligation of the provider is to obtain consent to a procedure or treatment before it is carried out. Traditionally, failure to do so could amount to an assault or battery. It is now well recognised that mere consent may not be sufficient if the user did not know all of the possible risks, and so consent that is given without adequate information that is relevant to the user is not valid consent and may give rise to a claim in negligence.⁵

Therefore the essence of the right is that the user will not receive treatment without first consenting. The exception to that obligation is where there is an emergency situation or the consumer is not competent to consent. I note that the Draft Code is silent on that point, and on the means of consenting where the patient lacks capacity. I would strongly recommend those items are covered, along the lines of Principle 3(3) of the NT Code and Rights 6 and 7 of the NZ Code.

Legally valid consent is essential before providing services, and therefore the provider "must", rather than "should", ensure that all steps are taken to ensure that consent is obtained. Some of the items that are included in footnote 2 would fit logically under this 3.1.3, such as information regarding prognosis, treatment options and health care arrangements, the risks

⁵ *Rogers v Whitaker* [1992] HCA 58.

involved and the provision of answers to the health service user's questions. Principle 3(2) of the NT Code and Right 6 of the NZ Code cover these matters well. I suggest that these important elements will have more impact if specified within the Code, rather than referred to in footnotes.

Paragraph 3.3.3 raised some flags for me. There is potential for conflict where a user requests a certain consultant, procedure or medication where the provider cannot accommodate the request, for professional or practical reasons. I think that if the essential elements of the informed consent process are covered in the Draft Code, this paragraph would be redundant.

Reading 3.4.1 and 3.4.2 in combination leaves one with the impression that users must document written advanced health directives and that providers must respect that written directive. It should be made clear, however, that users are able to make decisions about their future care in any form they wish, including orally to the provider (who should document this decision).

I do not propose to comment in detail on the rest of Right 3 except to note again, that rather than setting out user rights or entitlements, the Code seems to be imposing new responsibilities on users.

Right 4. You have a right to the involvement of family, friends, carers or advocates.

My suggestions about use of language arise again here. The right of the user has been expressed as a responsibility rather than an entitlement, and the provider's obligations have been diluted. This is particularly evident in relation to 4.3.2, which states that the provider "should" respect the wishes of the user to withhold information from family and others. As worded, it is not consistent with 6.3.2 which states that the providers "must" respect the right to confidentiality of information. I recommend clarifying that providers must respect the wishes of the user to withhold information from other persons, except in limited circumstances.

A possible solution would be to shorten and simplify Right 4, so that it is similar to Principle 6 of the NT Code or Right 8 of the NZ Code.

Right 5. You have a right to service of a satisfactory standard.

The essence of Right 5 seems to appear in 5.2.3, 5.3.2 and 5.4.3. Paragraph 5.2.3 refers to legal, professional, ethical and other relevant standards. If there was a general sub-right entitling users to care that complies with these standards, you may find no need to have these paragraphs. Moreover, the other paragraphs such as 5.1.2 and all of 5.5, which relates to pharmaceutical services, would be redundant. The specific requirements of paragraph 5.5.3 are already set out within obligation 1.2 the Code of Professional Conduct of the Pharmaceutical Society of Australia, and so are covered under the Draft Code by the obligation to comply with professional standards (5.2.3). The information contained in 5.5.4 would undoubtedly be covered under the existing Right 1, which covers the right to information. I have already commented on the need to include a provider responsibility to ensure effective communication, which applies to all providers, not just pharmacists.

Footnote 4, which is placed immediately after the word “satisfactory”, refers to the Health Practitioners (Professional Standards) Act 1999 (the HPPSA) and the Nursing Act 1992. Because of its placement, I had assumed that those statutes would contain a definition of that word, but I have been unable to find one. The HPPSA does include as a ground for disciplinary action, “unsatisfactory professional conduct”, and I wonder whether that was what you were referring to. I note that the ground for complaint under section 48 of the HPPSA is much wider. The grounds for discipline under the Nursing Act include no reference to satisfactory or unsatisfactory conduct. Therefore the reason for the reference to those Acts is not clear to the reader.

Without a specific legal definition of the word “satisfactory”, I query that choice of word. It lends itself to mediocrity, which seems to be at odds with the objects contained in section 3 of the HQCC Act which makes repeated reference to improvement in the quality of health services.

Right 6. You have a right to access your personal health information, confidentiality and accurate record keeping.

My comments about the use of the word “should” in relation to users also apply here. In particular, I believe that placing an obligation on users to report hazards (5.4.2), and to ask questions such as those outlined under Right 5, is onerous.

I also note that 6.2.1 does not fit easily under 6.2, which relates to accurate recording of information. In my view, placing such an obligation on the user erodes the responsibility of the provider for careful and non-judgmental communication to assist the user in remembering events, ascertaining what is relevant, and disclosing sometimes very sensitive information.

Right 7. You have a right to comment on services provided to you and a right to an effective complaints process.

I suggest that the key Right here is the right to an effective complaints system. That is consistent with one of the mandatory requirements of the Code, as required by section 34(g) and with the object contained in section 3(2)(d) of the HQCCA of helping users and providers to resolve health service complaints.

Right 7.1 covers the entitlement to continuously improving health services, and ties in with the first right in Right 7. I wonder whether this is so much a right as one of the desired outcomes of responding appropriately to complaints and reflecting on practice, as referred to in paragraph 7.2.4. I note that one of the main objects in section 3(1)(a) of the HQCCA is improvement in quality of health services, and that one of the means of achieving that improvement is by helping users and providers to resolve health service complaints (s 3(2)(d)), and by preserving and promoting health rights (s 3(2)(e)). Therefore inclusion of 7.1 may be somewhat circular and superfluous.

Under section 20(1) of the HQCCA:

- “(1) A provider must establish, maintain and implement reasonable processes to improve the quality of health services provided by or for the provider, including processes –

- (a) to monitor the quality of the health services; and
- (b) to protect the health and well being of users of health services.”

Therefore a Code duty for the provider to comply with legal requirements would cover compliance with section 20. I suggest that further involvement of the users is better managed by the Commission’s power to set standards for compliance under section 20(2).

The important aspects of the complaints process are captured in 7.3.2, 7.4.2 and 7.5.3. In other words, there is a right to complain, users must be advised of it, complaints must be responded to and in a sensitive, fair and timely manner, and providers should endeavour to outline timeframes. I would therefore recommend a simplification of Right 7. Principle 8 of the NT Code captures this right well.

Notable Omissions

I have already commented on the need to cover the types of information that must be given by providers and consent in emergencies or where the user lacks capacity.

On a different note, there is no reference in the Draft Code to a right to be free from sexual or financial exploitation. I appreciate that many codes of conduct issued by professional bodies will cover these serious abuses of trust, and so a requirement that providers comply with professional and ethical standards will address this. That is not necessarily the case with an unregistered provider, particularly one who does not belong to any association. I have received a number of serious complaints concerning such providers including counsellors, massage therapists, acupuncturists and social workers. I understand that these groups, which are included in the declared health services contained in Part 1 of Schedule 1 of the HQCCA, also do not require registration in Queensland. A Code of Rights and Responsibilities is an ideal opportunity to set out this responsibility. You may be interested in a recent decision of the Human Rights Review Tribunal in New Zealand, where a natural therapist who had provided massage and counselling to his clients had sexual relationships with them. I **enclose** a copy for your perusal.

Conclusion

In providing you with my comments I have tried to bear in mind the differing legislative frameworks and environments of Queensland and New Zealand. I hope that my comments are helpful.

I acknowledge the invaluable assistance of Director of Proceedings Theo Baker and Legal Advisor Sarah Parker in preparing this submission.

Theo or I would be happy to come to a workshop on the draft Code, if that would be of value to the Commission.

With best wishes for your important work.

Yours sincerely

Ron Paterson
Health and Disability Commissioner

Enc. HRRT decision