Submission for the Review of the Health and Disability Consumers' Code of Patient Rights and the New Zealand Health and Disability Commissioner Act.

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[redacted]

30/7/24

Introduction

The Health and Disability Commission is faced with major challenges. Complaints are rising rapidly, funding has been cut and investigation reports are often not published until 2-4 years after the episode complained of.

The work the Commission does in receiving, responding and resolving complaints is essential. A complaint can often reflect a diminution of trust in the health and welfare system and having an accessible service to address those complaints is vital to try to maintain public trust.

When the Commission was first established in 1996 there was no significant ability for Consumers to have their complaints heard. Since that time the large majority of providers have developed systems for complaint management and quality improvement, under policy guidance from the Health Quality and Safety Commission, the Health Registration Authorities, and of course the provisions of Right 10.

In resolving complaints, I am sure that Commission staff facilitate complainants complaining first to the provider of care where possible. However, the Act does not reflect this when it says in 14 (da) *to act as the initial recipient of complaints about health care providers and disability services providers.* There will always be a role for the HDC to receive complaints in relation to services that do not have adequate complaints processes, and where the complainant is dissatisfied with the response they have received.

The Act also prevents people from complaining directly to the Registration Authority of the provider. At the time the Act was passed there was significant distrust particularly of the Medical Council of New Zealand, due to its over-reliance on input from the New Zealand Medical Association, and lack of transparency of standards. This has changed markedly and I can see no good reason for preventing people who wish to, from complaining directly to the MCNZ or any other registration authority.

These two changes in the way complaints are handled could decrease the pressure on HDC resources

The HDC has no particular expertise in research. The National Ethics Advisory Committee has developed expertise in this area. The HDC should remove this area from its workload and delegate ethical management of research to NEAC.

The definition of teaching is unworkable.

There is no clause that provides the ability to set aside a patient right to prioritise the needs of public health. This was highlighted during the recent pandemic. For example Right 4(3) (3) *Every consumer has the right to have services provided in a manner consistent with his or her needs*. Provision of many health and disability services were constrained to minimise the transmission of Covid19. People were discouraged from seeing the doctor if they had respiratory symptoms. People were turned away from laboratory collection centres if they felt unwell.

There is considerable overlap between the HDC and the HQSC and the Registration Authorities, that was not present when The Code was first established. Given the pressure on resources discussion on how to avoid overlapping work would be beneficial.

Proposed Changes:

Teaching and Research have different characteristics, and clauses relating to teaching should be separated from clauses relating to research

1. **Research**. The ethical control of research should be delegated to the National Ethics Advisory Committee

a) Amend clause in **Right 6**:

(d) notification of any proposed participation in research [delete teaching], ensuring that a properly accredited research ethics committee has approved the research protocol, and that the research meets all regulatory and ethical requirements, under the guidance of the National Ethics Advisory committee.

b) Amend **Right 9**

(a) The rights in this Code do not apply to those occasions when a consumer is participating in, or it is proposed that a consumer participate in,[delete teaching or} research.

Ethical guidance for research is provided by the National Ethics Advisory Committee. Any research conducted must have approval from a properly accredited research ethics committee and the research must meet all the regulatory and ethical requirements.

Add a new definition in **Section 4:**

Research; health and disability research is any social science; kaupapa Māori methodology; or biomedical, behavioural or epidemiological activity that involves systematically collecting or analysing data to generate new knowledge, in which a human being is exposed to manipulation, intervention, observation or other interaction with researchers either directly or by changing their environment, or that involves collecting, preparing or using biological material or medical or other data to generate new knowledge about health and disability.(1)(p28)

For detailed argument see:

Appendix 1 Gray and Ballantyne "Adult decision-making capacity and health research in Aotearoa New Zealand"

2. Teaching

a. Add new clause in **Right 6**

(d+) notification of any proposed participation in teaching; and

b. Amend **Right 9**

(b) notification of any proposed participation in teaching

Amend **Section 4 Definitions**

Teaching is where a patient, a clinician teacher and a student or students are present, and the interaction is for the purpose of teaching.

For detailed argument see:

Appendix 2 Gray Winters and Ormondy "An Ethical Framework for teaching, learning and student involvement with patient care"

3. Interpreters

Amend **Right 5(1)** *Every consumer has the right to effective communication in a form, language, and manner that enables the consumer to understand the information provided.* [Delete *Where necessary and reasonably practicable*], *this includes the right to a* **credentialed** [delete *competent*] *interpreter.*

See *Language Assistance Services: Operational policy for New Zealand Public Sector Agencies and those they fund 2024.* See section 2: Language Assistance Services: Operational Policy for New Zealand Public Sector Agencies and those they fund 2024 (mbie.govt.nz)

Also note that this amendment is required if Right 4 is to be protected:

Right 4

Right to services of an appropriate standard

(1) Every consumer has the right to have services provided with reasonable care and skill.

(2) Every consumer has the right to have services provided that comply with legal, professional, ethical, and other relevant standards.

(3) Every consumer has the right to have services provided in a manner consistent with his or her needs.

(4) Every consumer has the right to have services provided in a manner that minimises the potential harm to, and optimises the quality of life of, that consumer.

Amend **Right 6(4)**

This currently reads *Every consumer has the right to receive, on request, a[delete written] summary of information provided.*

There is no mention here of what action to take if the consumer's written language is not English. The costs of formal translation are prohibitive and in my experience never used. An appropriate alternative would be the provision of "sight translation" by an interpreter. The Code does not have to specify that manner in which a summary might be provided.

See *Language Assistance Services: Operational policy for New Zealand Public Sector Agencies and those they fund 2024 (section 4.5.4)* Language Assistance Services: Operational Policy for New Zealand Public Sector Agencies and those they fund 2024 (mbie.govt.nz)

4. Public Health

Amend section 3:

(3) For the purposes of this clause, the circumstances means all the relevant circumstances, including the consumer's clinical circumstances, public health requirements, and the provider's resource constraints.

5. Adult Decision Making

Right 7(4) sets out the process for decision making in the event that a patient is assessed as lacking capacity. This section is the subject of detailed investigation by the Law Commission. The process reflects the current law. I hope that in proposing changes to the current law that consistency will be achieved between the HDC and the Law Commission.

The process described in 7(4) does not reflect regular practice for example in Rehabilitation wards where the process is much more around getting agreement from all those involved in the decision rather than focussing on which individual has the right to make the decision.

(4) Where a consumer is not competent to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where—

(a) it is in the best interests of the consumer as judged by the clinicians, the patient to the limit of their capacity, close family members and others affected by the decision and an agreed management plan has been reached; and

(b) reasonable steps have been taken to ascertain the views of the consumer; and

DELETE*[(c) either,—*

(i) if the consumer's views have been ascertained, and having regard to those views, the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if he or she were competent; or

(ii) if the consumer's views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.]

(c) If an agreed management plan cannot be reached then a mediator be appointed to help resolve the disagreement.

Best Interests is a problematic concept that is inevitably subjective. The problem arises if the view of "best Interests" that the provider holds differs from any of the other people involved in

the decision. Currently there is no guidance suggesting that reaching agreement should be a goal, nor any mechanism to resolve conflict. HDC is developing a mediation service and this would be a good setting for it to be used.

For detailed argument see:

Appendix 3 copy of submission to the Law Commission from Assoc Prof Ben Gray.

6. The Health and Disability Commissioner Act 1994 section 32.

This section in conjunction with section 64 of the Health Practitioners Competence Assurance Act 2003 has the effect that a consumer of health services cannot complain to the registration authority of the provider without the complaint being referred to the HDC. However, another practitioner is able to raise competence concerns about a colleague directly with the Resgistration Authority. This inconsistency is illogical.

The HDC should recommend **that section 64 of the Health Practitioners Competence Assurance Act** be rescinded.

7. Health and Disability Commissioner Act 1994 section 14(da)

Ammend to act as a [the initial *delete*] recipient of complaints about health care providers and disability services providers, and to ensure that each complaint is appropriately dealt with.

Complainants who wish intervention by registration authorities should be able to complain directly to them, for example incidents of sexual impropriety.

8. section 2 and 34

The Act does not refer to the Health Quality and Safety Commission.

Section 2 should be amended to include

Health Quality and Safety Commission means the Health Quality and Safety Commission as established under the Public Health and Disability Ammendment Act 2010

Section 34 should be amended section 34(c)

to the Director-General of Health or the Health Quality and Safety Commission *if it appears from the complaint that failures or inadequacies in the systems or practices of the health care provider or the disability services provider concerned may harm the health or safety of members of the public; or*

1. National Ethics Advisory Committee. National Ethical Standards for Health and Disability Research and Quality Improvement. In: Ministry of Health, editor. Wellington New Zealand2019.

Appendix 1

Adult decision-making capacity and health research in Aotearoa New Zealand

Associate Professor Ben Gray

Associate Professor Angela Ballantyne

Summary

The Code of Health and Disability Services Consumers' Rights (The Code) is up for review. The Code currently applies to both clinical care and research. When it was introduced, there were no mechanisms to control research but since then the National Ethics Advisory Committee (NEAC) has developed detailed guidelines and established a network of ethics committees at various institutional levels. As currently written The Code prohibits research on a patient who lacks capacity unless it is in their "best interests". This precludes some important research. The NEAC guidelines are more nuanced and measured, designed to balance the risks to the patient with the benefits to the community. We argue that The Code should be amended and should no longer apply to research and that management of research ethics be delegated to NEAC.

The Health and Disability Commissioner is currently conducting a review of The Code of Health and Disability Services Consumers' Rights (The Code)(1) and Health and Disability Commissioner Act (the Act). We are concerned about the role of The Code of Health and Disability Services Consumers' Rights (The Code) in limiting research with adults who lack the capacity to consent.

When The Code of Health and Disability Services Consumers' Rights (The Code)(1) was introduced in 1996 it was groundbreaking legislation, which for the first time provided normative standards for clinical care, research and teaching; quality improvement obligations, and a complaints mechanism. The Code works well in the context of clinical care. We think, the Health and Disability Commission

should focus exclusively on complaint resolution for *clinical care* and delegate the setting of normative standards for research to the National Ethics Advisory Committee.

Research is a more complex and multi-dimensional practice than the provision of clinical care. The goal of clinical care is to benefit the patient. While there may be disagreement on which course of action is in the patient's best interests, both clinicians and patients are typically aligned in their intent. By comparison the goal of research is to produce generalisable knowledge to benefit future patients – specifically to provide new knowledge to prevent, identify and treat illness and disease. (2) Therefore, in research, the goals of the researchers may conflict with the goals of the research participants – who are often motivated by the prospect of personal benefit, access to otherwise unavailable procedures or drugs, or last-ditch attempts at lifesaving interventions. A decision to proceed with clinical care involves the patient and clinician balancing risks and benefits for the specific patient. A decision about research requires research teams, research ethics committees and clinical governance groups to assess and weigh the risks to the participants against the potential benefits to the population. Exploitation is a greater threat in research than in clinical care. As a result, the National Ethics Advisory Committee (NEAC), established in 2001, issues detailed guidelines that set out the ethical standards that must be met by researchers when they undertake health and disability research in Aotearoa New Zealand(2). The current National Ethical Standards are 250 pages long, far exceeding the guidance offered in the Code.

Tensions between the application of the Code to clinical care versus research are most notable in relation to the Right 7(4) which requires that when the consumer (patient or research participant) is not competent to make decisions for themselves, providers (doctors or researchers) must act in their best interests. A report from the HDC Commissioner describes this issue succinctly:

When someone is unable to give informed consent, in certain limited circumstances, including that the research will be in the person's "best interests", Right 7(4) of the Code allows the person to be enrolled as a research participant. The "best interests" test does not

provide for any consideration of the potential for advances in knowledge that may benefit people other than the participant.(3)(p6)

Right 7(4) is particularly problematic for research with adults who are unable to give consent. A person with capacity can choose to be part of a research study because they value contributing to knowledge that will benefit other patients. But for a patient lacking capacity, the "best interests" test in Right 7(4) applies and research cannot proceed unless it is deemed to be in the best interests of the patient. In a letter from NEAC to the Minister of health on this topic they described a study that could be affected by these constraints: `

Among patients who are hospitalised with severe traumatic brain injury, 60 percent either die or survive with severe disability. One treatment - a decompressive craniectomy - showed promise in reducing deaths caused by traumatic brain injuries. To see whether this treatment that had started to become commonplace was the best approach, a study was conducted in 2011.(4) This study showed that what appeared to be a treatment with good outcomes, in fact ended up being worse for patients. The study's results, by changing standard practice, also saved an estimated 20 million dollars a year for New Zealand. (5)

As a matter of justice, all classes of patients deserve good evidence to inform their clinical care; this includes patients with conditions that impair their capacity to consent either permanently or for a critical period of time (e.g. dementia, lack of consciousness with a critical injury). If clinical care is offered during this period, we need evidence to inform this care. Inevitably this will entail some form of research. Conservative research ethics paradigms that restrict research with these groups may further entrench their vulnerability by denying them access to the standard of evidence-based clinical care that other, non-vulnerable groups, expect. This is unjust.

Balancing these competing interests, and adequately protecting patients who cannot consent themselves from exploitation in research, requires detail and nuance that is beyond the scope of the

Code. NEAC has developed considerable expertise in setting pragmatic standards that carefully navigate the complex interests at play in research. NEAC has expanded research ethics beyond the narrow protection of "informed consent" to include other ethical values, particularly those of more relevance to Māori.(6) NEAC has supported the development of a network of ethics committees at various institutional levels to provide guidance and review of specific research studies.

By comparison, the HDC has developed into an agency whose primary expertise is receiving and resolving complaints about individual level care. A search of HDC decisions for "research" locates just three cases of decisions relating to research. HDC has limited expertise in considering the balance between patient rights and population benefits in health research. It is redundant, confusing and constraining to have two agencies in Aotearoa New Zealand setting normative standards for health research.

The Medical Council of New Zealand is also responsible for setting standards for the ethical conduct of doctors in Aotearoa. But the Medical Council has largely delegated the task of balancing the benefits of the research with the risks to the participant to the NEAC ethics approval process (ref sec 81); and we argue that HDC should do the same. The HDC is under considerable resource pressure because of rising complaints (7) it would be sensible to focus their resources on complaint resolution and that they delegate the ethical control of research to NEAC.

Conflicts of Interest: Ben Gray and Angela Ballantyne are not and have not been members of NEAC.

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Appendix 2

An Ethical Framework for teaching, learning and student involvement with patient care.

Associate Professor Ben Gray

Dr Janine Winters

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Introduction

There is significant variation internationally in ethical guidance on teaching and involvement of students in patient care.

The New Zealand Code of Health and Disability Consumers' Rights(The NZ Code) specifies that all the rights in the code that apply to patient care also apply to teaching(1) (Rights 6 and 9) and defines teaching as including training of providers(1)(Section 4). A recent paper has provided an interpretation of implementing this clause for medical student involvement with patient care(2). Informed consent is required for all teaching.

The British General Medical Council requires consent for involving patients or volunteers in teaching(3)(clause 25) with no definition of teaching.

The Australian Medical Board requires patients to be Informed about the involvement of medical students and consent obtained for student participation, while respecting their right to choose not to consent(4).. Like New Zealand this has been interpreted to mean that informed consent is required for medical students to be involved. It makes no comment about teaching graduate students.

The American Medical Association Code of Ethics (AMA Code) requires that patients are aware that medical students may participate in their care and have the opportunity to decline care from students(5).

The World Medical Association Code of Ethics just says The physician must accord due respect to teachers and students(6) (clause 33).

The UNESCO Universal Declaration on Bioethics and Human Rights makes no mention of clinical teaching(7).

This divergence of positions is in sharp contrast to the general agreement in relation to consent for research and consent for clinical care(1, 4, 6, 7). This paper will discuss how to address consent for teaching and student involvement in patient care.

The ethical differences between clinical care, research, and teaching

The goal of clinical care is to benefit the patient. While there may be disagreement as to which course of action is in the patient's best interests, and treatment availability may be constrained by resource limitation, both clinicians and patients are typically aligned in their intent. By comparison the goal of research is to produce generalisable knowledge to benefit future patients – specifically to provide new knowledge to prevent, identify and treat illness and disease(8). The goal of clinical teaching is to train future doctors, for the benefit of future patients, although much teaching particularly for early post graduate doctors is interwoven with clinical care. Patients may wish to be cared for by the most senior doctor available(9)(p 24). In research and teaching the goals of the researchers and teachers may conflict with the goals of the research participants/patients.

For clinical care a process relying on Informed consent for a patient with capacity and best interests for those lacking capacity is the best approach. A decision to proceed with clinical care involves the patient and clinician balancing risks and benefits for the specific patient. A decision about research or teaching involves balancing of the risks and benefits to the individual patient and the benefits to the wider population. Exploitation is a significant threat in research, and detailed guidelines are needed to minimise the risk, along with a requirement for informed consent from the patient. The risks and benefits of teaching have been the subject of limited research and discussion by comparison with clinical care or research.

Definitions

Clinical care is reasonably straight forward to define, it is the service that a health provider provides(1).

By comparison the definition of research requires more attention. There is variation in the degree of formality of research studies. At one end is the classic double blind control trial, at the other would be the new knowledge gained whenever a patient is treated, and outcomes are measured. In New Zealand the ethical risk to the patient of quality assurance and quality improvement activities has been decided to be so low that it is outweighed by the benefits(8)(p31), and is not included in a definition of research for the purposes of considering ethical oversight. Also excluded are Public Health investigations, Public Health surveillance, routine Public Health activities and pharmacovigilance(10)(p29-30).

The definition of teaching, learning or training of providers also needs more attention. As with research many clinical interactions result in learning for the clinical staff involved, whether medical student, postgraduate student or fully qualified doctor. As with research

we need to define what teaching results in sufficient ethical risk to the patient to warrant ethical guidance. Our proposal is that we define teaching as an episode where the patient, a clinician teacher and a “student or students” are present, and the interaction is for the purpose of teaching, with no clinical benefit for the patient.

It is unclear exactly what consent means without a broader definition. Informed Consent (as is required in New Zealand) is an ethical concept that is defined as having five elements;(1) Competence (2) Disclosure (3) Understanding (4) Voluntariness and (5) Consent(11).(p 120). Tunzi(12) suggests the idea of a consent continuum that lies between full informed consent through permission, agreement, to non-dissent. On their paper on student involvement in patient care in New Zealand Walker et al say that the consent process should be proportional to the student involvement and the risk and inconvenience to the patient(2).

The risks of teaching

Atul Gawande identified the central ethical problem:

> *this is an uncomfortable truth about teaching. By traditional ethics and public insistence (not to mention court rulings), a patient’s right to best possible care must trump the objective of training novices. We want perfection without practice. Yet everyone is harmed if no one is trained for the future.(9)(p24).*

It seems intuitively true that receiving care from a fully trained person is better than having the same care from a lesser trained person. This would be unequivocally true if a fourth-year medical student were to perform a an appendicectomy without supervision. It is much harder to determine the level of risk in less extreme examples. This issue of how to manage

the risk of work being done by a junior has traditionally been addressed within the apprenticeship model. Doctors are taught using the apprenticeship model(13, 14). The interpretation of this model developed by Lave and Wegner(15) can be applied to medicine. Novices or apprentices are given small tasks with limited responsibility, then tasks of increasing complexity and responsibility until they become full members of a 'community of practice'. They are developing into a master in the context of the community. The care provided in a teaching hospital is not provided by individual doctors but by the 'community of practice'(16). The learning is intimately woven into the provision of care. Our public hospitals are dependent on this apprenticeship model to be able to function. Care is provided by teams of medical students and doctors of varying degrees of experience and qualification. Senior students and junior doctors will do many routine tasks such as taking blood tests, inserting intravenous lines, or taking the initial patient history, leaving the fully qualified doctors the time to do the tasks that require extra skill and experience.

While it is said that doctors are trained as apprentices, getting informed consent for apprentice involvement is not usually part of this model. There is no expectation of consenting the role of the apprentice when engaging a builder, a lawyer, an accountant, or an engineer. The contract is with the principal, who takes responsibility for completing the task. They decide whether their juniors are capable of elements of the task and provide supervision varying according to the level of accomplishment of the trainee. For each task, the principal is best suited to judge the trainee's capability, based on understanding the task's requirements and the trainee's abilities. They decide whether the task should be done under close supervision if it is particularly crucial and the trainee is a novice, or under no supervision if the task is more routine and within the ability of the trainee. These decisions are made based on the principal's judgement rather than measurable facts. Patient

accountability is held by the principal, based on developing the trust of the patient. Clinical care and research studies will often have significant amounts of empirical evidence that addresses the risks and benefits to the patient. By comparison there is unlikely to be useful empirical evidence relating to a particular learning episode. Gawande describes how he learned to insert a central venous line(9)(p11-) The risk of this procedure is hard to describe. It may be the first time the student has done the procedure, but what other similar procedures have they done? How good is their knowledge of anatomy? Are they particularly dextrous in general or are they ham fisted? A knowledge of the status of the learner is a poor guide to their ability to perform a particular task, which is more related to what specific experience they as an individual have had. The supervisor is the best judge of this risk. The act of supervision significantly decreases the risk, not only because of ensuring that the student is doing the task properly, but also because of the extra pair of eyes and hands present. The riskiest episode inserting a central line might be the first time it is done without supervision…depending on how many times it is done with supervision.

A consequence of this discussion is that informed consent is not a useful protection for patients, due to the lack of useful information. A process of having consented for the procedure with the supervisor, and having developed trust in their judgement as a provider and thus trusting their judgement that the risk of student performing the task is low is the process used in all other professions and is the best option for medicine too.

The benefits of teaching

The benefits of teaching are not always apparent to patients. In its statement on medical student involvement in patient care the American Medical Association says:

Much to the benefit of patients and medical education, medical students are participating in patient care from the start of their medical education. Initially, students may be mere observers, but soon they assume more responsibilities, such as monitoring the condition of patients and even becoming involved directly in treatment. Patients and the public benefit from the integrated care that is provided by health care teams that include medical students and other trainees. Students' limited experience is counter-balanced by the supervisory structure of medical teams and patient care generally is enhanced by the involvement of medical students.(5)

Historically, teaching hospitals were seen as more prestigious, and it was expected that trainees would be involved in care. Outcomes have been shown to be better in teaching hospitals compared to non-teaching hospitals(17). Teachers also learn from the process of teaching(18, 19). An essential role of the student is to ask why. As clinicians the authors have all benefited from the extra rigour required when consulting with a student present, of needing to justify the approach we are taking.

As part of the community of practice, students have more time than their seniors and can spend extended time with patients. They have the opportunity to do a more thorough history and examination and may identify important information or unexpected examination findings that benefit the patient's clinical care.

Medical Education

Whilst we use the apprenticeship model in medicine it is significantly complemented by learning away from the patient. This will include learning around all the sciences that apply

to medicine but also teaching of clinical skills in simulated settings. At our school there are three years of pre-clinical education followed by 3 years of advanced learning where the theoretical learning is combined with clinical exposure either as part of a clinical team as an "apprentice" or clinical teaching that occurs separate from the provision of care, where the patient, a clinician teacher and a "student or students" are present, and the interaction is for the purpose of teaching. Rowland et al did a literature review of what they described as the disparate body of literature on patient involvement in teaching, that is challenging to research, and came up with three interpretations of patient involvement in health professional education; patient as teachers, real patients as standardized patients, and bedside learning(20). Gaining consent for student involvement in these settings would be normal practice.

Social Obligation

A meaningful choice to be cared for only by a fully trained doctor is only available to New Zealand people who can afford to see a specialist in private, or in primary care practices, that decline to take students. This is not a realistic choice for most people seeking care in the public health system in New Zealand.

The social obligation to participate in research(21, 22) has been examined by scholars and ethicists. If individuals want to benefit from the findings of research, then there is some degree of obligation to be available to participate. It is argued that those who decline to participate in research are "freeloading" on those prepared to accept the risk and inconvenience of participating.

Like research, but to a much greater extent, there is a social obligation for patients to participate in training clinical staff. If informed consent is required for medical students,

then it is necessary for all other health students. It also applies to all the other nonprofessional staff involved in patient care, including those in training. To train the workforce that we need, we will need many more people to accept care from a student than currently happens. In 2022, over 290,000 weeks of placements were needed to train pre-registration health students(23). If being involved with teaching is a burden for patients, then it is fairest if that burden is shared by all rather than just those who cannot afford to avoid it.

Medical Student Involvement in Patient Care

If we are teaching medicine according to the apprenticeship model, there is no clear reason as to why the requirements for medical students should be any different from post graduate doctors who are learning. If there are risks involved in teaching then they are present for all teaching, no matter the level of the student. Part of medical student learning is understanding the codes of practice that they will adhere to when they graduate. In New Zealand the Code applies to any health provider which includes all students providing care. Any skill or procedure is learnt by firstly understanding the theoretical background (for example the anatomy of the chest for a central venous line). Secondly the procedure is observed and then it is attempted under close supervision. Walker et al(2) provided an interpretation of the NZ Code applying a mandatory requirement to obtain consent for teaching for medical student involvement. Their view was that;

1. students should not be involved with an unconscious patient unless they were needed to assist in providing lifesaving care(2)(p89)
2. the role of students in ICU should be restricted to observation (p91)
3. the student role in caring for babies should be limited to observation.(p92)

4. If the patient lacks capacity then student involvement should be limited to involvement that is in the patient's best interests.(p92)
5. That extra care be taken with gaining consent from vulnerable patients with sensitive examinations, withdrawal of life support, organ donation or the communication of bad news.

Any harm to a patient involved in any of these circumstances from a medical student being involved for the first time, will be no different from the harm experienced with a first-year postgraduate student involved for the first time. Limiting medical student involvement in this way will delay their professional development and present a serious risk that as a new graduate they are called on to do a task that they may not have attempted or may not have even observed before.

An Ethical Framework for teaching, learning and student involvement with patient care.

Standards should apply to all episodes of teaching irrespective of the role of the trainee.
If there are ethical risks to teaching then those risks are present whether the trainee is a medical student, a post graduate doctor or a fully qualified consultant learning a new procedure.

Information that teaching is part of the work of the institution.

Patients need to be informed that students are part of their care team (see quote above from AMA) and that the general expectation is that they will be involved in care.

Adequate Supervision is provided.

The AMA Code(24) has a requirement that adequate supervision is provided, with detail as to how this should be carried out. This is an essential part of a framework for teaching.

Consent for Teaching

The element of teaching that was the trigger in New Zealand for the inclusion of teaching in the NZ Code, and is specifically referred to in the USA(25), Australia(26) was the vaginal examination of women performed by medical students without their knowledge or consent. It is now widely accepted practice(25-27) that intimate examinations by medical students performed on anaesthetised patients for the purpose of learning the procedure, requires written informed consent.

Consent is required for teaching where the patient, a clinician teacher and a "student or students" are present, and the interaction is for the purpose of teaching. This is particularly important where the patient is anaesthetised.

Consent for teaching is not required where the teaching is part of the provision of clinical care.

As with research we can define what teaching requires ethical oversight. Teaching provided during clinical care where the student is being supervised is of low ethical risk. It is of high value in educating the student and in general patients have a social obligation to be involved in teaching. The ethical oversight of teaching that is included during the provision of clinical care, is achieved by adequate supervision. Consent for that teaching is not required. All the other requirements that relate to clinical care apply.

Transparent information about identity

The NZ Code explicitly requires all providers to inform the patient of their identity and qualification. The AMA Code is explicit saying *"Inform the patients about the identity and training status of individuals involved in care. Students, their supervisors, and all health care professionals should avoid confusing terms and properly identify themselves to patients." (5)*

There are inevitably exceptions to this particularly for patients who either temporarily or permanently lack capacity. An apprenticeship approach is taken with consent for surgery

where the surgeon gets the consent of the patient. The patient will be unaware of who all the personnel in theatre might be but trusts the person to whom they have given consent to care for them. In this context it would be illogical to require consent for a medical student to be present to either observe or participate under supervision if consent was not required for the presence of all the other staff.

Patient right to refuse treatment.

The patient has a right to refuse treatment from any provider, including any student. For example, The NZ Code right 7(1) *Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent,*

Conclusion

Current guidance on the ethical provision of teaching is inconsistent. We have argued that if there is ethical risk to the patient in being involved in teaching then that risk is present no matter what the seniority of the learner. Consent is required for teaching when the sole purpose of the interaction is teaching. If teaching is interwoven with provision of care then the ethical guidance for the provision of care applies. Protection of patient rights where students are learning in the apprenticeship model is provided by good supervision from the principal who is responsible for the care.

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Appendix 3

Supporting Adult Decision Making

Associate Professor Ben Gray

1. Health and Welfare

Introduction

It is 36 years since the Protection of Personal and Property Rights (PPPR act) setting the framework for adult decision making was passed(1) Much has changed since then. The United Nations Convention on the Rights of Persons with Disabilities article 12(2) requires rights of persons with disabilities to be protected and the current law is significantly in breach of our obligations under this convention. The approach to clinical decision making has developed significantly with a much greater focus on establishing the goals of care(3) and shared decision making(4). The current Act has no acknowledgement of Māori decision making processes, which differ significantly from the majority position(5). This paper identifies particular problems with the current structure and makes some recommendations on how we might change the law.

1. Where the patient has capacity

The structure we put in place depends on our presumptions about how decisions are made.

The current law is based on a presumption that decisions are made rationally by individuals. Implicit is that they agree with the clinician analysis of the problem, trust the information provided by the clinician and decide from the options offered to them by clinicians. Questions of resource availability are not explicitly discussed. Little allowance is made for decisions that may involve more than the concerns of the presenting person. Consider the scenario in box (1)

Box1

Joan and Harry are in their late 80's and have been married for 55 years. They live in the family home with the accretion of possessions they have collected over a lifetime. The living spaces (bedroom, bathroom kitchen living room are all on the upper floor). They both still drive and do an overseas cruise annually. They have regular walks in the neighbourhood. They both retain their mental capacity. They have one married son John who lives with his family in their own home a 15 minute drive away. Two daughters Susan and Emily live overseas.

Joan has a fall whilst hanging out the washing and fractures 6 ribs and a collar bone. These are healing well and she has been transferred to the rehabilitation ward. A decision has to be made on whether she can go home.

The physio is unhappy about her going home now because she has difficulty walking up a full flight of stairs.

The nurses are worried about whether she can manage personal cares due to the limits of her mobility.

Harry is quite worried. He cannot cook and is not much good at the housework, he would not know how to work the washing machine. He wants her home now but worries about what would happen if she fell again.

Joan wants to go home, she hates it in the hospital. The doctor is worried that she is inflating her capabilities.

Susan has come back to visit and is happy to stay with them at home and help until Joan is better.

John and his family have been providing meals for Harry and are happy to continue with that and provide further support as needed.

Emily has zoomed into family meetings and thinks she should not go home until she is much better, because she is worried about another fall.

Joan is eligible for home support twice a day.

After discussion with the whole team, it is decided that when Joan can walk up the full flight of stairs at the hospital, she will be able to go home, knowing that the home support will be going in, Susan will be staying with them and managing the household with the support from John and his family.

This scenario is a good example of the development of an agreed management plan involving all of those who are affected by the decision. The routine particularly in rehabilitation facilities is to involve the "next of kin" rather than presuming that this is just Joan' s decision. There are several variables that could make a difference to the option agreed on. If Susan were not able to stay, or if they were not eligible for home

help, or had no support system at all it would be much harder to come up with an acceptable solution. This process is a reflection of current clinical practice. We have moved from a traditional paternalistic doctor model to a patient centred model(6) through to reaching an agreed management plan, collaborative model. We teach the Calgary Cambridge model of consultation to our students(4) that provides a detailed description of how this model operates starting with developing a relationship, moving to an agreed understanding of the problem being addressed finding out about the patient goals and wishes, discussing possible treatment options that are available and reaching agreement on the way forward.

The Hui Process(5) aligns with this approach and has been developed as a culturally safe way to interact with Māori. It consists of: *Mihi: initial greeting and engagement Whakawhanaungatanga: making a connection, Kaupapa: attending to the main purpose of the encounter and Poroporoaki: concluding the encounter*.

These approaches of course include consent as part of the process, but it is of much less import if there has been a collaborative development of a plan. The current model of decision making embodied in the Code of Health and Disability Services Consumers' Rights (The Code) (7), that reflects the provisions of the PPPR Act does not align well with the process of an agreed management plan. There is no mention of the importance of relationship and trust, and no reference to the process that might be used in coming up with a treatment plan. Instead, it relies on informed consent (or not) to reach a good outcome. Manson and O'Neill describe the limitations of the concept of Informed consent well when they talk about the metaphor of consent hiding all the relational work that is embodied within a decision making consultation(8).

The right to refuse treatment is maintained. If Joan decided to go home against the advice of the clinicians she can, even if others disagree. If she is unable to be dissuaded, then obstructing her may be counterproductive disrupting relationships and trust. The agreed plan would then be to make the best of her going home, by providing the support she is eligible for and hoping things worked out. A common approach in this setting would be to "manage by crisis". The understanding being that there is likely to be a readmission if the assessment of her ability to manage is accurate. Work can be done to determine what care options are available, discuss those options with everyone, so that in the event of a crisis (for example a fall necessitating hospital admission), the developed plan would be easier to implement. This process could rightly be described as "supported decision making". It is the norm for most people, not something that is only adopted if a person has some level of disability.

2. Where the patient has impaired capacity

The disparity between the approach of The Code and current practice is more marked when the patient lacks capacity. The scenario in Box (b) illustrates some of the problems.

Box (b)

Joan went home successfully and continued to heal. Susan lived with them whilst Joan's pain abated, and her fitness returned. At that point they were no longer eligible for home help, particularly as Susan was living with them. The family had considered arranging an EPOA and had acquired the forms but did not make an appointment to see lawyers to complete them. Over many months Joan began to develop dementia and gradually became less able to manage any household tasks. They became reliant on Susan to prepare meals and manage the household. Harry had macular degeneration and his sight was significantly impaired. They were both still able to get up and down the stairs and walk in the neighbourhood although they both became more fragile. Susan tired of living with them always being "on call" and moved over to stay with John and his family, visiting every day. Harry bought Susan a car to facilitate this. Emily would visit a couple of times a year and would be unhappy with the standard of care, the state of the house and it being unfair that Harry had bought a car for Susan. Both Harry and Joan had episodes of falling down the internal stairs, fortunately without serious injury. When Joan first started to deteriorate, the family discussed the option of moving to an Aged Care Facility. Joan was amenable to the idea, although wanted to wait until the facility at the end of the road was built (likely several years away) but Harry said that the only way he would want to leave the house was in a box.

Joan began to get up in the night and go walking. On one occasion she went outside and down the drive. Harry became stressed from not sleeping well because of worrying about Joan. He wanted Susan to move back in to help with managing Joan. John was getting more late-night phone calls from Harry wanting him to go and help manage Joan. Things were becoming unmanageable. Susan was doing as much as she could and relying on John and family to support her. They were not eligible for any paid overnight support and could not afford to self-fund it even if they could find someone willing to do it. Emily felt that Harry's wish not to move should be honoured and the family would just have to provide more support. Harry agreed to go and look at a villa in a nearby Aged Care Facility. Joan was happy to go along but was thinking of it as being like going on a cruise and was unable to appreciate that this was going to be a permanent move from the family home. Harry decided that it was the best option. The GP was approached and did a capacity assessment for Joan and found her to have capacity. Harry, Joan, Susan and John went to the lawyer's office and the contract to move to the Aged Care Facility was signed by Joan and Harry. The family all rallied round to sort the furniture and chattels that they were able to take, to redirect the mail set up the internet connection and co-ordinate the moving company. Susan moved into the family home. Two weeks after moving in Harry declared that he wanted to move back home. John told him that he was welcome to do that but that no support would be provided. They stayed in the villa.

Is this Joan's decision? The GP "bent" the capacity assessment to enable the move to the Aged Care Facility to happen, which those most closely involved had agreed was the best available option. If Joan has capacity, then Susan and John going to the lawyer with her could be viewed as coercion given that they held a view that the Aged Care Facility was the best option.

If Joan had been assessed to lack capacity, either a Court order would have been needed or the appointment of a Welfare Guardian, which would have been one of the children. Susan would have been the most appropriate, but sister Emily does not trust Susan to look after Harry and Joan's best interests. Emily thought that her siblings had not tried hard enough to care for them at home. In the absence of a Court Order a "Best Interests" judgement might have been made by the GP based on Right 7(4) of The Code. This process is unable to disentangle Joan and Harry's interests. The law provides little support for resolving this sort of conflict apart from having a judge deciding on "Best Interests". Given Emily's limited involvement it would be unlikely that she would take a court case, nor that the court would find in her favour, but the process would be very divisive.

Where the patient lacks capacity, a Good Decision all things considered.

The current structure is based around maintaining individual patient rights. Where a patient lacks capacity it provides for their "Best Interests" by designating an individual who will make the decision; the Welfare Guardian or Enduring Power of Attorney for routine matters and the doctor for decisions that save life or prevent serious harm(1)Sect 18 (1)(c) It is premised on the presumption that the decision is solely the patient's to make and that their surrogates are able to know what they would have wanted, and that the decision is made rationally.

It does not reflect normal medical practice in making decisions.

It is focussed on outcome (the decision) without addressing the process underlying the reaching of a decision, apart from a requirement for information to be provided. As a structure it works well for important binary decisions that predominantly affect the patient who has full capacity, such as a decision to proceed with major surgery, or commence chemotherapy for cancer treatment. Although even in that setting it would be normal practice to have that discussion with the patient in the presence of their nominated support person/people/whanau. It is not well suited to Joan and Harry's situation.

A good decision all things considered would include:

- Clinical option(s) that is/are supported either by evidence or judgement of the clinicians involved in the care.
- Patient rights will and preferences

- Any document prepared whilst the patient had capacity; Advance Care Plan or Advance Directive.
- Resource availability
- The interest of others affected by the decision with input proportional to the extent to which they are affected.
- Input from the holder of the authority over property (if needed)

If all those involved in the decision agree, then the law does not need to be involved.

There is no one person who makes the decision so there is no need to be careful in deciding who should be involved in the decision making if agreement is reached. In the example above this would obviate the need to do a capacity assessment on Joan. There would be no need to single out one of the siblings as an Enduring Power of Attorney, nor to have provisions to ensure consultation of the sibling who held the EPOA with the other siblings.

It removes the need to have a different decision-making process for people with capacity compared to those with diminished capacity

Importantly it reflects normal practice.

Involving the law in a process such as this cannot make things any better, and in the example above would have led to extra cost, time delay and potentially more friction between the parties, as a result of a decision-making process settled on the basis of who had the power to decide rather than a consensus process.

A process that does not require input from the law is much easier to adapt according to the cultural norms of the participants.

Addressing Disagreement

The law needs to be involved if there are important rights that are being breached, and to provide a process to resolve disagreement. The current court processes available are unwieldy, costly and often delayed. Furthermore, they risk disrupting relationships by the usual binary adversarial approach to dispute resolution. What is needed is an accessible mediation service to assist people to resolve their disagreement. There are two current models that could be expanded to fulfil this role:

Clinical Ethics Advisory Committees.

Clinical ethics advisory committees have formed in some hospitals in New Zealand with a role of deliberating on clinical ethics problems. The exact structure and process of these committees in New Zealand has not been finalised(9) One approach discussed by Zaner(10) is that of Clinical ethics consultant as mediator.

> *the consultant's job is to help individuals whose situation it is think through their circumstances as thoroughly as possible, then help them understand what must be decided and what aftermath can be expected. It is not to make a recommendation, neither to the physician nor to the patient or family. Deciding (i.e., learning which*

decision or recommendation is best for them) is not my business; it is theirs, just as is the situation theirs and the problems and issues theirs.(p30)

Such a role would be useful in the hospital setting where there is dispute about clinical management, either between the clinical team and the patient and their supporters, or within the clinical team.

Health and Disability Commission Clinical Navigators.

In the most recent annual report the HDC discussed the role of Clinical Navigators(11)(p26). This role could be expanded to include mediation to resolve disputes. This is a different role from the advocates whose role is to advocate for the patient and the distinction between these roles would be important to keep to enhance the likelihood of a mediated resolution.

In addition to resolving disagreements whilst making decisions such bodies would be well placed to address concerns of elder abuse.

The option of referring any of these disagreements to the court for resolution would remain and would be important to consider in the event of harm or potential harm to the patient.

The role of Capacity Assessment for Health and Welfare

Capacity assessment is a mana diminishing activity. Whilst the aim is for it to be decision specific, it is frequently used in a binary way, either the patient has capacity or does not; either they make their own decision, or the decision is made for them. The assessment is inevitably subjective, affected by the biases of the assessor, and dependent on well-trained assessors, sufficient time, and the co-operation of the patient to do well(12)(chapter 7). The ability by the patient to contest a finding of loss of capacity will be impaired because by definition the assessor believes the patient lacks capacity.

All of these features mean that there are significant risks to relying on a capacity assessment, so such an assessment should be used sparingly when its use provides significant value.

If there is agreement upon a decision between the patient, the clinicians, the person who holds the EPOA and the wider family/whanau, nothing is gained by declaring the patient to lack capacity.

If there is disagreement between the patient and all others involved in the decision, then one way of resolving that disagreement would be to assess the patient's capacity. If the patient lacked capacity the decision would be made against the wishes of the patient. Finding a way of resolving the disagreement without explicitly going against the wishes of the patient would be preferable.

In exceptional circumstances the use of coercion or force may be considered, in which case a formal capacity assessment would be essential.

The role of those involved in reaching a decision.

1. The Patient

The patient should be involved in decisions no matter what their capacity. At the very least they should assent to treatment and care decisions. A patient with significantly impaired capacity who repeatedly pulls out a feeding tube needs to have that wish considered. It is well understood that capacity is dependent on the decision being made, and is affected by many other factors, not least pain and illness. Capacity fluctuates. A model of decision making where the decision is made by those involved and where the extent of input from the patient gradually declines as their capacity declines, makes much more sense than a binary decision of capacity or no capacity, particularly given the problems of reproducibility of capacity assessments. The patient input into decisions can also be made by the development of advance care plans and advance directives whilst they have capacity. The more detailed and more formally developed the plan or directive the more weight should be given to them.

2. The Clinicians

The clinician role is well covered in the Calgary Cambridge guide to the consultation as discussed above(4), but extends to all those who are part of the decision making. It is important for complex clinical decisions that the members of the clinical team reach consensus on what treatments they are prepared to offer. The relationship role is vital because if anyone involved in the decision does not trust them, then they will not consider their view of what the options are. Clinicians are responsible for knowing which treatments are not available because of resource limitations, and which treatments are not available for public health reasons (for example Rest Home visiting during Covid pandemic). There are some treatments that are against the law, particularly medical assistance in dying in a patient who does not have capacity to make that decision.

3. The next of kin/significant other/informal supporter

It has been normal medical practice to collect contact details for the "next of kin". Historically this was the closest relative (spouse or child) but more recently has been thought of as "significant other". They would be rung if the clinician was having trouble contacting the patient. If something bad happened, they would be notified. They would often be present when hard decisions were being made. Whilst The Code only refers to people in this category under Right 7(4) when the patient lacks capacity, the Health Information Privacy Code makes explicit reference to this role:

Right 11 Limits on Disclosure of Information

(1) A health agency that holds health information must not disclose the information unless the agency believes, on reasonable grounds…

(b) that the disclosure is authorised by— (i) the individual concerned; or (ii) the individual's representative where the individual is dead or is unable to give their authority under this rule;

(2) Compliance with subrule (1)(b) is not necessary if the health agency believes on reasonable grounds, that it is either not desirable or not practicable to obtain authorisation from the individual concerned and— (a) that the disclosure of the information is directly related to one of the purposes in connection with which the information was obtained; or (b) that the information is disclosed by a health practitioner to a person nominated by the individual concerned or ***to the principal caregiver or a near relative of the individual concerned in accordance with recognised professional practice*** *and the disclosure is not contrary to the express request of the individual or their representative;(13)*

There are several reasons that a role of informal supporter should be recognised under Adult Decision-Making Legislation:

1. This is the pattern of normal practice, and the law should recognise this.
2. The requirement to have a formally appointed supporter (Enduring Power of Attorney or Welfare Guardian) is unlikely to ever cover everyone in the population, either because of a lack of future planning, lack of time, lack of resource to pay for legal advice, or for younger people not thinking it necessary.
3. For a formal system to work significant infrastructure is needed, the minimum being an accessible data base of EPOA documents.
4. Informal support is much more flexible. It is used for people who retain capacity as well as people who either temporarily or permanently lack capacity.
5. Given that there is no power of decision making the checks and balances required for a formal decision maker can be omitted, ensuring that it is possible for nearly everyone to have an identified support person.
6. This could provide an opportunity to identify those vulnerable people who have no identified support person and consider whether some support should be put in place.

3. Formal Support Person

For a person born with an intellectual disability a support system develops around them as they grow. The parents are the legal guardians until the age of 18. Unlike elderly people with dementia these people are more likely to have a stable and possibly developing capacity; they may well still be learning. Up until the age of 18 decisions are made in the same way as for any other child, with the parents making all the decisions for an infant, and the child gradually being involved in decisions as they get older. Under the current law, at the age of 18, a Court Appointed Representative has to be appointed for decisions that they lack capacity for. This requires a capacity assessment and as discussed in the Second Issues Paper disability advocates are concerned about the frequency with which disabled people are found to lack capacity and their rights are effectively removed.

The option of a formal support person enables a court process to ensure that the proposed support person is appropriate. It identifies them as someone who must be involved in major decisions concerning the patient. There is no need for a capacity assessment for such a person to be appointed, and this aligns with the support people available in Court for neurodiverse and brain injured people. Such an appointment would clearly signal to care providers that the patient is still involved in decision making, but that the formal supporter is required to be present for important decisions. It removes the current legal requirement for those with impaired capacity to have capacity assessments, which in the setting of a person with a learning disability/intellectual disability can be particularly challenging, deciding exactly where the limit of their decision-making capacity is.

4. Enduring Power of Attorney

Anyone who wishes to can appointment an EPOA whilst they have capacity and this should continue. The main purpose would be to identify in advance the person that they trust the most to be involved in decisions concerning them in the event they lose capacity.

Enacting a Decision

The common circumstance would be that clinicians are likely to enact any decision on health and welfare that may have been made; provide surgery, prescribe and dispense medication, provide life support, arrange placement in an Aged Residential Care Facility. As discussed above the ideal is that the decision has been agreed by all those involved. There is a clear hierarchy in those making the decision as to how much weight should be given to their view. A recent advance directive for an available management plan should take priority over the EPOA who takes priority over the Formal Supporter (if they are a different person. Those materially affected by the decision have significant weight. Other family members and friends less so. As noted, the ideal is to reach agreement. If agreement is not reached, then involving a mediation process is the next step. A judgement could be made to enact a decision despite opposition from someone in the hierarchy on the basis that there is a general consensus. In the example above it may be that Emily remains opposed to the idea of the move.

People with no support

An important focus of the law needs to be on those who have no support. In the absence of any involvement of the law decisions would be made solely by the clinicians or care givers involved. Currently there are Welfare Guardianship Trusts in some parts of the country who train and support volunteers to fulfil this role. This is probably the best option if it is available. In the experience of the Wellington Welfare Guardianship Trust, volunteers are willing to visit regularly and happy to fill this support role. The alternative of a public servant whose role it might be to oversee these people may be necessary to ensure that everyone is covered but is unlikely to be as satisfactory as they are likely to have many people they are responsible for and be unable to provide the same level of attention. A private sector for profit arrangement for this work could only work with

significant oversight due to the vulnerability of these people and is not an attractive option.

Some institutional support for Welfare Guardianship Trusts may make them more viable. Funding to pay for administration, and the ability to pay the travel costs of volunteers would be welcome.

Conclusion

The current legal framework for decision making does not reflect current clinical practice. There are significant problems with the appointing of enduring powers of attorney, and capacity assessment is poorly executed. People with disability are poorly served. A structure based on the presumption of a shared decision making model and a process of resolving disagreement could be a better option.

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