

July 2018

Good medical practice needs to be founded on patients' rights

Grattan Institute submission to the Medical Board of Australia's Public Consultation Paper on the draft revised *Good medical practice: A Code of Conduct for doctors in Australia*

Stephen Duckett

Overview

The job of the regulator is to protect the public interest. Indeed, the first objective specified in the national law governing health professional registration is ‘to provide for the protection of the public by ensuring that only health practitioners who are suitably trained and qualified to practise in a competent and ethical manner are registered’.

The Code of Conduct, as a core part of the regulatory framework of Australian medicine, should clearly and explicitly be based on that principle of protection of the public. The draft Code, released by the Medical Board of Australia, needs to be strengthened in a number of areas.

The Code’s introduction states that ‘While good medical practice respects patients’ rights, this code is not a charter of rights’ (page 6). This suggests that patients’ rights and ethical practice are separate. But the reverse is true: medical practice can only be ethical if it respects patients’ rights. A key recommendation in this submission is therefore that the Australian Charter of Healthcare Rights be explicitly incorporated into the Code of Conduct, signalling the centrality of patient rights to medical practice.

The Code includes a section on Indigenous Australians, but this should be strengthened to help address unconscious racism and systemic discrimination in healthcare.

The Code’s consideration of fees assumes that transparency is enough. It isn’t. The Code should make clear that medical practitioners’ fees should be not just transparent, but fair. Doctors should be required to think about the cost to patients of referrals – some patients can’t afford the out-of-pocket charges involved in diagnostic tests and specialist consultations. Similarly, doctors should be required to think about the risks of over-diagnosis and over-treatment.

The Code does not adequately address the specific ethical obligations of doctors to both undertake healthcare leadership roles and follow the leadership of others. Nor reflect contemporary best practice in quality improvement which should be based on regular assessment of patient outcome data and which recognises the essential role of teamwork.

Finally, this submission argues that the Code also should be strengthened in other areas of contemporary concern, such as teamwork and end-of-life care.

Table of contents

Overview.....	1
1 The rights of patients should be explicitly acknowledged	3
2 The specific issues associated with the healthcare of Indigenous Australians need to be addressed better	5
3 Financial ethics is more than transparency.....	6
4 Consideration of end-of-life care needs to be updated.....	12
5 The crucial role of doctors in improving care is not currently reflected in the draft Code.....	13
6 Other obligations to be incorporated.....	17
References	19

1 The rights of patients should be explicitly acknowledged

The draft Code of Conduct issued by the Medical Board of Australia, *Good medical practice: A Code of Conduct for doctors in Australia*,¹ is deficient. And the Code is silent in a number of areas where it should not be. What is included in policy documents is as important as what is excluded.² What is left out sends messages about the relative importance of an issue. How an issue is framed in a Code sends signals about what is acceptable and what is not.

Ethics in practice do not arise fully-formed from a blank sheet. They must be grounded in core principles. In the Australian medical context, this is expressed through the Australian Charter of Healthcare Rights, endorsed by all governments (see Box 1).

The Australian Charter of Healthcare Rights should be incorporated into the Code of Conduct, possibly in the form of a new subsection in Section 1.

The Charter should explicitly be included in the Code as a table. The Code should have accompanying text stressing that the Charter forms the basis of all aspects of the Code. The text should say that medical practitioners, and medical practices, should ensure their practice is always consistent with, and supportive of, the Charter.

Including the Charter in the Code will increase the likelihood that patients' experiences will be consistent with their rights.

¹ <http://www.medicalboard.gov.au/News/Current-Consultations.aspx>

³ Section 4.7 is supplemented by section 4.8, which is about culturally safe practice generally.

Box 1: The Australian Charter of Healthcare Rights

My rights	What this means
Access I have a right to healthcare.	I can access services to address my healthcare needs.
Safety I have a right to receive safe and high-quality care.	I receive safe and high-quality health services, provided with professional care, skill and competence.
Respect I have a right to be shown respect, dignity and consideration.	The care provided shows respect to me and my culture, beliefs, values and personal characteristics.
Communication I have a right to be informed about services, treatment, options and costs in a clear and open way.	I receive open, timely and appropriate communication about my healthcare in a way I can understand.
Participation I have a right to be included in decisions and choices about my care.	I may join in making decisions and choices about my care and about health service planning.
Privacy I have a right to privacy and confidentiality of my personal information.	My personal privacy is maintained and proper handling of my personal health and other information is assured.
Comment I have a right to comment on my care and to have my concerns addressed.	I can comment on or complain about my care and have my concerns dealt with properly and promptly.

Source: <https://www.safetyandquality.gov.au/national-priorities/charter-of-healthcare-rights/>

2 The specific issues associated with the healthcare of Indigenous Australians need to be addressed better

The draft Code includes a section on Indigenous Australians (section 4.7), with a focus on ‘cultural competence’.³ This section is welcome but it does not go far enough: it squibs the fundamental issue about healthcare for Indigenous Australians. Professor Judith Dwyer and her colleagues conducted an extensive literature review on this issue and concluded:

Australian research on differentials in care has established that systemic racism is real, with damaging effects on access and quality.⁴

The most egregious aspects of overt racism are condemned by mainstream Australia. But the evidence about the way Indigenous Australians experience healthcare cannot be dismissed as a random artefact – unconscious racism may be at play. This may be as simple as well-intentioned people thinking that treating Indigenous Australians equally is good practice,⁵ when contemporary ethics acknowledge that unequal need warrants unequal care. That is, equal treatment is not enough to overcome Indigenous disadvantage; additional care is required. It is also important that health professionals ‘see’ the ways in which access to and quality of care are affected for Indigenous patients by the practices and policies of health care organisations.

³ Section 4.7 is supplemented by section 4.8, which is about culturally safe practice generally.

⁴ Dwyer, *et al.* (2016)

⁵ *Ibid.*

A key way to address racism in healthcare, whether unconscious, systemic or institutional, is to call it out and ask health professionals to take additional actions to overcome the bias. For this reason, the Code needs to direct medical practitioners’ attention to unconscious bias, and to the steps they need to take to redress it. *A new subsection should be added to the Code, in Section 4.7:*

Recognising that non-Indigenous Australians may exercise unconscious bias in their treatment of Indigenous Australians, who also experience other forms of discrimination in healthcare; and taking steps to overcome bias and address the impacts of discrimination in your treatment decisions.

3 Financial ethics is more than transparency

Australia's health system was famously described more than 50 years ago, as 'private practice publicly supported',⁶ and still operates this way. General medical practice is principally remunerated by fee-for-service. So, too, diagnostic services and specialists in private practice.

Because of the privileged position of medical practitioners, the financial relationship between doctor and patient is not simply a market one, to be governed by normal market relationships and laws (such as fair trading laws). Medical practitioners are trusted professionals; patients expect them to provide informed advice about what care is necessary. Patients rely on their doctor to judge what diagnostic tests are necessary, which specialists might be most appropriate for them and to recommend treatment and procedures that are necessary and beneficial.

The Code rightly includes several provisions relating to financial relationships and referrals. But these should be clarified and strengthened.

3.1 Informed financial consent is not enough

The draft Code principally conceptualises issues of fee-charging in terms of transparency. It includes ethical obligations about:

- Ensuring that your patients are informed about your fees and charges (4.5.3); and

- Being transparent in financial and commercial matters (10.13.5).

This frame, and the related obligations, are too weak and out-of-step with consumer expectations and with practices in other professions. The legal profession, for example, has a statutory obligation to charge 'costs that are no more than fair and reasonable in all the circumstances'.⁷

Fees charged by medical practitioners, especially specialists, have recently been the subject of media criticism, including by the respected medical journalist, Dr Norman Swan.⁸ Academic studies have also shown specialist fees – especially surgeons' - vary widely.⁹

⁶ Fox (1963)

⁷ Section 172 (1) Legal Profession Uniform Law (NSW). The legislation also sets out factors which may affect fees, such as 'the quality of the work done' and the 'level of skill, experience, specialisation and seniority' of the lawyers involved.

⁸ <http://www.abc.net.au/news/health/2018-05-28/how-out-of-pocket-medical-costs-can-get-out-of-control/9592792>

⁹ Freed and Allen (2017); Johar, *et al.* (2017); Hua, *et al.* (2017)

Policy responses have been based on the assumption that the problem is confined to a small number of specialists charging egregious fees.¹⁰ If this is the case, it could be argued that these doctors are operating outside professional norms. However it is clear that charging fees significantly in excess of even the AMA rate is not unusual and can be a particular issue for a patient with a number of chronic diseases who is 'excessively' billed by each of those practitioners several times a year.¹¹

However, under the draft Code, these doctors could not be seen as acting unethically if they had simply informed their patients of the proposed fees. Doctors, especially specialists, have a lot of power in these circumstances. Patients are often reluctant to shop around for a different specialist, if they have been referred to a specific specialist and have initiated contact with that specialist.

An obligation to be transparent is a necessary but not sufficient ethical obligation for contemporary practice. The draft Code includes an obligation about

'not exploiting patients' vulnerability or lack of medical knowledge when providing or recommending treatment or services' (10.13.1)

This sub-section could reasonably be interpreted as creating an obligation for fair fee setting, and not exploiting patients' vulnerability in that regard. However, patients and doctors may miss that implication, even though it is the first item in a section on

¹⁰ <https://www.theguardian.com/australia-news/2018/jan/03/greg-hunt-to-investigate-exorbitant-out-of-pocket-medical-expenses>

¹¹ Freed and Allen (2017)

'financial and commercial dealings'. The obligation about not exploiting patients' vulnerability should be clarified by adding a specific obligation to be set fair fees.

*The draft Code should be revised to incorporate an (ethical) obligation on doctors, similar to the obligation on the legal profession, to charge fees that are no more than fair and reasonable in all the circumstances.*¹²

The argument here is not that the transparency obligation is irrelevant, rather that the Code needs to supplement an obligation to disclose fees (transparency) with an obligation not to exploit patients financially.

The existing transparency obligation should also be tightened. Too often, patients do not learn of the proposed fees until their initial visit to the specialist.¹³ By then, the patient may not be able to assess properly whether they want to continue with this specialist.¹⁴ In some situations – particularly with anaesthetists – the fee discussion can take place at the time of an operation or procedure, leaving the patient with no effective choice.

¹² This should not be the only source of this obligation: states could legislate to create a statutory obligation of this kind.

¹³ Patients may be able to discover the out-of-pocket costs associated with the initial consultation when making the booking, but probably not the out-of-pockets for any procedures which might be recommended.

¹⁴ This is an example of what behavioural economists refer to as 'sunk costs'; Angner (2016).

It is therefore important that transparency of fees is timely – indicative fees for procedures could be revealed on specialists’ websites, so patients (and their general practitioners) can make informed decisions before committing to their first consultation. *Subsection 4.5.3 should be revised to read:*

Ensuring that your patients are informed about your fees and charges in a timely manner, including by ensuring indicative fees for possible procedures are available to patients in advance of consultations. (Additions underlined)

3.2 Thinking about downstream effects

A visit to a doctor – either a general practitioner or a specialist – may lead to downstream costs for the patient, because of diagnostic tests, or prescriptions. The draft Code articulates two relevant obligations:

- When referring a patient for investigation or treatment, advising the patient that there may be additional costs, which patients may wish to clarify before proceeding (4.5.4); and
- Not exploiting patients’ vulnerability or lack of medical knowledge when providing or recommending treatment or services (10.13.1)

Again, these do not go far enough.

3.2.1 The risks of over-diagnosis

Referrals for diagnostic tests should only be made when the tests

are likely to yield useful information which will inform treatment and other choices in the patient’s specific circumstances. Tests should only be ordered when the patient has consented to them, and unfortunately this is not always the case.¹⁵

Unfortunately, all diagnostic tests deliver results with an uncertainty band – where a result may simply be caused by random factors. Abnormal test results may simply be aberrant and risk starting a wild goose chase of over-investigation and consequent over-diagnosis, with little benefit to the patient and, worse, potential harm.¹⁶

The draft Code includes an ethical obligation to balance risk and enhancing treatment decisions (subsection 3.2.4), but this should be strengthened to include a more specific signal for medical professionals to consider the risk of a diagnosis.

Two new subsections should be added:

being aware of the risk to patients of over-diagnosis and of unnecessary interventions; and

ensuring that patients are fully aware of the tests you have ordered and the risks of over-diagnosis

¹⁵ Lowe, *et al.* (2012); Lowe, *et al.* (2013); Wong, *et al.* (2014); Pickles, *et al.* (2017)

¹⁶ Moynihan, *et al.* (2014); Moynihan, *et al.* (2012)

3.2.2 The risks of over-intervention

There is now substantial evidence, dating back at least two decades, of unexplained variation in rates of procedures.¹⁷ The Code should highlight this issue.

The hazards of variation are most obviously seen in obstetrics care.¹⁸ The evidence is now clear that patterns of obstetric intervention, including caesarean section, appear to be driven by factors unrelated to a patient's condition. Rates of obstetric intervention are higher in private hospitals.¹⁹ Higher rates of obstetric interventions are associated with higher rates of neonatal and maternal morbidity, and no benefit in terms of reduction in maternal or neonatal mortality.

Patients may not be fully informed about the risks of obstetric interventions, to them and their baby. Medical practitioners should have an explicit obligation to make these risks known. *The existing provisions of the code should be strengthened with a new subsection:*

ensuring that the balance of the risks and benefits of any procedures you recommend are fully disclosed to patients

¹⁷ Richardson (1998); Australian Commission on Safety and Quality in Health Care and National Health Performance Authority (2015); Australian Commission on Safety and Quality in Health Care and Australian Institute of Health and Welfare (2017)

¹⁹ Dahlen, *et al.* (2014); Dahlen, *et al.* (2012)

3.2.3 The costs of referrals

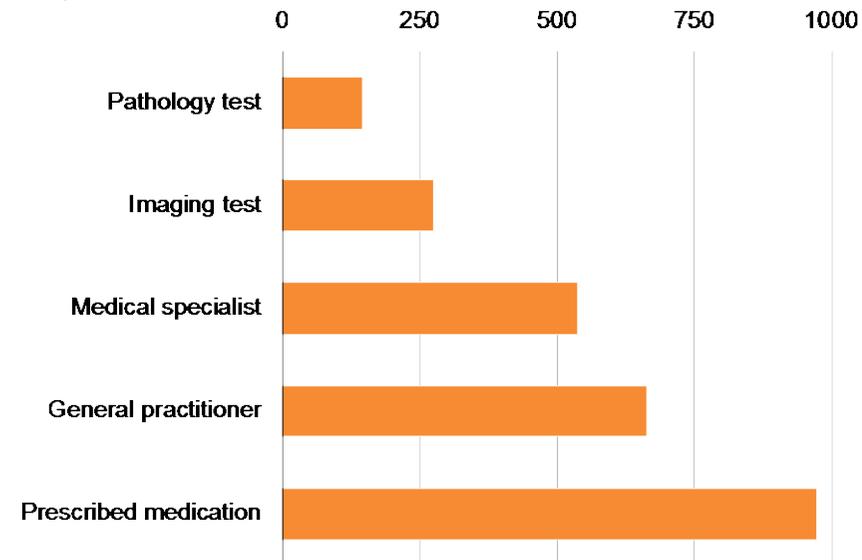
Despite the existence of Medicare, and safety nets for both Medicare and the Pharmaceutical Benefits Scheme, some Australians are missing out on care. In 2016-17, 7.4 million Australians needed to see a medical specialist at least once in the previous 12 months (see Figure 1). Of those, around 540,000 (7.3 per cent) did not see a specialist, or delayed doing so, due to cost.²⁰ Similarly, about 974,000 (7.3 per cent) who needed prescribed medication report that they delayed getting or did not get their prescribed medication due to cost. Around 662,000 Australians report that they at least once delayed seeing or did not see a general practitioner in the previous 12 months, representing 4.1 per cent of people who needed to see a GP.

Doctors, especially general practitioners, should be aware that some patients may face financial difficulty in paying for the tests they order, the prescriptions they write, and the specialist referrals they make. Patients can be faced with invidious decisions about which prescriptions to fill or which diagnostic tests to have. It is far better if these decisions can be taken jointly with their doctor, rather than by themselves or with the advice of another health professional who may not know the reasons the tests were requested or the medications were prescribed.

²⁰ Note: The percentages have different denominators, people who needed the different services.

Figure 1: Many Australians miss or delay care due to cost

The number of people (thousands) who delayed obtaining, or did not obtain, needed care for reasons including cost at least once in the previous 12 months, 2016-17



Source: ABS *Patient Experiences in Australia, 2016-17*, catalogue number 4839.0.

Not all diagnostic services require out-of-pocket payments; some services bulk-bill. And public hospital outpatient services provide specialist medical clinics as an alternative to private specialists

who charge an out-of-pocket fee.²¹

Doctors making referral decisions should have some responsibility for the entire episode of care involved in the consultation. This should include being aware of what the out-of-pocket costs might be, and what alternatives might be available, and then informing their patients about this.

As some patients can't afford the out-of-pocket charges involved in diagnostic tests and specialist consultations, the revised Code needs to encourage doctors to consider this issue and provide patients with options

*The Code should establish an obligation on doctors to provide patients with available information about the costs of referrals, and to provide clear information on, and facilitate access to, alternatives where patients indicate that fees are a barrier to care.*²²

3.3 Promoting the wise use of healthcare resources

The role of doctors in ensuring that healthcare resources are used wisely is canvassed in section 7 of the draft Code. Doctors have an important role as patient advocates, ensuring that their patients are able to get the care they need.

²¹ Although it should be noted that there are long waits for outpatient clinics in many states <https://theconversation.com/getting-an-initial-specialists-appointment-is-the-hidden-waitlist-99507>

²² For example, amend 4.5.3 to read 'Ensuring that patients are informed about your fees and charges, the fees and charges of the diagnostic tests you order, and the fees and charges of the specialist you refer to'. An additional subsection would need to be written about alternatives such as outpatient referrals.

Doctors have to recognise the importance of balancing the needs in their specialty with wider system needs. This is alluded to, but only in a most tangential way, in Section 7.2.4: 'Understanding that your use of resources can affect the access other patients have to healthcare resources'.

The draft Code fails to properly address the ethical obligations of patient advocacy. The Code should include clear guidance about how patient advocacy – including advocacy for additional resources – should be undertaken.

A new sub-section should be added which includes guidance for patient and resource advocacy. A good basis would be guidelines developed in Alberta jointly by the regulatory body (the College of Physicians & Surgeons of Alberta), the Alberta Medical Association, and the service delivery organisation, Alberta Health Services (see Box 2).

Box 2: How advocacy should work – the Alberta model

- The advocacy is delivered and received in a respectful and professional manner.
- The advocacy is acknowledged as a valued and legitimate part of a physician's role and responsibility.
- The advocacy should be well thought out, clear in purpose, and supported by data and facts.
- Potential conflicts of interest are acknowledged and mitigated, where possible.
- The advocacy should be balanced, in the sense that potential trade-offs and the bigger picture are acknowledged.
- The decision-making process and rationale for a decision is clear and transparent.
- There is a timely response and there is verbal and/or written follow-up to the advocacy (e.g. a written advocacy input should receive a written response).
- If the advocacy effort is rejected, there should be a clear explanation.
- Respect should be shown, when advancing the advocacy to the next or new level.

Source: <https://www.albertadoctors.org/advocating/physician-advocacy>

4 Consideration of end-of-life care needs to be updated

End-of-life care is changing, but Australians' expectations as to where and how they die are not being met.²³ Doctors have an important role here, including helping people to be clearer about what their expectations are, and to articulate those expectations to their family and carers.

The draft Code hints at some important issues here, especially ensuring that a medical practitioner's personal beliefs do not impede a patient's access to care that meets the patient's preferences. But the Code should go further to make the medical practitioner's role and obligations more explicit. Specifically, *the Code should ensure that the care doctors recommend is consistent with patients' end-of-life preferences to the extent reasonably possible in the circumstances.*

In particular, a new subsection should be added to the list in Section 3.2.13 about what good patient care looks like: *Ensuring that treatment recommendations are consistent with the patient's goals of care at that stage of their illness.*²⁴

Good end-of-life care, as with all medical care, requires good communication. The section on Effective communication should be strengthened to recognise the unique issues associated with end-of-life care, and to highlight the importance of discussions

with patients about their options. Specifically, subsection 4.5.3 should include an explicit reference to end-of-life conversations: *Discussing with patients their condition and the available management options, including their potential benefit and harm, as well as options for care at the end of their life.*²⁵

²³ Swerissen and Duckett (2014)

²⁴ The reference to 'goals of care' here is informed by the very useful framework proposed by Thomas, *et al.* (2014), although the absence of capitalisation in the proposed phrasing makes the proposed section appropriately generic. Goals of care also need to be discussed with families and carers.

²⁵ Proposed addition in italics

5 The crucial role of doctors in improving care is not currently reflected in the draft Code

5.1 Quality improvement

All professionals have an obligation to review their practice and learn from their mistakes. But the obligation in the draft Code of Conduct for doctors in Australia is too narrow. It reflects an outdated conception of how quality improvement occurs.²⁶

The draft Code implies that learning comes principally from reviewing adverse incidents. But contemporary safety thinking focuses on benchmarking against best practice, learning from people and places that provide care well,²⁷ and analysing patterns and trends in care,²⁸ rather than unusual incidents.

About one in every nine patients discharged from hospital suffer a complication – and many of these are not classified or regarded as ‘events’ but rather are often seen as just normal complications of care. However, there is significant variation in rates of complications across Australia, with some hospitals doing much better than others. Comparisons of risk-adjusted rates of all complications across Australian hospitals indicate that if all hospitals provided care as safe as the top 10 per cent of hospitals, the average rate of complications could be reduced by more than a quarter. This would mean an extra

250,000 patients would leave Australian hospitals complication-free each year.²⁹

Doctors’ obligation to participate in quality improvement should go beyond the draft section 8.2.4. *The Code should be revised to include a broader obligation to participate in monitoring of patterns of care, together with an obligation to learn from any issues identified.*

Specifically, new subsections should be included along the following lines:

- Participating in quality improvement activities, including monitoring of patterns and trends in complications of care
- Undertake specific professional development in areas where analysis of your performance or that of your unit suggests improvement is possible.

The draft Code recognises that good medical practice involves: Providing information to patients in a way that they can understand before asking for their consent (4.5.1).

Provision of risk information to patients is extremely complex and the subject of a voluminous literature.³⁰ As important as ways to present information is what information is presented. In particular,

²⁶ Duckett, *et al.* (2018); Duckett, *et al.* (2017)

²⁷ Hollnagel (2014)

²⁸ Duckett, *et al.* (2007); Coory, *et al.* (2007)

²⁹ Duckett, *et al.* (2018)

³⁰ Trevena, *et al.* (2013); Kabat (2017)

the risks of treatment presented to patients need to accurately reflect the actual risks. Unfortunately, all of us over-estimate our competence and performance.³¹ It is natural, therefore, that specialists might underestimate the risks patients might face in a procedure, and in particular they might inflate their competence relative to their peers.

Advice to patients should, as far as possible, be based on quantified evidence of risks for that patient, for that procedure, undertaken by that practitioner. The obligation in draft section 4.5.1 should be extended to reflect this, along the following lines: Providing information to patients in a way that they can understand, *and which is based on the best available evidence of risks specific to the patient and the practitioner*, before asking for their consent.³²

5.2 Doctors in leadership roles

One of the issues we identified in our 2016 review of quality and safety of care in Victoria was the important role played by doctors – and other health professionals – who have leadership roles.³³ Doctors hold a range of leadership roles that range from full time management jobs e.g. managing Local Health Districts or hospitals, to part time roles and to roles such as chairing clinical committees that are taken alongside their clinical work

Doctors in a clinical leadership role often have to balance what might appear to be competing factors in making a decision. We

saw in Bundaberg, Queensland, the devastating consequences when a hospital management weighed the hospital's short-term financial performance ahead of patient safety concerns.³⁴

Incorporating the Charter of Healthcare Rights into the Code of Conduct, as recommended in Chapter 1, will help to make clear to all doctors where their priorities should lie – each individual patient has a right to receive safe and high-quality care. This right is not qualified in any way by taking into account potential bonuses and penalties (as was the Bundaberg failure), nor by protecting sub-standard practice, even if it may be difficult to replace the practitioners concerned.

England's General Medical Council has had to consider the role of doctors in management roles in some detail, after a litany of clinical governance failures involving poor decisions by medically-qualified leaders.³⁵

The General Medical Council has issued guidelines for clinical leaders (see Box 3 for examples).³⁶ One element of the English guidance has been incorporated into the draft Australian Code as Subsection 8.2.5: If you have clinical leadership and/or management responsibilities, making sure that appropriate systems are in place for raising concerns about risks to patients. But this does not go far enough. *The Code should include a whole new section entitled 'Doctors in leadership roles', which expands and clarifies the responsibilities of doctors in these roles.*

³¹ Kruger and Dunning (1999)

³² Proposed addition in italics

³³ Review of Hospital Safety and Quality Assurance in Victoria (Chair: Dr Stephen Duckett) (2016)

³⁴ van der Weyden (2005)

³⁵ Starting with the tragedies at the Bristol Royal Infirmary see Coulter (2002); Kennedy (2001)

³⁶ https://www.gmc-uk.org/-/media/documents/raising-and-acting-on-concerns-about-patient-safety---english-0617_pdf-48902813.pdf

The Professional Standards Authority in the United Kingdom has a separate set of ‘Standards for members of NHS boards and Clinical Commissioning Group governing bodies in England’³⁷ which, although cast as directed at boards, provides insight into obligations for medical practitioners in leadership roles as well. The standards, for example, include an obligation about ‘Always putting the safety of patients and service users, the quality of care, and patient experience first, and enabling colleagues to do the same’.³⁸

The Australian Commission on Safety and Quality of Health Care’s advice on Clinical Governance for Doctors³⁹ provides a good outline of ‘roles and responsibilities of doctors for clinical governance’, which is much more comprehensive than those in the draft Code. The Commission’s list includes the following, which are particularly relevant to doctors in leadership roles:

- Contribute to the design of systems for the delivery of safe, high-quality clinical care.
- Ensure contemporary knowledge about safe system design.
- Maintain vigilance for opportunities to improve systems.

³⁷ <https://www.professionalstandards.org.uk/docs/default-source/publications/standards/standards-for-members-of-nhs-boards-and-cggs-2013.pdf?sfvrsn=2>

³⁸ Page 3

³⁹ Australian Commission on Safety and Quality in Health Care (2017)

- Ensure that identified opportunities for improvement are raised and reported appropriately.⁴⁰

Box 3: Some responsibilities of doctors in clinical leadership roles, as articulated by England’s General Medical Council

If you have a management role or responsibility, you must make sure that:

- * there are systems and policies in place to allow concerns to be raised and for incidents, concerns and complaints to be investigated promptly and fully;
- * clinical staff understand their duty to be open and honest about incidents or complaints with both patients and managers;
- * staff who raise a concern are protected from unfair criticism or action, including any detriment or dismissal.

If you are responsible for investigating incidents or complaints you should also make sure that:

- * appropriate adverse event and critical incident reports are made within the organisation and to other relevant external bodies;
- * recommendations that arise from investigations are put into practice or referred to senior management; and
- * patients who make a complaint receive a prompt, open, constructive and honest response.

⁴⁰ Ibid. Page 2

The Code of Conduct should be revised to include a new section on doctors in leadership roles. It should incorporate the best of the concepts from these sources.

5.3 Preparing for the future

Healthcare is dynamic: it develops with ongoing research and innovation. New professionals need to be trained to replace those who leave the workforce.

Existing professionals have important roles in participating in research and innovation, and in educating future generations of practitioners.

Not every medical practitioner can or should be involved in research and innovation. But where they are, the work should be subject to ethical oversight.

The section of the draft Code on research (Section 13) does not adequately capture all potential areas where research oversight is required. In particular, there is a grey area where novel treatments are introduced and patients are not fully informed of the fact that they are, in reality, part of an experiment. A new subsection should be added to section 13.2 along the following lines: Recognising when treatments you are undertaking are novel, or novel in this specific setting, and hence should be subject to research oversight.

If future generations of practitioners are to be appropriately prepared for practice, they must learn from current generations of practitioners. All practitioners have a role in contributing to developing the practitioners who will follow them and to

encourage their patients to be involved in research, in particular in clinical trials.

The Code should reflect this. It should incorporate a new obligation in the draft section on teaching (section 12.2), along the following lines: Accepting that teaching future generations of doctors is an important part of the work of doctors.⁴¹

⁴¹ The Australian Commission on Safety and Quality in Health Care identifies that 'Ensuring supervision of junior members of the workforce who provide patient care' requires the 'active participation of doctors', see *ibid*.

6 Other obligations to be incorporated

The draft code should also be changed in the following ways:

- The obligation in draft subsection 3.2.2 to ensure that the practitioner has adequate knowledge and skills should be expanded to emphasise that this knowledge should be contemporary. This recognises the prevailing expectations on medical practitioners to participate in appropriate professional development to ensure their knowledge is up-to-date. The subsection should be amended to read: Ensuring that you have adequate *contemporary* knowledge and skills to provide safe clinical care.⁴²
- Section 3.2.14 highlights that medical practitioners should ensure that their ‘personal views do not adversely affect the care’ their patient. Health professionals may have different views from patients about what an adverse impact might be, and this may be especially true in areas where opinion might be sharply divided such as abortion or assisted dying. In addition to the changes suggested in Section 4 of this submission, it is recommended that section 3.2.14 be extended to read: ‘Ensuring that your personal views do not adversely affect the care of your patient *or the referrals you make*’.⁴³
- The draft section on Public health does not go far enough. Medical practitioners can play an important role in highlighting

the wider socio-economic factors that influence the health of their patients. Subsection 7.4.2 should be amended to read: Participating in efforts to promote the health of the community and being aware of your obligations in disease prevention, screening and reporting notifiable diseases, *and facilitating interventions which may address community wide causes of disease and ill health*.⁴⁴

- The draft Code recognises that health care is a team endeavour that involves many different professionals. However, teamwork is hard and can be challenging if some members of the team do not fully recognise the expertise of others. The Code should recognise the reality that medical practitioners must *share* leadership in patient care. Subsection 5.3.2 should be amended to read: Advocating for a clear delineation of roles and responsibilities, including a recognised team leader or coordinator, *which may change at different points in the treatment cycle*.⁴⁵
- The draft section on patient records (10.5) appears to have been formulated before the widespread adoption of electronic health records. The use of shared electronic health records creates new risks and hence new ethical obligations. Medical practitioners should help patients understand the benefits and risks of shared electronic health records, and help them navigate the complexities. Medical practitioners should be sensitive to each patient’s privacy concerns and work with patients to ensure that shared records contain all the information patients want to make available, and only the

⁴² Proposed addition in italics

⁴³ Proposed addition in italics

⁴⁴ Proposed addition in italics

⁴⁵ Proposed addition in italics

information patients want to make available. *A new subsection should be added: Ensure that patients are aware of the information about them held in any shared electronic record (e.g. MyHealthRecord).*

- The draft section on advertising includes injunctions to ensure that claims made are ‘factual and verifiable’ (10.7.1) and ‘justifiable’ (10.7.2). *This should be strengthened, by replacing the word ‘justifiable’ with the phrase ‘evidence-based’.*

References

- Angner, E. (2016) *A course in behavioral economics*, Palgrave Macmillan
- Australian Commission on Safety and Quality in Health Care (2017) *Clinical Governance for Doctors*, ACSQHC from <https://www.safetyandquality.gov.au/wp-content/uploads/2017/12/Clinical-governance-for-doctors.pdf>
- Australian Commission on Safety and Quality in Health Care and Australian Institute of Health and Welfare (2017) *The Second Australian Atlas of Healthcare Variation*, ACSQHC
- Australian Commission on Safety and Quality in Health Care and National Health Performance Authority (2015) *Australian Atlas of Healthcare Variation*, ACSQHC
- Coory, M., Duckett, S. and Sketcher-Baker, K. (2007) 'Using control charts to monitor quality of hospital care with administrative data', *International Journal for Quality in Health Care*, 20(1), p 31-39
- Coulter, A. (2002) 'After Bristol: Putting patients at the centre', *Qual Saf Health Care*, 11, p 186-188
- Dahlen, H. G., Tracy, S., Tracy, M., Bisits, A., Brown, C. and Thornton, C. (2012) 'Rates of obstetric intervention among low-risk women giving birth in private and public hospitals in NSW: a population-based descriptive study', *BMJ Open*, 2(5), perinatal mortality and morbidity among low-risk women giving birth in private and public hospitals in NSW (2000–2008): a linked data population-based cohort study', *BMJ Open*, 4(5),
- Duckett, S., Coory, M. and Sketcher-Baker, K. (2007) 'Identifying variations in quality of care in Queensland hospitals', *Medical Journal of Australia*, 187 (10), p 571-575
- Duckett, S., Jorm, C. and Danks, L. (2017) *Strengthening safety statistics: how to make hospital safety data more useful*, Grattan Institute
- Duckett, S., Jorm, C., Danks, L. and Moran, G. (2018) *All complications should count: Using our data to make hospitals safer*, Grattan Institute
- Dwyer, J., O'Donnell, K., Willis, E. and Kelly, J. (2016) 'Equitable care for indigenous people: Every health service can do it', *Asia Pacific Journal of Health Management*, 11(3), p 11-17
- Fox, T. (1963) 'The Antipodes: Private Practice Publicly Supported', *The Lancet*, 281(7286), p 875-879
- Freed, G. L. and Allen, A. R. (2017) 'Variation in outpatient consultant physician fees in Australia by specialty and state and territory', *Medical journal of Australia*, 206(4), p 176-180
- Hollnagel, E. (2014) *Safety-I and Safety-II: The Past and Future of Safety Management*, Ashgate Publishing Limited
- Hua, X., Erreygers, G., Chalmers, J., Laba, T.-L. and Clarke, P. (2017)

- 'Using administrative data to look at changes in the level and distribution of out-of-pocket medical expenditure: An example using Medicare data from Australia', *Health Policy*, 121(4), p 426-433
- Johar, M., Mu, C., Van Gool, K. and Wong, C. Y. (2017) 'Bleeding Hearts, Profiteers, or Both: Specialist Physician Fees in an Unregulated Market', *Health Economics*, 26(4), p 528-535
- Kabat, G. C. (2017) *Getting risk right: understanding the science of elusive health risks*, Columbia University Press
- Kennedy, I. (2001) *The report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995: Learning from Bristol*, The Stationery Office Ltd.
- Kruger, J. and Dunning, D. (1999) 'Unskilled and unaware of it: how difficulties in recognizing one's own incompetence lead to inflated self-assessments', *Journal of personality and social psychology*, 77(6), p 1121-1134
- Lowe, A., Bennett, M. and Badenoch, S. (2012) *Research, awareness, support : ten years of progress in prostate cancer: 2012 community attitudes survey*, Prostate Cancer Foundation of Australia
- Lowe, A., Wong, T. and Lowe, S. (2013) *Prostate cancer: the next generation 2013 community attitudes survey*, Prostate Cancer Foundation of Australia
- Moynihan, R., Doust, J. and Henry, D. (2012) 'Preventing overdiagnosis: how to stop harming the healthy', *BMJ*, 344,
- Moynihan, R., Henry, D. and Moons, K. G. (2014) 'Using evidence to combat overdiagnosis and overtreatment: evaluating treatments, tests, and disease definitions in the time of too much', *PLoS Medicine*, 11(7),
- Pickles, K., Carter, S. M., Rychetnik, L., McCaffery, K. and Entwistle, V. A. (2017) 'Primary goals, information-giving and men's understanding: a qualitative study of Australian and UK doctors' varied communication about PSA screening', *BMJ Open*, 8(1), p e018009
- Review of Hospital Safety and Quality Assurance in Victoria (Chair: Dr Stephen Duckett) (2016) *Targeting zero: Supporting the Victorian hospital system to eliminate avoidable harm and strengthen quality of care*, Department of Health and Human Services
- Richardson, J. (1998) 'The health care financing debate', in *Economics and Australian Health Policy*, G. Mooney and R. Scotton, Eds., Allen & Unwin, p 192-213
- Swerissen, H. and Duckett, S. (2014) *Dying well*, Grattan Institute
- Thomas, R. L., Zubair, M. Y., Hayes, B. and Ashby, M. A. (2014) 'Goals of care: a clinical framework for limitation of medical treatment', *Medical Journal of Australia*, 201(8), p 452-455
- Trevena, L. J., Zikmund-Fisher, B. J., Edwards, A., Gaissmaier, W., Galesic, M., Han, P. K., King, J., Lawson, M. L., Linder, S. K., Lipkus, I., Ozanne, E., Peters, E., Timmermans, D. and Woloshin, S. (2013) 'Presenting quantitative information about decision outcomes: a risk communication primer for patient decision aid developers', *BMC Medical Informatics and Decision Making*, 13(2), p S7
- van der Weyden, M. B. (2005) 'The Bundaberg Hospital scandal: the

need for reform in Queensland and beyond', *MJA*, 183(6), p 284-285

Wong, T., Lowe, S. and Lowe, A. (2014) *Culturally and linguistically diverse communities and prostate cancer: 2014 community attitudes survey*, Prostate Cancer Foundation of Australia

I am grateful for helpful feedback on earlier drafts of this submission from Professors Lesley Barclay, Peter Brooks, Judith Dwyer, and Christine Jorm. The views expressed in the submission are my own.

July 2018

Good medical practice needs to be founded on patients' rights

Grattan Institute submission to the Medical Board of Australia's Public Consultation Paper on the draft revised *Good medical practice: A Code of Conduct for doctors in Australia*

Stephen Duckett

Overview

The job of the regulator is to protect the public interest. Indeed, the first objective specified in the national law governing health professional registration is ‘to provide for the protection of the public by ensuring that only health practitioners who are suitably trained and qualified to practise in a competent and ethical manner are registered’.

The Code of Conduct, as a core part of the regulatory framework of Australian medicine, should clearly and explicitly be based on that principle of protection of the public. The draft Code, released by the Medical Board of Australia, needs to be strengthened in a number of areas.

The Code’s introduction states that ‘While good medical practice respects patients’ rights, this code is not a charter of rights’ (page 6). This suggests that patients’ rights and ethical practice are separate. But the reverse is true: medical practice can only be ethical if it respects patients’ rights. A key recommendation in this submission is therefore that the Australian Charter of Healthcare Rights be explicitly incorporated into the Code of Conduct, signalling the centrality of patient rights to medical practice.

The Code includes a section on Indigenous Australians, but this should be strengthened to help address unconscious racism and systemic discrimination in healthcare.

The Code’s consideration of fees assumes that transparency is enough. It isn’t. The Code should make clear that medical practitioners’ fees should be not just transparent, but fair. Doctors should be required to think about the cost to patients of referrals – some patients can’t afford the out-of-pocket charges involved in diagnostic tests and specialist consultations. Similarly, doctors should be required to think about the risks of over-diagnosis and over-treatment.

The Code does not adequately address the specific ethical obligations of doctors to both undertake healthcare leadership roles and follow the leadership of others. Nor reflect contemporary best practice in quality improvement which should be based on regular assessment of patient outcome data and which recognises the essential role of teamwork.

Finally, this submission argues that the Code also should be strengthened in other areas of contemporary concern, such as teamwork and end-of-life care.

Table of contents

Overview.....	1
1 The rights of patients should be explicitly acknowledged	3
2 The specific issues associated with the healthcare of Indigenous Australians need to be addressed better	5
3 Financial ethics is more than transparency.....	6
4 Consideration of end-of-life care needs to be updated.....	12
5 The crucial role of doctors in improving care is not currently reflected in the draft Code.....	13
6 Other obligations to be incorporated.....	17
References	19

1 The rights of patients should be explicitly acknowledged

The draft Code of Conduct issued by the Medical Board of Australia, *Good medical practice: A Code of Conduct for doctors in Australia*,¹ is deficient. And the Code is silent in a number of areas where it should not be. What is included in policy documents is as important as what is excluded.² What is left out sends messages about the relative importance of an issue. How an issue is framed in a Code sends signals about what is acceptable and what is not.

Ethics in practice do not arise fully-formed from a blank sheet. They must be grounded in core principles. In the Australian medical context, this is expressed through the Australian Charter of Healthcare Rights, endorsed by all governments (see Box 1).

The Australian Charter of Healthcare Rights should be incorporated into the Code of Conduct, possibly in the form of a new subsection in Section 1.

The Charter should explicitly be included in the Code as a table. The Code should have accompanying text stressing that the Charter forms the basis of all aspects of the Code. The text should say that medical practitioners, and medical practices, should ensure their practice is always consistent with, and supportive of, the Charter.

Including the Charter in the Code will increase the likelihood that patients' experiences will be consistent with their rights.

¹ <http://www.medicalboard.gov.au/News/Current-Consultations.aspx>

³ Section 4.7 is supplemented by section 4.8, which is about culturally safe practice generally.

Box 1: The Australian Charter of Healthcare Rights

My rights

Access

I have a right to healthcare.

Safety

I have a right to receive safe and high-quality care.

Respect

I have a right to be shown respect, dignity and consideration.

Communication

I have a right to be informed about services, treatment, options and costs in a clear and open way.

Participation

I have a right to be included in decisions and choices about my care.

Privacy

I have a right to privacy and confidentiality of my personal information.

Comment

I have a right to comment on my care and to have my concerns addressed.

What this means

I can access services to address my healthcare needs.

I receive safe and high-quality health services, provided with professional care, skill and competence.

The care provided shows respect to me and my culture, beliefs, values and personal characteristics.

I receive open, timely and appropriate communication about my healthcare in a way I can understand.

I may join in making decisions and choices about my care and about health service planning.

My personal privacy is maintained and proper handling of my personal health and other information is assured.

I can comment on or complain about my care and have my concerns dealt with properly and promptly.

Source: <https://www.safetyandquality.gov.au/national-priorities/charter-of-healthcare-rights/>

2 The specific issues associated with the healthcare of Indigenous Australians need to be addressed better

The draft Code includes a section on Indigenous Australians (section 4.7), with a focus on ‘cultural competence’.³ This section is welcome but it does not go far enough: it squibs the fundamental issue about healthcare for Indigenous Australians. Professor Judith Dwyer and her colleagues conducted an extensive literature review on this issue and concluded:

Australian research on differentials in care has established that systemic racism is real, with damaging effects on access and quality.⁴

The most egregious aspects of overt racism are condemned by mainstream Australia. But the evidence about the way Indigenous Australians experience healthcare cannot be dismissed as a random artefact – unconscious racism may be at play. This may be as simple as well-intentioned people thinking that treating Indigenous Australians equally is good practice,⁵ when contemporary ethics acknowledge that unequal need warrants unequal care. That is, equal treatment is not enough to overcome Indigenous disadvantage; additional care is required. It is also important that health professionals ‘see’ the ways in which access to and quality of care are affected for Indigenous patients by the practices and policies of health care organisations.

A key way to address racism in healthcare, whether unconscious, systemic or institutional, is to call it out and ask health professionals to take additional actions to overcome the bias. For this reason, the Code needs to direct medical practitioners’ attention to unconscious bias, and to the steps they need to take to redress it. *A new subsection should be added to the Code, in Section 4.7:*

Recognising that non-Indigenous Australians may exercise unconscious bias in their treatment of Indigenous Australians, who also experience other forms of discrimination in healthcare; and taking steps to overcome bias and address the impacts of discrimination in your treatment decisions.

³ Section 4.7 is supplemented by section 4.8, which is about culturally safe practice generally.

⁴ Dwyer, *et al.* (2016)

⁵ *Ibid.*

3 Financial ethics is more than transparency

Australia's health system was famously described more than 50 years ago, as 'private practice publicly supported',⁶ and still operates this way. General medical practice is principally remunerated by fee-for-service. So, too, diagnostic services and specialists in private practice.

Because of the privileged position of medical practitioners, the financial relationship between doctor and patient is not simply a market one, to be governed by normal market relationships and laws (such as fair trading laws). Medical practitioners are trusted professionals; patients expect them to provide informed advice about what care is necessary. Patients rely on their doctor to judge what diagnostic tests are necessary, which specialists might be most appropriate for them and to recommend treatment and procedures that are necessary and beneficial.

The Code rightly includes several provisions relating to financial relationships and referrals. But these should be clarified and strengthened.

3.1 Informed financial consent is not enough

The draft Code principally conceptualises issues of fee-charging in terms of transparency. It includes ethical obligations about:

- Ensuring that your patients are informed about your fees and charges (4.5.3); and
- Being transparent in financial and commercial matters (10.13.5).

This frame, and the related obligations, are too weak and out-of-step with consumer expectations and with practices in other professions. The legal profession, for example, has a statutory obligation to charge 'costs that are no more than fair and reasonable in all the circumstances'.⁷

Fees charged by medical practitioners, especially specialists, have recently been the subject of media criticism, including by the respected medical journalist, Dr Norman Swan.⁸ Academic studies have also shown specialist fees – especially surgeons' – vary widely.⁹

⁶ Fox (1963)

⁷ Section 172 (1) Legal Profession Uniform Law (NSW). The legislation also sets out factors which may affect fees, such as 'the quality of the work done' and the 'level of skill, experience, specialisation and seniority' of the lawyers involved.

⁸ <http://www.abc.net.au/news/health/2018-05-28/how-out-of-pocket-medical-costs-can-get-out-of-control/9592792>

⁹ Freed and Allen (2017); Johar, *et al.* (2017); Hua, *et al.* (2017)

Policy responses have been based on the assumption that the problem is confined to a small number of specialists charging egregious fees.¹⁰ If this is the case, it could be argued that these doctors are operating outside professional norms. However it is clear that charging fees significantly in excess of even the AMA rate is not unusual and can be a particular issue for a patient with a number of chronic diseases who is 'excessively' billed by each of those practitioners several times a year.¹¹

However, under the draft Code, these doctors could not be seen as acting unethically if they had simply informed their patients of the proposed fees. Doctors, especially specialists, have a lot of power in these circumstances. Patients are often reluctant to shop around for a different specialist, if they have been referred to a specific specialist and have initiated contact with that specialist.

An obligation to be transparent is a necessary but not sufficient ethical obligation for contemporary practice. The draft Code includes an obligation about

'not exploiting patients' vulnerability or lack of medical knowledge when providing or recommending treatment or services' (10.13.1)

This sub-section could reasonably be interpreted as creating an obligation for fair fee setting, and not exploiting patients' vulnerability in that regard. However, patients and doctors may

¹⁰ <https://www.theguardian.com/australia-news/2018/jan/03/greg-hunt-to-investigate-exorbitant-out-of-pocket-medical-expenses>

¹¹ Freed and Allen (2017)

¹² This should not be the only source of this obligation: states could legislate to create a statutory obligation of this kind.

miss that implication, even though it is the first item in a section on 'financial and commercial dealings'. The obligation about not exploiting patients' vulnerability should be clarified by adding a specific obligation to be set fair fees.

*The draft Code should be revised to incorporate an (ethical) obligation on doctors, similar to the obligation on the legal profession, to charge fees that are no more than fair and reasonable in all the circumstances.*¹²

The argument here is not that the transparency obligation is irrelevant, rather that the Code needs to supplement an obligation to disclose fees (transparency) with an obligation not to exploit patients financially.

The existing transparency obligation should also be tightened. Too often, patients do not learn of the proposed fees until their initial visit to the specialist.¹³ By then, the patient may not be able to assess properly whether they want to continue with this specialist.¹⁴ In some situations – particularly with anaesthetists – the fee discussion can take place at the time of an operation or procedure, leaving the patient with no effective choice.

¹³ Patients may be able to discover the out-of-pocket costs associated with the initial consultation when making the booking, but probably not the out-of-pockets for any procedures which might be recommended.

¹⁴ This is an example of what behavioural economists refer to as 'sunk costs'; Angner (2016).

It is therefore important that transparency of fees is timely – indicative fees for procedures could be revealed on specialists’ websites, so patients (and their general practitioners) can make informed decisions before committing to their first consultation. *Subsection 4.5.3 should be revised to read:*

Ensuring that your patients are informed about your fees and charges in a timely manner, including by ensuring indicative fees for possible procedures are available to patients in advance of consultations. (Additions underlined)

3.2 Thinking about downstream effects

A visit to a doctor – either a general practitioner or a specialist – may lead to downstream costs for the patient, because of diagnostic tests, or prescriptions. The draft Code articulates two relevant obligations:

- When referring a patient for investigation or treatment, advising the patient that there may be additional costs, which patients may wish to clarify before proceeding (4.5.4); and
- Not exploiting patients’ vulnerability or lack of medical knowledge when providing or recommending treatment or services (10.13.1)

Again, these do not go far enough.

¹⁵ Lowe, *et al.* (2012); Lowe, *et al.* (2013); Wong, *et al.* (2014); Pickles, *et al.* (2017)

3.2.1 The risks of over-diagnosis

Referrals for diagnostic tests should only be made when the tests are likely to yield useful information which will inform treatment and other choices in the patient’s specific circumstances. Tests should only be ordered when the patient has consented to them, and unfortunately this is not always the case.¹⁵

Unfortunately, all diagnostic tests deliver results with an uncertainty band – where a result may simply be caused by random factors. Abnormal test results may simply be aberrant and risk starting a wild goose chase of over-investigation and consequent over-diagnosis, with little benefit to the patient and, worse, potential harm.¹⁶

The draft Code includes an ethical obligation to balance risk and enhancing treatment decisions (subsection 3.2.4), but this should be strengthened to include a more specific signal for medical professionals to consider the risk of a diagnosis.

Two new subsections should be added:

being aware of the risk to patients of over-diagnosis and of unnecessary interventions; and

ensuring that patients are fully aware of the tests you have ordered and the risks of over-diagnosis

¹⁶ Moynihan, *et al.* (2014); Moynihan, *et al.* (2012)

3.2.2 The risks of over-intervention

There is now substantial evidence, dating back at least two decades, of unexplained variation in rates of procedures.¹⁷ The Code should highlight this issue.

The hazards of variation are most obviously seen in obstetrics care.¹⁸ The evidence is now clear that patterns of obstetric intervention, including caesarean section, appear to be driven by factors unrelated to a patient's condition. Rates of obstetric intervention are higher in private hospitals.¹⁹ Higher rates of obstetric interventions are associated with higher rates of neonatal and maternal morbidity, and no benefit in terms of reduction in maternal or neonatal mortality.

Patients may not be fully informed about the risks of obstetric interventions, to them and their baby. Medical practitioners should have an explicit obligation to make these risks known. *The existing provisions of the code should be strengthened with a new subsection:*

ensuring that the balance of the risks and benefits of any procedures you recommend are fully disclosed to patients

3.2.3 The costs of referrals

Despite the existence of Medicare, and safety nets for both Medicare and the Pharmaceutical Benefits Scheme, some

Australians are missing out on care. In 2016-17, 7.4 million Australians needed to see a medical specialist at least once in the previous 12 months (see Figure 1). Of those, around 540,000 (7.3 per cent) did not see a specialist, or delayed doing so, due to cost.²⁰ Similarly, about 974,000 (7.3 per cent) who needed prescribed medication report that they delayed getting or did not get their prescribed medication due to cost. Around 662,000 Australians report that they at least once delayed seeing or did not see a general practitioner in the previous 12 months, representing 4.1 per cent of people who needed to see a GP.

Doctors, especially general practitioners, should be aware that some patients may face financial difficulty in paying for the tests they order, the prescriptions they write, and the specialist referrals they make. Patients can be faced with invidious decisions about which prescriptions to fill or which diagnostic tests to have. It is far better if these decisions can be taken jointly with their doctor, rather than by themselves or with the advice of another health professional who may not know the reasons the tests were requested or the medications were prescribed.

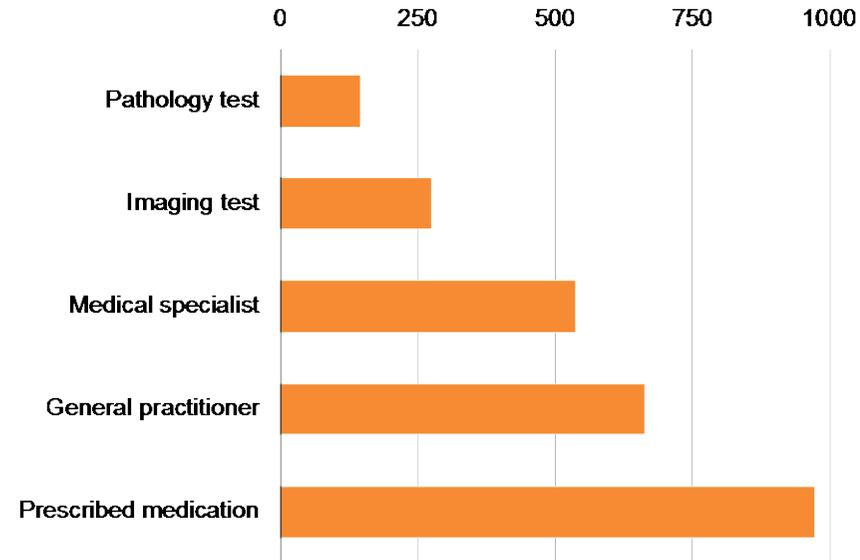
¹⁷ Richardson (1998); Australian Commission on Safety and Quality in Health Care and National Health Performance Authority (2015); Australian Commission on Safety and Quality in Health Care and Australian Institute of Health and Welfare (2017)

¹⁹ Dahlen, *et al.* (2014); Dahlen, *et al.* (2012)

²⁰ Note: The percentages have different denominators, people who needed the different services.

Figure 1: Many Australians miss or delay care due to cost

The number of people (thousands) who delayed obtaining, or did not obtain, needed care for reasons including cost at least once in the previous 12 months, 2016-17



Source: ABS Patient Experiences in Australia, 2016-17, catalogue number 4839.0.

Not all diagnostic services require out-of-pocket payments; some services bulk-bill. And public hospital outpatient services provide specialist medical clinics as an alternative to private specialists who charge an out-of-pocket fee.²¹

Doctors making referral decisions should have some responsibility for the entire episode of care involved in the consultation. This should include being aware of what the out-of-pocket costs might be, and what alternatives might be available, and then informing their patients about this.

As some patients can't afford the out-of-pocket charges involved in diagnostic tests and specialist consultations, the revised Code needs to encourage doctors to consider this issue and provide patients with options

*The Code should establish an obligation on doctors to provide patients with available information about the costs of referrals, and to provide clear information on, and facilitate access to, alternatives where patients indicate that fees are a barrier to care.*²²

3.3 Promoting the wise use of healthcare resources

The role of doctors in ensuring that healthcare resources are used wisely is canvassed in section 7 of the draft Code. Doctors have

²¹ Although it should be noted that there are long waits for outpatient clinics in many states <https://theconversation.com/getting-an-initial-specialists-appointment-is-the-hidden-waitlist-99507>

²² For example, amend 4.5.3 to read 'Ensuring that patients are informed about your fees and charges, the fees and charges of the diagnostic tests you order, and the fees and charges of the specialist you refer to'. An additional subsection would need to be written about alternatives such as outpatient referrals.

an important role as patient advocates, ensuring that their patients are able to get the care they need.

Doctors have to recognise the importance of balancing the needs in their specialty with wider system needs. This is alluded to, but only in a most tangential way, in Section 7.2.4: 'Understanding that your use of resources can affect the access other patients have to healthcare resources'.

The draft Code fails to properly address the ethical obligations of patient advocacy. The Code should include clear guidance about how patient advocacy – including advocacy for additional resources – should be undertaken.

A new sub-section should be added which includes guidance for patient and resource advocacy. A good basis would be guidelines developed in Alberta jointly by the regulatory body (the College of Physicians & Surgeons of Alberta), the Alberta Medical Association, and the service delivery organisation, Alberta Health Services (see Box 2).

Box 2: How advocacy should work – the Alberta model

- The advocacy is delivered and received in a respectful and professional manner.
- The advocacy is acknowledged as a valued and legitimate part of a physician's role and responsibility.
- The advocacy should be well thought out, clear in purpose, and supported by data and facts.
- Potential conflicts of interest are acknowledged and mitigated, where possible.
- The advocacy should be balanced, in the sense that potential trade-offs and the bigger picture are acknowledged.
- The decision-making process and rationale for a decision is clear and transparent.
- There is a timely response and there is verbal and/or written follow-up to the advocacy (e.g. a written advocacy input should receive a written response).
- If the advocacy effort is rejected, there should be a clear explanation.
- Respect should be shown, when advancing the advocacy to the next or new level.

Source: <https://www.albertadoctors.org/advocating/physician-advocacy>

4 Consideration of end-of-life care needs to be updated

End-of-life care is changing, but Australians' expectations as to where and how they die are not being met.²³ Doctors have an important role here, including helping people to be clearer about what their expectations are, and to articulate those expectations to their family and carers.

The draft Code hints at some important issues here, especially ensuring that a medical practitioner's personal beliefs do not impede a patient's access to care that meets the patient's preferences. But the Code should go further to make the medical practitioner's role and obligations more explicit. Specifically, *the Code should ensure that the care doctors recommend is consistent with patients' end-of-life preferences to the extent reasonably possible in the circumstances.*

In particular, a new subsection should be added to the list in Section 3.2.13 about what good patient care looks like: *Ensuring that treatment recommendations are consistent with the patient's goals of care at that stage of their illness.*²⁴

Good end-of-life care, as with all medical care, requires good communication. The section on Effective communication should be strengthened to recognise the unique issues associated with end-of-life care, and to highlight the importance of discussions

with patients about their options. Specifically, subsection 4.5.3 should include an explicit reference to end-of-life conversations: *Discussing with patients their condition and the available management options, including their potential benefit and harm, as well as options for care at the end of their life.*²⁵

²³ Swerissen and Duckett (2014)

²⁴ The reference to 'goals of care' here is informed by the very useful framework proposed by Thomas, *et al.* (2014), although the absence of capitalisation in the

proposed phrasing makes the proposed section appropriately generic. Goals of care also need to be discussed with families and carers.

²⁵ Proposed addition in italics

5 The crucial role of doctors in improving care is not currently reflected in the draft Code

5.1 Quality improvement

All professionals have an obligation to review their practice and learn from their mistakes. But the obligation in the draft Code of Conduct for doctors in Australia is too narrow. It reflects an outdated conception of how quality improvement occurs.²⁶

The draft Code implies that learning comes principally from reviewing adverse incidents. But contemporary safety thinking focuses on benchmarking against best practice, learning from people and places that provide care well,²⁷ and analysing patterns and trends in care,²⁸ rather than unusual incidents.

About one in every nine patients discharged from hospital suffer a complication – and many of these are not classified or regarded as ‘events’ but rather are often seen as just normal complications of care. However, there is significant variation in rates of complications across Australia, with some hospitals doing much better than others. Comparisons of risk-adjusted rates of all complications across Australian hospitals indicate that if all hospitals provided care as safe as the top 10 per cent of hospitals, the average rate of complications could be reduced by more than a quarter. This would mean an extra 250,000 patients would leave Australian hospitals complication-free each year.²⁹

²⁶ Duckett, *et al.* (2018); Duckett, *et al.* (2017)

²⁷ Hollnagel (2014)

²⁸ Duckett, *et al.* (2007); Coory, *et al.* (2007)

Doctors’ obligation to participate in quality improvement should go beyond the draft section 8.2.4. *The Code should be revised to include a broader obligation to participate in monitoring of patterns of care, together with an obligation to learn from any issues identified.*

Specifically, new subsections should be included along the following lines:

- Participating in quality improvement activities, including monitoring of patterns and trends in complications of care
- Undertake specific professional development in areas where analysis of your performance or that of your unit suggests improvement is possible.

The draft Code recognises that good medical practice involves: Providing information to patients in a way that they can understand before asking for their consent (4.5.1).

Provision of risk information to patients is extremely complex and the subject of a voluminous literature.³⁰ As important as ways to present information is what information is presented. In particular, the risks of treatment presented to patients need to accurately

²⁹ Duckett, *et al.* (2018)

³⁰ Trevena, *et al.* (2013); Kabat (2017)

reflect the actual risks. Unfortunately, all of us over-estimate our competence and performance.³¹ It is natural, therefore, that specialists might underestimate the risks patients might face in a procedure, and in particular they might inflate their competence relative to their peers.

Advice to patients should, as far as possible, be based on quantified evidence of risks for that patient, for that procedure, undertaken by that practitioner. The obligation in draft section 4.5.1 should be extended to reflect this, along the following lines: Providing information to patients in a way that they can understand, *and which is based on the best available evidence of risks specific to the patient and the practitioner*, before asking for their consent.³²

5.2 Doctors in leadership roles

One of the issues we identified in our 2016 review of quality and safety of care in Victoria was the important role played by doctors – and other health professionals – who have leadership roles.³³ Doctors hold a range of leadership roles that range from full time management jobs e.g. managing Local Health Districts or hospitals, to part time roles and to roles such as chairing clinical committees that are taken alongside their clinical work

Doctors in a clinical leadership role often have to balance what might appear to be competing factors in making a decision. We

saw in Bundaberg, Queensland, the devastating consequences when a hospital management weighed the hospital's short-term financial performance ahead of patient safety concerns.³⁴

Incorporating the Charter of Healthcare Rights into the Code of Conduct, as recommended in Chapter 1, will help to make clear to all doctors where their priorities should lie – each individual patient has a right to receive safe and high-quality care. This right is not qualified in any way by taking into account potential bonuses and penalties (as was the Bundaberg failure), nor by protecting sub-standard practice, even if it may be difficult to replace the practitioners concerned.

England's General Medical Council has had to consider the role of doctors in management roles in some detail, after a litany of clinical governance failures involving poor decisions by medically-qualified leaders.³⁵

The General Medical Council has issued guidelines for clinical leaders (see Box 3 for examples).³⁶ One element of the English guidance has been incorporated into the draft Australian Code as Subsection 8.2.5: If you have clinical leadership and/or management responsibilities, making sure that appropriate systems are in place for raising concerns about risks to patients. But this does not go far enough. *The Code should include a whole*

³¹ Kruger and Dunning (1999)

³² Proposed addition in italics

³³ Review of Hospital Safety and Quality Assurance in Victoria (Chair: Dr Stephen Duckett) (2016)

³⁴ van der Weyden (2005)

³⁵ Starting with the tragedies at the Bristol Royal Infirmary see Coulter (2002); Kennedy (2001)

³⁶ https://www.gmc-uk.org/-/media/documents/raising-and-acting-on-concerns-about-patient-safety---english-0617_pdf-48902813.pdf

new section entitled 'Doctors in leadership roles', which expands and clarifies the responsibilities of doctors in these roles.

The Professional Standards Authority in the United Kingdom has a separate set of 'Standards for members of NHS boards and Clinical Commissioning Group governing bodies in England'³⁷ which, although cast as directed at boards, provides insight into obligations for medical practitioners in leadership roles as well. The standards, for example, include an obligation about 'Always putting the safety of patients and service users, the quality of care, and patient experience first, and enabling colleagues to do the same'.³⁸

The Australian Commission on Safety and Quality of Health Care's advice on Clinical Governance for Doctors³⁹ provides a good outline of 'roles and responsibilities of doctors for clinical governance', which is much more comprehensive than those in the draft Code. The Commission's list includes the following, which are particularly relevant to doctors in leadership roles:

- Contribute to the design of systems for the delivery of safe, high-quality clinical care.
- Ensure contemporary knowledge about safe system design.
- Maintain vigilance for opportunities to improve systems.

- Ensure that identified opportunities for improvement are raised and reported appropriately.⁴⁰

Box 3: Some responsibilities of doctors in clinical leadership roles, as articulated by England's General Medical Council

If you have a management role or responsibility, you must make sure that:

- * there are systems and policies in place to allow concerns to be raised and for incidents, concerns and complaints to be investigated promptly and fully;
- * clinical staff understand their duty to be open and honest about incidents or complaints with both patients and managers;
- * staff who raise a concern are protected from unfair criticism or action, including any detriment or dismissal.

If you are responsible for investigating incidents or complaints you should also make sure that:

- * appropriate adverse event and critical incident reports are made within the organisation and to other relevant external bodies;
- * recommendations that arise from investigations are put into practice or referred to senior management; and

³⁷ <https://www.professionalstandards.org.uk/docs/default-source/publications/standards/standards-for-members-of-nhs-boards-and-ccgs-2013.pdf?sfvrsn=2>

³⁸ Page 3

³⁹ Australian Commission on Safety and Quality in Health Care (2017)

⁴⁰ Ibid. Page 2

* patients who make a complaint receive a prompt, open, constructive and honest response.

The Code of Conduct should be revised to include a new section on doctors in leadership roles. It should incorporate the best of the concepts from these sources.

5.3 Preparing for the future

Healthcare is dynamic: it develops with ongoing research and innovation. New professionals need to be trained to replace those who leave the workforce.

Existing professionals have important roles in participating in research and innovation, and in educating future generations of practitioners.

Not every medical practitioner can or should be involved in research and innovation. But where they are, the work should be subject to ethical oversight.

The section of the draft Code on research (Section 13) does not adequately capture all potential areas where research oversight is required. In particular, there is a grey area where novel treatments are introduced and patients are not fully informed of the fact that they are, in reality, part of an experiment. A new subsection should be added to section 13.2 along the following lines: Recognising when treatments you are undertaking are novel, or

novel in this specific setting, and hence should be subject to research oversight.

If future generations of practitioners are to be appropriately prepared for practice, they must learn from current generations of practitioners. All practitioners have a role in contributing to developing the practitioners who will follow them and to encourage their patients to be involved in research, in particular in clinical trials.

The Code should reflect this. It should incorporate a new obligation in the draft section on teaching (section 12.2), along the following lines: Accepting that teaching future generations of doctors is an important part of the work of doctors.⁴¹

⁴¹ The Australian Commission on Safety and Quality in Health Care identifies that 'Ensuring supervision of junior members of the workforce who provide patient care' requires the 'active participation of doctors', see *ibid*.

6 Other obligations to be incorporated

The draft code should also be changed in the following ways:

- The obligation in draft subsection 3.2.2 to ensure that the practitioner has adequate knowledge and skills should be expanded to emphasise that this knowledge should be contemporary. This recognises the prevailing expectations on medical practitioners to participate in appropriate professional development to ensure their knowledge is up-to-date. The subsection should be amended to read: Ensuring that you have adequate *contemporary* knowledge and skills to provide safe clinical care.⁴²
- Section 3.2.14 highlights that medical practitioners should ensure that their ‘personal views do not adversely affect the care’ their patient. Health professionals may have different views from patients about what an adverse impact might be, and this may be especially true in areas where opinion might be sharply divided such as abortion or assisted dying. In addition to the changes suggested in Section 4 of this submission, it is recommended that section 3.2.14 be extended to read: ‘Ensuring that your personal views do not adversely affect the care of your patient *or the referrals you make*’.⁴³
- The draft section on Public health does not go far enough. Medical practitioners can play an important role in highlighting

the wider socio-economic factors that influence the health of their patients. Subsection 7.4.2 should be amended to read: Participating in efforts to promote the health of the community and being aware of your obligations in disease prevention, screening and reporting notifiable diseases, *and facilitating interventions which may address community wide causes of disease and ill health*.⁴⁴

- The draft Code recognises that health care is a team endeavour that involves many different professionals. However, teamwork is hard and can be challenging if some members of the team do not fully recognise the expertise of others. The Code should recognise the reality that medical practitioners must *share* leadership in patient care. Subsection 5.3.2 should be amended to read: Advocating for a clear delineation of roles and responsibilities, including a recognised team leader or coordinator, *which may change at different points in the treatment cycle*.⁴⁵
- The draft section on patient records (10.5) appears to have been formulated before the widespread adoption of electronic health records. The use of shared electronic health records creates new risks and hence new ethical obligations. Medical practitioners should help patients understand the benefits and risks of shared electronic health records, and help them navigate the complexities. Medical practitioners should be sensitive to each patient’s privacy concerns and work with patients to ensure that shared records contain all the information patients want to make available, and only the

⁴² Proposed addition in italics

⁴³ Proposed addition in italics

⁴⁴ Proposed addition in italics

⁴⁵ Proposed addition in italics

information patients want to make available. *A new subsection should be added: Ensure that patients are aware of the information about them held in any shared electronic record (e.g. MyHealthRecord).*

- The draft section on advertising includes injunctions to ensure that claims made are ‘factual and verifiable’ (10.7.1) and ‘justifiable’ (10.7.2). *This should be strengthened, by replacing the word ‘justifiable’ with the phrase ‘evidence-based’.*

References

- Angner, E. (2016) *A course in behavioral economics*, Palgrave Macmillan
- Australian Commission on Safety and Quality in Health Care (2017) *Clinical Governance for Doctors*, ACSQHC from <https://www.safetyandquality.gov.au/wp-content/uploads/2017/12/Clinical-governance-for-doctors.pdf>
- Australian Commission on Safety and Quality in Health Care and Australian Institute of Health and Welfare (2017) *The Second Australian Atlas of Healthcare Variation*, ACSQHC
- Australian Commission on Safety and Quality in Health Care and National Health Performance Authority (2015) *Australian Atlas of Healthcare Variation*, ACSQHC
- Coory, M., Duckett, S. and Sketcher-Baker, K. (2007) 'Using control charts to monitor quality of hospital care with administrative data', *International Journal for Quality in Health Care*, 20(1), p 31-39
- Coulter, A. (2002) 'After Bristol: Putting patients at the centre', *Qual Saf Health Care*, 11, p 186-188
- Dahlen, H. G., Tracy, S., Tracy, M., Bisits, A., Brown, C. and Thornton, C. (2012) 'Rates of obstetric intervention among low-risk women giving birth in private and public hospitals in NSW: a population-based descriptive study', *BMJ Open*, 2(5),
- Dahlen, H. G., Tracy, S., Tracy, M., Bisits, A., Brown, C. and Thornton, C. (2014) 'Rates of obstetric intervention and associated perinatal mortality and morbidity among low-risk women giving birth in private and public hospitals in NSW (2000–2008): a linked data population-based cohort study', *BMJ Open*, 4(5),
- Duckett, S., Coory, M. and Sketcher-Baker, K. (2007) 'Identifying variations in quality of care in Queensland hospitals', *Medical Journal of Australia*, 187 (10), p 571-575
- Duckett, S., Jorm, C. and Danks, L. (2017) *Strengthening safety statistics: how to make hospital safety data more useful*, Grattan Institute
- Duckett, S., Jorm, C., Danks, L. and Moran, G. (2018) *All complications should count: Using our data to make hospitals safer*, Grattan Institute
- Dwyer, J., O'Donnell, K., Willis, E. and Kelly, J. (2016) 'Equitable care for indigenous people: Every health service can do it', *Asia Pacific Journal of Health Management*, 11(3), p 11-17
- Fox, T. (1963) 'The Antipodes: Private Practice Publicly Supported', *The Lancet*, 281(7286), p 875-879
- Freed, G. L. and Allen, A. R. (2017) 'Variation in outpatient consultant physician fees in Australia by specialty and state and territory', *Medical journal of Australia*, 206(4), p 176-180
- Hollnagel, E. (2014) *Safety-I and Safety-II: The Past and Future of Safety Management*, Ashgate Publishing Limited

- Hua, X., Erreygers, G., Chalmers, J., Laba, T.-L. and Clarke, P. (2017) 'Using administrative data to look at changes in the level and distribution of out-of-pocket medical expenditure: An example using Medicare data from Australia', *Health Policy*, 121(4), p 426-433
- Johar, M., Mu, C., Van Gool, K. and Wong, C. Y. (2017) 'Bleeding Hearts, Profiteers, or Both: Specialist Physician Fees in an Unregulated Market', *Health Economics*, 26(4), p 528-535
- Kabat, G. C. (2017) *Getting risk right: understanding the science of elusive health risks*, Columbia University Press
- Kennedy, I. (2001) *The report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995: Learning from Bristol*, The Stationery Office Ltd.
- Kruger, J. and Dunning, D. (1999) 'Unskilled and unaware of it: how difficulties in recognizing one's own incompetence lead to inflated self-assessments', *Journal of personality and social psychology*, 77(6), p 1121-1134
- Lowe, A., Bennett, M. and Badenoch, S. (2012) *Research, awareness, support : ten years of progress in prostate cancer: 2012 community attitudes survey*, Prostate Cancer Foundation of Australia
- Lowe, A., Wong, T. and Lowe, S. (2013) *Prostate cancer: the next generation 2013 community attitudes survey*, Prostate Cancer Foundation of Australia
- Moynihan, R., Doust, J. and Henry, D. (2012) 'Preventing overdiagnosis: how to stop harming the healthy', *BMJ*, 344,
- Moynihan, R., Henry, D. and Moons, K. G. (2014) 'Using evidence to combat overdiagnosis and overtreatment: evaluating treatments, tests, and disease definitions in the time of too much', *PLoS Medicine*, 11(7),
- Pickles, K., Carter, S. M., Rychetnik, L., McCaffery, K. and Entwistle, V. A. (2017) 'Primary goals, information-giving and men's understanding: a qualitative study of Australian and UK doctors' varied communication about PSA screening', *BMJ Open*, 8(1), p e018009
- Review of Hospital Safety and Quality Assurance in Victoria (Chair: Dr Stephen Duckett) (2016) *Targeting zero: Supporting the Victorian hospital system to eliminate avoidable harm and strengthen quality of care*, Department of Health and Human Services
- Richardson, J. (1998) 'The health care financing debate', in *Economics and Australian Health Policy*, G. Mooney and R. Scotton, Eds., Allen & Unwin, p 192-213
- Swerissen, H. and Duckett, S. (2014) *Dying well*, Grattan Institute
- Thomas, R. L., Zubair, M. Y., Hayes, B. and Ashby, M. A. (2014) 'Goals of care: a clinical framework for limitation of medical treatment', *Medical Journal of Australia*, 201(8), p 452-455
- Trevena, L. J., Zikmund-Fisher, B. J., Edwards, A., Gaissmaier, W., Galesic, M., Han, P. K., King, J., Lawson, M. L., Linder, S. K., Lipkus, I., Ozanne, E., Peters, E., Timmermans, D. and Woloshin, S. (2013) 'Presenting quantitative information about decision outcomes: a risk communication primer for patient decision aid developers', *BMC Medical Informatics and Decision Making*, 13(2), p S7

van der Weyden, M. B. (2005) 'The Bundaberg Hospital scandal: the need for reform in Queensland and beyond', *MJA*, 183(6), p 284-285

Wong, T., Lowe, S. and Lowe, A. (2014) *Culturally and linguistically diverse communities and prostate cancer: 2014 community attitudes survey*, Prostate Cancer Foundation of Australia

I am grateful for helpful feedback on earlier drafts of this submission from Professors Lesley Barclay, Peter Brooks, Judith Dwyer, and Christine Jorm. The views expressed in the submission are my own.