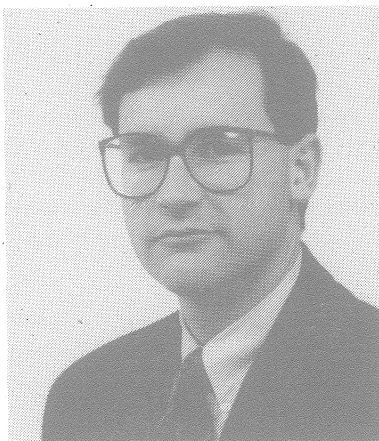


The Minister and Mr McKeown: the balance between privacy and public debate

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Earlier this year Mr James McKeown, who had end-stage renal failure and was 76 years old, sought access to renal dialysis without which he would have died very soon. His case commanded public attention when he told the *Holmes* television show that he had been refused because there were insufficient resources to fund his treatment. The Minister of Health, Mrs Jenny Shipley, became embroiled in the controversy when she discussed details of Mr McKeown's medical condition on television arguing that he had been refused on clinical, not resource grounds alone. This case raises many issues: age as an appropriate criterion for allocation decisions, the relative priority of funding for renal dialysis over other interventions, differential funding for the same treatment according to geographical area, and the adequacy of funding for health services generally. This note discusses the Minister's use of Mr McKeown's health information: to what extent does New Zealand law sanction the Minister's action? I attempt to set this issue in the wider context of the Minister's constitutional function.

The sequence of events saw Mr McKeown interviewed on television, followed the next day by the Minister. Before she appeared, the Minister requested and obtained, from the regional health authority (the public authority which purchases services from the hospital Mr McKeown attended) "information it was holding in respect of an individual who had been denied access to dialysis at Middlemore Hospital". The information was supplied with the name of the individual removed. It is not clear from information in the public domain how the RHA obtained the information from the hospital. Despite the formal attempt to anonymise the case, the Minister in her television appearance did not keep up any pretence; she discussed Mr McKeown. In particular, she revealed



aspects of his medical condition that were not previously publicly known and which were arguably not directly relevant to the question whether Mr McKeown should receive dialysis. (I should note at this point that it is also not clear that the Minister did not contact one of the attending physicians directly for information concerning Mr McKeown, or that she did obtain all the information that she had through the RHA: the Minister in response to my request under the Official Information Act refused to provide information concerning the means by which she obtained Mr McKeown's medical details. One reason she gave for withholding the information was to protect Mr McKeown's privacy.)

These actions have led to complaints to the Privacy Commissioner of

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interferences with Mr McKeown's privacy. Mrs Shipley argued that Mr McKeown's case, as presented, misled the public who were entitled to a fuller picture. In essence, the Minister's argument was that a person who goes public about his treatment in the public health system waives some or all rights to privacy that he would otherwise enjoy. Does New Zealand law support this proposition?

The Health Information Privacy Code permits disclosure

The starting point in the analysis is Rule 11 (limits on disclosure of health information) of the Health Information Privacy Code 1994, issued by the Privacy Commissioner under the Privacy Act 1993. This Code is of binding legal force. Rule 11 provides that health agencies must not disclose an individual's health information unless one or more of several exceptions apply. Assuming that the facts are as stated, three identifiable disclosures appear to have occurred. First, the doctors or hospital attending Mr McKeown disclosed to the RHA. Second, the RHA disclosed to the Minister. Third, the Minister disclosed to the public via television.

The individual may authorise disclosure

The health professionals could disclose to the RHA if Mr McKeown authorised them to, or, if he did not, if disclosure was one of the purposes for which the information was obtained. They held Mr McKeown's information for the purpose of treating him. Conceivably, they may have used his information to advance his prospects of dialysis in discussions with the CHE or the RHA. The health professionals could even voluntarily disclose it without Mr McKeown's authorisation if they reasonably believed that it was

impractical or undesirable to obtain his authorisation, and if disclosure was directly related to one of the

purposes for which they obtained the information, arguably if it was to further his prospects of treatment. Those are the only relevant grounds that the Health Information Privacy Code 1994 provides for disclosure.

As well, however, under the Health Act 1956, doctors *could*, but do not have to, provide the information to the RHA, if it was essential for the

purposes of the RHA's powers, duties, or functions under the Health and Disability Services Act 1993. One of the RHA's functions is to monitor the need for health services in its area.

Can there be implied authorisation?

Mr McKeown appears not to have given any explicit authorisation for the Minister to refer to details of his medical record. Does the Code contemplate some sort of implicit authorisation in circumstances like these where an individual puts some of his medical information in the public domain, an implicit authorisation for the Minister to access and disclose other health information of whatever degree of relevance?

The individual like Mr McKeown who discloses his renal problems in public has, I would argue, put that information, and that information only, into the public domain. That information is available for anyone to make use of as she sees fit. The action of putting the information into the public domain can be seen as an act of authorisation. (The Code and the Act indirectly recognise this argument: they both provide that where, information is obtained from a publicly available publication, it may be disclosed without further reference to the individual for his or her authorisation.) The Act and the Code are premised on the assumption that the individual has control and is entitled to continue to assert that control over information that concerns her. Control does not end in every case where a person allows another to collect or to have access to information about that person. Indeed the legislation centres around controls over use and disclosure of information. So even where an individual makes some information public, she is entitled to continue to exercise control over that which she withholds. (Indeed the Privacy Act recognises that there may be limits on, and thus some continuing control over, publicly available personal information in its Public Register Privacy Principles. These do not apply here.) However, while the person who makes public her private information invites questions from the news media and other

commentators, it is hard to see that that action of putting the information before the public also constitutes an authorisation for the news media, the Minister or any other person with an interest to trawl through the individual's records to find and disclose any other information, whether related to the disclosure or not. The individual by authorising use of some of his information has not authorised the use of all of his information. So at best it seems a limited authorisation. The difficult question in this context is not whether

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there can be an implied authorisation, but rather what information may the individual have implicitly authorised to be disclosed. Where a person asserts publicly that treatment has been denied only for reasons of his age, but, for argument's sake, the decision has been made on the grounds that pre-existing conditions make the person

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an inevitable prospect, what information has the individual authorised to be disclosed? Only that which he himself discloses, or other relevant information concerning the decision?

A special ministerial power to obtain private health information

As well, however, the Health Act 1956 provides in section 22D that the Minister of Health may, by giving a notice in writing, require a regional health authority or Crown health enterprise to provide information concerning any individual's health condition or treatment. The Minister may issue such a notice only if the information is required "to obtain statistics for health purposes or for the

purposes of advancing health knowledge, health education or health research". The information must not enable the identification of a person unless that person consents, or if the identifying information is essential for the purposes for which the Minister seeks the information.

From public comment the Minister made, it appears that she may have relied on this provision in order to obtain the information concerning Mr McKeown.¹ If this is so, section 22D also requires the CHE to disclose Mr McKeown's information to the RHA, and the RHA to provide the information to the Minister. Section 7 of the Privacy Act provides in effect that provisions like section 22D of the Health Act override Rule 11 of the Health Information Privacy Code, thus constituting a further ground to disclose health information without the individual's authorisation.

However, in order for the Minister to be able to rely on this provision, the information must be needed for one of the listed purposes. Of those, the only tenable possibility is that the Minister could claim the information was essential for the purpose of "advancing health knowledge". The Minister, I presume, claims that she is "advancing health knowledge" by providing information to the public concerning Mr McKeown's claims for treatment. It seemed to many who saw her appearance on television that she was concerned rather

more to defend the health system, and in particular the way the system makes allocative decisions since the government promoted substantial legislative changes (of which section 22D itself was part) in 1993. This might be part of a very broad definition of "health knowledge"

However, legislative history suggests that section 22D was more limited. Provisions under the Hospitals Act 1957 and the Area Health Boards Act 1983 permitted health professionals in hospitals to disclose non-identifying patient information for purposes of the "advancement of medical knowledge or research" and other provisions enabled the Director-General of Health to collect information for the purposes of

compiling statistics. Disclosure of identifying patient information without consent was an offence. Section 22D combined the statistics and health knowledge purposes, reposed the power in the Minister and not the Director-General, and gave the Minister a new power to obtain identifying information without consent if it was "essential" for the purpose sought. Officials writing the policy behind the 1993 changes were concerned to limit ministerial involvement in individual cases, for fear that individuals' information might be improperly used. (Parliament transferred the power to the Minister from the Director-General at a late stage in the passage of the legislation.) As the government coordinated the passage of the Privacy Act, the Health Act amendments and the Health and Disability Services Act, it is hard to believe that they deliberately took a power to enable the Minister to access an individual's health information for the purpose of participating in a political controversy. Indeed it is inconceivable that the use that the Minister appears to have made of section 22D was contemplated at the time the bills passed. Section 22D's reference to "health knowledge" should be read against this background. "Health knowledge" should mean something similar to but broader than "medical knowledge", like an "understanding of matters relating to human health". It would not be expected in this context to carry the meaning "knowledge about health policies".

However, even on the assumption that her exercise of section 22D is justified, that power is limited to *obtaining* the information from those who hold it. Section 22D does not go further and authorise the Minister to disclose the information once she has obtained it. For that one has to return to Rule 11 of the Health Information Privacy Code. The best argument that can be made for Rule 11 permitting the Minister to disclose information about Mr McKeown is that the purpose for which she obtained it (ostensibly the "advancement of health knowledge") required disclosure for its achievement. The Minister could still, however, even if lawfully entitled to obtain the information, have refrained from making as much of it public as she did.

It is hard in any event to see why the Minister needed to use or disclose full details of Mr McKeown's medical history in order to present her side in the debate. If her point was that the decision to refuse him was made on clinical grounds, that point could have been made without using or disclosing sensitive, and arguably irrelevant, material from Mr McKeown's file.

Conclusion on the legal position

Attempting to justify the Minister's actions on the ground that Mr McKeown impliedly authorised the Minister to disclose his medical information after he himself went public has an air of unreality about it. The arguments based on section 22D

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(that the Minister was advancing health knowledge) look tenuous. It seems difficult to conclude that the Minister acted lawfully in both accessing and disclosing personal details of Mr McKeown's condition.

The minister's constitutional position

If the law does indeed constrain the Minister from commenting on Mr McKeown's case in the way that she did, does it represent a proper public policy balance? The usual constitutional understanding is that the Minister is the member of the government responsible for the performance of the public health system. An express provision in the Health and Disability Services Act 1993 which declares the minister to be responsible to the House of Representatives for the performance of her functions, duties and powers as set out in the Act reinforces this notion. She is the person expected to answer both in the Parliament and in public for the successes or failings of the public health system. Can she discharge her constitutional duty if privacy legislation hamstringing her ability to comment on cases which demand a government response? That the Minister saw her obligation to respond as higher than any duty to protect Mr McKeown's privacy rights

appears obvious from her speed in reacting (she appeared on television armed with his personal information the very next day). If she had considered that her actions might have involved her in any possible breaches of the privacy legislation but still felt compelled to respond to the McKeown case with details from his medical record, she might waited until the House met and relied on parliamentary privilege as a shield. The Minister responded speedily, which is probably what the public expected.

Could she discharge her ministerial duty to comment and at the same time have avoided either accessing or accessing and disclosing details of Mr McKeown's case? It seems possible that she could have. However, the controversy was whether clinical or resource grounds dictated the initial refusal of Mr McKeown for treatment. The Minister might thus argue that this was the very type of case which necessitated her access to sensitive medical information in order to assess the strength of Mr McKeown's claim. It might justify access, but that in itself would not justify disclosure. The Minister might have made her point saying, "I have seen his record; the clinicians themselves do not consider him suitable for dialysis. I cannot, however, without Mr McKeown's authorisation, tell you exactly what their views are."

Is this sort of one-hand-tied-behind-your-back approach satisfactory? Should journalists and the public be left to draw inferences from failure on the part of an individual at the centre of a controversy like this to meet the ministerial challenge to put their personal information at the disposal of the news media? Is this the right balance between individual privacy interests and informed public debate?

People who enter the public arena can expect journalists to ask them difficult questions to ascertain the strength of their arguments. Indeed, a journalist who fails to establish some substance in a claim before giving it publicity is not discharging his responsibilities to the public. If the individual refuses to allow access to other information the public should draw its own conclusions.

The choices appear to range from restricting the minister totally, permitting her no more access to an individual's health information than the individual authorises, permitting her to seek the information as any other person might under the Official Information Act where the decision is made by the person holding the information, giving her a special power (similar to but more explicit than section 22D) to require disclosure of any information she judges to be necessary or relevant to the issue at hand, or allowing the minister a free hand in accessing any individual's information for any purpose. The last would, I hope, be rejected. Factors in the balance include the relevance of the detail of the individual's information to the matter of public debate, whether he or she is a willing or unwilling participant in the controversy, what degree of disclosure of his or her personal information has already occurred and in what circumstances and whether the issue raises any concern for the life or safety of any person. The minister's constitutional function is one factor too, but it is not, I believe, of overriding importance.

The Minister appears to regard the privacy legislation as a constraint. Her response to my official information request inviting her to state her views on whether the legislation discussed in this note enabled her adequately to discharge her ministerial responsibilities was that while the Privacy Commissioner was considering complaints relating to Mr McKeown's case, she did not believe it was appropriate for her to comment. The Minister has a constitutional duty to answer for her portfolio. She should be able to fulfil her obligations. If privacy legislation is improperly inhibiting her ability to answer to the public, then change might be needed.² It would be better to say, however, that the legislation did restrict her, than to rely on a strained interpretation of a special power, never previously available to ministers, to accord a dubious legality to the manner of exercising an undoubted ministerial responsibility.*

¹ An alternative is that she may have sought the information under the Official Information Act 1982. She could not, however, compel the supply of the information to her by this means.

² Ironically, the Official Information Act might provide either the appropriate

vehicle in a case involving the public health system (it applies only to public bodies) or alternatively a model for the future. The Minister could have sought access to Mr McKeown's information under the OIA; those holding it would have had to consider whether Mr McKeown's privacy interest was involved (section 9(2)(a)) as undoubtedly it was, and whether protection of his interest necessitated withholding the information. If they decided that it did not (unlikely) they could have provided the Minister with the information. If they decided that it did, then section 9(1) requires them to consider whether any countervailing considerations of the public interest, such as the accountability of ministers and officials, warrant disclosure nonetheless. This might have been such a case, if the information in question was needed to answer Mr McKeown's claims. However, the judgments under the OIA would have been in the first place for those holding the information, and not for the Minister.

* Mr McKeown's foray into the public arena succeeded in obtaining him renal dialysis.

Master in Bioethics and Health Law

Applications are invited for the Bioethics Research Centre's Master in Bioethics and Health Law. The course is designed for practitioners in medicine or law. It aims to assist these professionals to develop their expertise in this area by drawing on the resources of both ethical and legal theory. The program involves course work and the preparation of a thesis.

Those interested in the degree should contact
Professor Alastair V. Campbell
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PO Box 91, Dunedin
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Inquiries about legal aspects of the course should be directed to
Professor P.D.G. Skegg
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University of Otago
PO Box 56 Dunedin
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At the Centre

Christine Cooper, the Centre's administrative secretary, has taken up an appointment as Deputy Vice-Chancellor Smith's administrative assistant. It was a sad day for all of the Centre's staff when she left. Christine had been working at the Centre from its beginnings in 1990 and had been a pivotal figure in the Centre's efficient running, as well as being liked and admired by all that had contact with her. All the staff at the Centre wish her well in her appointment. Vicki Lang is the newest member of the Centre team. Vicki is taking up the position of administrative secretary, vacated by Christine.

The two new papers being taught by the centre in 1995 have begun well. Four of the Centre's staff have been involved in teaching module five of *Research Methods for Health Sciences* (HASC 403). Professors Gillett and Campbell gave three lectures that were audio-linked with groups in Christchurch and Wellington. Alex Lautensach and John McMillan tutored the Dunedin group. Jim Thornton and Helen Climo were the Christchurch and Wellington tutors (respectively).

The Centre's new paper BITC 403 *Issues in Law, Ethics and Medicine* has been a forum for many interesting lectures and discussion this Semester. The course has concentrated upon the interface between Ethics and Law. Having Professors Skegg (Law) and Campbell present at all the sessions has meant that students have been treated to depth in the two disciplines. The sessions have had a wide variety of perspectives with guest lecturers from diverse backgrounds. Sessions have included "The Natural Law Perspective" which was led Gregory McCormack from the Religious Studies department, William Evans Fellow Ian Freckleton on "The dependency of ethics on law", Fellow in Maori Health Care Ethics, Irihapeti Ramsden on "Culture, Ethics and the Law", and Professor Roger Higgs on "Doctors and Euthanasia".

Alex Lautensach spoke at Teschmakers Conference Centre (near Oamaru) on April 9. The topic of the conference was "Appropriate Health Care". Alex spoke on "Implications of the Gaia Theory for Health Care".