

28 November 2011

National Health Board  
133 Molesworth St  
PO Box 5013  
Wellington 6145

By email: [enquiries@ithealthboard.health.nz](mailto:enquiries@ithealthboard.health.nz)

### **Information Governance in the New Zealand Health Sector**

Thank you for the opportunity to comment on this proposal.

The New Zealand Medical Association (NZMA) is New Zealand's largest medical organisation and has a pan professional membership. Our members come from all disciplines within the medical profession and include specialists, general practitioners, doctors-in-training and medical students.

The NZMA aims to provide leadership of the medical profession, and promote:

- professional unity and values, and
- the health of all New Zealanders.

The key roles of the NZMA are to:

- provide advocacy on behalf of doctors and their patients
- provide support and services to members and their practices
- publish and maintain the Code of Ethics for the profession
- publish the New Zealand Medical Journal.

### **Overview of submission**

The NZMA:

- is concerned about the process the National Health IT Board had in communicating this consultation to stakeholders
- believes that our views need to be considered throughout the development of this framework, particularly in our role as writers of the Code of Ethics for the medical profession, but also more generally as the pan professional advocates for the profession
- strongly supports the initiative

- sees issues in terms of ownership, informed consent and storage of information overseas
- would like to see some principles developed under the framework for use of information for health research.

### **Communication**

The NZMA advises that it became aware of this consultation via a third party and, while it appreciates that the consultation document was placed on your website, the NZMA was not aware of the forthcoming consultation and did not know to peruse your website. In future the NZMA would appreciate your advising us directly of any matter you are consulting on. This is particularly so, given that there are likely to be significant ethical issues that will need to be addressed as this framework is developed, and as NZMA is the body responsible for publishing and promoting the Code of Ethics for the medical profession.

### **The proposal – detailed response**

In respect of the proposal itself, the NZMA advises that it strongly supports this initiative and looks forward to the development of a nationally consistent approach to information that will see an end to the current fragmented one that is adopted in respect of information governance. The NZMA notes however, that the draft proposal at this stage is very DHB centric and that greater consideration should be given to involvement of non-governmental organisations. In particular, as this framework is developed, the NZMA sees a need for a general practitioner to be involved as it is likely that some of the standards approved by IT managers working out of large organisations are not practical or affordable to primary care. In regard to this the NZMA would like to see general practitioner involvement on the Information Governance Framework Group and would be pleased to have an NZMA representative sitting on this group should you be open to this.

The discussion on “lack of leadership” and the “ownership” concept does raise some issues. In particular, views of ownership drive consideration of health information, and the legal rules governing “privacy” tend to mean that the focus is on the risk of wrongful use. The concept of managing privacy is often torn between a cost driver that stems from a management view, and a clinician approach which has a health provision driver. The new framework will need to be able to address these dichotomies.

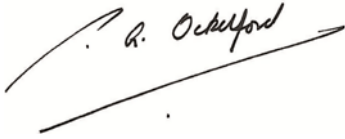
The NZMA also notes that in the discussion of ownership, the place of the end user/patient is addressed but that this does not appear to have been incorporated in the subsequent discussion and creation of the governance expertise. The NZMA considers that there needs to be some involvement of those who have cared for, or are caring for, people with long term medical conditions that are most likely to benefit from this improved integration and access.

The NZMA believes that the framework around informed consent needs to ensure that the advice provided includes a clear statement about the repercussions that can ensue from *not* allowing shared access to personal clinical information.

The NZMA is concerned about the idea of storing information internationally as there are subtle but diverse views around the world about what information sharing is, and should be. Before supporting such a proposal the NZMA would need to see a very compelling argument about the benefit of overseas hosting. On the other hand the idea of international collaboration in the use of data is something well worth promoting.

Finally the NZMA would like the framework to establish principles about what information, if any, can be accessed for health research and how this can be done through the framework.

Yours sincerely

A handwritten signature in black ink, appearing to read "P. Ockelford". The signature is written in a cursive style with a long, sweeping underline that extends to the right.

Dr Paul Ockelford  
NZMA Chair