



HEALTH INFORMATION STRATEGY ACTION COMMITTEE

Summary of Themes arising in the HISAC Consumer Forum held 13th February 2008

Throughout the day there were three themes that were prevalent through all the discussions. These were:

1. Consistency of use of information

It was made clear within the forum that there are concerns regarding the use of information. Some clinicians / organisations use information in one way and others will use it differently. It is easy for information to be used out of the context in which it was gathered, different regions do things differently and encourage various levels of understanding. There is a need for a greater level of consistency across the Health Sector.

2. Appropriate levels of control are required

Who has access; who controls the information; how does it get updated - these were among the concerns raised during the day. It was also made clear that controls need to be appropriate for the type of information (e.g. Mental Health records) and for how it is to be used.

3. Consumer involvement is necessary

Decisions shouldn't be made without more input from the consumer. How this input was/is obtained could be varied. It didn't just mean being appointed to committees but it also included such things as encouragement to take more ownership and to participate in debates around health information strategies and issues. Involvement improves "buy-in", understanding, confidence and trust.

Other themes have been grouped separately and are as follows:

Consumer Participation

- The public/consumers need to be involved in the governance/stewardship of health information.
- Consumer representatives are people who have expertise in providing consumer perspective(s) and who generally have networks into one or more specific consumer constituencies e.g. disability, mental health, women's health, Maori, migrant, refugee, older persons and rural
- Consumer input and involvement in decision-making is essential to building a greater level of trust.

Communication

- The need for the public to be more aware and have greater knowledge of what is health information and what is a personal health record.
- Communication about how information is used needs to be improved and in plain language.

- Improvement in the quality and frequency of the information being communicated. It needs to be reliable, authoritative and have consistency and purpose.
- Better recognition of the importance of consumers being educated and informed *before* they engage with health services.

Information Sharing

- The horizontal movement of health information is important and needs to happen but whom will it be made available to and on what basis?
- There is a risk of shared information being used to the consumer's disadvantage.
- There needs to be appropriate levels of control to ensure security of transfer for different levels health information which reflects the sensitivity of that information e.g. when an individual can be easily identified the security should be tighter.
- The importance of accuracy, along with the importance of creating good quality information and handing it on to other people who need it was stressed.
- Currently there is a lot of duplication of information within the Health sector.
- A balance is required between privacy and making sure the right people get the right information.
- Whenever we consider how to make sharing easier we need to discuss health outcomes and balance potential benefits against risks, particularly to privacy.
- The complexity and advancement of health knowledge requires the need for sharing of this information across care providers.
- Improved outcomes and a good information environment don't always co-exist.

IT Issues or concerns

- Consistent systems and processes are required throughout NZ e.g. if a discharge summary is sent to a GP, a copy should be sent to the patient so they know.
- Personal information could go on a memory stick controlled by the patient (it was acknowledged that this could cause another set of problems).

Other issues or concerns which will affect Information Sharing

- Information alone does not replace relationships and communication between people.
- Technology can get in the way of the clinical relationship e.g. the doctor focusing on the computer screen not the patient sitting opposite.

Data Collection – ownership and updating

- Who owns health information and who are the custodians?
- Who updates / corrects information?
- Who has access to health information and who decides this?

Security Risks of Information

- Accessibility and subsequent security is of concern.
- Fear that information placed on the internet may not be very secure.
- Concerns regarding information that is placed on devices such as memory sticks not being secured.

Trust

- *Question:* Trust in a system or trust in a person – what engenders each one?
Forum: "I trust a person when I can look in their eyes; I trust a system when I have had a hand in its creation".
- It is generally accepted that the intention is good, but public confidence is as good as the next scandal. Very careful controls / systems for managing announcements regarding such things as large databases etc. are needed.
- Fear of the unknown and what is not understood is natural and shouldn't be overlooked.

Purpose of collecting Health Information

- What is the definition of health information?
- Clear, nationally consistent guidelines on who collects what and who has access to it are wanted.
- There is a lack of understanding within the community about what information is collected, the purpose(s) for which it is collected, how it may lawfully be shared, and the benefits that arise.

Miscellaneous

- Don't deny that there are (potential) problems, but also don't approach this only from a problem solving perspective – look at opportunities.
- Advocacy and knowledge – the keys. If any patient asks/ wants advocacy it should be available.

The summary of desired outcomes:

- Forums to continue six monthly
- Coverage of the entire sector
- Knowing what information is available, written/ available in plain language
- Nationally consistent guidelines
- Evidence that 'things are better'
- Standardisation of practices
- Informed consent/informed choice
- Trusting relationships: e.g. Doctor, consumer, Lead Maternity Carer and the patient/consumer health record – respectful relationships amongst the health practitioners involved with the patient/consumer, acknowledging, valuing and being informed by the contribution each party makes to the record of an episode or episodes of care
- Education for consumers
- Consistency of systems and approaches across country – best practice
- Appropriate levels of control by consumers over their information
- Consumer rep(s) on HISAC
- Assurance that systems are secure
- Visible and accountable methods of enforcement
- There needs to be a Health Information Code
- Focus on health outcomes not minimum dataset