



Health Information Consumer Forum

10am to 4pm, 4 September 2008
West Lounge, Level 2, Wellington

NOTES OF MEETING

Item	Agenda
	<i>Morning Tea available from 9am</i>
1.	<p>INTRODUCTION AND WELCOME</p> <ul style="list-style-type: none"> Howard Fancy - Facilitator Marie Shroff, Privacy Commissioner, Office of the Privacy Commission (TBA), Health Information Strategy Action Committee (HISAC)
2.	<p>ACTION ITEMS FROM FEBRUARY FORUM</p> <ul style="list-style-type: none"> Reconvene the Consumer Forum within six months Improve communications with Consumers to ensure they understand what Health Information is collected and why it may be shared Agree to expedite the appointment of at least one consumer representative to HISAC and other HISAC initiatives Provide feedback from February forum to delegates. Communication around NHI
3.	<p>CONSUMER ENGAGEMENT FRAMEWORK (including Appointments)</p> <p>Dougal McKechnie <i>Manager, Office of the Health Information Strategy Action Committee</i></p>
	<ul style="list-style-type: none"> Table Discussion on Consumer Engagement Framework Report back
4.	<p>INFORMATION FLOWS MODEL</p> <p>Dougal McKechnie <i>Manager, Office of the Health Information Strategy Action Committee</i></p>
	<ul style="list-style-type: none"> Table Discussion on Information Flows Model
	<i>Lunch</i>
	<p>INFORMATION FLOWS MODEL (continues)</p> <ul style="list-style-type: none"> Group feedback and discussion

5.	<p>OVERVIEW OF WORK PROGRAMMES AND THEIR INTER-RELATION</p> <ul style="list-style-type: none"> • Ministry of Health Alan Hesketh <i>Deputy Director-General, Information Directorate, Ministry of Health</i> • HISAC and Quality Improvement Committee participation as required
	<i>Afternoon Tea</i>
6.	<p>REGIONAL MEETINGS</p> <p>Topics to be discussed: Action points raised at Regional Meetings.</p> <p>Feedback from Regional Meeting facilitators</p> <ul style="list-style-type: none"> • Dunedin - Jean Park • Auckland - Jo Fitzpatrick • Palmerston North - Barbara Robson
7.	<p>OTHER DISCUSSION</p>

Attendees:

- Aaron Morten, Auckland Health & Disability Advocacy Service
- Alan Hesketh, Ministry of Health
- Alyson Bradley, Aspergers Parallel Planet
- Anne McCracken, Health Trust
- Barbara Beckford, Federation of Women's Health Councils
- Barbara Robson, Federation of Women's Health Councils
- Brendan Kelly, Ministry of Health
- Bruce Van Essen, ACCLAIM Otago
- Dick Stark, Grey Power Federation
- Dougal McKechnie, HISAC
- Io Aleke, Auckland University Pacific Island Students Association Inc
- Jane Winder, HISAC
- Jayne Cooper-Woodhouse, Diabetes NZ
- Jean Park, MCA Consumer Representative Dunedin
- Jean Rombach, Palmerston North Kidney Support Group – Member
- Jo Fitzpatrick, Women's Health Action
- John Forman, NZ Organisation for Rare Disorders
- John Patterson, Pegasus Health
- John Scully, DPA
- Josephine Rangooni, Wanganui Regional PHO Rural Representative
- Linda Green, Acclaim Southland
- Lyn Dowsett, University of Otago
- Lynda Williams, Auckland Women's Health Council
- Marie Shroff, Office of the Privacy Commissioner
- Pat Murdoch, Wairarapa consumers group
- Patricia Cunniffe, New Zealand Council of Elders
- Rachel Pearce, National Heart Foundation
- Rosemary Jarmey, HISAC
- Sarah Parker, Health & Disability Commission
- Sarah Stacy-Baynes, Cancer Society
- Sebastian Morgan-Lynch, Office of the Privacy Commissioner
- Stephanie Kerruish, HISAC
- Trevor Smith, Acclaim Otago
- Warren Forster
- Wendi Wicks, DPA New Zealand

Apologies:

- Annabel Fordham, Office of the Privacy Commissioner
- Bev Clark, Chairperson Consumer Liaison Committee, College of GPs
- Bronwyn Hayward
- Christine Cowan, Ngati Kapo o Aotearoa Inc
- Dorothy Stewart, Age Concern Tauranga
- Ellen Ramsay, Rural Women of NZ
- Huhana Hickey, Maori Women's Welfare League, Mana Tuaakiri Branch
- Iris Pahau, Maori representative for Hutt Valley PHO
- Jane Bruning, Positive Women Incorporated
- Jane Lyndon
- Jock Scott, Body Positive
- Judi Strid, Health & Disability Commission
- Karen Walker, Central Potential Te Rito Maia Inc
- Liz Baxendine, Age Concern
- Marlene Mulholland
- Patricia Holborrow, Open Forum for Health Information
- Vishal Rishi, The Asian Network Inc

1. INTRODUCTION AND WELCOME

Initial discussion regarding the forum purpose

The group discussed the purpose of this and future meetings. Three questions were raised by the group.

- *How will the group define a successful outcome?*
- *What will be the impact of the consumer forum?*
- *What is the value added?*

The group indicated that they did not want this to be a token consultation but rather the group would like to make a difference, such as by having information to share through their formal and informal networks. The group also:

- expressed a desire to have tangible actions and outcomes
- want openness with information sharing
- would like to identify the policy issues and begin a process of meaningful engagement
- would like to have confidence in the process, develop an environment of trust, and describe a way forward.

Privacy Commissioner, Marie Shroff

Marie Shroff, Privacy Commissioner, provided an update to the forum group. There were four themes prevalent through the update and discussion with the group.

Privacy Issues

- With changes in technology, society is facing issues around privacy that never thought would require addressing. There is increased concern about privacy.

Consultation

- The Privacy Commissioner indicated that there are several phases to go through. They need to understand the consumer views and experience and see this as a very extensive task (will take longer than a day)
- They see that engagement with consumers is essential as information belongs to people and people are their reference point.
- These issues require and involve public consultation to assist them in finding a way forward.

Trust

- In a recent survey run by the Privacy Commission (Individual Privacy and Personal Information, July 2008), 92% indicated that they had trust in health providers; however the trust varied with different health providers.
- The public are more aware of privacy issues and have less trust. Trust must be earned as trust can fade.
- We need to identify what promotes trust in the system, where we can move with confidence.
- The systems are more transparent, however, with more transparency, we can see more problems.

Public awareness, consent and understanding of collecting health information

- The public are not well informed regarding national data collections. The public need to understand what information is entered, and what these databases do with their information.
- There are questions regarding what is informed consent when information is entered into a central database (the release of information should be based on informed consent).
- Individuals need to understand their right to informed consent and have trust in the system, and that they have the right to refuse, that they have the right to say no to practitioners.
- Would individuals trust the system if they knew more about the system?
- Trust is the cornerstone for informed consent.

- The Auckland DHB has a “break glass” policy that permits access to medical records without patient consent; however, each “break glass” event is audited and the practitioner is asked their rationale.
- Some of the other issues/topics include using stored DNA information and the public’s awareness of the NHI (e.g. Guthrie heel prick cards can now be used as DNA samples).
- In the recent Privacy Commission survey, the 50% knew they had an NHI number.

2. ACTION ITEMS FROM FEBRUARY FORUM

The following action items were discussed

- Reconvene the Consumer Forum within six months (*completed*)
- Improve communications with Consumers to ensure they understand what Health Information is collected and why it may be shared (*ongoing*)
- Agree to expedite the appointment of at least one consumer representative to HISAC and other HISAC initiatives (*the process of appointments would be discussed later in the day*)
- Provide feedback from February forum to delegates. (*completed*)
- Communication around NHI (*Brendan Kelly advised that this was a large task and requested assistance from the forum for going forward*).

3. CONSUMER ENGAGEMENT FRAMEWORK (AND APPOINTMENT PROCESS)

Dougal McKechnie and Brendan Kelly explained the process for making appointments to HISAC and advised that this is currently with the Minister. The appointment of members to HISAC is at the discretion of the Minister.

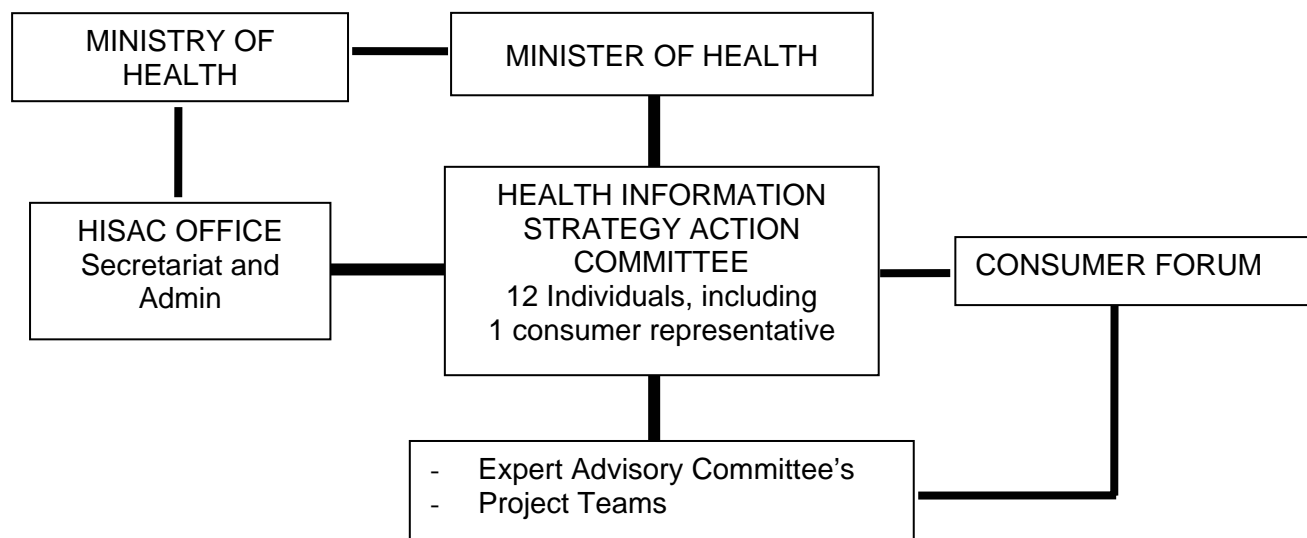
A draft Consumer Engagement Framework was provided for discussion to the group. The following list of questions was raised:

- *How can HISAC effectively engage with consumers?*
- *How can HISAC balance consumer group interests?*
- *How can HISAC consumer representatives be supported by HISAC and the consumer forum group?*
- *How to best inform HISAC regarding consumer perspectives?*
- *What are several ways to get consumer input?*

The group decided:

- The role of the consumer representative needed to be further defined. Several members of the group have volunteered their time to assist HISAC with the development of the framework.
- It is important to ensure that there is two way communication and consumer questions or concerns are answered.
- There is a need to establish a form of regular contact with representatives to seek a collective point of view (e.g. email or online chat rooms). This also gives representatives the opportunity to use this information to communicate further through their formal and informal networks.
- Provide consumer representatives with one page ‘fact sheets’ to assist them with communicating further through their formal and informal networks. The fact sheets should use plain English and be based on three points per page.
- Develop regional consumer forum groups to further communicate HISAC’s activities to gain the support from the community and ethnic groups.
- To develop the trust of consumers, ensure actions are followed through.

The following drawing indicates how HISAC sees the role of the consumer representative and the consumer forum group.



4. INFORMATION FLOWS MODEL

HISAC identified a need to develop a model explaining the concepts relating to the sharing and exchange of health information in New Zealand. This builds on the principles articulated in the Health Information Strategy for New Zealand (HIS-NZ) and in subsequent reference material produced by HISAC. The draft model has been communicated throughout the sector and was presented to the group.

Several issues and suggestions were raised regarding the model. They are:

The look

- There is too much writing and is too small.
- The blue makes it hard to read.
- Need a gender balance, depicts a stereotypical role for women; is more balanced for men

The information contained in the model.

- The model seems to be too academic. Use plain English, not jargon. Explain in simple terms, using patient experiences to describe how the information flows
- Provide basic information (e.g. what is the purpose, how to raise concerns and how to challenge).
- Use a consumer lens
- Show two way flows
- Pick one aspect of the patient journey.
- Use NZ stories, with good and bad outcomes; present a balanced and understandable view of how information is used in the health and disability sector.
- Educate about roles, rights and responsibilities at the same time as describing how information flows

How to communicate the information:

- Make a DVD, video to disseminate
- Use the library, community meetings and doctor offices to communicate this to the community.

Issues that will need to be communicated:

- how to correct information
- what are the benefits for patients regarding electronic sharing, storing of information
- options to opt in or out, and that they can change their mind
- principles of privacy
- ethical obligations of practitioners and organizations
- who has authorised access to patient information and for what purpose
- audits regarding access to information and whether enforcement occurs when breaches to information privacy
- when information is individualised/personalised and when information is aggregated
- when information is being used for research, that an ethics committee can grant access to individual's health information without consulting with them
- what security and safety measures are in place to protect patient information
- what backup and recovery measures are in place, to not destroy patient health records
- How does the code of rights and Privacy Commission principles fit in.

5. OVERVIEW OF WORK PROGRAMMES AND THEIR INTER-RELATION

Alan Hesketh, Deputy-Director General, Information Directorate of the Ministry of Health, provided the attendees with an overview of the health system as he sees it indicated that whatever the future brings, cost effectiveness is key to getting the best from future health technologies. Alan indicated to the consumer group that he is committed to going forward, ensuring that the consumer is involved.

6. REGIONAL MEETINGS

Three regional meetings were held in August providing the opportunity to seek consumers' views on key eHealth initiatives currently underway and to identify ways in which there can be strong consumer input the following initiatives:

- Security of health information
- Electronic prescribing and dispensing of medications
- Standardising clinical data
- Patient-approved transfer of medical records between GPs
- A model for the exchange of health information in New Zealand.

Feedback was provided by each of the Regional Meeting facilitators.

7. OTHER DISCUSSION

Possible topics for the next forum:

- General interest items
- Outside speakers – possibly Massey researchers project due February 2009
- Next Consumer Forum – March 2009

Action Points

No.	Action Required:	Action By:	Due Date:	Status:
1.	Sebastian/PC offered to hold a seminar for the consumer forum representatives regarding the Health Information privacy and related legislation and regulations (in next 6 months): topics might include, such things as: <ul style="list-style-type: none"> ▪ the difference between the Code of Rights, Health and Disability Commissioner, where consent is required for any health and disability service, and the Privacy Code, which focuses on the purpose the information was used for and the openness with which it was shared (GPs have an obligation to be open: Test Safe(a data repository for lab information) is not obliged to be open/to disclose what the information is being used for); ▪ why mandatory reporting of security breaches to personal information is not a requirement. 	Sebastian Morgan-Lynch	10/08 or 11/08	
2.	Sebastian to send out his presentation regarding the 12 privacy principles.	Sebastian Morgan-Lynch	30/09/08	
3.	Representatives to identify to Sebastian three key things that they need to know to understand the health information environment.	Forum Group	31/10/08	
Consumer Engagement Framework (and Appointment Process)				
4.	Sebastian, John, Jo, Barbara and Warren to work with HISAC on a model for consumer engagement and to have the process determined.	HISAC	30/11/08	
5.	HISAC to ensure proper referencing in the "Guidelines" for Consumer Engagement: change the title to "Guidelines".	HISAC	30/11/08	
6.	HISAC to work with consumer forum representatives to define the important characteristics of the consumer representative and to define the role(s) of the consumer representative, for the HISAC Committee, for Expert Advisory Groups and for the Consumer Forum Group.	HISAC	30/11/08	
7.	HISAC to facilitate a method by which representatives can keep in contact with one another, to share information and support one another	HISAC	31/10/08	
8.	HISAC to collect representative emails and create a list serve.	HISAC	30/09/08	
9.	HISAC to explore methods of ongoing communication with forum representatives so that they can raise issues and also receive feedback regarding what has happened with their concerns: check out Standards New Zealand discussion group set up.	HISAC	31/10/08	
10.	HISAC and representatives to define accountabilities: representatives with their formal and informal networks; and HISAC and MOH with the consumer representatives.	HISAC	30/11/08	

11.	HISAC to look more broadly for consumer representation, include the rural areas, other regions and other consumer groups.	HISAC	30/11/08	
12.	Provide the wording for the legislation of section 12 (1) (b) of the New Zealand Public Health and Disabilities Act 2000 in the Consumer Engagement Framework.	HISAC	30/09/08	
13.	HISAC to develop a Terms of Reference for the forum.	HISAC	30/11/08	
General				
14.	HISAC to send drawings by email to consumer representatives within two weeks: also to post on website.	HISAC	30/09/08	
15.	HISAC to develop Consumer Fact Sheets: regarding such things as HISAC role, MOH relationship, security of information.	HISAC	30/09/08	
16.	Organise engagement around what issues are a worry and what issues are not.	HISAC		
17.	Outreach to consumer groups in the next two to three months.	Forum Group/ HISAC	30/11/08	
18.	Would like apologies to be recorded formally and includes in the documentation.	HISAC	30/09/08	

Feedback from the Consumer Forum 4 September 2008

On evaluating the feedback from the Consumer Forum themes emerged which have been grouped together under the headings below and the number of corresponding responses has been given. There was a definite re affirmation for the attendees that ongoing consumer input into the decisions being made around Health information is necessary. It was felt that consumer representation keeps the focus on the individual. Many of the responses indicated that there were a lot of useful and practical discussions with good interaction between participants and speakers. It was felt to be a good opportunity to network and take back some useful ideas to their own areas.

There is a clear need for a prompt feedback of notes and visual material from the day to the participants. This stems from the difficulty the secretariat had in getting out the material from the previous forum. An increase in the frequency of communication from the HISAC office would be appreciated by many who attended the forum.

Also there was a clear indication from the feedback that there is a need for more clarity, explanation of role etc of Consumer Forum and how HISAC sees it fitting into the bigger picture; a framework to be in place for how consumers can input into process and for this to be made available to group and filled. The feedback included suggestions for discussion on the National Health Index (NHI) promotion, databases such as National Immunisation Register (NIR) as well as informed consent. It has also been suggested that individuals for the forum could also present/speak.

<u>What did I learn?</u>	Number of Responses
The need for ongoing Consumer input	10
Communication & collaboration	9
A clearer understanding of HISAC	7
Improved understanding of the systems of government	6
About the issues facing the health sector	5
Need to increase understanding	4
Importance of maintaining trust	3
About the Information flows model	3
Roles, rights and responsibilities	2
<u>What did I like?</u>	
Interaction and discussions	12
The great presentations	7
The Forum is making progress	6
The attitude & involvement of officials	5
Officials' showing a willingness to listen & involve consumers	5
Framework	4
The venue & catering	3
The facilitation	3
The feedback from the previous forum	2
The information flows model	2
<u>What could have been better/ what is needed</u>	
Better communication	12
Improved process	12
More discussion on issues	11
Clearer agenda	4
Communication strategy	3
No issues	3
Quality of presentations	3
More frequent meetings	2
Catering & venue	2