

In the valley of the missing link: The Consumer Experience

Tena koutou katoa. Ko Jo Fitzpatrick taku ingoa.

Greetings, my name is Jo Fitzpatrick and it falls to me today to provide a consumer perspective on Cartwright.

A couple of weeks ago I was asked to provide a consumer perspective at a clinical meeting. As usual - at my first meeting with clinicians - I listened more than I spoke, was careful and constructive in my contributions, and measured in manner.

At the end of the meeting, one of the clinicians approached me and complimented me on my contribution. She also quizzed me on my credentials as a consumer advocate - which go back 12 or so years and stand up to scrutiny. That's when the kicker came. 'Oh' she said 'you're not a real consumer advocate. You know too much. It's probably time for you to step aside and let a real consumer take your place.'

I am sure I looked as startled as I felt and I'm not sure where my response came from. 'So, how long have you been a specialist?' I asked politely. Twenty years she answered proudly. Goodness, I said - that's longer than I've been a consumer advocate. So, when do you plan to stand aside? Now she looked as startled as I felt. 'Oh' she said, 'Now that's given me something to think about. I may need to revise my assumptions about consumer advocates' And she slunk away on a sheepish grin.

I have called this presentation In the valley of the missing link : The Consumer Experience. It is based on a 1973 Bob Dylan song 'No Time to Think' off the Street Legal album. One of the verses goes -

Memory, ecstasy, tyranny, hypocrisy

Betrayed by a kiss

On a cold night of bliss

In the valley of the missing link

And you have no time to think...*

Just as I gave my clinician something to think about, this presentation has given me the rare opportunity to think and reflect on the consumer journey which indeed has elements of memory, ecstasy, tyranny and hypocrisy. There are also times when we have been betrayed by a kiss on a cold night of bliss. And the first reflection is to consider the assumptions clinicians make about consumer advocates and what that means for us. I'll leave that though, for you to consider in your own time!

For the people of New Zealand , and most starkly for the women of Cartwright and their whanau, the sobering 'take home' lesson from Cartwright was that a 'Trust Me' message from medicine was no better than that from a used car salesman. Relying unquestionably on either had the ability to maim and sometimes kill. This realisation shook us to our foundations. The earth moved uneasily under one of life's accepted certainties.

There were structural responses to Cartwright – some of which we have reviewed today. But the fundamental realisation that medicine was fallible reinforced and energised the women's health movement at the time which was arguing for more self determination and control of personal health. They were using kitchen tables, speculums and mirrors to acquaint women with their bodies, advocating for home birth and beginning the task of educating consumers to be agents in their own health and wellbeing in a myriad of ways. It was empowering and heady stuff.

But twenty five years later, women take control of their genitals by having them surgically enhanced to create designer vaginas, maternity has become a life phase fraught with worry as women are screened for everything and medical intervention rates soar at birth, and people use the internet to educate themselves on matters health.

Cartwright established informed consent as a basic foundation for health service delivery. It gave us the Code of Rights and the Office of the Health and Disability Commissioner. These were a good start but where do consumers find themselves 25 years after Cartwright?

To bring us into the present let's look at the MoH 2013 – 2016 Sttmt of Intent. In that the Minister tells us he is driving an 'integrated approach that puts the patient and user at the centre of service delivery'.

And the Ministry tells us

- it will work to 'continue to influence New Zealanders decisions about how to *influence their own health*';
- it will work on 'more timely and efficient *patient focused services*';
- that it will '*ensure patients and carers are at the centre of service delivery*' ;
- that 'Whanau Ora places whanau *in the centre, and in control of achieving their own goals*';
- that the Government is committed to providing *people centred* services for older New Zealanders so they can live healthier and more independent lives
- that they ' will establish an electronic health record for every person and invest in more opportunities for *patient selfcare, including better IT tools that enable people to take greater control of their own care*'
- that they will support the development of 'telehealth tools that help *patients to take greater control of their own care.*'
- that patient portals will be ' a *self care tool for individuals*, with the addition of a shared care plan for more difficult health needs if required
- that one of the desired Ministry impacts is that 'The public is *supported to make informed decisions about their own health and independence*'
- That they are aiming for a health system 'that is *people-centric* and more convenient.'

The rhetoric is rampant but is it reflected in reality? So much in health is about us. Without us, the whole enterprise becomes somewhat pointless! With today's emphasis on patient centred care, patient portals, patient journeys and patient directed care pathways, has the power in medicine shifted towards consumers as partners in care? Have we moved from a culture of 'Trust Me' to 'Trust You and Me together' in the last 25 years?

This is a question I find myself asking every time we commemorate the anniversary of Cartwright. As an active consumer advocate in health it is also a question I grapple with on a daily and weekly basis.

Health is a huge and complex system. An in depth analysis of this question is not possible in the time we have available. So today I will describe and analyse some consumer initiatives in health and draw some general conclusions based on my observations and experiences for us to think about.

So, let's have a look at the balance between health professionals and consumers. Sitting under the Ministers are a number of groups and entities but the three I want to focus on today are the Ministry itself – briefly! ; the National Health Board and in particular its subcommittee –the National IT health Board with its consumer forum; and the Health Quality and Safety Commission. The latter two have the most comprehensive consumer initiatives which is why I have chosen them.

The closest the Ministry comes to an organised consumer network is the NGO (Non Government Organisations) Health and Disability Network. This group was established in 2001 by a group of NGO leaders including Family Planning and Women's Health Action to provide a platform for health sector NGO's to engage with the Ministry. Members of the group are elected by the sector they represent. They organise annual forums to report back to the sector and identify key NGO issues and take these to the Minister and the Ministry. I was Chair of this group from 2006 to 2009 and while it performs a useful forum for consumer based organisations, it addresses primarily NGO sector issues.

So, on to the National Health Board. There is no specific consumer representation amongst their 10 Minister appointed board members but they have three non medical professionals - the Chair, Murray Horn who was in Treasury for 18 years and is a professional board member; Murray Milner , an IT professional ; and Hayden Wano a health administrator.

Sitting under the National Health Board is the National IT (Information Technology) Health Board. The IT health board members are five health professionals chaired by an IT specialist but, and here at last is the exciting bit. There is a Consumer Panel. The IT Health Board has also recently established the Health Information Governance Expert Advisory Group and the Consumer Panel chair is one of 4 non health professionals on that eight member group. Equity at last!

Consumer Panel

I have been a member of the health IT consumer panel since forever. Our membership is described on the website like this:

The current panel comprises about 20 ordinary New Zealanders who come from a mixture of walks of life, ethnicities, age groups, regions and health status. Some have a background in the health sector as consumer representatives, but all are there to wear their 'consumer hats' - scrutinising the details of the projects to make sure every aspect is optimised for the average user.

Consumer engagement is essential to ensuring that health information solutions are person-centred and people-focused.

It also says:

The Consumer Panel has been initiated to support the delivery of the IT Health Board priority projects. Health information is uniquely personal. Privacy and access rules are absolutely essential to public confidence, and the Consumer Panel has been established to represent the needs of the health consumer.

Actually, the IT consumer panel was a concerted labour of love by consumers. It started under HISAC (the Health Information Strategy Advisory Committee) around 2006 , when a group of us persuaded HISAC that a consumer panel was a good idea. Women's Health Action was a prime mover in this initiative. So, by the time HISAC was replaced by the National IT Health Board, we were a part of the landscape it was difficult to leave us behind.

Something interesting happened on the journey from HISAC to the IT Health Board though. We established the HISAC consumer forum as an open membership group. If you were dumb enough to be interested in health information and you were a consumer, you were in! The consumer panel is an elite group and selection to it has not always been transparent. Things are getting better though and there is now the facility to register your interest on the website. In my experience, these are now the first people considered when a vacancy arises. So, if you're dumb enough to be interested in health information and you are a consumer, please lodge an Expression of Interest.

- **So, what do we do?**

In general:

Panel members meet three or four times a year to compare notes. More importantly, we go into the many governance groups and project teams that are working on various components of Health Information technology.

Currently members of the panel have been assigned as members of about 10 groups, governing a diverse range of National Health IT Board projects including long-term conditions, health identity, medications management, standards, maternity care, and Telehealth. We are also attached to umbrella groups such as the national clinical leadership group, and several local programmes. There is scope for much greater engagement but we often have to fight for consumer representation, despite this being essentially a supportive environment.

Specific initiatives include the Shared Health Information Seminars 2012

In 2012, the National Health IT Board (NHITB) held a series of public and community seminars to discuss improvements to the way personal health information is shared electronically.

The seminars were an opportunity to provide updates on progress and to gather feedback, and they followed on from the NHITB's 2010 Future of Health workshops.

A major consumer panel initiative which flowed from these was the development of a consumer expectations paper in response to issues raised about sharing health information and the high profile cases which were in the public domain – principally around accidental breaches of ACC and other personal information held by government. That paper will shortly be available for public scrutiny.

This is also the home of Shared Care and Patient portals and I have been involved in both these initiatives.

The National Shared Care Plan programme has been developed in partnership with the National Health IT Board and the Auckland Regional District Health Boards. The programme supports the National Health IT Board's e-Health vision and the delivery of the goals of *Better, Sooner, More Convenient Health Care*.

To achieve high-quality health care and improve patient safety, by 2014 New Zealanders will have a core set of personal health information available electronically to them and their treatment providers regardless of the setting as they access health services.

Their home page states:

The Shared Care Plan programme is seeking a collaborative approach with all care providers supporting people with Long Term Conditions, to develop a comprehensive and coordinated electronic care plan. The care plan will define mutually agreed problems, goals, actions, timeframes and accountabilities for all involved and increase the person's participation in their care.

Evidence suggests that patients with long term conditions benefit from a care plan developed in partnership with their care team and with a person centered view of care. For the person this will improve coordination of care and communication with their care team, reduce the number of times information is repeated and reduce duplication of investigations or services.

Is it clear to you that the Care Plan goals and priorities are set by the patient in this description? That this is a partnership between them and their carers? Contrast this with the patient brochure – written by the consumers on governance group.

If you have an on-going or recurrent health condition..., you might find a shared care plan helpful. You and your health care worker, put together a shared care plan based on your health goals and priorities. The plan becomes part of your personal health information and is shared electronically with all those involved in your care so that you can work together to manage your on-going health and wellbeing.

And this symbolises the battle on this Governance group – constantly having to remind the clinicians that Shared Care is not just about them sharing information but working with their patients as partners. We have been lucky as the majority of the health professionals on this group are committed to that but, even so, it has still been an issue.

Did you know that by the end of next year, the National IT Health Board wants every New Zealander to have electronic access to their health information? Interesting eh? Here's some relevant extracts from the June 2013 National Health IT Board newsletter:

Patient portals: the way of the future

The National Health IT Board (NHITB) wants integrated family health centres, general practices and primary health organisations (PHOs) to provide patients with electronic access to their health information within the next two years.

NHITB Director Graeme Osborne says a number of district health boards (DHBs) and GPs are already leading the way with developing and using patient portals, and he's urging other health professionals to drive further progress.

"The time is right for patient portals," he says. "People increasingly want to manage aspects of their own health care and health information, and we need to respond to that. Secure online access to health information and health activities is the way of the future."

The NHITB wants every New Zealander to have electronic access to their health information by the end of 2014. It supports development of patient portals on two levels – a self-care patient portal for managing everyday health, and the addition of a shared care plan for more complex health needs.

Over the next two years the NHITB will work with general practices, district health boards (DHBs) and information technology vendors to provide improved electronic access to health information, and will develop information toolkits to support the process. The IT Board will also actively encourage people using health services to ask their providers for patient portals.

"We're expecting demand for improved electronic access to personal health information to grow as both clinicians and patients see the benefits," says Graeme Osborne. Wellington GP Richard Medicott, whose Island Bay Medical Centre offers patients use of an online patient portal, says people increasingly want to manage aspects of their own health care and health information.

"The days of people waiting for a phone call to confirm their medical laboratory results are coming to an end," he says.

"People want to be able to log in online to see for themselves if their lab results are available. And while they're logged in, they might decide to book an appointment with their GP, check when they're due for a mammogram, email the practice nurse with a question about their medicine, and confirm the vaccination schedule for one of their children."

He says patient portals also offer real benefits to clinicians. As well as saving time, the use of a patient portal will enhance the relationship doctors, nurses and other health professionals have with their patients.

Graeme Osborne says that having confidence in the security of information provided will be a key issue for organisations developing portals. The NHITB has developed a brand, Connected Health, so the public can see quickly and easily that the systems and portals which are collecting, transferring, storing and sharing their health information are secure and trustworthy. All private information will be encrypted on a secure Connected Health network.

I have mixed feelings about this major initiative. Done well, it may be a mechanism for shifting power into the hands of health consumers and changing health care into a partnership between health consumers and their health professionals. For some people with long term conditions, the right patient portal provides huge opportunities.

Done badly, this could become a tool for transferring responsibility for care to consumers ill prepared to deal with it. I am also not convinced about the extent to which consumers want to manage their own health care and health information. I am wary of a scenario which transfers responsibilities to patients and allows blame to be transferred with it. If things go pear shaped, I know who bears the consequences. It is not the clinician who must live with them 24/7. To use a clumsy analogy, if my car is broke I take it to a mechanic because he is an expert. While I accept responsibility for routine maintenance, it is unreasonable to expect that I can fix it. If I could, I wouldn't need a mechanic. The new health initiatives must facilitate a partnership model of care where the responsibilities on both sides are clear and mutually agreed. Responsibility devolved to consumers also needs to be within their scopes of practice!

My reservations around patient portals are that the consumer panel has not been engaged in a systematic programme of work around these despite the fact that we have been raising this since it was raised with us. When the consumer panel were told of this initiative, we were somewhat perplexed and asked just one question: 'What for? We think there should be clear goals, priorities and purposes for patient portals with standards and protocols. We also think there should be engagement with consumers about what they would like and find useful. I am doing some work on this but as it is not mandated yet, it is also not paid!

The Health Quality and Safety Commission (HQSC) is the last entity I want to deal with. The HSQC was established in 2010 to ensure all New Zealanders receive the best health and disability care within our available resources.

They tell us on their home page that: *Working together we can build a world class, innovative, **patient and family/whanau centred** health and disability support system.*

Six of their 8 board members and the Chief executive are health professionals, and nine of their ten programmes are firmly based in clinical health services. It is no surprise then that their consumer engagement work programme is also heavily biased that way, especially given that their staff leader in this area was once a registered nurse. They support and fund Co-design initiatives, which is where clinicians work with service users to improve health services and health service delivery.

They have a consumer network of six which makes interesting reading. My assessment is that to qualify you need to

1. Be part of a special interest health group – mental health and disability networks feature as do support groups for stillbirth and family violence
2. Have had serious health issues and/or been saved by the NZ medical system. There is a cancer survivor, three of the six have spent days in a coma not expected to live, and one is deaf and has been treated for heart attack and gout.

The HQSC Consumer engagement areas of work are: Health literacy, Leadership capability and Consumer engagement. Their most recent piece of work in the leadership capability area was a consumer and provider leaders forum in May this year addressing the question 'How can we co-create a national leadership pathway. Six consumers and six providers were involved. The consumers included two from the patient advocacy groups - breast cancer Aotearoa coalition and rare disorders , one from mental health, a person who works for 'Recovery Solutions Limited, one from a DHB clinical board and the HSQC staff member who once was a nurse. I'll leave you to decide whether these six represent general health consumers.

It is in the secondary consumer engagement section on the HSQC website that you find non service related links with the Directory of Consumer organisations and the Consumer Collaboration. You can also sign on to the Health Consumer Register, something I have done twice without yet receiving an acknowledgement.

The Consumer Collaboration started around 2004 and was a partnership originally between the New Zealand Guidelines Group, the Health and Disability Commission and consumer organisations – notably Women's Health Action. It's development was guided by an excellent resource published in November 2004 called ' Effective Consumer Voice and participation for NZ: A Systematic review of the Evidence.' This paper was researched and written by Sandra Coney and discussed at a forum for consumers and health bodies. The idea was for an independent peak body for consumers which would link them up and provide opportunities for consumer training, resource sharing and participation in health policy and decisions across the whole health sector.

A lot of people did a lot of work to make it happen but somehow the funding never arrived in sufficient amounts to make it happen. With the 2010 re-organisation of the health sector, I thought it might disappear completely but it lingers on in this deep dark corner of the HQSC website. Arguably, in my opinion as Chair for two years, the problem was that it was too far out of the ambit of control for a health system that likes to keep its fingers on all elements of potential risk.

In the end, the personal is political. Nothing demonstrates this better than a TED talk by American Eric Dishman entitled 'Health care should be a team sport'. Diagnosed in his teens with a terminal kidney condition he tells of being at the centre of 'a clash of medical titans all trying to figure out which one of them was right about what was wrong with me.'

They all agreed on one thing, however. Eric had two rare kidney diseases and was unlikely to live more than 2 or 3 years. He says

' the gravity of that doomsday diagnosis sucked me in and I immediately prepared myself, as a patient, to die according to the schedule they had just given me.' That is, until he met a patient named Verna in the waiting room who took him off to the medical library and did a bunch of research on the diagnosis and diseases. They revealed that the conditions typically struck people in their 70's and 80's. '

They don't know anything about YOU, Verna told him ' Wake up, take control of your health and get on with your life.' Twenty four years later, Eric is certainly doing that.

He argues that the medical people are not bad people but miracle workers working in a flawed and expensive medical system set up the wrong way. It is a system dependent on

- Hospitals and clinics for every care need
- Specialists who just look at parts of us
- A guesswork of diagnoses and drug cocktails tried until something either works or you die
- And importantly PASSIVE patients who accept this and don't ask any questions.

Eric argues that there is a need to reinvent medical systems around the world, that the sacred and over romanticised doctor/patient is a relic of the past and that the future of health care is smart teams and ' you had better be on that team for yourself.'

So, here's what I think based on my observations and experiences in the valley of the missing link.

On the plus side –

- the rhetoric around patient centred care and consumer control is strong, we must leverage off that and do ensure that there are patients active at the centre. We must be careful to ensure that the expectations placed on that patient or consumer are appropriate and serve their best interests.
- There are some useful initiatives with consumers well placed to make the most of them, especially in health IT.
- There are health professionals eager to work with consumers as partners in care.
- There are a million opportunities to get involved – as health and disability committee members, as partners in service delivery, as a member of the IT Health Board consumer forum or by filling out the HQSC Consumer Registry form. PHARMAC, the Office of the Health and Disability Commissioner and National Screening Unit all have consumer advisory groups. You could stand for the DHB Board, or get involved in their consumer networks or the Public health, Disability Service or Hospital Advisory Committees

So those are the positives

BUT

- There has been very little ceding of power to consumers in health in the last 25 years.
- Gatekeeping is alive and well in the health sector. Most often it comes from health professionals and health managers but it also comes from other consumers.

- there is no systematic structure to ensure consumer participation. We need to join up consumers and work collaboratively. We need an independent and functioning consumer collaboration working as it was originally intended.
- consumer participation remains an act of good will by the medical system and subject to its patronage and control.
- While not exactly an afterthought, achieving real progress for consumers is hard work, as clinicians and clinical priorities dominate.
- The transition from a medical model to a model of shared care which includes health consumers as active partners will be a long hard road. We have the rhetoric, the reality will be much more difficult.
- We need more consumer advocates in many more places in health. Consumer representation is not a competitive sport, we can all bring our experiences and advocacy to the role.

My first title for this presentation was lifesaver. Why – because lifesavers are the candy with the hole in the middle. Also to be effective and save lives, a life ring needs a consumer at its centre. To fulfil the promise of Cartwright and save our lives, consumers need to fill that hole.

So despite progress being made I believe consumers and patients are currently lost in the valley of the missing link. Our challenge is to take ourselves out of the valley and into the centre of that lifesaver.

Despite the memory, ecstasy, tyranny, hypocrisy

And despite the risk of being

Betrayed by a kiss

On a cold night of bliss

And that's what I think from the valley of the missing link.

Thank you