



# What poorly integrated care looks like: or how WE could do it better

Janelle Colquhoun

16<sup>th</sup> October 2015

Your Integration is my Fragmentation



# The Year I got Diabetes







# World Expo '88



# Australian Opera





*Così*



*Il Trovatore*



*Madama Butterfly*



*Masked Ball*



Janelle and Dame Joan



## Who is a Consumer?

A consumer is a person who uses, or potentially uses health services, including their family and carers. Consumers may participate as individuals, groups, organisations of consumers, consumer representatives or communities.

## *Our Mission:*

*Health Consumers  
Queensland empowers  
Queensland consumers  
to lead and drive better  
health outcomes.*

Oper Frankfurt





*Gypsy Princess*



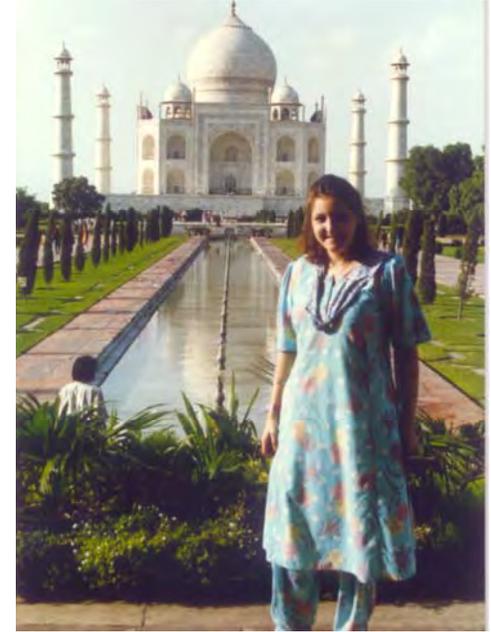
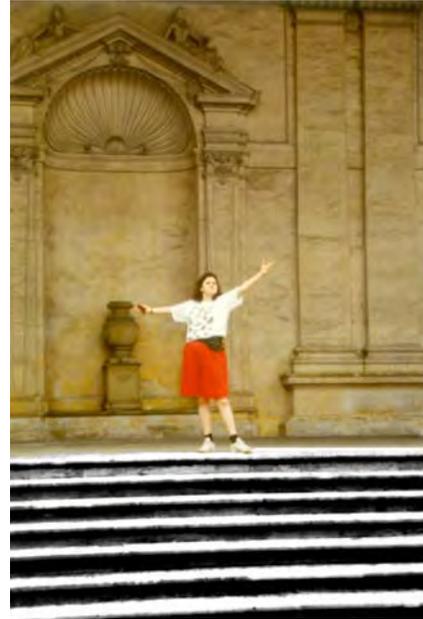
*Les Huguenots*



*Pearl Fishers*



*Lucrezia Borgia*



Aged 29, over 6 months  
I went totally blind

---

From Diabetic Macular Edema (D.M.E.)

# My Life

Before Blindness



After Blindness











# CONSUMER ENGAGEMENT

*Consumer engagement* informs broader community engagement. Health consumers **actively participate in their own healthcare and in health policy, planning, service delivery and evaluation** at service and agency levels.



Paris World  
Diabetes  
Congress  
(WDC)



## Bermuda



# Consumer-Centred Care is:

- accessible, safe and responsive
- informed, active decision making
- coordinated care
- inclusive of the patient's support network
- mutually respectful partnerships





My journey: Janelle Colquhoun

Janelle loves to cook, and is guided by scent and taste.

## About diabetes

Diabetes is a chronic disease caused by the pancreas failing to produce sufficient insulin to convert glucose into energy or by the body failing to respond to the insulin produced. This deficiency results in increased concentrations of glucose in the blood, damaging many of the body's systems, in particular the blood vessels and nerves. Major health risks include heart failure, kidney failure, blindness, stroke, and limb amputation due to chronic ulcers and poor circulation.

- Type 1 (formerly known as insulin-dependent) is an inherited disease in which the pancreas fails to produce the insulin essential for survival. The disease develops most frequently in children and adolescents and entails a lifetime of insulin injections.
- Type 2 (formerly named non-insulin-dependent) results from the body's inability to respond properly to the insulin produced by the pancreas. Type 2 diabetes accounts for around 90 per cent of all diabetes cases worldwide. It occurs most frequently in adults, but is being increasingly noted in adolescents. The disease can often be managed by modifying your lifestyle choices.

being blind is such a big deal. Since losing my sight I've sung for Opera Queensland; if I know the stage and there are other chorus members, the audience needn't know there's a blind singer up there.

I set up Salubrious Promotions the year we married with initial seed funding from the Queensland Government's Access Arts. I realised there were many professional-level artists without an agent who couldn't get work because of their disability. I now represent about 200 performers Australia wide. I'm working to overcome people's perceptions. I get a brief of what a client wants for a function, and recommend the best talent for the job. For me, selection is about ability, not disability. If they're the best for the job, they get it. None of us want sympathy employment.

Over the past six years I've produced more than 600 mainstream and disability events including the lunchtime classic concerts for Brisbane City Council. I've also had some singing gigs overseas in Paris, Bermuda and Seoul (usually related to organisations working for diabetes research, but not exclusively) and I've spoken at forums in Australia and abroad, trying to get the message across to 'do as I say, not as I do'.

I was a very visual person. Now I need to learn musical pieces

by ear. A dear friend of mine, pianist Mark Leung, records new pieces and his wife D'Arne Sleeman, a soprano with Opera Queensland, puts the words down for me to listen to over and over again. I learn while I'm cooking. I cook curries, using taste and smell to determine how I'm going.

Right now, the challenge is time; time to get everything done and get a donor organ before mine totally fail. I'm on the transplant list for a pancreas and kidneys. Dialysis is for the interim; but the doctors say we're pushing that to the limit. I have a portable dialysis machine at home and I'm hooked up to that at night during my beauty sleep. To get to Chicago, Bart organised flight legs that allowed dialysis in between. The idea of not being able to say 'yes' to these opportunities – being chained to a seat hours at a time day after day – is anathema to all I believe.

I'm not happy about being blind, but what's the good of whingeing and moaning? People don't want to spend time with a sour sop. I love people; I love life; and there's still plenty to do. Yes I learned a hard lesson, but I never do things by halves. Even now, I'll occasionally take a shortcut with my dialysis – I'll limit the fluid intake before a performance so I don't have a bloated belly. I may be blind, but I am still a woman: and a little vain! ■

Canberra  
“Employer  
Awards”



# Korea



# Diabetic Nephropathy – My kidneys totally failed.

---

First Haemo then Peritoneal dialysis for the next 3 years



# Consumers' Priorities

When it come to Consumer-Centred Care, consumers' priorities are:

- Right care, right time, right place
- Us at the centre
- Timely access
- Continuity of carer
- Care in the community
- Travel support
- Evidence based information
- Informed decision making

Despite everything,  
I made it to 40!



Glendon (mining town), North Queensland



Gold Coast,  
Queensland



## Turning point

By Heather Grant

***Janelle Colquhoun, 40, tried to ignore a life-threatening condition in the name of her singing career. But blindness and daily dialysis have enabled her to find a new use for her voice.***

“I grew up in Brisbane and music was always a part of my life. I was a bit of a geek though. While friends were swooning over the Bay City Rollers, I was into Frank Sinatra and Louis Armstrong. Jazz was my first love. As a 16th birthday present, Mum gave me singing lessons. A year later, the end of school was looming and my singing coach recommended an audition at the Queensland Conservatorium of Music. I gained a scholarship in opera – I’d never even listened to opera! – but Dame Joan Sutherland and Kiri de Kanawa soon replaced Louis and Frank in my music collection.

“Brisbane hosted the World EXPO in 1988. I was offered a six-month performing contract with my vocal quartet. The Conservatorium

dons warned against it. They said I’d ruin my voice and any chance of a career. But what’s a girl to do? I *had* to give it a go, and as it turned out a year later I successfully auditioned with the Australian Opera.

“It didn’t matter how many times I walked down to the (Sydney) Opera House. That was my office, my workplace, and it was just such a fantastic feeling. In 1990, as an understudy, I was called up to sing with Joan Sutherland as one of the grand dame’s maids of honour. It was a dream come true. But still not enough. “I had itchy feet. I wanted more. So I took off to Europe. No job; just high hopes. I went to auditions by day, and paid for vocal training cleaning at night.

“Throughout all this time, I’d been ignoring my health. I’d been diagnosed with juvenile diabetes when I was ten. Specialists said I needed routine: eat, exercise, rest at set times. Music is not a nine-to-five job though and there just seemed to be too many negatives to the illness. I just didn’t want to know. I was so hopeless at looking after it.

“I was on the verge of defeat musically, when an offer came from the Frankfurt Opera to sing with them. I grabbed it and stayed for six years. Six more years of ignoring the tell-tale warnings my body showed. The last straw came when I was trying to lose a couple of kilos. I stopped taking my insulin to try and speed up my metabolism

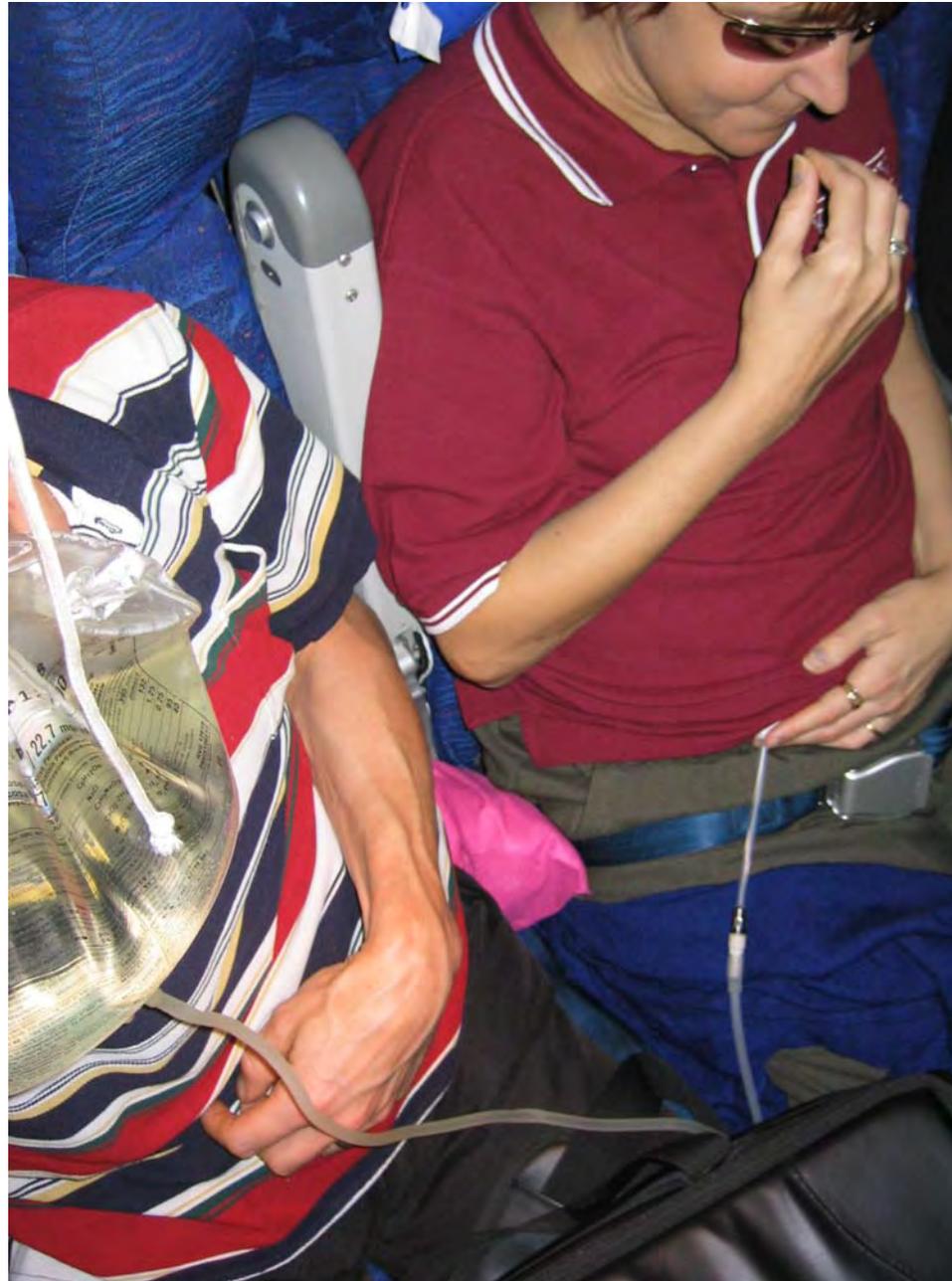


# Why patient-centred care?

*Research increasingly suggests that, not only is patient-centred care the right thing to do, it is associated with better health outcomes. Health services with high patient centricity are associated with reduced mortality and infection rates, reduced cost of care, decreased length of stay, and fewer readmissions, adverse incidents and complaints leading to litigation. The case for patient-centred care is compelling.*

From QH Centre for Healthcare Improvement's report:

“Patient safety: from learning to action 2012. Fifth Queensland Health report on clinical incidents and sentinel events in the Queensland public health system 2009–10 and 2010–11”.



# Chicago



# Appeal for lift in life fight

By EMMA GUMBLETON  
AND BROOKE FALVEY

KIDNEY dialysis patients have been forced to catch public transport to and from treatments due to a volunteer shortage at the Kidney Support Network.

The network, based at The Gap, runs a patient transport service to the Royal Brisbane and Princess Alexandra hospitals, but a lack of drivers means it only operates three times a week.

Chief executive officer Kay Schafer said many patients were forced to take public transport.

"They're drained and nauseous and nearly all just want to go home to bed, but they're waiting in the sun to catch buses," she said.

"Our patient list is endless ... but we just can't (transport them) due to a lack of manpower."

Kepperra resident and network president, Janelle Colquhoun, opted for home dialysis because of trans-

 **closeup**  
transport crisis

- Volunteer shortage.
- Patients forced to catch public transport.
- Service cut to three times a week.

port difficulties.

But the 40-year-old, who is also blind due to diabetes, will soon have to return to the hospital for three days a week, eight hours a day for treatment.

"My husband used to spend three hours a day driving up and back to the hospital because there was no other way," she said.

"Home dialysis is failing on me at the moment, so I will have to go back. I hope to be using the network bus, but the service can only work with volunteers."

■ Phone 3300 0909 to volunteer.



■ Arduous journey ... Janelle Colquhoun of Kepperra has to find own her way to hospital.

PC112224

# Canberra 2020 Summit



## PM backs idea on organ donation

***KEPERRA: A local woman who is awaiting organ transplants is heartened by Prime Minister Kevin Rudd's response to her call for an opt-out organ donation system.***

Janelle Colquhoun has been waiting seven years for pancreas and kidney transplants.

At the weekend's 2020 Summit in Canberra, Mr Rudd supported Ms Colquhoun's call. The opt-out system requires people to inform authorities about whether they want to donate organs, essentially making everyone a mandatory donor unless they have notified the government to the contrary.

Mr Rudd said in his closing speech last Sunday: "I'm a beneficiary. We as a nation need to get this right. So many people are depending on us to get it right with urgency."

Ms Colquhoun said: "I'm over the moon. I wasn't aware he had received a transplant."

Mr Rudd received an aortic valve transplant.

The 42-year-old attended the summit under sponsorship from radio station 4BC.

Ms Colquhoun was diagnosed with Type I diabetes at the age of 10 and is on dialysis. She has to inject herself with insulin every day.

Aged 29, she lost her eyesight from complications and was diagnosed with stomach cancer at 38.

She survived all of this and etched a career in opera, singing with Opera Queensland, Opera Australia, the Frankfurt Opera and at World Expo 88.

Deputy Prime Minister Julia Gillard also publicly supported Ms Colquhoun's idea on

Monday, claiming it was one of the most significant contributions at the summit. Ms Colquhoun was delighted to get her point across.

"I was in the health stream with 100 people and everyone had their own agenda," she said.

The two-day summit in Canberra finished on Sunday after 1000 of "the best and brightest brains" from across the country tackled big issues, such as housing affordability and indigenous health.

While Ms Colquhoun is not as well-known as some, she is anything but ordinary. She has overcome numerous battles caused by ill-health.

# “The Gift of Life”

Combined simultaneous kidney & pancreas transplant.

---

Westmead, Sydney, 20 July 2008

## “A Night with the Stars”

Westmead  
Hospital  
Fundraiser



# Principles

1. **Participation**
2. **Person-centered**
3. **Accessible and inclusive**
4. **Partnership**
5. **Diversity**
6. **Mutual respect and value**
7. **Support**
8. **Influence**
9. **Continuous improvement**



## *The Gift of Life*

*Sad and suffering yesterday, Janelle enjoys life today because she received the gift of life from an organ donor.*

**KIDNEY**

support • network

My Third CD



# Montreal WDC



# Thailand





# Switzerland



# A new chapter begins

MARNIE LUDGATE  
ludgate@m@qst.news1td.com.au

AN opera singer with a hankering for crime writing has adopted an alter ego to play out the role of a crime sleuth with a difference in her first novel idea.

Keperra resident Janelle Colquhoun is part of Sisters in Crime – a writing group for women whose Brisbane chapter was officially launched recently by bestselling author Katherine Howell during the Brisbane Writers Festival.

Sisters in Crime was launched in Australia in 1991 and attracts female crime writers who meet each month to plot murder and discuss crimes in gory detail – all in the pursuit of a good whodunit yarn.

Like her, Colquhoun's text heroine is blind, and the character sets about solving cold cases alongside her trusted guide dog, a former police dog.

Colquhoun lost her sight more than 15 years ago as a result of diabetes.

"The more I write it the



**CRIME WRITER:** Sisters in Crime member Janelle Colquhoun.

more I think I really need this super dog!" Colquhoun laughed.

The successful opera singer has now finished the first draft of her first crime novel.

➔ **The group meets on the first Saturday of every month at 12.30pm at the Queensland Writers Centre at the State Library. Contact Meg Vann at megvann@gmail.com**





Health Consumers Queensland Ministerial Advisory Committee



# Enablers for Effective Consumer Engagement

- Valuing of consumer voices
- Shared vision
- Committed action
- Effective communication
- Long term relationships

## Dubai WDC





### Diabetes

## My life, career and complications - the power of a health consumer voice to motivate and inspire

A story of living and surviving diabetes told in the candid words and songs of Australian opera and jazz singer Janelle Colquhoun.

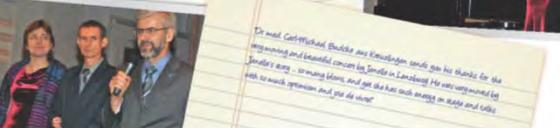
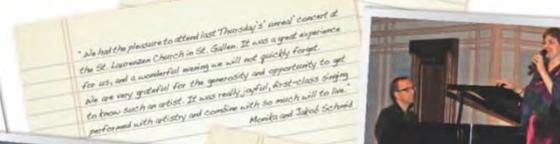
By combining a talk about my diabetes journey with the gift of my singing voice, I have presented this educational concert format around Australia and in countries including Bermuda and North America.

In autumn 2010, I undertook a concert tour in Switzerland, invited by *Bayer Diabetes Care Country Management*. I gave three concerts and told the story of my career as an international opera singer, concert producer, business owner, writer, health consumer representative and my life with Diabetes - living with Type 1 from age 10, suffering the complications - peripheral and autonomic neuropathy, retinopathy (resulting in total blindness), mastopathy (resulting in breast surgery), stomach cancer (resulting in a total gastrectomy), nephropathy (resulting in 3 years of daily home dialysis), cardiovascular disease (resulting in a stent), and in 2008 aged 42, a combined simultaneous pancreas kidney transplant.

The three Swiss regional concerts were attended by almost 600 people; the majority with diabetes, as well as their relatives and Health Care professionals.

I do not lecture my audiences or give them advice, and I am not a healthcare professional. I share my story from a patient's perspective and as a peer who empathises the struggles and emotions of living every minute with this insidious disease. As a positive and driven person, I hope to inspire and motivate my audience and empower my listeners to manage Diabetes to the best of their abilities, and prevent the awful complications I have suffered.

Education in a form people do not perceive as teaching is the result I have achieved with my concerts. My testimonials from Switzerland affirm that it is an effective method and worth undertaking. People were motivated to make changes to their lifestyle and take diabetes and its consequences seriously.



My business since  
1999 “Salubrious  
Productions”



London



# The Australian Charter of Healthcare Rights

[http://www.safetyandquality.gov.au/acsqhc\\_program/australian-charter-of-healthcare-rights/](http://www.safetyandquality.gov.au/acsqhc_program/australian-charter-of-healthcare-rights/)

## AUSTRALIAN CHARTER OF HEALTHCARE RIGHTS

The Australian Charter of Healthcare Rights describes the rights of patients and other people using the Australian health system. These rights are essential to make sure that, wherever and whenever care is provided, it is of high quality and is safe.

The Charter recognises that people receiving care and people providing care all have important parts to play in achieving healthcare rights. The Charter allows patients, consumers, families, carers and services providing health care to share an understanding of the rights of people receiving health care. This helps everyone to work together towards a safe and high quality health system. A genuine partnership between patients, consumers and providers is important so that everyone achieves the best possible outcomes.

### Guiding Principles

These three principles describe how this Charter applies in the Australian health system.

- 1** Everyone has the right to be able to access health care and this right is essential for the Charter to be meaningful.
- 2** The Australian Government commits to international agreements about human rights which recognise everyone's right to have the highest possible standard of physical and mental health.
- 3** Australia is a society made up of people with different cultures and ways of life, and the Charter acknowledges and respects these differences.



For further information please visit [www.safetyandquality.gov.au](http://www.safetyandquality.gov.au)

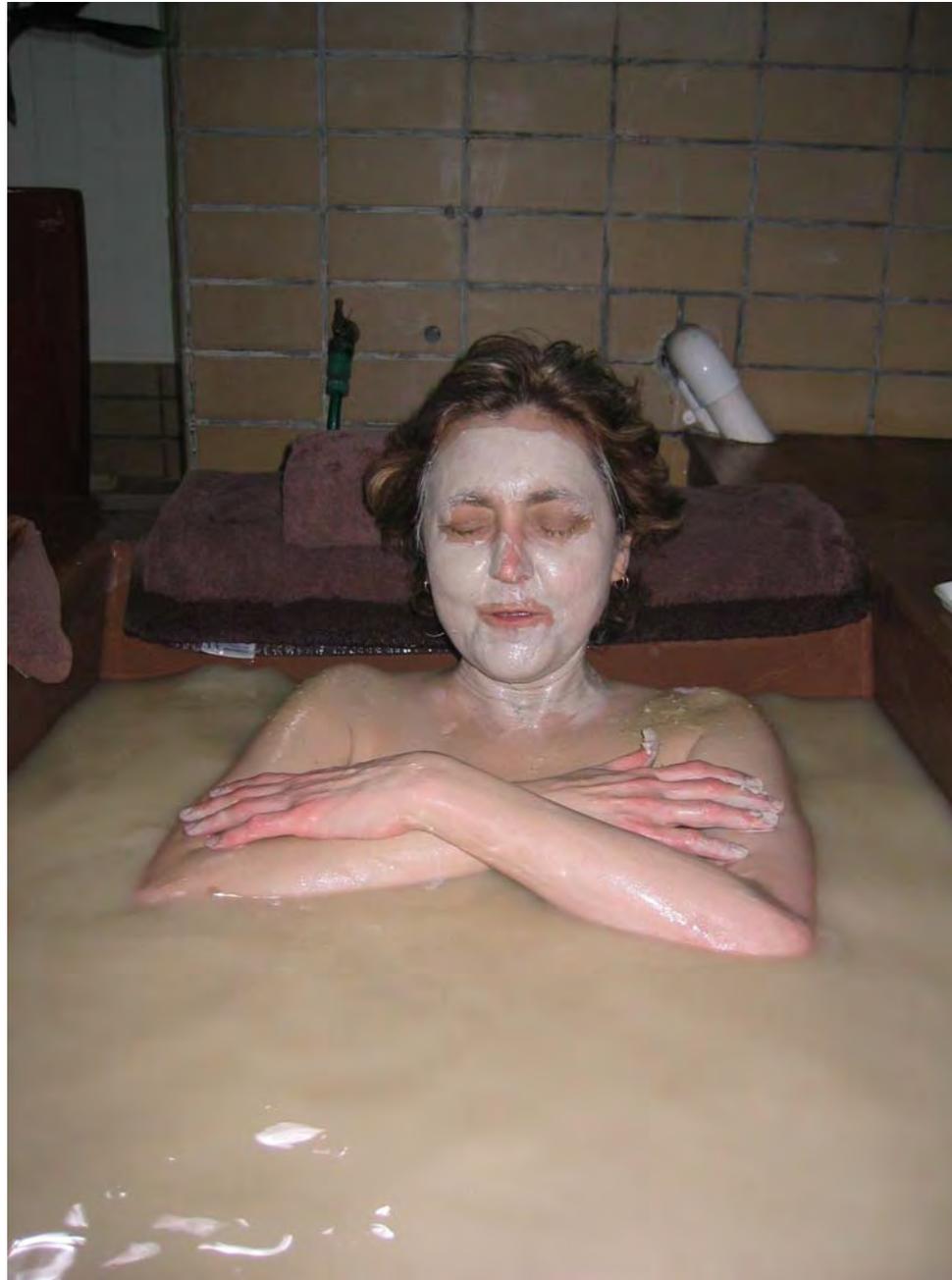
AUSTRALIAN COMMISSION  
SAFETY AND QUALITY OF HEALTHCARE

### What can I expect from the Australian health system?

MY RIGHTS	WHAT THIS MEANS
<b>Access</b> I have a right to health care.	I can access services to address my healthcare needs.
<b>Safety</b> I have a right to receive safe and high quality care.	I receive safe and high quality health services, provided with professional care, skill and competence.
<b>Respect</b> I have a right to be shown respect, dignity and consideration.	The care provided shows respect to me and my culture, beliefs, values and personal characteristics.
<b>Communication</b> I have a right to be informed about services, treatment, options and costs in a clear and open way.	I receive open, timely and appropriate communication about my health care in a way I can understand.
<b>Participation</b> I have a right to be included in decisions and choices about my care.	I may join in making decisions and choices about my care and about health service planning.
<b>Privacy</b> I have a right to privacy and confidentiality of my personal information.	My personal privacy is maintained and proper handling of my personal health and other information is assured.
<b>Comment</b> I have a right to comment on my care and to have my concerns addressed.	I can comment on or complain about my care and have my concerns dealt with properly and promptly.

New Zealand



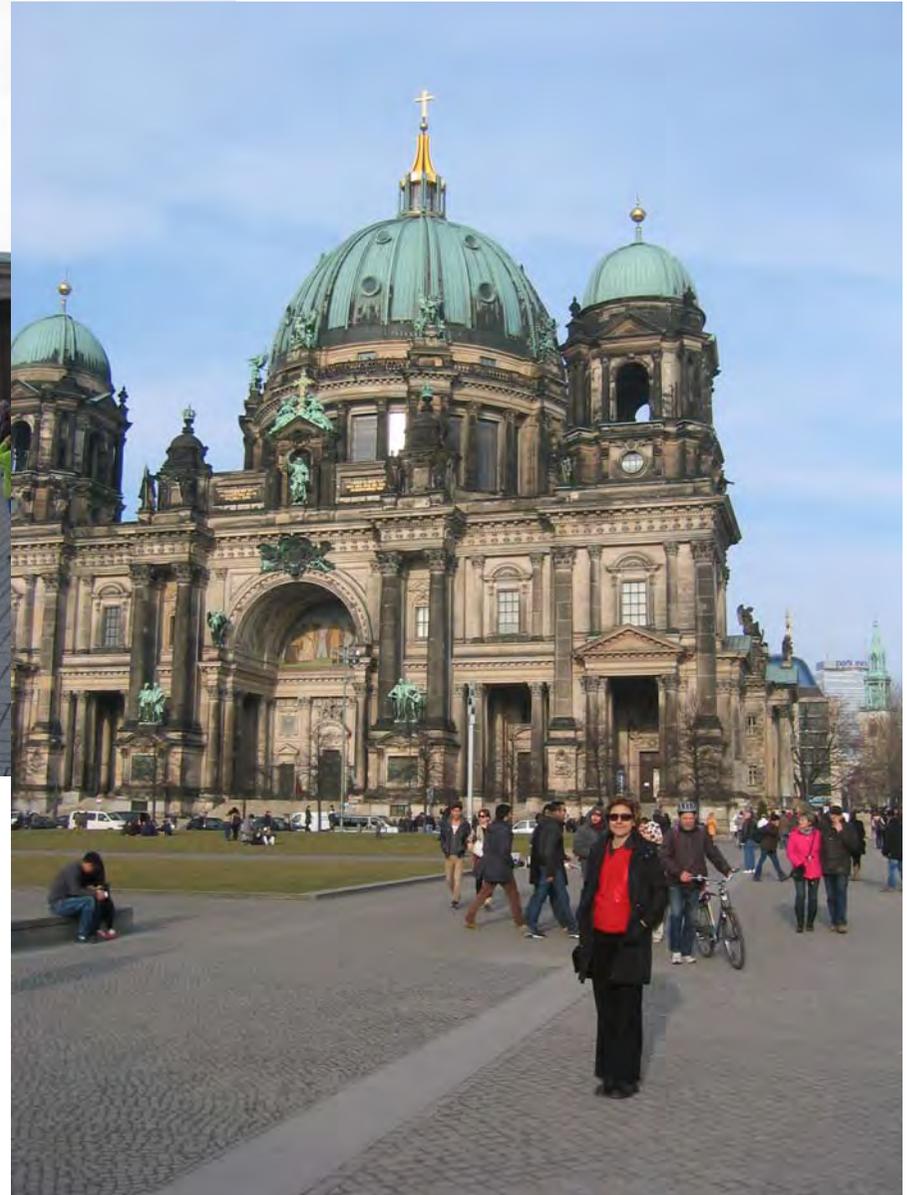


# Melbourne WDC



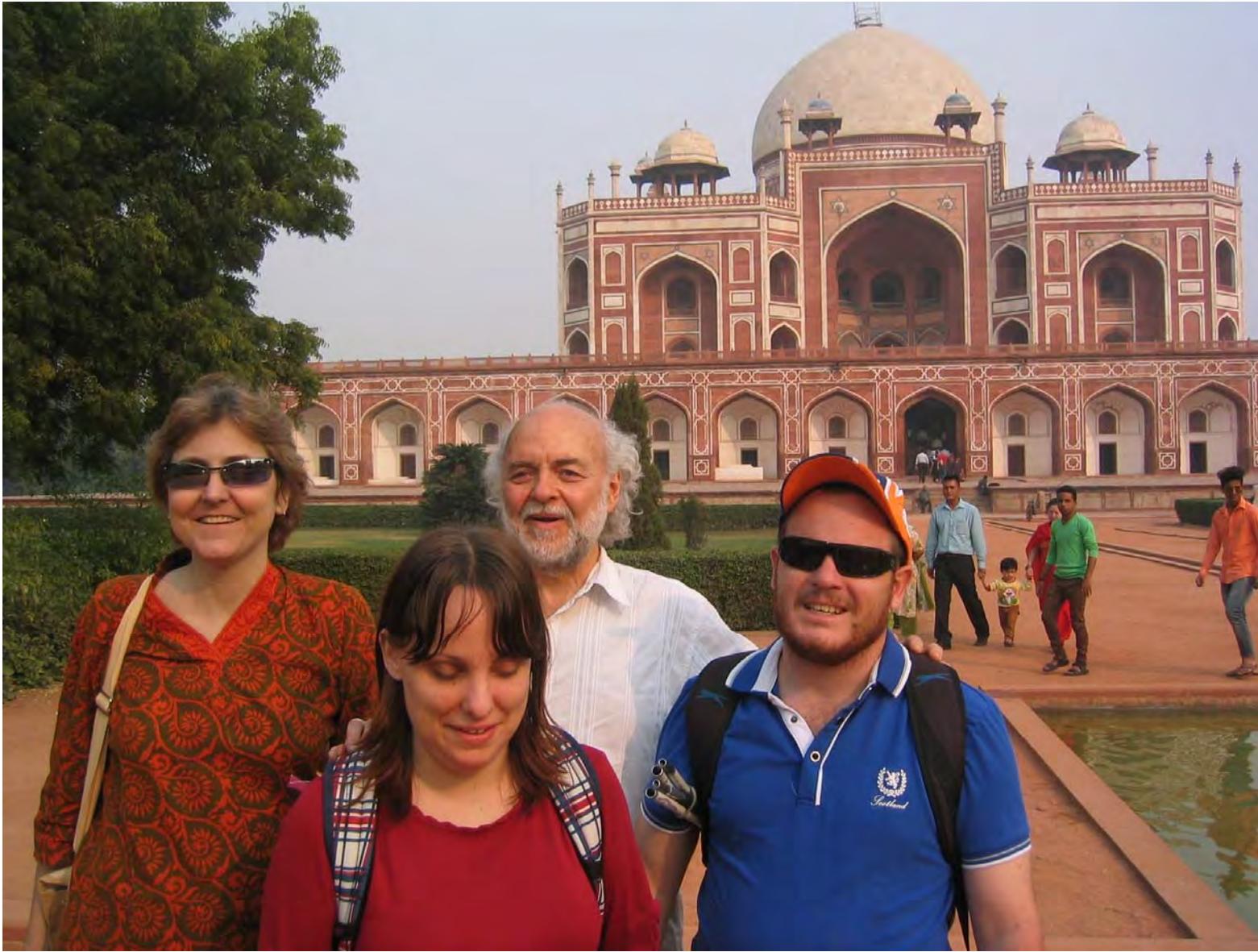
# Berlin







Sync – Intensive Arts Leadership Course  
Sydney 2014



New Delhi



# My Babies



*Elektra*

*Boris*



*Figaro*

*Macbeth*



*Tristan*



Foot fetish

