



Consumers Health
Forum **OF** Australia

Treating Each Other With Respect:

Philosophy, Goals, & Experience Wheels

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Consumers shaping health

Who am I?

Digital Comms for CHF

- National peak body
 - chf.org.au

Designer

- Web, Social, Industrial
 - User-Centred Design, Co-design

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What will I cover?

- Our Communication Philosophy
 - Why do you need one?
- Our Real People, Real Data Toolkit
 - Experience Wheel



Philosophy

- Utilitarian vs Kantian
 - Greatest good for greatest number doesn't always help individuals

Always recognize that human individuals are ends, and do not use them as means to your end.

- Immanuel Kant



Philosophy

- Philosophy in Action
 - We interact with people at their most vulnerable, and often most motivated
 - Experience wants to be heard, and acknowledged
 - Wait before you reply, let your emotions subside.



Philosophy

- Goals
 - Not to solve a problem necessarily
 - Communication itself is the goal
 -



Philosophy

- Our Comms Goals
 - To affect national policy
 - To amplify consumer voice
 - Get Consumer Reps on boards & committees

More Rep Info: bit.ly/CHFReps



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Real People, Real Data

Method and tools to capture & analyse consumer narratives of health, illness & the health system

- Identify key stages of experience
- Semi structured interview
- Create an Experience Wheel
- Compare wheel to indicators of effective care



Real People, Real Data

Patient Narrative Benefits

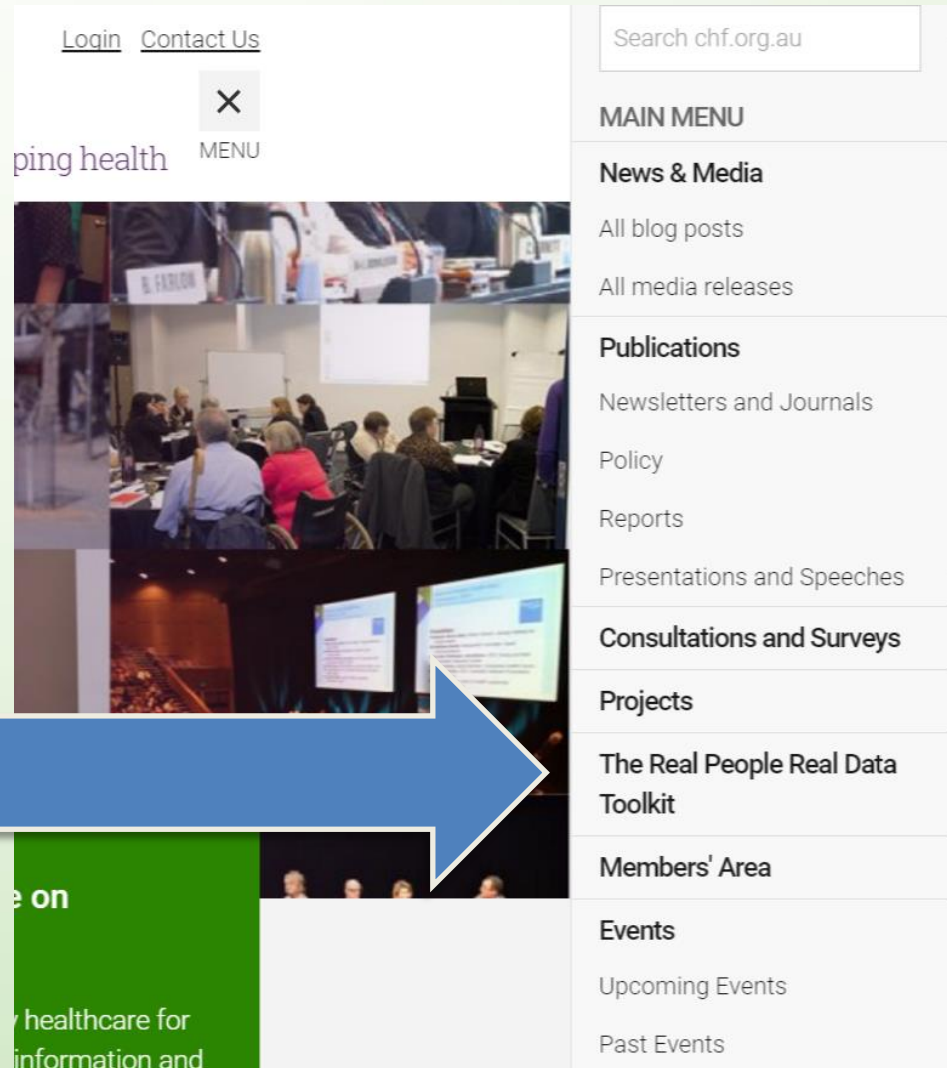
- Whole of life and system insights
- *What* happens versus *why*
- Quality and safety compliance
- Innovation
- Effective self management of health
- Overcome risk-averse cultures



Real People, Real Data

More Info:
bit.ly/RPRDtoolkit

PS: Free to use



The image shows a screenshot of the CHF website's navigation menu and a collage of event photos. The menu is on the right side, with a search bar at the top. The main menu items are: News & Media, Publications, Consultations and Surveys, Projects, The Real People Real Data Toolkit, Members' Area, and Events. The event photos show people in a meeting room, a presentation slide, and a stage with a screen.

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MAIN MENU

- News & Media**
 - All blog posts
 - All media releases
- Publications**
 - Newsletters and Journals
 - Policy
 - Reports
 - Presentations and Speeches
- Consultations and Surveys**
- Projects**
 - The Real People Real Data Toolkit
- Members' Area**
- Events**
 - Upcoming Events
 - Past Events



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Real People, Real Data

What's in the Toolkit?

- Patient/Carer Life Journey Model
- Guide for Support Organisations
- Experience Wheel Tool



Real People, Real Data

Patient/Carer Life Journey Model

- Similar experiences, similar stages
- Tool is *FLEXIBLE*
 - *Prevention, A change in health, Seeking assistance, Diagnosis, Treatment, Life with a condition Recovery, End of life*



Real People, Real Data

Guide for Support Organisations

- Many sections to help with thinking, prep
- Consent, consumer control & risk management are vital



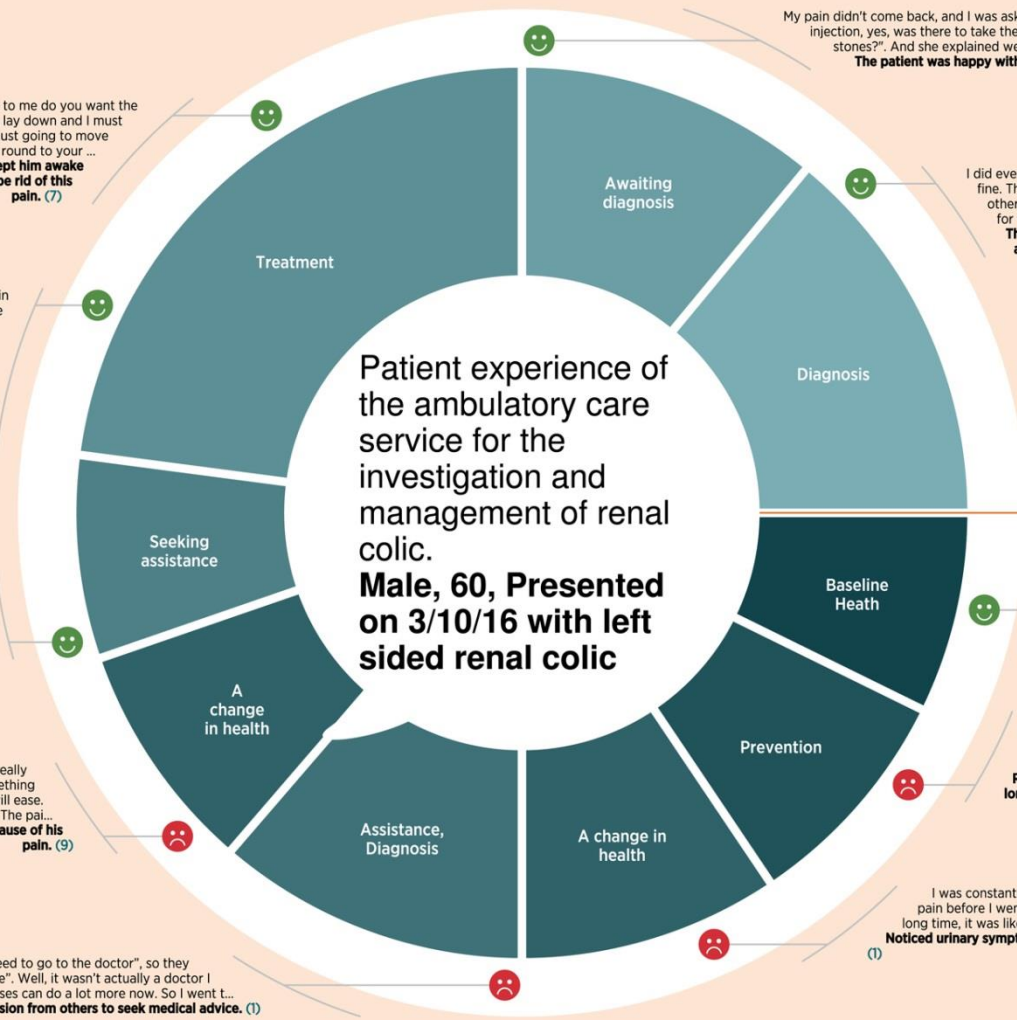
Real People, Real Data

Process

- Conduct semi-structured interview
- Transcribe the Interview
- Upload & Create Experience Wheel
- *CONFIRM IT WITH THE SUBJECT*



Renal Colic Patient Experience Wheel



My pain didn't come back, and I was asking the doctor about that as well, when she was in speaking to me. I said the injection, yes, was there to take the pain away, but it hasn't come back again, which made me think "was it kidney stones?". And she explained well yes it could have been kidney st...
The patient was happy with explanations he received. (2)

I did eventually [get the CT scan results], yes. And they were good results. Kidneys are fine. There were no stones at all. I'm assuming there must have been something the otherwise I wouldn't have been in so much pain. And that drug that they give you for that purpose and it took it away...
The patient had to wait several hours for his CT result, but was understanding about this. He was pleased about the outcome and follow up arranged. (2)

In general my health is absolutely fine, and has been for the past 10 years. 10 years ago I had my gallbladder out, which was pretty painful at the time! But since then, I am healthy, definitely. I didn't attend a doctor for anything, until about 6 weeks ago, when I had a urine infection. And t...
The patient feels he has generally good health. He equates not having to consult the doctor with being healthy. (9)

No, I don't watch what I'm eating, and it is hard. And since I've had my gallbladder out I've put weight on, because I think it kind of controlled my fat intake a bit. But I don't watch what I eat, no, I must admit, I don't. I just eat. I mean, I should be healthy but I'm not. And I do need to L...
Recognises the importance of diet and exercise in health prevention, but no longer keeps as active as he once did. (9)

I was constantly running to the toilet and it was very painful going to the toilet. But I was in pain before I went to the doctor. I must have had it for, oh, a good 2 months. I suffered it for a long time, it was like my gallbladder. I suffered it for 2 years before I went to the doctor. I just ...
Noticed urinary symptoms but was reluctant to seek help, hoping the symptoms would self-resol (1)

I came round [to ambulatory care] very quickly actually. They did say to me do you want the lights out and we'll shut the curtain for you and you can have a sleep. So I lay down and I must have lay for not even 10 minutes then the nurse came in and said we're just going to move you round to your ...
The patient was transferred to the ward quickly. Noise in the ward kept him awake though the night, but this did not bother him as he was so pleased to be rid of this pain. (7)

And that pain went on. The ambulance gave me morphine, and I came in here and it was a wee while after I came in here that the doctor gave me morphine, well I think it was morphine, I'm not too sure. But I suffered it from half past 8 until, well it must have been between half 10 and 11 o'clock...
IV morphine in the ambulance eased the pain, however it got worse while the patient waited to see a doctor in the ED. The patient didn't feel they waited too long to see a doctor, and felt as though other checks eg observations, ECG's were done in the interim period. Within 15-20 minutes of receiving the injection, IM diclofenac took the pain away. (7)

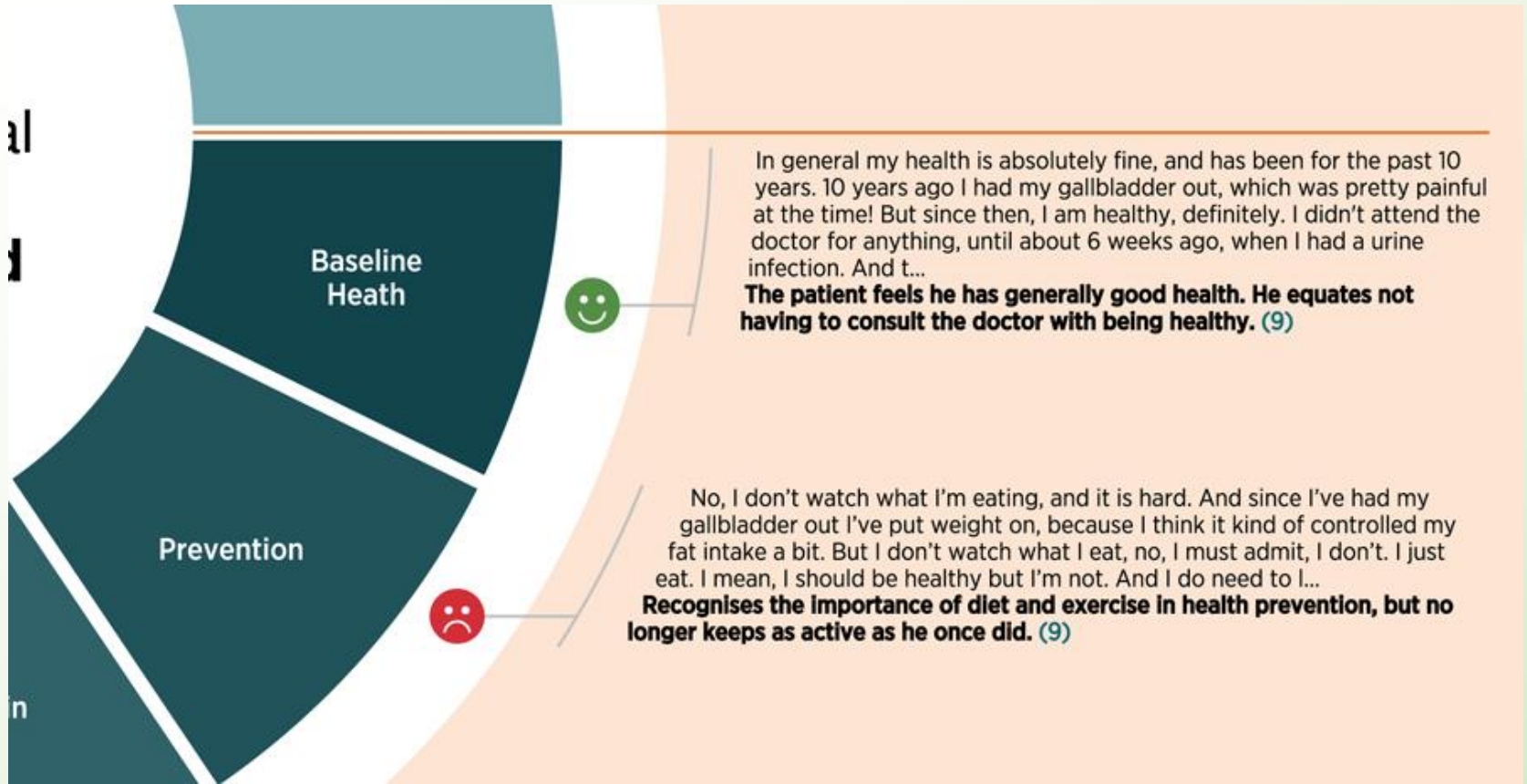
My partner said "what do you want me to do?" and I said "just leave me I'll be fine, just let me get through this. It's a pain and it will go away". So I kept it from about half past 8 to about half past 9, about an hour later he said "look, I'm going to phone an ambulance". Within about 10 minut...
Tried to walk to ease the pain, and give it time to pass. Although doesn't usually consult doctor was actually quite grateful when partner phoned ambulance. (1)

I got this pain in the left side of my back. And I thought "oh God, this is a really bad pain". And I'd had a bowel movement and thought maybe it was something to do with that. I thought I'll go lie down for half an hour just to see if it will ease. And, well it didn't ease. It got worse. The pai...
Pain was the main symptom. The patient didn't know what could be the cause of his pain. (9)

I mean I don't go to the doctor, as I said, but people at work said "you need to go to the doctor", so they forced me to go. So I did. I got up one morning and said "right I'll phone". Well, it wasn't actually a doctor I saw, it was a nurse; I think the nurses can do a lot more now. So I went t...
It took persuasion from others to seek medical advice. (1)

Consumer Centred Care

1.	Access, equity and affordability	☹️☹️😊
2.	Information and understanding	😊😊
7.	Coordinated care and supported transitions	😊😊
9.	Control and choice	😊☹️☹️



Real People, Real Data

Where could it go?

- Much scope for development
- Needs more flexibility, usability
- Seeking partners
- Considering open sourcing it

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