



Consumers  
Health Forum  
*of Australia*

Representing consumers on national health issues

# *Real People, Real Data:* Consumer evidence for measurement and evaluation

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# Why consumer stories?



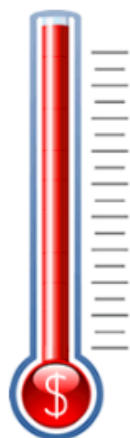
## Why consumer stories?

“Stories contain almost everything that is required for a deep appreciative understanding of the strengths and weaknesses of a service or system”

This is part of the evidence base to shape better decisions about health policies, services and spending – and to measure and evaluate performance.

# Real People, Real Data

**“The aim** is to equip consumer health advocates, health services and health policy makers with a relevant and practical tool that can assist them to gather, analyse and present consumer stories, and **use this often overlooked evidence base to shape health decision-making.**”



Losing  
\$1 billion  
a year

MEDIC  
SAVING  
NEVER

[Click here to read](#)

WHY?

→ Find your way!

Find your way to consumer organisations and info to help you use the health system. [Read about how we choose this list.](#)

Have a say!

Share your health system experiences, views and ideas for better Australian healthcare. [Read all latest posts.](#)

Consumer & Community Organisations

Useful info

OurHealth discussions

Hot topics



## The Real People Real Data Toolkit



Bringing consumer experience to  
evidence-based decision-making  
Collecting, analysing and using  
consumer stories to improve healthcare

# Four tools in the toolkit

- Planning to engage and partner with consumers
- Patient life journey
- Consumer interviews
- The health experience wheel



# Planning



1. **What:** Define *what* your objectives are



2. **Why:** Define *why* you're using stories to achieve your objectives



3. **Who:** Define your *participants* (who do you need to hear from, and how many stories you do need)



4. **How:** Define how you will invite and support your participants when you use the Real People, Real Data Toolkit, and how you will identify and manage risks to participants and support their control of the process.



5. **Assess:** Assess whether your objectives were met, and share what you find with participants



# The patient life journey

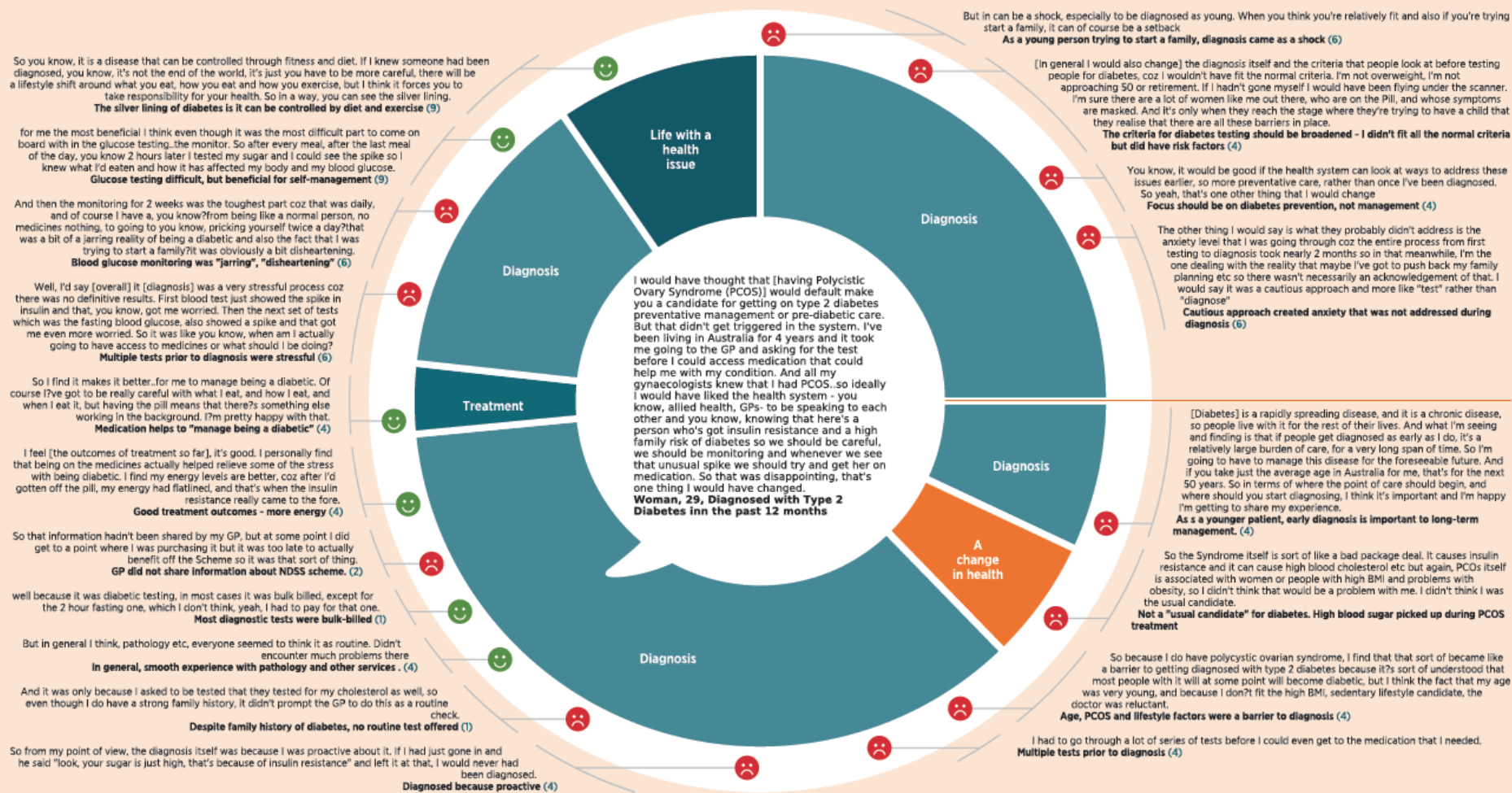
- A change in health
- Seeking assistance
- Diagnosis
- Treatment
- Life with a health issue



# Consumer interviews

- Semi-structured interviewing/ structured listening
- Based on the stages in the patient life journey
- Highlights what matters to consumers
- Rich information about what's working, and what's not, as people navigate a complex health system





## Consumer Centred Care

1.	Access, equity and affordability	☹️ 😊
2.	Information and understanding	☹️
4.	Appropriate care	😊 × 3 ☹️ × 6
6.	Whole of person care	☹️ ☹️ ☹️ ☹️ ☹️
9.	Control and choice	😊 😊

I've only ever had that one blood test. Now, with a history of diabetes in the family. My mother was a diabetic. I was very surprised that they didn't proceed sort of with the first alarms that occur.  
**That was the first and only diabetes test she did, despite a strong family history (4)**

I thought well it can't do any harm [to get tested at the chemist], and that's what they came up with. Just an ordinary finger prick test. Got the reading on the spot of eleven. She wrote on a piece of paper, said that she had done a finger prick test and it came up with eleven and she recommended that I be tested for diabetes. She was a registered nurse that they had, going around various pharmacies.  
**Thought it "couldn't do any harm" to be tested at the pharmacy (4)**

And we started on a low dose of Metformin.  
**Treatment began (4)**

Really there are no problems with my treatment. I was a bit concerned when they decided to put me on insulin but then then as I tell everybody if your doctor says he wants you on insulin take the opportunity to go on insulin because you will feel a lot better because you get a better control and if you don't have control that's when you start to get the complications  
**Reluctant to go on insulin at first, but it is effective (4)**

And I came back in a couple days' time and he says yes the blood test says you're a diabetic.  
**Blood test confirmed diabetes (4)**

So I went and saw the doctor. He did a blood test and sent it off.  
**GP did an on the spot blood test on the basis of free test at chemist (4)**

It's best to be tested. The longer you remain untested the more likely you're going to have complications and complications can be what I call silent. I have diabetic neuropathy in my legs and and that comes with non-diagnosis for a certain period of time. No matter how good my self-control could be it's not going to stop the damage that has already been done.  
**Get tested early to avoid problems later (9)**

And, she says, how long ago did you eat? And I said seven o'clock this morning. What did you eat? I said two pieces of toast and a cup of coffee. And she gave me a slip of paper and she said you go and see your doctor.  
**Nurse gave a slip of paper and said she should see her GP (4)**

My actual diagnosis was in 1995.  
**Diagnosed in 1995 (4)**

Then in 95 I was walking past the chemist in the shopping centre and they were doing free diabetic checks. This is eleven o'clock in the morning and I came up with an eleven.  
**Happened on a free diabetes check at a chemist, which returned a high blood glucose reading (4)**

Now, there's a story behind that. My diagnosis started when I had surgery on my foot. I got an infection. I wasn't happy with the way they were treating it. So I asked my GP to refer me to another surgeon. He said, I've got to go in there and clean that wound out. That meant another operation. Fair enough. I worried about the fact that I could lose the foot.  
**Infected foot required surgery (4)**

My GP was quite comfortable that I wasn't a diabetic but he wasn't running tests  
**GP was comfortable she was not diabetic and did not run a test (4)**

And he operated. And he says we've got to heal this by granulating it. That means I will not stitch it, it will be an open wound and it will take about three months. Fair enough.  
**Infection expected to take three months to heal (4)**

About twelve months later I just got that healed and the problem came back and had to be reoperated on. And we, this time he closed it over with sutures because it was a clean wound. And it still took longer. during the checks that he was doing on the foot he says, are you sure you're not a diabetic? So I repeated it to the GP.  
**12 months later, infection reappeared, and surgeon again requested whether she was diabetic. (4)**

It took longer and longer to heal. And he says, are you sure you're not a diabetic? And I said, well the GP has never alerted me to this. So I reported it to the GP, but nothing happened.  
**Wound took too long to heal, and surgeon asked whether she was diabetic. She asked GP, who did not order a test. (4)**

I would say the surgeon should have asked the staff at the hospital to run a test. It would have been so simple, to have just even to run a test. To see what was happening because it was affecting my healing.  
**Female, Retired, Diagnosed with Type 2 Diabetes in 1995**

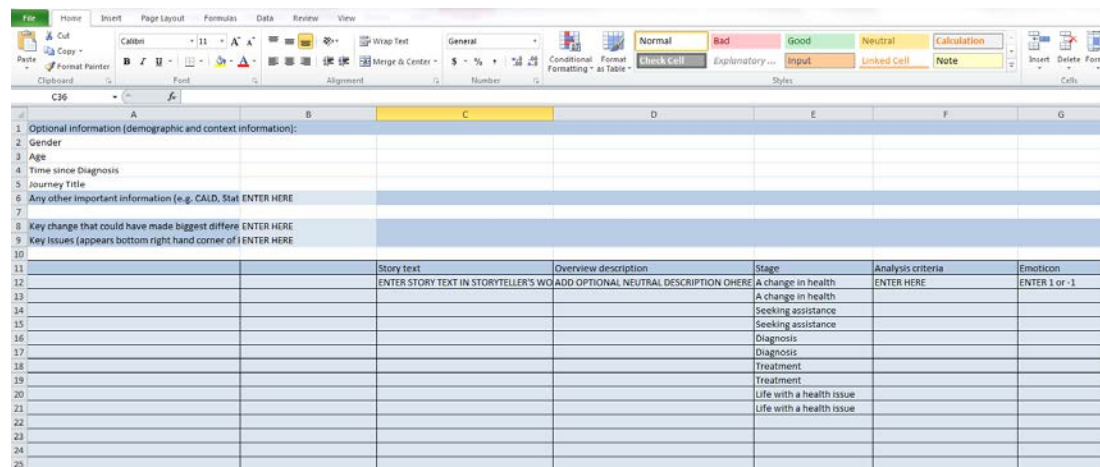
## Consumer Centred Care

4. Appropriate care

😊 × 8 😞 × 6

9. Control and choice

😊



CHF Experience Wheel

Patient Life Journeys

Upload RPRD CSV

Logout

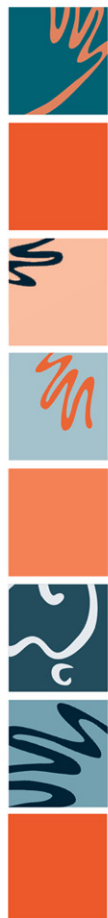
Upload your RPRD CSV

## Your Uploaded Life Journeys

Real People Real Data File	Uploaded Date	Download
Template Spreadsheet RPRD YODKW 1.csv	26 March 2015 05:47AM	<a href="#">Download Experience Wheel</a> <a href="#">Download RPRD Spreadsheet</a>
Template Spreadsheet RPRD YODKW 1 excel to csv.csv	26 March 2015 05:54AM	<a href="#">Download Experience Wheel</a> <a href="#">Download RPRD Spreadsheet</a>
Template Spreadsheet RPRD YODKW 1 excel to csv.csv	26 March 2015 06:06AM	<a href="#">Download Experience Wheel</a> <a href="#">Download RPRD Spreadsheet</a>
Template Spreadsheet RPRD YODKW example .csv	7 April 2015 03:07AM	<a href="#">Download Experience Wheel</a> <a href="#">Download RPRD Spreadsheet</a>
CHF practice wheel.csv	23 April 2015 01:56AM	<a href="#">Download Experience Wheel</a> <a href="#">Download RPRD Spreadsheet</a>

## But does it work?

- Piloted in five settings
- Tested and validated
- Like all methods, pros.... and cons!
- *When and where does it work best?*
- It's flexible and adaptable – and CHF can help.



# Consumer perspectives

- *“I felt heard.”*
- *“The easy way the questions were asked.”*
- *“I have done surveys before about my experiences with health care providers. I have found these questions to be limiting. On this occasion I was interviewed in a way that encouraged me to tell my story. Consequently I feel that relevant useful information has been collected.”*
- *“The conversion of my experience into the different... graphical representations. And that through this a greater understanding of the issues involved may have been obtained by people in a position to improve healthcare for others”*



# Interviewer views

- I felt confident about using the toolkit – 100%\*
- This data will influence decision-making – 100%\*
- This tool helped me use consumer evidence – 100%\*
- The tool captures the consumer voice – 100%\*

\*Agree or strongly agree



# Decision-makers

- The consumer evidence will make an impact on our organisation's decisions – 100%\*
- This process allows consumers to make a meaningful contribution to decisions – 100%\*

- \*Agree or strongly agree

# The Health Experience Wheel

- *“It’s useful because it very clearly articulates and presents what the key hotspots are, what the patient’s perception is in terms of their experiences of using healthcare, what the negatives were and also what the positives were.”*
- *“You don’t need many of those to get a picture, what the key issues are in the organisation or in a service. Because they are so powerful in terms of how they communicate the issues”.*

## Key points

- The toolkit is a guide to planning and undertaking a consumer storytelling project
- Various applications including measuring and evaluating
- Tested and validated
- One additional method to add your own 'toolkit'.



# Thank you

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