

Tools and methods for capturing experiences

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Experience?

A person's thoughts and feelings of the journey they have. These are shaped by the interactions they have throughout an episode or journey of care (clinical, personal and emotional).

Delighted

Underwhelmed

Frustrated



Why capture experiences?

- Experience and evidence has shown that actively involving health consumers at all levels of the health and disability system:
 - 1. assists with identifying care that is most likely to be acceptable to consumers
 - 2. identifies areas where waste can be reduced or services can be reconfigured to ensure that more people use them
 - 3. ensures that consumer rights are upheld and that the chance of harm is reduced.
- Patient experience, clinical effectiveness and patient safety are all linked.

Many ways to capture experience

Surveys

Observation

Shadowing

Comments cards

In-depth conversations

Focus groups and panels

Patient experience questionnaire

Patient Stories

Story Board

Diary

Complaints/compliments

Source: The Health Foundation. Measuring patient experience (June 2013)





https://www.redbubble.com/people/jcorbettcartoon/works/23369092-one-size-fits-all. Accessed 2 July 2018.



Thinking about your last experience at a shop...

Your feedback



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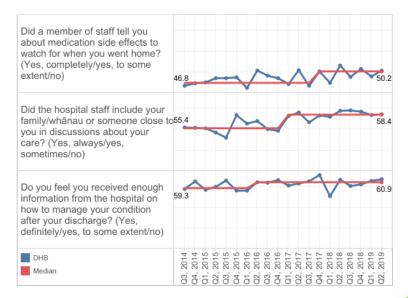
Shadowing

- Often need two people in order to listen and capture.
- Consumers and whānau often have very different experiences and this may be useful to understand.
- Shadowing someone through an experience is time consuming but provides a lot of data what actually happens (the process), what went well, even better if ideas can be captured.



Experience questionnaires (aggregated)

Run chart of the lowest-rating questions of the four domains of the adult inpatient experience survey, 2014–19 (percent of patients answering most positively)





Experience questionnaires (individualised)

the ebd approach | The four steps the ebd approach | The four steps

How do you feel?

This experience questionnaire will help you think about how you feel at different stages in your journey.

Circle the words that best describe your feelings at each stage, or write your own words at the bottom.



See pages 54-55 for more information on experience questionnaires

Why?

We'd like to know why you felt like this. Was it friendly staff, a nice conversation, or a long wait – whatever it is we'd like to know

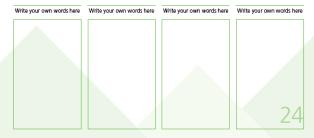
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rite your own words here	Write your own words here	Write your own words here	

Going to Theatre	Recovery	Check Ups	Leaving
happy	happy	happy	happy
supported	supported	supported	supported
safe	safe	safe	safe
good	good	good	A good
comfortable	comfortable	comfortable	comfortable
in pain	in pain	in pain	in pain
worried	worried	worried	worried
lonely	lonely	lonely	lonely
sad	sad	sad	sad





Focus groups

- Focus groups are a form of group interview that capitalises on communication between participants in order to generate data.
- Focus groups explicitly use group interaction as part of the method. This means that instead of asking each person to respond to a question in turn, people are encouraged to talk to one another: asking questions, exchanging anecdotes and commenting on each other's experiences and points of view.

Kitzinger J. The methodology of focus groups: the importance of interactions between research participants. Sociology of Health and Illness 1994;16;103–21



Focus group logistics

- 1. Where should a focus group be held?
- 2. How should we choose participants?
- 3. How should we invite participants?
- 4. How much notice should we provide?
- 5. How long should the focus group be?
- 6. What do we need to prepare prior to the focus group?
- 7. What do we need at the venue?





Benefits of focus groups

- They do not discriminate against people who cannot read or write.
- They can encourage participation from those who are reluctant to be interviewed on their own (such as those intimidated by the formality and isolation of a one to one interview).
- They can encourage contributions from people who feel they have nothing to say or who are deemed "unresponsive"



Caution of using focus groups

- The group can feel overwhelming to some and can silence individual voices.
- Need to take care of confidentiality of participants as they
 may share personal stories and there may be organisational
 elements that should be confidential to the
 group/work/project.
- They require a level of expertise to facilitate and need more than one facilitator even for small groups.



Individual interviews: framing questions

- We want to understand experiences and enable people to feel safe while they are sharing them
- Use the concepts of appreciative inquiry
- Focus can be on process and experience
 - what went well, how did that make you feel
 - even better if, how did that make you feel
 - what would make that (even) better



Framing questions example



Hello my name is and I am (elevator pitch and informed consent). I would like to start our conversation today at the point you knew that you were going to be discharged. Can you tell me what happened? And how did that make you feel? What happened next? How was that for you? And what did you think of the information you were given? Did anyone take you through it? How did that make you feel? What was it like for you when you got home? (listen for an emotion word). What were you expecting to happen next in terms of your ongoing care? And did that happen? How did that make you feel?

Mapping: Zero seclusion example





'Need to build links between secondary/primary and education services rather than isolate the support services. This requires negotiation around the sharing of information.' Health professional

"... since the age of 13 I have worked with over 25 different counsellors, social workers, psychologists, psychiatrists and nurses. This has affected my willingness to open up and ability to trust in new relationships and has severely impacted in the way I have been able to talk about my illness and the way I feel about myself." Consumer



Common themes

Cost and timeliness of access to support are barriers

Youth Self-Harm

Better evaluation of services

Change and

instability within

services

More engaged follow-up needed

Repeat presentations

Better communication between primary, secondary care and consumers

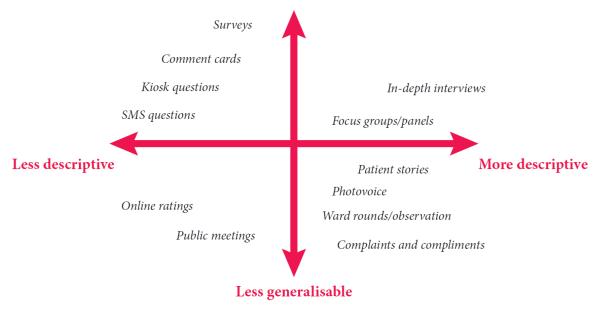
Education to address assumptions

More resources needed



A note on generalisability...

More generalisable



https://www.health.org.uk/sites/default/files/MeasuringPatientExperience.pdf. Accessed 1 July 2019



Informed consent

- Why are you looking for input and what do you plan to do with the responses?
- Ensuring agreement to engage and understanding how data will be used
- Do participants wish to be informed of progress and outcomes? (In a co-design context, this should be straightforward.)
- Succinct and informative communication.
- How will people be compensated for time and contribution?



Which 'capture' method are you thinking of using and why?

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Photo booth

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