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# Choosing the right tool for the job: Selecting a patient-reported experience measure (PREM) to suit your research and quality improvement objectives

Miss Claudia Bull
Associate Professor Josh Byrnes
Centre for Applied Health Economics
School of Medicine, Griffith University

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## Workshop Part A

By the end of this session, you should be able to:

1. Describe the concept of PEx
2. Recognise the differences between PEx and Patient Satisfaction (PSat)
3. Recognise the differences between PREMs and PROMs
4. Have knowledge of the evolution and growth of PEx

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# The concept of PEx

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## Defining Patient Experience

*'What' happened before, during and after a specific instance of care for a patient, and 'how' it happened.*

Tremblay et al (2015); Schembri (2015); Ahmed et al (2014)

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In terms of the dimensions of the PEx e.g. communication; patient-centeredness.

The patient experience captures more than just the experience of receiving care.

*'**What**' happened **before, during and after** a **specific instance of care** for a **patient**, and '**how**' it happened.*

PEx most commonly captured from the patients' perspective.*

In terms of how well the dimensions of PEx were delivered e.g. effective communication, no communication at all

The PEx measures the care at one specific point in time.

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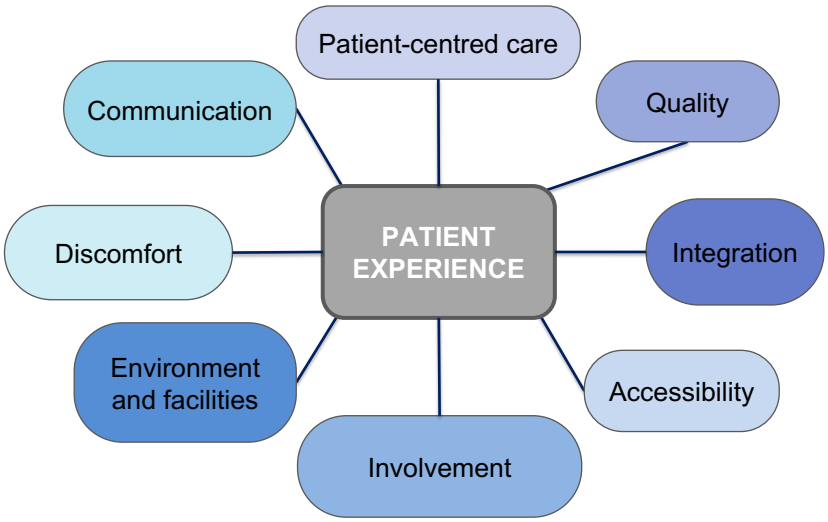


Bull et al (2019)

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# Differences between PEx and Patient Satisfaction (PSat)

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## Patient experience vs Patient satisfaction

**PEx**

Measure of 'what' happened before, during and after a specific instance of care for a patient, and 'how' it happened. → Emphasis in the specific instance of care.

**PSat**

Measure of how well the care experience met a patient's *a priori* expectations. → Compares the patient experience to an established expectation(s) of what the care experience *should* have been.

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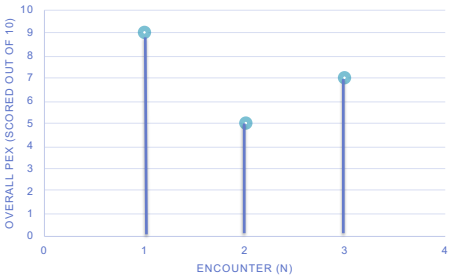
## Why we should be measuring PEx and not PSat

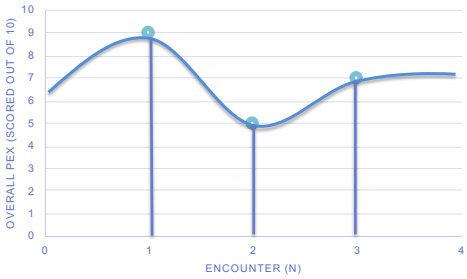
$PEx_{overall} = PEx_1 + PEx_2 + PEx_3$
$PEx_{overall} = 9 + 5 + 7$
$= 21$ (out of 30)

$PSat_{overall} = Expectation_0 + (PEx_1 + \Delta Expectation_1) + (PEx_2 + \Delta Expectation_2) + (PEx_3 + \Delta Expectation_3)$
$PSat_{overall} = ? + (9 + ?) + (5 + ?) + (7 + ?)$
$PSat_{overall} = ???$

$PEx_{overall}$ (score out of 30)




$PSat_{overall}$ (score out of 30)

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## Differences between PREMs and PROMs

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## PREMs vs PROMs

**PREMs** — Measure of 'what' happened before, during and after a specific instance of care for a patient, and 'how' it happened. → **Experience**

**PROMs** — Measure of how a patient's illness or care impacts upon their health outcomes, health-related quality of life and wellbeing. → **Health outcomes**

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## PREMs vs PROMs

| Types of PREMs | Types of PROMs |
|---|---|
| • AHPEQs<br>• NSW PREMs<br>• QH PREMs<br>• HCAHPS (+ CAHPS suite of measures)<br>• NHS GPPS, Accident and Emergency etc. | • SF-36<br>• EQ-5D-3L/5L<br>• AQoL<br>• Numeric Pain Rating Scale (NPRS)<br>• General Self-Efficacy Scale (GSE) |

- Some PROMs can be used in **economic evaluation***
  - Utility value set required
  - PROM needs to be administered at baseline and follow-up in order to produce a change score
- PREMs cannot (yet) be used in economic evaluation
  - PREMs typically only used as a retrospective measure
- PROMs can be either generic or disease-specific (similar to PREMs)

AIHW (2018); Verma, n.d.

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# The evolution of PEx

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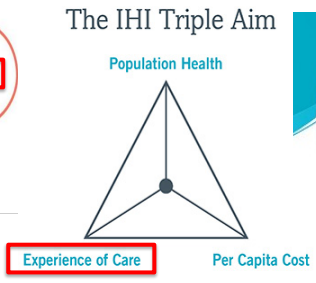
## Evolution of PEx

- Last 50 years: Biomedical model → patient-centred model of care
- Today: PEx core pillar of healthcare quality


NHS





Australian Productivity Commission NHA outcome – Better health services: Australians have positive health and aged care **experiences** which take account of individual circumstances and care needs.

Donabedian (1966)

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## Evolution of PEx

↑ Focus on PEx in HC quality frameworks →
↑ Measurement of PEx

- Recent systematic review of PREMs published in the peer-reviewed literature identified n=88 PREMs published since 1990
  - But there have also been +++ PREMs published in the grey literature over this time also
- Most published by researchers from USA and UK
- Combination of disease/condition-specific PREMs and setting-specific PREMs

Bull et al (2019)

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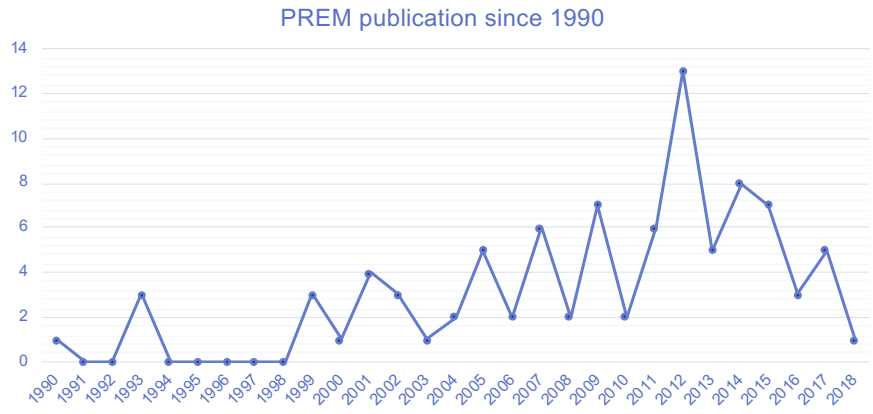
## Growth in measuring PEx (quantity)




Bull et al (2019)

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## Changes in what PREMs are measuring – Domains

- Thematic analysis of n=59 of these PREMs' items indicates that there have been no significant advancements in the domains of PEx that PREMs capture.
- This is suggestive of one of two things:
  1. The multidimensional concept of patient experience is well established, or
  2. Though the concept of patient experience has continued to evolve over time, the way in which it is captured by PREMs has not.

Bull et al (2019)

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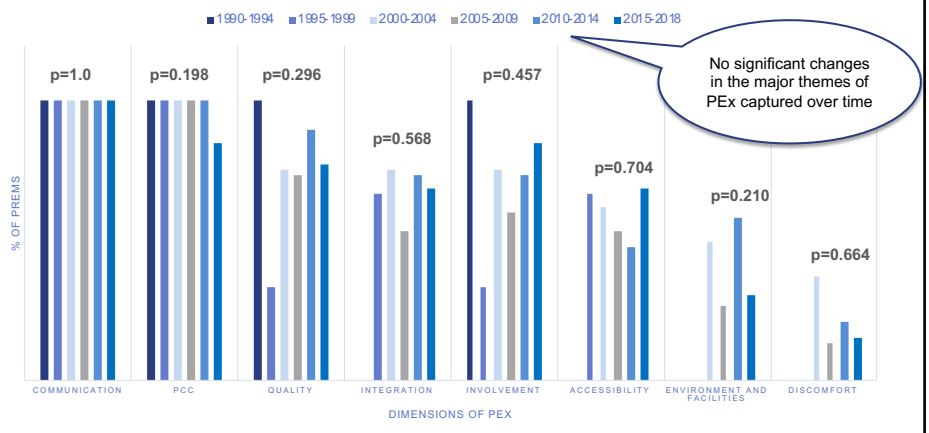
## Changes in what PREMs are measuring – Domains




Bull et al (2019)

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## Changes in what PREMs are measuring – Domains

Recent development!

Alternatively…

- Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) 2006 vs 2019 versions

2006 (first launched): 3x items in 'Pain management' domain

1. *During this hospital stay, did you need medicine for pain?*
2. *During this hospital stay, how often was your pain well controlled?*
3. *During this hospital stay, how often did the hospital staff do everything they could to help with your pain?*

2019 (most recent version): 3x items in 'Communication about pain' domain

1. *During this hospital stay, did you have any pain?*
2. *During this hospital stay, how often did hospital staff talk with you about how much pain you had?*
3. *During this hospital stay, how often did hospital staff talk with you about how to treat your pain?*

CMS (2019)

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## An interesting point…

Are Pain Management Questions in Patient Satisfaction Surveys Driving the Opioid Epidemic?

*Jerome Adams, MD, MPH*
*Gregory H. Bledsoe, MD, MPH*
*John H. Armstrong, MD*

- Recognised that the original items promoted a *"misperception that patients should experience no pain"*
- PEx results → behaviour changes → unintended consequences (over prescription of opioids)
- This subsequently → revisions to HCAHPS items + changes to hospital reimbursement processes

Adams et al (2016)

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## Activity 1 – Recognising the differences and similarities between generic, disease-specific and setting-specific PREMs

- 15 mins for activity + 10 mins for discussion
- In your groups, you will each have:
  - 1x generic PREM (Picker Patient Experience Questionnaire 15: PPE-15)
  - 1x disease-specific PREM (Patient-Centred Questionnaire for Parkinson's Disease: PCQ-PD)
  - 1x setting-specific PREM (Hospital Consumer Assessment of Healthcare Providers and Systems: HCAHPS)
  - 1x 3-way Venn diagram (template)
  - Butchers paper
  - Pens

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## Your task:

- Using the butchers paper, identify and document as many similarities and differences between the PREMs as you can.
  - You may find the Venn diagram a usual template for how to write-up your findings.
- Differences and similarities to think about…
  - Domains captured
  - Length of PREM/number of items
  - Specificity in wording

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# Group discussion (10 mins)

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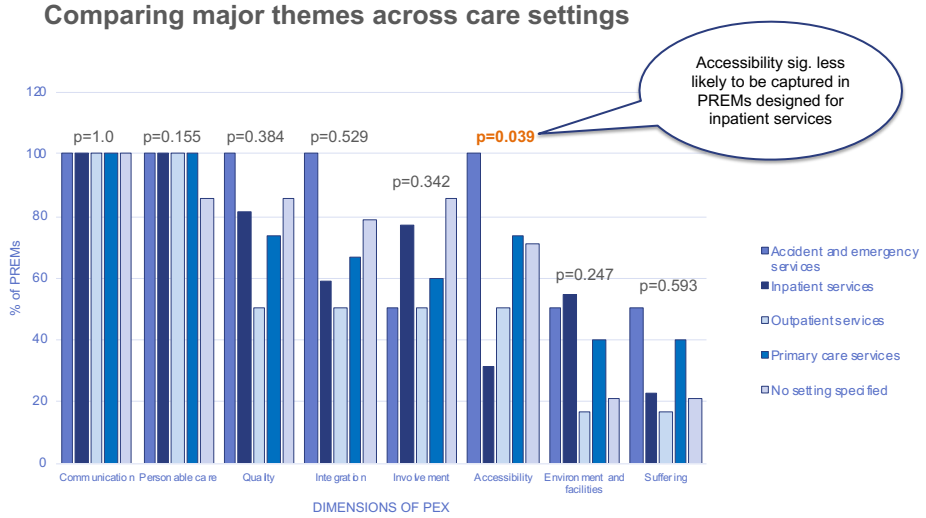
## Comparing major themes across care settings




Bull et al (2019)

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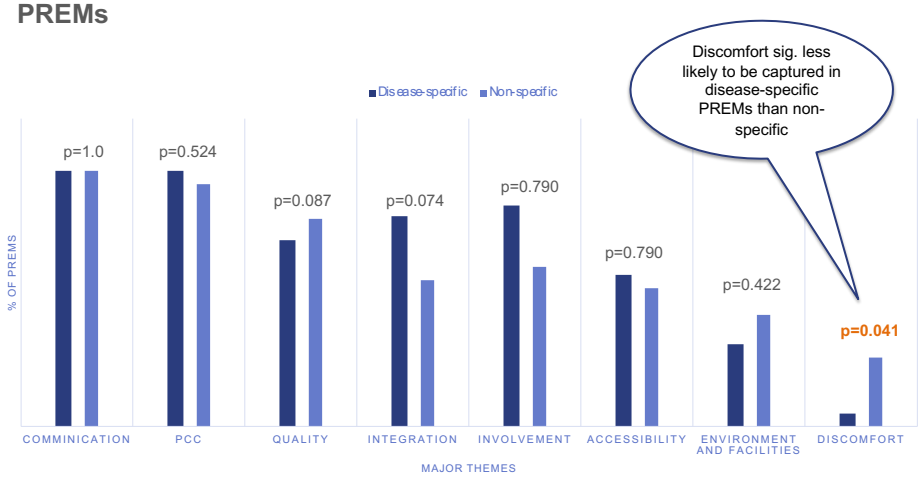
## Comparing major themes between disease-specific and non-specific PREMs




Bull et al (2019)

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## Workshop Part A: Wrap-up

### Take-home messages:

- The concept of PEx is comprised of 8 major themes
- PEx and PSat are different concepts (but likely to have a statistical relationship)
- Unlike PSat, PEx data is more meaningful and actionable for research activities and QI
- PEx – as a concept and as a component of healthcare quality – is still evolving!

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## Workshop Part B

By the end of this session, you should be able to:

1. Appreciate the importance of PREM validity, reliability and responsiveness
2. Be aware of the key "Don'ts" in choosing and using PREMs
3. Be aware of some of the key questions to ask when choosing and using PREMs

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## Validity, Reliability and *Responsiveness*

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| RELIABLE BUT NOT VALID | VALID BUT NOT RELIABLE | RELIABLE *AND* VALID |
|---|---|---|
|  |  |  |
| Consistently testing the same thing over and over, but it's not measuring what you want it to measure. | You are measuring what you want to measure, but doing so inconsistently. | You are consistently measuring exactly what you want to measure, time and time again – hitting the bullseye. |

Howell (2017).

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## Validity

**Definition:** *The extent to which an instrument measures what it claims to measure.*

- Content validity
- Construct validity
- Criterion validity

Brazier & Deverill (1998); Howell (2017).

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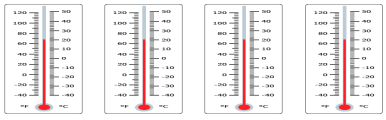
## Reliability

**Definition:** *The extent to which the results can be replicated, consistently.*

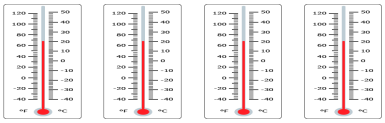
A lack of reliability is likely caused by measurement error.

- Internal consistency
- Inter-rater
- Inter-method
- Test-retest



Day 1 – Actual temp: 20℃ | Day 2 - Actual temp: 20℃ | Day 3 - Actual temp: 20℃ | Day 4 - Actual temp: 20℃

**Reliably reporting the actual temperature, consistently.**



Day 1 – Actual temp: 20℃ | Day 2 - Actual temp: 28℃ | Day 3 - Actual temp: 30℃ | Day 4 - Actual temp: 22℃

**Reports the actual temperature initially, but unreliable thereafter.**

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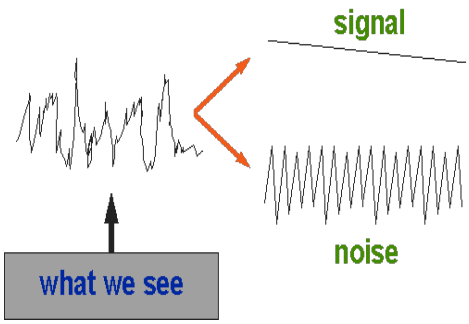
## Importance of valid and reliable measurement

### "signal" or "noise"?

**What we observe can be divided into:**




Validity – the signal is the one we are interested in

Reliable – the noise does not mask the signal

Streiner & Norman (2008); Smith et al (2015); Dash (2016); Swank & Mullnen (2017); Byrne (2001); Guilleman et al (1993); Eremenco et al (2005).

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## What is adequate validity and reliability?

- Good question!
- How long is a piece of string?

A general rule of thumb…

↑ Validity and Reliability ≅ ↓ Risk of bias

Some validity and Reliability ≅ Some risk of bias

↓ Validity and Reliability ≅ ↑ Risk of bias

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## Responsiveness

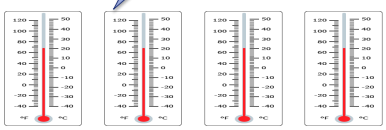
**Definition:** *The ability of an instrument to detect meaningful changes.*

***Example:*** Difference between test and retest = Measurement error → smallest detectable change;

Anchor-based mean change score technique between 2 time points → Minimal important change = the smallest change patients perceive as important

MIC < SDC

Some debate if distinct to validity / reliability



Day 1 – Actual temp: 20℃

Day 2 - Actual temp: 28℃

Day 3 - Actual temp: 30℃

Day 4 - Actual temp: 22℃

Terwee et al (2007); Steiner & Norman (2008); Guyatt et al (1987).

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## Ceiling and floor effects

- Clustering of observations at either the minimum or maximum response option
- Prevents an accurate representation of the deviation beyond these points.
- Compromise scientific truth and understanding through a number of related statistical aberrations.

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## How can I assess the validity, reliability and responsiveness of PREMs?

| Measurement property | | Criteria for appraisal of the results on measurement properties evaluation |
|---|---|---|
| **Internal consistency** | + | Cronbach's alpha(s) are ≥ 0.70 |
| | ? | Not able to score because of unclear or missing information, e.g., the dimensionality is not known or Cronbach's alpha(s) are not presented. |
| | - | Criteria for '+' not met. |
| **Reliability** | + | ICCagreement/weighted Kappa ≥ 0.70 OR ICCconsistency/ICC without approach stated/Pearson's r ≥ 0.80 OR unweighted kappa/or kappa without approach stated ≥ 0.80 |
| | ? | Not able to score because of unclear or missing information, e.g., neither ICC, Kappa, nor Pearson's r is determined. |
| | - | Criteria for '+' not met. |
| **Measurement error/ Agreement** | + | MIC ≥ SDC OR MIC outside the LOA OR convincing arguments that agreement is acceptable |
| | ? | Not able to score because of unclear or missing information, e.g. SEM, SDC not calculated, or MIC not defined. |
| | - | Criteria for '+' not met. |
| **Content validity** | + | Target group and/or experts considered all items to be relevant AND considered the item set to be complete. |
| | ? | Not able to score because of unclear or missing information, e.g. no results on item relevance according to experts reported |
| | - | Criteria for '+' not met. |

Mokkink et al (2010)

**COSMIN checklist:**

- Best available tool to assess measurement properties such as validity, reliability and responsiveness
- Scores a measure based on whether a psychometric test was undertaken successfully (+), unsuccessfully (-) or not reported on and therefore unable to indicate (un)successfulness (?)

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## Some key questions to ask when choosing and using PREMs

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## Important questions to ask – Choosing a PREM:

- Is the PREM you want to use valid/reliable/responsive?
  - If yes, excellent! [As far as we're aware though, this is unlikely to be the case…]
  - When is it appropriate to develop your own PREM?
- Who is your target population?
  - Was the PREM designed and tested for use in a similar population and setting?
- What are the domains of PEx that you need your PREM to capture?
  - Consider your research questions/PEx goals – what do you want to know?

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## Important questions to ask – Using a PREM:

- Do I need to assess the properties of the PREM ? [Yes…]
- What mode of data collection?
  - Inter-method reliability
  - Potential forms of bias that may be introduced
    - Self-completed surveys → interviewer bias; social desirability bias
    - Postal and online surveying → non-response bias; recall bias
    - Online surveying → sampling bias
- What are my study/data collection constraints?
  - Budget
  - Time

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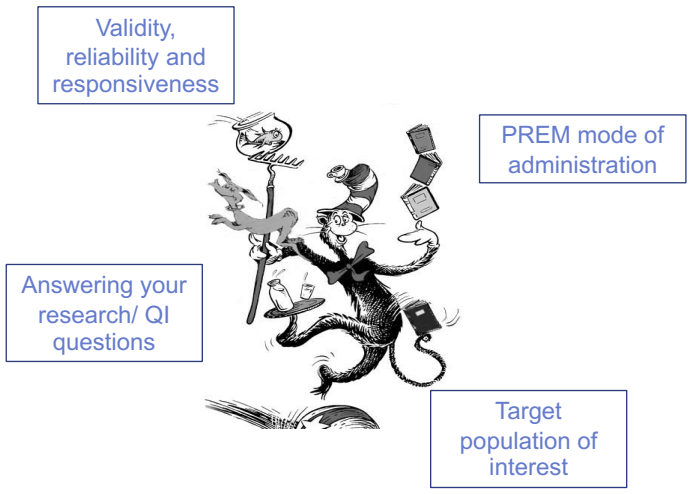


**Choosing and using PREMs is a balancing act!**

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## Don’ts in choosing and using PREMs:

If the PREM already has some form of established validity/reliability/responsiveness, it is advisable not to:

1. Use only certain items from a PREM → an invalid PREM
2. Add items from another tool to your chosen PREM → an invalid PREM
3. Add items that you have made up to your chosen PREM → an invalid PREM
4. Change the wording of items → an invalid PREM
5. Not assess the validity, reliability and responsiveness of the PREM

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## And importantly!

- Don’t pick the longest PREM just for the sake of getting more information.
  - This is a decision that is likely to haunt you when you need to actually collect and analyse the data.
- Don’t pick the shortest PREM just to make data collection easier.
  - This is a decision that is likely to haunt you when you need to actually analyse the data.


Doyle M (2014).

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## Analysis and reporting

- Is there an established scoring system ?
  - Item
  - Domain
  - Collective
  - Summary Question
- What does the score mean
  - How was it developed / based on
  - What is the MID & SDC

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## Types of analysis

- What is your question / $H_0$
- Types of analysis
  - Descriptive (ceiling effect desirable)
  - Comparative
    - Controlled vs. Uncontrolled
  - Attribution (individual or inter-organization)
  - Independent variable
    - ↑ PExp → ↑ Adherence / DNA → ↑ HO
    - ↑ PEX → ↑ HCPExp → ↓ TO

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## Activity 2 – Choosing the right PREM case studies

- 15 mins for activity + 10 mins for discussion
- Each group will receive a case study (3 total, so some groups will overlap)
- Within each case study there is:
  - 3x different PREMs
  - Case study information:
    - Study background
    - Target population information
    - Fixed study constraints
    - PREM psychometric evaluation information

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## Your task:

Using butchers paper and pens again:

- Choose the most appropriate PREM (in your opinion) for the purposes of the study.
  - We have given you the actual PREM so that you can use the items and domains to inform your choice as well.
- Provide a rationale for your choice.
- Identify the method(s) of data collection you would use.
- Identify the type of data you would report.

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## Group discussion (10 mins)

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## Workshop Part B: Wrap-up

Take-home messages:

- Validity, reliability and responsiveness are very important for PREMs
  - BUT it is unlikely that you will find a published PREM that possesses all of these (so just do the best with what is available to you)
- Don't adapt a valid/reliable PREM to suit your purposes → an invalid PREM
- Remember that choosing and using PREMs is a balancing act between minimising bias that you may introduce into your study, and doing the best with what is available to you!

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Miss Claudia Bull
PhD Candidate (Health economics)
E: c.bull@griffith.edu.au
P: (07) 3735 9102

A/Prof Josh Byrnes
Health Economist
E: j.byrnes@griffith.edu.au
P: (07) 3735 9111

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## References

1. Tremblay D, Roberge D, Berbiche D. Determinants of patient-reported experience of cancer services responsiveness. *BMC Health Serv Res.* 2015;15:425.
2. Schembri S. Experiencing health care service quality: through patients' eyes. *Aust Health Rev.* 2015;39(1):109-116.
3. Ahmed F, Burt J, Roland M. Measuring patient experience: concepts and methods. *Patient.* 2014;7(3):235-241.
4. Bull C, Chaboyer W, Downes M, Scuffham P & Byrnes J. Patient experience matters, so what are patient-reported experience measures actually measuring? A systematic review and thematic analysis of existing measures. *BMJ Qual Saf* (under review).
5. Australian Commission on Safety and Quality in Health Care. Australian Hospital Patient Experience Question Set (AHPEQS). 2018.
6. Jean-Pierre P, Fiscella K, Freund KM, et al. Structural and reliability analysis of a patient satisfaction with cancer-related care measure: a multisite patient navigation research program study. *Cancer.* 2010;117(4):854-61.
7. Donabedian A. Evaluating the quality of medical care. 1966. *Milbank Q.* 2005;83(4):691-729.
8. Institute of Medicine (US) Committee on Quality of Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington (DC): National Academies Press (US); 2001. 1, A New Health System for the 21st Century. Available from: https://www.ncbi.nlm.nih.gov/pubmed/25057539
9. CAHPS Surveys and Guidance. Content last reviewed February 2019. Agency for Healthcare Research and Quality, Rockville, MD. http://www.ahrq.gov/cahps/surveys-guidance/index.html

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10. Institute of Medicine (US) Committee on Quality of Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington (DC): National Academies Press (US); 2001. 1, A New Health System for the 21st Century. Available from: https://www.ncbi.nlm.nih.gov/pubmed/25057539
11. NHS Greater Preston CCG. 2019. Quality and Clinical Effectiveness. Available from: https://www.greaterprestonccg.nhs.uk/quality-and-clinical-effectiveness
12. Australian Commission on Safety and Quality in Healthcare. 2012. Australian Safety and Quality Framework for Health Care. Available from: https://www.safetyandquality.gov.au/wp-content/uploads/2012/04/Australian-SandQ-Framework1.pdf
13. Bull C, Byrnes J, Hettiarachchi R & Downes M. (2019) . A systematic review the validity and reliability of patient reported experience measures. In-press (Health Serv Res).
14. Centers for Medicare and Medicaid Services. (2019). CAHPS® Hospital Survey. Available from: https://www.hcahpsonline.org/
15. Gualtieri L & Akhtar F. (2013). Cancer Patient Blogs: How Patients, Clinicians, and Researchers Learn from Rich Narratives of Illness. doi:10.2498/iti.2013.0586
16. Ranard, Werner, Antanavicius et al. (2016). What can Yelp teach us about measuring hospital quality? Health Aff (Millwood); 35(4): 697-705. doi: 10.1377/hlthaff.2015.1030
15. Australian Institute of Health and Welfare 2018. Australia's health 2018. Australia's health series no. 16. AUS 221. Canberra: AIHW.
16. Verma R. (n.d.). Overview: What are PROMs and PREMs? Available from: https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0003/253164/Overview-What_are_PROMs_and_PREMs.pdf
17. Brazier J, Deverill M. A checklist for judging preference-based measures of health related quality of life: learning from psychometrics. Health Econ. 1999;8(1):41-51.


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18. Australian Institute of Health and Welfare 2018. Australia's health 2018. Australia's health series no. 16. AUS 221. Canberra: AIHW.
19. Verma R. (n.d.). Overview: What are PROMs and PREMs? Available from: https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0003/253164/Overview-What_are_PROMs_and_PREMs.pdf
20. Brazier J, Deverill M. A checklist for judging preference-based measures of health related quality of life: learning from psychometrics. Health Econ. 1999;8(1):41-51.
21. Howell A. (2017). A quick and dirty guide to validity and reliability. Available from: https://www.hoganassessments.com/quick-dirty-guide-validity-reliability/
22. Koo TK, Li MY. A Guideline of Selecting and Reporting Intraclass Correlation Coefficients for Reliability Research. J Chiropr Med. 2016;15(2):155-63.
23. Streiner DL, Norman GR. Health Measurement Scales: A practical guide to their development and use. Oxford Scholarship Online: Oxford Scholarship Online; 2008.
24. Kimberlin CL, Winterstein AG. Validity and reliability of measurement instruments used in research. Am J Health Syst Pharm. 2008;65(23):2276-84.
22. Frost MH, Reeve BB, Liepa AM, Stauffer JW, Hays RD, The Mayo/FDA Patient-Reported Outcomes Consensus Meeting Group. What is sufficient evidence for the relaibility and validity of patient-reported outcome measures? Value Health. 2007;10(22):S94-S105.
23. Williams Y. Internal consistency reliability: Example & definition: Study.com; 2019. Available from: https://study.com/academy/lesson/internal-consistency-reliability-example-definition-quiz.html
24. Linde L, Sorensen J, Ostergaard M, Horslev-Petersen K, Hetland ML. Health-related quality of life: validity, reliability, and responsiveness of SF-36, 15D, EQ-5D [corrected] RAQoL, and HAQ in patients with rheumatoid arthritis. J Rheumatol. 2008;35(8):1528-37.

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25. Smith SC, Cano S, Lamping DL, Staniszewska S. Patient-reported outcome measures (PROMs) for routine use in treatment centres: Recommendations based on a review of the scientific evidence. London, UK: London School of Hygiene & Tropical Medicine; 2005.
26. Dash R. What is the difference between a concept and a construct? : Quora; 2016. Available from: https://www.quora.com/What-is-the-difference-between-a-concept-and-a-construct
27. Swank JM, Mullen PR. Evaluating Evidence for Conceptually Related Constructs Using Bivariate Correlations. Meas Eval Couns Dev. 2017;50(4):270-4.
28. Byrne BM. Structural equation modelling with AMOS, EQS, and LISREL: Comparative approaches to testing for the factorial validity of a measure instrument. Int J Testing. 2001;1(1):55-86.
29. Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. J Clin Epidemiol. 1993;46(12):1417-32.
30. Eremenco SL, Cella D, Arnold BJ. A comprehensive method for the translation and cross-cultural validation of health status questionnaires. Eval Health Prof. 2005;28(2):212-32.
31. Guyatt G, Walter S, Norman G. Measuring change over time: assessing the usefulness of evaluative instruments. J Chronic Dis. 1987;40(2):171-8.
32. Terwee CB, Bot SD, de Boer MR, van der Windt DA, Knol DL, Dekker J, et al. Quality criteria were proposed for measurement properties of health status questionnaires. J Clin Epidemiol. 2007;60(1):34-42.
33. Bowling A. Mode of questionnaire administration can have serious effects on data quality. J Public Health (Oxf). 2005;27(3):281-91.
34. Jones TL, Baxter MA, Khanduja V. A quick guide to survey research. Ann R Coll Surg Engl. 2013;95(1):5-7.


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35. Pruncho RA, J.M. H. Interview modality: Effects on costs and data quality in a sample of older women. JAH. 2000;12(1):22.
36. Althubaiti A. Information bias in health research: definition, pitfalls, and adjustment methods. J Multidiscip Healthc. 2016;9:211-7.
37. Bambrick H, Fear J, Denniss R. What does %50,000 buy in a population survey? Canberra: The Australia Institute; 2009.
38. van de Mortel TF. Faking it: social desirability response bias in self-report research. Aust J Adv Nurs. 2008;25(4):40-8.
39. Etter JF, Perneger TV. Analysis of non-response bias in a mailed health survey. J Clin Epidemiol. 1997;50(10):1123-8.
40. SAGE research methods. Sampling bias. 2008. In: Encyclopedia of Survey Research Methods [Internet]. SAGE research methods: SAGE.
41. SCRGSP (Steering Committee for the Review of Government Service Provision) 2013, National Agreement performance information 2012-13: National Healthcare Agreement, Productivity Commission, Canberra.
42. Adams J, Bledsoe GH, Armstrong JH. Are Pain Management Questions in Patient Satisfaction Surveys Driving the Opioid Epidemic?. Am J Public Health. 2016;106(6):985–986. doi:10.2105/AJPH.2016.303228.
43. Bardach NS, AsteriaPeñaloza R, Boscardin WJ, et al. BMJ Qual Saf 2013;22:194–202.
44. Mokkink, L. B., Terwee, C. B., Patrick, D. L., Alonso, J., Stratford, P. W., Knol, D. L., ... & De Vet, H. C. (2010). The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. *Quality of life research*, *19*(4), 539-549.

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## Additional take-home information

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## Dimensions of PEx

Bull et al (2019)

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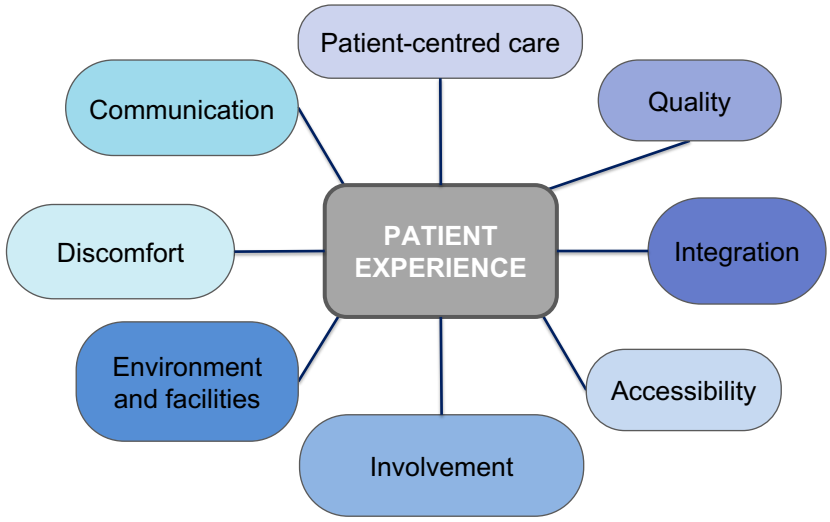


Bull et al (2019)

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## Communication

*The two-way transfer of information between healthcare provider and patient.*

- Provision of information
- Explanations were understandable
- Opportunity to talk
- Enough time to talk

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## Patient-Centred Care

*Care that is compassionate, attentive and tailored to the needs, preferences and values of the holistic person behind the patient.*

- Emotional support
- Feeling listened to
- Individualised care
- Privacy
- Being treated respectfully

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## Quality

*The patient's perceptions of quality in the care they receive based on the trust and confidence instilled by healthcare providers and institutions.*

- Awareness of the patient's medical history
- Confidence in the healthcare provider(s)
- Confidence in the healthcare institution(s)
- Professionalism
- Assisted when needed

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## Integration

*The ability of the patient to move seamlessly within the healthcare system and between different healthcare providers.*

- Continuity of care
- Coordination of care
- Follow-up and transition

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## Involvement

*The acknowledgement and active participation of patients, and should they so choose, their family and friends in* care *processes and decisions.*

- Promoting autonomy
- Opportunity to share in decision-making
- Including family and friends

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## Accessibility

*The availability of healthcare services to those who need them, when they need them, in terms of affordability, physicality/location and acceptability.*

- Scheduling
- Ability to choose provider
- Registration, admission and paperwork
- Contacting healthcare providers
- Healthcare plans and costs
- Getting care in good time
- Location
- Waiting time

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## Environment and facilities

*The environment in which care takes place, and the amenities available to the patient during their episode of care.*

- Comfort and appearance
- Available amenities
- Getting around in the healthcare services
- Cleanliness and maintenance
- Noise
- Feeling safe
- Social surroundings

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## Discomfort

*Psychosocial and physical pain or discomfort associated with receiving treatment or dysfunctions in healthcare delivery.*

- Comfort during procedures
- Pain relief and control

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## Evolution of PEx

- Donabedian's *Framework for Health Care Quality* (1966)
  - Structure: the settings, qualifications of providers, and administrative systems through which care takes places
  - Process: the components of care delivered
  - Outcome: recovery, restoration of function and survival
- Very much in line with a biomedical model of care – freedom from disease, pain or defect → "healthy" humans

Donabedian (1966)

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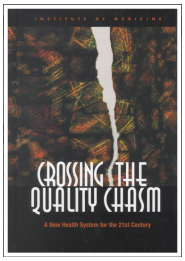
## Evolution of PEx

- Institute of Medicine (US) *Crossing the Quality Chasm: A New Health System for the 21st Century* (2001):
  - Safe: avoiding injuries to patients from the care that is intended to help them
  - Effective: providing services based on scientific knowledge to all who could benefit, and refraining from providing services to those not likely to benefit
  - Patient-centred: providing care that is respectful or and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions
  - Timely: reducing waits and sometimes harmful delays for both those who receive and those who give care
  - Efficient: avoiding waste, in particular waste of equipment, supplies, ideas and energy
  - Equitable: providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status




IoM (2001)

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## Evolution of PEx


NHS

- Current: National Health Service *Quality and Clinical Effectiveness*
  - Clinical effectiveness: the application of the best knowledge, derived from research, clinical experience, and patient preferences to achieve optimum processes and outcomes of care for patients
  - Patient safety: covers everything from technology and redesigning hospitals to washing hands correctly
  - Patient experience: the way a patient feels about their care based on all interactions before, during, and after delivery of care.

NHS Greater Preston CCG (2019)

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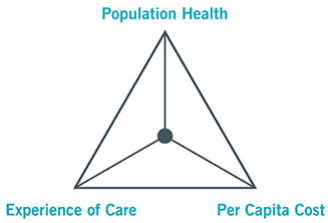
## Evolution of PEx

The IHI Triple Aim




- Current: Institute for Healthcare Improvement (IHI) *Triple Aim*
  - Improving the patient experience of care
  - Improving the health of populations
  - Reducing the per capita cost of healthcare

IHI (2019)

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## Evolution of PEx

- Current: Australian Safety and Quality Framework for Health Care *Safe and high quality health care for Australia* (2012)
  - Consumer centred: providing care that is easy for patients to get when they need it; making sure that healthcare staff respect and respond to patient choices, needs and values; and forming partnerships between patients, their family, carers and healthcare providers.
  - Driven by information: using up-to-date knowledge and evidence to guide decisions about are; safety and quality data are collected, analysed and fed back for improvement; and taking action to improve patient's experiences.
  - Organised for safety: making safety a central feature of how healthcare facilities are run, how staff work and how funding is organised.

ACSQHC (2012)

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## Evolution of PEx

- Current: Australian Productivity Commission – National Healthcare agreement: Outcomes and outcome areas
  - Better health: Australians are born and remain healthy
  - Better health services: Australians receive appropriate high quality and affordable primary and community health services
  - Better health services: Australians receive appropriate high quality and affordable hospital and hospital-related care
  - Better health services: Older Australians receive appropriate high quality and affordable health and aged care services
  - Better health services: Australians have positive health and aged care **experiences** which take account of individual circumstances and care needs
  - Social Inclusion and Indigenous Health: Australians have a health system that promotes social inclusion and reduces disadvantage, especially for Indigenous Australians
  - Sustainability of the health system: Australians have a sustainable health system

SCRGSP (2013)

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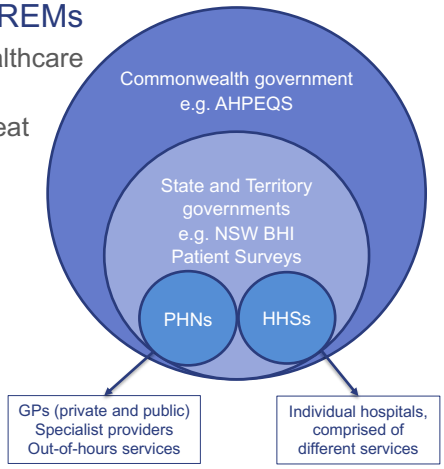
## Looking to the future?

- Still a low number of generic PREMs
  - ?PEx is too different between healthcare services/settings
  - ?The loss of information is too great
- Shorter PREMs
  - Median number of items per PREM is ~27 (ranging up to 82)
- Consistent adoption of PREMs nationally
  - Different agendas at different levels of government, PHNs, HHSs, clinics and providers



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# Ways in which PEx data can be collected

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## Cross-sectional surveying

- A type of observational study that uses survey to collect data from a population (or a representative subset of a population) at a *specific point in time*.
- E.g. QLD ED patient experience survey (EDPES)

| Advantages | Disadvantages |
|---|---|
| • Very common PX research technique (→ strong evidence base)<br>• Relatively easy (if PREM is already developed and tested)<br>• Wide healthcare consumer reach → large number of responses<br>• Can be administered in a variety of ways (e.g. face-to-face, CATI/telephone, online, SMS) | • Response bias: ↓ response rate; overly positive or negative responders reporting<br>• Provides superficial/broad data that might not be informative for specific goals/objectives<br>  • Further compounded by closed-ended questions |

Gualtieri & Akhtar (2013); Ranard et al (2016).

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## Focus groups

- A small but deliberately selected (?representative) group of people who participate in a structured or semi-structured discussion about a contained topic.
- E.g. Focus group with chemotherapy patients' experiences of receiving treatment at home

| Advantages | Disadvantages |
|---|---|
| • Able to obtain in-depth data on a complex topic or for a certain patient group<br>• More cost-effective and timely than individual interviews (though this should NOT be the reason you undertake focus groups instead of interviews).<br>• Offer the opportunity to ad-lib and seek participant clarification or delve further into certain responses<br>• Can be structured or semi-structured | • May bring up irrelevant discussions that distract from the main foci<br>• Sampling bias (e.g. only very invested individuals willing to participate + only small numbers involved)<br>• Group dynamics can be difficult to manage<br>• Analysis is time consuming and requires experience |

Gualtieri & Akhtar (2013); Ranard et al (2016).

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## How do focus groups differ from interviews?

- Aside from the group vs individual approach…
- Share similar advantages and disadvantages
- Interviews better for gaining an in-depth understanding of an individuals lived experience of a certain topic
- Interviewing better for vulnerable populations or when discussing sensitive topics
- Focus groups aim to utilise the group dynamic to explore interactions between views and preferences of the participants

Coast (2019)

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## Blogs, consumer websites and social media

By Benjamin L. Ranard, Rachel M. Werner, Tadas Antanavicius, H. Andrew Schwartz, Robert J. Smith, Zachary F. Meisel, David A. Asch, Lyle H. Ungar, and Raina M. Merchant

**Yelp Reviews Of Hospital Care Can Supplement And Inform Traditional Surveys Of The Patient Experience Of Care**

DOI: 10.1377/hlthaff.2015.1030
HEALTH AFFAIRS 35,
NO. 4 (2016): 697–705


ORIGINAL RESEARCH

**The relationship between commercial website ratings and traditional hospital performance measures in the USA**

Naomi S Bardach,[1,2] Renée Asteria-Peñaloza,[2] W John Boscardin,[3] R Adams Dudley[2]

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## Blogs, consumer websites and social media

- Blog: a regularly updated website or webpage, typically run by an individual or small group, written in an informal or conversational style.
- Consumer websites: a commercial or non-commercial website that posts consumer ratings of businesses or products (or more recently, healthcare services)

| Advantages | Disadvantages |
|---|---|
| • Inexpensive way of collecting PEx data<br>• Can be a rich repository of data (however, this may be specific to certain patient groups or health services) | • Response bias: overly positive or negative responders reporting<br>• Unstructured<br>• Hard to analyse (easier if the data is numerical ratings as opposed to consumer comments<br>• Filtering of comments/ratings can occur via the owner of commercial websites e.g. Yelp |

Gualtieri & Akhtar (2013); Ranard et al (2016); Bardach et al (2012).

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## Tests of validity

*Disclaimer – there are lots of tests of validity*

We focus on the 3 C's:

1. Content validity
2. Criterion validity
3. Construct validity
   - Convergent validity
   - Discriminant validity
   - Structural validity
   - Cross-cultural validity

| Type of validity | Definition |
|---|---|
| **Content validity** | The extent to which the PREM measures the entire breadth of content comprising the construct in question i.e. the patient experience. |
| **Criterion validity** | The extent to which the PREM correlates with a "gold standard" measure of patient experience (e.g. some other well-recognised and well-used PREM). |
| **Construct validity** | The extent to which the construct of a PREM measures the concept that it is designed to measure. |
| Convergent validity | How closely the PREM correlates with other PREMs or measures (e.g. shared-decision making, or patient-centeredness) of the same construct. |
| Discriminant validity | Inverse of the above – the extent to which a PREM differs to other, similar measures. |
| Structural validity | The extent to which the underlying structure of the measure (i.e. domains/dimensions) is in line with the construct. |
| Cross-cultural validity | The extent to which an existing measure has undergone appropriate cross-cultural adaptation for use in a different cultural setting and/or language. |

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## Tests of reliability

Unlike validity, the following tests of reliability are relatively standard across the board:

1. Internal consistency
2. Intraclass correlation coefficient (ICC)
3. Test retest reliability

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| Type of reliability | Definition |
|---|---|
| **Internal consistency** | The extent to which responses to items in an instrument measure the same construct; presented as a summary statistic (Cronbach's α). |
| **Intraclass correlation coefficient** | The extent to which interactions occur between responders and their responses to individual items in the instrument; presented as individual item statistics (ICC). |
| **Test retest reliability** | The ability of the instrument to replicate similar results when used repeatedly. |

Ko & Li (2016); Streiner & Norman (2008); Frost et al (2007); Williams (2019). Linde et al (2008).

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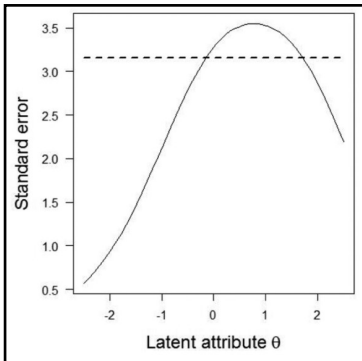
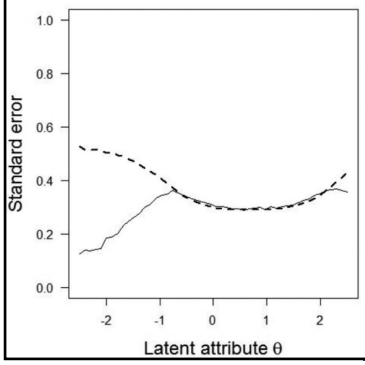
## Classical test theory (CTT) vs Item response theory (IRT)

- Tests of validity and reliability are CTT methods
  - Most commonly used
- IRT is an extension to CTT methods by modelling item-level data
  - Measures the relationship between individual items and the construct being measured
  - Less commonly used, but is up and coming due to ability to reduce item numbers whilst also retaining a tools' validity and reliability

Jabrayilov et al (2016).




**CTT:**
- Uses one common sample-level (average) standard error of measure (dotted line) to estimate the precision of responses to items on a scale
- Therefore if the average standard error is high, the precision of responses may be underestimated → poor validity and reliability (false positive)
- If average standard error is low, the precision of responses may be overestimated → high validity and reliability (false positive)




**IRT:**
- Uses an item-level standard error of measure (dotted line) to estimate the precision of responses to items on a scale
- Therefore estimates of measurement validity and reliability are more accurate (more likely to obtain true positive results)

Jabrayilov et al (2016).

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## Mode of PREM administration

| PREM mode of admin | Advantages | Disadvantages |
|---|---|---|
| **Face-to-face/ In-person** | • Visual aids can be used (e.g. a card with a Likert scale)<br>• Higher response rates<br>• Respondents have the opportunity to ask for clarification<br>• Even if someone refuses to participate, there is still a good chance of obtaining non-responder data (enabling you to describe non-responders)<br>• Lower percentage of missing data<br>• Opportunity to ask follow-up questions to open-ended responses<br>• Data collection and entry can be undertaken using tools most convenient to PREM administers<br>• Lower cognitive burden on respondents | • Potentially expensive (~AUD$65 per respondent)<br>• Time consuming<br>• Requires a trained interviewer (to ask questions in the same way; handle respondent clarification consistently etc.)<br>• May introduce biases such as interview bias* and social desirability bias^<br>• Potential for inaccurate data entry<br>• Inter-rater reliability assessment required where multiple data collectors are employed |

Streiner & Norman (2008); Bowling (2005); Jones et al (2013); Pruncho & Haydenm (2000); Althubaiti (2016); van de Mortel (2008); Etter & Perneger (1997); Sage research methods (2008)

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## Mode of PREM administration cont.

| PREM mode of admin | Advantages | Disadvantages |
|---|---|---|
| **Postal** | • Relatively inexpensive (~AUD$2 per respondent)<br>• Easy to administer<br>• Reduced chances of biases including social desirability bias^ (particularly where responses remain anonymous)<br>• Easier to mass distribute | • Lower response rates<br>• Responders likely to be those with overly negative or overly positive experience (less likely to capture a representative range of patient experiences)<br>• Inability to know who non-responders are if anonymous or not tracked (non-response bias[a])<br>• Greater chance of missing data<br>• Time consuming (in waiting for responses to be returned and needing to send multiple surveys in reminding participants to respond)<br>• Inflexible (no opportunity for on the spot clarification or to build rapport)<br>• Greater potential for recall bias[§]<br>• Slow data compilation (e.g. transcribing into excel from postal survey)<br>• Potential for inaccurate data entry |

Streiner & Norman (2008); Bowling (2005); Jones et al (2013); Pruncho & Haydenm (2000); Althubaiti (2016); van de Mortel (2008); Etter & Perneger (1997); Sage research methods (2008)

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## Mode of PREM administration cont.

| PREM mode of admin | Advantages | Disadvantages |
|---|---|---|
| **Electronic**<br>• **Email**<br>• **Internet survey**<br>• **SMS** | • Relatively inexpensive (~AUD$6 per respondent)<br>• Easy to administer<br>• Reduced chances of biases including social desirability bias^ (particularly where responses remain anonymous)<br>• Able to have a large participant sample pool<br>• Visual aids can be used<br>• Quick responses<br>• Ability to control for missing data (by making it so that all questions have to be answered before you can progress onwards with the survey)<br>• Reduced chance of data transferal errors<br>• Quick data compilation | • Lower response rates<br>• Responders likely to present overly negative or overly positive experiences (less likely to capture a range of patient experiences)<br>• Inability to know who non-responders are if anonymous or not tracked (non-response bias[a])<br>• Sampling bias[β] (not everyone has access to a computer, telephone or the internet, nor is everyone computer literate)<br>• May be difficult to assess how many people have received the survey, thus making it hard to establish an accurate response rate |

Streiner & Norman (2008); Bowling (2005); Jones et al (2013); Pruncho & Haydenm (2000); Althubaiti (2016); van de Mortel (2008); Etter & Perneger (1997); Sage research methods (2008)

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## Mode of PREM administration cont.

| PREM mode of admin | Advantages | Disadvantages |
|---|---|---|
| **Telephone** | • Generally higher response rates<br>• Lower percentage of missing data<br>• Respondents can ask for clarification<br>• Good chance of obtaining non-responder data<br>• Lower percentage of missing data<br>• Less chance of interview bias* than face-to-face<br>• Opportunity to ask open-ended questions<br>• Timesaving (16, 69) | • Potentially expensive (~AUD$55 per respondent) (72)<br>• No visual aids<br>• Potential for social desirability bias^ (68)<br>• Another person on the other end of the phone may be prompting the respondents answers (potentially inaccurate data)<br>• Potential for sampling bias[β] (e.g. day-time calls may over sample housewives, elderly, the unemployed etc.)<br>• Can be difficult for the interviewer to develop rapport with respondent |

Streiner & Norman (2008); Bowling (2005); Jones et al (2013); Pruncho & Haydenm (2000); Althubaiti (2016); van de Mortel (2008); Etter & Perneger (1997); Sage research methods (2008)

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## And then once you have your PEx data…

### Data management:

- Data compilation/transcribing
  - + double-checking to ensure data is transferred from one format (e.g. paper) to another (e.g. excel) error free
- Safe (and ethical) data storage
- Data cleaning and coding


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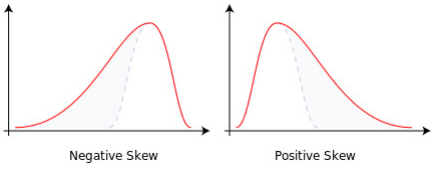
### Data analysis:

- Meaningful representation of the results
  - Who are you presenting this data to?
- Data distribution
  - May find that the data is not normally distributed
  - Means vs medians




- Representativeness of your sample vs the population
  - How can you test this?
- Item vs domain scoring and analysis
  - What is the most robust and succinct way to present the results?