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Special Interest Group Perinatal and Infant Psychiatry (SIGPIP) NSW

# Measuring quality outcomes in PIMH: what will work for patients?

## And how can we know?

# The core question

**Do patient reported outcome measures adequately capture valuable outcomes for perinatal and infant mental health services?**

- Do patients minimise their distress?
- Are patients always conscious about their experience?
- Do external factors influence their responses (culture, family, stigma, shame)?
- Can mental illness or distress be accurately *quantified and therefore tracked?*

**If PROMs are problematic then what can we do to fully assess effectiveness or quality?**

**The issue is that evaluation efforts are reifying PROMS**

# How can I know?

- At a service level
- Growing awareness of patient reported outcome measures
- Value based healthcare
- Big data
- Clinical Lead Psychiatrist – role is responsible for reporting on clinical outcomes and ensuring quality best practice care provided

But how?

# Patient reported outcome measures

- 1980s onwards?
- Going to the patient
- Allegedly measuring what patients deem as important
- “The reliability of PROMs is similar to that of clinical measures such as diastolic blood pressure or blood glucose.” (Black, 2013)

- Black, N “Patient reported outcome measures could help transform healthcare.” in *British Medical Journal*, 2013, p346

# NHS data set

- Intake scores
- Discharge scores
- “Move into recovery” based on reduction in scores

- Neat, seductive, enticing

- And probably misleading

# What's the appeal?

Proponents of state:

- Providing information on what is working for patients
- Assessing the quality between providers/services/clinicians
- Providing information on implementation of policies/change of practice

However…

- "There is a danger of PROMs being used crudely to ration care." (Black, 2013)
- and other dangers…

# Power

**“It is not clear that they really measure what researchers intend for them to measure. Inferences are being drawn from measurement data that may not be justified, and with patient well being at stake, this is no small problem.”**

M. Cupples, L.(2018). Epistemological Issues in Quality of Life Measurement and their Implications. (Doctoral dissertation). Retrieved from https://scholarcommons.sc.edu/etd/4509

# Epistemological naivete

- Assumptions of PROMS in MH:
  - Patient can identify what their experience is
  - Patient ***can*** and ***will*** communicate what their experience is
  - That experience ***can be quantified***
  - Statistical analysis can indicate 'change'
- But the mind is more complicated and mental illness or distress complicates this

# Example 1

- 38 year old father of two: 5/12, 3yo; two older sons from previous relationship
- Partner complex PTSD and MDD
- Recovering, but marriage strained
- Hugely complex background
- Scores on intake: extremely severe in all DASS 21;
- 2 sessions later – all normal ('Flight into health') → remission of severe depression and anxiety

- Really?

# Example 2

- 26 year old woman, repeated faints at medical settings; started several years ago
- Traumatic death of father in ICU
- First time pregnancy
- ‘La Belle Indifference’ – ‘Why’s everyone making a fuss about it?’
- Agrees to graded exposure/brief grief work
- Scores normal on all measures throughout
- Required 34 sessions of treatment
- On simplistic outcome measurement assessment a complete waste of resources… but not

# Everyone's so sensitive

- Another complicating factor:
  - Sensitivies and specificities:
  - EPDS: >= 13 sensitivity: 0.61, specificity 0.94
  - So, … about 40% will not score although they are ill
  - So, … those 40% will not be seen as 'cases' statistically so…
  - Any treatment effects will not be picked up
- PHQ 9 – sensitivity and specificity of 88% with cut off of ten:
    - 12% who are ill will be marked as 'normal'
    - 12% of those who are well will be marked as 'ill'

# It’s more complicated

“The apparent failure of the EPDS to adequately distinguish between depression and BPD or those with significant borderline personality traits is a significant clinical issue as the distinction between these two disorders has important implications. The recommended treatments for these disorders are distinct and different. So too are the potential negative impacts on obstetric and neonatal outcomes, and the longer term effects on children. Importantly, BPD has also been associated with greater likelihood of teenage pregnancy and unplanned pregnancies.”

Judd, Fiona et al “Screening for depression with the Edinburgh Postnatal Depression Scale and finding borderline personality disorder.” in *Australian and New Zealand Journal of Psychiatry,* 2019, Vol 53 (5), pp 424 - 432

# So far…

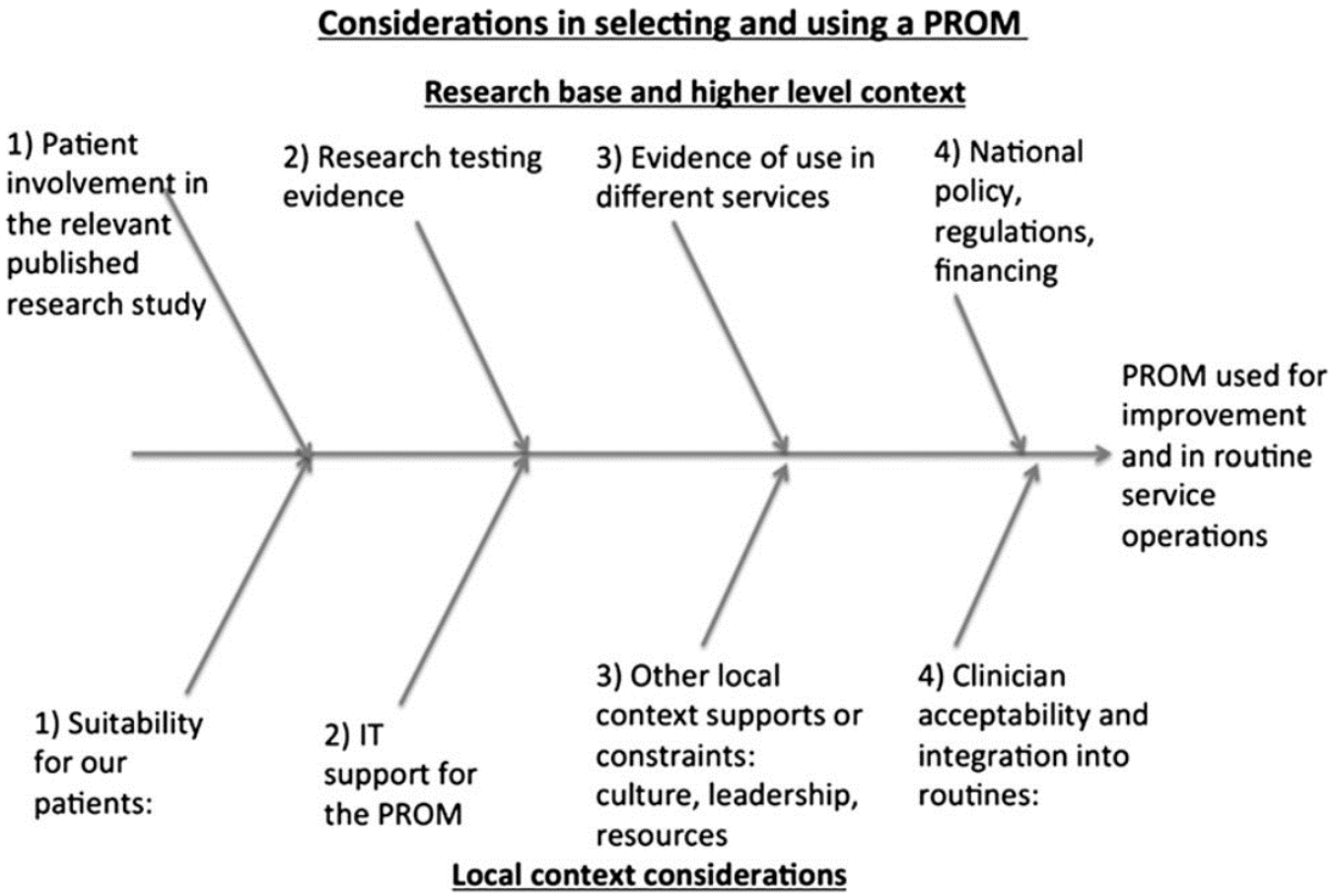
- Patients may not report accurately
- Screening tools reified as the ‘truth’ of a patient’s mental state
- No PROM will have 100% sensitivity or specificity -over time this will distort outcomes
- (And don’t get me started on response rates etc)
- I would argue: rely on them at your peril, but still collect them; they offer part of the picture

# Solutions?

- Quantitative PROMS offers one subset of evaluation of a service's quality
- Other's perspectives - carers, clinicians; quantitative
- Qualitative data is essential to really capture outcomes
- Follow up data also imperative (do the gains last?)
- 'Patient experience' applications that are being used: Net Promoter Scores? Word maps?

- If PROMS are used then…

# Solutions




Øvretveit et al. "Using patient-reported outcome measurement to improve patient care." *International Journal for Quality in Health Care*, 2017, 29(6), 874–879

# Summary

- Collect quantitative data from multiple sources, including clinicians and carers
- Supplement and complement with qualitative data - patient feedback forms, interviews conducted by external agencies (to remove bias), online tracking i.e. NPS or others
- Follow up data essential to ensure changes are sustained
- Encourage collaboration and discussion across and within services to clarify what works and what doesn't

# Questions?

## How would you rate my talk out of ten?