PROMs and PREMs

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Picker Institute Europe

- A not-for-profit organisation that makes patients’ views count in healthcare

- We:
  - build & use evidence to champion the best possible patient-centred care
  - work with patients, professionals & policy makers to strive continuously for the highest standards of patient experience for all their patients

- www.pickereurope.org
Why conduct patient surveys?

- Because “to measure is to know” & “if you cannot measure it, you cannot improve it”
  - Lord Kelvin, 1883

- To see ‘through the patient’s eyes’
  - Gerteis, M., 1993

- To ‘put patients at the heart of healthcare’
  - NHS Plan, 2001

- “Patient experience is the most powerful lever [for choice and quality] and will be used for service improvement”
  - Lord Darzi, 2008
PREMs: patient reported experience

- Experience ≠ satisfaction OR outcome
- Focus on specific, reportable events
- Measure what matters to patients
- Results identify areas for improvement…
- …and allow comparisons/benchmarking
What do patients want?

- Fast access to reliable health advice
- Effective treatment delivered by provided professionals
- Continuity of care and smooth transitions
- Emotional support, empathy and respect
- Involvement in decisions and respect for preferences
- Clear, comprehensible information and support for self-care
- Involvement of, and support for, family and careers
- Attention to physical and environmental needs
Qualitative scoping

Questionnaire Design

Questionnaire Testing

Amending & re-testing
Focus Groups to uncover main issues:
- Patients/users
- Carers

Qualitative scoping

Questionnaire Design
- Best practice approach
- Focus on issues that matter to patients

Questionnaire Testing
- Cognitive Testing for:
  - Comprehension
  - Question wording and length
  - Recall/importance to patients

Amending and re-testing
- Comprehension
- Question wording/length
- Recall/importance to children
- Design
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- Focus on issues that matter to patients/users

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Questionnaire Testing
F12. Did a midwife or health visitor ask you how you were feeling emotionally?

1. Yes
2. No
3. Don't know / can't remember
PREMs examples

B14. Thinking about your antenatal care, were you spoken to in a way you could understand?

1. □ Yes, always
2. □ Yes, sometimes
3. □ No
4. □ Don't know / can't remember
Good outcome, poor experience?

- 29 y.o. 2\textsuperscript{nd} trimester pregnancy: admitted from A&E after severe abdominal pain.
- Ovarian cist - initially misdiagnosed as miscarriage
- “\textit{lost confidence}” in doctors
- “\textit{Never saw my surgeon}” & “\textit{wasn’t told the outcome of surgery until two months later}”
- But... “\textit{I’m just fine now}” as treatment “\textit{definitely fixed the problem}”
Experience and effectiveness

- Limited published evidence

- Doyle, Lennox, & Bell (2013):
  - “patient experience is positively associated with clinical effectiveness and patient safety… the three… should be looked at as a group and not in isolation”.
  - NB: particularly strong evidence re: link b/w patient experience & adherence to treatment
PROMs and PREMs

- Complementary approaches: give patient perspective on outcomes and experiences
- Easy to measure simultaneously
- Users’ views on experience & effectiveness
- Move towards more routine collection