What patients want?
Patient reported outcomes and patient reported experience measures-An update

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Medical Director, UK Renal Registry
Background

Terminology
• PROM
  – Patient Reported Outcome Measure
  – Quality of life
    • Generic
    • Disease specific

• PREM
  – Patient Reported Experience Measure
  – Questions relating to their healthcare experience
PROMs for kidney patients

• Lord Darzi “Next Stage” Review, 2008
  – PROMs before and after 4 surgical procedures
  – Trial of PROMs in long term conditions (mainly primary care)
• First meeting with NHS Kidney Care, Sheffield Jan 2009
• Oxford PROM group systematic review
• Stakeholders meeting, Jan 2010
  • Not sufficient evidence of benefit from major time and resource investment – needed research
• Unsuccessful application to NIHR HSR, April 2010
• First meeting with DH, March 2012
What are we trying to achieve?

Outcomes:
• To improve patients health status
• To improve patient satisfaction with their care
• To improve efficiency of resource use

Processes:
• To increase and improve communication between patients and staff relating to their health and health care
• To increase patient engagement – behaviour, concordance, adherence
• To alter provider behaviour (and make it more patient centred)
Which instrument?

Type:
• Health-related QOL
  – Generic (e.g. SF-36, EQ-5D)
  – Kidney disease specific (e.g. KDQOL, Dialysis symptom index)
• Patient experience/ patient satisfaction?

• Which instruments have been validated in the UK renal population?
• Which have the properties most suited for the purpose?
• Or use a bank of questions?
• What is the appropriate balance between information richness and respondent burden?
• Compare with other conditions (NHS question banks) in UK or kidney services in other countries (CAHPS)
Instrument properties

- **Appropriateness** - Is the content of the instrument appropriate to the questions which [it’s routine collection] intended to address?
- **Reliability** - Does the instrument produce results that are reproducible and internally consistent?
- **Validity** - Does the instrument measure what it claims to measure?
- **Interpretability** - How interpretable are the scores of an instrument?
- **Responsiveness** - Does the instrument detect changes that matter to patients (1) between respondents at a point in time (discriminative) or (2) in the same patients over time (evaluative)?
- **Precision** - How precise are the scores of the instrument? (For example, number of gradations of response)
- **Acceptability** - Is the instrument acceptable to patients?
- **Feasibility** - Is the instrument easy to administer and process?
Which patients?

Options:

• Renal replacement therapy:
  – Haemodialysis, in centre
  – Haemodialysis, at home
  – Peritoneal dialysis
  – Kidney transplant

• +/- Conservative (non-dialytic therapy)

• +/- Chronic kidney disease stage 5, not yet on RRT

• +/- Acute kidney injury
The proposal – draft!

• 10 sites
• All dialysis patients – HD (in centre/ satellite/ home), PD
• PROM/ PREM collected quarterly for 12 months
• PROM:
  – EQ-5D
  – POS-s renal (symptoms)
  – ? Recovery time question (for HD)
• PREM:
  – Scottish Renal Patient Experience Questionnaire

EVALUATE
  – Link with DOPPS – BRS funded
  – Staff & patients interviews & survey
EQ-5D-5L

Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY
- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

SELF-CARE
- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

USUAL ACTIVITIES (e.g., work, study, housework, family or leisure activities)
- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

PAIN / DISCOMFORT
- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

ANXIETY / DEPRESSION
- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed

The best health you can imagine

We would like to know how good or bad your health is TODAY.
This scale is numbered from 0 to 100.
100 means the best health you can imagine.
0 means the worst health you can imagine.
Mark an X on the scale to indicate how your health is TODAY.
Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

The worst health you can imagine
<table>
<thead>
<tr>
<th>Symptom</th>
<th>Not at all</th>
<th>Slightly but not bothered to be rid of it</th>
<th>Moderately limits some activity or concentration</th>
<th>Severely activities or concentration markedly affected</th>
<th>Overwhelmingly unable to think of anything else</th>
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<tbody>
<tr>
<td>Pain</td>
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<td>Shortness of breath</td>
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<td>Weakness or lack of energy</td>
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<td>Nausea (feeling like you are going to be sick)</td>
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<td>Vomiting (being sick)</td>
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<td>Poor appetite</td>
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<td>Constipation</td>
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<td>Poor mobility</td>
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<td>Itching</td>
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<td>Difficulty sleeping</td>
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<td>Restless legs or difficulty keeping legs still</td>
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<td>Feeling anxious</td>
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<td>Feeling depressed</td>
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<td>Changes in skin</td>
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<td>Diarrhoea</td>
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Patient Experience Questionnaire

8. The environment

8.1 When you attended the hospital, how would you grade the following aspects of your out/patient dialysis area or peritoneal dialysis unit/clinic?

8.1.1 Catering
8.1.2 Cleanliness of area
8.1.3 Comfort
8.1.4 Accessibility (e.g., lifts, ramps, automatic doors)
8.1.5 Entertainment (TV, etc)
8.1.6 General surroundings
8.1.7 Toilets, showers
8.1.8 Waiting area
8.1.9 Other (please specify)

9. Hand hygiene

When you attend hospital for dialysis or clinic appointments

9.1 Do the staff usually clean their hands, either by washing them with soap and water or using alcohol gel, before treating you?

9.2 Other than in the toilet areas, are there handwashing facilities for patients?

9.3 Do you usually wash your hands with soap and water or use alcohol gel before entering the dialysis unit?

9.4 Do you have any other comments about hand hygiene in the renal unit?
Collection and reporting

Paper data collection

Options:
• Local
  – Collection and entry - immediately available
  – Extracted by UKRR for reporting/ benchmarking
• National
  – Posted to UKRR and scanned into database
  – Weekly upload to local renal IT system
The proposal – outcomes

• Outcome measures
  – Response rates
  – Feasibility
  – Cost

• Evaluation
  – Mixed methods: interviews & survey
Scepticism

• “… written instruments are not helpful for history taking… the nuances of collecting a history cannot be embodied in a form… Forms are useless and time consuming.”

• “Is a PRO test really better than just asking: How is your walking [pain, depression,…] doing since I last saw you?’
2013 NHS STRUCTURE

NHS OUTCOMES FRAMEWORK

DOMAIN 1: Preventing people from dying prematurely;
DOMAINT 2: Enhancing quality of life for people with long-term conditions;
DOMAIN 3: Helping people to recover from episodes of ill health or following injury;
DOMAIN 4: Ensuring that people have a positive experience of care;
DOMAIN 5: Treating and caring for people in a safe environment; and protecting them from avoidable harm.

NICE QUALITY STANDARDS

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Where do we go from here?

THE PILOT ✅
• 10 sites
• All dialysis patients – HD (in centre/ satellite/ home), PD
• PROM/ PREM collected quarterly for 12 months
• PROM:
  – EQ-5D
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THE EVALUATION
✅ – Link with DOPPS – BRS funded
❌ – Staff & patients interviews & survey

TECHNICAL: “How does the instrument perform?”
FUNDAMENTAL: “Is this useful?”
“How could we make it more useful?”
WE THINK THIS IS IMPORTANT

I WANT TO SPEND QUALITY TIME WITH MY FAMILY...

NOBODY EVER ASKS MY OPINION...

I WANT THE STAFF TO LISTEN TO ME...

I WANT TO FEEL SAFE...
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Healthcare Improvement Scotland