

# What patients want?

Patient reported outcomes and patient reported experience measures-An update

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UK Renal Registry  
2013 Annual Audit Meeting

# 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

BMJ

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**ANALYSIS**

**Patient reported outcome measures could help transform healthcare**

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# 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

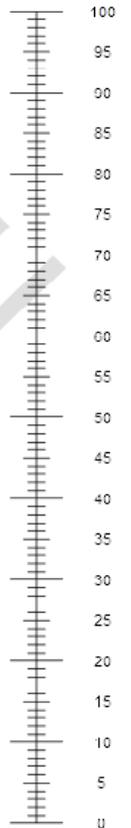
## ANXIETY / DEPRESSION

- 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

- 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 best health you can imagine



The worst health you can imagine

# POS-S renal

	<b>Not at all</b> No effect	<b>Slightly</b> but not bothered to be rid of it	<b>Moderately</b> limits some activity or concentration	<b>Severely</b> activities or concentration markedly affected	<b>Overwhelmingly</b> unable to think of anything else
Pain	<input type="checkbox"/> <sub>0</sub>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
Shortness of breath	<input type="checkbox"/> <sub>0</sub>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
Weakness or lack of energy	<input type="checkbox"/> <sub>0</sub>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
Nausea (feeling like you are going to be sick)	<input type="checkbox"/> <sub>0</sub>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
Vomiting (being sick)	<input type="checkbox"/> <sub>0</sub>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
Poor appetite	<input type="checkbox"/> <sub>0</sub>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
Constipation	<input type="checkbox"/> <sub>0</sub>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
Mouth problems	<input type="checkbox"/> <sub>0</sub>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
Drowsiness	<input type="checkbox"/> <sub>0</sub>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
Poor mobility	<input type="checkbox"/> <sub>0</sub>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
Itching	<input type="checkbox"/> <sub>0</sub>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
Difficulty sleeping	<input type="checkbox"/> <sub>0</sub>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
Restless legs or difficulty keeping legs still	<input type="checkbox"/> <sub>0</sub>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
Feeling anxious	<input type="checkbox"/> <sub>0</sub>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
Feeling depressed	<input type="checkbox"/> <sub>0</sub>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
Changes in skin	<input type="checkbox"/> <sub>0</sub>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
Diarrhoea	<input type="checkbox"/> <sub>0</sub>	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>

# Patient Experience Questionnaire

8. The environment					
<b>8.1</b>	When you attend the hospital, how would you <b>grade</b> the following aspects of your outpatient dialysis area or peritoneal dialysis unit/clinic?	<b>Good</b>	<b>Average</b>	<b>Poor</b>	<b>Not applicable</b>
<b>8.1.1</b>	Catering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>8.1.2</b>	Cleanliness of area	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>8.1.3</b>	Comfort	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>8.1.4</b>	Accessibility (e.g. lifts, ramps, automatic doors)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>8.1.5</b>	Entertainment (TV, etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>8.1.6</b>	General surroundings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>8.1.7</b>	Toilets, showers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>8.1.8</b>	Waiting area	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>8.1.9</b>	Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
					
9. Hand hygiene					
	When you attend hospital for dialysis or clinic appointments	<b>Yes</b>	<b>No</b>	<b>Not sure</b>	<b>Not applicable</b>
<b>9.1</b>	Do the staff usually clean their hands, either by <b>washing</b> them <b>with soap and water</b> or <b>using alcohol gel</b> , before treating you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>9.2</b>	Other than in the toilet areas, are there <b>handwashing facilities</b> for patients?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>9.3</b>	Do you usually <b>wash your hands with soap and water</b> or use <b>alcohol gel</b> before entering the dialysis unit?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>9.4</b>	Do you have <b>any other comments</b> about hand hygiene in the renal unit?				

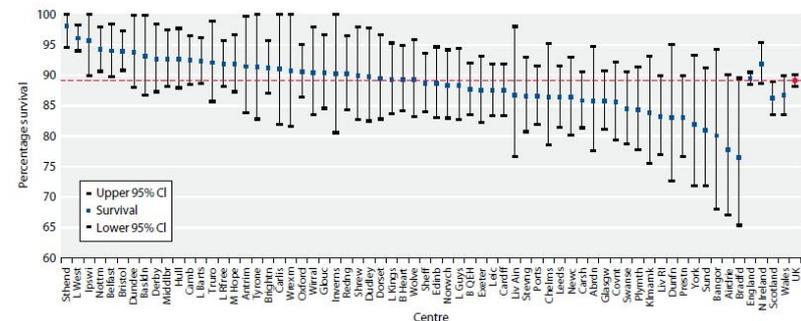
# Collection and reporting



## 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



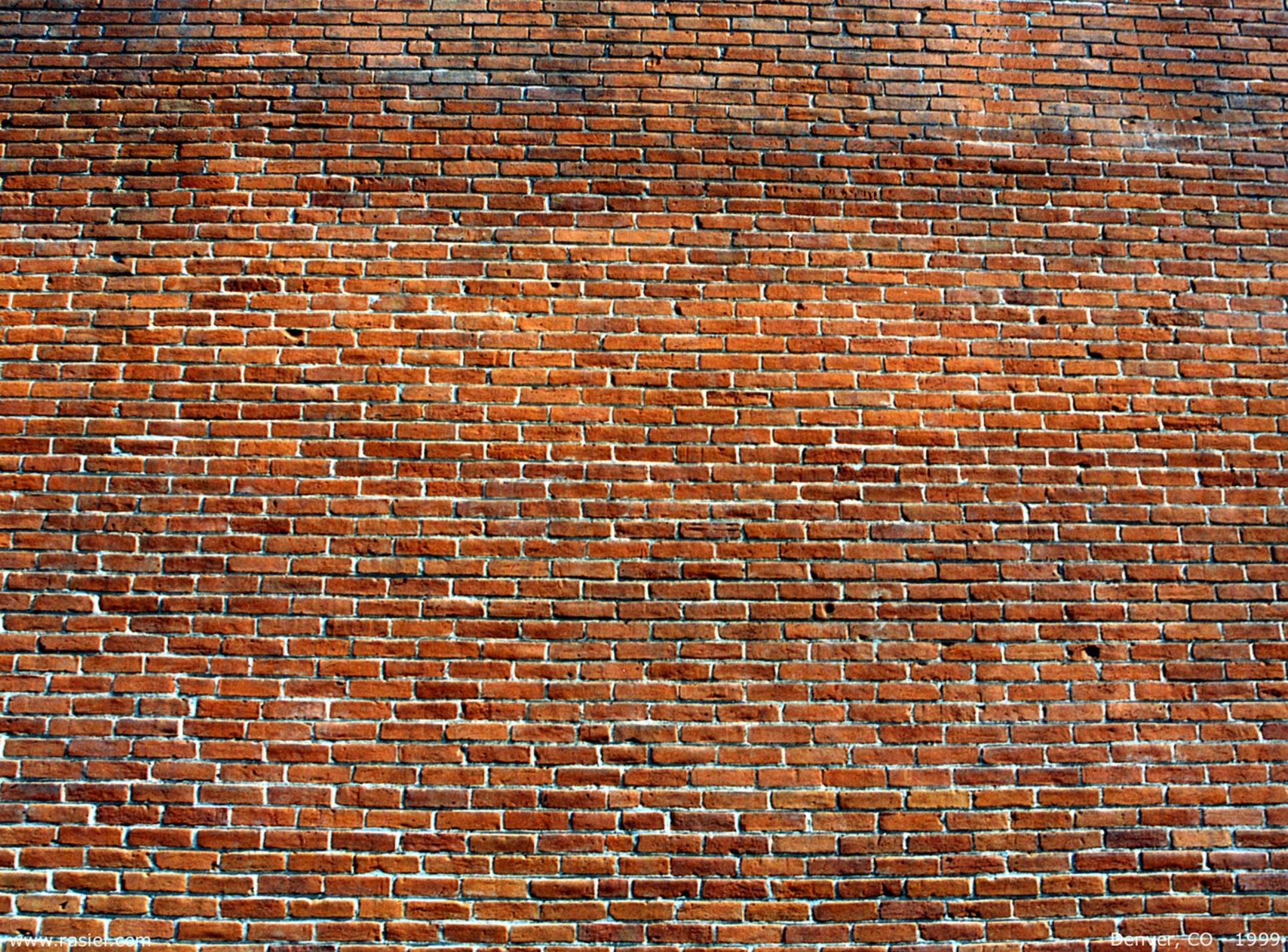
# The proposal – outcomes



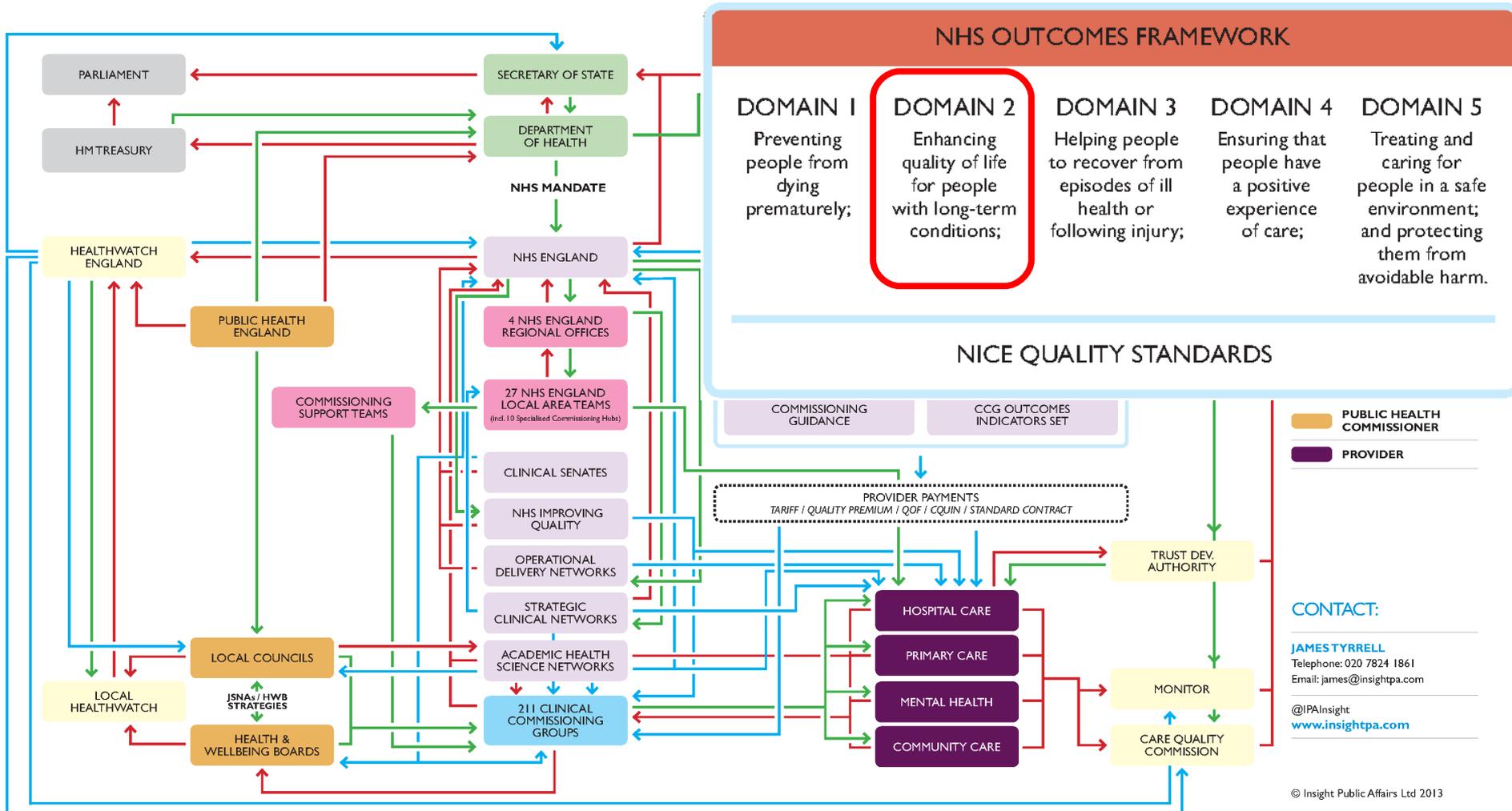
- Outcome measures
  - Response rates
  - Feasibility
  - Cost
- Evaluation
  - Mixed methods: interviews & survey

# 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



# Where do we go from here?

## THE PILOT ✓

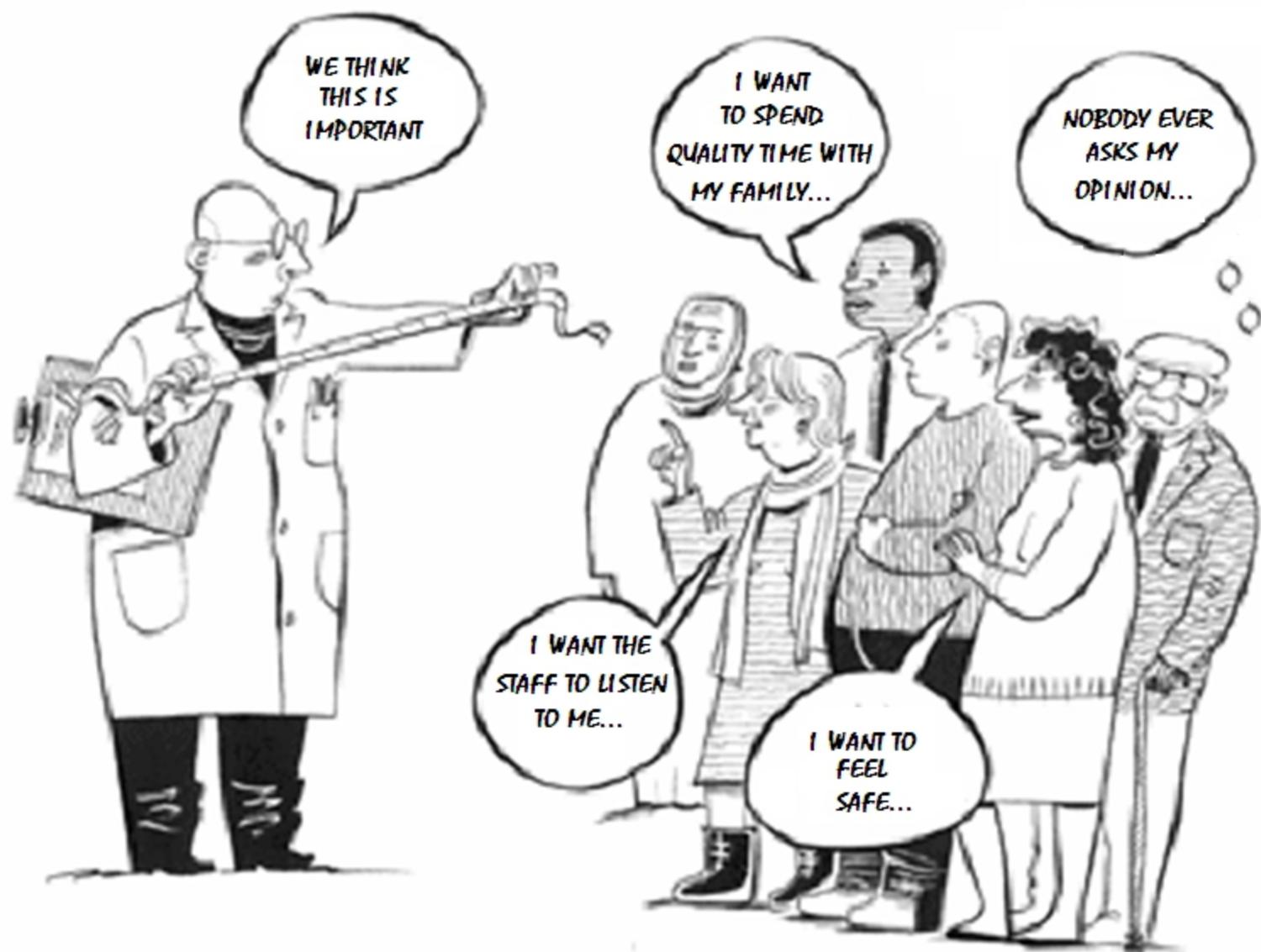
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## THE EVALUATION

- ✓ – 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?”



# Acknowledgements



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