Research agenda

- Effect of question sequencing
- Free-text entries: Potential benefits vs burden of data management
- Optimal recall length. Ability to recall vs accuracy of estimates
- Accuracy in recall of medical terms
- Ability of instrument (and respondents) to distinguish between resource use related / unrelated to the context of use (specificity of the instrument)
- Comprehensiveness of the items recorded by the instruments (sensitivity of the instrument)

- Length of questionnaire and potential burden on respondent
- Missing data: Assessment of the underlying causes
- Reliability testing. Applicability and appropriateness of reliability testing
- Validity testing. Applicability and appropriateness of validity testing
- Appropriateness (or otherwise) of generic resource use instruments
- Transferability for different populations, settings or context
- Cognition and readability
- Lessons from large national health surveys?
- Multinational trials

Validity – research questions

Should we validate

- Questionnaires?
- Questions?
- Approaches? (e.g. Recall periods, phrasing of questions, data collection approaches)
- How generalisable will validity studies be?
- How much resource should be put into validation of RUQ?

Joanna Coast: Challenges in validating cost questionnaires

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Validity plus?

Is it the validity of RUQs that we are ultimately interested in?

□ OR the validity of the calculated cost:

- Taking account of any extrapolation?
- Taking account of any missing items from the RUQ?
- Taking account of unit cost data?
- (Akin to outcomes where we apply values?)

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Future Research

- Is there still a need for standardisation in patient resource instruments (is it sufficient to have broad guidelines rather than being too prescriptive)?
- Do we need a different approach to resource use collection in clinical trials?
- Productivity costs valuation is still debated, how much does this matter for measurement?
- Recall period We used 2 weeks in PCQ, although Clarke (2008) argues there is no compelling reason why a short recall period is the default design in many studies.
- How do we actually measure how precise & accurate instruments are?



Future Research Questionnaire Design

- Examination of the different resource use categories to identify which categories are most prone to missing data
- Placement of resource use questions within the main questionnaire.
- Placement of resource use categories within the RUQ





Questionnaire Design cont.

- Short versus long RUQ
- Use of closed questions

Administration of Questionnaires

- Separate questionnaires versus combined trial questionnaires
- Use of electronic versus paper RUQ.





Priorities for Future Research

•Total v condition specific resource use and for total, the minimum sample size to ensure randomisation balances unrelated resource use between arms

- •In long term follow-up whether a series of accurate snapshots with gaps is better than complete data of questionable quality
- •Further evidence of whether the marginal value of patient logs exceeds their marginal cost