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?
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?)
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