Developing a Stated Choice Experiment to Understand Preferences for Information Provision in an Expanded Newborn Bloodspot Screening Programme

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Key messages
- A hybrid stated choice experiment was designed to elicit parent and midwife preferences for newborn bloodspot screening (NBS) information provision.
- The survey comprised a conjoint analysis linked with a discrete choice experiment.
- The outcome of information provision ‘being able to make an informed decision’ was used as the linking attribute.
- The next phase is to pilot the survey design in a larger sample of parents (current and future) and practising midwives.

Introduction
Newborn bloodspot screening (NBS) is a public health programme which aims to detect severe inherited illnesses in newborn children. By identifying children of all newborns in a specified population for processes and outcomes into a conjoint analysis and sCE and including the individual’s preference rating for the former as an attribute in the latter.

Conclusion
This study developed a hybrid sCE to provide a practical solution to understanding preferences in complex situations. This was achieved by separating preferences for processes and outcomes into a conjoint analysis and sCE and including the individual’s preference rating for the former as an attribute in the latter.

Aim
To design a stated choice experiment (sCE) to develop parent and midwife preferences for information provision in an expanded NBS programme in the UK.

Method
Mixed methods were used to define the (i) choice question (ii) type of sCE (iii) way the sample was to be recruited.

Results
Systematic Review
A total of 58 relevant DCEs were identified and unique attributes were tabulated. A systematic review of published (2001-2014) discrete choice experiments (DCEs) was conducted to identify attributes, with 11 being represented in the conjoint analysis (part A of the survey).

Qualitative interviews and Consultation with Experts
Two senior academic midwives, 4 screening co-ordinators, 2 laboratory scientists, and a patient support charity also offered their opinions on the design of the sCE. These were used to guide the development of a number of attributes.

Rapid Review
Three key newborn screening documents were reviewed to aid the development of the sCE. These were:
- patient preferences for control in medical decision making: an individual’s preference rating for the former as an attribute in the latter.
- patient preferences for control in medical decision making: an individual’s preference rating for the former as an attribute in the latter.

References
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