

## **The development of a discrete choice experiment questionnaire to elicit parents' perspectives on centralised services for children with cleft lip and palate**

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### **Abstract:**

There has been increasing use of qualitative methods to establish attributes and their levels in an effort to improve the face validity of discrete choice experiments (DCEs) in health care research. Few studies adequately describe the qualitative processes in the development of DCEs, especially when the views of parents who are accessing health care services on behalf of their children are sought. This qualitative investigation with parents of children born with cleft lip and palate (CLP) was undertaken to identify attributes and develop attribute-levels for a DCE of secondary care CLP services. The DCE aims to determine the relative value of different aspects of centralised cleft care from the perspective of parents/guardians of children born with CLP. Semi-structured telephone interviews were conducted with 16 parents from across the UK, except Wales. Using the constant comparative method, five attributes and their levels were inductively identified: (a) usefulness and amount of information given (4 levels); (b) staff attitude at cleft centres (2 levels); (c) continuity of care (2 levels); (d) personal costs of attending appointments (4 levels); and (e) facilities at cleft centres (2 levels). An unexpected finding was that parents' sense of responsibility to care and provide for their child made a 'willingness to travel' attribute unacceptable to them but they were receptive to a 'willingness to pay' attribute. Using qualitative methods with service users in attribute development for a DCE helps to uncover issues that may not be apparent to researchers or health service staff.

### **Introduction**

Discrete choice experiments (DCEs) have been applied to an increasing range of health care issues.<sup>1</sup> The technique is based on the premise that the value of health-care interventions, services or policies, is derived from key attributes (e.g. effectiveness, safety, cost, convenience, etc.). Patients may consider some of these attributes to be of more importance than others. Health services vary in the extent to which they are able to achieve each attribute (e.g. a service may be convenient to get to but provided at a high cost). A DCE asks respondents to choose between two or more hypothetical alternatives that have been created to contain different combinations of attribute levels. A respondent's choices between these alternatives are assumed to reflect their underlying utility function, i.e. relative satisfaction derived from using a particular health-care

intervention or service. For example, a DCE can explore the trade off between providing more specialised and centralised cancer care against the distance people with cancer are required to travel to receive that care.

Incorporating the perspectives of users in healthcare planning and delivery has been recognised as important.<sup>2</sup> Simple questionnaires and patient satisfaction surveys may not capture these perspectives adequately. However, a DCE may be used to describe users' perspectives in greater detail because they allow the investigation of the relative value of different attributes of a service and the trade-offs between these to more accurately quantify the preferences of users.<sup>3</sup>

Cleft lip and/or palate (CLP) is one of the commonest congenital abnormalities in the UK, occurring in 1 in 700 live births.<sup>4-5</sup> Management of a person born with CLP can be complex and often requires resource intensive multidisciplinary care. More than fifteen years ago a review of the treatment of CLP in the UK found that outcomes of cleft care in the UK were generally poor. Recommendations for changes to the UK cleft service included the centralisation of cleft care.<sup>4</sup> This centralisation of cleft services has shown regional variation in implementation with different models of centralised care. The impact of the re-organisation of this service is currently being evaluated in relation to process and outcomes. A further approach is to use a DCE to examine the relative value of the different aspects of centralised care from the perspective of parents/guardians of children with CLP.

In the design of a DCE it is important to ensure that appropriate attributes and attribute-levels are included, reflecting the priorities of the target population. Different methods can be used to identify attributes including literature review, focus group discussions, one-to-one interviews, and expert opinion. Increasingly, qualitative interviews are being used to establish attributes and their levels in an effort to improve the face validity of DCEs.<sup>6</sup> A small number of published DCE studies have used qualitative interviews to elicit parents' perspectives on health services provided to their children.<sup>7-9</sup> Only one of these studies has reported the secondary analysis of qualitative data supporting the development of attributes (not their levels).<sup>7</sup> It is essential that qualitative interviews are designed for attribute development and not to rely on secondary analysis of interview

data. Attributes need to be described in appropriate lay language and elicit the views of parents who are accessing health services on behalf of their children.

This study describes qualitative investigations with parents of children born with CLP to identify attributes and develop attribute-levels of secondary care CLP services. This forms the basis of a DCE to evaluate the relative value of different aspects of centralised cleft care from the perspective of parents/guardians of children born with CLP.

## **Methods**

The DCE was developed as part of a programme of research to evaluate process and outcomes of care in children born with unilateral CLP in the UK.

Three qualitative methods may be used to develop attributes for a DCE; interviews, focus groups and meta-ethnography.<sup>10</sup> Each method has advantages and disadvantages in terms of the level of skills required, time commitment, richness of data yielded, and potential for mis-specification of attributes. Interviews may yield richer data than focus groups and meta-ethnography but they require the greatest investment in time.

Semi-structured telephone interviews were chosen as the most appropriate method of data collection. This was a pragmatic approach to sampling of informants from a wide geographical area rather than using focus groups. There were insufficient data to consider using meta-ethnography. Parents/guardians were contacted by post or personally at the cleft centre where their children were registered. They were given or sent an invitation to participate and provided with an information sheet and consent form to return to the researcher. Parents/guardians consenting to the study were contacted to arrange for a convenient time to conduct the telephone interview.

A topic guide was used to aid data collection and provide some consistency between interviews. At the start of each interview, more general questions were used. These helped to build rapport and served as an 'icebreaker'. The questions provided a framework for interviews and helped stimulate interaction between the researcher and

informant, but were used flexibly so that informants could raise issues pertinent to them. Two sources informed the development of the topic guide. The first was a review of the literature on parents' preferences for the provision of their children's health care services. The second was a UK-based survey of parents' satisfaction with cleft services carried out by the Cleft Lip and Palate Association (CLAPA) in the UK. The main topics were informants' experiences of travelling to the larger specialist cleft centre, their experience of receiving cleft care for their children, their expectations about the provision of cleft services, and their perspectives of what were important aspects of cleft care services.

With full informed consent, all telephone interviews were digitally audio-recorded, transcribed verbatim and subsequently anonymised and checked for accuracy by KMK. In line with the constant comparative method,<sup>11</sup> analysis and data collection occurred iteratively. For the purpose of the DCE development, there were two main iterations; the first described key themes within the data, which were subsequently developed into attributes and attribute-levels during the second iteration. The final number of interviews was guided by analysis. Interviewing was stopped when the attribute and attribute levels were judged to be sufficiently well described.

Analysis involved comparing newly collected data with data already collected. Early transcripts were inductively coded, i.e. segments of text were given descriptive labels, and new transcripts were scrutinised using the emerging code list. The codes were developed and eventually codes were grouped to reflect key themes with the data. Later transcripts were compared with the properties of these,<sup>11-12</sup> and they formed the basis of attributes and attribute levels. A descriptive account of the data and diagrams providing visual representations of the data, facilitated analysis. The analysis was conducted by one researcher (KMK). A second researcher (FM) read a random sample of transcripts and the research team met regularly to review the analysis and discuss interpretations of the data.

Ethical approval was granted by the South West Research Ethics Committee, in accordance with the tenets of the Declaration of Helsinki on the participation of human volunteers.

## Results

All telephone interviews with parents/guardians were conducted between January and August 2011. A total of 241 parents/guardians were contacted through the cleft centres. Of 24 parents/guardians who gave consent for a telephone interview, three eventually decided not to take part, and five were not contactable despite several attempts to reach them. Thus, a total of 16 interviews were conducted. Attributes and levels were felt to be sufficiently and clearly described after analysis of these 16 interviews. Thereafter, no additional parents/guardians were invited to participate. Table 1 summarises some key characteristics of informants.

**Table 1: Characteristics of informants (n = 16)**

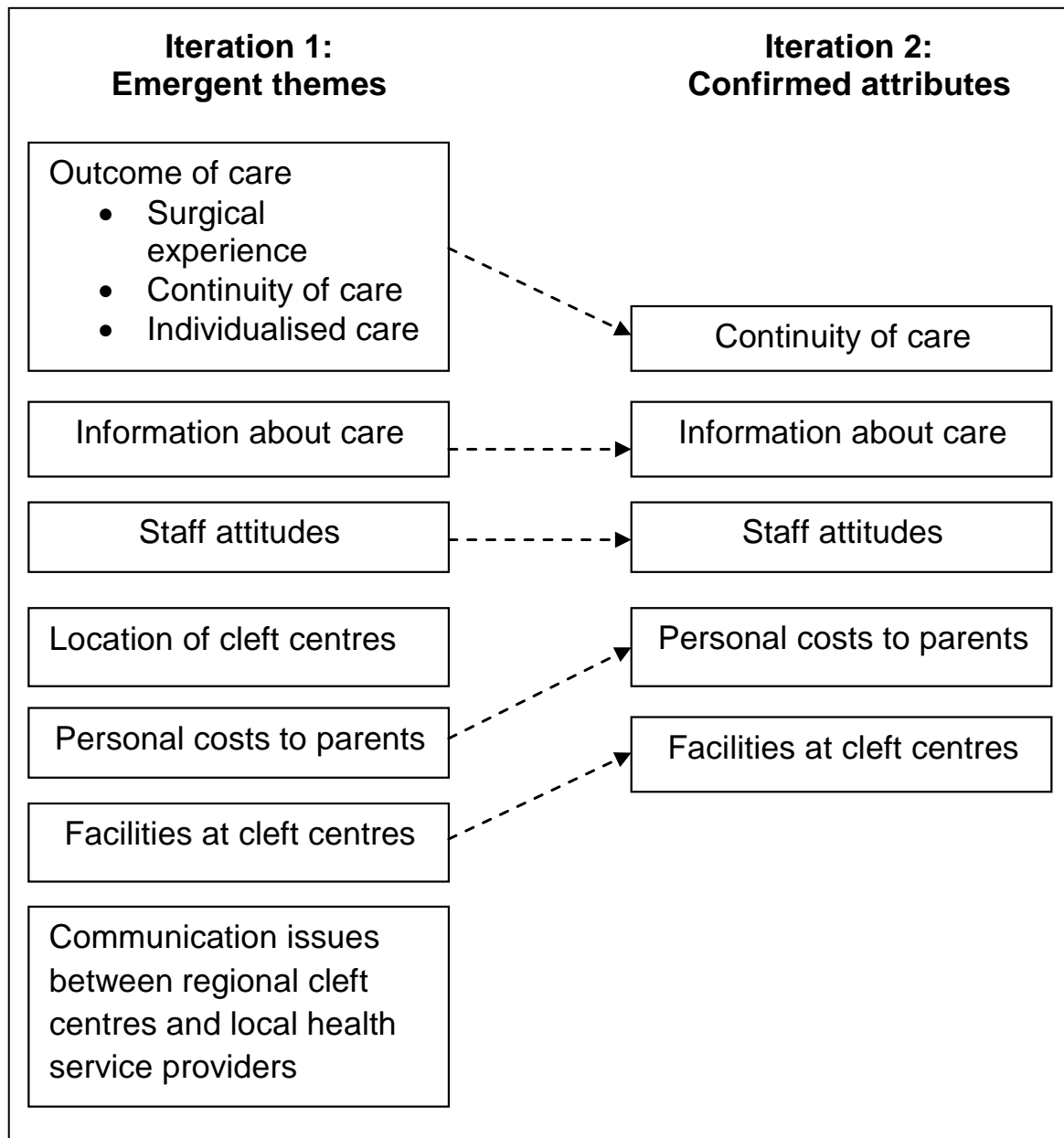
Characteristics	Number
Gender	
Male	4
Female	12
Age	
30-34	6
35-39	6
40-44	1
45-49	2
50-54	1
Residential location	
London and Southeast	4
Southwest	2
Midlands	2
Northwest	2
Northeast	2
Scotland	3
Northern Ireland	1
Round trip travel time to cleft centre	
≤ 1 hour	1
1 to 2 hours	7
2 to 3 hours	3
3 to 4 hours	4
> 4 hours	1

### *First iteration: Key emergent themes*

Seven key themes were inductively derived from analysis of the first six interviews. In descending order of their prevalence in the data, these were: outcome of care;

information given to informants about the care of their children; staff attitudes, location of cleft centres; personal costs of attending appointments, facilities at cleft centres; and communication issues between regional cleft centres and local health service providers. Figure 1 provides a diagrammatic representation of the overall analysis.

**Figure 1: Summary of attribute development process**



Outcome of care

All informants talked about their satisfaction with the outcome of the care for their child. With CLP being a visual birth defect, it was not surprising that the physical appearance of their child after corrective surgery was most commonly cited. Informants were also

concerned with their child's speech because of its potential impact on their social and educational development. The three key factors that emerged to contribute to a good outcome of care were surgical experience of cleft team, having more or less the same team of people looking after their child over the years, and having the child and the family being treated as an individual case and 'not just another number'. The latter two factors appeared to be closely related as illustrated by the following quotes:

It's not been changed about with that at all. So we have... we've got good... we've good contacts with them...they know about case history and things like that which is good... [father, aged 45-49]

My view is I like the continuous care that you get, the same staff that are dealing with you so you're not bounced around from different people, you get to see the same and it's reassuring that you do get to see the same people every time. They get to know your child and they know all her history, whereas if I think... if they started bouncing people about from different specialists, I don't think you'd get the same care as you do now. [mother, aged 30-34]

While surgical experience was obviously considered an important aspect of cleft care, it was also clear from the interviews that if this was included as an attribute in the proposed DCE, people are unlikely to trade off this attribute for another. In other words, people would not be prepared to accept a higher level of another attribute of cleft care, such as shorter travelling time to a cleft centre, to compensate for a lower level of the attribute of surgical experience. This form of behaviour known as non-compensatory decision making or lexicographic preference orderings would result in a DCE that would not yield any meaningful welfare estimates or trade-offs.<sup>13</sup> Therefore, the focus in subsequent analysis was to clarify the other two factors, namely, continuity of care and individualised/personalised care, and determine the levels of the final attributes.

#### Information about care and staff attitudes

Many of the informants discussed their expectations and experience of being given information about the care of their child, such as feeding and a defined care pathway. It was not just a case of whether they were given information, sometimes the information given was more useful than at other times. This inconsistency was attributed by some to the manner in which the information was given, for example:

I found her [nurse] quite rude and abrupt....She actually scared my husband half to death and he wouldn't help feed our son or anything because she told him that he would... he would choke... he would choke him if he did something wrong. [mother, aged 30-34]

At this stage, it seemed that staff attitudes in terms of how approachable, supportive and reassuring they were was closely linked to the issue of receiving information about their child's care.

They were great. They were brilliant. See the next day I went up to see my wife and she was a lot more positive; she's spoken to the cleft team and all that...They told her obviously what was going to happen, what to expect...[father, aged 45-49]

The linkage, if any, of these two themes was explored further in subsequent analysis, where the final attributes and their levels were determined.

#### Location of cleft centres and personal costs to parents

One of the implications of centralised cleft care is that some families would have to travel a considerable distance for their child's cleft appointment. Not surprisingly, many informants talked about their journeys to hospital appointments. When asked to indicate the greatest distance they were willing to travel for their children's appointment at a cleft centre, informants were very hesitant to give a precise figure and would always emphasise that they were prepared to travel as far as was necessary to receive care for their child.

...when it came to it you'd probably travel to the end of the earth for your kids. [mother, aged 35-39]

This may be an expression of a parent's sense of responsibility to provide and care for his or her child. However, when informants were asked to talk about the out-of-pocket expenses, such as on travel, food, parking, which they were prepared to spend for each appointment at a cleft centre, there was more willingness to state an amount.



I suppose if I had to spend like £30 or £40 a time then I would think that's a lot of money. But £15 doesn't seem so bad. [father, aged 30-34]

Based on the assumption that travel expenses are likely to be positively correlated with distances between informants' residences and cleft centres, and that travel expenses form a substantial proportion of out-of-pocket expenses, then the amount which informants are willing to pay would indirectly give an indication of their preference for the location of cleft centres. This issue was pursued in later interviews and analysis, and was eventually used as a proxy measure of informants' perspectives on location of cleft centre.

#### Facilities at cleft centres and Intra-NHS communication issues

Two other themes that emerged, though they were raised less frequently and seen as less important by the informants, were facilities at the specialist cleft centre (i.e. overnight accommodation for parents when their child is hospitalised, car parking, accessibility to public transport, play area for children, shops), and communication issues between local care providers and specialist cleft centres. The latter issue may arise where a hub and spoke model of care existed. The hub in this case would be the regional specialist cleft centre while the spoke would be care provided in the local area where patients reside. In this model, care would be delivered by personnel from the hub as well as from the spoke, and to optimise care provision, both parties should be communicating with each other about the health status and care plan for the child concerned. The significance of these two themes was investigated further in later analysis to ascertain if they would be included as attributes.

#### *Second iteration: Clarification and confirmation of attributes*

The second iteration of data collection and analysis were based on the last ten interviews. In this iteration, data were scrutinised to a) fully describe themes and explore any linkages between themes, b) confirm which themes would be most appropriate for inclusion as attributes in the DCE questionnaire, and c), refine the description of attributes and attribute levels.

### Continuity of care

There was a sense in the earlier analysis that continuity of care and individualised care were significant factors that would influence preferences, and were closely correlated. The relationship between the two factors was highlighted again by the majority of informants in the second iteration.

So from a continuity point of view they all know [child's name] and remember him, and you feel... there must be hundreds of children that they see but you feel very much an individual which must be quite difficult to achieve. [mother, aged 35-39]

I think probably from the speech therapist part it would have bothered me because [child's name] was going quite frequently so I think if it changed, the person changed all the time then I don't think they'd probably have got as much out of her. [mother, aged 35-39]

It would appear that informants generally felt that individualised care was a result of continuity of care, i.e. the cleft team looking after their child remained the same over the care pathway. In other words, when a child has been seen and treated by the same core group of clinicians at different appointments over a long period of time, it is more likely that clinicians have a chance to get to know the child as an individual and hence treatment and management plans can be better tailored to suit the needs of each child. Therefore, it was decided that it would be more appropriate to include the primary factor, i.e. continuity of care, as an attribute in the DCE. Wording used by informants to describe this attribute were either 'same team, or people' or 'changed or different team or people'. Given that the issue of attending different appointments spread over a long period of time was also repeatedly mentioned by informants in this context, it was deemed appropriate to set this attribute at two levels in order to represent being seen by the same or different cleft team at different appointments (refer to table 2 for exact wording).

### Information about care

Initially, it appeared that the inter-connectedness between the themes of information about care and staff attitudes seen in earlier analysis was confirmed. In other words, these two themes could be part of one attribute called 'support' which would capture the help and support that informants felt they had received from cleft teams.

I mean you know any questions we've ever had they've always answered them...it's never been too much trouble you know and even sort of where we've... you know we've had the cleft nurse that sort of... you know certainly supported us a lot in... at the beginning. You know we never felt like we were alone ever. And I think that sort of... but you can feel very sort of isolated, especially with something like a cleft because there's not many children you see around. [father, aged 35-39]

Yes if I ever had any problems or queries or worries I wouldn't hesitate to pick up the phone and ask. You know and they were more than willing to spend time to discuss it through with me. [mother, aged 35-39]

...she gave us lots and lots of information, leaflets and sort of reassurance really and just sort of started building a relationship with us from there. And throughout the whole process we've always been kept informed and been told what the next step is so we know what to expect. [father, aged 30-34]

**Table 2: Attributes and levels derived from interviews**

Attributes	Levels
<b>INFORMATION:</b> The information given to me about the care for my child is	Not always useful and not as much as I would like Not always useful but as much as I would like Always useful but not as much as I would like Always useful and as much as I would like
<b>STAFF:</b> The cleft team	Is professional Is professional, approachable, supportive, and reassuring
<b>CONTINUITY:</b> The cleft team looking after my child is	Often different people at different visits Usually the same people at different visits
<b>COSTS:</b> To attend each appointment at the regional centre would cost about	£10 £20 £30 £40
<b>FACILITIES:</b> The facilities (e.g. parking, overnight accommodation, play area etc) at the regional centre are	Satisfactory Excellent

### Staff attitudes

However, there were instances where informants felt that while they were well supported by cleft teams because the staff was approachable, reassuring, and understanding, they did not think that they were given as much information as they would like or in a way that that was helpful.

...we're sitting here still thinking "well is he going to get a further operation? When is that going to be? Is he going to get grommets because we talked about that?" So it's just that type of stuff you know, maybe just a kind of letter after just to summarise how the day went perhaps....[father, aged 45-49]

So they might have a conversation about one aspect of [child's name] care, but then I might come out thinking "I don't quite understand what... what was the summary of that appointment"...Because some appointments I come out of feeling quite confused...[mother, aged 35-39]

it's almost like we need to say to them "we understand this, could you aim it a little bit higher?" [mother, aged 30-34]

When informants were probed about what 'support' meant to them, some said that it meant being given good advice and useful information, some said that it referred to being shown care and concern, and some felt that it meant both. In other words, there appeared to be some distinction between being given practical support in terms of useful information, and emotional or psychological support by having someone who is caring and whom they could turn to whenever needed. In light of this, it seemed appropriate to have two separate attributes to capture these two themes. Therefore, one attribute would reflect the level of information that was received, and the distinction between levels drawn by informants allowed for four levels to be described (see table 2). The other attribute – staff attitudes - then would represent the theme of emotional support. This attribute was divided into two levels to distinguish between staff who were professional and those who were professional but also empathetic and approachable.

### Personal costs to parents

The same reticence displayed by informants when talking about how far they were willing to travel to get to a cleft centre was also present in the second iteration.

I'd travel any distance for [child's name] sake, to get best care.  
[guardian, aged 50-54]

I'd go... I'd go anywhere. Yeah no I would do anything. I would.  
[mother, aged 35-39]

Equally, they were more forthcoming when asked how much they were willing to spend in terms of travel costs, food, parking (where applicable), for each appointment. The range of responses allowed for four levels to be identified for this attribute, i.e. £10, £20, £30, and £40. The variation in responses was influenced mainly by the informants' budget.

If its £15 you know every few months it's not... you know it's not a problem for us, and finances because we both work. Yeah I wouldn't... I wouldn't like to think that I'd have to pay more than £15 for a hospital trip. [mother, aged 35-39]

#### Facilities at cleft centres

The facilities at the specialist cleft centres were generally felt to be of some importance in influencing preferences. Nine of the informants talked about the availability and ease of parking at the centres.

The parking at [cleft centre] is horrific...would be good if it was easier and cheaper. [mother, aged 30-34]

The provision of overnight accommodation for parents/guardians when their children were hospitalised for surgeries was also discussed and it seemed to make a big difference sometimes whether there was enough room for one or both parents to stay overnight.

So it was only an issue that only one of us could stay because obviously both of us wanted to stay being that we were so far away... we were really worried that they were going to kick him [child's father] out and I kept thinking "oh god I hope they let you stay, I hope they let you stay". [mother, aged 30-34]

Some informants also talked about how child-friendly the cleft centres were or not.

Yeah I mean certainly where the outpatients clinic is they have got... you know the area they've got toys and they've got videos for the older ones, it's good. [mother, aged 35-39]

Therefore, it was decided to include facilities as an attribute in the DCE questionnaire.

#### Intra-NHS communication issues

The communication issues between local care providers and specialist cleft centres were either not raised by informants or were felt to be relatively unimportant in influencing preferences among informants when the issue was probed.

It's not really that important...more important to be able to access the regional centre. [mother, aged 35-39]

## **Discussion**

### Summary of findings

Five attributes and their levels for a DCE questionnaire aimed at eliciting the relative value of different aspects of centralised cleft care from the perspective of parents/guardians of children with CLP were identified through this qualitative work. These were (a) usefulness and amount of information given; (b) staff attitude at cleft centres; (c) continuity of care; (d) personal costs of attending appointments; and (e) facilities at cleft centres.

This qualitative work has identified themes and clarified issues relating to the development of these attributes and their levels. From an initial pool of seven themes, a process of clarification and confirmation during semi-structured telephone interviews helped to derive the final set of five attributes and their levels for the planned DCE.

### Design of DCE questionnaire

The five attributes and their levels identified through this study will be used to generate hypothetical scenarios for a DCE questionnaire that will be used in parents of children born with UCLP. This questionnaire aims to assess the relative values parents would

place on each level of each attribute, and therefore determine the aspects of care that are most important to them. Cleft centres might use the findings from this DCE questionnaire in two ways. First, they might conduct a survey to ascertain how well they were currently performing on those attributes that were important to parents. Second, they might target service improvements in those aspects of care that were important to parents.

### Strengths and limitations of this study

The key strength of this study is that it captured a wide range of perspectives from parents/guardians of children born with CLP. Informants resided at varying distances from the cleft centre where their child received care. This diversity strengthens the extrapolation of the study's findings to the entire cleft care service in the UK. However there were limitations. The parents interviewed in this study had children born with unilateral CLP. These children (and as such their parents) are a good representation of a cleft service user since they require resource intensive treatment by a multidisciplinary team of specialists. Other phenotypes require fewer or more resources but unilateral CLP is a good benchmark. Additionally, whilst the sampling frame was designed to facilitate maximum variation sampling (i.e., to achieve data from a wide range of informants), there was a low response to the invitation. Despite this, there was diversity within the sample.

### Comparison with cleft literature on attributes

This is the first attempt at developing a DCE in cleft care. Seven previous studies have reported parental views about the care for their child with CLP (see appendix 1).<sup>14-20</sup> Unlike this current study which aimed to elicit parental views about different aspects of centralised UK cleft care service, the other studies focused either only on parents' needs for information, their satisfaction with the care received, or their suggestions to health care professionals to improve the care provided to their children. Qualitative methods were used in 3 out of the seven studies.<sup>15, 17-18</sup> The findings of these seven studies all point to perceived need of parents for the right sort of information to be given in an appropriate manner at the appropriate time in their children's care pathway, and also for practical and emotional support. These were two key attributes identified in our study.

### Comparison with other qualitative DCE development studies

While there have been an increasing number of studies that have used qualitative methods to develop attributes and levels for DCEs, only a small number of these have provided sufficient detail to enable an assessment of the rigor of the methods used and replication.<sup>1</sup> The qualitative methods used in this study are comparable to those reported in other qualitative DCE development studies. The use of a topic guide, which is common in qualitative research methodology, has been reported in two other studies.<sup>21-</sup>  
<sup>22</sup> The approach of developing attributes in iterations has also been reported in previous studies.<sup>21-23</sup>

The current study is distinctive in that it describes the attribute development process for indirect users of health services, namely the parents of children with CLP, rather than the direct users reported in the other studies. A parent's sense of responsibility to care and provide for his/her child affected the development of a 'willingness to travel' attribute. Informants in this study, just like parents who were accessing care for their children with cancer,<sup>24</sup> said that they were prepared to travel to wherever in order to receive care for their children. However, when they were quizzed about the amount they were willing to spend for travel, and other miscellaneous items, for their children's cleft appointments, they were more prepared to state an amount and added that the amount would be constrained by their income.

### Implications for future DCE development

There is growing recognition of the value of using qualitative methods to develop attributes for DCEs in healthcare.<sup>6, 21, 25</sup> This paper has contributed to the research of using qualitative methods for attribute development in two ways. First, it has described in detail the process of adopting the qualitative methodology in the development of a DCE questionnaire. New researchers can draw on the information, thus reducing the need for a constant 'reinventing of the wheel'. Second, it has highlighted that specific issues could be encountered in attribute development when engaging parents who are not direct users of health services, in the process. In this study, parents' sense of responsibility to care and provide for their child has on the one hand made a 'willingness to travel' attribute unacceptable but did not prevent them from being receptive to a



'willingness to pay' attribute. This would not have been apparent without the qualitative work.

## **Conclusions**

The rigorous use of semi-structured interviews has helped to determine the final selection of attributes and attribute-levels for the design of a DCE to elicit the views of parents with children born with CLP on the centralisation of cleft services in the UK. The adoption of qualitative methods in attribute development should be the gold standard as it provides a means of uncovering issues that may not be obvious, especially if the target population are indirect users of services.

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## Appendix 1: Studies reporting parents' views about care for their child born with CLP

Authors, year of publication, country	Sample size; response rate; cleft phenotype	Aims of study	Methods	Relevant findings
Horner, et al., 1987, USA	164; 35.5%; CL, CP, CLP	Needs of parents with a chronically ill or disabled child (including cleft lip or palate)	Postal questionnaire	Parental needs include information; and professionals need to listen and understand problems faced by parents
Pannbacker and Scheuerle, 1993, USA	42, 56%; CL, CP, CLP	Gather information about characteristics and attitudes of families; the extent to which parents participate in decisions about treatment; and parents' ideas about their participation	Self-administered questionnaire	Most parents wanted more information about treatment for their child, more participation in the treatment decision for their child, and were interested in attending programmes about treatment.
Dolger-Hafner et al., 1997, Germany	55; nil; CL, syndromic CP, CP	Understand parents/ views about information-giving to them about their children born with CLP	Semi-structured interviews	Parents had a need for information and emotional support from medical staff.
Young et al., 2001, USA	40, 100%; CLP	Determine what information parents wanted on child's first day of life, distinguish these "critical" points from information that could be heard later; and evaluate whether informers met parents' needs.	Self-administered questionnaire	Parents of newborns with CL/P want basic information, such as feeding and recognising illness, during the baby's first day of life; more complicated information could wait.

Authors, year of publication, country	Sample size; response rate; cleft phenotype	Aims of study	Methods	Relevant findings
Byrnes et al., 2003, USA	98; 43%; CL, CP, CLP	Assess parental satisfaction with and preferences for conversations that informed them about CLP	Self-administered questionnaire	Health professionals show more caring and confidence, give parents more of an opportunity to talk and show feelings, provide more information during the informing interview.
Johansson et al., 2004, Sweden	32, nil; UCLP, BCLP, BCL	Describe parents' experiences of having a child with unilateral or bilateral CL or CLP, and their perception of support from professionals, family and friends	Semi-structured interviews	A psychologist should be part of the cleft care team to provide support for parents who do not have a social network to depend on; and information given about child's care and development.
Knapke et al., 2010, USA	17, 52%; CL, CP, CLP	Assess parental perspectives on effective interventions and summarise their suggestions for improvement to cleft care	Semi-structured interviews	Effective Interventions included repetition of information, showing pictures of other children (before and after surgery), and anticipatory guidance about surgeries and child's development.

CL – cleft lip; CP – cleft palate; CLP – cleft lip and palate; BCL – bilateral cleft lip; BCLP – bilateral cleft lip and palate; UCLP – unilateral cleft lip and palate; nil – response rate not reported