

# **A discrete choice experiment of family preferences for routine consultations in paediatric diabetes**

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## **Background**

A discrete choice experiment (DCE) is a stated preference elicitation technique. Services are described in terms of attributes and a series of “treatment profiles” are generated by varying the levels of these attributes. Respondents choose between sets of profiles from which preferences are modelled.

We conducted a DCE alongside a cluster RCT testing a complex intervention in the management of paediatric diabetes to identify the key attributes of routine consultations and their relative importance to patients (aged 12- 16) and carers. The authors identified only one previous DCE (for dental treatment) which included paediatric participants.

## **Methods**

Literature review and focus groups informed the design of the DCE. A fractional factorial design of 27 treatment profiles was used. Cognitive interviews were used to pre-test the questionnaire. Multilevel modelling was used to analyse the data collected via postal questionnaire from patients and carers at 12 month trial follow-up.

## **Results**

Patients and carers identified the same five attributes, each with three levels. Patients (and carers) with poorer diabetes control at follow up were less represented. All attributes were statistically significant ( $p < .001$ ). Both patients and carers prefer the doctor to address both parties. Carers prefer their children to be involved in the goal setting process whereas children want the doctor to be involved.

## **Conclusions**

This study is the first to use DCE to explore young patients’ and their carers’ preferences for clinic consultations in the management of diabetes. Rigorous piloting was vital to ensure feasibility and interpretation of results. The identified key attributes may not reflect preferences of patients with poorly controlled diabetes.

## **Introduction**

Diabetes is the third most common chronic disease in childhood, with 1-2 per 1000 children and adolescents in the U.K. receiving prescriptions of insulin in recent years (1998 and 2005) (Hsia et al, 2009). Children and teenagers with type 1 diabetes frequently experience sub-optimal glycaemic control which may be improved by changes in their self-management. Previous systematic reviews of psycho-educational interventions have shown modest

improvements in HbA1c and psycho-social outcomes though there is little evidence of their clinical and cost effectiveness in a UK-setting. Due to the shortage of trained psychologists, there is a need to improve the skills of paediatric diabetes health-care professionals in counselling their patients and carers during routine clinical encounters, particularly in relation to issues requiring behaviour change. The DEPICTED study (Gregory et al, 2011) developed over two phases, in the first phase a training package was developed to help paediatric diabetes health-care professionals to counsel their patients and families more skilfully during routine health-care encounters, particularly in relation to issues requiring behaviour change. In the second phase a cluster randomised controlled trial in 26 paediatric diabetes services in England and Wales was conducted to evaluate the effect of communication skills training for health-care professionals on HbA1c and psycho-social outcomes in patients and on the latter in their carers. Six hundred and ninety-three children aged 4-15 years with type 1 diabetes of at least one year duration and one of their carers were recruited.

We conducted a discrete choice experiment (DCE) alongside the cluster RCT to identify the key attributes of routine consultations and their relative importance to patients (aged 12- 16) and carers.

Stated choices technique represents a recent development in health economics to elicit patient preferences for health care interventions. Within health care, stated choice studies describe health care services in terms of collections of attributes (Ryan et al, 2008). By varying the levels (ranges) of these attributes, different “treatment profiles” are created. Patients are then asked either to order (ranking experiments) or to choose between a set of choices (discrete choice experiments) to infer the relative importance of different service attributes. Stated choices resemble experiments because the researcher can manipulate attributes and levels to study how patients react (i.e. modelling patient’s behaviour) to treatment options or processes of care that might be in place yet. However, because choices are made in regard to hypothetical scenarios, they may differ from revealed preferences. It is therefore important that the attributes and levels used are realistic as well as tradable to ensure valid and reliable inferences about respondents’ behaviour (Ryan and Gerard, 2003) and that the choices are subjected to rigorous pre-testing (DeShazo and Fermo 2002, Presser et al, 2004).

Modifying the clinical encounter to engage patients and families better, to enhance their clinic experience and to support self-management are aims of the Talking Diabetes intervention. In this DCE we aimed to formally identify the key components sought in a routine consultation in paediatric diabetes and determine the relative importance that patients and carers attach to these components.

Furthermore, the DEPICTED study offered an important opportunity to investigate two methodological issues in the use of DCEs. First, it allowed exploration of the feasibility of using a DCE design with young respondents and second it enabled comparisons of patients' and parents' preferences. Only a few studies have included young participants. (e.g. Gibson and Nelson, 2009; Espelid and colleagues, 2006), only a few studies have compared health professionals and carers ( e.g. Gidman and colleagues, 2007). However, no study was found which compared childrens' and carers' preferences.

## **Methods**

The conduct of a DCE involves key steps (Lancsar and Louviere, 2008): a) identification of attributes and their levels; b) designing the experiment (identifying the choice sets to use); c) piloting the questionnaire (e.g. to address cognitive burden); d) administering the questionnaire; and e) data analysis and interpretation. These components will be presented in sequence.

### **Step 1) Identification of attributes and levels**

The attributes of routine clinic consultations which are of importance to patients and their carers have to be realistic, tradable and relevant to respondents (Ryan and Gerard, 2003). This was achieved via a series of focus groups. As focus groups can inhibit some quieter participants, principles of nominal group technique were used to structure and facilitate input from all participants (Patton, 2001; Jones and Hunter, 1995). The focus groups involved individual working, group discussions and a formal ranking exercise of key attributes. Separate focus groups were conducted for carers and patients.

Each group was run by two facilitators using a semi-structured guide to identify 5-7 key attributes, construct realistic levels for these attributes, ascertain if any attribute might be too dominant and assess whether other important attributes had been overlooked. Group discussions were audio-recorded and transcribed. Content Analysis was used to analyse the

data in combination with individually produced participants' response sheet data, to identify the attributes and levels.

The patient group included 12 individuals aged between 12 and 16 (7 boys), the carer group included 11 carers (4 with children aged 11 or younger).

**Table 1: Ranking the most important attributes in a consultation**

Rank	Patient	Total points allocated	Carer	Total points allocated
1	Get me involved	24	Putting the patient first	35
2	Listen to me	18	Interaction skills of the clinician	27
3	Usable, understandable advice + information	15	Continuity of care	25
4	Problems solved	13	Time	22
5	Time (according to need)	8	Setting objectives/action plan	8
6	Continuity	7	Guidance (including info provision)	7
7	Body language	6	Having a positive approach	4
8	Goal setting – realistic/individualised	6	Clinic organisation	3

The final selection of attributes and levels involved combining some attributes and rejecting those which could not be affected by the DEPICTED intervention (e.g. distance to clinic). A final list of 5 attributes with 3 levels each was produced (Table 2). The same attributes and levels were identified for both groups with wording adjusted to fit either patients or carers.

**Table 2: List of attributes and levels for the DCE questionnaire (Design coding)**

Attributes	Levels for Patient (Design coding)	Levels for Carer (Design coding)
<i>Who the doctor talks to</i>	talks mainly with my parent (0) talks mainly with me (1) talks with both me and my parent (2)	talks mainly with me (0) talks mainly with my child (1) talks with both me and my child (2)
<i>The amount of information I am given</i>	a little bit of information (0) some information (1) a lot of information (2)	a little bit of information (0) some information (1) a lot of information (2)
<i>Who sets the goals on how to look after my child' diabetes</i>	the doctor (0) me (1) the doctor and me together (2)	the doctor (0) my child and I (1) the doctor, my child and I together (2)
<i>Which doctor do I see</i>	a different doctor each time (0) the same doctor most of the time (1) the same doctor each time (2)	a different doctor each time (0) the same doctor most of the time (1) the same doctor each time (2)
<i>In the consultation I have time for</i>	a few of my questions (0) most of my questions (1) all my questions (2)	a few of my questions (0) most of my questions (1) all my questions (2)

## Step 2) Designing the experiment

The resultant attributes and levels generate 243 ( $3^5$ ) profiles (full factorial design). As this would require a large number of respondents, a regular fraction factorial design was used whereby only a subset of the combinations are used to model respondents' choices ( $3^{5-x}$ ) (Street and Burgess, 2007). However, the smallest regular fraction is defined by the number of parameters that need to be estimated, including the interactions to be investigated. As the above attributes are all categorical and have 3 levels each, 11 parameters (10 for the attributes and one for the constant term – explained below) would be needed to estimate the main effect of the model and 4 additional parameters to estimate each two-way interaction.

The present study determined a regular fraction design of 27 treatment profiles ( $3^{5-2}$ ), where 3 attributes are the generator factors the other two attributes are defined using defining equations of the three generator factors. As 27 is still a considerable number for each individual to answer it was decided to use a 2 level attribute to generate two orthogonal questionnaires (Version A and Version B). Each questionnaire included the lowest and the highest treatment combinations (00000 and 22222) producing a total of 15 profiles for each version of the questionnaire. In order to construct a pair-wise choice set, it was decided to compare each treatment option to a constant scenario (Ryan et al, 2008). In this study the middle term of each attribute (11111) was used as a constant scenario.

To facilitate interpretation of the parameters to be estimated by the model, we report below the utility model function for the main model only.

### Figure 1 Utility model function for the Discrete Choice Experiment

$$V_i = \beta_0 \text{ constant term} + \beta_1 \text{ talks to me} + \beta_2 \text{ talks to me and my parent} + \beta_3 \text{ some information} + \beta_4 \text{ a lot of information} + \beta_5 \text{ I set the goals} + \beta_6 \text{ the doctor and I set the goals} + \beta_7 \text{ same doctor most of the times} + \beta_8 \text{ always the same doctor} + \beta_9 \text{ time for most of my questions} + \beta_{10} \text{ time for all of my questions} + \varepsilon_1 \text{ error term at center level} + \varepsilon_2 \text{ error term at respondent level} + \varepsilon_3 \text{ error term at observation level}$$

Where:

$V_i$  = the change in utility in moving from consultation A to consultation B

$\beta_0$  = constant term

$\beta_1 - \beta_{10}$  = the beta coefficients of the model to be estimated

$\varepsilon_1$  error term at center level = error because of differences across centers

$\varepsilon_2$  error term at respondent level = error because of differences across respondents

$\varepsilon_3$  error term at observation level = error because of differences across observation (each respondent was asked to answer 15 pairwise choices)

In this is multi-level logistic regression equation model, the betas represent the probability of moving away from the constant scenario. For example, if the respondent prefers a lot of information to some or little information, then it would be expected that when the alternative treatment option includes a lot of information, the respondent will choose this over the constant scenario and  $\beta_4$  would be positive (all other attributes' levels being (or perceived) similar between visit options).

The DCE questionnaire was presented in its own booklet which included three sections. In Part 1 presented the list of attributes and levels and asked respondents to report what usually happens in their clinic consultation. This enabled respondents to familiarise themselves with the attributes and levels and also provided a baseline picture of respondents' current experience of consultations. In Part 2 respondents were asked to rank attributes in order of importance. Part 3 included the 15 pair-wise choices. Different sets of choices were presented in two questionnaire versions (A or B) in otherwise identical booklets.

### **Step 3) Piloting the questionnaire**

Cognitive interviews using retrospective probing were used to pilot the questionnaire to ensure that respondents understood the task as intended and that the task was not too burdensome (Tourangeau et al 2007; Collins 2003). A structured interview guide was designed to probe possible problem areas.

Two rounds of pilots were carried out; 55 invitation packs were sent to families attending the paediatric diabetes clinical service in Cardiff. In the first round of piloting, participants were given the DCE questionnaire (incorporated into the main trial outcome questionnaire form) to complete and interviewed afterwards for approximately 15 minutes. Interviews were audio-recorded and responses were summarised and coded.

Eleven families expressed interest in taking part in the piloting during the next clinic visit. Interviews were carried out with 6 patients (aged 10 to 14, 5 female) and 5 carers (all female). Key findings (problems) were: completion of only a single pair-wise choice, completion based on actual rather than preferred consultation, inattention to provided instructions, misinterpretation of some terms and problems understanding the ranking exercise.

Subsequent changes to the questionnaire included; a) clearer instructions and modified layout for the ranking exercise, b) modified instructions for the pair-wise choices, c) presenting the questionnaire in a separate booklet to the main trial outcome questionnaire, d) emphasising the hypothetical nature of the consultation styles used, e) emphasising that the pair-wise choices might seem very similar, f) various wording changes.

Following revisions to the questionnaire, a second round of piloting was carried out with lay stakeholders via telephone. The cognitive debriefing interview was concurrent to the participant answering the questionnaire. A series of vignettes indicating to pause were included at key parts of the questionnaire (e.g. ranking exercise, to indicate this). Each interview was audio-recorded and transcribed for analysis. Three parents and two teenagers took part. None of the participants showed any problems with the instructions, wording and ranking exercise. No changes were made to the questionnaire.

#### **Step 4) administering the questionnaire**

The DCE questionnaire was administered at one-year follow up.

#### **Step 5) Data analysis and interpretation**

Responders and non-responders were compared on the basis of clinical and socio-demographic characteristics. A multilevel logistic regression model using MIWin software (MIWin, 2000) was used which took account of correlations at site level (level 3), individual level (level 2) and the multiple responses from within each individual (level 1). Two models were estimated; one for carers, one for patients (aged 12 to 16). The dependent variable represented the probability of choosing the alternative scenario. The explanatory variables include the attributes, the randomisation group and a range of relevant clinical and socio-demographic characteristics. Dummy variables were used for the attributes' levels to avoid assuming that the changes between attributes options were ordinal.

The analysis in MIWin was firstly carried out using the default setting for distributional assumptions (Binomial), linearization (first order) and estimation type (marginal quasilielihood MQL). These assumptions were later relaxed and the model with a better fit (measured with the log-likelihood function) was presented. When additional variables were added the START function was used to ease model convergence. These variables were added one at the time and removed before adding new ones if not significant.

The carer and the patient DCE questionnaire data were analysed and presented separately, and for each group results are presented in the following order: a) response rate and representativeness of the sample, b) current consultation style, c) ranking exercise, d) pair-wise choices - trading and non-trading choices pattern, e) pair-wise choices - main effect model, and f) pairwise choices: interactions with key variables.

## Results

The DCE questionnaire was administered to all the carers (n = 693) participating in the study and to patients aged 12 years and over (n= 344) with 435 and 230 questionnaires respectively being returned, giving a response rate of 63% and 67% for carers and patients respectively.

### 1: Patients

#### a) Response rate and representativeness

Respondents and non-responders were balanced in terms of age, whereas patients in the intervention arm and with a higher HbA1c level were less likely to return the questionnaire (Table 3). The two versions of the questionnaire were balanced in terms of response rate, so no weighting was applied to the analysis of the data.

**Table 3: comparison of responders and non-responders to DCE questionnaire (patients)**

Item	Responders	Non-responders	p value
Mean (SD) age mean at follow up	13.77 (1.3)	13.70 (1.4)	.64~
Mean (SD) HbA1c at follow up	9.67 (1.8)	10.50 (2.2)	.000~
Gender – number (%):			.66#
Male	107 (63.3)	62 (36.7)	
Female	123 (66.1)	63 (33.9)	
Trial allocation - number (%):			.001#
Control group	132 (73.3)	48 (26.7)	
Intervention group	98 (66.0)	77 (44.0)	
DCE version – number (%):			.32#
A	119 (67.6)	57 (32.4)	
B	111(62.0)	68 (38.0)	

~t-test, #Chi-square test



Five respondents did not answer six or more pairs of choices and were removed from the analysis. Four additional respondents did not answer one of the 15 pair-wise choices and, for these participants, only these choices were eliminated from the analysis. This left 3,386 usable observations.

*b) Current consultation style*

The consultation style experienced by respondents from intervention and control centres was slightly different (Table 4) but none of the items reached statistical significance.

**Table 4: Consultation style experienced at one year follow-up (patients)**

Attributes	Control Number (%)	Intervention Number (%)
Who the doctor talks to~		
• talks mainly with me	20(15.4)	6(6.6)
• talks with both me and my parent	105(80.8)	82(90.1)
• talks mainly with my parent	5(3.8)	3(3.3)
The amount of information I am given#		
• a little bit of information	12(9.2)	9(10)
• some information	61(46.9)	49(54.4)
• a lot of information	57(43.8)	32(35.6)
Who sets the goals on how to look after my child' diabetes~		
• me	2(1.5)	3(3.3)
• the doctor	22(16.9)	23(25.3)
• the doctor and me together	106(81.6)	65(71.4)
Which doctor do I see~		
• a different doctor each time	14(10.8)	10(11)
• the same doctor most of the time	78(60)	62(68.1)
• the same doctor each time	38(29.2)	19(20.9)
In the consultation I have time for#		
• a few of my questions	20(15.5)	16(17.6)
• most of my questions	26(20.1)	27(29.7)
• all my questions	83(63.4)	48(52.7)

~n = 221; # n = 220

*c) Ranking exercise*

Control and intervention group patients ranked the attributes similarly; 'who sets the goals' and 'continuity of care' were the most and least important attributes respectively (Table 5)

**Table 5: Patients' ranking order of attributes (1st = most important)**

Attributes	Control		Intervention	
	N (%)	Rank	N (%)	Rank
Who the doctor talks to	31 (24.2)	4th	28 (30.4)	4th
Amount of information given	46 (36)	2nd	32 (34.4)	2nd
Who sets the goals on how to manage the diabetes	40 (32)	1st	39 (41.9)	1st
Who do you see at the consultation	44 (36.7)	5th	24 (26.1)	5th
Time for your questions	35 (27.3)	3rd	28 (30.1)	3rd

*d) Trading and non-trading choices pattern*

The repetitiveness of the DCE task might deter respondents from reading each set of choices leading to repeatedly making the same choice ('not trading') particularly if one visit option is constant throughout (as in this study). In the patient group, only one respondent chose the constant scenario for all choices suggesting that children can manage this type of questionnaire and 15 sets of choices seem acceptable.

*e) Pair-wise choices – main model and interactions*

All attributes were statistically significant implying that the qualitative work correctly identified the factors which are relevant to patients when presenting for a clinic consultation in paediatric diabetes (Table 6). The betas represent the probability of moving away from the constant scenario and in economic terms it predicts the utility (if accompanied by a positive sign) or disutility (if accompanied by a negative sign) that the attribute bears. For instance in Table 54 the beta value for 'the doctor talks mainly with me' and 'the doctor talks with both me and my parent' are .332 and 1.507 respectively. This indicates that any move away from 'the doctor talks mainly to my parent' is preferred by the patients (i.e. bears higher utility) and that the option 'the doctor talks with both me and my parent' is much more preferred to 'the doctor talks mainly with me'.

The table below gives some evidence that the patient wants the doctor to address both him/her and the carer, that the goals on how to manage diabetes should be jointly set with the doctor and that continuity of care is preferred to seeing a different doctor each time. Finally, amount of information and consultation time are relatively less important, yet still significant with the sign indicating that more information and enough time to get answers to all questions are preferred.

**Table 6: Multilevel Regression of attributes and study variables on choice (patients)**

Attributes	$\beta$	SE	p value
Who the doctor talks to			<.001
• talks mainly with my parent	0	Ref.	
• talks mainly with me	0.332	0.102	
• talks with both me and my parent	1.507	0.103	
The amount of information I am given			<.001
• a little bit of information	0	Ref.	
• some information	0.457	0.104	
• a lot of information	0.888	0.103	
Who sets the goals on how to look after my diabetes			<.001
• the doctor	0	Ref.	
• me	0.083	0.102	
• the doctor and me together	0.931	0.101	
Which doctor do I see			<.001
• a different doctor each time	0	Ref.	
• the same doctor most of the time	1.690	0.112	
• the same doctor each time	1.658	0.112	
In the consultation I have time for			<.01
• a few of my questions	0	Ref.	
• most of my questions	0.136	0.103	
• all my questions	0.337	0.105	
Constant term	-2.791	0.163	
Centre level	0.013	0.044	
Patient level	0.885	0.126	
Observation level	0.958	0.024	
Extra-binomial, 2 <sup>nd</sup> order, PQL; -2loglikelihood = 3245.45; N = 3386			

Using the betas from the table above we can rank the set of scenarios (treatment profiles) and determine the ones that bear the highest predicted utility. This study included 27 scenarios and table 7 lists the 10 treatment options with the highest predicted utility.

It can be seen that if a scenario includes ‘the doctor talks with me and my parent’, ‘the doctor and me together set the goals on how to look after my diabetes’ and ‘I see the same doctor every time’ which are attributes leading to the highest level of utility, the patient sacrifices (trades off) the amount of information and consultation time. In fact a reduction in any of these options can only be compensated by the presence of one or both the other attributes.

**Table 7: 10 scenarios with the highest predicted utility (patients)**

S*	Who the doctor talks to	The amount of information I am given	Who sets the goals on how to look after my diabetes	Which doctor do I see	In the consultation I have time for	Predicted utilities
1	talks with both me and my parent	some information	the doctor and me together	the same doctor each time	most of my questions	4.689
2	talks with both me and my parent	a little bit of information	the doctor and me together	the same doctor most of the time	all my questions	4.465
3	talks mainly with me	a lot of information	the doctor and me together	the same doctor each time	all my questions	4.146
4	talks with both me and my parent	a lot of information	me	the same doctor each time	a few of my questions	4.136
5	talks with both me and my parent	a lot of information	the doctor	the same doctor most of the time	a few of my questions	4.085
6	talks with both me and my parent	some information	me	the same doctor most of the time	most of my questions	3.873
7	talks mainly with my parent	a lot of information	the doctor and me together	the same doctor most of the time	most of my questions	3.645
8	talks with both me and my parent	a little bit of information	the doctor	the same doctor each time	all my questions	3.502
9	talks mainly with me	some information	the doctor and me together	the same doctor most of the time	a few of my questions	3.41
10	talks mainly with me	a lot of information	me	the same doctor most of the time	all my questions	3.33

\*Scenario

The interaction between main attributes and study group was not significant which suggests that the intervention did not generate a shift in patients' preferences. Patient preferences did not show any interaction with gender. There was a significant interaction between attributes and questionnaire version which is expected from creating two orthogonal designs (alias blocks).

## 2: Carers

### a) Response rate and representativeness

As shown in Table 8, there were no differences in terms of patient age and gender but carers of patients with higher HbA1c levels at follow-up were less inclined to respond.

There was also good balance in terms of control and intervention group and version A and B of the questionnaire, the latter implying that no weighting needed to be applied for the analysis.

**Table 8: Comparison of carer responders and non-responders to DCE questionnaire**

Item	Responders	Non-responders	p value
Mean (SD) patient age at follow up	11.6 (2.8)	11.5 (2.8)	.673~
Mean (SD) patient HbA1c at follow up	9.42 (1.6)	9.93 (1.8)	.000~
Patient gender – number (%)			.70#
Male	212 (48.7)	130 (50.4)	
Female	223 (51.3)	128 (49.6)	
Trial arm – number (%):			.157#
Control	219 (50.3)	115 (46.6)	
Intervention	216 (49.7)	143(55.4)	
DCE version – number (%):			.43#
A	213 (49)	135 (52.3)	
B	222 (51)	123 (47.7)	

~t-test, #Chi-square test

Four hundred and nine respondents (94%) answered all choices. Of the remaining 26, 10 did not answer six or more choices and these participants were removed from the sample. Data from those answering three or fewer choices were analysed, eliminating the missing choices. HbA1c concentration at follow up was missing for three children and the values at baseline were imputed. In total 6,356 observations were available for analysis.

*b) Current consultation style*

At one year follow up, both control and intervention group respondents experience similar clinical consultation style (Table 9). Over 80% of both groups reported seeing the same doctor either ‘most of the time’ or ‘always’.

**Table 9: Consultation style experienced by carers at one year follow-up**

Attributes	Control		Intervention	
	Number	(%)	Number	(%)
Who the doctor talks to				
• talks mainly with me	18	(8.2)	19	(8.9)
• talks mainly with my child	176	(80.4%)	163	(76.2)
• talks with both me and my child	25	(11.4)	32	(14.9)
The amount of information I am given				
• a little bit of information	26	(11.9)	27	(12.6)
• some information	102	(46.8)	93	(43.4)
• a lot of information	90	(41.3)	94	(43.9)
Who sets the goals on how to look after my child’ diabetes				
• the doctor	7	(3.3)	4	(1.9)
• my child and I	31	(14.4)	27	(12.7)
• the doctor, my child and I together	177	(82.3)	181	(85.4)
Which doctor do I see				
• a different doctor each time	39	(17.8)	30	(14)
• the same doctor most of the time	118	(53.9)	121	(56.5)
• the same doctor each time	62	(28.3)	63	(29.4)
In the consultation I have time for				
• a few of my questions	22	(10)	13	(6.1)
• most of my questions	35	(16)	40	(18.7)
• all my questions	162	(74)	161	(76.2)

*c) Ranking exercise*

At one year follow up, there was no difference between study groups in ranking of the top two attributes (‘continuity of care’ and ‘who the doctor talks to’ respectively). The order of the remaining attributes was slightly different (Table 10).

**Table 10: Carers’ rank order of attributes (1st = most important)**

Attributes	Control		Intervention	
	N (%)	Rank	N (%)	Rank
Who the doctor talks to	98 (45.8)	5th	87 (41.2)	5th
Amount of information given	68 (31.8)	2nd	60 (28.4)	2nd
Who sets the goals on how to manage the diabetes	60 (28)	3rd	41 (19.4)	4th
Who do you see at the consultation	89 (41.6)	1st	78 (37)	1st
Time for your questions	36 (16.7)	4th	62 (29.3)	3rd

d) *Trading and non-trading choices*

Only three carers (two with version A) chose the constant scenario throughout - evidence that respondents read all questions and were willing to trade between attributes.

e) *Pair-wise choices: main model and interactions*

All attributes were statistically significant with ‘continuity of care’ being the most important attribute relative to the others, followed by ‘who the doctors talks to’ and ‘who sets the goals’ (Table 11). Carers showed a strong preference for their child to be part of the consultation and involved in setting goals on how to look after their diabetes.

**Table 11: Multilevel regression of attributes and study variables on choice made.**

Attributes	$\beta$	SE	p value
Who the doctor talks to			<.001
• talks mainly with me	0	Ref.	
• talks mainly with my child	0.737	0.100	
• talks with both me and my child	1.849	0.084	
The amount of information I am given			<.001
• a little bit of information	0	Ref.	
• some information	0.782	0.088	
• a lot of information	0.862	0.091	
Who sets the goals on how to look after my child’ diabetes			<.001
• the doctor	0	Ref.	
• my child and I	0.434	0.085	
• the doctor, my child and I together	1.608	0.088	
Which doctor do I see			<.001
• a different doctor each time	0	Ref.	
• the same doctor most of the time	2.202	0.099	
• the same doctor each time	2.328	0.103	
In the consultation I have time for			<.001
• a few of my questions	0	Ref.	
• most of my questions	0.684	0.088	
• all my questions	1.050	0.090	
Constant term	-4.415	0.162	
Centre level	0.002	0.036	
Carer level	1.576	0.149	
Observation level	1.047	0.019	
Extra-binomial, 2 <sup>nd</sup> order, PQL; -2loglikelihood = 4440.54; N = 6356			

Table 12 lists the 10 scenarios with the highest expected utility. Carers show a strong preference for their child to be part of the consultation and setting the goals on how to look after the diabetes.

**Table 12: 10 scenarios with the highest predicted utility (carers)**

S*	Who the doctor talks to	The amount of information I am given	Who sets the goals on how to look after my diabetes	Which doctor do I see	In the consultation I have time for	Predicted utilities
1	talks with both me and my child	some information	the doctor, my child and I together	the same doctor each time	most of my questions	7.251
2	talks with both me and my child	a little bit of information	the doctor, my child and I together	the same doctor most of the time	all my questions	6.709
3	talks mainly with my child	a lot of information	the doctor, my child and I together	the same doctor each time	all my questions	6.585
4	talks with both me and my child	some information	my child and I	the same doctor most of the time	most of my questions	5.951
5	talks with both me and my child	a lot of information	my child and I	the same doctor each time	a few of my questions	5.473
6	talks mainly with me	a lot of information	the doctor, my child and I together	the same doctor most of the time	most of my questions	5.356
7	talks mainly with my child	some information	the doctor, my child and I together	the same doctor most of the time	a few of my questions	5.329
8	talks mainly with my child	a lot of information	my child and I	the same doctor each time	all my questions	5.285
9	talks with both me and my child	a little bit of information	the doctor	the same doctor each time	all my questions	5.227
10	talks with both me and my child	a lot of information	the doctor	the same doctor most of the time	a few of my questions	4.913

The interaction between main attributes and study group was not significant. There were no significant interactions between parents' preferences and patients' HbA1c at follow up or with the child's age.

## Discussion

A rigorously developed DCE questionnaire with five categorical attributes of three levels each, modelled both patients' and carers' preferences for the clinic consultation. In terms of



consultation style reportedly experienced, patients in intervention sites report that their doctor addresses both them and their parent more frequently than do patients in control sites. Patients in intervention sites also report that their doctor alone sets goals more frequently than do patients in control sites. The former is consistent with the trial results but the latter is not what would have been expected if trained practitioners are attempting to share decision-making with patients. Neither however, reached statistical significance at the conventional level.

The ranking exercise showed no significant differences between control and intervention groups. However, the ranking differed between patients and carers with patients listing 'who sets the goals' and 'continuity of care' as most and least important respectively while 'continuity of care' and 'who the doctor talks to' were listed by carers as most and least important respectively.

All attributes and levels were statistically significant and both patient and carers wanted the other to be part of the consultation as well as part of the goal setting. Trial allocation was not associated with any difference in either patient or carer preferences.

### **Strengths and weaknesses of the DCE**

A strength of this DCE study is that it was conducted alongside an RCT which enabled assessment of any preference changes produced by the intervention. It also offered an opportunity to investigate the feasibility and acceptability of this type of questionnaire in a young population. The complete data sets supplied by over 90% of responding patients coupled with the fact that only one respondent constantly chose the constant scenario supports the use of DCE questionnaires with this cohort of participants.

The response rate was good for this type of questionnaire. However, both groups were less representative of the cohort at baseline which needs to be accounted for when interpreting the results.

Only a small number of discrete choice experiment surveys have been conducted in the field of diabetes (including 3 with UK participants) (Aristides et al, 2004, Chancellor et al, 2008,

Hauber et al, 2009). One investigated doctors' preferences for a report card (Chen et al, 2010), whereas the others focused on patient preferences for alternative routes of insulin administration (Chancellor et al, 2008), patients' willingness to pay for insulin delivery systems (Aristides et al, 2004, Guimarães et al, 2009a, Guimarães et al, 2009b) and treatment preferences and medication adherence (Hauber et al, 2009). However, none of these studies related to the clinic consultation and none of them was limited to people with type I diabetes or included children.

### **Future work**

The current data set will be used to investigate how other reported psychosocial outcomes relate to DCE choices. It will also explore the feasibility of combining both patient and carer data sets for analysis and the result of using effects coding as opposed to using the dummy coding.

### **Conclusions**

This study presents the first example of using a DCE to explore young patients' and their carers' preferences for clinic consultations in the management of diabetes. The approach was shown to be practical, with piloting vital to ensure feasibility and interpretation of the results.

The results show that both patients and carers prefer the doctor to address both parties and carers prefer their children to be involved in deciding goals on how to manage their diabetes whereas the children want the doctor to be involved in the goal-setting process. This is consistent with the aims of the DEPICTED trial although the DCE did not indentify any trial effects. Future work will carry out sub-group analysis which may produce a clearer picture of respondent preferences and intervention effects.

From a policy perspective the study identified the key attributes of a routine consultation in paediatric diabetes services. However the results might not reflect entirely the preferences of patients with higher concentrations of HbA1c or their carers.

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