

# Preferences for a transition service

All information will be kept strictly confidential.

Dear Participant

We are interested in your views on the best way to organise NHS services for young people with long term health conditions. We want to hear from young people who are or will soon be making the transition from children's health services to adult health services.

You kindly agreed to participate in this study.

In this document, there is:

Section 1 This helps you to think about what the questionnaire will ask about

Section 2 This asks you about your current situation

Section 3 This is an example question

Section 4 This is the questionnaire itself

Please follow carefully the guidance about how to answer the questionnaire. There are no right or wrong answers; we are interested in your opinions. Don't spend too much time answering each question, as your first impression is likely to be the most accurate.

Please ask me if there is something you don't understand or find difficult to answer.

We will only use your answers for research purposes, and we will keep your answers private. No-one from outside the study team will see your answers, and you will not be identifiable when we report the results.

Thank you for taking the time to answer this questionnaire.

Yours sincerely, Jenni Hislop, on behalf of the Transition Collaborative Group

## SECTION ONE

**This section is to help you get used to the ideas we want to ask you about later on**

Below are some aspects of transition that we want you to think about. Please read the descriptions and think about what you would prefer. We are not asking you to answer anything here; this comes later in Sections 2 and 4.

### **Appointment flexibility**

Would you like the service to offer you an appointment:	<b>During office hours only</b>  The service is open from 9am to 5pm during weekdays only.	<b>OR</b>	<b>During and outside office hours</b>  The service is open at various times throughout the week and may be able to offer you an appointment outside the hours of 9am to 5pm during weekdays.
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### **Staff consistency**

Would you like to see the same team of staff regularly?	<b>Yes</b>  You would like to see the same staff members on each of your visits to the service.	<b>OR</b>	<b>No</b>  You don't mind seeing a team that is different from the team you saw at your previous appointment.
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### **A key worker**

Would you like to have a named 'key worker'?	<b>Yes</b>  You would like there to always be one staff member you know who takes responsibility for sorting out any problems regarding your healthcare.	<b>OR</b>	<b>No</b>  You don't mind which staff member(s) take responsibility for sorting out any problems regarding your healthcare – it doesn't need to be done by one specific person.
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### **Communication between staff members**

Is it important to you that staff communicate well with each other to pass on relevant information about your care?	<b>Yes</b>  You would like information about your care to always be passed on to the right people straight away	<b>OR</b>	<b>No</b>  You don't mind if information about your care isn't passed on to the right people straight away.
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### **Parental/carer involvement**

At your appointments, how do you think staff should involve your parents?	<b>Welcomed</b>  You would like staff at the service to welcome your parents' involvement in your treatment.	<b>OR</b>	<b>Discouraged</b>  You would like staff at the service to discourage the involvement of your parents in your treatment as you get older.
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### My autonomy in decisions

<p>When there are decisions to make about your care, what would you like to happen?</p>	<p><b>My treatment is discussed but staff make the decisions</b></p> <p>You would like the staff talk to you about how your care could be managed, but then the staff decide on the best way forward.</p>	<p><b>OR</b></p>	<p><b>I am given choices and I make the decisions</b></p> <p>You would like the staff talk to you about how your care could be managed, but you will decide on the best way forward.</p>
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### Support

<p>Would you like the service to offer extra support to help prepare you for everyday living with your condition in the future (e.g. for financial help, equipment, advice about life changes)?</p>	<p><b>Yes</b></p> <p>You would like to be offered support to help prepare you for the future.</p>	<p><b>OR</b></p>	<p><b>No</b></p> <p>You would not like to be offered extra support to help prepare you for the future.</p>
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## **SECTION TWO: YOUR CURRENT SITUATION**

We would like to know some details about the care that you currently receive. This will help us better understand the choices you make.

*Please tick ONE box for each question.*

### **Question 1**

Do you currently attend a special health service for your condition?

- Yes
- No - I do not attend a special health service for my condition because there is no service available.
- No - I do not attend a special health service for my condition because I choose not to do so.

*If you ticked 'Yes' to Question 1 please move on to Question 2. If you ticked either of the 'No' boxes, please just move on to Section Three on Page 6 now.*

### **Question 2**

When you visit the service, are appointments available outside of office hours (i.e. 9am to 5pm on weekdays)?

- Yes.
- No.

### **Question 3**

When you visit the service, do you usually see the same team of people that you've met before?

- Yes, I usually see the same team of people I've met before on each of my visits to the service.
- No, the team people are usually different.

### **Question 4**

When you attend the service, how do staff involve your parent(s)/carer(s) in your treatment?

- Staff welcome the involvement of my parent(s)/carer(s) in my treatment.
- Staff discourage the involvement of my parent(s)/carer(s) in my treatment.

### **Question 5**

When you talk with staff at the service about your treatment, how are decisions made?

- Staff discuss my treatment with me but make the decisions on my behalf.
- Staff give me with choices about my treatment but expect me to make the decisions.

### **Question 6**

Thinking about support for your condition (e.g. financial support, getting new equipment, advice on coping etc.), is help with this provided by the service you attend?

- Yes, the service provides extra support to help me prepare for everyday living with my condition in the future.
- No, the service does not provide extra support to help me prepare for everyday living with my condition in the future.

### **SECTION THREE: AN EXAMPLE QUESTION**

Here is an example of a question. We want you to imagine that you have the choice to attend either of two transition services for your condition. These services are described in the box below. We want you to choose which service you think would be best for you if you had to choose between those two services and there was no other option available for you. We then want you to think about which situation would be best if you could choose either of the two transition services described, or your current situation in real life.

If you have already moved to the adult service in real life, just imagine you get to do it all again and choose the option that you would prefer.

For each question we ask you to select the **best** for you by putting a **tick** in the appropriate box.

**Figure 15 Example DCE question**

	<b>Care at Service A</b>	<b>Care at Service B</b>	
<b>Appointment flexibility:</b> The service offers appointments:	During and outside of office hours	During office hours only	
<b>Staff consistency</b> The staff I see at the service are:	Usually same staff members that I've met before but I do not have a key worker	Not usually the same staff members I've met before but I do have a key-worker	
<b>Staff communication</b> Information about my care always seems to get passed on to the right person who can help me	Yes	No	
<b>Parental involvement</b> My parents' involvement is:	Welcomed	Discouraged	
<b>My autonomy</b> When it comes to decisions about my care:	My treatment is discussed but staff make the decisions	I am given choices and I make the decisions	
<b>Support:</b> The clinic provides extra support to help me prepare for everyday life with my condition in future	Yes	No	
<b>Which service do you think is better?</b> (please tick <i>one</i> box)	Service A <input checked="" type="checkbox"/>	Service B <input type="checkbox"/>	
<b>Which service would you choose?</b> (please tick <i>one</i> box)	Service A <input checked="" type="checkbox"/>	Service B <input type="checkbox"/>	My current situation <input type="checkbox"/>

In this example, the participant has ticked 'Service A' for both parts of the question. This shows that the participant prefers what happens in Service A to what would be available in Service B, and that the participant prefers what happens in Service A to what would be available in both Service B or the service they currently receive in in their life.

#### **SECTION 4: THE ACTUAL QUESTIONNAIRE**

The questionnaire sets out eight questions with the layout of the example question on the previous page.

The response options varied with each question. The full questionnaire is available on request.

## DCE Report

### A discrete choice experiment of the service preferences of young people with long-term conditions as they transition from paediatric to adult care.

Jenni Hislop, Hannah Merrick, Jeremy Parr, Allan Colver, Luke Vale

#### Introduction

Young people with long-term conditions diagnosed during childhood face the prospect of having their health care transferred, at some point, from paediatric services to adult health services. This process of transfer occurs within a wider ‘purposeful, planned process that addresses the medical, psychosocial, educational, and vocational needs of adolescents and young adults with chronic medical and physical conditions as they move from child-centred to adult-oriented health care systems’ known as ‘transition’.<sup>5</sup> It is known that this period of transition can be difficult for young people, and that this can lead to poorer long-term health, social and educational outcomes.<sup>17, 18, 205, 206</sup> By developing a full understanding of young people’s preferences for services during this time, it may be possible to minimise withdrawal from or reduced uptake of health services during transition, thereby preventing future health risks associated with this. The Transition Research Programme<sup>61</sup> aimed to establish how successful transition can be facilitated in the United Kingdom to improve health and social outcomes. Part of the work involved a longitudinal study of young people at four time points during their transition (baseline and follow-up at one, two and three years respectively). This paper reports one component of this longitudinal study which sought to quantify young people’s preferences for health services using a discrete choice experiment (DCE).

#### Methods

A sample of young people was drawn from the third annual visit (or fourth visit if they did not attend the third visit) of a longitudinal cohort study to identify which features of transitional healthcare are effective and efficient.<sup>61</sup> These young people were aged 14-18 at the time of the baseline visit and had been in receipt of specialist paediatric services at that time point, for one of three conditions; autistic spectrum disorder (with an additional mental health need), cerebral palsy or diabetes. DCEs are well-established methodology in health economics.<sup>207</sup> DCEs describe a service in terms of a number of characteristics, or ‘attributes’ (e.g. the flexibility of appointments, parental involvement). The extent to which an individual values an intervention is expected to depend upon the ‘level’ these attributes take (e.g. can appointments be made outside office hours or not; is parental involvement encouraged or not). In other words, DCEs explore relative preferences for the different ways services can be organised where the services are defined by differing levels of their attributes.<sup>93</sup> The design and conduct of the DCE involved four steps:

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

Attributes and levels of the DCE were informed by a Q-sort<sup>51</sup> From this work, the transition issues that young people had strong opinions about (regardless of their viewpoint) were selected for further consideration as attributes for the DCE and were discussed with ‘United Progression’ (UP) a young people’s group convened specifically for the Transition Research Programme.<sup>208</sup> Other information was drawn from the findings from the literature about important features of transition.<sup>94</sup> Refinements on content and layout of the DCE were undertaken in conjunction with the members of the Transition Research Programme’s Collaborative Group and the UP young people’s group. The chosen attributes and levels are shown in Table 21.

**Table 21: Description of the attributes and levels used in the DCE**

Attribute	Number of levels	Description
Flexibility	2	0 = Does not offer appointments outside of office hours 1 = Offer appointments outside of office hours
Staff at appointments	4	0 = Do not see the same staff at my appointments and do not have a key worker 1 = Do not see the same staff at my appointments but have a keyworker 2 = See the same staff at my appointments but do not have a key worker 3 = See the same staff at my appointments and have a keyworker
Staff communication	2	0 = Yes 1 = No
Parental involvement	2	0 = Discouraged 1 = Welcomed 'if I want it'
Decisions about care	2	0 = Staff discuss my care but make the decisions 1 = Staff give me choices but expect me to make the decisions
Extra support	2	0 = No 1 = Yes

***Step 2: Experimental design***

The number of attributes and levels described in Table 21 gives 128 possible combinations. Therefore, statistical approaches were used to reduce the number of scenarios to be more manageable. N-gene software was used to identify the most statistically efficient number of questions to ask. The resulting d-efficient design contained twenty-four discrete choice questions. The number of questions was further reduced by 'blocking' the design into three groups, so that each respondent in each block was asked to complete eight questions (thereby reducing response burden). Young people were also asked to answer questions about the current care they received in terms of the attributes and levels used in the DCE.

In each choice question respondents were presented with two hypothetical ways the service might be organised. Respondents were asked to consider whether they would prefer either of these two hypothetical options or their own care. Details of the service the respondent was receiving were collected in a separate part of the questionnaire. Figure 16 gives an example of a choice question.



**Figure 16: Illustrative example of a choice question presented in the DCE**

We want you to imagine that you have care of the type at Clinic A or Clinic B.

We then want you to choose which would be best for you between those two imaginary situations and your current situation.

If you have already moved to the adult service in real life, just imagine you get to do it all again and choose the option that you would prefer.

For each question we ask you to select the **best** by putting a **tick** in the appropriate box. Please tick just **one** box for every question. Here is an example question:

	Care at Clinic A	Care at Clinic B	My current care
<b>Appointment flexibility</b> The service offers appointments:	During and outside of office hours	During office hours only	
<b>Staff at my appointments</b> The staff I see at the service are:	Usually same staff members that I've met before but I do not have a key worker	Not usually the same staff members I've met before but I do have a key-worker	
<b>Staff communication</b> Information about my care always seems to get passed on to the right person who can help me	Yes	No	
<b>Parental involvement</b> My parents' involvement is:	Welcomed	Discouraged	
<b>Decisions about my care</b> When it comes to decisions about my care:	My treatment is discussed but staff make the decisions	I am given choices and I make the decisions	
<b>Support</b> The clinic provides extra support to help me prepare for everyday life with my condition	Yes	No	
<b>I would choose</b> (please tick <i>one</i> box)	Clinic A <input checked="" type="checkbox"/>	Clinic B <input type="checkbox"/>	

In this example, the participant has ticked 'Clinic A'. This shows that the participant prefers what happens in Clinic A to what would be available in Clinic B or their current care.

Refinements on content and layout of the questionnaire developed following discussion and feedback with the UP group. Further advice was provided by members of the Transition Research Programme’s Collaborative Group on how best to help facilitate completion by the programme’s longitudinal cohort with autistic spectrum disorder (ASD).

**Step 3: Data collection**

Following completion of the design work for the DCE and receipt of ethics approval the DCE was completed during visit 3 or 4 of the longitudinal study.<sup>61</sup> The paper-based DCE was administered in a face to face setting by researchers, trained to facilitate completion of this particular DCE. To further minimise non-response, a range of additional tools were created to aid completion (Table 22). The final DCE questionnaire therefore contained five parts: the reference guide describing each of the attributes, questions about the service they currently received, the discrete choice experiment questions, the ranking exercise and an office-use only section allowing the researcher to document use of additional tools.

**Table 22: Description of tools developed to aid completion of the DCE**

<b>Additional tool</b>	<b>Description</b>
Attribute ticking	For each attribute, if the respondent was struggling to choose they were permitted to tick, for each attribute within the question, their preferred alternative.
Current practice grid	Paper grid showing respondent’s own levels of ‘current care’ being received. The grid can then be placed alongside the two hypothetical alternatives in each question to readily show how the respondents own care corresponds to each alternative.
Scenario grid	Empty paper grid version of the hypothetical alternatives. The researcher made up the grid using cut-out pieces of paper printed with the levels for each attribute. They could then move the pieces of paper as the respondent progressed from one question to the next, to show that each question was different to the previous one.
Skip to ranking exercise	If the respondent was struggling, the researcher had the option of asking them if they would prefer to skip to the ranking exercise and omit the remaining choice questions.
Tear off reference guide	The first section of the DCE questionnaire described each of the attributes and what they meant. If the respondent was struggling to recall what these meant at any point during the DCE, this reference guide could be torn out of the DCE questionnaire so that the respondent could re-read these definitions without having to turn pages back and forth.
Researcher prompting	If the researcher was concerned that the respondent was struggling, or not considering the options before answering, they could ask the respondent to articulate their thinking behind their choice. This would enable the researcher to either verify that they respondent understood the exercise, or help facilitate completion using any of the other tools if the respondent was struggling.

**Step 4: Data analysis and interpretation**

Data were analysed within a random utility model framework using logistic regression techniques to predict the value that young people placed on the different attributes and levels of the DCE. DCE analysis can provide estimates of the predicted uptake of the service. This can illustrate the relative importance of attributes and their associated level – the more an attribute is preferred by young people, then the higher the predicted uptake.

**Results**

**Response rates and participants characteristics**

Of the 375 participants who commenced the longitudinal study, by the time of the DCE 101 participants had left the study or could not be contacted. Of the remaining 274 participants, 247 had completed at least one DCE question (238 completed it at visit 3 and 9 completed it during visit 4). Of those completing the questionnaire it was fully completed by 223 participants and partially completed by 24 participants. All data collected between September 2014 and December 2016. Demographic details for study participants are provided in Table 23.

**Table 23: Characteristics of participants**

<b>Characteristic</b>	<b>Responders (Partial and complete)</b>	<b>Non-responders (Did not complete any DCE question)</b>	<b>Total</b>
Total sample	247	27	274
Gender: Female	109	8	117
Gender: Male	138	19	157
Mean (SD) age at time of data collection	17.92(1.28)	18.11 (1.53)	17.94 (1.31)
Condition: ASD	71	16	87
Condition: Cerebral palsy	71	4	75
Condition: Diabetes	105	7	112
Block: A	76	13	89
Block: B	90	6	96
Block: C	81	7	88
Block: Missing	0	1	1
Additional tools used: Y	85	12	97
Additional tools used: N	162	7	169
Additional tools used: Missing	0	8	8
Attends specialist service: Y	196	13	209
Attends specialist service: N	50	6	56
Attends specialist service: Missing	1	8	9
Transfer status at time of data collection: Transferred	162	18	180
Transfer status at time of data collection: Not transferred	85	8	93
Transfer status: Missing	0	1	1

In terms of these characteristics there were no statistically significant (0.05 level) differences, except that compared to participants with diabetes, young people with ASD were less likely to be respondents ( $p<0.001$ ). Also when comparing complete and partial responders (data not shown), partial responders were less likely to be attending a service ( $p=0.0032$ ).

With respect to the ranking exercise complete rankings data were available from 259 respondents, including 16 of the 27 who did not complete the DCE, and 243 of those who did. Whilst not formally tested there appeared to a high priority given to 'Decisions about care' whilst 'Extra support' is consistently given a low priority (Table 24). Although not shown in Table 24 those with ASD and those who had not yet transferred, may prioritise flexible clinics compared with those with other long-term conditions. Those with ASD, those with cerebral palsy may give less priority to which staff they see at their appointments compared to those with diabetes. Likewise those with ASD and those with cerebral palsy. Compared to those who had transferred those who had transferred also may give less priority to who they see at their appointment and to staff communication.

**Table 24: Result of ranking exercise**

	Respondents	Median (IQR)	Mean (SD)	Estimated rank based on scores
Flexibility of clinics	260	5 (3)	3.4 (1.7)	4
Staff coordination	260	3 (2)	3.3 (1.6)	3
Staff communication	261	3 (2)	3.1 (1.4)	2
Parental involvement	260	4 (3)	4.0 (1.7)	6
Decisions about care	261	2 (3)	2.6 (1.5)	1
Extra support	259	4 (3)	3.8 (1.7)	5

### ***Results of DCE***

Table 25 reports the result of the DCE analysis. There were 43 respondents who always chose their current care and 60 who never chose it. Those not currently receiving a service were significantly less likely to choose current care ( $p<0.001$ ).

In the analysis the attributes levels are compared to the situation where the attribute is absent. For example, the base level for flexibility of clinics attributes is that clinics are only available during office hours. As this table shows all the attributes including the alternative specific constant, which shows an underlying preference for current care are statistically significant.

**Table 25: Summary results of the discrete choice experiment**

	Coefficient (95% CI)	Standard error of coefficient	Exponential of coefficient	z	p-value
Alternative specific constant for current care option	0.23 (0.10-0.37)	0.07	1.26	3.33	<0.001
Appointments available: during & outside office hours	0.38 (0.33-0.51)	0.07	1.46	5.75	<0.001
Sees same staff: No & keyworker: Yes	0.29 (0.06-0.54)	0.13	1.34	2.33	0.002
Sees same staff: Yes & keyworker: No	0.78 (0.57-0.98)	0.11	2.18	7.39	<0.001
Sees same staff: Yes & keyworker: Yes	0.67 (0.48-0.86)	0.10	1.96	7	<0.001
Staff communication: Good	0.97 (0.84-1.11)	0.07	2.63	13.47	<0.001
Parental involvement welcomed	0.92 (0.78-1.07)	0.08	2.52	12.27	<0.001
Young person given choices and they make the decisions	0.83 (0.70-0.96)	0.07	2.29	12.54	<0.001
Extra support: Available	0.60 (0.48-0.73)	0.06	1.83	9.5	<0.001

The model results reported in Table 25 do not take into account respondent characteristics. Doing this showed that preferring current care itself (ASC) more pronounced amongst men than women and less pronounced among those who had transferred compared with those yet to transfer. Those with ASD compared with those with cerebral palsy had less pronounced preferences for parental involvement and for being the ones to make decisions about their treatment. Appointment flexibility was the only attribute no longer statistically significant once demographics were taken into consideration, but men had a significantly more pronounced preference for out-of-hours clinics than women, and less pronounced preference for making decisions about treatment.

Table 26 shows that in a service where none of the attributes were present the uptake of the service would be 78% (95% CI: 75% to 81%). This is as would be expected given the chronic nature of the young people's conditions. So as an example, adding a new service with flexible appointments would result in predicted uptake by young people of 81% (95% CI: 78% to 84%).

**Table 26: Predicted probabilities of uptake of services as attributes are added**

Attribute	Probability of uptake	Lower 95% CI	Upper 95% CI
Current service (none of the attributes)	0.78	0.75	0.81
New service with flexible appointments	0.81	0.78	0.84
New service with a keyworker	0.79	0.74	0.85
New service seeing the same staff at each appointment	0.90	0.85	0.94
New service seeing the same staff and having a keyworker	0.88	0.84	0.92
New service with good staff communication	0.93	0.91	0.95
New service with parental involvement	0.93	0.90	0.95
New service offering young people decisions about treatment	0.91	0.88	0.93
New service offering extra support to young people for their future	0.86	0.83	0.89

### **Comparison of Ranking and DCE results**

Using the results of the DCE it is possible to indicate the relative importance respondents gave to each attribute (Table 27). The initial model showed that staff communication was on the most important attribute and use of a keyworker the least. However once we controlled for demographic characteristics and condition, decisions about care was the attribute shown to be most important to young people and clinic flexibility was least important. A direct comparison with the ranking exercise was only possible when the attribute around which staff the young person saw at an appointment (which has 4 levels – see Table 27) was collapsed into a 2 level.

**Table 27: The relative importance respondents gave to each attribute**

Attribute	Initial model	With interactions	Initial model	With interactions	Ranking exercise
Flexibility of clinics	7	8	6	6	4
Keyworker only	8	7	5*	5*	3
Same staff only	4	4			
Both same staff and keyworker	5	6			
Staff communication	1	3	1	3	2
Parental involvement	2	2	2	2	6
Decisions about care	3	1	3	1	1
Extra support	6	5	4	4	5

\*staff attribute averaged to compare with ranking exercise

When comparing the DCE results and the ranking exercise it is clear that young people have consistent and well-formed preferences around how much they value making decisions about their care and staff having good communication with each other. This is consistent with the model findings, once we have accounted for demographics. However, the most striking differences between the DCE and ranking are that young people may consciously underestimate the importance they place on parental involvement in their care, and over-estimate the value of having clinics with flexible hours.

### **Discussion**

The purpose of the DCE was to explore the importance that young people with complex health needs place on different ways their care can be organised. It was anticipated at the outset that some of the young people may struggle with this completing the DCE because it is considered demanding and it does require that respondents choose between different hypothetical ways a service can be organised. It was for this reason a number of aids to help the young people complete the task were devised and that a simpler ranking of the attributes and levels was also used.

Of those young people who had not withdrawn from the longitudinal study (n=274) over 90% were able to complete at least one DCE question. Those participants with ASD were more likely to be non-responders to the DCE but a significant proportion of those with ASD were able to complete the DCE and ranking exercise.

The results of the DCE suggest that the features of care a priori considered potentially important to young people were found to be valued with the exception of flexibility of appointments. As might be expected preference for the way care was currently provided was strong and this preference was more pronounced amongst young men than young women. It was also stronger for those who had not transferred.

Most young people (and especially women) least valued being able to have appointments outside of office hours. Clinics that welcomed parental involvement were highly valued by the young people, but this appeared more important in the DCE results than the ranking exercise. This may indicate that young people might underestimate how important this involvement is to them and the DCE by presenting a more complex set of choices allows this to be teased out. The young people also placed a high value on clinics in which: information is passed on to the right person. Young people also valued when staff give them choices and allowed them to make decisions about their care; and that those staff provide extra support to help young people prepare for everyday life with their condition in future. Notably, young people valued seeing the same staff at each clinic appointment more than having a keyworker.

### ***Strengths and limitations***

A major strength of the DCE was that it was embedded within a rigorous longitudinal study. Within this study extensive and exhaustive efforts were made to recruit, engage and retain a large cohort of young people throughout a period of major change in their lives. Whilst potentially framing the responses, the various aids to completing the DCE were arrived at using the study team's considerable experience of working with these groups and following advice and piloting with the young people themselves. The aids to completion of the DCE might have infringed strict DCE methodology but they enabled young people, with a wide range of confidence, intellectual ability and flexibility of thinking, to complete it. Indeed the use of aids has been advocated.<sup>97-99</sup>

The results of the DCE suggest that the condition itself was not of central importance in preferences, this is not to say that the condition the young person had did not have an effect. The number of withdrawals and dropouts from the longitudinal study limited the ability to detect differences in preferences when they existed. A DCE can be demanding to complete. Whilst most young people were able to respond, proportionately fewer with ASD responded.

It is possible that these young people may have different preferences to those that did complete the DCE. Furthermore, it is possible that the DCE failed to accurately capture the preferences of those young people who did complete the DCE. For this latter issue some reassurance was provided by the broad similarities between the DCE findings and the ranking exercise. The advantage of the DCE over the ranking exercise was that the DCE provided an indication of the relative importance of each attribute.

As a methodological approach DCEs are widely accepted and are a tool preferred by many organisations. For example, they form the basis of eliciting EQ-5D-5L population tariffs throughout the world<sup>95</sup> and Center for Devices and Radiological Health, part of the Federal Food and Drug Administration have stated that DCEs are a suitable method for eliciting patient preferences.<sup>96</sup>

The approach adopted is consistent with best practice with respect to design and conduct of the DCE. With respect to analysis, a fixed-effects modelling assumed respondents were consistent in their choices over time. Whilst the approaches adopted are not incorrect, more sophisticated econometric modelling approaches could be used to explore heterogeneity and whether participants considered only a subset of attributes when choosing among alternatives. This might help explain why an appreciable proportion of respondents always chose current care. Further interrogation of the data set might help but there is a limit to how complex an analysis can be within the confines of the sample size.

### **Conclusions**

These findings from the DCE may help those tasked with designing services in deciding how services might be redesigned. The study has shown that all the different aspects of organising a service are wanted, except flexibility in clinic appointments. Most young people prefer clinics where staff give them choices and allow them make decisions about their care. They also place a high value on clinics where staff communication is good and information about them always seems to get passed on to the right person. Young people may also underestimate how much they would like clinics that welcome parental involvement. Young people generally liked their current care although this was less marked for those who had made the transfer to adult services.