

# **Opinions On And Attitudes Towards Genetic Screening**

**A: Pre-natal Screening for Cystic Fibrosis**

Young People's Understanding  
Of, And Attitude To, 'The New  
Genetics'  
Working Paper 5



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## Working Paper 5: Students' opinions about, and attitudes towards, genetic screening A: Prenatal screening for cystic fibrosis

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### Abstract

In this paper, we report findings on students' opinions about prenatal screening for cystic fibrosis and the attitudes that might underpin these opinions, as elicited through group discussions following the presentation of stimulus material. The rationale, design and methodology of this approach to probing attitudes and opinions is presented. Many students in the 15-16 age range seemed able to form justified opinions about prenatal screening. In cases where the opinions formed by students were not justified, the limiting factor on performance tended to be in terms of the students' argument skills rather than their genetics knowledge. The implications of these findings for teaching about areas of genetics with a strong attitudinal component are discussed, as are links between school genetics teaching and the broader concept of 'genetic literacy'.

## 1 Introduction

This probe was designed to investigate the opinions that students form about prenatal screening for cystic fibrosis (CF). Students were presented with information about a number of issues that surround screening of embryos for CF status, as well as issues that surround the screening of individuals for CF carrier status. They were then asked to decide whether particular individuals who had both been identified as CF carriers should proceed with prenatal screening of their unborn child. The probe was administered as a group discussion activity following video and audio presentation of information about CF and the issues that surround screening. Our reasons for using this approach to data collection, as opposed to the use of decontextualised fixed response items (as used by Lock and Miles, 1993), is discussed in Appendix 1.

Screening for genetic diseases appears in a number of other probes used in this project, notably *The Telephone Tale* (screening for Huntington Disease). This is reported elsewhere.

Cystic fibrosis is an autosomal, recessively inherited disorder. This means that the condition will only occur in people who have inherited two copies of the CF allele - that is, one copy from each parent. A person with only 1 copy of the CF allele will be unaffected themselves, although they are able to pass the CF allele to their offspring. Such people are referred to as 'carriers' of CF. Individuals who carry two copies of the CF allele will experience

symptoms from birth, which include the excessive production of sticky mucus in the lungs and digestive problems. In order to alleviate breathing difficulties which result from this mucus in the lungs, individuals with CF have to undergo strenuous daily physiotherapy to clear the lungs. In addition, there is a high risk of lung infections. Digestive symptoms involve an inability to digest food normally. Enzymes and other drugs therefore have to be taken with each meal. Individuals with CF typically experience exhaustion and breathlessness from minimal activity. The life expectancy of individuals with CF is reduced (20 - 40 years), mainly due to strain on the heart and circulatory system.

There has been considerable research into the development of gene therapy for the treatment of cystic fibrosis. In theory, if functional alleles can be inserted into the epithelial cells lining the lungs then these cells should function normally, relieving symptoms. In practice, although it is possible to introduce functional alleles into the lungs, their effectiveness is very limited and short term. In addition, somatic gene therapy targeted at the lungs will have no effect on the digestive system. The development of effective gene therapy for cystic fibrosis is still very much at the experimental stage.

Screening for CF carrier status of individuals is carried out using cheek epithelial cells, collected from a mouthwash. About 90% of occurrences of affected alleles can be identified. In practice, this means that a negative result for CF carrier status still involves a 10% risk of the individual being a carrier. Positive results for carrier status are highly reliable, however. Prenatal screening for embryos with CF (or carrying the CF form of the gene) is carried out by amniocentesis. The same principles of reliability of the test apply as for the screening of individuals.

The ethical issues that surround prenatal screening vary for different genetic conditions. CF, for example, affects individuals from birth, having a major affect on the sufferer's quality of life and decreasing life expectancy. With modern treatments, however, individuals can enjoy a relatively good quality of life and there is a possibility of further improvements in gene therapy. The symptoms of Huntington disease, by contrast, typically start to affect sufferers during middle age, and involve a major deterioration in quality of life and life expectancy. The possibilities for treatment are more limited than for CF. The condition of club foot (*Talipes equinovarus*) is inherited, but is not terminal. Treatment of club foot involves a series of operations. Should prenatal screening be offered for all these conditions? If so, should the possibility of abortion be offered, or should screening merely be treated as a way of providing parents with information about their child to allow for preparation for the condition? [The present situation is that prenatal screening tends to be offered in cases where there is reason to suspect that both parents are carriers of CF. Prenatal screening does not tend to be offered for the other conditions.]

## 2 Design, methodology and administration of the probe

Part of the rationale of this project was to investigate the ways in which young people at the end of their compulsory science education interact with information about 'the new genetics' and identify, evaluate and form opinions on issues that arise (see Working Paper 1). In recent years, arguments have been put forward for teaching science as part of the compulsory curriculum for all young people in order to promote 'scientific literacy' or 'the public understanding of science' (e.g. AAAS, 1989; Office for Science and Technology, 1993; The European Commission, 1995). Three main reasons tend to be put forward for promoting the 'scientific literacy' of all students, including those who will not study science beyond the age of compulsory schooling:

- the *utilitarian* case: knowledge from school science will be practically useful in personal or professional contexts in later life;
- the *democratic* case: in order to participate in democratic decision-making on issues with science content, a minimum level of scientific understanding is required; and
- the *cultural* case: science is a major cultural product and should therefore be studied as part of a general education.

Suggestions that knowledge learnt during school science is likely to be directly useful in later life for utilitarian and democratic purposes seem unhelpfully naive. For example, it is highly unlikely that the school science curriculum will cover in depth all the scientific fields likely to be encountered by all future citizens in their personal and professional lives. (For further discussion of the problematic nature of scientific literacy see Leach, 1996).

In designing this study, we adopted a cautious position about possible links between the content of compulsory science education and adult 'scientific literacy'. Adults making decisions about issues such as personal and prenatal screening for CF will be influenced by a range of factors, most of which are likely to have little or nothing to do with school science. However, it is likely that at some point such adults would be presented with information about the genetic basis of CF, existing and possible future treatments, the implications of the condition for future lifestyle and so on. We do not think it unreasonable to assume that knowledge from school science education might be drawn upon, along with other knowledge, in this situation. This probe was therefore designed to investigate the ways in which students at the end of their compulsory science education interpret information about the genetic basis of the inheritance CF, its screening and treatment, in order to identify, evaluate and form opinions on issues that emerge.

## 2.1 Design of the probe

Firstly, students were shown a video which was designed to present background information about CF. Particular issues about CF were included in the video if they had a bearing on issues that relate to prenatal testing for the condition. Table 1 shows points highlighted in the video. The script of the video can be found in Appendix 2.

**Table 1: Substantive Features Of CF Highlighted In Video**

A	Differentiation of genetic and pathogenic illness.
B	Recognition of CF as a genetic disease with onset from birth; no cure currently available.
C	Symptoms of CF related to lungs and digestive system. Susceptibility to infection, breathing and digestive problems.
D	Daily treatment required.
E	Genetic basis of inheritance of CF. Probabilities of inheritance according to genotypes of parents.
F	Notion of chance in inheritance.
G	Possibility of gene therapy for lung-related symptoms, but not digestive symptoms.
H	Screening for carrier status using cheek cells collected from a mouthwash.
I	Prenatal screening of embryos carried out by amniocentesis.
J	Reliability of results of prenatal screening discussed. Small risks of miscarriage due to prenatal screening discussed.

Students' understanding of the content of the video was then probed through a cardsort activity. Groups of students were presented with 6 statements about CF on cards. They were instructed to sort the cards into three groups: those statements that they agreed with, those that they disagreed with, and those that they were not sure about. An interviewer then discussed their reasoning with the group, correcting misunderstandings where necessary. The statements used can be found in Table 2. Table 3 shows how the statements used to probe understanding of the video relate to the specific points about CF listed in Table 1.

Students were then played an audiotape in which a couple discuss the possibility of accepting prenatal screening for their unborn child. The context of the story is that the couple have just arrived home from a meeting with a genetic counsellor: they have to reach a decision about whether to accept the offer of screening within a week. The couple had themselves been identified as carriers of CF, after conceiving a child. They raise a number of issues that might influence their decision, some of which relate to the future of the child, others of which relate to the process of prenatal screening itself. Table 4 shows the issues raised in the audioscript (and those also mentioned in the video). The audioscript can be found in Appendix 3.

**Table 2: Statements About CF Used On Card Sort Activity**

1	"I think that the person giving physiotherapy to the CF sufferer on the video ought to have been wearing a mask..."
2	"We already have a CF child, so our next baby is certain to be all right..."
3	"I've just found out I'm a CF carrier. But there's still a chance of having normal babies..."
4	"I'd like to go for a test to see if I'm a CF carrier, but they have to put a needle in you..."
5	"Because we're both carriers there's still a 1 in 4 chance that our next baby will have CF, even though our other two children are fine..."
6	"Won't it be wonderful when one nasal spray will cure my CF, and I won't have to have all this treatment..."

**Table 3: Mapping Of Statements About CF Onto Substantive Points Raised In The Video**

<i>Substantive features of CF (from Table 1)</i>	A	B	C	D	E	F	G	H	I	J
<i>Statement about CF where understanding is probed (from Table 2)</i>	1	6	6	6	5	2,3,5 (positive and negative phrasing)				Not raised here. Dealt with in audiscript

**Table 4: Issues About Prenatal Screening Raised In The Audioscript And Videoscript**

<i>Issues raised</i>	<i>Place raised</i>
CF sufferers experience symptoms all their lives, and have reduced life expectancy. CF affects quality of life.	Video
Individual screening can lead to complex decisions about future reproduction.	Video
Prenatal screening may give indications about the future carrier status of the unborn child	Audio
Prenatal screening may give indications about the future CF status of the unborn child	Audio
Prenatal screening may raise the issue of abortion	Audio
Prenatal screening may raise the issue of feelings of guilt about future outcomes	Audio
Prenatal screening may raise the issue of family values and pressure	Audio
Prenatal screening may raise the issue of the future quality of life of CF sufferers	Audio
Prenatal screening may raise the issue of future advances in treatment of CF	Audio
Prenatal screening is only 90% accurate for negative results	Video Audio
Prenatal screening is uncomfortable for the mother	Audio
There is a very small risk of miscarriage associated with prenatal screening	Audio

Groups of students were then presented with an A3 sheet, on which Sue and Dave had placed headings relating to advantages and disadvantages of having, or not having, prenatal screening. In addition, they had listed advantages and disadvantages of the possible outcomes of the test. This sheet can be found in Appendix 4. The first activity presented to students was to fill in the advantages and disadvantages of having, or not having the test that they could identify. After completing this activity, their reasoning was probed by an interviewer. Potential advantages and disadvantages not raised by students were introduced for discussion by the interviewer, and if students felt these to be relevant they were written onto the sheet in a different colour. The group were then presented with a question written on a piece of card for discussion:

'What do you think Sue and Dave should do?' - This may differ from what you personally would do.'

The purpose of this question was to get students to evaluate the various issues raised as advantages and disadvantages of prenatal testing. It was recognised, however, that the relative importance of such issues is very context-dependent, and that students' views about what Sue and Dave should do in their particular situation might differ significantly from what individual students might do themselves in the future.

The interviewer withdrew from the group while this discussion was in progress, returning to the group when they had finished. Initially, interviewers asked the group what they thought Sue and Dave should do, ensuring that each individual viewpoint was raised. If particular outcomes of testing were not raised, interviewers then introduced these into the discussion. Finally, groups were asked whether they thought that such tests ought to be available, and who ought to make the decision about whether testing should be carried out.

The probe was piloted a number of times during its design, to maximise the effective use of the video and audiotape in engaging students' interest and promoting their understanding, and also to maximise the validity of the data collection activities in the probe.

## 2.2 Sampling

The sample for this probe involved three whole classes in three different schools. Each class had also completed the *Knowledge and Understanding Pack*. Although it is not possible to claim that this small sample is statistically representative of the sample as a whole, the classes were selected to maximise representativeness in that they were selected from three different schools and spanned the ability range and age span of the sample. It was not, however, possible to carry out this probe with a lower ability group. A characterisation of the sample can be found in Table 5:

**Table 5: Characterisation Of Sample For The Prenatal Screening Probe**

<i>School</i>	<i>Characteristics of whole class</i>	<i>Group no.</i>	<i>Gender composition of small groups</i>
<i>A</i>	<i>Middle ability range Year 10 (age 14-15)</i>	1	3 Male
		2	3 Female
		3	4 F
		4	3 M
		5	4 F
		6	3 F
<i>B</i>	<i>Middle ability range Year 11 (age 15-16)</i>	1	3 F
		2	4 M
		3	3 M
		4	4 F
		5	3 F, 1 M
		6	4 F
		7	3 M
<i>C</i>	<i>Upper ability range Year 11 (age 15-16)</i>	1	3 F, 1 M
		2	Data not recorded
		3	3 M, 1 F
		4	3 M, 2 F
		5	Data not recorded
		6	3 M, 1 F

### 2.3 Administration of the probe

The probe was administered to whole classes of students, arranged into smaller groups of 3 or 4. Students selected which of their peers they worked with in small groups. Each small group was assigned an interviewer. All interviewers, including members of the project team, attended a training session prior to data collection.

Initially, one member of the project team introduced the activity to the whole class, and the video was shown. Then, individual interviewers introduced themselves to their small groups and asked whether any members of the group had heard of CF before, or knew anyone who suffered from CF. The purpose of this was to allow interviewers to identify any students who might find the activity disturbing for personal reasons at an early stage (though as it happened no students had close personal contact with CF sufferers). The interviewer then introduced the cardsort activity to the small group, and withdrew to allow them to complete it. Interviewers did observe the group's progress at all times, however, and listened for specific points that they might want to return to later. Once the groups had finished the cardsort activity interviewers returned and discussed their decisions and justifications, correcting any misunderstandings as necessary.

The audiotape was then introduced to the whole class by one researcher, and played. The activity was introduced to the whole group by one researcher

(see Appendix 3 postscript), and individual interviewers then explained *Sue and Dave's Summary Sheet* to the group, reading through the material and showing how it was organised on the sheet. The task about identifying advantages and disadvantages of particular courses of action was then introduced to the group, and the interviewer withdrew. Once the group had finished the activity, the interviewer returned and discussed their responses as previously described. Finally, the activity where groups have to decide what Sue and Dave should do was introduced. Interviewers withdrew from the group while this was carried out, returning to discuss the groups' responses and to ask some more general questions as previously described.

## 2.4 Analysis

The data sample for the probe comprised the transcribed audiotapes of group discussions and group interviews, and the A3 sheets written on by groups. The general principle of analysis was to identify how groups drew upon the information that had been presented to them in the video and audiotapes, as well as other possible sources of information, in identifying issues about prenatal screening for CF and forming attitudes about those issues.

Coding schemes were generated by an iterative process of reading through transcripts and A3 sheets and identifying common features in groups' responses. In addition, the coding scheme identified the use of specific points about issues surrounding prenatal screening for CF from the audiotape and video [see table 4]. These coding schemes were used to characterise the range of points voiced in each discussion group.

A slightly different procedure was used for the analysis of students' discussions of whether Sue and Dave proceed with prenatal screening. In the first instance, data were treated as described in the previous paragraph: transcripts were examined and points where students were stating a viewpoint were underlined. A coding scheme was then written to allow each of these points to be categorised. This scheme was checked against the data, and new coding categories were added where necessary. Although this approach to coding allowed for a characterisation of points of argument raised in the data, it did not allow us to characterise the arguments and priorities raised within particular groups. Summaries were therefore written of each group discussion, highlighting areas of consensus and disagreement, as well as points about the nature of discourse within the group. These summaries were then used to make general points about lines of argument within various groups.

In all cases, coding was carried out at the group level. This was for two reasons. Firstly, it was often not possible from the transcripts to identify which individual was speaking. In addition, it was not possible to attribute general group positions to particular individuals. In many groups, different individuals had different viewpoints about particular issues. This has been dealt with in coding by attributing a code to every viewpoint articulated in discussion. In some cases, individuals raised points which they themselves quickly refuted. Codes were not allocated to such points if no member of the group appeared to agree with them.

### 3 Results

The results of analysis are reported in three sections. The first of these addresses students' understanding of the material about CF presented to them in the video. Then, students' identification of advantages and disadvantages of prenatal screening for CF are reported. Finally, students' positions on whether the couple should go ahead with prenatal screening or not are presented.

#### 3.1 Understanding of background science as presented in the video

Audio data for 18 groups out of 19 were available for analysis. Overall, students' understanding of the background information about CF presented on the video was very good. Although it was not uncommon for individuals to voice incorrect statements about CF in group discussion, these were usually corrected by other group members, the corrected responses being accepted willingly<sup>1</sup>:

*S1 (...) I'd like to go for a test to see if I'm a CF carrier but they have to put a needle in you?*

*S2 Yeah that's true*

*S3 I think that's true..*

*S1 Yeah.. Well it said, they said in some you could get it from your cheeks?*

*S2 It's false, yeah.*

*S3 Its false. From your cheeks, no, it's a mouthwash.*

*School A Group 5 lines 14-19*

A coding scheme for this part of the probe, together with coding decisions, can be found in Appendix 5. The following sections briefly summarise students' understanding, and identify problematic areas that had to be corrected by interviewers.

##### 3.1.1 Differentiation of genetic and pathogenic disease

This was understood by all groups.

##### 3.1.2 Recognition that CF is a genetic disease affecting sufferers from birth to death; Recognition that there is no cure, and that daily treatment is therefore required.

This area was generally well understood. Most groups recognised that CF affects from birth to death, though 2 groups appeared to think that gene therapy would result in a permanent cure. The students were willing to accept interviewers' corrections on this issue, however.

<sup>1</sup> See note on format of transcript at the end of this report

3.1.3 *Recognition that the symptoms of CF affect both the lungs and digestive systems, and that gene therapy currently treats the lung symptoms only*

Again, this issue was well understood and although only 8 groups explicitly differentiated lung and digestive symptoms in discussion, others willingly accepted further information from interviewers. Only 2 groups assumed that gene therapy would result in permanent changes.

3.1.4 *Recognition of the notion of chance in inheritance, and that 2 carriers are required to produce a child with CF*

In designing the probe, this area was anticipated to be the most problematic for students to understand. In practice, all groups correctly understood the role of chance in inheritance. However, there were some interesting discussions between individuals within groups, as they worked towards reaching a consensus:

S *Because we're both carriers there's still a 1 in 4 chance that our next baby will have CF even though our other 2 children are fine.*

S *I agree*

S *No, cos they reckon that their other two children are fine but like if they've had two children there's like quite a big chance they could be carriers.*

S *Yeah, but that's sort of like mathematically correct. Cos it sort of resets every time. Yeah, it resets every time then chance.*

*School C Group 2*

In this case, although one student recognises that probabilities in reproduction are independent for each child, the other student seems to be arguing that the CF status of existing children may influence the probability of conceiving individuals with particular genotypes in the future.

Many individuals showed that they had understood and correctly remembered the complex information about probabilities of inheritance from the video.

3.1.5 *Differentiation of the methods of screening of individuals for carrier status and prenatal screening*

15 groups understood this issue. When interviewers explained the distinction between individual and prenatal screening to the remaining 3 groups, it was readily accepted that cheek cells are used to test carrier status and that needles are not therefore required.

3.1.6 *Recognition that negative results from prenatal screening are not completely accurate*

This issue was not raised at this stage in the probe.

### 3.2 Identification of issues as advantages and disadvantages of prenatal screening

In this activity, students were asked to note down on a prepared sheet of A3 paper the advantages and disadvantages for Sue and Dave of deciding to go ahead with prenatal screening, or deciding not to go ahead (see Appendix 4). In practice, students could identify an issue as an advantage or disadvantage of prenatal screening, or as an advantage or disadvantage of not going ahead with prenatal screening. In addition, students were invited to add additional points to Sue and Dave's list of issues that arise from various possible outcomes of testing. In practice, students did not tend to add to this list, however.

Data from all 19 groups were available for analysis.

In the previous activity, students were required to draw upon scientific knowledge presented in a video to evaluate the scientific accuracy of various statements. In this activity, by contrast, students were drawing upon information about issues surrounding prenatal screening to decide their implications in a variety of possible scenarios. Group discussions were predictably varied. Some groups identified a range of issues and thought through their implications in a variety of scenarios, considering both positive and negative aspects. Links between issues were also articulated. Other groups, however, raised a very limited number of issues, suggesting that each one was either an 'advantage' or 'disadvantage'. The possibility of issues having positive and negative aspects was not drawn upon by such groups. The characteristics of group discussions are discussed in more detail later in this section.

Information about the coding scheme used, and coding decisions, can be found in Appendix 6. Students identified issues that arise from outcomes of prenatal screening, as well as issues associated with the accuracy and risks of the test itself.

#### 3.2.1 *The future CF carrier status of the baby*

This issue was mentioned by 3 groups, the argument being that knowing the CF status of a baby before birth would be an advantage. The three groups did not, however, say in what respects this might be an advantage, or compare prenatal testing with testing for carrier status after birth.

#### 3.2.2 *The future CF status of the baby*

This issue was mentioned in one form or another by all the groups. Typically, groups argued that if parents had information about the CF status of the baby they would know what to prepare for, and that the possibility of abortion could be considered. A similar argument was also phrased in the negative as a *disadvantage* of *not* having prenatal screening.

Most groups talked about preparation for a child with CF in the abstract, or referring to isolated factors such as learning how to carry out the

physiotherapy that the child would need. By contrast, a small number of groups gave the issue of preparation considerable thought at various points in their discussions, addressing psychological preparation of themselves as parents, and other family members:

*I Do you think it would every be less worrying not to know?*

*S I think it would be more worrying.*

*(...)*

*S At least if you know then you can prepare for it but if you don't know you'd still be worrying wouldn't you?*

*(...)*

*S You'll have a better chance or be certain about the baby...*

*(...)*

*S You can prepare for it, tell your friends and family, they're going to need to know.*

*S The baby has CF, you can decide whether to go ahead and have the baby or not.*

*School A Group 3*

A number of groups addressed the question of whether having prenatal screening would affect the amount of worry experienced during the pregnancy by the mother. Some groups suggested that a negative result for CF would do this, whereas other groups recognised that there was still risk of having a CF sufferer or carrier following a negative test result.

*S The test could still leave them wondering whether they should have it or not?*

*S Yeah, the test it's not 100% certain*

*School B Group 1 Lines 45-46*

The issue of financial planning for a CF child was also raised by one group. Other matters raised included the ability of prenatal screening to reduce the shock of having a baby with CF at birth, the stress of the testing process on Sue and Dave's relationship and the idea that 'ignorance is bliss' - it is less stressful to deal with situations as they arise, than to plan for them in advance.

### *3.2.3 The possibility of abortion*

This issue was raised by all but one group, often provoking fairly intense discussion evaluating the pros and cons of abortion. These discussions are reported alongside students' decisions about whether Sue and Dave should go ahead with prenatal screening. Many groups suggested that being able to consider the possibility of abortion was an advantage of going ahead with prenatal screening. A small number of groups suggested that the possibility of abortion was a disadvantage of prenatal screening, as the test results may result in Sue and Dave having to make a further decision. No groups suggested that there was a possibility of aborting a foetus without CF,

suggesting that students had understood the certainty of positive results of prenatal screening compared with the errors associated with negative results.

#### 3.2.4 *Feelings of guilt associated with prenatal screening*

7 groups explicitly mentioned feelings of guilt in their discussion, and a further 2 groups raised this issue following intervention by the interviewer. Typically, groups mentioned guilt as being associated with considering abortion as a possibility. Some students also suggested that couples may feel guilty if they had a child with CF and had not had the test, though these students did not state explicitly that they would definitely consider abortion following a positive result for CF. One group stated explicitly that guilt could potentially be associated with any course of action relating to prenatal screening:

*S (...) If you did have a test and baby was normal but it miscarried you'd feel guilty there. If you didn't have the test and the baby was a CF carrier then you'd feel guilty there. So really in all possible outcomes you'd feel guilty.*

*School B Group 1 Line 20.4*

#### 3.2.5 *Family pressure*

Although this issue was discussed by Sue and Dave at some length in the audiotape, it was hardly mentioned by groups at this stage.

#### 3.2.6 *Future quality of life of CF sufferers*

This issue was only raised explicitly by 2 groups at this stage, in the context of discussions about abortion. A variety of perspectives on the seriousness of the effect of CF on quality of life, and how this might influence decisions about prenatal screening, can be seen in the following extracts:

*S It's like that kid would grow up, if like, you know, if like my Mum if I had Cystic fibrosis right and my Mum and Dad had me, everything would be different cos like all my mates would be like that lass on the video (...)*

*S They still have a life, don't they?*

*S Yeah, its not like erm its about I mean its bad but its not like some illnesses where they can't feed their selves or do stuff for themselves (...) I don't think they should abort it*

*School 1 Group 3 Lines 60-65*

In this case, the students agreed that the effect of CF on quality of life was not so severe as to merit consideration of abortion. By contrast, one member of the group in the next extract argued that he personally would have preferred to have been aborted rather than to suffer the symptoms of CF:

*S I wouldn't want to have it. If I did have it I would rather be terminated.*

*S 24 hours per day - its only 2 1/2 hours that you've got to do, something like that.*

*School 3 Group 3*

*3.2.7 Future advances in treatment*

4 groups mentioned explicitly that possible advances in the treatment of CF in the future might influence Sue and Dave's decision to keep a child with CF, and that this might have implications about whether they would go ahead with prenatal screening. A further group made a similar case following prompting from an interviewer.

*3.2.8 The reliability of the test itself*

Most groups raised the possibility of false negative results for CF that might be generated from prenatal screening (12 groups without prompting, a further 6 groups after prompting). This was normally raised in connection with worry that might be experienced during the pregnancy, and the limited ability of prenatal screening to reduce this. Some groups, however, recognised that although there is a 10% risk of a negative result being inaccurate, the test result nonetheless means that Sue and Dave can be more confident that the baby will not have CF than had they not had the test:

*S It puts limitations to the worries cos it cuts the percentage chance of it being say (...) From 75% to 10%.*

*S (...) It eliminates some of the uncertainty*

*School C Group 3*

Although the mathematics of probability have been simplified by these students, they are nonetheless clear that a negative test result reduces the probability of the baby having CF.

Only one group overtly misunderstood the asymmetry in the accuracy of positive and negative test results. This was easily corrected by the interviewer.

*3.2.9 The discomfort of testing experienced by the mother*

Although this issue was touched upon by 12 groups, viewpoints were not elaborated and there is no evidence that this was seen as a major disadvantage to prenatal screening.

*3.2.10 The risk of miscarriage associated with testing*

This issue was touched upon by all groups. Students' comments suggested, however, that the risk was judged to be very small and that this was not therefore a major disadvantage of prenatal screening.

### 3.3 Decisions reached about whether the couple should proceed with prenatal screening

In this part of the probe, students were asked to evaluate the various advantages and disadvantages of prenatal screening, and come to a decision about what they thought Sue and Dave ought to do. Again, the quality of discussion was very varied. Some groups considered issues from various perspectives, and evaluated advantages and disadvantages explicitly. By contrast, other groups focused on one issue at a time, in one context at a time. Indeed, it appeared that some groups were only sufficiently immersed in the context by the end of the interview, to engage in discussion that involved the evaluation of advantages and disadvantages.

Opposing viewpoints were noted in about half of the small groups.

In overview, the overwhelming view of students was that Sue and Dave should proceed with prenatal screening. In such cases, the unreliability of the test and the risk of miscarriage were considered insignificant compared to the advantages of allowing Sue and Dave to prepare should the test prove to be positive for CF, or to consider abortion. Students who felt that Sue and Dave should not proceed with testing cited a number of reasons for their view, notably disagreement in principle with abortion, disagreement with abortion for CF, the unreliability of the test and the risk of miscarriage.

Data from 16 out of 19 groups were available for this part of the analysis.

Information about the coding scheme used, and coding decisions, can be found in Appendix 7.

#### 3.3.1 *Reasons cited in support of a view that Sue and Dave should proceed with prenatal screening*

At least one student in each of the 16 groups expressed the viewpoint that Sue and Dave should proceed with prenatal screening, in order to allow for preparation for the care of a CF sufferer in the event of a positive test (9 groups), or to allow for consideration of abortion (10 groups). A number of students argued that having the test would reduce worry and provide Sue and Dave with a better insight into the likely CF status of their baby, in spite of the limited reliability of the test:

*I You think they should go ahead and have the test? (...)*

*S The advantages of having the test were more than not having the test.*

*S And also they would know so they could make a better informed decision..*

*(...)*

*I OK, let's say you have the test and the baby is completely unaffected. I mean there's still a chance, a 1 in 10 chance that the test will be wrong..*

*(...)*

*S Even that, well it's better than not knowing at all in a way.  
School B, Group 4, Lines 45-49.1*

In general, the discomfort associated with testing and the risk of miscarriage were judged to be insignificant by virtually all students. Only one student argued that the risk of miscarriage was sufficient to warrant a decision not to proceed with screening.

In 7 groups, one or more students argued that Sue and Dave's personal circumstances would critically affect the decision as to whether to proceed with screening, and as such the decision would vary according to the strength of particular couples' relationships, their financial security, and their ability to cope with the rigours of bringing up a child with CF.

### *3.3.2 Reasons cited in support of a view that Sue and Dave should not proceed with prenatal screening*

This viewpoint was argued by at least one student in 6 groups. The main line of argument used was that Sue and Dave did not appear willing to consider abortion as they had wanted a baby so much, so there was little point in having the test. Some students argued strongly that abortion is unethical, and there is little point in having the test if abortion is not a possibility. Students using each of these arguments did not appear to see much advantage in knowing the baby's CF status in advance, arguing for making decisions after the baby's birth.

### *3.3.3 Reasons cited for keeping a baby shown to have CF through screening*

Arguments were presented for keeping a baby shown to have CF in 11 groups. In practice, groups often suggested multiple reasons for taking this decision. Justifications fell into two broad areas. In a number of cases, students justified their positions around a case that Sue and Dave had wanted a baby, and would therefore still be fulfilled by a baby with CF. This argument was often coupled with viewpoints opposed to abortion in principle. A few students suggested that Sue and Dave could reappraise whether they wanted to keep the baby after its birth, adoption being a possibility. This option was not explored in detail, however, and groups did not identify any of the potential problems that this course of action might present.

A further dimension argued by some groups involved evaluating the quality of life likely to be experienced by CF sufferers together with the possibility of advances in the treatment of CF in the future. In such cases, students concluded that the quality of life enjoyed by CF sufferers precluded abortion as an option on the grounds of poor quality of life for CF sufferers.

### *3.3.4 Reasons cited for aborting a baby shown to have CF through screening*

Arguments were presented for considering termination if prenatal testing for CF proved positive by 9 groups, though this did tend to be a minority position in most groups. This position tended to be justified in terms of a

view of the quality of life of people with CF, and the ability of the parents to cope with a child with CF. In addition, one group raised the issue of gene therapy, concluding that advances that would significantly improve quality of life and life expectancy were still distant.

Two groups made the point that any decision about abortion following a positive result from prenatal screening for CF would depend critically on the parents' ability to cope with a CF child. In particular, students suggested that different parents would cope differently with the practical, psychological and financial pressures of having such a child.

### 3.3.5 *Suggested action following screening showing a baby to be a carrier of CF*

Only four groups addressed this possibility in their discussions. In three of these groups, a number of pertinent points were made about the need in future to prepare the child for their carrier status, particularly in the context of future reproductive decisions. In two groups, the point was made that the risk of a child actually having CF following prenatal screening which indicated that the child would be a carrier, was still small. One group expressed the view that they would consider abortion following a positive result for carrier status, though the reasons behind this viewpoint were not elaborated.

### 3.3.6 *Students' views about the provision of screening for CF*

Students in five groups were asked directly by interviewers whether they thought that screening for CF should be available. The majority of students felt that such tests should be available in order to inform various decisions that parents or potential parents might face. A few students suggested that couples ought to consider submitting themselves to screening at the point where they were first considering the possibility of having a family; other students suggested that screening should only be considered after conception, in order to minimise worry that might be experienced if screening were carried out earlier. Students felt strongly that individuals themselves should make the decision as to whether to submit to screening, as they would ultimately have to deal with the results of screening. In one group, there was an interesting discussion about whether potential mothers or fathers should be responsible for decisions about screening and abortion:

I (...) *Who do you think should decide whether or not adults should have these tests?*

S *The mother..*

S *It's going to affect her more than the child..*

(...)

S *And she's the one who's actually carrying the baby so its probably her that it's going to affect most probably or as well it could be the dad..*

S *She should have more say in it, because it's going to affect her more than the father.*

*School A Group 4 Lines 39-39.6*

### 3.3.7 Students' views about screening for a variety of other genetic conditions

In a small number of groups, interviewers asked students how their views about prenatal screening for CF compared with their views on prenatal screening for other medical conditions, or 'the criminal gene'. Although this was not discussed by many groups, some interesting points were made where students evaluated the relative effect of different conditions on quality of life, and the cost of caring for sufferers of particular conditions.

In the following extract, for example, students appeared to recognise that different genetic diseases would affect the future lifestyle of sufferers differently:

- I (...) There are lots and lots of genetic illnesses. (...) Would you think about having tests for all of those?  
S No, it depends.. like the deadly disease ones.  
S And how much it will affect the baby.  
(...)  
S Only ones that would really affect it through its life, you know, like the CF one.

School A Group 6 Lines 47 - 48.3

In the following extract, students discuss the possibility of inheriting criminality, following a suggestion of the possibility by the interviewer:

- S It doesn't matter (...) It doesn't make you do crimes just because you've got a gene.  
(...)  
S But some people's families are nothing like kids, some kids really are criminals, and parents are really against all crime...

School A Group 3 Lines 55.2 - 57.2

These students appeared to question the validity of the notion of a criminal gene, drawing on experience of actual family differences in social behaviour. It is interesting to note that the students did not raise the probability of inheriting conditions between generations in families.

## 3.4 Characteristics of group discussion

Mercer (1996) has characterised three ways of talking and thinking in small groups. *Disputational talk* involves short exchanges between students which are characterised by individual decision-making or disagreement between students. There are no apparent attempts to pool ideas to reach decisions, or to offer constructive criticism to ideas raised by others. *Cumulative talk* involves speakers in building positively and uncritically upon everything that is said in discussion. In *exploratory talk*, speakers engage in critical but constructive discussion about each other's ideas. When challenges are made, they are backed up with argumentation and alternative viewpoints are

suggested. Mercer suggests that in exploratory talk 'knowledge is made more publicly accountable and reasoning is more visible in the talk.' (p. 104).

We find this characterisation of group discussion very useful in describing the styles of talk noted in the small groups. Although this probe was not designed to allow for analysis of group discussion styles, there appear to be at least 4 groups using exploratory talk (School A Group 6, School B Groups 1 and 5, and School C group 3). The talk of these groups was peppered with statements of the form 'If *a* then *b*', as is illustrated by the following extract:

*S Yeah, and also how the parents bring up the baby as well. If they're bringing it up to be sensible about the condition and, you know, respect that they've got it... Yeah, it just depends on what they think they'd do, do they think that they're going to terminate, they would terminate if they found out? Cos if they feel that then they wouldn't be able to cope with a CF sufferer then you know they should have a test. But if they feel that they'll love it so much that no matter what then they shouldn't.*

*School B Group 1 Line 24.29*

Some groups explicitly discussed the disadvantages of a chosen course of action:

*S Yeah, they should have the test but they shouldn't have an abortion*

*(...)*

*S It's a lot of discomfort for Sue as well.*

*(...)*

*S She might feel pressurised into having one..*

*(...) Yeah, she might feel guilty for having an abortion cos its summat that could be lived with (...)*

*School A Group 6 Lines 19.9-19.16*

The talk of other groups appeared much more like Mercer's disputational talk, discussion being characterised by individual students restating viewpoints again and again, no attempt being made to justify statements or present rational arguments to counter opposing points of view. It is interesting to note that, within this small sample, groups using exploratory talk tended to be comprised of girls whereas those using disputational talk tended to be comprised of boys.

It did not appear valid to distinguish examples of cumulative talk and disputational talk in these transcripts. In some cases, the style of talk was cumulative in that contributions were accepted uncritically. Students in these groups maintained similar positions throughout discussions, however, and

consequently the need to make arguments for particular viewpoints did not arise.

Not surprisingly, different groups within the sample appeared to be differently motivated for the activity. The talk of groups with least motivation tended to be very limited in quantity, and disputational in nature. The talk of some groups, particularly mixed groups with confident girls and boys, tended to be of a different quality at different points in the transcripts, in some cases being disputational yet in other cases being exploratory.

### **3.5 Summary of findings**

Students in the sample generally had a good understanding of the scientific background to the condition of CF following the video presentation. In particular, there was good overall understanding of the difference between genetic and pathogenic disease and the lifelong nature of genetic disease, the role of probability in inheritance of CF, and the different methods of testing used for individual and prenatal screening. A few students saw the probability of a child having a particular genotype as being influenced by the genotype of previous children. In a number of cases, interviewers had to re-emphasise the differences between the lung and digestive symptoms of CF, as well as the fact that gene therapy as currently envisaged provides a temporary approach to treating the lung symptoms of CF, but not the digestive symptoms.

The quality of group discussion in identifying, evaluating and forming opinions on issues that surround prenatal screening for CF was varied. In a small number of groups, all discussion involved identifying a range of issues and evaluating each one in a range of circumstances. By contrast, in a small number of groups only a few issues were identified, each one being presented as either positive or negative with no reference to contextual factors. The quality of discussion in the majority of groups lay somewhere in between these characterisations.

The majority of students felt that Sue and Dave should go ahead with prenatal testing for CF, in order to allow them to consider abortion and/or prepare themselves for the birth of a CF baby. Such students viewed the risks associated with the test and the inherent uncertainty of a negative result as insignificant compared to the advantages of testing. The students who felt that Sue and Dave should not go ahead with prenatal testing tended to justify their positions in terms of a negative attitude to abortion. They argued that if abortion was not a possibility, then the advantages of testing are not sufficient to outweigh the risks of testing and the possibility of an inaccurate test result.

The majority of students felt that abortion was not appropriate for a foetus with CF, having made a judgement about the quality of life of CF sufferers. A significant number of students also recognised the possibility of future advances in gene therapy for CF. A few students argued an opposing

viewpoint, seeing significant advances in gene therapy as distant and judging the quality of life of CF sufferers as sufficiently bad as to merit abortion.

Opposing viewpoints were voiced in about half of the discussion groups. In many of the groups, individuals argued at some point that decisions about prenatal screening and abortion depend critically on the parents' circumstances, including their attitude to abortion, how much they want a baby, their financial situation and their ability to cope with a child with CF.



#### 4 Educational implications

A number of important educational questions surround teaching about the condition of cystic fibrosis and the issues that surround prenatal screening. How much formal genetic knowledge do students need in order to engage with discussions about the advantages and disadvantages of prenatal screening? How is this knowledge drawn upon? In what ways do students reach viewpoints on prenatal screening, and how are the issues evaluated? Similar questions apply to teaching about other areas of science with an important social dimension. From the point of view of curriculum design, we would argue that it is necessary to include teaching about a range of scientific topics with a broad social dimension, however, recognising that each one raises an unique collection of issues on which viewpoints might be formed. In the area of 'the new genetics', for example, students will only come to appreciate the different social issues arising from different genetic disorders by studying a range of disorders in themselves, followed by some sort of overview of the issues that emerge. For example, studying CF in isolation would not introduce to students the different issues that arise in late onset genetic conditions such as Huntington Disease or breast cancer.

The structure of this research activity had three main parts: instruction for students about the condition of cystic fibrosis and the range of issues that surround prenatal screening for the condition, activities to allow student engagement with this information, and activities where students could evaluate the various issues surrounding CF in order to reach viewpoints. The topic of prenatal screening for CF is intellectually demanding for a number of reasons. Firstly, there is evidence that the genetic basis of inheritance is poorly understood by students (Lewis *et al.*, 1996; Wood-Robinson *et al.*, 1996), and as we have seen there is a complex web of social, ethical and financial issues surrounding prenatal screening for CF. In general, however, the students with whom we worked were able to understand the genetic basis of CF and engage with a range of issues relating to prenatal screening, following instruction as described. A significant majority of students were able to evaluate these issues and justify particular points of view about prenatal screening. We see this as providing evidence that many young people in the age range of 15 - 16 have the intellectual resources to address subject matter such as prenatal screening for CF in the curriculum.

Group discussion was a major feature of the research approach used. This was for two reasons. Firstly, in order to get access to students' thinking about prenatal screening it was necessary to engender situations where they would articulate their thinking on particular issues. Secondly, and perhaps most importantly, we believe that it is only through articulation of viewpoints and engagement with opposing arguments that people clarify their thinking on particular issues (Barnes and Todd, 1977). Within the transcripts of group discussions, we see many cases where students are influenced by their peers. We would argue that students could not engage

with topics such as prenatal screening for CF without the opportunity for discussion work. We will return to the question of the nature of such discussion work later in this section. In addition, in the cardsort activity to probe understanding of the material presented in the video, many individual students voiced incorrect statements about screening for CF (such as the idea that individual screening tests involve needles). By the end of group discussion, however, such ideas were not part of the 'common knowledge' of the groups (Edwards and Mercer, 1987), the points having been corrected by other group members and accepted by the whole group. In general, following the instructional approach used in this topic, we found little evidence that students' conceptual understanding of genetics constrained their ability to engage in evaluative discussions of the advantages and disadvantages of prenatal screening for CF.

In designing the video and audiotape, we were conscious of the need to address particular aspects of the genetic basis of the inheritance of CF, the scientific basis of individual screening and prenatal screening, the nature of CF as a condition and issues that arise from prenatal screening. In general, the video and audiotape appeared very successful in immersing students in the context of CF as was reflected in the subsequent discussions of the groups. For a significant number of groups, however, it appeared to take a considerable amount of time for issues surrounding prenatal screening for CF to be picked up in group discussion. Perhaps it should come as no surprise that, even with carefully designed materials and teaching interventions, it takes many students a significant amount of time to become sufficiently immersed in a context to engage in the involved argumentation required to justify viewpoints which involve balancing issues, against a complex scientific background. We would argue that for teaching about topics such as prenatal screening for CF to be successful, teachers are likely to need high quality materials which make both scientific and broader social dimensions of the topic explicit. Only then will teachers be in a position to engage students in the complex evaluative discussion required to get to the heart of the topic.

In some cases, students did not engage in discussions in which issues were balanced and judgements were made. This appeared to be due to a number of reasons. In a few cases, particular statements made by students reflected a lack of empathy with some issues as they would affect adults as they thought about starting a family. For example, in one group students suggested that Sue and Dave might toss a coin in order to solve a disagreement about the possibility of abortion. Issues such as the ethics of the situation and the long-term effects of a possible abortion on Sue and Dave were not addressed. In other cases, it appeared that students' goals for the activity were other than producing a carefully thought through viewpoint. In particular, some students appeared to tackle the task in a way that suggested that their goal was to complete each part of the activity as quickly as possible, and in any event before their peers had finished. In other groups it appeared particularly important for some students to make their individual viewpoints heard,

whereas in others students seemed to work more towards establishing a group consensus.

We have already shown how some groups appeared to use exploratory talk (Mercer, 1996) in order to reach clearly articulated and justified viewpoints in which conflicting issues were balanced. Indeed, we would argue that such discourse is a necessary process in reaching such viewpoints about unfamiliar contexts. Cross and Price (1992) present a characterisation of the types of skills required by students to judge social issues:

- Skills for understanding the argument;
- Skills for judging the expert;
- Skills for making independent investigations in the literature or in the field;
- Skills for participation in democratic ways of influencing decision-making.

(p.104)

The question arises as to how more students can be introduced to such modes of argumentation through teaching. In order to promote exploratory talk, Mercer (1996) suggests asking members of discussion groups to reflect on the nature and quality of their discourse after activities have been completed. We see some limitations in the ability of this approach to advance students' discussion skills in that students from groups in which discourse has been primarily disputational and cumulative, would have no model of exploratory talk to learn from. A more productive approach may be to provide models of discussion for students, possibly through the use of video, where students' attention is focused more upon the structure of the discourse than its contents.

This research suggests that young people at the end of their compulsory education are able to engage with scientific issues of broad social interest, such as prenatal screening for CF, where appropriate background resource material is provided and classroom activities are structured to allow viewpoints to be articulated and discussed. In this case, students were able to develop from the video a sufficient conceptual understanding of genetics as it relates to CF, to allow them to engage with issues surrounding prenatal screening for CF.

In practice, the number of students who are likely to encounter decisions about prenatal screening for CF in future life is small, though a larger number are likely to encounter genetic screening for a broad range of conditions. However, we see no reason to assume that students would be less likely to form justified viewpoints about screening for such conditions, given appropriate stimulus materials and opportunities for discussion.

We have already argued that the contribution that can be made to such decision-making by school science education is rather modest. The rate of progress in genetics is rapid, and it is unlikely that school science teaching,

even if remembered in adult life, would provide accurate knowledge about screening for particular conditions. In addition, the decisions taken by the adults of the future on genetic screening will depend upon their personal circumstances and values, as well as upon their understanding of the genetic basis of the condition, its treatment and inheritance.

If teaching about 'the new genetics' in the school science curriculum is to be for utilitarian purposes - to equip individuals to make better informed decisions about issues such as screening in later life - we would argue that it should enable students to seek out and interpret information, in order to make informed decisions in a variety of contexts. We can see a number of ways in which school science education might equip young people to do this in their adult lives.

In order to understand information about genetic screening, it is likely that some basic genetic knowledge will be needed, such as the role of probability in inheritance. We see an important role for school science education in developing this sort of knowledge. In addition, school science education could equip young people with knowledge about various types of genetic conditions and the issues that surround them. We can see a case that such knowledge may well be useful in adult life, should decisions about genetic screening be encountered. At the present time, we suspect that most students learn how to form and justify opinions in contexts without a science dimension, in humanities and arts subjects in school as well as various situations outside formal education. Furthermore, there is evidence that a significant number of students at the end of compulsory education believe that social issues with a science dimension are easily solvable by empirical means such as collecting data (Driver *et al.*, 1996). Perhaps the most important contribution of school science education is therefore to teach students how to identify, evaluate and form justified opinions about issues in complex domains with a science dimension.

## **A note on the format of transcript used in this report**

Verbatim transcript is presented in italics, inset from the margins. The letter 'S' denotes that a student is speaking, the letter 'I' denotes that the interviewer is speaking. Where possible, the utterances of different students have been numbered. Line numbers indicate where in discussions extracts have been taken from.

*I The notation (...) on a line indicates that part of an utterance has been edited.*

*(...)*

*I The above notation at the beginning of a line indicates that one or more utterances have been missed out completely*

In order to enhance comprehensibility, the transcript has been 'cleaned' to remove repetitions and other 'noise'. In addition, the local dialect of some students has been standardised.



## References

- AMERICAN ASSOCIATION FOR THE ADVANCEMENT OF SCIENCE (1989)  
*Science for all Americans: a Project 2061 report on literacy goals in science, mathematics and technology* Washington, DC: AAAS.
- BARNES, D. AND TODD, F. (1977) *Communication and learning in small groups*  
London: Routledge and Kegan Paul.
- DRIVER, R., LEACH, J., MILLAR, R. AND SCOTT, P. (1996): *Young People's Images of Science* Buckingham: Open University Press.
- EDWARDS, D. AND MERCER, N. (1991). *Common Knowledge: the development of understanding in the classroom*. London: Methuen
- EUROPEAN COMMISSION. (1995) *Science Education: a case for European Action? A White Paper on Science Education in Europe presented to the European Commission*. Brussels: The European Commission
- LEACH, J. (1996) *Students' understanding of the nature of science* in Welford, G., Osborne, J. And Scott, P. *Research in Science Education in Europe: Current Issues and Themes*, 269 - 282
- LEWIS, J., DRIVER, R., LEACH, J., and WOOD-ROBINSON, C. (1996a). *Young people's understanding of, and attitudes to, 'the new genetics' project. Working Paper 2: Understanding of basic genetics and DNA technology*. University of Leeds, Centre for Studies in Science and Mathematics Education, Learning in Science Research Group.
- LEWIS, J., DRIVER, R., LEACH, J., and WOOD-ROBINSON, C. (1996b). *Young people's understanding of, and attitudes to, 'the new genetics' project. Working Paper 4: Understanding the genetics of cells, B: The written probes*. University of Leeds, Centre for Studies in Science and Mathematics Education, Learning in Science Research Group.
- LOCK, R. AND MILES, C. (1993). Biotechnology and genetic engineering: students' knowledge and attitudes. *Journal of Biological Education*, 27 (4) 267-272.
- MERCER, N. (1996) *The guided construction of knowledge* Clevedon, Avon: Multilingual Matters Ltd.
- OFFICE FOR SCIENCE AND TECHNOLOGY (1993) *Realising our potential*  
London: HMSO
- WOOD-ROBINSON, C., LEWIS, J., DRIVER, R. and LEACH, J. (1996). *Young people's understanding of, and attitudes to, 'the new genetics' project*.

*Working Paper 3: Understanding the genetics of cells, A: The Discussion Task*. University of Leeds, Centre for Studies in Science and Mathematics Education, Learning in Science Research Group.

### **Appendix 1: Limitations in the use of decontextualised fixed response items for probing student opinions**

Previous research on students' opinions about various genetic technologies has used decontextualised questions, responses being made on Lickert scales. We were doubtful as to whether such a mode of data collection would allow us to develop meaningful understandings of students' opinions. Opinions are formed about particular situations or contexts. For example, it is quite reasonable for an individual to agree with prenatal screening for one genetic condition, but not for another. The implications of this issue for the methodology of the study are discussed in the body of this paper.

An added problem inherent in using fixed response items for probing opinions is the danger of biasing responses according to the wording of questions. Consider the following questions, both of which relate to nuclear energy:

- ♦ Nuclear power generation should be developed in the UK, in order to decrease our dependency on fossil fuels
  
- ♦ Nuclear power generation should be developed in the UK because it is clean and safe

Both questions relate to 'opinions about nuclear energy'. However, it is not difficult to imagine how an individual might give apparently opposing responses to the questions. The first question mentions dependency on fossil fuels, which might well be associated with atmospheric pollution in the minds of people responding to a questionnaire. This might result in an 'agree' response. The second question, by contrast, states that nuclear power generation is clean and safe. This might well result in a 'disagree' response by the same individual, on the grounds that nuclear power generation is not thought to be safe.

In order to investigate whether reliable insights into students' opinions about 'the new genetics' could be elicited from fixed response items, the following set of 6 pairs of opposing statements was generated, with Lickert-style responses:

	Agree strongly	Agree	Disagree	Disagree strongly	Not sure
1 Changing human genes is more worrying than changing animal genes					
2 If it were possible, I would like to know how my genes could affect my future					
3 Just because scientists can change the genes in a few lung cells doesn't mean they are bound to end up changing genes in eggs and sperm					
4 Changing genes in plants is just as worrying as changing genes in animals					
5 I don't want to know how my genes will affect my future					
6 Changing genes, even when it is being done for good reasons, is always wrong					
7 Everybody's DNA fingerprint should be on a national data base					
8 Changing animal genes is more worrying than changing genes in plants					
9 If we can improve peoples' lives by changing genes then we should do it					
10 Changing genes in animals is just as worrying as changing genes in humans					
11 With gene therapy scientists may start by changing a few lung cells but they will end up by changing eggs and sperm					
12 No one should have access to my DNA fingerprint without my permission					

Statements 1:10, 2:5, 3:11, 4:8, 6:9, and 7:12 were designed to express opposing viewpoints. It is acknowledged, however, that the statements are not completely opposite.

All students completed this questionnaire at the end of the *Issues and Attitudes* pack. In analysis, we were interested to know whether there was a negative correlation between students' responses to opposing questions. Consider the case of statements 4 and 8: Changing genes in animals is just as worrying as changing genes in plants, and changing animal genes is more worrying than changing plant genes. These statements are logically opposed, and yet 56 students (20% of the sample; n=274) made an apparently illogical response (i.e. agreed with both statements, or disagreed with both statements). In the case of statements 1 and 10 ('Changing human genes is more worrying than changing animal genes', and 'Changing genes in animals is just as worrying as changing genes in humans') a similar trend is apparent. 88 students (32% of the sample; n=274) made apparently illogical responses.

Similar trends were apparent for the other pairs of statements, as shown below:

<i>Pair of statements</i>	1:10	2:5	3:11	4:8	6:9	7:12
<i>% of students making apparently illogical responses (n=274)</i>	32	13	18	20	16	40

For this reason, students' responses to decontextualised fixed response items were not analysed further.



## **Appendix 2: Video Script**

- At some point in our lives, most of us become ill for one reason or another. We'll probably suffer from coughs and colds, or might even catch a more serious disease like hepatitis or AIDS.
- These sorts of illnesses are caused by micro-organisms such as bacteria and viruses. When people are infected, it's possible for them to pass on the disease to other people.
- Curing the diseases involves using drugs to kill the micro-organisms. Although we don't yet have drugs which can kill all micro-organisms, such as HIV which causes AIDS, it's possible that drugs will be invented.
- But some diseases are not caused by micro-organisms. Rather, they are passed on from parent to child in the genes in the same sort of way as hair colour and eye colour. At the moment, it is not possible to cure genetic diseases, only to treat the symptoms. In this video, we are going to look at a genetic disease called cystic fibrosis, or CF for short.
- Because it's passed on in the genes, cystic fibrosis sufferers are born with the illness, and will carry it in their genes for the rest of their lives. In the case of CF, there is no cure and they can expect to suffer symptoms right from birth until death.
- But some diseases are not caused by micro-organisms. Rather, they are passed on from parent to child in the genes in the same sort of way as hair colour and eye colour. At the moment, it is not possible to cure genetic diseases, only to treat the symptoms. In this video, we are going to look at a genetic disease called cystic fibrosis, or CF for short.
- Because it's passed on in the genes, cystic fibrosis sufferers are born with the illness, and will carry it in their genes for the rest of their lives. In the case of CF, there is no cure and they can expect to suffer symptoms right from birth until death.
- The illness affects the lungs and digestive system. The problem is that people with CF make too much thick mucus, which is difficult to clear. This clogs the lungs, making it difficult to breathe and encouraging the growth of bacteria - which can cause dangerous lung infections.
- It also interferes with the digestive system, making it difficult to take in food. These symptoms have to be treated daily with

antibiotics, to prevent lung infections, and lots of drugs to help the digestion of food.

- Also, a large amount of time each day has to be set aside for physiotherapy, which helps to clear the mucus from the lungs of sufferers. Remember, these treatments have to be applied every day of the person's life. There is no long-term cure for genetic diseases as yet.
- The damage that CF causes to the lungs and the digestive system, and the extra strain that it puts on the heart, means that affected people usually die young - around 20 to 40 years old. But people with CF can sometimes live longer with a heart and lung transplant.
- So what is life like for people with CF? These two teenage girls have CF. What is life like for them? (Interview with two girls not scripted).
- Cystic fibrosis is passed on through the genes. Genes contain information in the form of DNA, which is passed from parent to offspring.
- About 1 in 25 of us carry a defective form of a gene which causes CF. But far fewer people actually have the disease. How can that be? Well, in order to have the disease a person must inherit one copy of the CF form of the gene from each parent. If only ONE parent passes on a copy of the CF form of the gene, the person will not have the disease and will not appear different from anyone else. But they can still pass on the CF form of the gene to their children. They are called 'carriers' of CF.
- This couple are both carriers of CF. That means that they each have one copy of the CF form of the gene and one copy of the normal form of the gene, so although they don't have CF themselves, they can pass it on to their children. The normal form of the gene here is shown as a capital G, and the CF form as a small g. [Appropriate diagrams shown for this part of the video.]
- When eggs and sperm from the parents are joined, all sorts of new combinations of genes can come about. This is why children tend to resemble their parents in some ways but not others, and they may also resemble other close relatives.
- This simplified diagram shows the inheritance of CF. There are 4 possible combinations of genes.

- The first combination shows two capital Gs. This means that the CF form of the gene has not been inherited, and the child will be completely unaffected.
- The next two combinations have inherited one capital G, which is normal, and one small g, which is responsible for CF. In these cases, the individuals will not have CF - they will be unaffected - but they will be carriers of CF, like their parents.
- In the case of the last combination, two small g's have been inherited. In this case the individuals will have CF.
- When sperms and eggs join to form embryos, it is a complete lottery as to which combination of genes arises. In this case, 2 out of 4 possibilities result in the children carrying CF, so this is the most likely outcome. But there is also a 1 in 4 chance of a child being completely unaffected, and a 1 in 4 chance of a child having the disease. Even if they know that they are carriers, parents just can't predict the genes that their children will inherit.
- At the moment, the possibilities for treating CF are limited. However, a new approach called 'gene therapy' is being developed. The idea of gene therapy is that working genes are sprayed into the lungs, from an inhaler. If these genes get into the cells which line the lungs, they could then take over from the CF form of the gene and the lungs would begin to work normally.
- So far, attempts to put working genes into the lungs of people with CF in this way have had only very limited success. And even if it could be done efficiently, it wouldn't be a cure - the therapy would have to be repeated on a regular basis throughout the person's life. However, the intensive physiotherapy that we saw earlier would no longer be necessary, and there'd be less risk of lung infections. Sufferers would be able to breath better - giving them more energy and putting less strain on their hearts. In this way, gene therapy would increase the quality of life, and the life expectancy of people with CF.
- However, the digestive system cannot be treated in the same way by gene therapy, so CF sufferers would still have to use lots of drugs.
- Most people are unaware as to whether or not they carry the CF form of the gene, because there's no obvious difference between CF carriers and non-carriers. But now, a test is available which can tell them whether they are a carrier or not.
- All that is needed is a small sample of cheek cells, which can be collected from a mouth wash. Then these can be sent to the

laboratory where tests can be performed to find out whether the CF form of the gene is present.

- This test can be done at any time. Most people can expect to find out that they aren't carriers. But some people will discover that they do carry the CF form of the gene. This may have important implications for them and their families.
- If you're a carrier but your partner isn't, you can't have children with CF. But there is a 1 in 2 chance that any child that you have will be a carrier, like you.
- However, if your partner is also a carrier, there's a 1 in 2 chance that any child you have will be a carrier, and also a 1 in 4 chance that they may have CF. And as we saw earlier, there is a 1 in 4 chance that any child you have will be unaffected by CF.
- This test has only recently become available, and therefore most people don't know whether they are carriers or not. For many, the first time that they're offered a test is when they're already expecting a baby.
- Think for a moment about the implications of this. A couple are expecting a baby, and each partner is tested for CF carrier status. The results come back that both partners are carriers. This means that there's a 1 in 4 chance that their baby will have CF, and a 1 in 2 chance that it will be a carrier. Of course, there's also a 1 in 4 chance that it will be unaffected with respect to CF.
- A couple in this situation would be offered the option of having their baby's CF status tested while it's still in the womb, at around 3 months of pregnancy. In order to carry out the test, a small sample of cells is taken from within the womb. Although uncomfortable, the test is not painful for the mother or the baby. And the risk of the test harming the baby is very small indeed.
- This test will accurately identify babies with CF. But there's only about 90% accuracy for those identified as carriers or unaffected. So when parents get a negative result, it only tells them that their baby PROBABLY won't have CF - there's still a 10% chance that it will.
- In this session, you will be considering some of the issues that arise from the genetic testing of embryos for CF. But first, you will have the opportunity to check that you have understood the background information about CF, presented in this video.

### Appendix 3: Audio Script

Sue is nearly three months pregnant. Her local ante-natal clinic has been running a screening programme for Cystic fibrosis. As a result of this she has discovered that she is a carrier for cystic fibrosis. When Dave was tested, he too was found to be a carrier for cystic fibrosis. They have been told that this means the baby has a 1 in 4 chance of having the illness and they are very concerned. Today they have been to see the genetic counsellor. They have said very little on the way home. Each has been trying to make sense of the information they have been given and come to terms with the implications.....

*Key turns in lock, door opens/shuts*

Dave        Come on love, it's been a long day. Why don't you put your feet up while I make the tea, then we'll talk. If we start going over everything the counsellor said now, you'll be too tired to eat.

Sue         You're right, I am tired - and my head's still buzzing. It'd be lovely if you made the tea.

*Cooking sounds ....*

Sue         *Talking from next room*  
I wish I'd never heard of that screening programme. It seemed like a good idea at the time - but then I never thought it would be me that was affected.

Dave        *Calling back*  
It's no use regretting now, Sue. We can't go back.....and in some ways I suppose it's better to know. At least we can be prepared and make choices.

Sue         Right now I don't want to be 'prepared' - I want to be ignorant!  
And as for choices, I hate making choices. I can't even decide which chocolate I want and suddenly, here I am having to make terrible choices about this baby, just as I was getting used to being pregnant.

Dave        It's hard for us both love. Just hold on while I put this food in the oven and bring the tea, then we can talk about it in comfort.

*Cooking/tea noises*

Dave        There you are.....and if you move up I can sit with you!

Sue         Sorry, I wasn't thinking

- Dave            That's OK....  
(time - as if to sit down and give Sue a cuddle)
- The food should look after itself now, so lets go through what we know.
- Sue             Where do we start? I've learnt so much in the last few weeks - and all about things that I'd rather not know.
- Dave            Well, let's start with ourselves. The tests have shown that we're both carriers of cystic fibrosis.  
                  That means that half of all the eggs that you produce will contain the cystic fibrosis form of the gene.
- Sue             Why don't you start with you first - half of all the sperm you produce will have it too!
- Dave            I know that. I wasn't trying to make you feel worse. The important thing is what this means for the baby.  
                  If one of your cystic fibrosis eggs was fertilised by one of my cystic fibrosis sperms then our baby will have cystic fibrosis. The counsellor said that the chances of this happening are 1 in 4.
- Sue             Hold on a minute. Let's write it all down, otherwise we're bound to forget something important.
- Dave            OK. Can you pass me that note pad?....Thanks...Right,....  
  
(pause, scribbling, muttering)
- Sue             I prefer to think that it's got a 3 in 4 chance of being perfectly normal !
- Dave            Well not quite - there's only a 1 in 4 chance of it being completely unaffected. There's a 1 in 2 chance that it will be a carrier, just like us. It wouldn't have CF but it would have to face some of the same difficult choices as us, one day. But anyway, the point is, a 1 in 4 risk that it will have CF is still quite a big risk.
- Sue             I know. I'd just rather not think about it,... but I know I have to.  
                  It's the choices the counsellor gave us that seem most difficult to think about.
- Dave            Well let's write each option down and see what's good about it and what's a problem. Where shall we start?

- Sue           The 'do nothing' option! It's very tempting.....but I can see it's not as easy as it looks. Now that we know what the risks are I might spend all my time worrying and if, when it was born, it turned out to have cystic fibrosis I think I might feel very guilty. I could end up regretting doing nothing.
- Dave           But just a moment ago you pointed out that a 1 in 4 risk is actually a 3 in 4 chance that the baby will be perfectly OK and that if we did nothing we wouldn't have to make any more choices. I feel just as uncomfortable as you about some of those choices.
- Sue           Well let's look at the other choices. Perhaps talking about them will make them easier to cope with. The alternative to doing nothing is to have the baby tested and find out if it has got cystic fibrosis.
- Dave           But it isn't as simple as that. From what the counsellor said, having the baby tested leads to all sorts of other problems - but I didn't really follow everything he said. I'm not even very sure how they test an unborn baby without hurting it.
- Sue           They use a lot of technology. They'll be able to see exactly where the baby is and they'll be monitoring it all the time to make sure they don't accidentally damage it. They don't take cells from the baby itself. They take them from the fluid around it. He said that thousands of similar tests had been successfully carried out and there was no record of a baby ever being damaged. He did say that there was just a slight suspicion that very occasionally it might cause a miscarriage but the risk of that happening was very, very slight.  
It may not hurt the baby but I'm not sure it won't hurt me! Did you notice, he gave all those details about the baby but he didn't say a lot about how I would feel?
- Dave           No, I didn't. The moment he mentioned needles I went a bit blank. Next thing I remember he was talking about the accuracy of the test.
- Sue           Oh Dave! I thought you'd gone a bit pale. I'd forgotten how squeamish you are - and you say you want to be there when the baby's born! Oh..... I suppose it might not be born. That's one of the choices too, isn't it?
- Dave           Yes..... I can hardly believe we're sitting here, thinking about abortion. We wanted this baby so much.
- Sue           And we still want this baby - but if we have the test and find out that it will definitely have cystic fibrosis then we'll need to think about the kind of life it would have and how we would cope.

- Dave Can you imagine how our families will feel if we don't have this baby - your Mum is already knitting booties and it's my parent's first grandchild. The worst will be my mum. You know what she thinks of abortion - for any reason. We'll never hear the end of it.
- Sue I'm not saying I'd want an abortion. I'm saying that we'd have to think about it.  
I know they'd all be upset but we're the ones responsible for this child and we're the ones who'll have to live with the consequences - whatever we choose to do. I used to feel like your mum but I hate the thought of watching my own child suffer. If we have the choice, do we have the right to give birth to a baby that we know will always be ill?
- Dave But isn't there any hope of a cure? I read something about gene therapy in one of those leaflets you brought home. It's only experimental at the moment but it might work one day. What if we had the test, and the baby did have cystic fibrosis and we decided to have an abortion and then next year we hear that there's been a big break through - cystic fibrosis can now be cured. How would we feel then?
- Sue Pretty bad, I think ..but I'm not sure we would feel any better if we went ahead and had the baby, knowing it would have cystic fibrosis.
- Dave If we're going to feel bad either way, perhaps we shouldn't have the test.
- Sue But we might have the test and find that the baby's a carrier or perfectly OK. Then we could relax and put all this behind us. We could really look forward to having the baby.
- Dave I'm not sure we could . Didn't the counsellor say something about the test only being 90% reliable? 10 % of cystic fibrosis babies are missed.
- Sue You're right, he did. (Pause)  
We seem to be going around in circles. Let's have a look at what you've written down and see if that helps.
- Dave OK.(rustle of paper - tear sheet off pad) Let's try to put it into a more sensible order too. We seem to have gone all over the place. It's no wonder we're confused.
- Sue Well, there's one main decision and we have to make it before the end of this week - are we, or are we not, going to have the baby tested to see if it has got cystic fibrosis?
- Dave If we decide not to have the test you don't have to go through the discomfort, we don't have to make any more difficult choices and there's a 75% chance that the baby will be fine anyway.

- Sue But, knowing there's a 25% chance that it won't be all right means we're going to be worried right up until it's born and even if the baby seems fine, it might be a while before we could relax and actually believe it.  
If the baby turned out to have cystic fibrosis we might feel very guilty and wish that we had gone for the test.
- Dave So how will we feel if we decide to go ahead with the testing?
- Sue Still worried! There's a very slight risk that the test itself might cause a miscarriage - we could lose a perfectly healthy baby. And even if the test suggests that the baby doesn't have cystic fibrosis, it's not 100% accurate. We won't be completely sure until it's born.
- Dave And if, when we get the results, they show that the baby does have cystic fibrosis, we'll have another difficult decision to make - should we go ahead and have the baby anyway or should we go for an abortion.
- Sue If we decide to have an abortion we won't have to watch our child suffer or worry about how we will look after it but it will be a terrible loss and we'll always wonder if we did the right thing, especially if better treatment became available. If we decide to go ahead with the pregnancy at least all the uncertainty will be ended, and knowing in advance means that we'll have time to prepare ourselves and plan out how we're going to cope .....but even if we can cope, do we have the right to give birth to a baby that we know is going to suffer?
- Dave I wish all this technology had never been invented. If none of these tests could be done we wouldn't have to make these difficult decisions or feel so worried and guilty. Worst of all, if we ever decide to have another child we'll have to go through the whole process all over again.
- Sue Not knowing wouldn't alter the risks or make us feel less awful if we did have a very ill child. All it would mean was that we had less control over our lives - not that I feel very in control at the moment. All the options are difficult, in different ways, and we don't seem any nearer to making a decision.
- Dave Well we may not have made a decision yet but at least we're clearer about the options and the possible consequences of each one. Let's go and eat and try to forget it for the rest of the evening. I know we have to tell Dr Deakin what we want to do by the end of the week but we'll probably find it easier to decide in the morning, when we've slept on it.

*Postscript*

Sue and Dave face some difficult choices. They know that they are both carriers of cystic fibrosis and that there is a 1 in 4 chance that their baby will actually have CF. There is also a 1 in 2 chance that it will, like them, be a carrier of CF.

There is one decision that they need to make before the end of the week - whether or not to have their unborn baby tested for CF.

Should they :-

Do nothing. .... Wait until the baby's born to find out whether or not it has CF.

OR

Have the test and find out now whether or not the baby has CF, is a carrier of CF or appears to be completely free of CF.

They know that the test can only be about 90% accurate.

They also know that either of these options might leave them with further difficult decisions to make, at some point.

In your groups, we would like you to talk through the advantages and disadvantages of each option - your interviewer will give you a sheet to help you - and decide what you think Dave and Sue should do.

Appendix 4: Sue and Dave's Summary Sheet

Sue and Dave's Summary Sheet

We have been offered a test which will tell us whether or not our unborn baby has Cystic Fibrosis. WE NOW HAVE TWO CHOICES:

TEST THE BABY, SO THAT WE KNOW BEFORE IT'S BORN  
 Possible advantages:-  
 Possible disadvantages:-

NOT TEST THE BABY, AND WAIT UNTIL IT'S BORN TO FIND OUT  
 Possible advantages:-  
 Possible disadvantages:-

THERE ARE THREE POSSIBLE OUTCOMES TO THE TEST:-

- 1) No CF detected  
 - But there is still a risk that the baby may have CF - up to 1 in 10.
- 2) The baby appears to be a carrier  
 - But there is still a risk that the baby may have CF - up to 1 in 10.
- 3) The baby has CF  
 In this case, we'll have another decision to make.

IF WE DECIDE TO KEEP THE BABY...  
 At least we'll have time to find out about CF and prepare ourselves to look after the baby. But we might feel responsible for the baby's suffering. Might there be a cure in the future?  
 - There must be other points that were missed out!

IF WE DECIDE NOT TO KEEP THE BABY (TO HAVE AN ABORTION)...  
 At least we avoid the problems of caring for the affected child, and avoid the child's suffering. But what if a cure is found in the future - how would we feel?  
 And we'd be distressed at losing the baby and we'd both feel guilty. Our families would not approve. And a late abortion would be awful for Sue.  
 - There must be other points we've missed



**Appendix 5: Coding of students' understanding of information about CF from the video**

		Y	N	C	NC
<b>1</b>	<b>Notion of genetic disease</b>				
1.1	Differentiation of genetic and pathogenic disease	16			
<b>2</b>	<b>CF as a genetic disease</b>				
2.1	From birth to death - no cure	8	2	4	
2.2	Both lung and digestive symptoms	7		5	
2.3	Daily treatment required	11		3	
2.4	Gene therapy for lung symptoms only - and at early stages	5	2	4	
<b>3</b>	<b>Inheritance of CF</b>				
3.1	2 carries required to have CF child	11			
3.2	Notion of chance in inheritance	16		1	
<b>14</b>	<b>Screening for CF</b>				
4.1	Screening for carrier status from cheek cells	13		3	
4.2	Prenatal screening in utero	1			
4.3	Prenatal screening not 100% reliable for -ve results				

**Y** Understood by students

**N** Not understood, or misunderstood, by students

**C** Clarified by interviewer

**NC** Not clarified by interviewer

*The numbers in the table represent the total number of groups raising a given issue*



**Appendix 6: Coding of the issues surrounding prenatal screening raised by students**

	Issue	Students				Interviewer			
		A	B	C	D	A	B	C	D
<i>1</i>	<i>Issues that arise from having the test</i>								
1.1	Future carrier status of the baby	1							
1.2	Future CF status of the baby	18		2	11				1
1.3	Possibility of abortion	9	6	3	5		3		
1.4	Feelings of guilt		4	2	6				1
1.5	Family pressure	1						1	1
1.6	Future quality of life of the baby	2							
1.7	Future advances in treatment		3	2					
1.8	Worry associated with knowing/not knowing	8	5	3	16			1	2
1.9	Higher degree of certainty about CF status	4			1				
1.10	Timing of other decisions and choices	3	7	6	2		2	2	1
<i>2</i>	<i>Issues about the test itself</i>								
2.1	Reliability of testing for negative results		10	2			5	2	
2.2	Discomfort of test		4	5			6		
2.3	Risk associated with test		14	10			3	1	

The numbers in the table represent the numbers of groups recording particular issues as advantages or disadvantages of particular courses of action:

- A Advantage of having test
- B Disadvantage of having test
- C Advantage of not having test
- D Disadvantage of not having test



### Appendix 7: Coding of students' views about the various courses of action open to Sue and Dave

The bullets summarise the positions expressed in each small discussion group.

*Should they have the test?*

		School A					School B							School C				
		2	3	4	5	6	1	2	4	5	6	7	2	3	4	5	6	
	<i>Should they have the test?</i>																	
1.1	Yes	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*
1.2	No						*	*	*			*	*				*	
1.3	Don't know						*	*										
	<i>Justification</i>																	
2.1	Prepare for carrier status			*														
2.2	Prepare for CF status				*	*	*	*	*	*	*	*	*	*	*	*	*	
2.3	Allows consideration of abortion			*	*	*	*	*	*	*	*	*	*	*	*	*	*	
2.4	Reduces guilt associated with...				*													
2.5	In response to family pressure						*	*	*									
2.6	In response to quality of life issue						*											
2.7	Possible future treatments			*			*						*					
2.8	Reduces worry	*	*	*	*				*	*	*		*	*	*		*	
2.9	More certainty of possible outcome			*	*	*			*	*	*		*	*	*	*	*	
2.10	Timing of other decisions									*		*	*					
2.11	Reliability of test	w					*	*	*	*						*		
2.12	Discomfort of test				*		*			*								
2.13	Risk of test			*	*		*	*	*						*	*	*	
2.14	Ethics of abortion:			*														
	a) Personally opposed to it			*														
	b) Up to individual			*														
	c) Only if woman raped			*														
	d) Harder, later in pregnancy							*										
	e) Child would prefer to live																*	
2.15	Ethics of adoption:																	
	a) Children end up in homes			*														
	b) Cruel on child's future feelings			*														
	c) OK if child placed in a family			*														
2.16	Personal circumstances of S+D matter (financial, relationship, ability to cope...)						*	*	*	*			*	*	*	*	*	
2.17	How much having a 'normal child' matters to them						*											
2.18	They would keep it irrespective of test outcome							*				*	*	*	*	*	*	
2.19	Testing is interfering with nature												*					

[W = Wrong assumption about testing]

If they have the test, what should they do in each possible situation?

		School A					School B					School C					
		2	3	4	5	6	1	2	4	5	6	7	2	3	4	5	6
3.1	+ve result for CF																
3.1.1	KEEP THE BABY								*	*			*				
	a) Family pressure	*								*							
	b) Wanted a baby anyway	*	*								*						*
	c) Still a baby/still going to love it		*								*		*	*			*
	d) Evaluation of degree of suffering for child and suffering for parent		*						*				*	*			*
	e) Future cure		*						*	*	*		*				
	f) Abortion is wrong				*						*		*				
	g) Adoption is possible after birth				*				*								*
	h) Decisions about whether they can cope after birth				*												
	i) Abortion hard for Sue					*											
	j) Their responsibility					*											
	k) Relatively good quality of life								*	*							
3.1.2	ABORT THE BABY								*	*				*			
	a) Not fair on child, guilt for parents	*			*					*	*						
	b) Depends if parents are willing and able to cope				*						*						*
	c) Depends if parents can afford to cope				*												
	d) Try for a non-CF baby later																*
	e) Cure is distant																*
3.2	+ve result for carrier																
3.2.1	KEEP THE BABY										*	*					
	a) Prepare baby for future reprod. decisions					*											
	b) Get information: their next baby may still have CF					*											
	c) The risk of it still having CF small										*	*					
	d) It is still your baby										*						
3.2.2	ABORT THE BABY				*												

Should the tests be available?

		School A					School B					School C					
		2	3	4	5	6	1	2	4	5	6	7	2	3	4	5	6
	Should the tests be available?																
4.1	Yes	*	*	*	*	*											
4.2	No																
4.3	Don't know	*															
	Justification																
	a) Reduce worry				*												
	b) Inform reproductive decisions prior to conception				*	*	*										

*When should individuals be tested?*

		School A					School B							School C					
		2	3	4	5	6	1	2	4	5	6	7	2	3	4	5	6		
5.1	After conception...	*																	
	a) Because of worry	*																	
5.2	Before conception, but at reproductive age																		
	a) Inform reproductive decisions				*						*								
5.3	Recognition that carrier status may influence future partners				*														

*Who decides the testing?*

		School A					School B							School C					
		2	3	4	5	6	1	2	4	5	6	7	2	3	4	5	6		
6.1	Themselves	*			*														
	a) They have to deal with the consequences of test results	*			*	*													
	b) Some people won't want to know or feel bad about the results		*																
	c) Confidentiality issue discussed		*																
	d) May need expert and family advice		*																
	e) Family have no say				*														
6.2	The mother			*															
	a) Affects her more than the child			*	*														
	b) She carries the baby			*											*				
	c) Notion that mother carries the disease 'more' than the father			*															
	d) Affects mother more than father, but father has some say			*	*														
	e) Mother decides whether father should be tested			*															
	f) Although many others have a perspective, ultimately an individual choice				*				*										

*Discussion of different genetic conditions*

		School A					School B							School C					
		2	3	4	5	6	1	2	4	5	6	7	2	3	4	5	6		
7.1	Raised explicitly?																		
	a) Context of 'criminal gene'		*																
	b) Cost of care raised		*																
	c) Relative effect on quality of life evaluated				*														
7.2	No differentiation between different conditions		*																