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**Principles of distributive justice used by members of the general public in
the allocation of donor liver grafts for transplantation: a qualitative study**

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1. Background

Despite greater use of split livers (two liver grafts from one donor) and livers from marginal donors (e.g. non-heart beating donors or those aged over 60 years) the supply of donor liver grafts for transplantation in the UK has remained relatively constant [Neuberger 1997]. However, every year more patients are referred for liver transplantation, resulting in an increase in the waiting list. Given this imbalance in demand and supply, **decision criteria have necessarily to be employed to determine which patients should be given priority in receiving a donor organ.** Unlike the United States, the UK has no explicit guidelines for the allocation of donor liver grafts. In general, however, the length of time spent on the waiting list is used as the main criterion for donor liver allocation within the UK [UKTSSA, 1998].

In recent years, the public has become increasingly aware of the finite supply of donor organs for transplantation and the consequent need to define criteria as to how such organs should be allocated. Within the US in particular there has been and continues to be strong public debate regarding the guidelines which are used for the allocation of donor liver grafts [Moss and Siegler, 1991; Ubel *et al*, 1993]. Within the UK, it is now becoming more widely accepted by decision makers that some form of public involvement in the process is of value in informing the evidential base upon which a more explicit system of donor liver graft allocation would be based [Neuberger *et al*, 1998]. However there are legitimate concerns about (i) the extent to which the public can ultimately be involved in setting the criteria for determining patient priority for donor liver graft allocation (ii) the weight that should be attached to public preferences (iii) the methods that should be used to extract their views (iv) the amount and type of information presented and (v) the individuals who should be properly consulted as 'representatives of the public'. Whilst recognising the importance of the other listed concerns, this paper focuses mainly upon issues relating to items (iii) and (iv), the methods by which public views are extracted and the amount and type of information presented.

Several quantitative surveys of the general public's allocation decisions in liver transplantation have appeared recently within the health economics literature [Ubel and Loewenstein, 1995; Ubel and Loewenstein, 1996; Neuberger *et al*, 1998, Ratcliffe, 2000]. These surveys have suggested that public preferences may differ quite markedly from

the traditional health economics view that scarce resources should be allocated (within a given budget constraint) so as to maximise health related quality of life. A common theme emerging from these surveys is the conclusion that members of the general public would be willing to exchange an overall reduction in the efficiency of the transplantation system, as defined by the maximisation of health related quality of life, for a 'fairer' or more 'equitable' distribution of donor organs for transplantation.

However this conclusion begs several questions. 'What would a fairer or more equitable system of donor liver graft allocation look like in the eyes of the general public?' 'What criteria may be used to discriminate amongst competing individuals on the liver transplant waiting list and how should such criteria be invoked?' All of the quantitative surveys undertaken to date have used a similar methodology, whereby hypothetical choice contexts have been used to elicit respondents' preferences for the allocation of donor organs either to named individuals or more commonly to groups of individuals with particular characteristics. Although empirical data is important in this context its usefulness is limited because it does not allow the investigator to 'get behind the numbers'. There is evidence that the public change their views about priority setting in health care as a result of discussion and deliberation [Dolan *et al*, 1999]. However, the methodology used in quantitative surveys typically does not allow respondents the opportunity to reflect upon and explain the thinking behind their preferences. Consequently, this may lead the investigator to mis-interpret or mis-represent individuals' preferences based upon the quantitative data presented.

2. Study Design

This study used qualitative research techniques to investigate the nature of public preferences in the allocation of donor liver grafts. The principle aim of the qualitative study was to inform the results of a previous quantitative survey undertaken by Ratcliffe [2000], facilitating an in-depth understanding of the arguments and explanations used by respondents in determining and justifying allocation decisions for transplantation and the ethical and moral arguments expressed. The qualitative survey was undertaken using four focus group sessions comprising members of the general public in the Derby locality. Individuals were recruited to the focus groups through local community groups

and parent teacher organisations. The sessions were facilitated by the study coordinators, JR and SW. Discussions were recorded, the recordings transcribed, and the transcripts analysed in detail. The methods of analysis were based on the grounded theory model of identification of codes and themes [Strauss, 1993], but were template-based in accordance with the focus of the study [Crabtree and Miller, 1992]. The main focus was on the content of the group discussion.

On the basis of an extensive literature review, five main potential discriminating factors were identified which could be used in the prioritisation of patients on the waiting list for liver transplantation namely:

- a) Expected prognosis following the operation
- b) Age of the patient
- c) Whether the patient can be considered to be personally responsible for their illness e.g. through alcoholic liver disease
- d) Length of time spent on the waiting list
- e) Whether the patient is being transplanted for the first time or is being re-transplanted

a) Expected prognosis following the operation

This criterion expresses in its most immediate form one of the major principles of distributive justice in health care, and also reflects the traditional health economics view that health gain is the most important criterion in the allocation of scarce health care resources. The importance of this criterion in health policy and practice argues in favour of exposing it to comparison with other criteria by members of the public. What is particularly important here, however, is the potential of the study design to enable informants to articulate their thinking behind any such comparison.

b) Age of the patient

This criterion has been shown to be important in previous quantitative studies addressing priority setting issues in health care, with the most common conclusion being that there should be positive discrimination in favour of the young [Charney *et al*, 1989; Busschbach *et al*, 1993; Nord *et al*, 1995; Ratcliffe, 2000]. However, the majority of previous studies have failed to distinguish between equity reasons for age discrimination and efficiency reasons (given that young people will live longer and hence more health will be gained

relative to older people). This study provides an occasion to establish the reasoning behind age discrimination and enables this criterion to be considered in a more critical context, in potential conflict with such principles as equality of care.

c) Whether the patient can be considered to be personally responsible for their illness e.g. through alcoholic liver disease

Alcoholic liver disease (ALD) is the most common indication for liver transplantation in the UK. In addition the trend is increasing implying that greater numbers of ALD patients will be referred to transplant units in the future [HERG, 1999]. This rising trend of transplanting patients with ALD may provoke concern amongst the general public as there are fears that these patients may return to alcohol misuse, become non-compliant and have a poor medical outcome [Howard and Fahy, 1997]. Some commentators have suggested that patients with ALD are personally responsible for their illness and should not be given the same priority as patients who have acquired liver disease through no fault of their own [Moss and Siegler, 1991]. Alternatively members of the general public may view alcoholism as a disease and therefore consider that these patients should receive the same priority as all other patients awaiting transplantation.

d) Length of time spent on the waiting list

This criterion is already used to determine priority for liver transplantation in the UK [UKTSSA, 1998]. It reflects a principle of equal entitlement through equal waiting which legitimises the tradition of rationing by waiting-list in the UK. This offers a way of highlighting the principle of equality and making it available in a familiar form for informants to apply if they so choose. At the same time this criterion may be used to point out conflicting principles, as a longer period on the waiting list may be associated with more advanced disease and a worse prognosis following the operation.

e). Whether the patient is being transplanted for the first time or is being re-transplanted

This criterion allows another way for the principle of equality - in this case relating to the

number of transplants allocated to each person, to be set against other principles such as need and entitlement. Members of the general public may feel that such candidates should be given a lower priority on the basis that they have already received one transplant. Alternatively it may be considered that such patients should receive an equal or even a higher priority on the basis that the health care system failed them the first time around and hence such patients should not be abandoned by the health care system.

In each of the above cases (a) - (e) the main concern was to enable respondents to explain their reactions, not simply to state them. The researchers also recognised that the respondents reaction to the issues may have taken a form not predicted by the researchers, and the qualitative design of the study was intended to accommodate this.

The views of focus group members as to the relevance and importance (or otherwise) of each of these criteria in differentiating between patients on the waiting list for liver transplantation were investigated. Each group were provided with a hypothetical case study which contained written descriptions of the characteristics of five individuals waiting for a liver transplant. The groups were told that all of these individuals were in urgent need of the transplant and would die within a few weeks if the transplant were not made available to them. However, only one donor liver was currently available which would match any of the individuals on the list. For the first part of the exercise (Appendix 1), the characteristics of the individuals concerned were based upon the criteria (a) to (e) previously described. In the second part of the exercise (Appendix 2), the focus group members were provided with more information relating to the social background of the individuals concerned in order to explore the extent to which this additional information would impact upon their views regarding priority for transplantation.

3. Results

3.1 Response to criteria

a) Expected prognosis following operation

The expected prognosis following the liver transplant operation caused the least moral discomfort as a criterion for differentiating between patients on the waiting list and was considered to be highly important by all four focus groups. In general it was felt that the

greater the life expectancy post transplant the greater the priority for transplantation. Some focus group members suggested that prognosis was so important that it should outweigh the time spent on the waiting list as a criteria for differentiation.

'Well you are talking of 9 months as against 10 years...the one guy he has waited 9 months more but the other guy could live 10 years more and I think 10 years outweighs 9 months'.

Other focus group members commented that the difference in survival times between the individuals although significant in general was not as important to them within the context of this exercise because the lowest level of survival (5 years) would still be quite significant to the individual/s concerned:

'Well the minimum is 5 years isn't it? I mean 5 years is not much, but in the context of dying now, it's a substantial choice isn't it, whatever your age'.

Although quality of life was not included specifically within the profile descriptions, all focus groups raised the question of the quality of survival post-transplant independently. Group 2 considered this issue at length and concluded that the quality of life experienced was an important criteria which needed to be balanced against the expected length of survival following the transplant:

' And having had a transplant, your quality of life has got to be improved and you can make the most of what you have got left, be it 5 years, 10 years, 15 years or whatever. I mean as far as each and every one of them is concerned, I mean life expectancy is not final, you've got to make the best use of what you have got'.

'I mean if I look at my mum and my mother in law...I think there's about a couple of years difference in age between the two of them, but if it came to the case that they were both up for a liver transplant, without having any disrespect to the mother in law I know who I would vote for, just basically because of the amount they can get up and do and the quality of life and whatever. One tends to sit at home all day and smoke a lot and doesn't do an awful lot else other than moan and grumble, and the other one is out and about and doing things with other people and whatever....I mean she is 68 and she is out marshalling for the RAC at the moment somewhere'.

'I think as far as I was concerned, if I was on a liver transplant waiting list and I knew that even if I had the transplant I wouldn't be able to get up and about and do things, I would basically be virtually housebound and whatever, I would seriously consider whether it was

worth it. I would need to know for my own piece of mind that I was going to go through the surgery knowing that there was going to be something better on the other side'.

Whilst it was recognised that interpersonal comparisons were inevitable, the difficulties of measuring and interpreting quality of life were also remarked upon:

'Yes I think all of us would resist the idea of somebody else making judgements about our quality of life and I think that's just natural that you would do that, in the sense that you would feel you would be the only person who would evaluate what it would mean to you and this (exercise) is about the opposite of that really, which is not you evaluating that but somebody else evaluating it'.

'I suppose it's like saying that we have got a better life, a better standard of life than somebody in a wheelchair, yet they would argue that their standard of life is just as good as ours.'

'At least you can count and compare-say between 5 and 15 (years). Comparing different qualities of life is much more difficult'.

b) Age of the patient

The significance of age was interpreted in two main ways. The majority of focus group members felt quite strongly that age should not be a discriminatory factor except in a situation where it would have some impact upon the expected prognosis following the operation:

'Everyone should have the right to treatment, and age really, in my mind, shouldn't come into it unless there are other factors which would perhaps exclude that person because they are 60 and they perhaps have a dicky heart or some other disease which in pounds, shillings and pence wise isn't good value for money to do it'.

'Surely the only reason it (age) should matter is if it had some bearing on the amount of the success of the actual operation, if the older you get, the far less or far more likely the operation is not to succeed, then perhaps that should have some bearing on it'.

A minority thought that age was an important criterion and expressed a preference to differentiate in favour of the younger individuals in the exercise. The reasoning behind this argument was expressed in terms of an efficiency criterion on the basis that they would have the benefit of more life years in the future and on the basis of a fair innings [Williams 1997]:

'The person who is 60 (Tom) he has already lived 20 years longer than the person who is 40, so they have had 20 years more life than the 40 year old' 'Tom would not be high on my list.....because he is 60...he has had a good do, he has obviously had a good life, let the young ones have a go'.

There was a general feeling that discrimination on the basis of age *per se* (an equity criterion) would only become important if the age differences between the individuals were more pronounced:

'I think that would probably be the emotional sort of aspect.....I mean none of these are young, young, I mean the youngest is what 40, so you are not talking about children or adolescents.....

'A say 10 or 11 year old compared to a 40 year old is quite different really isn't it?'

One possible interpretation of this latter argument is that group members thinking was shaped by a conception of 'age zones' and that the 40 and 60 year olds could effectively be considered as positioned within the same zone, whereas children and the elderly e.g. 80 year olds are seen as in a separate and special zone with different moral implications.

c) Whether the patient can be considered to be personally responsible for their illness e.g. through alcoholic liver disease

The debate around the issue of patient responsibility oscillated between the ethics of responsibility and character, and the ethics of impartial justice. Some group members considered that alcoholism should be viewed as an illness and that these individuals should be given a chance on the basis that they had now given up drinking:

' I mean alcoholism is just as much a disease as hepatitis if you like. To start off with it might be sort of self-inflicted, but I mean these people have said they have given up drinking and it has been sort of decided, well by psychologists that they are unlikely to start again. So as far as I am concerned they should be given the same chance as anybody else. I mean if they say 'well no, I am not packing up drinking, why should I?' Well fair enough go to the back of the queue.'

'My next instinctive reaction to it is to think I need to get past that (the alcoholism) and think it's about you know their values as individuals'.

Other group members were less benevolent in their views because they considered that those individuals with alcoholic liver disease had already had their chance and there would always be the possibility in the future that these individuals would return to drinking.

'I don't think the people who drink alcohol deserve, basically I don't think they deserve it.

'I agree with you at this point in time, with the information that we have got, I totally agree with what you say. That's my belief as well, that somebody who has abused their liver doesn't deserve to have a replacement'.

After some discussion and deliberation all of the focus groups eventually came to a consensus view that individuals with alcoholic liver disease should be given another chance (through a liver transplant operation) provided that there was strong evidence that they would not relapse in the future. Although there was a general feeling that such individuals should not be barred completely from the list because of their alcoholism, there was also a feeling that they shouldn't have the same chance as people who had acquired a non alcohol related liver disease :

'Well yes I think you have got to (give them another chance) or otherwise you know they would go back to drinking'.

'I mean I would be quite willing to give them another chance but if it were between them and me, I am sorry.....'

'I wouldn't want them to have another chance in front of me!'

'Well yes, I wouldn't say that they don't deserve any treatment, but if people who drink know what it does, they do it, they should face the consequences. That's my opinion'.

d) Length of time spent on the waiting list

In two focus groups the length of time already spent on the waiting list was seen as an 'automatic' criterion invoking a mechanistic process which helped to avoid making difficult decisions:

'I mean if the only criteria you have is who has been on the waiting list the longest then it is very easy, you don't have to make any other decision at all do you. You just look at Jayne who has been on the waiting list for 12 months, and Tom who has only been on for three months, so we will give it to Jayne and that is it and so it's much easier isn't it?'

'But it is very fair isn't it.....in a sense what they do now.....because nobody is making any judgement'

The time spent on the waiting list was also perceived as a culturally acceptable phenomenon:

'Well the waiting list is normal for our country because we queue for most things'

However, in group 2 (the youngest in age profile) there was suspicion that time spent on the waiting list potentially disguised manipulations and massaging:

'I am a bit suspicious about the idea of waiting lists anyway because in a sense they can be massaged...clinicians can say 'yes I will put you on the waiting list because I know you are going to have to wait a long time so I will put you on now'. Somebody who is maybe more urgent may not be put on until a later time'.

In group 4 (the oldest in age profile) the cultural acceptability of this criterion was questioned. It was argued that liver transplantation was too important a procedure for the simple queuing response:

'But there is no life and death in the things we queue for but there is in livers'.

e). Whether the patient is being transplanted for the first time or is being re-transplanted.

In all the focus groups despite the efforts of the study co-ordinators in prompting the discussion, it was difficult to get the group members to discuss this criterion at length. Members tended to quickly move off this subject and consider the other factors included in the exercise. The brief discussion around this criterion in all focus groups lent support to the view that it may not be ethical to re-transplant an individual when this would mean that another individual waiting for their first transplant would not receive a donor liver as a consequence:

'I don't know whether they should be given another chance or not. But if you do give somebody a second one is it depriving another person?'

'Well you could say that they have already had a go, let someone else have a turn and let them go through the stage of waiting on that waiting list until they get to the top'.

f) Social background of the individuals

Although there was a consensus of opinion that this extra information was important in all four focus groups, the presentation of further information regarding the social background of each of the individuals concerned (Appendix 2) made it more difficult for members to come to a decision regarding priority for transplantation:

'They have all got as far as I can see.....something that's worth having the liver transplant for, but they have all got something in their background that is making you stand back and think, 'well no, not really'. So it's made it even harder'.

'I quite honestly think that everyone of them in some way deserves a liver transplant, deserves to be the one out of the five to get the one liver that is on offer, and they have all got things that would drop them down the list...'

In all four focus groups, 'family responsibilities' in the form of caring for dependant and young children were expressed as a valid criterion for prioritisation:

'Jayne.....is the main carer for her grandchildren because her daughter is too mentally ill to look after them....if anything happens to Jayne her grandchildren, who knows, will probably go into care'

'Jayne has got a mentally handicapped daughter who has got two young children, so you are looking then at having to find somebody else to act as carer for both her and the grandchildren, which is then going to put quite a lot of financial strain on the health service'.

However, there was disagreement amongst group members as to the extent to which social standing should enter into the equation:

'I would pick Tom..... when you read that Tom could possibly by receiving this operation go on to help other people in the wider issues'

'Is it fair to discriminate against (Adam) and say he doesn't deserve a transplant because he is in and out of prison and is unlikely to get a stable job? That doesn't seem to me to be a fair justification'.

'Well I think Adam, I mean call me heartless, but if he was my husband I would be glad to get shut!!! If he had left me for 16 years, in and out of prison with a 6 year old and a 10 year old I would be glad to see the back of him. And he has never done a decent day's work in his life and he has never brought any money home - I wouldn't put him at the top of my list to be fair'.

3.2 Processes of argument

Although all of the focus groups commented upon the difficulty of the task they were asked to undertake, there were examples of arguments becoming more sophisticated as the discussion progressed, suggesting that a steep learning curve can be achieved in public involvement in discussion of these issues. Group 4's discussion of the expected prognosis criterion provides an example of an argument developing during the discussion. Initially, the group members chose to treat the donor liver as an end in itself: 'Ignore the people, the transplanted liver has a choice of living for 5 years or 15 years' to a later justification with (we would argue) more moral depth and sophistication: 'You are not only looking at the patient, you are also looking at the family of the person who gives the liver'.

A more striking example of arguments becoming more sophisticated as the discussion progressed was the tendency for all four focus groups to discuss methods for weighting the criteria involved and procedures for prioritising patients on that basis. Groups 1-3 took some time to get to this and developed their thinking during the latter part of the discussion. Two groups, 1 and 3, considered using the criteria in a stratified way:

'But if you have 10 people all with the same success rate and you have only one liver, then I think circumstances should come into it'.

'I'm coming to think its got to be a waiting list plus a certain points system but based on what? I haven't made my mind up yet. I think the points system has got to be a little bit geared to age'.

Group 2 discussed the possibility of validating scores for criteria associated with social background by using several indices to measure the same criterion'.

'If you look at a scoring system based upon a number of issues, those issues should be tested at least twice in the scoring chart... So you may mark low say on academic or social standard, but you could test it in some other way further along the process to double check your mark'.

Group 4 started to discuss a system of percentage weightings for the criteria early on and then proceeded to accommodate additional criteria within this system. When presented with the additional information on social background from the second part of the exercise, Group 4 remained confident of being able to accommodate this additional information within their system. However, the other three groups began to express

doubts, suspecting that there is a point beyond which new information becomes unmanageable:

'I suppose that's why I find this (new) information has disabled me completely'

and also an attraction to a quantifiable system for prioritisation, to simplify matters and to avoid prejudice:

'Its got to be something very cut and dried. Black and white. Your age is your age. Full stop'.

'Maybe that's the attraction of simply counting years because at least that is quantifiable'.

4. Discussion

In contrast to the previous quantitative surveys undertaken on this topic, most notably the quantitative survey upon which this study was based [Ratcliffe, 2000], equity in the provision of donor organs did not come through very strongly in the focus group discussions as an issue of particular importance to the participants. This may partly be explained by the study design in which participants were encouraged to think in terms of the allocation of one available donor organ to one of five patients on the waiting list, rather than the allocation of a number of organs to specific groups of patients. The issue of patient responsibility for their illness took up a disproportionate amount of time and attention in all of the focus groups and produced a wide range of responses. This may reflect the potential ambiguity surrounding the concept of personal responsibility and personal blame and an awareness of conflicting arguments. By the end of the discussion on this issue, most focus group members resisted the 'hard line' position on personal responsibility and gave real weight to their doubts as to whether people can always be considered as personally responsible for their self-abusive behaviour. Respondents appreciated that the expected prognosis following transplantation provided a good index of value for money and were attracted by its quantifiable nature after having struggled with more qualitative criteria. However there was also an acute awareness, particularly in Group 2 that prognosis was not just about life expectancy but was also about the quality of future life years. With the exception of one or two members (who suggested that they would differentiate between the individuals in this exercise on the basis of age), the majority of respondents seemed to prefer to view age in terms of broad life zones which militated against discriminating between the 40 year olds and the 60 year olds. There

was strong evidence to suggest, however, that wider age intervals, in particular the case of young children, would invoke more wide-spread discrimination and that the reasoning behind such discrimination would be based more strongly on the principle of equity rather than efficiency. The mechanistic fairness of the waiting list was attractive to two of the groups, but the youngest group was mistrustful of this, suspecting that it disguised the manipulations of the transplant physicians. The oldest group felt that too much was at stake to rely on the simplistic justice of the waiting list. The reason/s as to why the first transplant versus re-transplant criterion was not debated to the same degree as all of the other criteria are not entirely clear. However, it is likely that focus group members did not place as much importance upon this criterion as a discriminating factor. This observation draws parallels with the results of the quantitative survey from which this qualitative study originates. The quantitative survey found that of the five criteria considered (these being identical to the five criteria used in this qualitative study), the majority of respondents ranked first transplant over a re-transplant as the least important criterion overall [Ratcliffe, 2000].

In terms of the processes of argument, three groups exhibited progress in the sophistication of their thinking during the course of the discussion, moving slowly towards developing systems to weight criteria and assign scores to individual patients – then expressing doubts as to the viability of such systems to accommodate a large quantity of information (incidentally, the groups were not at any time asked or encouraged to develop systems for weighting criteria by the study co-ordinators, this was an entirely spontaneous development). The fourth group (the oldest, male dominated group) developed the idea of a weighting system early on and seemed resolved to keep to this, confident in their ability to accommodate new information.

5. Conclusions

The focus group members were more receptive to the importance of some criteria than others, though they saw some difficulties in applying all of the criteria presented. In the case of most criteria, they were willing to explore their possibilities in terms of fairness in some depth and make a real effort to balance them. The introduction of systems for weighting the criteria represented an attempt to do this in a formal and explicit manner.

This suggestion of a weighting system is interesting, not only because of the sponaneity of it's introduction in all four focus groups but also because it mirrors the 'points system' for donor liver allocation which is currently in place in the United States [Ubel and Loewenstein, 1993] (although no focus group members appeared to have any knowledge of the U.S. system). The results of these discussions suggest that there would potentially be wide public support for a more open and explicit system of donor liver prioritisation than exists presently within the UK and that this system should be based on wider criteria than simply the time spent on the waiting list. However, the exact nature of such a system (in terms of the criteria to be included and the weight which should be attached to each criterion) remains difficult for members of the general public to define.

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Appendix 1: Descriptions of patient profiles

Jackie

Jackie is 40 years old

She has spent 12 months on the waiting list for a liver transplant

Jackie's need for a liver transplant has arisen because she has damaged her liver by drinking a lot of alcohol
However, she has now given up alcohol, and has been assessed by a psychologist as unlikely to return to drinking

This is Jackie's first transplant

If the operation goes well, Jackie's expected length of survival following the transplant is 5 years

Tom

Tom is 60 years old

He has spent 3 months on the waiting list for a liver transplant. Tom's need for a liver transplant has not arisen due to alcohol but because he has acquired a naturally occurring liver disease

This is Tom's first transplant

If the operation goes well, Tom's expected length of survival following the transplant is 15 years

James

James is 40 years old

He has spent 12 months on the waiting list for a liver transplant. James's need for a liver transplant has not arisen due to alcohol but because he has acquired a naturally occurring liver disease

This is not James' first transplant. He has been transplanted previously but the operation was not successful. This failure was due to clinical factors beyond his control

If the operation goes well, James' expected length of survival following the transplant is 5 years

Jane

Jane is 60 years old

She has spent 12 months on the waiting list for a liver transplant

Jane's need for a liver transplant has arisen because she has damaged her liver by drinking a lot of alcohol
However, she has now given up alcohol, and has been assessed by a psychologist as unlikely to return to drinking

This is Jane's first transplant

If the operation goes well, Jane's expected length of survival following the transplant is 15 years

Adam

Adam is 40 years old

He has spent 3 months on the waiting list for a liver transplant. Adam's need for a liver transplant has not arisen due to alcohol but because he has acquired a naturally occurring liver disease

This is not Adam's first transplant. He has been transplanted previously but the operation was not successful. This failure was due to clinical factors beyond his control

If the operation goes well, Adam's expected length of survival following the transplant is 15 years

Appendix 2: Further information presented on social background

Jackie

Jackie is divorced and is now living in a long-term relationship. She and her partner have care of her two children from her marriage, aged 13 and 10.

Jackie worked for many years on the checkout at Sainsbury's. She is too ill to work at present but if her health improves she is likely to be able to find similar employment without difficulty

Tom

Tom is a widower with no children.

He is an eminent geneticist but he has had to retire from his full-time research post through ill health. However if his health improves he is certain to be offered consultancy in relation to a research project into genetic disease

James

James has no children. He lives in a gay relationship with a long-term partner

He is an electrician by trade but is too ill to work at present. If his health improves he would be able to earn a good living at his trade again

Jane

Jane is married with a daughter in her 30's and two grandchildren. Jane is the main carer for her grandchildren, as her daughter is mentally ill and is often unable to look after her children

Jane worked as a school teacher but retired in her 50s. She is too ill to work at present and has little prospect of paid work if her health improves

Adam

Adam is married with three children aged 16, 13 and 10

His employment history is irregular, unskilled and casual. He has also been involved in petty crime on a number of occasions and he has had two short prison sentences. He is too ill to work at present but if his health improves his prospects of regular and stable employment are not good