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Development of a questionnaire to elicit public preferences regarding health inequalities

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Introduction

A review of relevant literature within health economics, psychology and moral philosophy suggests that people want resource allocation decisions in health to be informed by considerations of equity as well as efficiency. A number of empirical studies demonstrate that people are willing to sacrifice overall health benefits for a more equal distribution of health (Dolan and Shaw 2001a). However, it is not clear from the available evidence exactly which distributional considerations people want to take into account when allocating resources. Further, on the whole, discussions about equity are rarely cast in quantitative terms (but see Olsen 1994) and so it is not clear to what extent people want various equity notions to be taken into account.

In this study funded by the ESRC Health Variations Programme, we have elicited the views of the general public in order to quantify people's preferences regarding equity in health. The two-year study first explored whether people wish to give differential priority to groups with different characteristics (such as age, family responsibilities and the extent to which people are 'responsible' for their illness). The study then derived a way of asking questions on various inequality issues which enable people to indicate their strength of preference for different sorts of reduction in health inequalities.

This paper reports upon these attempts to present to members of the general public meaningful trade-offs between efficiency and equity. The purpose of this paper is to report on the development of the questions and to indicate how they might be used by other researchers. Part A shows how the questions were developed from a series of pilot interviews and made suitable for use in either an interview setting or postal survey. Part B provides some guidance on administration and reproduces the questions in order to make them available to interested researchers and policy makers. Those readers whose main aim is to access the questions, may wish to move straight on to Part B.

PART A

The first part of the paper, Part A, shows how the questions were developed during a series of pilot interviews and made suitable for use in either an interview setting or postal survey. Part A comprises five sections. Section 1 provides the research context and a brief over-view of the questions. Section 2 provides information on the pilot sample and describes the development of the 'inequalities in health' questions. Section 3 describes the development of the 'age' questions. Both of these sections describe how piloting led to the final format of the questions and note any additional changes that are needed for postal administration of the questions. Section 4 provides some summary comments and contact details for further information.

SECTION 1

Background

Until recently, the National Health Service has sought to allocate resources between areas on the basis of securing equal opportunity of access for equal need. The entire basis of allocating resources is now under review, and ministers are considering adopting a new criterion: contributing to the reduction in avoidable health inequalities (Department of Health 1999). If fairness, in the form of addressing health inequalities, becomes another policy objective, then the policy makers' problem becomes far more complex. They must know what is meant by a 'fairer' distribution of health care resources, and the extent to which such equity considerations should be traded off against efficiency considerations.

Rationing, according to the Oxford English dictionary is the fair distribution of finite resources. Therefore the rationing debate comprises two questions, one about what allocations are fair and another about who are to make these decisions. The objectives of our research are to identify what *ordinary citizens* interpret as 'fair' in relation to health and health care. This analysis of lay perspectives shifts the focus from the 'expert' views of ethicists and philosophers. It also allows the body of research evidence to move on from investigating the existence and correlates of health inequalities, and proceed to the systematic investigation of the relative importance attached to them by members of the general public.

Literature

The inequality debate has produced a wealth of empirical facts about the existing inequalities. However, it has rarely sought people's preferences over these inequalities. In response, Williams (1988) has suggested that people may place different importance on different forms of inequality. The published literature suggests that the general public is willing to sacrifice some gains in health in order to achieve a more equitable distribution of gains. Further, it seems that they are willing to differentiate between different groups of individuals on the basis of a number of personal characteristics.

There are some recurring themes in the published literature. There is a perceived need to give *higher* priority to some categories of people, and *lower* priority to others in the provision of health care; a finding more or less in accord with the concept of *vertical equity* (where individuals who are unequal in society are treated differently). In terms of higher priority, a number of studies show that the general public feel the young should be given priority over the old (Williams 1988; Charny *et al.* 1989; Busschbach *et al.* 1993; Bowling 1996; Nord *et al.* 1996; Ratcliffe 2000), and that those looking after children should be accorded higher priority than those without such responsibilities (Williams 1988; Charny *et al.* 1989; Neuberger *et al.* 1998). In terms of lower priority, the question most often asked of the public is whether those people who contribute to their own illness deserve to be treated the same as those who do not. There is some evidence to suggest that people wish to discriminate against those who are considered to be responsible for their ill health by smoking, drug abuse or heavy drinking (Williams 1988; Charny *et al.* 1989; Nord *et al.* 1995; Bowling 1996; Dolan *et al.* 1999; Ratcliffe 2000).

However, on a closer reading, there are some contradictions in the available evidence (Kneeshaw 1997). For instance, some evidence suggests that the young should be prioritised at the expense of the old, whilst some suggests that age should make no difference to the provision of healthcare. The problem seems to arise when respondents give different answers because they are being presented with questions framed in different ways. To illustrate this, compare the inconsistencies within the OPCS (Office of Population and Censuses and Surveys) omnibus survey May-June 1995. Although 50% of the respondents in the OPCS omnibus survey agreed that "higher priority should be given to treating the young than the elderly", 80% agreed that "high cost technology...should be available to all regardless of age" (Bowling 1996). When presented with a direct choice between the young and old, respondents to the OPCS omnibus survey chose to prioritise young people. That is, differences in wording between the questions means that the questions are not actually tapping into the same public preferences. It is often the case that poorly or ambiguously worded questions lead to inconsistent responses. Respondents may answer two questions designed to elicit the same response, in two different ways (as is likely in this example). Alternatively, they may give views that are incompatible, or they may not understand the question being asked (Mulkay et al. 1987).

Further, most of the studies cited above have asked respondents to self-compete questionnaires, and those questioning the quality of survey evidence have pointed out that it can often provide 'simple and superficial' information (Donovan and Coast 1994). The studies conducted within health economics have largely asked respondents to give quantitative answers to tightly defined questions, often with little or no time for deliberation. However, respondents' views may change with knowledge (McIver 1995) or through deliberation (Dolan *et al.* 1999). This calls into question the validity of some of the survey data and may cause the elicited opinions or preferences to lack stability.

Slovic et al. (1990) observe that preferences for and beliefs about events of any complexity, are often constructed (not merely revealed) in the generation of a response

to a choice task. A wide psychological and sociological literature demonstrates that values change significantly in accordance with variations in the process of elicitation (Denzin 1978). There is some evidence (Abelson *et al.* 1995) that individuals respond differently to questions about preferences when they are asked in groups as opposed to individually. Different response modes can lead to differential weightings of attributes and different preference assessments. For instance, Tversky and Kahneman (1974) demonstrate that the predominant attribute is given more weight when preferences are assessed using a choice mode, than when preferences are assessed using a matching task. Tversky and Kahneman (1981) also note that simple wording changes (e.g. from describing outcomes in terms of lives saved to describing them in terms of lives lost) can lead to different preferences.

In addition to perceptual framing effects on choice, sociological analyses highlight the importance of social framing effects. A recent re-statement of the sociological approach to decision-making shows that whilst choices depend upon current preferences and local contexts, they also influence the development of the social context which is a conditioning factor in the development of future preferences (see Giddens 1991). The implications of this are similar to those emanating from the psychological literature; that is, choices are not simply the expression of a set of pre-existing preferences but are developed and constructed in the process of making them.

However, some way of quantifying the public's views is necessary if they are going to be of use to policy-makers. That is, the *strength* of the public's preferences are required in addition to the general direction of them. Where social surveys (like the OPCS) present people with rather general statements such as 'treatments for children should be given high priority' it is difficult to convert results into practical policy. There have been studies which have attempted to estimate equity-efficiency trade-offs, but they have provided a very wide range of implied trade-offs (see Busschbach *et al.* 1993; Cropper *et al.* 1994; Johannesson and Gerdtham 1996; Lindholm *et al.* 1996; Nord *et al.* 1996; Johannesson and Johansson 1997).

The implication for future research is that care must be taken to ensure respondents are answering the questions researchers actually want answered. It may be that other methods can be used either to supplement survey data or to offset some of its shortcomings. In response to these problems, researchers at the Universities of York and Sheffield, funded by the ESRC Health Variations Programme, conducted a study to elicit and quantify the publics' preferences regarding equity and variations in health. The study combined a large-scale structured questionnaire survey with more detailed discursive interviewing. The polarisation between quantitative and qualitative research is artificial and both types of research and data are usually required in order to provide the highest quality evidence. The advantage of a combined approach is that it enables the research to pursue the statistical analysis of behaviour in the aggregate with the individual exploration of the way in which choices are understood by the individuals who make them. This enables the link between social context and the way in which an individual understands the relevance of that context to be examined. More specifically in this instance quantitative questions were developed from qualitative analysis at an early stage, to ensure greater confidence in the interpretation of answers.

The interview schedule was constructed during a period of qualitative research involving in-depth interviews and focus groups and was refined during extensive piloting. The interview schedule was subsequently simplified into a format suitable for postal administration. During the pilot interviews, attempts were made to define both equity and efficiency in terms that are policy-relevant and unambiguous, and in a manner that makes measurement possible (c.f. Williams 1997).

Overview of the questions

The pilot interviews experimented with different ways of presenting the trade-off questions in an interview setting. In addition, qualitative prompts were used to explore more deeply what people are thinking about when they answer these questions. The findings from the pilot interviews led to the construction of a series of trade-off questions which were suitable for either interviewer or postal administration. In the pilot interviews, respondents' talk was coded to check how they coped with the questions and instructions; to check whether respondents understood the questions as intended; and to check how respondents set about answering the questions. Respondents provided feedback in one of two ways to the interviewer. Half were asked to think-aloud as they went through the questions. Half self-completed the questions, unobtrusively observed by the interviewer, and were taken though the questions after completion by the interviewer using prompts as necessary.

The 'inequalities in health' questions

A number of 'inequalities in health' trade-off questions were presented to respondents. Each constrained choice question presented information on differences in health between two groups of people. Question 1 presented information on life expectancy at birth. Question 2 showed prevalence of self-reported limiting long-term illness for men aged 45 to 64 and Question 3 showed rates of childhood death (from 3 months to 14 years). The questions were preceded by a brief description of the task and an explanation of the population sub-groups.

Each question comprised a number of pair-wise choices. In order to explore whether respondents prefer to treat both groups equally, or to give more priority to the disadvantaged group, respondents were asked to choose between an untargeted and targeted programme (labelled Programme A and Programme B respectively). Respondents were told at the beginning of the interviews that the two groups were of approximately equal size and for each question were reminded that the two programmes would cost the same.

It was assumed that of those who chose Programme B (i.e. to target the worse off group), some would be prepared to sacrifice more than the stated cases to reduce inequality and so these respondents were presented with a series of reductions in efficiency in terms of health outcome.

In addition, respondents were presented with a question - Question 4 - which in exactly the same way asked them to trade-off two groups of people: one of which have taken care of their health and one of which have not.

The 'age' questions

Respondents were asked how they would allocate resources across different age groups. First they were asked to rank five ages in order of priority and explain why they had placed the ages in the order they had. Respondents were first told that they could prevent the premature deaths of groups of people at five different ages; then that they could only give the groups an extra five years of life.

Following this, respondents were asked to choose between two programmes which would provide the same benefits to two different age groups. The person trade-off approach involves asking respondents how many outcomes of one kind they consider equivalent in terms of social value to x outcomes of another kind. It was originally developed by Patrick *et al.* (1973) who called it the equivalence of numbers procedure, and later deployed by Nord (1992) under the new name. In this instance, respondents

were asked to consider pairs of programmes that differ with respect to the age of the people involved and to indicate how many people there would have to be in the first programme relative to the second for the two programmes to be equal in social value.

Table 1 displays all the questions which have been successfully completed in either an interview or survey setting.

Table 1: The questions

Th	e ' inequalities in health' questions		The 'age' questions
Π	Average life expectancy	П	Ranking of five ages - preventing death
Π	Long-term illness	П	Ranking of five ages - five extra years
Π	Childhood death	П	Person trade-off – by age
П	Person trade-off - by 'lifestyle'		

SECTION 2

Pilot interviews sample

Every 8th person appearing on the electoral register in 3 wards in York was contacted and invited to participate. Out of a total of 1,500 letters initially distributed, 467 people (31%) agreed to participate. To ensure that the sample was broadly representative of the wider population, respondents were selected for interview based on information on a broad range of characteristics obtained from their reply slips. A sub-set of the sample (40) was invited to attend pilot interviews. All interviews were carried out by one of the authors and two other researchers. Each interview took place at the University of York and lasted for approximately one hour. Table 2 shows the characteristics of the pilot interview sample. The characteristics of those who attended the pilot interviews were similar to those of the population of Yorkshire and Humberside.

Table 2: Characteristics of the pilot interviews

Category	%	Yorkshire and Humberside*
Sex:		
Male	45%	47%
Female	55%	53%
Age:		
<44 years	45%	49%
>45 years	55%	51%
Mean age	49	
Dependants:		
Children	67%	66%
No-children	33%	34%
Smoking status:		
Smoker	25%	27%
Ex-smoker		
Non-smoker	75%	73%
Economic status:		
Employed	53%	56%
Other	47%	44%
Tenure		
Owner	100%	67%
Social sector	-	24%
Private renters	-	9%
School leaving age:		
Minimum	60%	68%
Stayed on	40%	32%
Total	40	4014

^{*} The Annual Survey of English Housing 1998/1999 and The British Household Panel Survey 1998.

Development of the 'inequalities in health' questions

In the first pilot interviews (n = 20), respondents were presented with questions as shown in Figure 1.

Figure 1: Average life expectancy

As you might know, average life expectancy differs by social class.

Whilst actual life expectancy varies between individuals, on average, men in social class 1 live to be **78**. On average, men in social class 5 live to be **73**.

Imagine that you are asked to choose between two programmes which will increase average life expectancy. Both programmes will cost the same.

Programme A is aimed at both social classes equally and Programme B is aimed more at social class 5.

Please indicate whether you would choose A or B by ticking one box.

Pro	ogramme A			Programm	еВ
Increase in a	verage life expe	ctancy	Incre	ase in average lif	e expectancy
Class I	Class V	√for A	√for B	Class I	Class 5
2 years	2 years			0 years	4
					p
2 years	2 years			0 years	3.5
2 years	2 years			0 years	3
2 years	2 years	A STATE OF THE STA	T	0 years	2.5
2 70013	2 years		L	o years	2.5
2 years	2 years	The state of the s		0 years	2
			T		
2 years	2 years			0 years	1.5
2 years	2 years			0 years	1
2 years	2 years			0 years	0.5

All 20 respondents found the table difficult to understand. All except one needed guidance with reading the rows and columns, often not realising that there were six choices to make. Of the 20 respondents, 17 failed to discern the efficiency loss and a number could not integrate the textual and tabular information. For instance, one respondent talked about the text as they read it; saying 'that's terrible, I want to aim the programme at class 5', but then failed to target in the table. The general consensus was that the task was too difficult and confusing.

It was therefore decided to present the questions to respondents in two distinct parts and in the form of pictorial representations (see figure 2). The explanatory text was simplified and the factual information presented this time not in tabular form, but as two bar-charts, one for each programme. The charts were drawn in Microsoft Word 6. The present situation was depicted by light grey bars, and the change brought about by the programmes as darker grey blocks. The direction of the change (an increase or decrease) was indicated by an arrow. The magnitude of the change was clearly labelled (i.e. 2 years).

In the first part of each question, in order to explore whether respondents prefer to give more priority to the disadvantaged group, or to treat both groups equally, respondents were asked to choose between an untargeted and targeted programme (the charts were labelled Programme A and Programme B respectively). Respondents were told that both programmes cost the same. If respondents chose Programme A, they were directed to the next question. If they chose Programme B, they were asked to turn over the page to the second part of the same question.

It was assumed that of the respondents who chose Programme B, some would be prepared to sacrifice some efficiency in order to reduce the inequality. So, in the second part of each question, respondents were presented with a series of reductions in efficiency. They were then asked to state whether they would continue to choose Programme B in each response category, or whether at some point they would switch to Programme A.

Figure 2: Average life expectancy

As you might know, average life expectancy differs by social class. There are differences between people in social class 1 (for example, doctors and lawyers) and people in social class 5 (for example, road-sweepers and cleaners). These two groups are more or less equal in size (they each make up about 7% of the population).

Whilst actual life expectancy varies between individuals, on average, people in social class 1 live to be 78 and in social class 5 they live to be 73.

Imagine that you are asked to choose between two programmes which will increase average life expectancy. Both programmes cost the same.

In the two graphs below the light grey part shows average life expectancy, and the dark grey part shows the increase in life expectancy. There is a separate graph for each of the programmes.

As you can see, Programme A is aimed at both social classes and Programme B is aimed only at social class $\bf 5$.

Please indicate whether you would choose A or B by ticking one box.

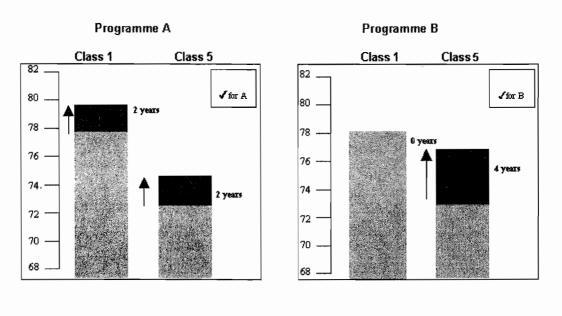
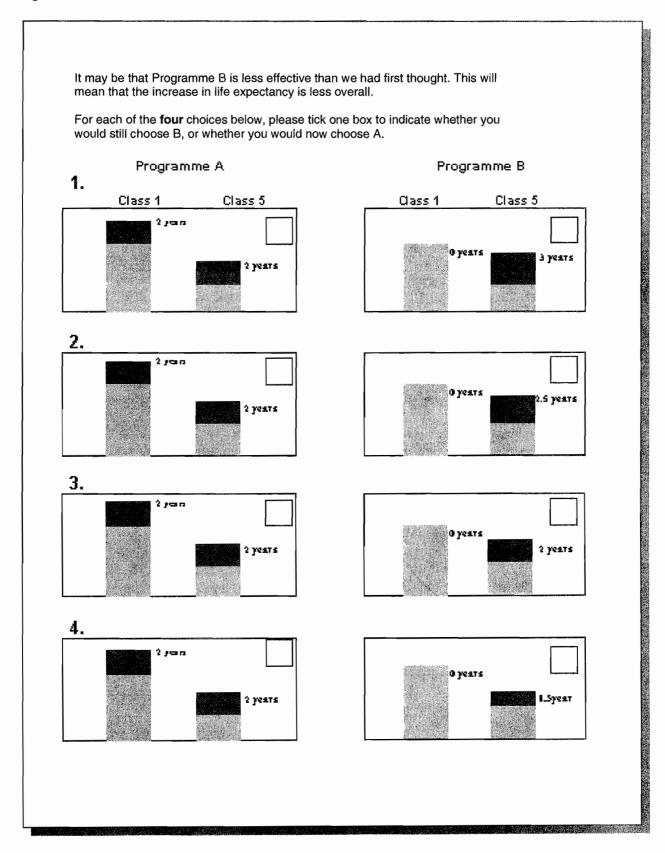


Figure 2: continued



In the first part of each question, the information regarding the size of the health gains (efficiency) in the alternatives is easy to understand and possible to assess by the respondents. In the second part, the implications of choices are made clear (through changes in size of the shaded part in the graph). In the second batch of pilot interviews (n = 20), respondents successfully discerned the efficiency loss. They realised that the pursuit of equity requires a sacrifice, namely the conscious departure from the pursuit of health maximisation:

"Looking at it, it seems at first fairer to give everyone the chance to live longer, treat them all the same. But it's not so simple, because of the differences. I want to make class five live longer. It's not just how many lives are prolonged, it's which lives".

The results from the pilot interviews suggest that trade-off questions are cognitively too difficult when presented in a table. In contrast, the graphs enable a broad range of people to indicate their strength of preference for a reduction in health inequalities. The final version of the 'inequalities in health' questions used the same trade-off template to present a number of different sorts of reduction in health inequalities.

The health inequalities presented were defined in terms of average life expectancy at birth (Question 1), limiting long-term illness for men aged 45 to 64 in (Question 2) and rates of childhood death in (Question 3), as people are familiar with these representations of health (Dolan and Shaw 2001b). In order to explore whether preferences vary because of the type of difference in health, a number of variants of the equity/efficiency questions were produced, altering the frame of reference. Questions presented identical information on inequalities defined by (a) social class, (b) the healthiest 20% and unhealthiest 20% of the population, (c) sex and (d) smoking status.

In addition, respondents were presented with Question 4, which asked them to trade-off two groups of people: one of which have taken care of their health and one of which have not. This 'life-style' sub-grouping was defined as those who 'have taken care of their health (have eaten healthily, exercised, not smoked)', and those who 'have not taken care of their health'.

The relevant sub-groups were explained at the beginning of each question and respondents told that the two groups were more or less equal in size. For instance, respondents were told that social class one included peoples such as doctors and lawyers and that social class five included people such as road-sweepers and cleaners. No changes were made to the substance of the questions when different sub-groups were presented in different variants (the text and data presented were left unchanged, just the appropriate sub-group labels substituted).

Further, to test whether respondents might be following a particular pattern of response, in the second part of the questions two sets of response categories were produced (numbering six and four). In the postal questionnaire there were four response categories in each question, as the interviews show this number to be manageable for respondents whilst still allowing sufficiently detailed data to be collected.

The pilot interviews probed respondents to explain their reasoning after each part of each question, and from the pilot transcripts, a set of predetermined categories were generated. After the first part of each question, respondents were asked 'can you tell me why you have answered the way you have' and their answers coded as 'treat everybody the same', 'reduce the differences between the groups' or 'other'.

If the respondent chose Programme A (i.e. not to target) they were probed whether they would have chosen to target if the degree of targeting had been smaller, or whether they would always want the benefits to be distributed equally. If the respondent chose Programme B (i.e. to target), they were probed again and their answers coded as 'concern with loss of efficiency', 'concern with reducing inequalities' or 'other'.

In Question 4, responses were coded as 'whether or not a person has taken care of their health is not relevant' if the respondent *refused* to make the person trade-off choice. If they chose B, at the point where the respondent switched from programme B to A, the relevant trade-off was verbally presented to check that they had understood the implications of their choice. Again they were asked 'why is this?' and their answers were coded as 'loss of efficiency', 'too few people', or if they didn't switch to A at any point 'whether or not a person has taken care of their health is important'.

Responses to the prompts demonstrate that respondents understood the questions they were being asked. The 'inequalities in health' questions have been successfully completed by members of the general public in both an interview and postal survey (and the prompts for use in the former are available on request). If the questions are to be used on other research however, the ordering and type of question can, of course, be varied.

SECTION 3

Development of the 'age' questions

In the first pilot interviews (n = 20) respondents were presented with a person trade-off question followed by an open-ended person trade-off questions (see figure 3a&b); both of which provoked questions for clarification and complaints that the questions were too abstract. This reiterates the observation made by Lindholm *et al.* (1996) that open-ended questions are too difficult for respondents. It was decided to present the 'age' questions in the same format as the 'inequalities in health' questions (see figure 4 below).

Figure 3a Person trade-off question

Imagine that you are asked to choose between two programmes which could benefit two different groups of patients. Both programmes cost the same. Without the intervention, people will die in a few days but with the intervention will live for another five years in good health and then die.

In progamme A, people are **70 years old.** In programme B they are **five years old.** For each of the choices, please indicate whether you would prefer programme A or programme B, by placing a tick beside your preferred option.

Programme A Number of 70 year olds w		Programme B	
Number of 70 year olds what for five years	o will live	Number of 5 year olds who will live for five years	
TOT THE YEAR	√for A	√for B	
100		100	
100		99	
100		98	
100		97	
100		96	
100		95	
100		90	
100		80	
100		70	
100		60	
100		50	
100		40	
100		30	
100		20	
100		10	
100		5	

Figure 3b: Open-ended person trade-off question

If given the choice between giving an extra five years of life to **35 year olds** and giving an extra five years of life to **70 year olds**, how many **35 year olds** would you judge to be equal to 100 **70 year olds**?

Figure 4: Person trade-off question

Imagine that you are asked to choose between two programmes which could benefit two different groups of people. Both programmes cost the same.

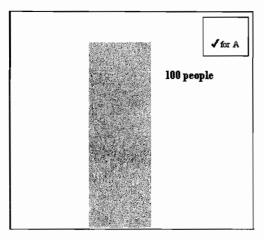
Without the intervention, patients will die within a few days but with the intervention they will live for another 10 years in good health and then die.

People in Programme A are 20 years old, and people in Programme B are 35 years old

Please indicate whether you would choose A or B by ticking one box.

Programme A

Number of **20 year olds**, who will live for ten more years, rather than die in a few days.



Programme B

Number of **35 year olds**, who will live for ten more years, rather than die in a few days.

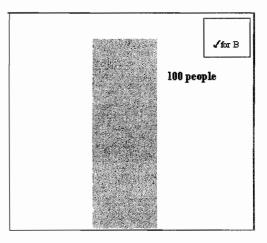
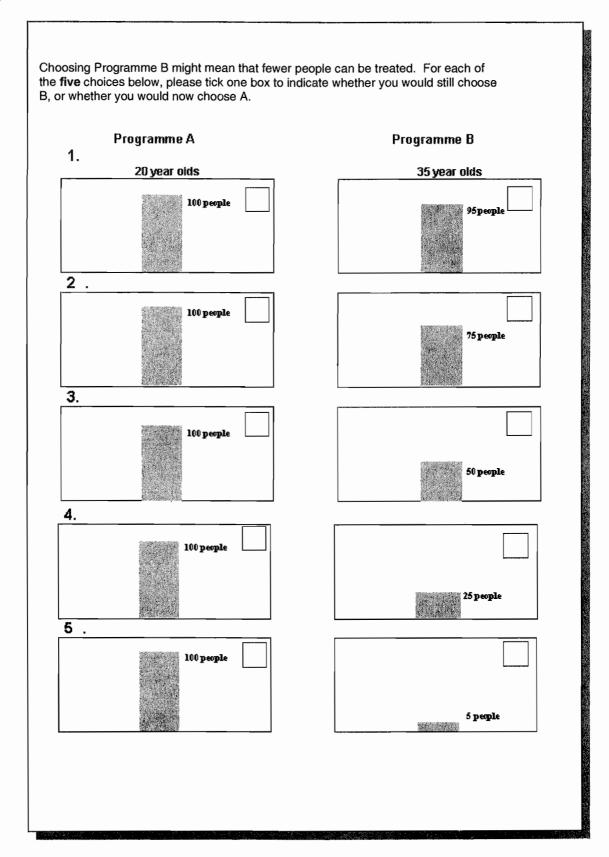


Figure 4: continued



We also wanted to uncover what people were thinking about when presented with people of different ages. In the second batch of pilot interviews (n = 20) respondents were presented with five groups of ages, selected to represent five different stages in the life cycle. The five ages were 5 year olds, 20 year olds, 35 year olds, 55 year olds and 70 year olds. Respondents were told that each group would die in a few days. They were asked to rank the groups in the order in which they would want to prevent their premature death, and so enable them to live a normal life expectancy. Responses from the pilot interviews show clearly that preferences over ages are a function of the life-stage people are seen to be at:

"70 year olds have had a fair innings -so in all instances I would favour the 5 year olds".

I've put the 20 year old first, before the 5 year old, because the child has its whole life before it, but the 20 year old, is a mature adult, with their whole life ahead of them".

"The 35 year old has more to lose. Their death would leave a lot of people bereft. The 20 year old is probably on the first step of the career ladder, but is single and has no responsibilities".

"Death at a young age is a tragic event. At 70 you've had your three score and ten, you're aware of your mortality and may perhaps die at any time anyway. It's less shocking if a 70 year olds dies, less tragic".

Respondents were asked to rank the same five ages on the basis that they could give an extra five years of life to people who would otherwise die in a few days. Respondents were again probed for their reasoning. The objective of this question was to highlight the limited nature of the (five year) benefit by opposing it to a benefit that lasted for the remainder of the recipient's life. Responses from the pilot interviews suggest that presenting respondents with a 'full life benefit' question before a 'five year benefit' question has a profound effect on their response. A number of respondents stated explicitly that the shift in their ranking of 35 year olds was due to exposure to the 'full life benefit':

"For five years the choice is more difficult. It's only five years, so you have to think about who would get most from an extra five years and the thirty-five year old probably has young children".

After the ranking exercises, a number of person trade-off questions asked respondents to consider pairs of programmes differing in respect to the age of the people involved. Respondents were asked to indicate how many people there would have to be in the second programme relative to the first for the two programmes to be of equal social value. In pilot interviews and also the main batch of interviews we carried out, the age groups used were those that each individual respondent had ranked first, third and fifth in the previous question. Since ages 5 and 70 were often ranked first and last, respectively, these ages were dropped from the postal survey and the ages used were 20, 35 and 55. However, it should be noted that any ages may be substituted, depending on the research question to be answered.

Again, respondents were probed to explain their reasoning and in order to ensure that they had understood the person trade-off task, the point at which they expressed indifference was stated verbally and confirmation sought. In conjunction with the

qualitative data collected, a number of consistency tests were carried out on the PTO responses. Since the distance, in terms of strength of preference, between the 5th and 1st ranked ages should be greater than each of the distances between the 5th and 3rd and 3rd and 1st ranked ages, there are two consistency conditions that each respondent's PTO responses should satisfy. First, the number of 1st ranked ages that is equivalent to x 5th ranked ages should be less than the number of 3rd ranked ages that is equivalent to x 5th ranked ages and, second, it should also less than the number of 1st ranked ages that is equivalent to x 3rd ranked ages. This should hold for all values of x.

Researchers have typically interpreted responses to PTO questions as the *ratio* of the number of people in the two groups. If respondents were basing their PTO responses on the ratio between the numbers of people in the two ages, then the strength of preference for the 1st over the 5th age should be the product of the strength of preference for the 1st over 3rd age and 3rd over 5th age. However, the PTO responses in the interviews seem to be driven by the *relative* and the *absolute* difference in the number of people in the two groups, as respondents were willing to trade-off *less* first ranked for fifth ranked people than is implied from their responses to the two other PTO questions.

A number of respondents chose to work from both ends of the table where the choices are clearer. A majority found the switching point difficult and spoke of a 'grey area' where the choice of A or B seemed arbitrary. A number wanted to look at each case individually rather as a group, reasoning that 'people have different situations':

"If the choice was between individuals, then I would want to know other things, whether they had children. But if it's a choice between groups of people, as it is here, then I would just choose the youngest. Because the treatment will be more effective"

"Hm, having said that [that the 35 and 55 year olds may have family] I'll still put the five year old first, because it's a child"

The point at which respondents switched varied across the ages; switching soon when there was not "much to choose between the ages" (i.e. 35 year olds and 55 year olds), and switching later when the ages are more extreme (i.e. 70 year olds and 5 year olds).

A number of respondents in the pilots (n = 8) were reluctant to make the kind of difficult choices that PTO presupposes. It is obviously difficult and unpleasant to make such decisions (Rosser and Kind 1978; Baron 1995). Some avoided the issue by maintaining that all patients should be equally entitled to treatment. But, in those cases where people had preferences for extending equal priorities, they seemed to have good reasons.

"Everybody should get the same healthcare, as everyone pays National Insurance. Except for the children, who aren't responsible for themselves"

"I want to treat everybody the same. You shouldn't get special treatment because you are poor, or female or whatever".

"I'd treat both equally. Programme A covers a broader spectrum of people. Other factors are probably involved, like lifestyle, which programmes couldn't undo". However, the majority did choose to target:

"It's more important, I think, to reduce the differences than reduce the absolute number of deaths".

At the end of the interview respondents were asked how difficult they found the questions and the interviewer coded how much help was needed and the time taken to complete the questions in order to discern whether differences in response could be attributed to systematic differences in respondent characteristics (Mulkay *et al.* 1987). When the questions were presented in a self-completion format, respondents were asked to state the start and finish time for the questions and to rate the difficulty of the questions.

SECTION 4

Summary comments

The preceding discussion has described how the questions were constructed and refined during piloting, and modified into a format suitable for either interviewer or postal administration. Results from the pilot interviews demonstrate that tables of data do not work without a huge amount of explanation, but that graphs seem to work for both self-completion and completion in an interview setting.

Further information on the analysis of the questions completed in interviews and postal survey can be found in papers currently in preparation for publication (Dolan *et al.* 2000, Dolan *et al.* 2001). However, it should be noted that although the descriptive information provided in this paper makes reference to the specifics of our study design in order to ease understanding, any trade-off question about anything can be presented in this general way, and the ordering and type of question can be varied according to individual research interests.

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PART B

In the second part of the paper, Part B, some guidance is provided on the administration of the questions (Section 1) and the questions are reproduced in full (Section 2).

SECTION 1

Guidance on administration of the questions

Concerns about equity are central to any health care system. Yet variations in health make the formulation and pursuit of equity objectives difficult, and give rise to serious policy problems. This study therefore sought to identify what citizens mean by the concept of equity in relation to health and health care; to examine the extent to which the public are prepared to trade-off efficiency against equity in the distribution of healthcare resources; and to furnish policy makers and other researchers with the means to ask the public meaningful questions in relation to equity.

The empirical literature reviewed demonstrates that people want to take fairness into account when allocating health care resources. However, on the whole, the health inequalities debate is not cast in quantitative terms, and so it is not clear to what extent people want various equity notions to be taken into account. Moreover, whilst there are exceptions in the health economics literature, the actual numbers generated by these studies need to be interpreted with care, as most ask respondents to give precise quantitative responses to tightly defined questions with little or no time for deliberation.

At the first empirical stage of this study, an interview schedule was constructed during a period of qualitative research involving in-depth interviews and focus groups (Dolan and Shaw 2001b) and was refined during extensive piloting. The purpose of the interviews was to gain insight into the cognitive processes that respondents used in order to arrive at their stated views. The interview schedule was subsequently simplified into a format suitable for postal administration. The purpose of the postal questionnaire was to determine whether meaningful responses can be generated without the presence of an interviewer; to compare the results of the one-to-one interview and the survey and to generate a dataset which is large enough to test hypotheses statistically.

The interview and self-completion questions were devised to present to members of the general public the tension between the goals of generating health gain and the reduction of inequalities. It was decided to present the questions to respondents in two distinct parts, and in the form of pictorial representations (see below). Table 1 shows all the questions asked.

Table 1: The questions

Th	e ' inequalities in health' questions		The 'age' questions
П	Average life expectancy	П	Ranking of five ages - preventing death
П	Long-term illness	П	Ranking of five ages - five extra years
Π	Childhood death	П	Person trade-off – by age
П	Person trade-off - by 'lifestyle'		

The 'inequalities in health' questions

A number of 'inequalities in health' questions present information on differences in health between two groups (see figure 1). In the first part of each question, in order to

explore whether respondents prefer to give more priority to the disadvantaged group, or to treat both groups equally, respondents are asked to make a discrete choice between an untargeted and a targeted programme (labelled Programme A and Programme B respectively) with the same total benefits. If respondents choose Programme A, they are directed to the next question. If they choose Programme B, they are asked to continue with the question.

It is assumed that of the respondents who choose Programme B, some will be prepared to sacrifice more than the stated cases to reduce inequality. So, in the second part of each question, respondents are presented with a series of reductions in the level of total health gain. Respondents are then asked to state whether they want to continue choosing Programme B in each response category, or whether at some point they want to switch to Programme A.

In the self-completion format of the questions there are 4 response categories in the second part of each question, as the interviews show this number to be manageable for respondents, whilst still allowing data in sufficient detail to be collected.

Figure 1: Average life expectancy

As you might know, average life expectancy differs by social class. There are differences between people in social class 1 (for example, doctors and lawyers) and people in social class 5 (for example, road-sweepers and cleaners). These two groups are more or less equal in size (they each make up about 7% of the population).

Whilst actual life expectancy varies between individuals, on average, people in social class 1 live to be **78** and in social class 5 they live to be **73**.

Imagine that you are asked to choose between two programmes which will increase average life expectancy. Both programmes cost the same.

In the two graphs below the light grey part shows average life expectancy, and the dark grey part shows the increase in life expectancy. There is a separate graph for each of the programmes.

As you can see, Programme A is aimed at both social classes and Programme B is aimed only at social class 5.

Please indicate whether you would choose A or B by ticking one box.

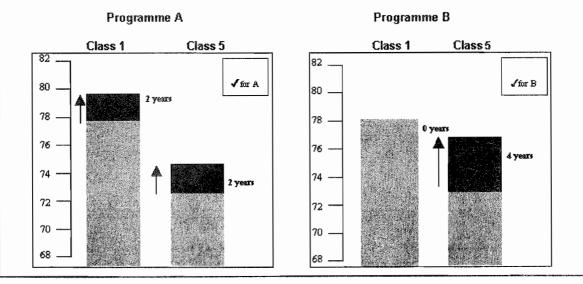
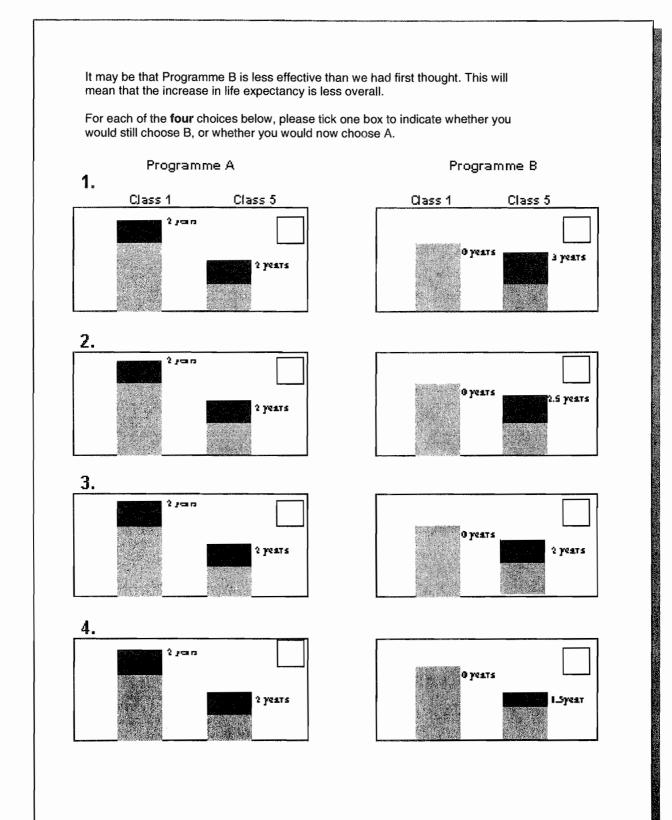


Figure 1: continued



The qualitative research carried out earlier showed that people are familiar with a number of representations of health and health inequalities. As a consequence, Question 1 presents information on life expectancy at birth. Question 2 shows prevalence of self-reported limiting long-term illness for men aged 45 to 64 and Question 3 shows rates of childhood death (from 3 months to 14 years). Each question is preceded by a brief description of the task and a reminder that both programmes cost the same.

In order to explore whether preferences vary because of the type of difference in health, there are a number of variants of the questions. Questions present identical information on inequalities by (a) social class, (b) the healthiest 20% and unhealthiest 20% of the population, (c) sex and (d) smoking status. In addition, Question 4 asks respondents to trade-off two groups of people: one of which has taken care of their health, and one of which have not. No changes are made to the substance of the questions when different sub-groups are presented (the text and data presented are left unchanged, just the appropriate sub-group label substituted). Each sub-grouping is explained at the beginning of each question, which also tells respondents that the groups are more or less equal in size.

The 'age' questions

Two questions present five groups of ages, selected to represent five different stages in the life cycle. The five ages are 5 year olds, 20 year olds, 35 year olds, 55 year olds and 70 year olds. Respondents are told that each group will die in a few days if not treated and the first of the two questions asks respondents to rank the groups in the order in which they want to prevent their premature death, and so enable them to live a normal life expectancy. The second of the two questions asks respondents to rank the same five ages on the basis that they can give people an extra five years of life.

A number of person trade-off questions (see figure 2) ask respondents to consider pairs of programmes that differ only with respect to the age of the people involved. Without the intervention, patients will die within a few days, but with the intervention will live for another 10 years in good health and then die.

The questions have been successfully completed in interview and postal questionnaire, the results of which can be found in papers currently in preparation for publication (see Dolan *et al* 2000, Dolan *et al*. 2001). However, the specifics of our study design have only been referred to in order to ease understanding. It should be noted that any trade-off question can be asked in this general way, and the ordering and type of question can be varied according to individual research interests.

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Figure 2: Person trade-off question

Imagine that you are asked to choose between two programmes which could benefit two different groups of people. Both programmes cost the same.

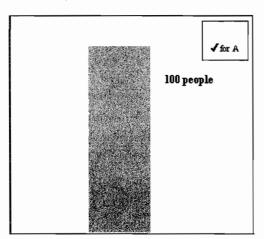
Without the intervention, patients will die within a few days but with the intervention they will live for another 10 years in good health and then die.

People in Programme A are **20 years old**, and people in Programme B are **35 years old**.

Please indicate whether you would choose A or B by ticking one box.

Programme A

Number of **20 year olds**, who will live for ten more years, rather than die in a few days.



Programme B

Number of **35 year olds**, who will live for ten more years, rather than die in a few days.

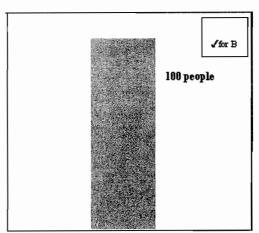
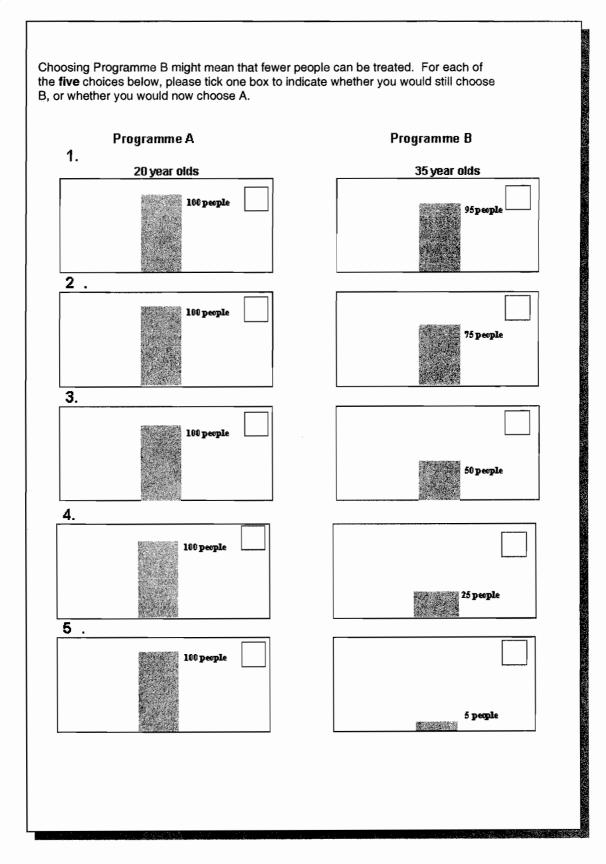
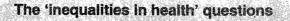


Figure 2: continued



SECTION 2 The questions



Average life expectancy

As you might know, average life expectancy differs by social class. There are differences between people in social class 1 (for example, doctors and lawyers) and people in social class 5 (for example, road-sweepers and cleaners). These two groups are more or less equal in size (they each make up about 7% of the population).

Whilst actual life expectancy varies between individuals, on average, people in social class 1 live to be **78** and in social class 5 they live to be **73**.

Imagine that you are asked to choose between two programmes which will increase average life expectancy. Both programmes cost the same.

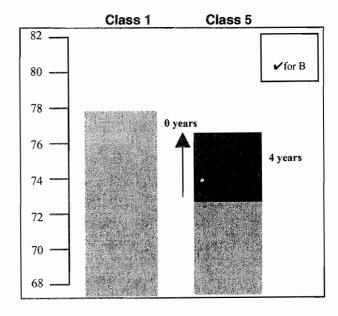
In the two graphs below the light grey part shows average life expectancy, and the dark grey part shows the increase in life expectancy. There is a separate graph for each of the programmes.

As you can see, Programme A is aimed at both social classes and Programme B is aimed only at social class 5.

Please indicate whether you would choose A or B by ticking one box.

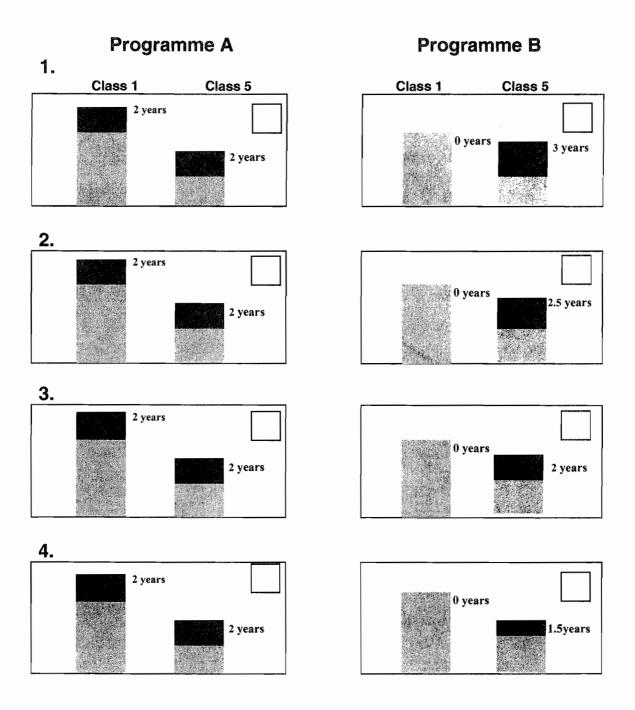
Programme A

Programme B



It may be that Programme B is less effective than we had first thought. This will mean that the increase in life expectancy is less overall.

For each of the **four** choices below, please tick one box to indicate whether you would still choose B, or whether you would now choose A.



Long-term illness amongst men aged 45 to 64

The number of men aged 45 to 64 who report having a long-term illness differs between those who have taken care of their health and those who haven't.

Of men aged 45 to 64 who have taken care of their health (have eaten healthily, exercised, not smoked), 12% report long-term illness. Of men aged 45 to 64 who haven't taken care of their health, 40% report long-term illness.

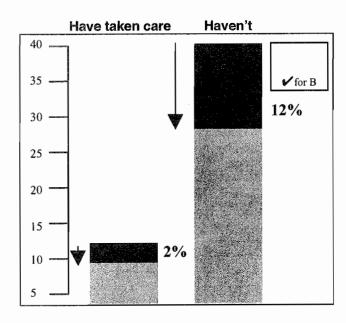
Imagine that you are asked to choose between two programmes which will decrease rates of long-term illness. Both programmes cost the same.

The graphs below show rates of long-term illness. The dark grey parts show the reduction in illness brought about by each of the programmes.

As you can see, Programme A is aimed at both groups and Programme B is aimed more at those who haven't taken care of their health. Please indicate whether you would choose A or B by ticking one box.

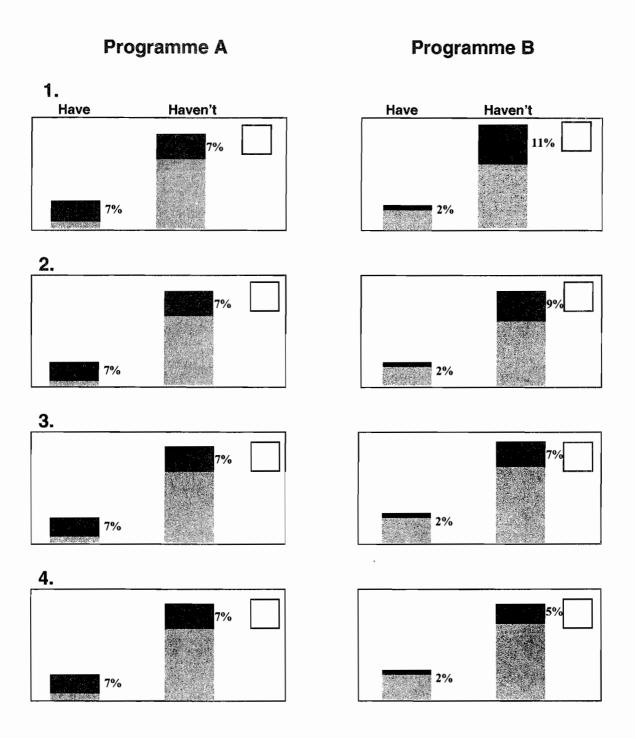
Programme A

Programme B



It may be that Programme B is less effective than we had first thought. This will mean that the reduction in long-term illness is less overall.

For each of the **four** choices below, please tick one box to indicate whether you would still choose B, or whether you would now choose A.



Childhood death

As you might know, there are more deaths amongst children in the lowest social class than there are amongst those in the highest social class.

In the next year, out of every 100,000 children in social class 1, 37 will die. Out of every 100,000 children in social class 5, 122 will die.

Imagine that you are asked to choose between two programmes which will reduce the number of childhood deaths over the next year. Both programmes cost the same.

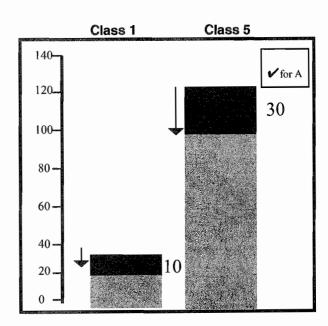
The graphs below show the number of childhood deaths each year. The dark grey parts show the reduction in deaths brought about by each of the programmes.

As you can see, Programme A is aimed at both social classes and Programme B is aimed more at social class 5. Please indicate whether you would choose A or B by ticking one box.

Programme A

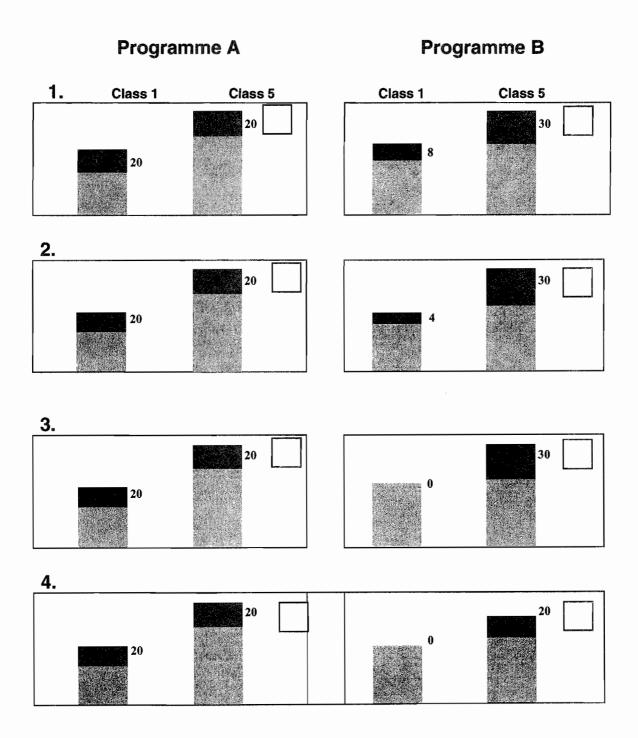
Class 1 Class 5 140120100806040200 - 20

Programme B



It may be that Programme B is less effective than we had first thought. This will mean that the reduction in childhood deaths is less overall.

For each of the **four** choices below, please tick one box to indicate whether you would still choose B, or whether you would now choose A.



Imagine that you are asked to choose between two programmes which could benefit two different groups of people. Both programmes cost the same.

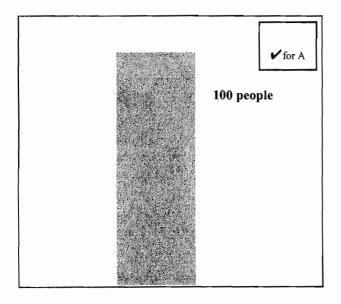
Without the intervention, patients will die within a few days but with the intervention they will live for another 10 years in good health and then die.

People in both groups are 20 years old. They are similar to one another except that those in Programme A have not taken care of their health, whilst those in Programme B have.

Please indicate whether you would choose A or B by ticking one box.

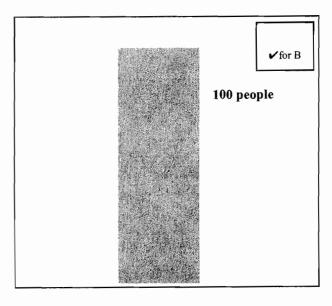
Programme A

Number of 20 year olds who **haven't** taken care of their health, who will live for ten more years, rather than die in a few days.



Programme B

Number of 20 year olds who **have** taken care of their health, who will live for ten more years, rather than die in a few days.



It may be that Programme B is less effective than we had first thought. This will mean that fewer people can be treated,

For each of the **five** choices below, please tick one box to indicate whether you would still choose B, or whether you would now choose A.

	Programme A	Programme B
1.		
	20 year olds who haven't taken care of their health.	20 year olds who have taken care of their health.
	100 people	95 people
2		
	100 people	75 people
3.		
	100 people	So people
4.		
	100 people	25 people
5	•	
	100 people	5 people

The 'age' questions

One of the priorities of governments around the world is to reduce the number of premature deaths. Preventing deaths at one age might be preferred to preventing the same number of deaths at a different age.

Assume that when a death is prevented, people live a normal life expectancy (which is about 75 years).

Now imagine that you can either prevent the premature deaths of:-

or one hundred 5 year olds
or one hundred 20 year olds
or one hundred 35 year olds
or one hundred 55 year olds
or one hundred 70 year olds.

Which age would you choose first?

Which age would you choose second, third, fourth and fifth?

Please write you answer in the table below:-

First	year olds
Second	year olds
Third	year olds
Fourth	year olds
Fifth	year olds

Now imagine that you can only give an extra **five years** of life to people who would otherwise die within a few days:-

or one hundred 5 year olds
or one hundred 20 year olds
or one hundred 35 year olds
or one hundred 55 year olds
or one hundred 70 year olds.

Which age would you choose first?

Which age would you chose second, third, fourth and fifth?

Please write your answer in the table below:-

First	year olds
Second	year olds
Third	year olds
Fourth	year olds
Fifth	year olds

Imagine that you are asked to choose between two programmes which could benefit two different groups of people. Both programmes cost the same.

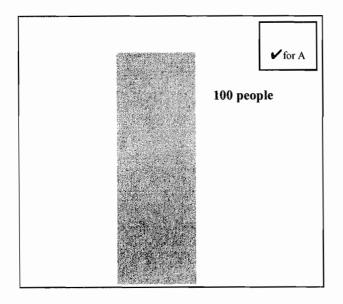
Without the intervention, patients will die within a few days but with the intervention they will live for another 10 years in good health and then die.

People in Programme A are 20 years old, and people in Programme B are 35 years old.

Please indicate whether you would choose A or B by ticking one box.

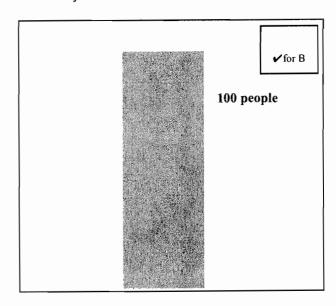
Programme A

Number of **20 year olds**, who will live for ten more years, rather than die in a few days.

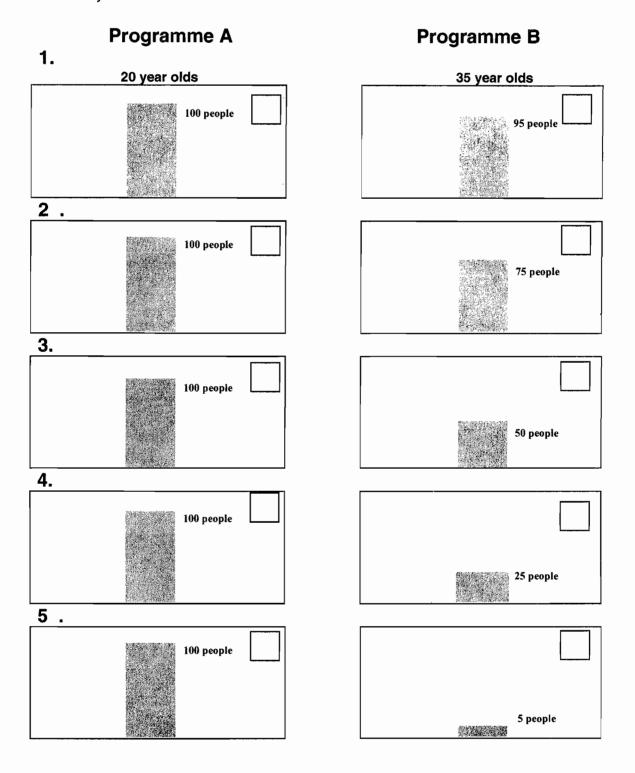


Programme B

Number of **35 year olds**, who will live for ten more years, rather than die in a few days.



Choosing Programme B might mean that fewer people can be treated. For each of the **five** choices below, please tick one box to indicate whether you would still choose B, or whether you would now choose A.



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