

Bedfordshire Humanists Organ Donation Survey: 3rd – 31st May 2008

Report of Findings

Prepared by Charles Baily, Chair, Bedfordshire Humanists, 2nd June 2008.

The Survey

The Government has established a working party to investigate the principle of presumed consent in regard to posthumous organ donation. In this context, members of the Bedfordshire Humanists conducted a survey in Bedford town centre on each of the five Saturdays in May 2008.

269 people were interviewed. For those unfamiliar with the issues, a short briefing note had been prepared (See Appendix A). In the event however most of our subjects knew what we were talking about.

Every attempt was made to balance the sample in terms of age, gender and background, but it must be acknowledged that the sample is more representative of the older generation, because we could only interview the people who were willing to stop and talk to us. Young men proved particularly difficult to engage. Representatives of ethnic minorities tended also to be reluctant to respond.

However, there was a lot of extremely positive feedback. Once people realized what they were being asked about, they engaged very seriously and constructively, and a number expressed warm appreciation of our efforts to raise the profile of an important issue. We hope that, in addition to the simple information-gathering aspect of the survey, we have been instrumental in converting at least a percentage of the willing to registered donors.

A device that we used quite commonly was to interview couples. This seems to have had no inhibiting effect – we were not aware of any cases where one party seemed to be suppressing their own views in deference to the other – but commonly appeared to have the positive consequence of setting in train a constructive dialogue.

The members and associates of the Bedfordshire Humanists who participated in the survey were: Charles Baily, David Brittain, Andrew Dodgshon, Ollie Killingback, Chantal Lewis, Kim Northwood, Peggy Simmons and Dave Wilkinson.



The Results

(Detailed analysis below at Appendix B)

Question 1

It is known that, nationally, some 25% of adults are on the NHS donor register. This figure has been more or less static for some years. Our first question, 'Are you on the NHS donor register?', yielded a higher proportion than this, perhaps because being prepared to participate in such a survey in the street goes with the higher level of social awareness implied by existing registration as a donor. Of our 269 subjects, 102 (38%) were already on the register.

Question 2

In this case they were asked our second question, 'Do you think that the wishes of your relatives should be allowed to override your decision to place yourself on the donor register?' as provided for in the 2006 Act. 83 of our registered donors (81%) did not believe this should be the case. This demonstrates the importance of ensuring that if you are on the register, you should make sure that your relatives are aware of the fact. One problem that the medical profession is acutely aware of is the difficulty of broaching the question for the first time immediately on bereavement.

Question 3

Those not on the register were asked Question 3: 'If you died suddenly, would you be happy for your organs to be used to save lives and relieve suffering?' Of 167 subjects, 125 (75%) said yes, 30 said no, and 12 did not know. Taken together with those already on the register, 84% of our subjects are willing to have their organs put to use, while only 11% are not. This finding conforms closely to previous surveys of this kind, and more than confirms the general estimate that for every person on the donor register, there are at least two more who would not mind being on the register, but for reasons of ignorance, or inertia, or simply not having thought about it, have not taken the necessary action.

At this point non-donors who would be willing for their organs to be used were given the booklet and registration form issued by UKTransplant, and invited to act upon it.

Question 4

Those who said that they would not be willing for their organs to be used to were asked to characterise their reasons as moral, religious or aesthetic. Because of the small sample the response to this is not particularly significant, but religious and aesthetic reasons figured more or less equally.

Question 5

All subjects were asked Question 5: 'Do you agree that we should move from an opt-in to an opt-out system?' 203 said yes, 59 said no, only seven did not know. The figure in favour of over 75% suggests that excessive timidity in moving in this direction would not be justified. There was, perhaps surprisingly, little variation across the sectors identified in the survey. Registered donors were not significantly more or less likely to support the introduction of presumed consent than their unregistered counterparts. Warmest support (83%) came from those not currently registered, but willing to donate – 5 points above registered donors. Perhaps virtue is a little reluctant to be diluted!

Question 6

The 'Moral Maze' question was 6, 'Should people who opt out be considered for an NHS transplant themselves, if they need one?' Few people answered it straight out, taking time to weigh up the implications in terms of the basic reciprocity of social interaction, as against compassion, and medical ethics, at point of need. The most typical initial response was, 'Ouch!' In the end a comfortable majority opted for the compassionate route, although, perhaps surprisingly, the toughest cookies were older women! However, positive responses were commonly qualified, say by stipulating a lower place in the queue. There was support for a suggestion that the opt-out form should have two declarations side by side: 'I refuse permission for my organs to be removed from my body for therapeutic purposes after my death,' and 'I decline to receive implantation of an organ from a human donor.'

Conclusions

What struck us throughout the survey was how little differentiation in attitudes could be detected across distinctions of gender, age or generation. Women across all age bands showed a small edge in the level of existing registration, but it is well known that women are in general more proactive in addressing health issues, and this seems to be no more than an example of this trend in action.

One surprise was the small number of 'don't knows', even on the deliberately controversial Question 6. However, although they had no difficulty making up their minds, it was clear that many had not seriously considered the issues before.

Very few of our subjects mentioned any kind of religious dimension at all to the issues, which were almost universally considered simply as a matter of secular public morality, compassion and mutual obligation. We found no indication whatever

of the kind of hysteria that government seems to expect as the norm in such matters, which apparently caused John Reid to forbid any consideration of the introduction of Presumed Consent in his 2004 Act.

As chance would have it, a news item broadcast on BBC Anglia News at 6:30 and at 10:30 on 30th May concerned a young black woman – Caribbean from her name – who had been waiting for a transplant since going on dialysis three years ago. The point of the story was that her father has now been accepted as a live donor. But the observation was made that, nationally, 20% of the patients awaiting a transplant are of black or Asian extraction, but only 1% of those communities are on the donor register. There is clearly scope for activity here.

In particular, the supportive stance taken by the BHA in its submission to the task force seems to be thoroughly vindicated by the voice on the Bedford street. We would like to thank all our interviewees for their time and trouble in helping us to explore this vital issue, and demonstrating that what is believed in some quarters to be highly contentious is in fact the subject of an overwhelming public consensus.

Appendix A: Survey specification

BH Organ Transplant Survey

At present in the UK there are over 9000 patients awaiting an organ transplant – kidney, liver, heart, lungs etc. Every year about 1000 of them die, still waiting. The rest live on under constant pain, or at best severe limitations to their freedom, unless a suitable organ can be found. Around 3000 each year strike lucky, and their lives are transformed as a result.

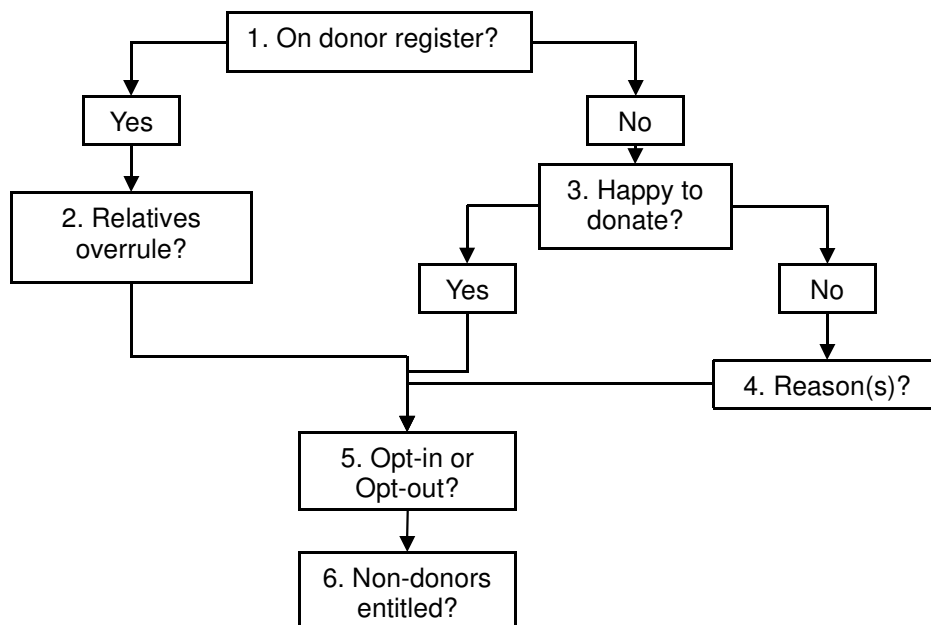
About 25% of UK residents are on the Donor Register, which means that in the event of their premature death, their organs may be used to help others.

The Prime Minister and the Secretary of State for Health have both declared their support for a change in the law, also supported by the BMA and the great majority of the medical profession, to follow the example of other European countries and move to a system of 'presumed consent', which would mean that unless a person has explicitly said that they do not want their organs to be used in this way, doctors may use them to save other lives. A task force has been set up to consider the issues.

Questionnaire

1. Are you on the NHS organ donor register?
2. If so, do you think that the wishes of your relatives should be allowed to override your decision to place yourself on the donor register?
3. If you are not on the donor register, and you died suddenly, would you be happy for your organs to be used to save lives and relieve suffering?
4. If you would not want your organs recycled, would you say that your reasons were
 - a) moral – you think that it's wrong,
 - b) religious – your faith tells you that it's wrong,
 - c) aesthetic – it makes you feel a bit yukky?(Pick as many as you like.)
5. Do you agree that we should move from an opt-in to an opt-out system?
6. Should people who opt out be considered for an NHS transplant themselves, if they need one?

Flow Chart



	Gender	Age	1	2	3	4a	4b	4c	5	6
1										
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25										

Age ranges: 1: Up to 20; 2: 21 – 35; 3: 36 – 50; 4: Over 50.

Appendix B: Analysis

1. Are you on the NHS organ donor register?

By gender

<i>Gender</i>	<i>Y</i>	<i>N</i>	<i>Total</i>
F	60 (43%)	79 (57%)	139
M	42 (32%)	88 (68%)	130
Total	102 (38%)	167(62%)	269

By age

<i>Age</i>	<i>Y</i>	<i>N</i>	<i>Total</i>
Up to 20	4 (27%)	11 (73%)	15
21-35	18 (32%)	38 (68%)	56
36-50	35 (40%)	52 (60%)	87
Over 50	45 (41%)	66 (59%)	111
Total	102 (38%)	167 (62%)	269

2. If so, do you think that the wishes of your relatives should be allowed to override your decision to place yourself on the donor register? (Only put to existing registered donors)

By gender

<i>Gender</i>	<i>Y</i>	<i>N</i>	<i>D</i>	<i>Total</i>
F	8 (13%)	50 (83%)	2 (3%)	60
M	8 (19%)	33 (79%)	1 (2%)	42
Total	16 (16%)	83 (81%)	3 (3%)	102

By age

<i>Age</i>	<i>Y</i>	<i>N</i>	<i>D</i>	<i>Total</i>
Up to 20		4 (100%)		4
21-35	6 (33%)	12 (67%)		18
36-50	7 (20%)	28 (80%)		35
Over 50	3 (7%)	39 (86%)	3 (7%)	45
Total	16 (16%)	83 (81%)	3 (3%)	102

3. **If you are not on the donor register, and you died suddenly, would you be happy for your organs to be used to save lives and relieve suffering?** (Only put to non-registered subjects)

By gender

<i>Gender</i>	<i>Y</i>	<i>N</i>	<i>D</i>	<i>Total</i>
F	59 (75%)	14 (18%)	6 (7%)	79
M	66 (75%)	16 (18%)	6 (7%)	88
Total	125 (75%)	30 (18%)	12 (7%)	167

By age

<i>Age</i>	<i>Y</i>	<i>N</i>	<i>D</i>	<i>Total</i>
Up to 20	11 (100%)			11
21-35	29 (76%)	9 (24%)		38
36-50	38 (73%)	10 (19%)	4 (8%)	52
Over 50	47 (71%)	11 (17%)	8 (12%)	66
Total	125 (75%)	30 (18%)	12 (7%)	167

Taken together with those already on the Register, the overall figures for those willing to donate their organs are:

By gender

<i>Gender</i>	<i>Y</i>	<i>N</i>	<i>D</i>	<i>Total</i>
F	119 (86%)	14 (10%)	6 (4%)	139
M	108 (83%)	16 (12%)	6 (5%)	130
Total	227 (84%)	30 (11%)	12 (5%)	269

By age

<i>Age</i>	<i>Y</i>	<i>N</i>	<i>D</i>	<i>Total</i>
Up to 20	15 (100%)			15
21-35	47 (84%)	9 (16%)		56
36-50	73 (84%)	10 (11%)	4 (5%)	87
Over 50	92 (83%)	11 (10%)	8 (7%)	111
Total	227 (84%)	30 (11%)	12 (5%)	269

5. Do you agree that we should move from an opt-in to an opt-out system?

By gender

<i>Gender</i>	<i>Y</i>	<i>N</i>	<i>D</i>	<i>Total</i>
F	106 (76%)	30 (22%)	3 (2%)	139
M	97 (75%)	29 (22%)	4 (3%)	130
Total	203 (75%)	59 (22%)	7 (93%)	269

By age

<i>Age</i>	<i>Y</i>	<i>N</i>	<i>D</i>	<i>Total</i>
Up to 20	11 (73%)	4 (27%)		15
21-35	46 (82%)	8 (14%)	2 (4%)	56
36-50	68 (78%)	18 (21%)	1 (1%)	87
Over 50	78 (70%)	29 (26%)	4 (4%)	111
Total	203 (75%)	59 (22%)	7 (93%)	269

By current status

<i>On Register</i>	<i>Y</i>	<i>N</i>	<i>D</i>	<i>Total</i>
Yes	80 (78%)	22 (22%)		102
No	123 (74%)	37 (22%)	7 (4%)	167
Grand Total	203 (75%)	59 (22%)	7 (93%)	269

By willingness (non-registered only)

<i>Willing to Donate</i>	<i>Y</i>	<i>N</i>	<i>D</i>	<i>Total</i>
Yes	104 (83%)	20 (16%)	1 (1%)	125
No	12 (40%)	15 (50%)	3 (10%)	30
Don't know	7 (58%)	2 (17%)	3 (25%)	12
Total	123 (74%)	37(22%)	7 (4%)	167

6. Should people who opt out be considered for an NHS transplant themselves, if they need one?

By gender

<i>Gender</i>	<i>Y</i>	<i>N</i>	<i>D</i>	<i>Total</i>
F	93 (67%)	30 (22%)	16 (11%)	139
M	93 (72%)	21 (16%)	16 (12%)	130
Total	186	51	32	269

By age

<i>Age</i>	<i>Y</i>	<i>N</i>	<i>D</i>	<i>Total</i>
Up to 20	13 (87%)	2 (13%)		15
21-35	39 (70%)	10 (18%)	7 (12%)	56
36-50	63 (72%)	12 (14%)	12 (14%)	87
Over 50	71 (64%)	27 (24%)	13 (12%)	111
Total	186	51	32	269