

## Post 2013 Organ Donation Strategy Written Engagement Exercise Summary of responses

### Background

The online engagement exercise opened on 28<sup>th</sup> July 2012 and closed on the morning of 25<sup>th</sup> September 2012.

In each question people were asked to rank the given options in order of preference, one being the answer that should be given the highest priority.

There were eight questions in total though question 1 was split in to parts A and B

### Respondents

772 people began filling in the survey, however only 412 people got to the second question. When the survey was written it was designed to be accessible to non-experts. The promotion of the survey in the mainstream press (Guardian article on 29<sup>th</sup> July 2012) meant that a significant number of members of the general public chose to take part and were put off by the complexity of the questions. 312 people completed the final question, and around 130 people left comments on the various questions. With hindsight we might have helped the members of the public wishing to engage by ordering the questions differently so the question about changing public behaviour was at the beginning of the survey.

People were asked to choose from a list of options to describe their background. These results were grouped into the board categories 'NHS', 'Public', and 'Other'.

Unless otherwise specified in the summary of the question responses below, the percentages given in the summary of the answers relates to the total of all the three categories. In most cases the three groups agreed on the options that should be given the highest and lowest priority, where this is not the case it is referenced in the summary.

44% of respondents came under the NHS category, which was used for anyone with clinical or other expert knowledge of any part of the transplantation or donation process. NHSBT staff were included in this category.

40% of respondents were members of the public. The public category was used for people who only identified themselves as members of this public with no professional or personal involvement with the donation or transplantation process.

15% of respondents were classified as 'other'. This category picks up people who do not have expertise in organ donation/transplantation but who gave us other background information. This includes people on the transplant waiting list and their families, as well as people from the voluntary sector, or people with a professional interest in organ donation/transplantation.

### Question 1a of 8: How do we get the best results for those listed for a transplant? Best practice in transplantation

Four choices were given for this question. The most popular answer was *'NHSBT should monitor patients' health from when they are placed on the transplant waiting list, as well as from when patients receive their transplant'*. *'Clinician-led audit of decisions regarding suitability of organs for transplantation'* was also very popular. Combined, these two responses attracted 70% of people's first preferences.

*'Develop more guidance in partnership with professional bodies (e.g. BTS)'* attracted only 10% of first preferences and 50% of people who answered the question ranked it as the option that should be given the lowest priority.

### Question 1b of 8: How do we get the best results for those listed for a transplant? Post transplant outcomes

There were only two options for this question. *'Develop a national system for monitoring Transplant Centres'* got 70% of people's first preferences while *'Some patients who have*

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*received a transplant have better outcomes than others. NHSBT could undertake research to better understand what factors influence patients' health following an organ transplant' got 30%*

## **Question 2 of 8: How do we maximise use of every offered organ, and thereby maximise the gift of donation?**

Eight options were given for this question though in all groups 'Develop a system to speed up the process for offering donated organs to transplant units' and 'Take further steps, at an earlier stage, to take care of donors to make sure that as many organs as possible can be retrieved for transplantation' combined got over 50% of people's first preferences.

The options that were consistently ranked the lowest were 'Provide greater clarity about which contraindications to donation (e.g. if the potential donor had CJD)' and 'Employ medical staff as donor coordinators', which combined attracted a little over 10% of first preferences while combined 50% of people rated them the lowest priority.

## **Question 3 of 8: How do we ensure that everyone with the potential to donate is given that opportunity at the time of their death?**

Five choices were given for this question. 'Ensure that the families of potential donors are given the best possible support when approached about organ donation' was the preferred option of over 60% of respondents, while 'Part fund critical care capacity in units with high donation potential' was the least preferred option of 45% of people.

## **Question 4 of 8: What should we do to increase the pool of appropriate potential donors?**

Five choices were given for this question. First preferences were broadly spread across all five options. With 'NHSBT could develop systems to identify potential donors from other clinical environments, and approach their families' and 'Support organ retrieval from patients who have died unexpectedly from a cardiac arrest in emergency departments and other clinical areas (Uncontrolled Donation after Circulatory Death)' attracting 45% of first preferences between them. 'Review the ethical, legal and professional acceptability of so-called elective ventilation (i.e., intubation and ventilation of a gravely ill patient whose death is inevitable in order to promote donation after brainstem death)' was ranked by 40% of people as the lowest priority option, though between 15% and 20% of all grouped rated it their highest priority.

## **Question 5 of 8: How do we make organ donation a normal part of UK culture?**

Nine options were given for this question. Almost 50% of respondents went for 'Change the consent system for organ donation – either to presumed consent for organ donation unless a person has 'opted-out' of the Register, or mandate that people make a choice about whether or not they want to be organ donors ('mandated choice')'. Among the NHS group this was still the option which was selected as the highest priority most number of times (35%), but a little over 20% of NHS respondents also ranked it their lowest priority.

## **Question 6 of 8: What changes do we need to make to infrastructure, workforce, IT etc?**

Four options were given for this question. 40% of respondents ranked 'Train staff in hospitals in how to approach families about organ donation, backed up by NHSBT staff to help manage the donation and transplantation process' as the highest priority. Combined 60% of people believed the options which should be given the lowest priority were 'Run national and regional training programmes in support of the regional organ donation 'Collaborative' and 'Create an improved, efficient electronic support system for the whole donation and transplantation pathway'.

## **Question 7 of 8: Below are the 15 stages of the care pathway for a potential organ donor, and four additional options. Where do you think the greatest potential lies to increase the number of people to receive a transplant? (You can tick as many options as you wish)**

The care pathway stages that were seen as the areas with the greatest potential were (in decreasing order), 'Family approached for consent', 'Public behaviour' 'Imminent death anticipated', and 'Consent given'. 'Medical contraindications' and 'SNOD, CLOD and Committee Chairs' were seen as the areas with the least potential.

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Among NHS respondents '*Transportation Process*' was ranked as highly as '*imminent death*' and '*consent given*', though it was among the lowest answers in the other two groups. This can most likely be attributed to lack of knowledge among non-experts of this part of the care pathway.

### Question 8 of 8: Do you agree that a person who has signed up to the Organ Donor Register should be a priority recipient for an organ if they subsequently require a transplant?

This was a simple yes or no question, in all groups there was a majority saying 'No' though there was some variation among the groups.

Total Yes	44%
Total No	56%
Public Yes	49%
Public No	51%
NHS Yes	40%
NHS No	60%
Other Yes	44%
Other No	56%

The answers from the public are especially interesting with the group being split down the middle, and 40% of NHS respondents thinking it should be allowed.

### Comments

Around 330 comments were received from 130 respondents. Specific comments were identified from BMA, Nuffield Council for Bioethics, The Cystic Fibrosis trust and the Christian Medical Fellowship.

Below is a list of suggestions that came up most often and the number of times they were mentioned.

More research on the donation and transplantation processes	37
Presumed Consent/Opt-out - FOR	35
More promotion	25
Education (both public and clinical)	25
Elective Ventilation - AGAINST	21
Mandatory referral	18
Presumed Consent/Opt-out - AGAINST	14
Do not allow family to override deceased wishes	13
Mandated choice	11
Financial incentives AGAINST	11
Promote using NHS staff	9
Better use of marginal organs	7
Elective Ventilation FOR	7
Better IT systems	7
Priority transplantations for people on the ODR - FOR	6
Financial incentives FOR	5
More SNODS	4
Change offering system	3
Change to EOS	3
Ask on admission	2
Coroner	2
GPs	2
Living donation	2
Priority transplantations for people on the ODR - AGAINST	1