From Andrew Miller MP, Chair

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Thank you for providing evidence to the Committee on 30 April in relation to our current inquiry on blood, tissue and organ screening.

You will recall that as part of this inquiry we requested information on the Government’s current strategy: Taking organ transplantation to 2020. This strategy was generally well received by those from whom we received evidence and we congratulate the Department for its continued efforts to drive up rates of organ donation. However, as a result of our work on this topic, we would like to raise (and request a reply on) several points.

1. Consent for organ donation

At present, UK consent for organ donation is provided via an “opt-in” system, in which individuals are asked to register their willingness to be a donor. According to figures quoted in the strategy, there are signs that this system of consent is not working. Nine out of ten people in the UK support organ donation, but fewer than one in three are registered as donors. Even when an individual is registered, their wishes may be overridden by family members, and when the wishes of the individual are not known, nearly 50% of families say no to donation. The resulting shortage of organs means that three people die every day while waiting for a transplant.

The Government’s new strategy rightly emphasises the need to improve donor consent rates and sets an ambitious target for doing so: an increase from the current rate of 57% to 80%, which would bring UK performance in line with Spain, the best in the world. Unfortunately, despite efforts by successive administrations, UK consent rates have shown little improvement under the current system, remaining stable at approximately 60% ever since they were first measured as part of the annual national potential donor audit in 2003.

You told us in evidence that you had “no current plans” to review the existing “opt-in” system of consent. However, the Government’s failure to
deliver improvements under this system suggests that, if it is to achieve the step-change in organ donation that is targeted, it must be open to other options. This includes systems based on presumed consent.

When presumed consent was last evaluated in 2008, the organ donation taskforce noted that existing evidence was “not robust enough to provide clear guidance for policy”. The forthcoming implementation of the Human Transplantation (Wales) Act next year offers a unique opportunity for this evidence gap to be filled and for current policy to be reviewed. Please explain how the Department plans to monitor and collect data on the situation in Wales—both before and after implementation of the Act in December 2015—and how this data will be used to strengthen the evidence-base relating to options for obtaining informed consent for organ donation. We hope that this data will be used during the next Parliament as part of a re-evaluation of current policy.

2. Organ allocation

Although organ allocation is not discussed in the Government’s current strategy document, we were made aware during our inquiry of inconsistencies in the UK approach to this matter. In particular, concerns were raised about the use of local rather than national allocation policies for scarce organs such as lungs.

While we understand the reasons for allocating lungs on a local basis, we are also cognisant of this system’s weaknesses. As one witness pointed out, under the current scheme “donor lungs go to the nearest waiting list, despite the fact that elsewhere in the UK there could be an individual in greater need, with greater survival prospects”. We were pleased to hear from Professor James Neuberger that NHS Blood and Transplant (NHSBT) was open to considering a move to a national allocation scheme for lungs, if evidence supported such a change. We request that NHSBT detail, via this correspondence, how and when it plans to conduct this review of the available evidence.

3. Strategy implementation

When Taking organ transplantation to 2020 was published last July, it stated that the first step towards achieving the strategy’s goals would be the development of “a series of operational plans, which will provide the detail” for the actions set out by the strategy. It was unclear from the evidence that you subsequently provided to us whether or not those plans had been developed. Through the strategy, the Department also undertook to provide regular reports to Parliament on progress made in the strategy’s implementation.

One year on from its publication, we ask that the Government—working with NHSBT—provide an update on progress made against the actions detailed in the strategy to date. We suggest that this form the first in a series of short updates reported to Parliament on an annual basis.

We would be grateful if you could respond to these points by September 2014. If you have any questions, Victoria Charlton, a member of the Committee’s staff, would be happy to assist you (charltonv@parliament.uk).
Yours sincerely,

Andrew Miller
Chair