This response was submitted to the consultation held by the Nuffield Council on Bioethics on Give and take? Human bodies in medicine and research between April 2010 and July 2010. The views expressed are solely those of the respondent(s) and not those of the Council.

Royal Brompton & Harefield NHS Foundation Trust

**Question 30**

This statement is written on behalf of the Royal Brompton and Harefield NHS Foundation Trust. As a specialist provider of cardiothoracic care, we have a long and established reputation in organ transplantation. Indeed the UK’s first heart transplant programme was at Harefield hospital in 1980 and the world’s first combined heart and lung transplant was undertaken there by Sir Magdi Yacoub in 1983. We are also an active research organisation including studies in human volunteers and patients as well as research on biological material. We welcome this consultation on ethical issues around human bodies for medicine and research. We have chosen not to respond to individual questions in the consultation but rather aim to highlight our experience of developments in organ transplantation which is most relevant to the section on Responding to Demand. Organs for Transplantation and emerging technologies. The heart and lung transplant unit based at the Royal Brompton & Harefield NHS Foundation Trust is the UK’s largest and most experienced centre for heart and lung transplantation. Whilst we continue to run both a successful heart and lung transplantation programme, the rate-limiting step for both clinical services is the supply of viable organs, with the demand for organs exceeding, as it has done for many years, the number available. This supply is further compromised in that a high proportion of donor organs are currently not suitable for transplant in the UK. We, and the wider medical community, have responded to these market forces by developing devices and technologies aimed at improving the number of patients able to have successful organ transplants. In lung transplantation, the lack of suitable donor organs has led to the development of new techniques aimed at improving the viability of those that are donated, in particular a technique known as Ex-vivo Lung Perfusion (EVLP) which “reconditions” donor lungs prior to transplantation. Transplant surgeons at Harefield Hospital performed the first UK lung transplant using EVLP in 2009. Since its introduction at this Trust, EVLP has increased our donor lung retrieval rate by around 50% and in due course we expect this to translate into significantly more successful transplants provided organs continue to become available. For heart transplantation, limitations in the supply of suitable organs has led to the development of “artificial heart” devices, known as Left Ventricular Assist Devices (LVADs) as mentioned in the consultation. These were initially developed as a bridge to transplant for patients awaiting transplantation. However, research and the long term follow-up of LVAD patients has shown LVADs can actually stimulate myocardial recovery, and in some cases remove the need for transplantation completely. However as a transplant unit technically able to provide this treatment, the current barrier to the use of LVADs as a destination therapy is the perceived
costs of this therapy and the lack of definitive evidence to establish LVADs effectiveness. Without this, it is unlikely that NHS commissioners will approve use of LVADs as an alternative to transplantation in heart failure patients. Our own attempts to pursue research funding on this issue have to date been unsuccessful. Therefore whilst alternatives to transplantation may emerge, this is not sufficient to obviate the need for organ donors, as new therapies have to be accessible. Therefore in the case of heart transplantation, our clinical programme continues to be limited by organ supply. Both of these examples highlight how medicine, through the development of new technology, has responded to limitations in donor organ supply. Whilst the journey from a common clinical problem, through scientific discovery and medical innovation, has led to different outcomes in terms of the way technology improves patient outcomes, none of it would have been possible without organ donation from the outset. It is therefore difficult to assess whether a greater supply of organs from the outset or the widespread implementation of the emerging technologies would have the greatest impact on lives saved and cost-effectiveness of care required for transplant patients. What is clear however if that without an approved alternative to organ transplantation and or endorsement by NHS commissioners of new approaches in organ donation, increased supply of donor organs is the only real route by which lung and heart failure patients can be treated effectively. It is worth noting also that transplantation, as a treatment option, is only considered in a minority of patients who have chronic heart and lung failure (which also mirrors the eligible patient population for LVADs). A step change in availability of organs or alternative treatments however would presumably provide commissioners with the option to extend treatment to a wider and older patient population. Given the rises in longevity and quality of life, it may also be increasingly difficult to restrict organ transplantation or alternative treatments to relatively young patient groups. Obtaining post-mortem tissue for research. One area where it has been much more difficult in obtaining tissue for research following the HTA Act (2004) is research on tissue from cadaver transplant donors. This has been made virtually impossible because of the ruling that tissue for use in research cannot be taken from cadavers, even with consent from the deceased relatives, unless the hospital site where the cadaver originates is licensed by the HTA for performing Post Mortem Examinations. This has resulted in a substantial reduction in the amount of valuable tissue available for researchers conducting significant research in the field of transplantation and also in enabling access to “healthy” tissue to researchers in other areas of cardiac and respiratory medicine. It also specifically prevents prospective research with parallel clinical and laboratory investigations on patients benefiting from donor organs. As a care and research organisation, the Royal Brompton & Harefield NHS Foundation Trust welcomes and supports, in principle, any new or extended initiatives to encourage donation of organs and tissue for use in both medicine and research. I hope you find these comments helpful. If you have any further questions or require any clarification please do not hesitate to contact me.