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Uk Guidelines for Living Organ Donation From Prisoners

Compiled by a Working Party of
The British Transplantation Society
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BRITISH TRANSPLANTATION SOCIETY

UK GUIDELINES FOR LIVING ORGAN DONATION FROM PRISONERS

PURPOSE OF GUIDELINES

The purpose of these guidelines is to provide clarity and transparency for the management of donor referrals for living organ donation from prisoners for NHS staff, potential donors, recipients and the general public. The guidance is relevant to all potential donors who are imprisoned within the UK but does not represent National Offender Management Service (NOMS) policy.

These guidelines should be used in conjunction with existing clinical and legal guidelines in the assessment of the prospective donor (1,2). The guidelines apply to both living donor kidney and living donor liver transplantation.

This is the first attempt to define guidelines for living organ donation from prisoners. They have been compiled by a joint working group with representation from the British Transplantation Society (BTS), Department of Health (DH), NHS Blood and Transplant (NHSBT) and in consultation with NOMS although, as previously stated, this does not represent NOMS policy. Wide consultation has achieved consensus and support for the recommendations within the transplant community.

This guidance will be reviewed in two years.

BACKGROUND

Living donor transplantation is now established practice in the UK and represents 35% of overall solid organ transplant activity (3). Living donor kidney transplantation (LDKT) accounts for 97% of activity and is justified on the basis of excellent patient and transplant outcomes, low donor risk, and donor and recipient choice (1). Living liver donation comprises the remaining 3%.

Since the Human Tissue Act and Human Tissue (Scotland) Act (HT Acts) came into force in September 2006 (4), non-directed altruistic kidney donation (NDAD) (to a recipient whom the donor does not know or has never met) is increasing and has become an accepted part of LDKT practice, representing 10% of LDKT activity (3). NDADs can either donate to a single recipient on the national transplant waiting list or trigger a ‘chain’ of up to three transplants within the National Living Donor Kidney Sharing Schemes (NLDKSS) by donating into the paired/pooled donation scheme. To date, there have been two NDAD liver lobe donations in the UK.

Directed altruistic donation (where there is no existing emotional relationship between donor and recipient and/or no pre-existing relationship prior to the donor becoming aware of the recipient's need for a transplant) is also permitted under the HT Acts. This creates additional challenges. In response to the publication of a revised legal framework by the Human Tissue Authority (HTA) in September 2012, the British Transplantation Society (BTS) developed guidelines to support the clinical community to manage referrals from directed altruistic donors (2).

PRISONERS AS LIVING DONORS

The safety and welfare of living donors is paramount. Historically, living donation from prisoners has only been considered in exceptional circumstances and between family members when:

- There are no other suitable living donor options for the recipient
- The risk to the recipient of not receiving a transplant from the imprisoned family member is unacceptably high

Reluctance to accept prisoners as living donors is more often due to practical and/or logistical reasons rather than philosophical objections. The key issues are:

I. Restricted contact with the prisoner creates limitations in providing information to the potential donor, achieving valid consent, and providing clinical support throughout the assessment process, preparation for donation and long-term follow-up.

II. Heightened security requirements, risk of escape, and risk to public safety when a prisoner is managed in a non-secure healthcare environment for outpatient and inpatient episodes. This may also impact on the privacy and welfare of the potential donor, other patients, and their relatives and staff.

III. Resource implications for NHS and Ministry of Justice (MoJ) staff who are responsible for the logistics and supervision of the potential donor outside the prison environment.

PRISONERS AS ALTRUISTIC DONORS

Increased public awareness of altruistic donation has prompted requests from prisoners who wish to be considered as NDADs. In this context, there are additional considerations.

Arguments in favour of accepting prisoners as altruistic donors

I. In comparison with the number of people waiting for a transplant in the UK, there is a shortfall in the number of organs available (3). Many people with organ failure die waiting for a transplant or never get on to the transplant waiting list. There is a moral imperative to accept offers of donation from potentially suitable donors, regardless of their personal circumstances.

II. It has been argued that it is a human right for an individual to choose to be considered for organ donation, and it is an infringement upon his/her liberty if the right to make that choice is denied.

III. Prisoners serving indeterminate sentences (have no automatic right to be released) or lengthy determinate sentences (who must be released at the end of their sentence) will be released only after a prolonged period of imprisonment when they may be older and less suitable to donate. It would be preferable for them to donate when they are younger.

IV. In the interests of clinical need, equal consideration should be given to offers of altruistic kidney and liver lobe donation.

Arguments against accepting prisoners as altruistic donors

I. It is not in the public interest to focus resources on this small but complex group of individuals to overcome the logistical and practical challenges previously detailed. This may result in the diversion of resources from other HMP and/or NHS recipients.

II. With the exception of prisoners serving indeterminate or lengthy determinate sentences, it is more appropriate to defer donor assessment and surgery until after release from prison.

III. Mental health pathology in motivating prisoners' decisions to donate may be more prevalent than in the general population (e.g. reparation), which requires a high level of expertise to avoid inflicting psychological harm on the potential donor.

IV. Potential reputational risk and damage to public confidence in the UK-wide donation and transplantation programme from the publicity associated with novel donations. Although anonymity is protected as far as possible prior to surgery, the altruistic donor pool is small and subsequent media interest could result in inadvertent disclosure of donor identity to the recipient. A high profile case could damage public and patient perception due to the perceived risk of

coercion to donate and/or expectation of reward (e.g. parole) within the prison environment.

V. The right of the individual prisoner to choose to donate is not absolute and cannot override the public interest if the balance of risk is inappropriate. This is consistent with limits on liberty and choice in the context of imprisonment.

VI. The opportunity to manage care needs and follow-up imprisoned donors effectively post donor nephrectomy in the short and long term is constrained and may impact on long-term health and well-being.

VII. The transplant team and wider transplant community are not obliged to accept donors whom they do not consider suitable for donation for either clinical, moral or logistical reasons, or where there may be a significant risk to the reputation and/or function of the organ donation and transplantation programme.

RECOMMENDATIONS

All potential prisoner organ donors must be referred to the NOMS Equality, Rights and Decency Group for consideration at ERDGPolicyTeam@noms.gsi.gov.uk. This does not apply to those who are imprisoned overseas (i.e. not eligible to be considered) nor those who have previously been imprisoned (i.e. eligible to be considered under existing guidelines) (1,2).

For the purposes of these guidelines, living organ donation from prisoners is defined as follows:

1. Living organ donation from prisoners in the context of close family/friend relationships, i.e. between close genetically and/or emotionally related donors.

2. Living organ donation from altruistic donors, including non-directed and directed altruistic donors.

1. Living Organ Donation From Prisoners: Close Family or Friend (see figure 1)

a) This will only be considered in exceptional circumstances, in accordance with current practice, i.e.:

- There are no other suitable living donor options for the recipient
- The risk to the recipient of not receiving a transplant from the imprisoned family member is unacceptably high, i.e. severe morbidity or mortality may result

b) Prisoners are categorised according to risk to public safety. All categories of prisoner may be considered as a living donor in the context of family/friend relationships.

c) All potential prisoner organ donation cases must be referred to NOMS Equality, Rights and Decency Group at ERDGPolicyTeam@noms.gsi.gov.uk for consideration before donor clinical evaluation is started. If this has not been done prior to referral to the transplant team, the case must be referred using the instructions and template letter in appendix 1.

d) After NOMS approval, referrals to the transplant team must be accompanied by letters of endorsement from both the prison GP/Medical Officer and prison Governor to confirm candidacy for initial donor assessment. Transplant teams reserve the right not to accept referrals.

e) A case conference between relevant personnel in the transplant centre, prison and NOMS is recommended at an early stage to ensure that the process of donor evaluation, surgery and in-patient stay can be appropriately managed and resourced, e.g. additional security requirements. A memorandum of understanding (MoU) will be drawn up between all parties, taking into account existing policies (e.g. donor reimbursement) and guidelines (1).

f) A standard operating procedure (SOP) will be agreed to inform case conference discussions and MoUs. This will include the following aspects:

- Confidentiality
- Safety and security
- Lines of communication

f) Written referral to the prison GP/Medical Officer must accompany the donor on discharge back to the prison after donor nephrectomy. This must include contact details for the transplant team in the donating hospital and information about immediate after care and short and long-term follow-up requirements.

2. Living Organ Donation From Prisoners: Altruistic Donation (directed and non-directed) (see figure 1)

a) In accordance with the above guidance for close family and friends (see 1a), it is recommended that all offers of *non-directed* altruistic organ donation from prisoners are considered as 'exceptional' rather than 'routine' practice and must only be accepted after careful consideration

b) If appropriate, it is recommended that prisoners who offer to be considered as *non-directed* altruistic donors are encouraged to wait until they are released from prison. If this is not an acceptable option, recommendations 2 b) to g) apply.

c) Offers of *non-directed* altruistic donation may be considered from all categories of prisoners at the discretion of the transplant centre and prison services according to the recommendations for acceptance, assessment and surgery as described in section 1 a) to e).

d) Once assessed, such donors may donate to a single recipient on the national transplant list or opt in to an altruistic donor chain.

e) Offers of *directed* altruistic donation from prisoners are not recommended due to the potential risk of inappropriate and/or complex relationship and attachment issues arising from the donation.

f) The potential additional risks associated with donation from prisoners in the context of non-directed altruistic donation [e.g. expectations of preferential treatment or de-classification; potential risk of duress/coercion; psychological motivation (e.g. reparation)] are not absolute contra-indications but must be given careful consideration, using existing guidelines and policies to help manage this risk.

g) The potential risk of adverse publicity or breach of donor and/or recipient confidentiality must be anticipated as this may damage the credibility of the organ donation and transplantation programme. It is recommended that transplant teams consult with their local Trust Communications Team to agree a communication plan that can be implemented if necessary. The NHS Blood and Transplant press office at pressoffice@nhbst.nhs.office and the BTS ethics committee at ethics@bts.org.uk can also be contacted for further advice and support.

h) It is recommended that the information given to the recipient about the donor is consistent with the principles that are applied to cases of non-directed

altruistic donation, i.e. there is no entitlement for the recipient to be informed that the donor is a prisoner and/or the reason for imprisonment.

References

1. British Transplantation Society/Renal Association 'UK Guidelines for Living Donor Kidney Transplantation', 3rd Edition, May 2011. http://www.bts.org.uk/MBR/Clinical/Guidelines/Current/Member/Clinical/Current_Guidelines.aspx
2. British Transplantation Society 'Guidelines for Directed Altruistic Organ Donation', Revised June 2014 http://www.bts.org.uk/MBR/Clinical/Guidelines/Current/Member/Clinical/Current_Guidelines.aspx
3. NHS Blood and Transplant www.odt.nhs.uk
4. Human Tissue Act 2004 and Human Tissue (Scotland) Act 2006. http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/legislation/humantissueact.cfm

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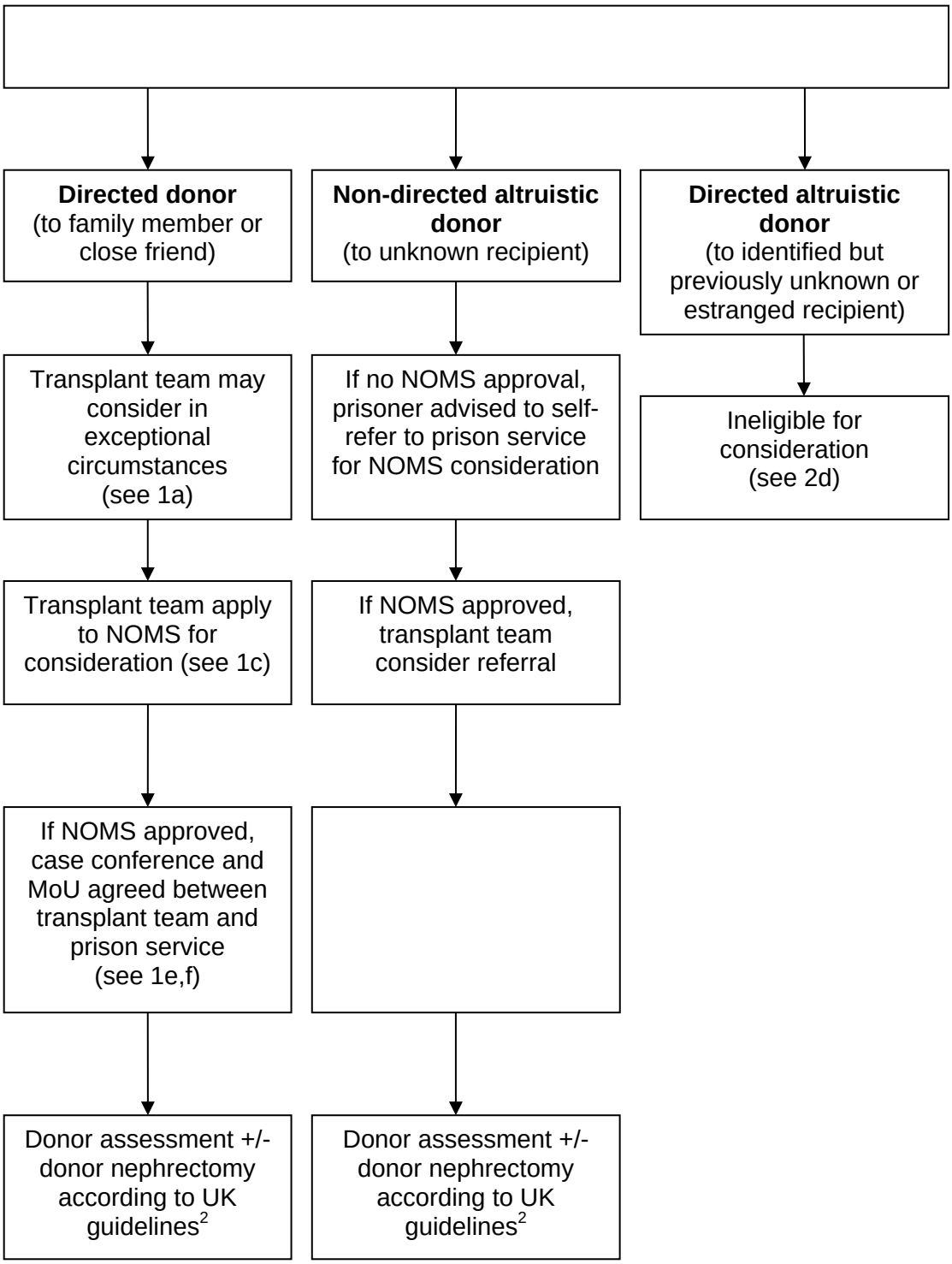
Figure 1: Management of Prisoner Referrals for Living Organ Donation



Appendix 1

Referral Process to NOMS Equality, Rights and Decency Group for consideration of Living Organ Donation

If approval has not been given from NOMS to a prisoner who is referred or self-refers to a clinical team for consideration of living organ donation, a written request for approval must be sent to ERDGPolicyTeam@noms.gsi.gov.uk from the clinical team.

The referral must be:

1. Authorised by a medical consultant*
2. Written on hospital or Trust headed paper
3. Include the donor name, date of birth and current prison address
4. Specify the relationship of the donor to recipient, i.e. direct family, friend or non-directed donor (see figure 1)
5. Provide reasons for consideration of living organ donation and supporting information (see 1a, 2a, 2b)
6. Include name and contact details for the referring hospital consultant and/or living donor co-ordinator directly involved with the case*

   * The medical consultant can give delegated responsibility for another member of the clinical team e.g. living donor co-ordinator, to send the letter on his/her behalf and to be the primary point of contact for communication and correspondence.