

### NHS Blood and Transplant Action Plan

#### Actions from an Overview Report into the Death of Two Renal Transplant Recipients from a Donor-Acquired Encephalitis\* Serious Untoward Incident Number INC 423

Desired Outcome (s)	Action to be taken	Responsible person(s)	Completion date	Progress - completed or date extended	Date closed
1. There needs to be a clear way of documenting adverse social or life style circumstances which could impact on the health of a donor and their suitability to be an organ donor. Where the cause of death is unclear, clinicians in the donor hospital need to consider as wide a range of factors as possible that could be contributory to the patient's illness, especially behavioural and social circumstances if these are not clearly documented. This information should be routinely collected by the SNODs and included in the Core Donor Data Form. We are aware that NHSBT	Specialist Nurses currently conduct a systematic patient assessment on all potential donors. This involves a full medical, behavioural, social and travel history, collectively termed "donor characterisation". The importance of a full and rigorous donor characterisation to be reiterated to all NHSBT specialist nurses (SNODs).	A [REDACTED]	21/11/14	Completed	21/11/14
	Ensure that all Regional Clinical Leads for Organ Donation (CLODs) are reminded to impart all	A [REDACTED]	21/11/14	Completed	21/11/14

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<p>are currently developing the Electronic Offering System (EOS) record so that it can contain information on a donor's lifestyle and other risk factors. We would strongly support this. (Change of practice: NHSBT, SNODs, Donor Hospital Intensive Care Units)</p>	<p>information that is known to them about the potential donor to the specialist nurse. Request that the reminder is shared widely by the CLODs with Intensive Care Colleagues.</p> <p>Letter to all Heads of Transplant Units to be sent reinforcing; A) It is the role of the SNOD to ensure that all relevant information is obtained as far as possible and recorded on EOS. B) It is the role of the transplant surgeon to ensure that the full Core Donor Data Form is reviewed (accessed via EOS) before organs are used. C) The recipient should give fully informed consent and this should be fully documented. There is national guidance on the use of organs from higher risk donors and this can be accessed through NHSBT's</p>	<p>Professor James Neuberger</p>	<p>21/11/2014</p>	<p>Completed</p>	<p>21/11/2014</p>
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	website.				
2. The decision to accept organs from a donor where there is a question over the suitability of the organs for that recipient should not be made by one person. There must be discussion with at least one other consultant transplant surgeon and a member of the appropriate medical team. This discussion should be documented in the recipient's case records and the recipient must be informed that this discussion has taken place. (Compliance with existing guidance: Transplant Centres)	<p>This is an action for Transplant Centres but NHSBT will ensure that;</p> <p>A) All transplant centres are made aware of this very sad and unique case. B) The report authored by O'Donoghue &amp; Gunning will be published on NHSBT's website, including the recommendations and learning points made. C) Guidelines for consent for solid organ transplantation in adults (NHSBT &amp; British Transplant Society, 2013), to be reinforced to all Transplant Centres.</p> <p>This will be done via the NHSBT Associate Medical Director Communications which is sent electronically to Transplant Centres</p>	Professor James Neuberger		To be completed within 4 weeks of publication of report	
3. In the case of a potentially	This is an action for	Professor James		To be completed	

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<p>infected donor the decision must include discussion with a microbiologist, virologist, or infectious disease specialist. The specialist should be clinically qualified and have an understanding of both the risks of transplantation and or declining organs. (Compliance with existing guidance: Transplant centres)</p>	<p>Transplant Centres but NHSBT will ensure that;</p> <p>A) All transplant centres are made aware of this very sad and unique case. B) The following reports and guidance are reiterated to Transplant Centres;</p> <ul style="list-style-type: none"> <li>• Use of organs from high risk donors (NHSBT 2014)</li> <li>• SaBTO Guidance</li> <li>• Guidelines for consent for solid organ transplantation in adults (NHSBT &amp; British Transplant Society, 2013),</li> </ul> <p>This will be done via the NHSBT Associate Medical Director Communications</p>	<p>Neuberger</p>		<p>within 4 weeks of publication of report</p>	
<p>4. There should be discussion with the Office of the Chief Coroner about the need to perform an autopsy and the retention of tissue in cases of</p>	<p>NHSBT will forward this recommendation to the Chief Coroner</p>	<p>Professor James Neuberger</p>		<p>To be completed within 4 weeks of publication of report</p>	

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<p>donation where the cause of death is not fully known. It would be appropriate for NHSBT to lead this discussion. (Change of practice: NHSBT)</p>					
<p>5. Whilst recognising that there are often multiple reasons for declining organs, there should be better documentation of the reasons given by a transplant centre. Clinicians should be encouraged to be open and transparent in their reasons for turning down organs and we recommend that NHSBT works with clinicians to see whether the reasons can be defined more precisely. There should also be discussion with patients about what information they need and how to communicate this. (Change of practice: NHSBT, transplant surgeons, patient representatives)</p>	<p>NHSBT have established a working group to review the information that is given when organs are fast tracked to transplant centres. This information will be reviewed in its entirety, but particular attention will be given to reviewing the necessity for a “reason for decline” to be stated on each organ that is fast tracked.</p> <p>Co-opt surgical expertise onto the working group as subject matter experts as required.</p> <p>This working group will consider with clinicians, if reasons for declining organs can be defined more precisely.</p> <p>This work will be overseen by</p>	<p>[REDACTED]</p>	<p>01/04/2015</p>		

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	Members of NHSBT's Organ Donation and Transplantation directorate's Clinical Audit Risk and Effectiveness (ODT CARE) and endorsed by the Organ Advisory Groups.				
6. A full discussion of the use of marginal donors and the risks of transplantation needs to take place at the time a potential recipient is placed on a transplant list. This information also needs to be included in the Patient Information booklet. This is currently recommended good practice and should be reinforced by NHSBT so that it is standard practice in all transplant centres. There should also be a checklist or other means of verifying and documenting that the patient has received and read this information. (Reinforcement of existing guidance, new checklist: NHSBT, Transplant centres)	<p>Consent of potential recipients is the responsibility of the Transplant centres. NHSBT will re-iterate good consent practice.</p> <p>NHSBT will reinforce Guidelines for consent for solid organ transplantation in adults (NHSBT &amp; British Transplant Society, 2013), via the Associate Medical Director Communications.</p>	Professor James Neuberger		To be completed within 4 weeks of publication of the report	
7. All discussion that takes place around the consent at the time of	As above. NHSBT will reinforce good	Professor James Neuberger		To be completed within 4 weeks of	

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<p>the transplant of a recipient must be clearly documented in the case records. Recipients should be informed of the use of a marginal or high-risk donor. Recipients should be informed why the use of a higher risk donor is justified in their individual circumstances. This discussion must take place before the recipient is taken to the operating theatres. It should be good practice for the recipient's family to be involved in this discussion and to receive the information with the patient's agreement. (Reinforcement of existing guidance: Transplant centres)</p>	<p>consent practice as per action 6</p>			<p>publication of the report</p>	
<p>8. The use of an organ specific consent form for transplantation should be routine. Consideration should be given as to whether the record or transcript of any discussion should be signed by both a consultant surgeon and the patient or their responsible next of kin. (Reinforcement of existing guidance: Transplant</p>	<p>As above NHSBT will reinforce good consent practice</p>	<p>Professor James Neuberger</p>		<p>To be completed within 4 weeks of publication of the report</p>	

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centres)					
9. Work that is currently being undertaken by NHSBT into improving patient understanding of the risks associated with transplantation should continue. This is important work and we would support the production of a standard booklet on risk that is available on the NHSBT website. (New information: NHSBT, Transplant clinicians, patient representatives)	<p>NHSBT to continue with their work on risk in transplantation. Prior to the publication of this report a BTS/NHSBT workshop was held on 22/10/14. It was agreed, and NHSBT will continue to reinforce, that advice on consent is the responsibility of the professional societies but NHSBT will continue with this work with key stakeholders to ensure additional information and guidance is readily available.</p> <p>NHSBT to publish findings on Their website.</p>	Professor James Neuberger		Ongoing	
10. The Transplantation Society and NHSBT should recirculate the SaBTO Guidance on the transmission of infection to the transplant community including doctors in training, SNODs and Clinical Leads for Organ Donation (CLODs) stressing the	<p>NHSBT will ensure that Transplant centres are made aware of this sad and unique case and that the following documentation is highlighted ;</p> <ul style="list-style-type: none"> <li>• Use of organs from high risk donors</li> </ul>	Professor James Neuberger		To be completed within 4 weeks of publication of the report	

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<p>importance of adhering to the guidance. (Reinforcement of existing guidance: NHSBT, SNODs, Transplant centres)</p>	<p>(NHSBT 2014)</p> <ul style="list-style-type: none"> <li>• SaBTO Guidance.</li> <li>• Guidelines for consent for solid organ transplantation in adults (NHSBT &amp; British Transplant Society, 2013),</li> </ul> <p>This will be done via the NHSBT Associate Medical Director Communications.</p>				
<p>11. This report, the NHSBT report and recommendations should be circulated to the British Transplantation Society, the Intensive Care Society and the Faculty of Intensive Care Medicine for circulation to their members. (NHSBT, transplant community, ICS, FICM)</p>	<p>NHSBT to circulate this report to professional bodies and request circulation to members of British Transplant Society, Intensive Care Society and the Faculty of Intensive Care Medicine</p>	<p>Professor James Neuberger</p>		<p>To be completed within 4 weeks of publication of report</p>	
<p>12. NHSBT should ensure that all SNODs, regional and hospital CLODs circulate the reports to their local hospitals. We do not think there should be any change</p>	<p>NHSBT will ensure that;</p> <ul style="list-style-type: none"> <li>• All transplant centres are made aware of this very sad and unique</li> </ul>	<p>Professor James Neuberger</p>		<p>To be completed within 4 weeks of publication of report</p>	

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<p>to the policy where all potential donors are referred to the SNODs. (Reinforcement of existing guidance: NHSBT)</p>	<p>case.</p> <ul style="list-style-type: none"> <li>This report, along with the recommendations and learning points, are published on the website.</li> </ul> <p>This will be done via the NHSBT Associate Medical Director Communications</p>				
<p>13. The Case Report should be presented at national transplant and critical care meetings and we are pleased to note that this has already been done.</p>	<p>As acknowledged, the case report has been shared extensively.</p>	<p>01/12/14</p>	<p>Closed 01/12/14</p>		<p>Closed</p>
<p>14. The incident should be written up in the peer-reviewed literature. (Article: Recipient hospital)</p>	<p>NHSBT have requested that this is overseen by Dr [REDACTED]</p>	<p>Professor James Neuberger</p>	<p>21/11/2014</p>		<p>Closed</p>
<p>15. An article on the importance of the consent process should be published in a transplant patient magazine such as Kidney Life. (Article: BTS and NHSBT)</p>	<p>NHSBT Communications Department will contact Kidney Life and request that this sad case is published in a future edition.</p>	<p>[REDACTED]</p>	<p>20/12/2104</p>		

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<p>16. The recommendations should become standard practice throughout England, Wales, Scotland and N Ireland. NHSBT should establish a working group to look at how the recommendations in all the reports (NHSBT, Cardiff &amp; Vale, PHE and O'Donoghue &amp; Gunning) can be put into practice and disseminated to the transplant teams in England and Wales. The group should have met and established a time line for implementation of the changes within three months of the publication of this report. A major focus should be on the communication and documentation of donor risk and the consent process. (Change in practice: NHSBT, BTS, patient representatives)</p>	<p>NHSBT will liaise with NHS England to ask that these recommendations are incorporated into the peer review of transplant units to ensure that all relevant professional organisations and individuals are aware of the risks and lessons learnt through the investigations undertaken.</p>	<p>Professor James Neuberger</p>		<p>To be completed Within 3 months of publication of this report</p>	
<p>17. An audit should be performed one year after the recommendations have been put in place to ensure that they are embedded in current clinical practice. (Audit: NHSBT)</p>	<p>NHSBT will ensure that the desired outcomes in points 1, 3, and 4 will be incorporated into the established ongoing clinical audit programme.</p>	<p>██████████</p>	<p>14/11/2015</p>		

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