IMPROVING RATES OF CONSENT / AUTHORISATION FOR ORGAN DONATION OPTIONS WITHIN CURRENT APPROVED ACTIVITIES

Purpose of the paper

To summarise the actions being taken to improve current rates of consent / authorisation for organ donation in the UK and seek guidance / approval from SMT regarding further interventions that might be made within the current portfolio of approved activities.

Discussion and evidence

1. Family refusal represents the biggest obstacle to deceased donation and transplantation in the UK. Despite a series of interventions over a number of years, there has been little overall improvement in consent rates in the UK over the last decade.
2. There is considerable variation in the rates of family consent in different parts of the UK and it is recognised that a number of factors impact upon this. In population terms these include the socio-economic circumstances and ethnic origin of the area. More family centred factors such as prior knowledge of the patient's wishes, and in the case of DCD donation a knowledge of the length of the donation process also impact on decisions to consent or refuse donation.
3. A small number of studies suggest that involving a trained requestor in the family approach may increase consent rates. This evidence has been rated as poor by NICE so can only be considered as indicative of potential impacts and not conclusive.
4. Current ODT strategies to increase family consent rates are largely based upon involving a trained requestor in as many family approaches as possible by:
    a. developing the role of the SN-OD as the trained requestor
    b. promoting the involvement of SN-ODs in the family approach wherever possible
    c. sharing the broader principles of best practice in the family approach with the wider clinical community
5. The evidence that UK consent rates can be / are being improved by such interventions is mixed:

Positive	**Negative**
Consent rates are higher if SN-ODs are involved in the family approach, particularly for DCD*.	The ACRE study failed to demonstrate any positive impact from the presence of a transplant coordinator in the family approach.
Consent rates for DBD have risen from 61% in 2005/6 to 68% in 2013/14, although this effect appears to be levelling off.	Consent rates for DCD donation have fallen from 60% in 2005/6 to 54% in 2013/14.
There is significant variation in SN-OD consent rates, with a small number of SN-ODs having consent rates of around 80%.	There is no correlation between regional rates of collaborative requesting and family consent rates*.

* This data is from the PDA therefore uncontrolled

Actions

The actions listed below are restricted to one aspect of consent, *viz.* modification of the way in which donation is raised with a family. Some are already in progress, whilst others could be enacted within current business activity. Whilst any reference to behaviour change has been specifically excluded, it is emphasised that a substantial alteration in the way sections of society view deceased donation is central to delivering the strategic ambitions for consent as laid out in TOT2020.

Actions	**Advantages**	**Disadvantages**
SN-OD training and practice development		
Complete the development of the SN-OD workforce as trained requestors, monitoring the impact of this training on the outcome of the family approach.	Already funded and in progress.	Unproven intervention, with no evidence of benefit as yet. Unlikely to deliver the required increase in family consent/ authorisation rates in isolation.

Each SN-OD team to facilitate PEER review and ALS's to scrutinise each others consent/ authorisation practice, supporting SN-ODs with low consent rates and learning from those with high rates.	Systems in place to support action. Will support SN-ODs development in a constructive manner. The existing and in-house skills of highest performing SN-ODs are utilised to train the general SN-OD workforce in clinical practice	Will pull SN-ODs away from their embedded role. May be unpopular and unsettling for SN-ODs with low consent rates
Understand the relevant qualities of the leading SN-OD requestors (top 12) and use this to inform practice, training packages and the recruitment process.	Systems in place to do this. Will enhance the recruitment process.	Gaining consent is only one objective for the SN-OD so need to ensure other skills / attributes are not missed or de-valued.
Pilot the impact of more frequent consent training with professional actors and combined Action Learning Sets on SN-OD consent rate.	Pilot will commence October 1st 2014, in three designated teams	Requirement for the SN-ODs to attend training monthly for the duration of the trial, reducing embedded time during this period
Operational Management		
Team managers to take a more operational role in consent by mobilising the most appropriate SN-OD when a referral is received, by briefing the SN-OD on specific features of a unit and by immediately reviewing all refusals with the SN-OD.	Timely attendance of well briefed SN-OD at a donor hospital. Assessment can be made as to the appropriateness of any additional interventions or a repeat approach.	Removes TM from other management duties. May reduce donor exposure for some SN-ODs. If not handled well SN-OD and hospital staff may find this challenging / inappropriate. Requires a database of unit profiles.
On the weekly alert add the top 3 teams with the highest consent rate.	Creates competition between teams and provides recognition for the teams identified.	Rates are not currently calculated weekly. Staff in teams with lower rates may be de-motivated.
Reinstate regional donation targets.	The regional team will engage with a more tangible target.	Drives staff to focus on the outcome rather than the process.
Support the Workforce Role Redesign project in developing and implementing a pilot for 'designated requestors' within SN-OD teams.	SN-ODs with the best consent rates are deployed to support family approaches across their region.	May be unpopular with non-requesting SN-ODs. May increase delays in family approach.
Hospital Practice and Development		
Ensure that early identification and referral and meaningful collaborative requesting are	Strategies already developed. Considerable improvement in collaborative requesting rates already achieved.	Little information from the PDA regarding opportunities to refer donors earlier, thereby

seen as key objectives for Regional Collaboratives and Hospital Donation Committees.		enabling interventions.
Develop and deliver bespoke training packages for CL-ODs and Intensive Care Medicine trainees that supports the role of SN-ODs as trained / designated requestors.	CL-OD training can be incorporated into the Congress planning. Template for ICM trainee development already prepared. Important for circumstances where collaborative model might not be appropriate or possible such as paediatrics or emergency medicine.	Lack of clarity within ODT regarding the role of medical staff in the family request. Funding for CL-OD and ICM trainee training not yet established within ODT financial plan. Benefits are largely enabling.
Introduce operational communications with Trusts, eg e-mail to hospital donation committee when a SN-OD has been mobilised, weekly alerts to R-CLOD, CL-ODs and SN-ODs highlighting areas of best practice followed.	Help ensure best practice and facilitate role of SN-OD.	May not be welcomed by all committees.

Recommendation
These options are not mutually exclusive and represent a reasonable summary of the additional actions that might be possible within current resourcing and business support. It is recommended that they are viewed – and approved - as a whole rather than individually.

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