

Improving the outcome of the family approach

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Background to Education team

- Education previously delivered by external trainers
- Education team established Jan 2013
 - Recruited from Specialist Nurse: Organ Donation (SNOD) workforce
 - 2 Education and Service Development Managers
 - 10 Practice Development Specialists (PDS) (Based in regional teams)
- Redesigned courses
 - Building on existing communication skills
 - Set up courses nationwide/local delivery



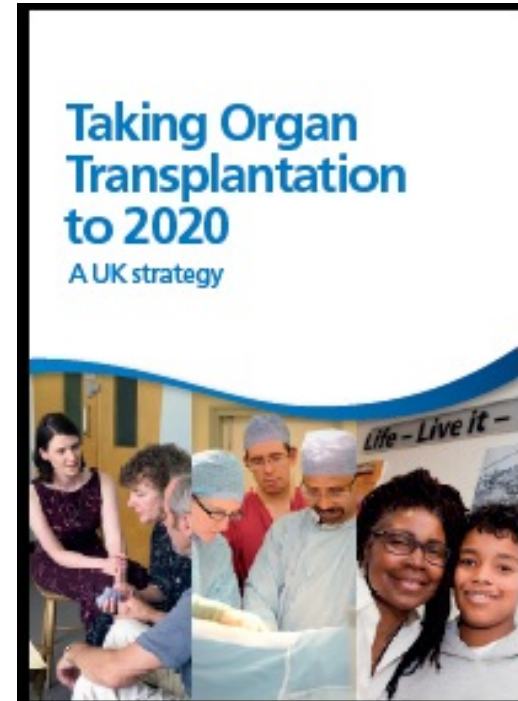
Current consent/authorisation rates

	DBD	DCD
Overall Consent/authorisation Rate	68.2%	54%
Consent/ authorisation rate when SNOD <u>not involved</u> in approach	58%	25.4%
Consent/ authorisation rate when SNOD <u>involved</u> in approach	70%	65.4%



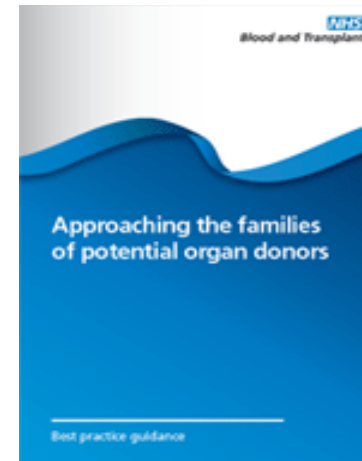
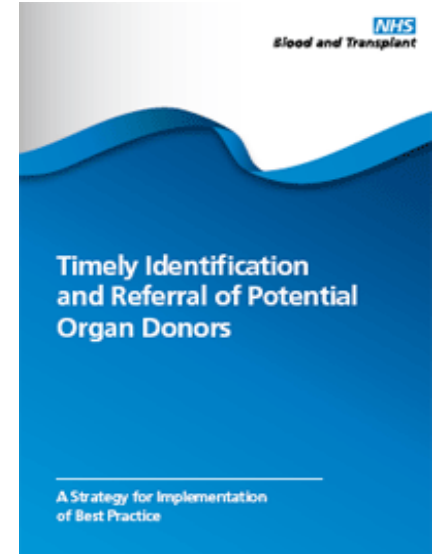
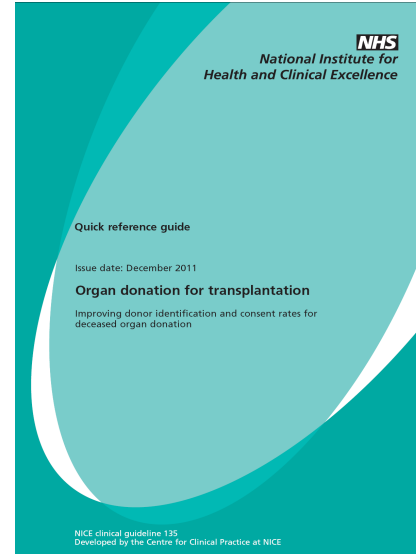
NHSBT 2020 strategy

- Increasing consent / authorisation rate to above 80%
- Increase deceased donor rate to 26 per million of the population (currently 19pmp)



SNOD involved in approach

- SNOD needs to negotiate planned approach for the subject of organ donation
 - ensures families are supported by people with the right skills / knowledge and are given time to consider the benefits of donation
 - Requires Timely referral to Organ Donation Service
 - Organ Donor Register should be checked prior to approach



The legal system in the UK

- Human Tissue Act 2004 (England, Wales & Northern Ireland) (Consent)
- Human Tissue (Scotland) Act 2006 (Authorisation)
- Both Acts give primacy to the wishes of the individual
- Lawful to take organs for transplantation where the deceased consented or gave authorisation before his / her death
- Relatives have no legal right to veto the patient's wish
- If the patient had not made their wishes known:
 - Nominated representative
 - Qualifying relationship/ Nearest relative (Scotland)



Planning



Confirming
understanding
and acceptance



Discussing
donation

Planned Approach

- **Who:** Consultant, SN-OD and nurse
- **Why:**
 - Clarify clinical situation
 - Seek evidence of prior consent/authorisation (eg ODR or other)
 - Identify key family members by name
 - Define key family issues
 - Agree a process of approach and who will be involved
 - Agree timing and setting, ensuring these are appropriate to family needs
 - Involve others as required, eg faith leaders
- **When and where:** in private and before meeting the family to confirm understanding and acceptance of loss



How to get SNOD into room...

- Negotiating and Influencing in Complex conversations course
 - Building rapport utilising Neuro Linguistic programming techniques
 - 'Insights colours' (understanding best way to communicate with different individuals)
 - Understanding levers that can be used to change peoples minds
 - Use/understanding of body language and active listening
 - Gives SNODs skills and confidence to negotiate self into room and challenge missed potential Organ Donors



Approaching families

- Utilise 'Ask-Tell-Ask' principle (Back et al (2005) Approaching Difficult Communication Tasks in Oncology. A Cancer journal for Clinicians p164-177)
- Ask question to assess understanding of futility (outcome of Brain Stem Death tests/decision to withdraw treatment)
- Give information (Tell)
 - Information to get family to position of acceptance of futility
 - Approach for donation
- Ask question to check understanding or explore concerns



Discussion with families when patient on ODR

- Presumptive discussion with family
- Tell them that family member is ODR & how we can make their wish a reality

“Mr....., your wife has registered on the Organ donor register. I am going to give you some information to help you understand how we will honour her wishes and I want you to ask me any questions you have. “



**Join the Organ
Donor Register**
0300 123 23 23



Approach for donation when patients wishes unknown

- Emphasis on the next of kin (qualifying relationship/nearest relative) decision
 - Its their gift, their altruism (not the patients)
 - Because too many families use “he said he didn’t want to be a donor” and “he never mentioned it, so we assume he didn’t want to donate” as ways of getting out of the conversation
- “Mrs....., you now have the opportunity to make a decision about donation for transplant.has the potential to save many lives. I’ll give you some information to help you. I want you to ask me any questions you have. After I’ve given you the information and answered your questions, you can tell me what you want to do”



What families need to know about DCD

- Approach same for both DBD and DCD however additional information given:
- Donation proceeds only if patient dies within a minimum 3 -5 hours (NORS Standards)
- Death declared after 5 minutes of asystole
- Transferred to theatre after 5 minutes



Revisiting a 'No'

- **If the family gave their decline to someone other than a SNOD, they should be approached again by SNOD**
 - **Check that understood brain stem death / futility**
 - **Have been given correct information regarding donation**
 - **Have been given the opportunity to ask questions and have their questions answered**
- **If SNOD gets a decline, they should explore 'No'**
 - **Ask questions to understand concerns**
 - **Give information to address concerns**
 - **Reapproach for donation**



Format of consent training

- 2 tiers to training
- Consent training for new staff
 - Theory (Legislative, best practice, literature)
 - Analysis of national data
 - Key phrases/ways to describe donation, Brain stem death, withdrawal of treatment to families
 - Demonstration of best practice approach
 - Role play with actors



Annual consent

- Analysis of local data
- Revision of theory
- Basics of Neuro Linguistic programming (Body language etc)
- Action learning sets/Shared practice
 - Discuss issues in individual consent practice
 - Utilise experience of peers
- Role play with Actors (complex situations)
- Commitment tool to put learning into practice



Providing feedback to SNODs

- Feedback comes from peers in group & Actors
- Utilise Pendletons model of feedback
 - Any obvious missed feedback picked up by PDS (rarely needed)
- External peer review of PDS facilitation



Plans for future training

- Take consent training to next level
 - More in depth Neuro linguistic programming
 - Shadow 'Sales' training/apply to consent training
 - Learn from international programmes
 - Shadow our own best consenters



Questions?

