

# Mandated Choice

A plan designed to increase  
consent rates for posthumous  
organ donation

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# **Our Current Organ Procurement System**

- **Requires explicit consent: opting-in**
- **An inefficient system, fails recipients**
- **Despite UAGA, left for the family**
- **About 50% of families say “No”**
- **Family refusal is the major barrier to deceased donor organ recovery**

# Why Do Families Say “No”?

- Often unaware of loved one's wishes
- Concerns: religion & unfair allocation
- Brain death is difficult to understand
- May not trust unfamiliar physicians
- Stress → inability to think clearly
- Asking is stressful for requestors
- Grief, confusion, distrust, anxiety

# **Overcoming the Family Barrier**

- **High refusal rates contrast with polls - widespread support for organ donation**
- **If stressful decisionmaking could be avoided, consent rates might increase**
- **Accomplished by ensuring that each person's wishes are known and honored, thereby eliminating the need to ask relatives for consent at a difficult time**
- **Consistent with the intent of the UAGA**

# **Mandated Choice**

**Would transfer control from the family to the individual, thereby accomplishing these goals.**

# **Mandated Choice**

- **All competent adults would be required to consider and record their wishes regarding posthumous organ donation**
- **Driver's license, tax return, ID cards**
- **Processing would require a response**
- **Choices recorded in accessible registry**
- **Change of mind easily communicated**
- **A person's decision would be binding**

# Advantages of Mandated Choice

- Decisions reached in a relaxed setting
- Each person's choice known / honored
- Family consent barrier eliminated
- Avoids stress for families / requestors
- Requirement to choose → ↑ awareness
- Avoids risky delays waiting for consent
- Preserves altruism, respects autonomy

## **Who Should Decide About Organ Donation – Family or the Individual?**

**“The individual’s interest in controlling the disposition of his or her own body and property after death suggests that it is ethically preferable for the individual, rather than the family, to decide to donate organs.”** CEJA – AMA, JAMA 272:809, 1994

**1993 survey** – 82% of 1002 adults agreed

JAMA 273:504, 1995

# Concerns about Mandated Choice

- Coercive, as it forces people to choose
- Could → resentment or discomfort about going on record as a donor
- Lead to “no’s” - no chance for family
- Insensitive to grief stricken families
- Bad publicity if family wishes ignored

# Concern About Coercion

“Since the gain to the public . . . is likely to be substantial . . . we as a society can legitimately decide to tolerate the negligible intrusion on an individual’s privacy presented”

- Mandated choice is not coercive re the choice a person makes, respects autonomy
- More than any other system, MC would ensure that a person’s wishes are honored

## **Concern About Resentment, Fear of Going on Record as a Donor**

- Survey of 1,000 U.S. adults - 10/92
- 65% would support mandated choice
- 80% of respondents < 30 supportive
- Second survey 1,002 U.S. adults – 7/93
- Under MC, 63% would say yes, 13% ?
- Third survey, 1993, for Partnership
- 89% - MDs will do all they can first

Clinical Transplant 7:525, 1993; JAMA 273:504, 1995; Partnership for OD, 1993

# **Impact of MC on the Family**

- **May be kinder than opting-in because:  
no need to consider organ donation,  
comforting - decedent's wishes honored**
- **Family discussion would be encouraged**
- **Families would be informed of recovery**
- **Families would likely become accepting  
once realize that MC is the best way  
to protect autonomy, including their own**
- **Could grant relatives veto power**

# Concern About Bad Publicity

- Theoretical risk of acting on donor card
- Some OPOs already do this ( CORE )
- Surveys suggest most people believe:
  - 1) individual is best suited to decide
  - 2) when an advanced directive exists, the family should not override it

JAMA 253:3111,1985; Clinical Transplant 7:525, 1993; JAMA 273:504, 1995

# Would Mandated Choice Work?

- There have been no actual trials
- Encouraging observations:
  - 1) Surveys MC - most would accept, “yes”
  - 2) NKF study 1992 - 52% of those who had not signed donor card - never asked
  - 3) Gallup poll - 69% want organs donated

Clinical Transplant 7:525, 1993; JAMA 273:504, 1995; Partnership for OD, 1993

# **Support for Mandated Choice**

- **CEJA of the American Medical Association**
- **Presumed Consent Subcommittee of the UNOS Ethics Committee**

**JAMA 272:809,1994; UNOS Update Vol 10:16, February 1994**

# **System Choice Should Reflect Our Top Priority**

- If our top priority is recovering organs, best choice is conscription
- If our top priority is protecting autonomy, MC is the best option
- We need to make a choice - we cannot have it both ways

Lancet 352:150, 1998

# Conclusion Regarding MC

- Ethically acceptable approach to consent
- Advantages over our current system
- Eliminates the family consent barrier
- Greater protection of autonomous choice
- Moves the decision to a relaxed setting
- Takes advantage of favorable attitudes
- Polls suggest that the public would accept
- A pilot trial of MC should be undertaken