

The Donation Conversation as a Process: How Research and Experience can be Used to Develop Evidence-Based Standards of Practice

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- You will receive a certificate via email upon completion of a certificate request or an evaluation
- Group leaders, please share the follow-up email with all group participants who attended the webinar.



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Leadership & Engaged Learning in Organ Donation & Transplantation



Today's Speakers



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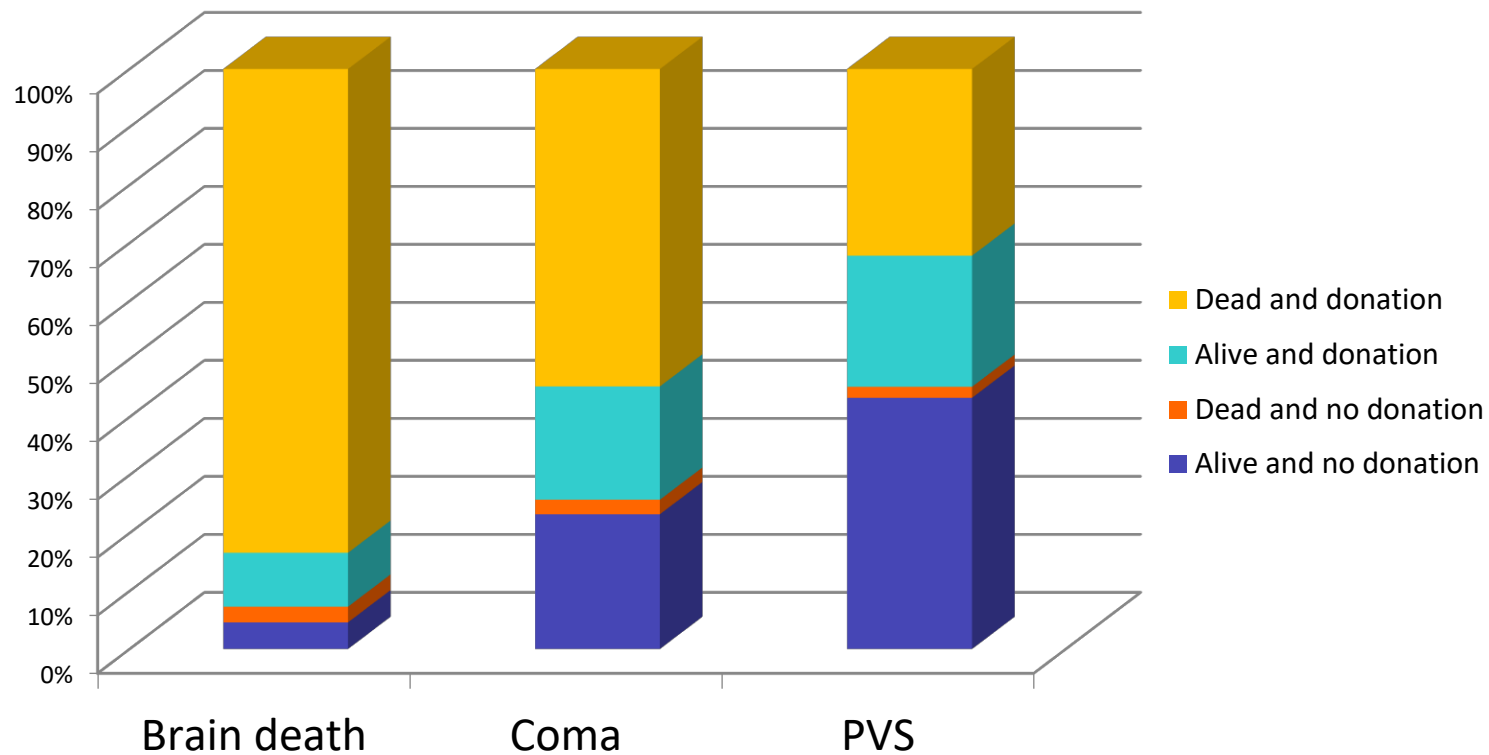


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The Donation Conversation as a Process: How Research and Experience Can Be Used To Develop Evidence-based Standards of Practice



Agenda



Welcome & Overview



Standard of Practice - Research and Experience



Donation Conversation as a Process



Family Donation Conversation (FDC) Timing / Planning



FDC – Critical Elements of an Effective Conversation



"The National Standard of Care requires a physician to use the degree of skill and care of a reasonably competent practitioner in their field under the same or similar circumstances."

"The standard of care is a measure of the duty practitioners owe patients to make medical decisions in accordance with any other prudent practitioner's treatment of the same condition in a similar patient."

Sources:

- 1. What Do You Need to Know About the Standard of Care? <https://www.miller-wagner.com> › Articles;*
- 2. Smith H. A model for validating an expert's opinion in medical negligence cases. *J Leg Med.* 2005;26(2):207-231.*

Standard of Practice / Care



Family Donation Conversation as a Process: Not An Event

- Timely Referral
- Information gathering and sharing
- Team planning/huddle



- Family given grave prognosis
- Support/basic needs
- Team explains BD or WD
- Questions and answers
- Active listening



- Grief support
- Family Readiness assessment
- Given BD news
- W/D decision is finalized



- Donation conversation
- Questions & answers
- Informed, proactive, enduring decision
- Next steps



- Plan for closure, final needs, and aftercare



FDC Planning: Timing is Critical

A *Timely* Referral Occurs:

- *When* the HCT identifies that a patient has a potentially irreversible and non-survivable neurologic injury
- Before brain death exams begin
- Before families are approached to implement DNRs
- Before families are asked to consider w/d decisions
- *Allows* adequate time for OPOs to respond on-site, evaluate donor potential, and thoughtfully partner with HCT to plan timely FDC and assure communication prepares family to understand brain death is death



HCT Common Concerns About Referral Timing

A background image showing four healthcare professionals (three men and one woman) in a clinical setting, looking down at a device or document. They are wearing light blue scrubs and stethoscopes. The image is slightly blurred and has a soft focus.

Family will see the
OPO on the unit

HCT will somehow be
breaking a *trust* they
have with family by
involving OPO without
family knowledge

OPO will bring up
donation too soon

Loss of control

Common Concerns About When to Initiate the Donation Conversation



Brain Death

- Understanding
- Differentiating brain death from cardio-pulmonary determinations of death

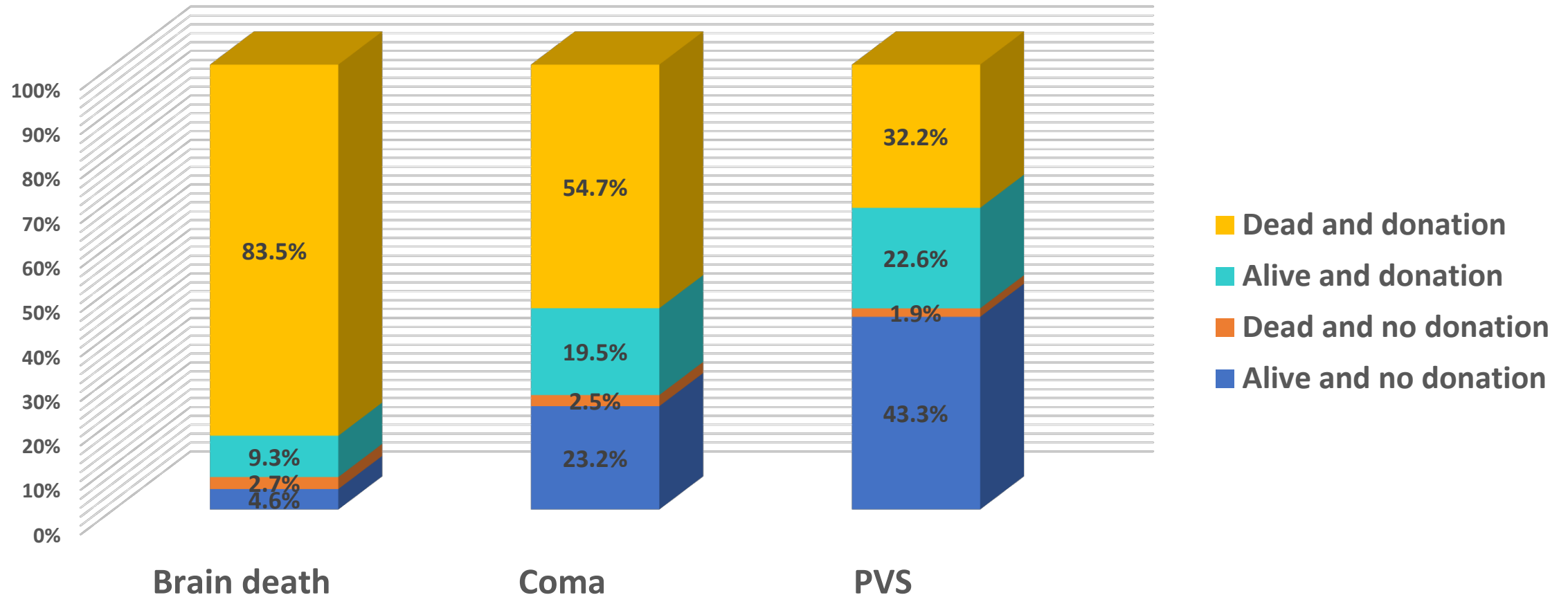


Decoupling

- The line between understanding brain death and the donation decision isn't what we thought it was

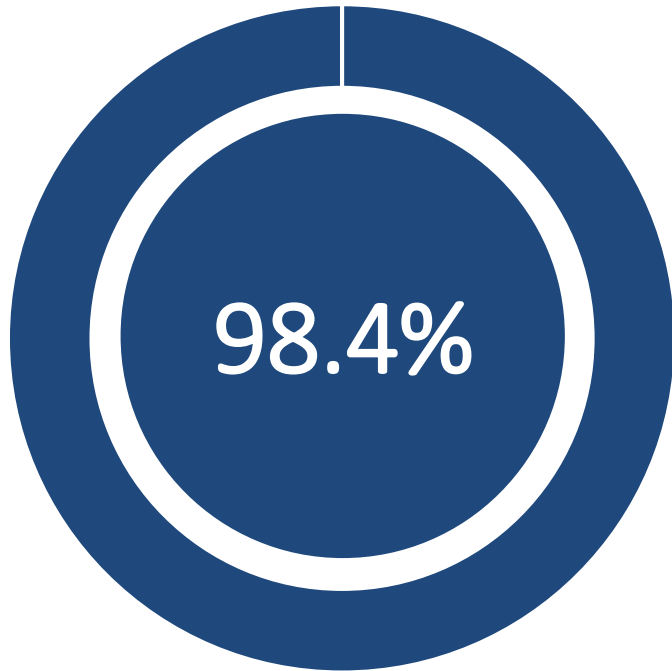
Understanding of Brain Death Does Not Determine Willingness to Donate

Survey of the general public (n=1,351)

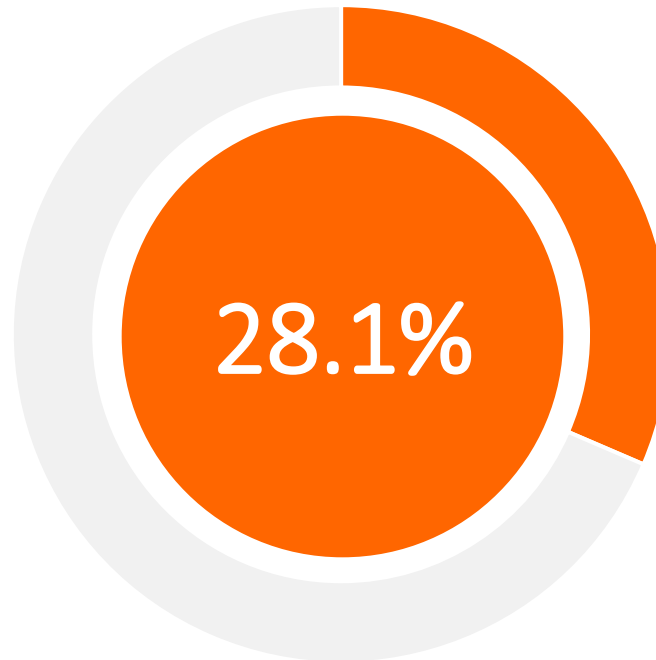


(Siminoff, Burant, et al, 2004)

Understanding Brain Death

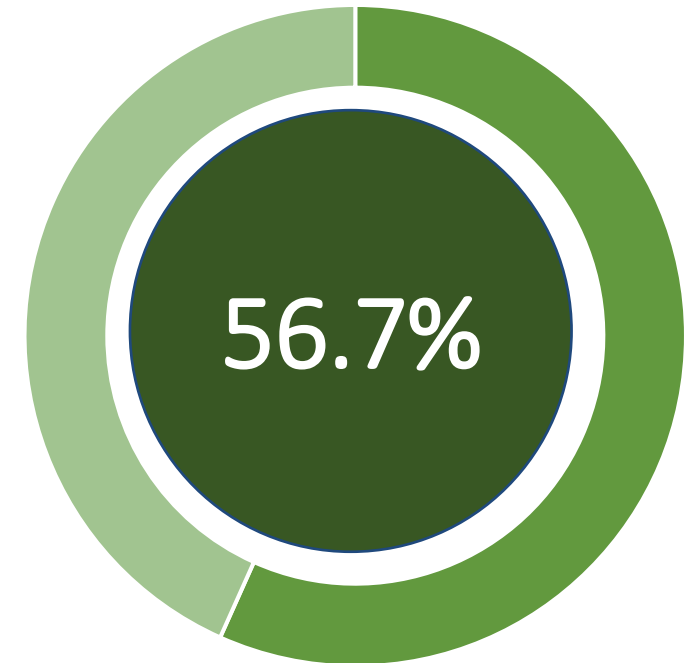


Have heard of brain death



**Believed a brain-dead person
can hear**

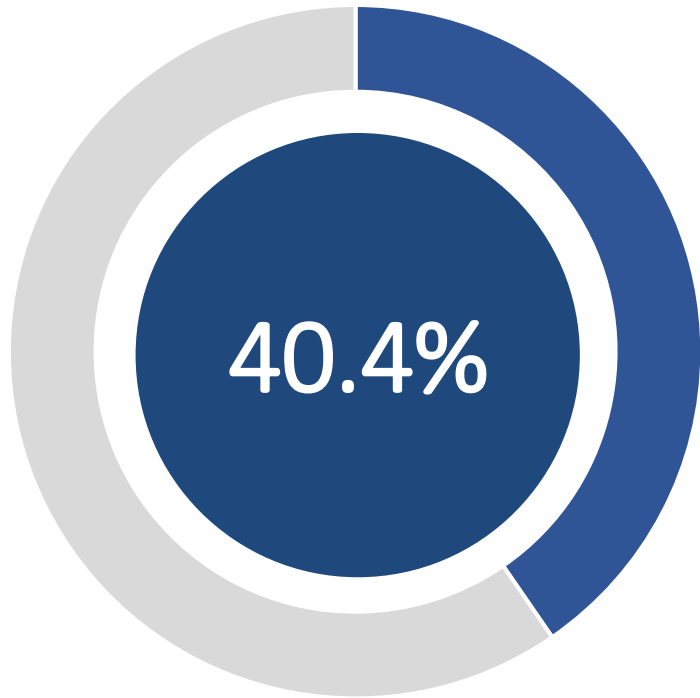
(n=1,351)



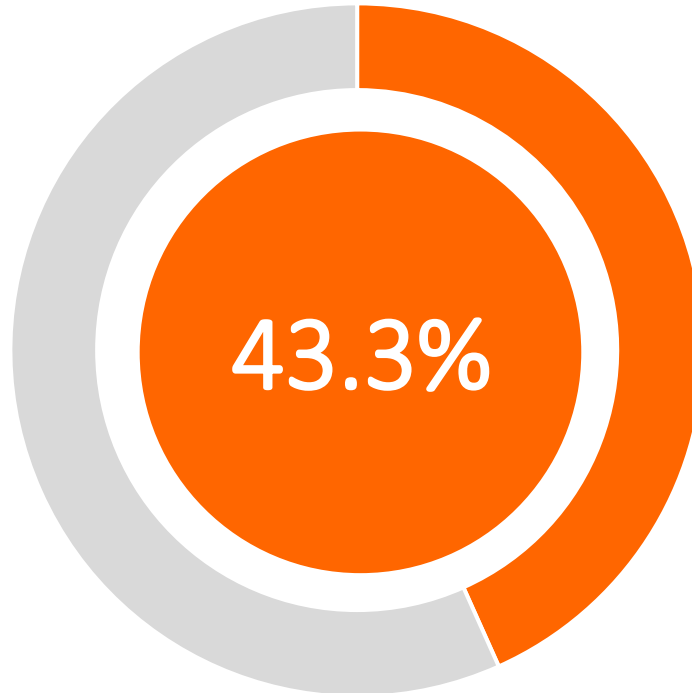
**Believed respirator removed
when organs recovered from a
brain-dead person**

Understanding Brain Death

People declared brain dead are:

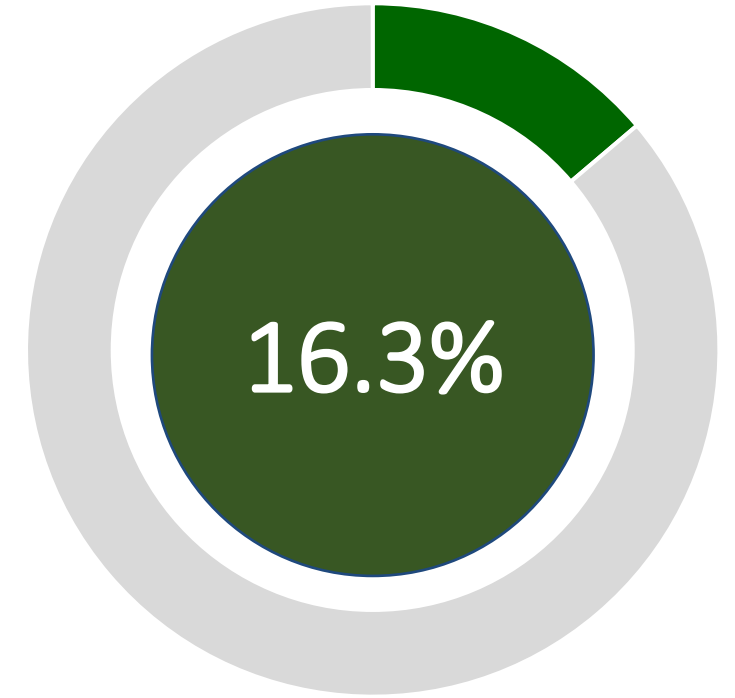


Dead



As good as dead

(n=1,351)



Alive

(Siminoff, Burant, et al, 2004)

Determine FDC Timing by Assessing Family Readiness

Definition of Family Readiness

An assessment of a family's understanding in which it has been determined that the family:

- Asks the healthcare team about organ donation, or
- Indicates an understanding that their loved one has died or that they have suffered an irreversible injury for which there is no hope of meaningful survival.

Ideally, they have been prepared by the best means possible to participate in making a proactive, informed, enduring donation decision.

Six Events that Trigger A Donation Conversation

Family Understands Death/Non-Survivable Nature of Injury (...hold no hope for survival)

The family indicates that they understand patient has died and/or that they have no hope for patient's meaningful survival (can occur *prior* to formal brain death pronouncement or prior to final withdrawal meeting).

Brain Death Pronounced: Family Verbalizes Understanding

Patient has been pronounced brain dead; family has been given this news and time of death. Verbalizes understanding that the patient is dead.

Decision Made to Limit, Decelerate or WD Treatment

The family indicates that they want to limit, decelerate, or withdraw medical treatment (action may compromise or limit opportunity for donation).

HCT Shares Donation Opportunity with Family

Any member of the health care team mentions the opportunity for donation with a family or initiates a donation conversation without the OPO being present. Not optimal practice.

Family Brings Up Donation

The family mentions donation or expresses an interest in talking about donation.

Pulmonary or Hemodynamic Instability

The patient suffers pulmonary and/or hemodynamic instability, which may result in compromising the family's and their loved one's donation opportunity.

Understanding Brain Death

Families understanding of brain death does not predict authorization but...

- Important for families to understand basics of brain death
- Assists families to make knowledgeable decisions about removing mechanical supports
- 12% of refusals to donate resulted from families who did not understand that withdrawing mechanical supports would preclude brain death
- 43% of families refuse because of failing 'stamina'; need to support them through the process and understanding of need to conduct tests to determine brain death



Research Does Not
Support
Decoupling,

But...

It Does Support
Timely Referral &
Request/Offer

Late Discussions Are Less Likely to Result in a Successful Request / Offer

- Compared to asking after death pronouncement, asking *prior* to notification of brain death is associated with higher consent rates—63% vs. 56.6%. (Siminoff, Laurence, et al., 2002)
- Families asked at the time of or within 1 hour of brain death had higher consent rate than families approached >3 hours after brain death—61% vs. 51%, $p < 0.001$. (Brown, Foulkrod, et al., 2010)
- Significantly higher donation rates were observed when donation was first mentioned *before or during* the pronouncement of brain death than when families were approached after being informed of brain death—93% vs. 84%. (Exley, White & Martin, 2002)

Creating The Right Environment To Introduce The Donation Conversation

Partnering for a timely referral and planning process

Understanding the importance of being a team, sense of solidarity r/t family care

Both teams understanding the rationale for timing and...

Factors important to consider when assessing family readiness

Assuring family has been communicated to all along in simple, easy to comprehend language

Family has rapport with both teams so they can feel comfortable in candidly expressing questions, worries and concerns

Pause for...



Q & A



Idea
Sharing

Donation Conversation Goal

Informed Decision

Ensures that the family is aware of the powerful significance of the decision they are making; this requires sensitivity and careful attention to protecting the family from feeling pressured in any way.

Proactive Decision

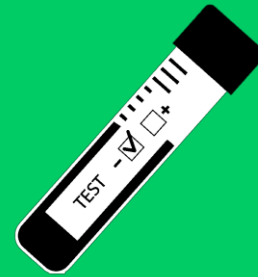
Is characterized as a decision the family and the donor would have made on an ordinary day, at a time when they had full knowledge of the impact and meaning of the decision and could make a determination that was consistent with their values and beliefs.

Enduring Decision

Is one that the family could look back on in the years to come, as the right decision for them, and the one they would make again.

Donation Conversation

Why Do People Donate?



PEOPLE
PROCESS

BLACK BOX OF COMMUNICATION



1. Effective communication has been shown to be the single most important variable to obtaining authorization. It is a skill that can be learned, not an innate ability.
2. A **skill** is a behavior that can be performed *purposefully, consistently, and appropriately*.
3. Goes above and beyond whether you are a “people person” or your personal style or personality.
4. Always room for refinement, practice, and learning new skills.

Pre-existing attitudes, beliefs, and values



Socio-demographic characteristics

Refutational

- Ex: *No, you will still be able to have an open casket at the funeral.*

Approval

- Ex: *This is a generous gift.*

Reassurance

- Ex: *We will treat [patient] with the utmost respect.*

Partnership

- Ex: *You're not in this alone, we'll get through this together.*

Dispels false beliefs

Creates trust, connection, & sends positive message about donation

Increased likelihood to donate

Effective Communication Message Types



The Authorization Environment

Acknowledge this is a highly stressful environment for the family

Stressful aspects of the authorization environment identified by families include:

- 1 ICU setting
- 2 Feeling lost or unsupported
- 3 Threat of losing a loved one
- 4 Adjusting to the loss
- 5 Confirmation of brain death
- 6 Shock/surprise in being asked to donate

Factors that mitigate family's stress:

- 1 Support of family and friends
- 2 Being able to spend time with patient
- 3 Receiving information emotional support
- 4 Adequate time to understand patient's condition
- 5 Preparation to hear organ donation request / offer
- 6 Displays of empathy
- 7 Quality of communication and patient care



Factors Known To Influence The Donation Decision

- Family and patient pre-existing characteristics and attitudes
 - Socio-demographic characteristics
 - Family prior attitudes and beliefs about organ donation
 - Patient pre-designation of self as a donor
 - Experiences (current and past) with the healthcare system
- Hospital's donation environment



- Communication

Predictors of Donor Registration^{^*}

Total Sample (n=1595)	Odds Ratio
Race (White)	2.78
Age	.98
Education	1.29
Income	1.26
Attitudes Toward Donation	1.18
Trust in Medical System	1.10

[^]From data reported in: Traino MH, Siminoff LA. Attitudes and Acceptance of First Person Authorization: A National Comparison of Donor and Nondonor Families. J Trauma Acute Care Surg. 2013 Jan;74(1): 294-300.

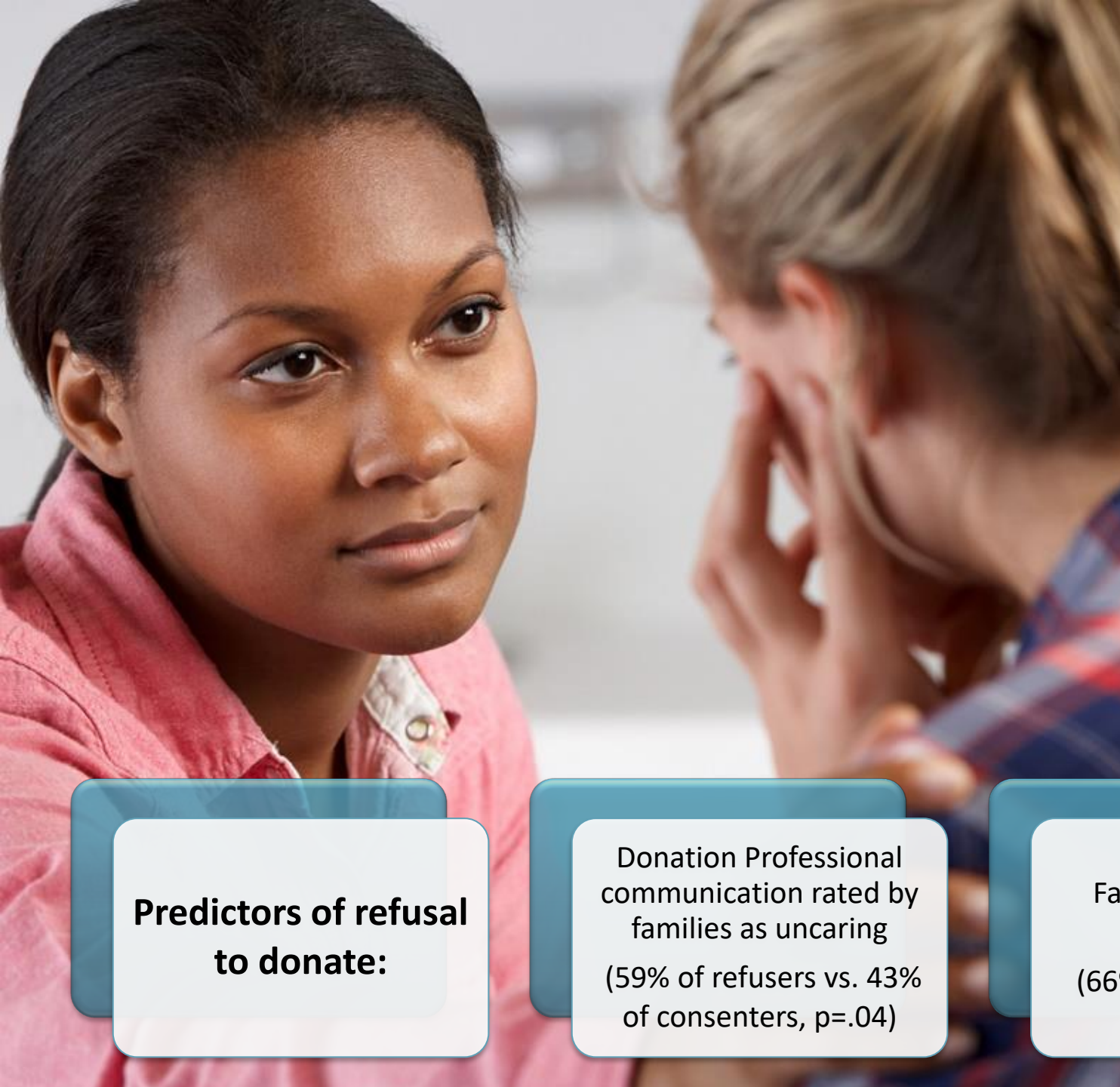
*All factors are significant in the logistic regression model

Socio- demographic Characteristics as Predictors of Donation

- Female family decision makers more likely to donate
- Families more frequently deny offers for organ donation of older patients as compared to younger patients (by about 5%) ¹
- Families of pediatric patients donate more frequently (by about 6%)
- Black Americans about 1/4 - 1/3 less likely to donate compared to white Americans
- Nearly half (48%) of older adults cite two reasons for “opting out” of registration ³
 - Older age (e.g., “I’m too old”)
 - Health-related concerns (e.g., “I have heart problems”)

Communication and Authorization Predictors

- Predictors of authorization to donate:
 - Family response to the initial conversation about donation
 - Development of rapport with family
 - More issues of concern to family are:
 - Funeral
 - Costs
 - Donation equity (will people who look like me get a chance at a transplant?)
 - Treatment of the deceased's body
 - Need in my community
 - Time spent discussing donation
 - Meet emotional needs
- Predictors of refusal to donate:
 - Donor professional communication rated by families as uncaring
 - Family surprised by request/offer for donation
 - Family felt harassed or pressured about donation decision



Communication Factors and Donation

Predictors of refusal to donate:

Donation Professional communication rated by families as uncaring (59% of refusers vs. 43% of consenters, $p=.04$)

Family surprised by request/offer (66% vs. 34%, $p<.002$)

Family felt harassed or pressured about donation decision (66% vs. 34%, $p<.002$)

Communication Components Significantly Associated with Authorization

Positively associated with authorization

Confirmational messages

Higher ratings of OPO professional communication skills

Legitimization

Reassurance

Expressions of concern

Repetition

Offers of services

Negatively associated with authorization

Apology

Interruptions

Not enough time spent with the family discussing donation



Conversations With Black Families: A Case For Effective Communication

Analyses compared the in-hospital donation experiences of 276 Black Families who donated and those who did not:

- No differences in socio-demographic (age, education, gender, income, marital status)
- No differences in cause of death
- No differences in general attitudes and beliefs about organ donation
 - Composite organ donation attitude scores were similar for families who authorized (M=55.0, sd=8.1) and (M=54.0, sd=7.8) for those who refused donation

(Siminoff, Traino, et al 2021)

Logistic Regression Examining Decision to Decline Authorization

Variable	Odds ratio (95% CL)
Donation helps families grieve	0.89 (0.70-1.1)
Relational communication (RCS)	0.95 (0.90-.98)*
Quality of communication	1.3 (0.72-2.2)*
Satisfaction with time spent	0.93 (0.68-1.3)
Satisfaction with how requestor answered questions	0.96 (0.52-1.5)
Satisfaction with request process	0.75 (0.53-1.1)
Initial reaction to donation	0.17 (0.08-.43)**
Pressured or harassed	0.92 (0.73-1.2)
Requester communication skills	1.0 (0.96-1.1)
Topics discussed	0.76 (0.69-.83)**
FDM assessment of how caring and concerned the primary hospital (HCP was)	0.96 (0.74-1.2)
FDM spoke with hospital staff about organ donation	0.80 (0.38-1.7)



Effective Communication Skills For Organ Donation Offers

Initiating the Family Donation Conversation:

- Greets each family member individually
- Uses names correctly
- Clarifies family relationships if necessary
- Introduces self
- Clarifies role
- Attends to physical comfort of family
- Attends to privacy issues
- Acknowledges loss (if patient is declared)
- Acknowledges difficult situation (if not declared)
- Provides empathy statement



Effective Communication Skills For Organ Donation Offers

Giving Information

- Gives information about need for organs
- Gives information about the opportunity available to help someone
- Gives information about family having a choice about what to donate (if not +DD)
- Gives information about no financial cost to family if they donate
- Gives information about appearance of deceased after donation
- Gives information about impact on funeral arrangements
- Provides information in small enough segments to be absorbed
- Repeats and summarizes important information when appropriate
- Checks in to ascertain what is understood
- Uses language that is easy to understand; avoids jargon



Effective Communication Skills For Organ Donation Offers

Eliciting Family's Perspective / Core Beliefs

- Elicits each family member's understanding of patient's status
- Determines each family member's current beliefs about organ donation
- Explores if family knows what deceased's wishes were about donation
- Explores and acknowledges individual concerns / worries about organ donation
- Encourages expressions of thoughts and feelings



Effective Communication Skills For Organ Donation Offers

Finalizing the Donation Decision

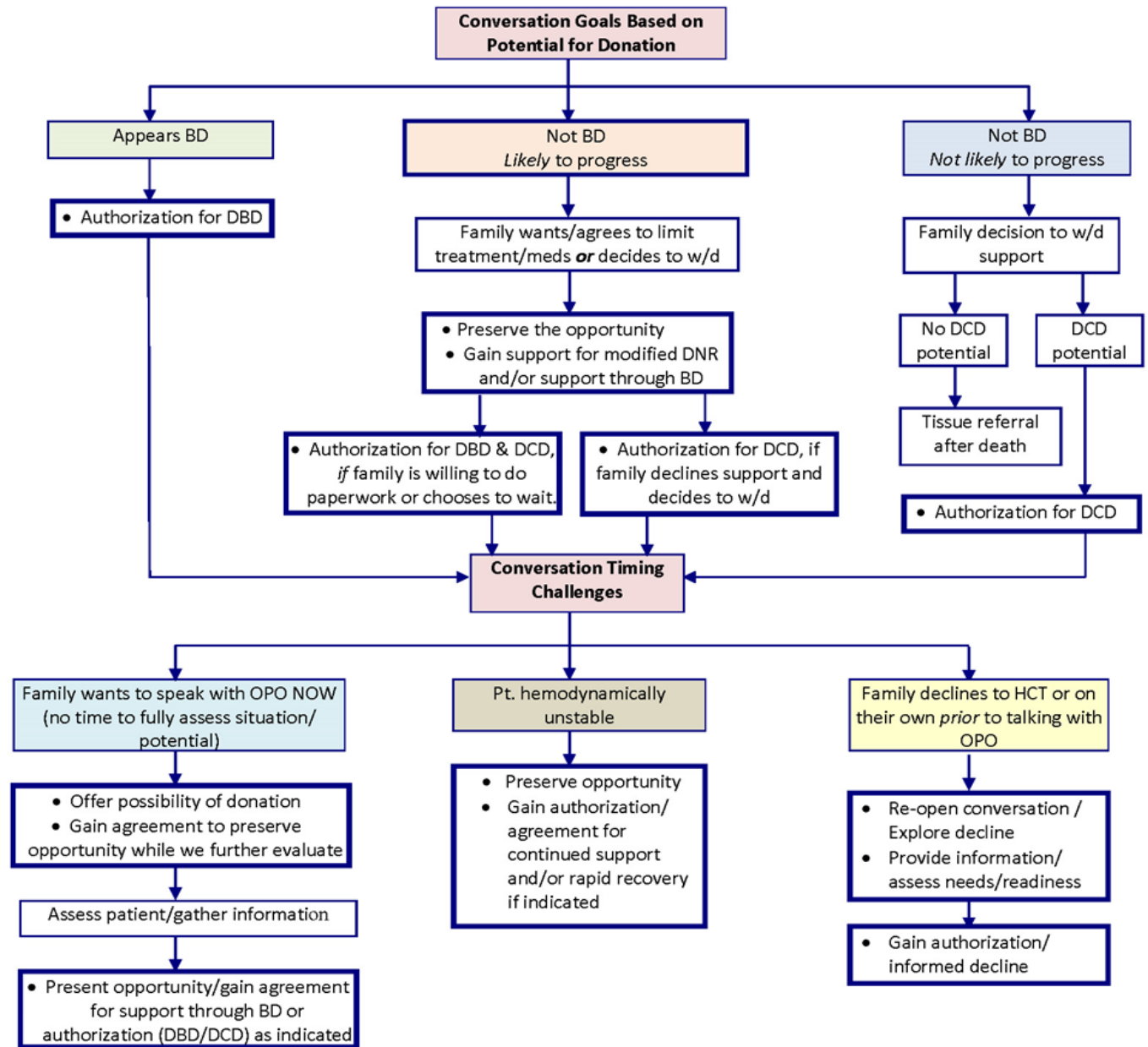
Closure:

- Signals closure
- Checks for remaining questions
- Summarizes understanding of family's decision and/or position at that point in time
- Gives opportunity to ask questions and/or clarify future plans
- Explores outstanding worries/concerns
- Clearly states what the next step is
- Thanks family and makes appropriate parting statement
- In cases of decline, explores to be sure decision is fully informed, proactive, enduring
- Thanks family / offers support / makes appropriate parting statement
- Prepares them for what to expect next

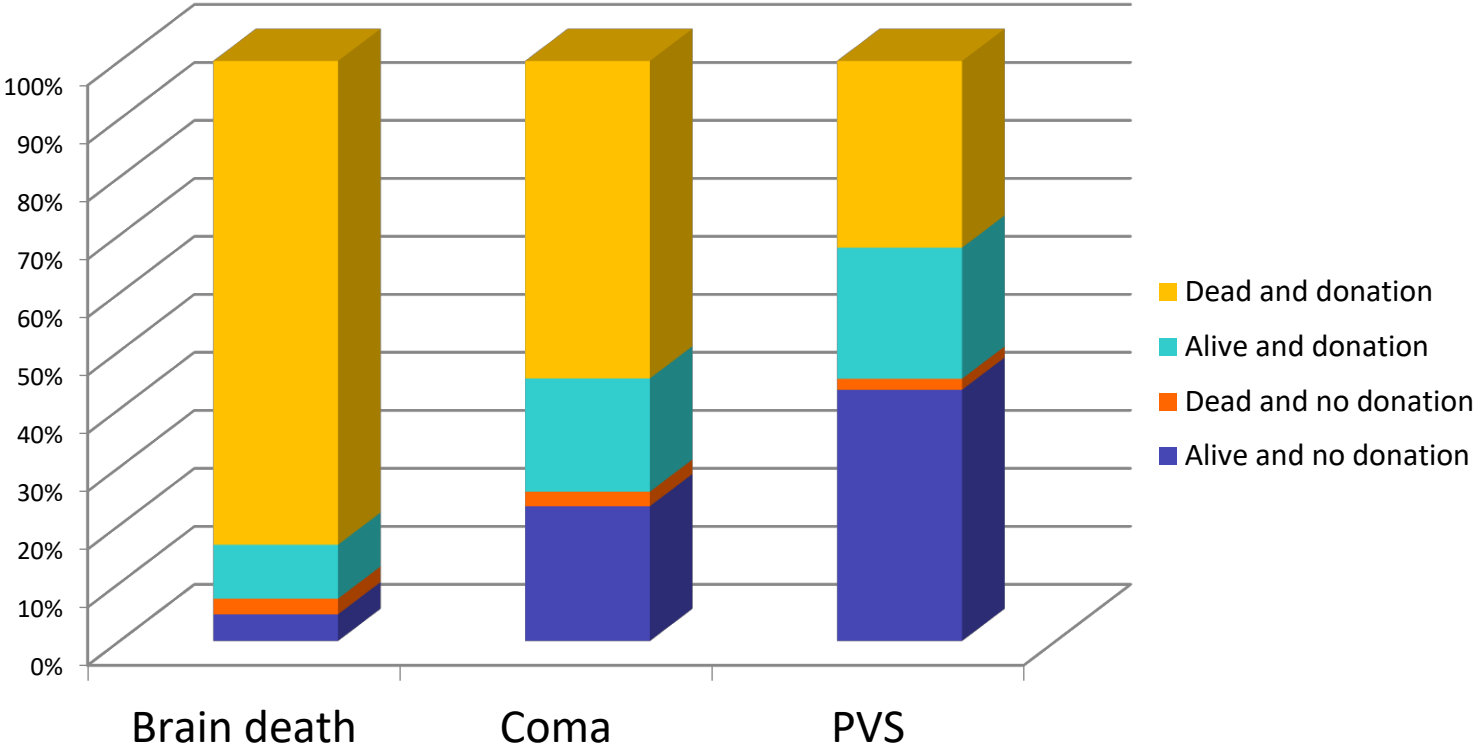
Dual Advocacy Elements		
Introduction		1. Introduces self from GLDP and as colleague & member of team caring for family
		2. Expresses condolences and / or acknowledges gravity of situation
		3. Offers family care/comfort measures; assures basic needs are met (throughout)
		4. Prompts for & answers questions/checks understanding of information received so far
Engages family		5. Assures understanding of brain death or confirms withdrawal decision - Explains brain death simply if needed
		6. Personalizes conversation /engages family about loved one, etc.
Communication skills (throughout)		7. Avoids use of medical / OPO language and jargon
		8. Uses open-ended / avoids close-ended questions
		9. Uses overall effective communication techniques: - Active listening
		- Speaks slowly & clearly/ matches "tone" of the situation (Attunement)
		- Allows for silences
		- Conveys positive regard and non-judgmental attitude
		- Provides information in "chunks", assures comprehension
		- Attentive to verbal and / or physical cues
		- Speaks professionally / avoids casual terms such as "you guys", "yeah", etc.
		- Acknowledges strong emotion
	- Uses tools such as normalization, seek to understand, L-A-S-T, primacy etc.	
Transition	- DD	10a. Makes a meaningful transition to donation discussion <i>Does NOT ask</i> if family has discussed donation or if they know their loved one's wishes concerning donation
	+ DD	10b. Meaningful transition to donation including disclosure that loved one has indicated decision to be an organ/tissue donor on driver's license/registry
Donation conversation		11. Uses inspiring explanation of donation and rare nature of opportunity - Includes at least one example of recipient/ donor family info / story
Offer	- DD	12a. Makes an empowering "offer"
	+ DD	12b. Empowers family to work with OPO to honor loved one's decision ; <i>does not present donation as a choice</i>
		13. Gives family something to say "Yes" to (informed, proactive, enduring decision)
		14. Demonstrates Dual Advocacy, competence, confidence, and family guidance

A Simple Plan Family Communication Goals

KEY: • Bullet indicates conversation goal



Translating Research/Experience Into Standard of Practice



Pause for...



Q & A



Idea
Sharing

A Special Thanks to Our Presenters



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Q & A

QUESTIONS & ANSWERS