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Eye, Organ & Tissue Donation: The Measurement of Meaning Among Hospice Professionals

January 2005

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CASE STATEMENT

Several facts about eye, organ and tissue donation raise important questions and point out significant ironies when compared with facts about the use of hospice care. Residents in the region are choosing to be donors in record numbers. At the same time, record numbers are also choosing to die under the care of a hospice, where there is likely no routine mechanism to discover or carry out the donation decision. This survey was designed to assess the attitudes of hospice professionals toward several concepts related to the donation process. It is meant to help the Public & Professional Relations Department counsel the management of the Rocky Mountain Lions Eye Bank on how best to serve those eye donors and families who choose hospice care as well as the professionals who work with these patients and families. This survey is a part of a body of research the department will pursue. Other research includes interviews with families of hospice patients (donor and non-donor) as well as a literature review and survey of other recovery agencies around the nation.

Advances in an individual's right to make the decision to become an eye, organ & tissue donor have progressed due to two separate initiatives. Since 1998, the Centers for Medicare and Medicaid Services (CMS) has required hospitals receiving Medicare funds to implement certain provisions surrounding eye, organ & tissue donation. Namely, these hospitals must ensure that:

- Every patient is evaluated at the time of death for eligibility to be a donor.
- If eligible, the patient's family is given the option to donate and the decision is followed.
- The person offering this option to the family is trained to do so by the recovery agencies, so that informed decisions can be made.

These conditions of Medicare participation do not currently extend to hospices.

To further strengthen individual rights, the Colorado legislature created the Colorado Donor Registry in 2000 — a confidential, electronic database whereby residents can make their decision to be a donor known and followed at the time of death. While the driver's license has always been the popular mechanism for expressing this intent, it was only after the registry's creation that the donor's decision could be known and followed. According to the Donor Awareness Council, 59% of Coloradans say yes to donation at the time of driver's license renewal. At the time of the registry's creation in 2000, only 35% did so. In 2004, 50% of all eye donations received by the Rocky Mountain Lions Eye Bank came through donor registries.¹

Accompanying this movement is another trend in individual autonomy — the number of people who choose to die at home or under hospice care is increasing. According to the Colorado Hospice Organization, 12,644 patients were admitted to hospice care in Colorado in 2002. This represents a 57% increase from 1998. Historically, hospices have not been a target audience for donation education programs and recovery agencies such as the Rocky Mountain Lions Eye Bank have not been involved in putting donation systems in place. Of 1,743 Colorado eye donors in 2004, only 31 were from patients of hospice programs.

These numbers clearly show the increased risk that many people may make the decision to be a donor by joining the donor registry, yet have that opportunity missed by choosing to die under hospice care.

¹ The Rocky Mountain Lions Eye Bank serves Colorado, Wyoming and a portion of Montana. All three states have similar donor registries that honor the donor's decision. Colorado's registry was the first among the three to be implemented.

METHODOLOGY: SEMANTIC DIFFERENTIAL

This survey used the semantic differential method developed by the psychologist and communications scholar Charles E. Osgood.² The semantic differential method plots the differences between individuals' connotations for words and thus differentiates attitudes toward a concept. The intention is that this should differentiate between attitudes in a way that other methods don't and should shed more light on the links between attitudes and behavior. This methodology has been widely applied to communications research.

Opinion research often uses the Likert scale, whereby a statement is made and respondents are asked to rate their agreement along a 3 or 5 point scale from "strongly disagree" to "strongly agree." The semantic differential method uses a similar scale, however, respondents are asked to rate a concept according to a series of several bipolar opposite adjectives. For example, respondents would be asked to consider the word "foreigners" and place a mark somewhere between each of the following sample paired adjectives.

FOREIGNERS

good ___ : ___ : ___ : ___ : ___ : ___ : ___ bad
weak ___ : ___ : ___ : ___ : ___ : ___ : ___ strong
active ___ : ___ : ___ : ___ : ___ : ___ : ___ passive

Osgood's factorial analysis of numerous bipolar adjectives classified them into various dimensions of judgment he called "semantic space." These dimensional factors are:

- Evaluative factors (good/bad)
- Potency factors (strong/weak, threatening/non-threatening)
- Activity factors (active/passive)

In the above example using the concept "foreigners," two subjects' connotations for the word might be:

Subject 1: bad, strong, active

Subject 2: bad, weak, passive

Both views are unfavorable, but the actual behavior of each subject towards foreigners may well be different. Subject 1 might be inclined to treat foreigners in a placatory manner, anxious to avoid conflict; subject 2 might be inclined to treat them exploitatively, being more likely to boss them around.

² Osgood, Charles, George Suci and Percy Tannenbaum. *The Measurement of Meaning*. Urbana: University of Illinois Press, 1957.

SCORING AND INTERPRETATION FOR THIS SURVEY

Multiple series of paired, bipolar adjectives were chosen from the work of Osgood and a 7-point scale was assigned. Scales were scored from -3 to +3 with the positive end assigned to the desired, positive response. Adjective pairs were then grouped by dimensional factors and averaged again within the group to obtain a dimensional factor score. In our survey, the dimensional factors were scored and interpreted as:

- **Evaluative:** Scores >0 are interpreted as "good" or "positive." Scores <0 are interpreted as "bad" or "negative."
- **Potency:** Scores >0 are interpreted as "non-threatening." Scores <0 are interpreted as "threatening."
- **Activity:** Scores >0 are interpreted as "Active." Scores <0 are interpreted as "Passive."

Dimensional factor scores were plotted on a line graph for easy interpretation. The graph shows both direction and distance from the origin (0 on our scale). The direction (+/-) indicates the *quality* of meaning as outlined above, while the distance (number up or down the scale) indicates the *intensity* of the meaning.

A copy of the survey instrument is in the appendix of this report.

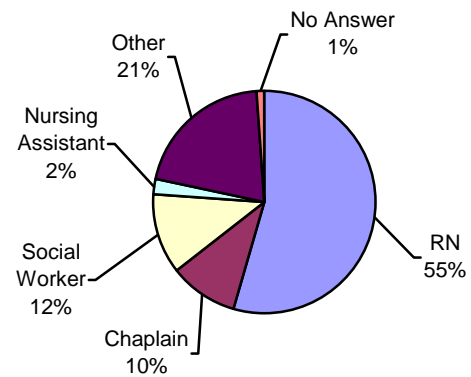
RESPONDENT DEMOGRAPHICS & HOSPICE INFORMATION

500 surveys were mailed to 40 hospices in Colorado and three in Wyoming with instruction for distribution to staff involved in direct patient care. Volunteers were excluded. Of these, 165 surveys were returned, 15 of these were collected at the Colorado hospice Organization's fall exhibition and conference. The return rate was 33%.

The following informational questions were asked concerning the respondent and the hospice for which he or she works:³

1. What position do you occupy?

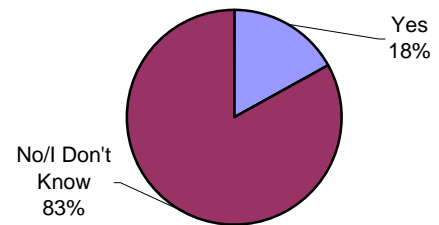
RN	55%	91
Chaplain	10%	16
Social Worker	12%	19
Nursing Assistant	2%	3
Other	21%	35
No Answer	<1%	1



2. Does your hospice have a formal policy or protocol used to offer the option of donation to patients and their families?

Yes	18%	29
No/I Don't Know	83%	136

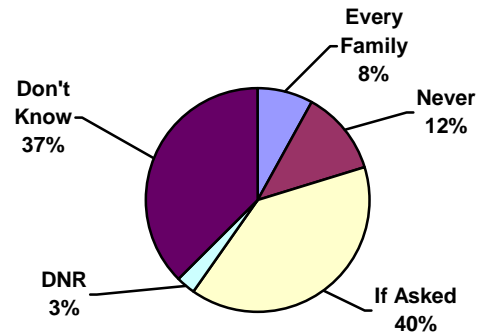
Discussion: The question asked if there was a formal policy concerning eye, organ and tissue donation. It did not seek information on what that formal policy does or does not provide. The Rocky Mountain Lions Eye Bank, through experience and anecdotal evidence, knows that hospice practices range from simply pointing out the option on DNR forms to requiring the option be actively offered to eligible patients/families.



³ While presented here at the beginning of the report, these questions were asked last in the survey. See the sample survey form in the appendix.

3. Does your hospice offer the option of donation to every patient and/or their families?

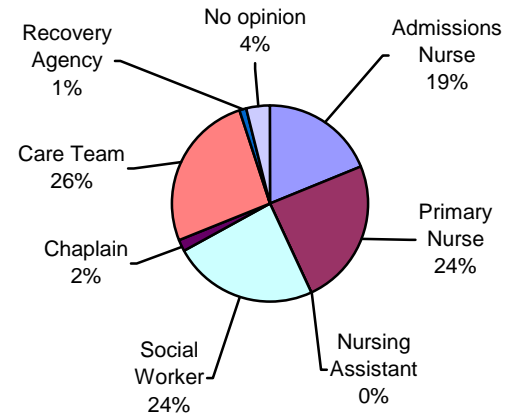
Yes, we offer the option to every patient/family	8%	14
No, never offers the option	12%	20
Only if patient/family asks	40%	65
As part of DNR order	3%	5
I don't know	37%	61



Discussion: The question does not delineate how the option is offered to patients/families. Only one hospice in the Colorado service area has completed formal, routine training given by the eye bank on making a donation referral and how to hold a donation discussion with patients or families.

4. Who do you believe is the best person to present the patient or family with the information about being a donor?

Admissions Nurse	19%	31
Primary Nurse	24%	39
Nursing Assistant	0%	0
Social Worker	24%	41
Chaplain	2%	3
Care Team Should Decide Together	26%	43
Recovery Agency Staff	1%	2
No opinion	4%	6

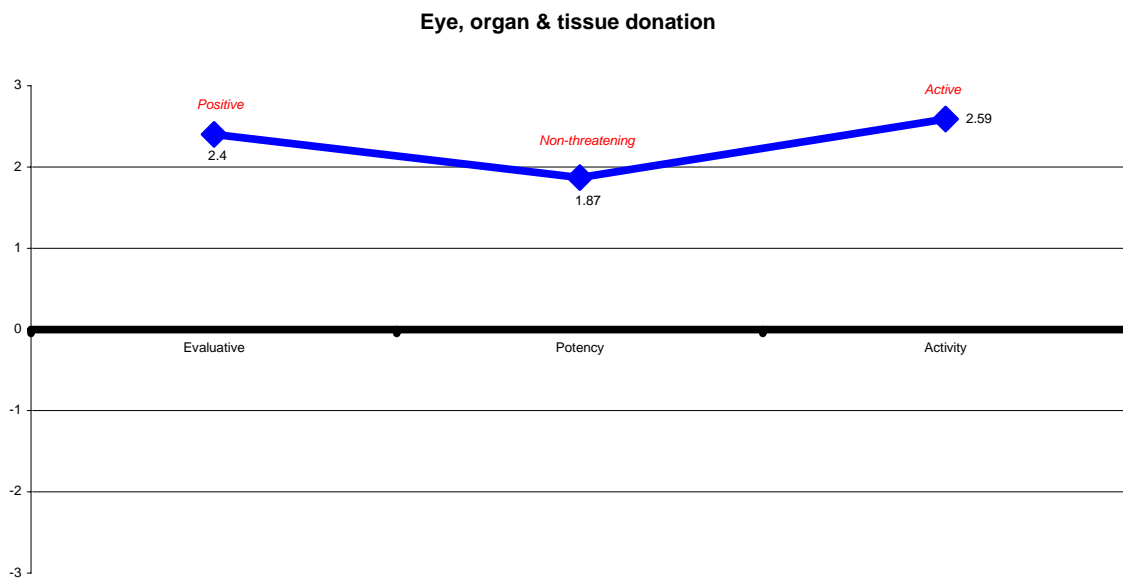


Discussion: Who initiates the donation conversation with families or patients is less important than the timing of the conversation. For example, at the time of admission, families and patients are rarely prepared to discuss the imminent death, much less other plans such as donation or funeral home selection. For this reason, training provided by the eye bank emphasizes a team approach that looks for clues that the time is right for the introduction of the subject. This approach suggests that a care team decision may be most effective. In all cases, the eye bank also advocates determination of donation eligibility prior to introducing the subject.

SEMANTIC DIFFERENTIAL RESULTS

CONCEPT 1: EYE, ORGAN & TISSUE DONATION

Eye, Organ & Tissue Donation	
Evaluative	2.4
Potency	1.87
Activity	2.59

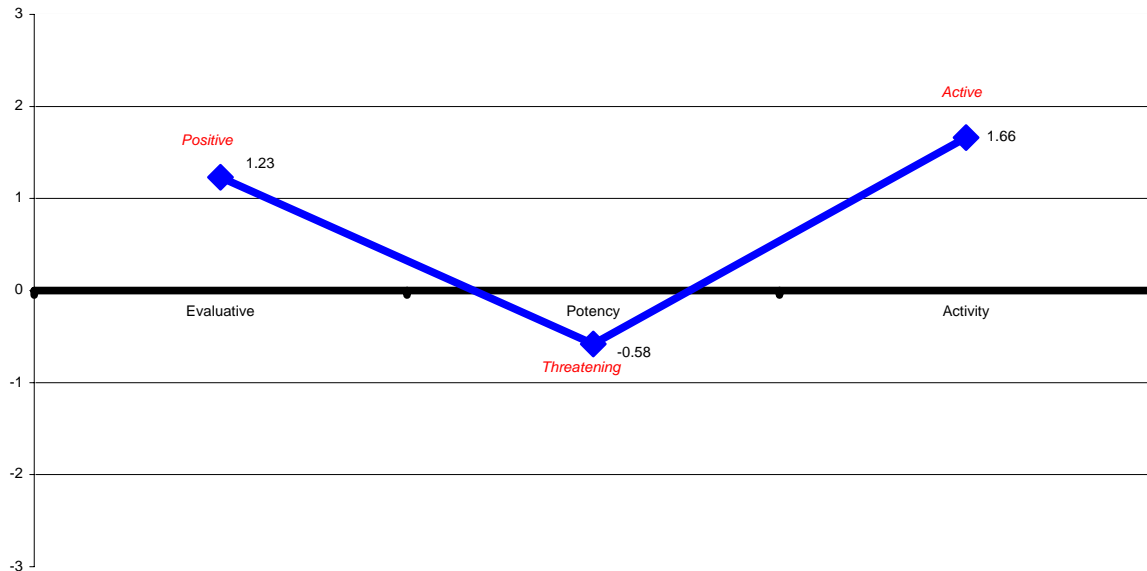


Interpretive information: Positive; Non-threatening; Active. Scores show that, as a group, the respondents rate the concept of donation very highly. The high potency and activity scores hint that the group is supportive of donation and likely made up of those who would choose to be eye, organ and tissue donors.

CONCEPT 2: TALKING TO MY PATIENTS ABOUT EYE, ORGAN & TISSUE DONATION

Talking to my patients and their families about eye, organ & tissue donation.	
Evaluative	1.23
Potency	-0.58
Activity	1.66

Talking to my patients and their families about eye, organ & tissue donation.



Interpretive information: Positive; Threatening; Active. Results suggest that, while the group feels talking to patients and families about donation is a positive and proactive action, there is a threatening aspect to the idea. The low potency score is indicative of this perceived threatening aspect.

Discussion: Knowing how hospice professionals feel about the prospect of holding a donation discussion with patients and families is vital before considering a model that would proactively introduce the subject. Such practice is supported by research and experience, but is new to most hospices in the service area. Given that hospice professionals have historically had little experience with the topic of eye, organ and tissue donation, it is not surprising to find that holding such a conversation with patients and families is a somewhat intimidating, as indicated by the Potency score. Factors other than experience may include knowledge of the subject; lack of familiarity with the donation process; or even the sensitive nature of the subject at a difficult time. All of these factors may be addressed through professional education and a supportive donation process.

Much research has been done in the hospital setting showing that when healthcare professionals have this discussion with family members after a traumatic death, it can give added meaning to an otherwise perceived “meaningless” death. While this does not make grief any less bearable, it can change the emphasis to the achievement of the donor, making the death seem “less harsh” and “less final.”⁴ In the hospice setting, family

⁴ Sque M, Payne S. Dissonant loss: the experiences of donor relatives. *Soc Sci Med* 1996; 43: 1359-70.

members may often, although not always, face different circumstances from those found in the unexpected, traumatic hospital setting. Some hospice-based research highlights the importance of fostering communication within the family in order to allow discussion of beliefs and concerns, even with the dying person, before being faced with a decision about donation.⁵ This research also suggests that a sensitive inquiry is acceptable to the majority of families.

Other findings support the proactive introduction of the subject by healthcare professionals as well:

- Patients may have already made a donation decision, yet family members may not be aware of that decision. Family members are, however, very likely to carry out a loved one's decision if known.⁶
- Public information surveys repeatedly show that many people rule themselves out because they think they are too sick, have a chronic illness or are otherwise not "healthy" enough to be a good donation candidate. This is particularly true of those with diabetes or cancer.⁷
- Even those who are actively pro-donation will often not think to bring the subject up at the time of death.

The Rocky Mountain Lions Eye Bank holds the philosophy that every eligible patient and family be given the option to donate through a proactive discussion with a care team member. This discussion should not only review what can be donated, but how it is used; how it may affect funeral preferences; how long it takes and the general process after death. The goal of this conversation is not to get a "yes" response, but rather to provide information that gives patients or families the opportunity to make an informed donation decision.

The low Potency score among high Evaluative and Activity scores suggest willingness on the part of hospice professionals to have this conversation, provided they develop more confidence in the process.

⁵ Carey I, Forbes K. The experiences of donor families in the hospice. *Palliative Medicine* 2003; 17: 241-247.

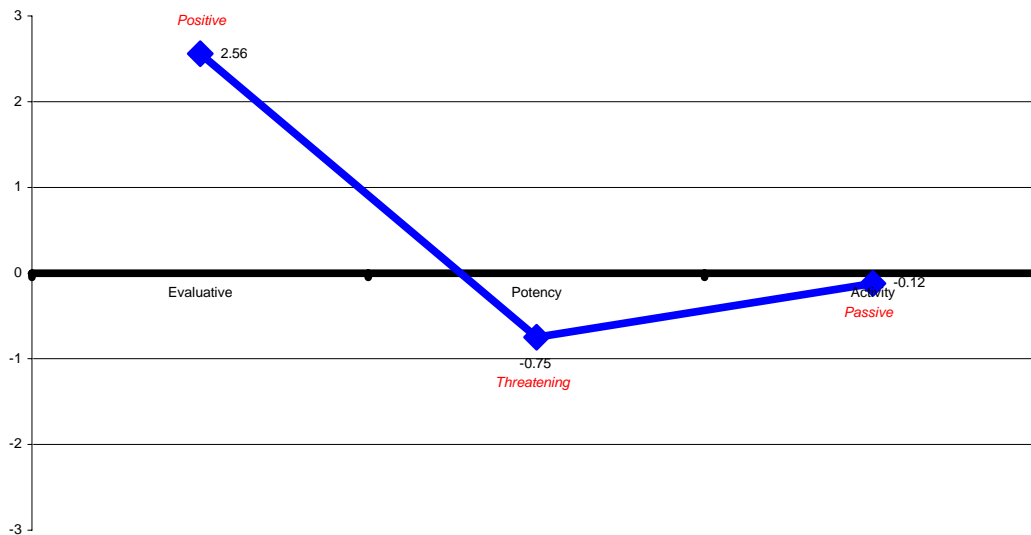
⁶ Donor Awareness Council, *Colorado Donor Perception & Attitude Report*, January 2000. In this telephone survey of Colorado residents, 49% of non-donors said they had not shared their decision with family members while 12% of donors had discussed their wishes with family members. 93% indicated they would follow the decision a loved one made if it was known.

⁷ Donor Awareness Council, *Colorado Donor Perception & Attitude Report*, January 2000.

CONCEPT 3: FOLLOWING A WISH TO BE A DONOR FOUND ON A DRIVER'S LICENSE

Following a patient's wish to be a donor found on a driver's license.	
Evaluative	2.56
Potency	-0.75
Activity	-0.12

Following a patient's wish to be a donor as found on a driver's license.



Interpretive Information: Positive; Threatening; Passive. The respondents clearly evaluate the concept of following a wish to be a donor, as indicated in the registry or driver's license, as exceptionally positive. The Potency score, however, displays a moderate threatening aspect to doing so. The Activity score, at -0.12, is nearly neutral.

Discussion: That hospice professionals rate this concept highly in the Evaluative factor is not surprising, given the emphasis on self-determination and autonomy in hospice care. However, the Potency score raises questions, as the result is somewhat incongruent with the following question (concept 4), which explores following a wish when the family doesn't want to do it. That prospect was seen as considerably less threatening. This is in contrast with a survey of hospital-based Designated Requestors⁸ conducted by the eye bank in early 2004, where respondents indicated it was easier and less threatening to interact with families in cases where the decedent had made the decision to donate through the registry. More research is needed in this area and we suggest that follow-up focus groups with hospice professionals explore the question further.

⁸ "Designated Requestor" is the term coined by the Centers for Medicare and Medicaid Services for those individuals identified by hospitals to offer the option of donation to families at the time of death as part of the conditions of participation. These individuals must undergo training provided by recovery agencies. The Rocky Mountain Lions Eye Bank does not favor the term, as it implies that the role is to ask families for something, rather than offering an option to arrive at an informed decision.

In both Colorado and Wyoming, the decision to be an eye, organ and tissue donor as indicated on a driver's license is a legal consent to the donation at the time of death. Unless revoked by the individual prior to death, it is irrevocable after death.⁹ A listing on the driver's license enters one into the state's donor registry, which can be accessed by recovery agencies at the time of death. In the hospital setting, this registry listing is checked at the time of referral to determine donation eligibility. If the individual is in the registry, then the next-of-kin need not be burdened with having to make the donation decision, as the decedent has already done so. If an individual is not listed in the donor registry, then the next-of-kin retains the right to make the donation decision.

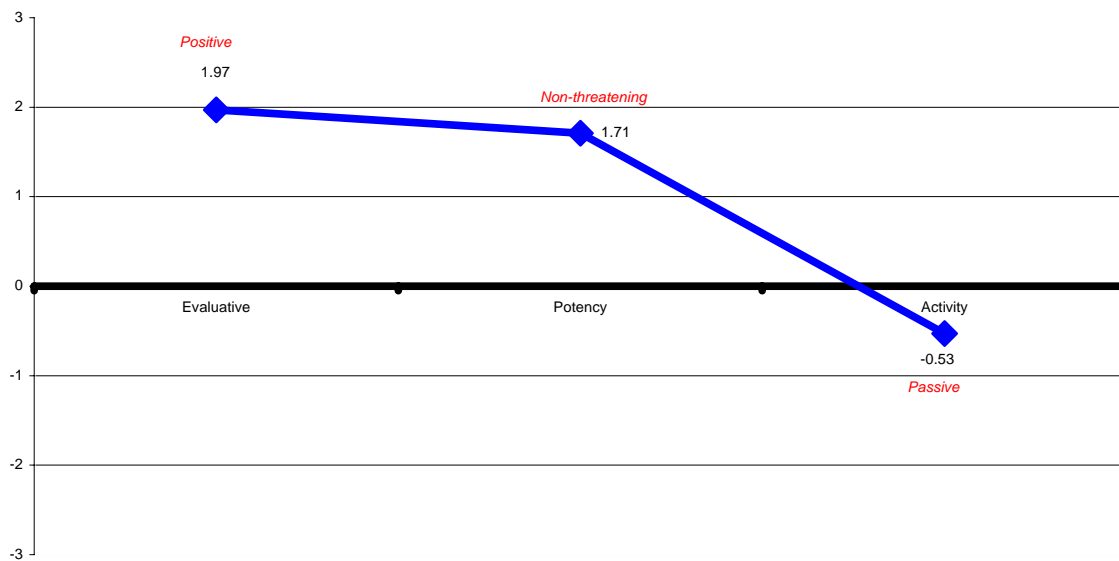
Nearly 60% of Coloradoans and 85% of Wyoming residents join the registry at the time of obtaining or renewing a driver's license and one-half of all eye donors at the Rocky Mountain Lions Eye Bank are registered donors. This population of intended eye, organ and tissue donors is only expected to increase and is one motivating factor for this study.

⁹ Colorado Revised Statute 12-34-110. Wyoming Statute 35-5-119.

CONCEPT 4: FOLLOWING A PATIENT'S WISH TO BE A DONOR WHEN THE FAMILY DOESN'T WANT TO DO IT

Following a patient's wish to be a donor when the family doesn't want to do it.	
Evaluative	1.97
Potency	1.71
Activity	-0.53

Following a patient's wish to be a donor when the family doesn't want to do it.



Interpretive Information: Positive; Non-threatening; Passive. Respondents felt that following a patient's wish when the family doesn't want to do it was significantly less threatening than the previous concept of merely following the wish. Both concepts had very high, positive Evaluative scores.

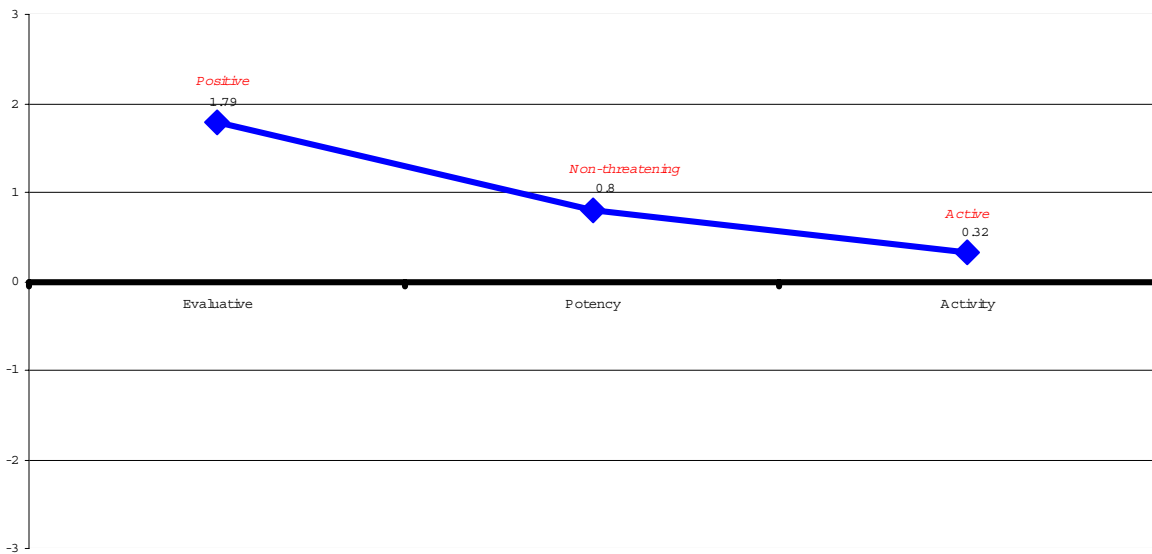
Discussion: A patient's wish to donate is most often known through the donor registry, or driver's license designation. There are instances where family members may be in opposition to an individual's decision. Among hospital-based Designated Requestors, this scenario is the most threatening, whereas hospice professionals in this survey rated this as non-threatening with a high intensity, as indicated by the Potency score.

As suggested in concept 3, more research is needed concerning this subject and we suggest focus groups explore the issue further. Please see Concept 3, "Following a patient's wish to be a donor found on a driver's license" for more information.

CONCEPT 5: EVALUATING WHETHER MY PATIENT IS ELIGIBLE TO DONATE BEFORE DEATH HAS OCCURRED

Evaluating whether my patient is eligible to donate before death has occurred.	
Evaluative	1.79
Potency	0.8
Activity	0.32

Evaluating whether my patient is eligible to donate before death has occurred.



Interpretive Information: Positive; Non-threatening; Active. The evaluation of a patient's eligibility to be an eye, organ and tissue donor prior to death is seen as a positive, proactive step by the respondents.

Discussion: In a hospital setting, the determination of donation eligibility most often takes place after death occurs. In the single hospice in our service area where donation is routinely offered, calls to determine eligibility are often made prior to the death. This gives the staff the opportunity to explore the issue in a timely manner with patients and/or family members. As suggested in hospice-based research, this practice may best serve patients and families.¹⁰

This concept was included in the survey because it is a vital part of the donation process. Offering the option of donation to patients or families prior to determining eligibility can result in a "double loss" if, eventually, the patient is not eligible to donate. Many families regard a donation as a positive outcome from a

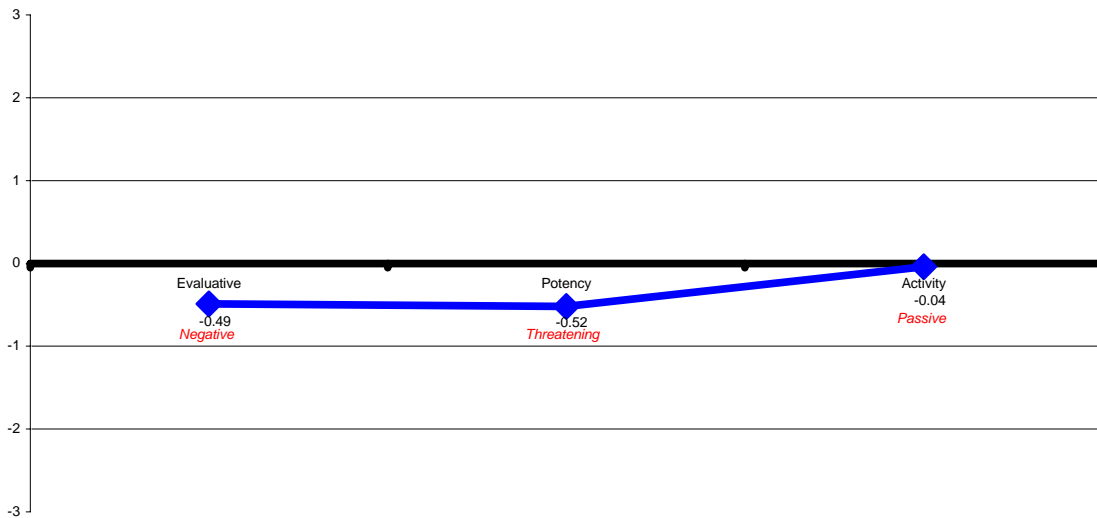
¹⁰ Carey I, Forbes K. The experiences of donor families in the hospice. *Palliative Medicine* 2003; 17: 241-247.

terrible situation. As a result, many pour hope into the idea of someone else benefiting from a loved one's death. It should be noted, however, that initial eligibility does not guarantee a transplant will take place. Many things can surface to prevent transplantation of recovered tissues. An important part of the donation conversation is a gentle explanation of this fact. In some cases, eye tissues that cannot be transplanted may be used for medical research or training, which offers yet another option for patients and families. In any case, the eye bank advocates that donation information only go to those whose eligibility has been pre-determined so as not to add to the loss family members will already experience.

CONCEPT 6: EVALUATING WHETHER MY PATIENT IS ELIGIBLE TO DONATE WITHOUT HIM/HER OR THE FAMILY KNOWING ABOUT IT

Evaluating whether my patient is eligible to donate without him/her or the family knowing about it.	
Evaluative	-0.49
Potency	-0.52
Activity	-0.04

Evaluating whether my patient is eligible to donate without him/her or the family knowing about it.



Interpretive Information: Negative; Threatening; Slightly Passive. Respondents clearly viewed this concept very negatively. There is a perceived threatening element to this concept, while the Activity factor is nearly neutral.

Discussion: In retrospect, this question implies deceit and is perhaps an unfair one. Nonetheless, experience has shown a reluctance to determine eligibility for each patient via a telephone call prior to any discussion or introduction of the subject of donation via literature or other means. Concerns over HIPAA compliance have also been expressed. Specifically, many in healthcare believe that permission must be obtained before releasing medical information necessary to determine eligibility for donation.¹¹

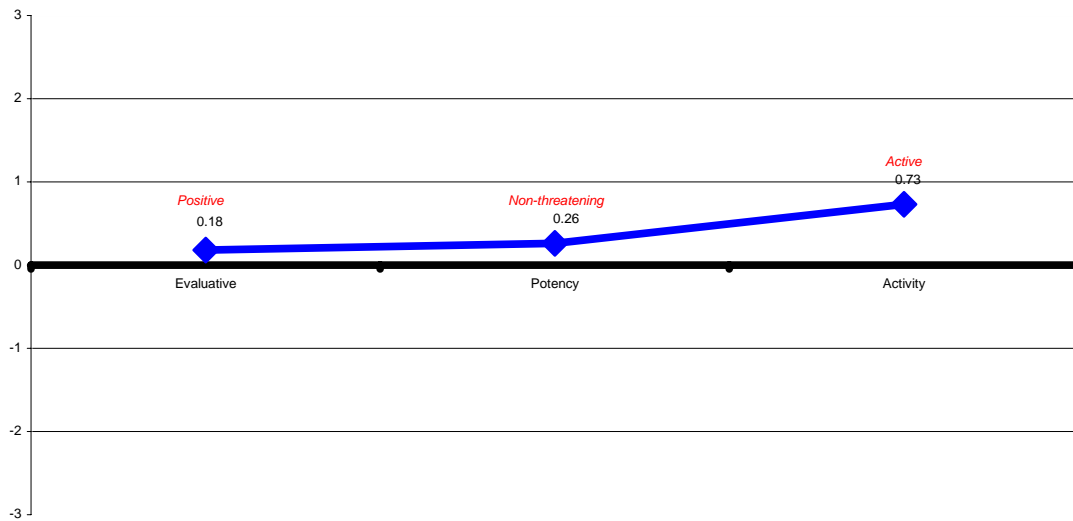
The importance of evaluating a patient prior to introducing the idea of donation cannot be overstressed, as stated before in concept 5. We suspect that concept 6 would score quite differently if framed within this context. We suggest this concept be revised and explored with focus groups.

¹¹ The HIPAA rule provides an exemption for information used in the donation and transplantation of organs and tissues. Permission to release information is not necessary. The exemption also removes recovery agencies from the covered entities and business associate definitions. The exemption may be found in the *Federal Register* Vol 65, No 250, December 28, 2000, §164.512

CONCEPT 7: DISCUSSING DONATION ONLY IF THE PATIENT OR FAMILY THINKS OF IT AND BRINGS IT UP

Discussing donation only if the family brings it up.	
Evaluative	0.18
Potency	0.26
Activity	0.73

Discussing donation only if the family brings it up.



Interpretive Information: Slightly Positive; Slightly Non-threatening; Active. Respondents expressed a very mild attitude toward this concept. The Activity score had the greatest intensity, although the concept itself is proactive only on the part of the family.

Discussion: This concept appears to be the standard practice of hospices in the service area, as illustrated in this survey and in a survey of hospice administrators conducted in 2000.¹² When viewed in the context of other concepts in this survey, hospice professionals may be comfortable taking a more active role in facilitating the option of donation for their patients. Respondents held a more intensely positive attitude in the Evaluative score in all of the following concepts:

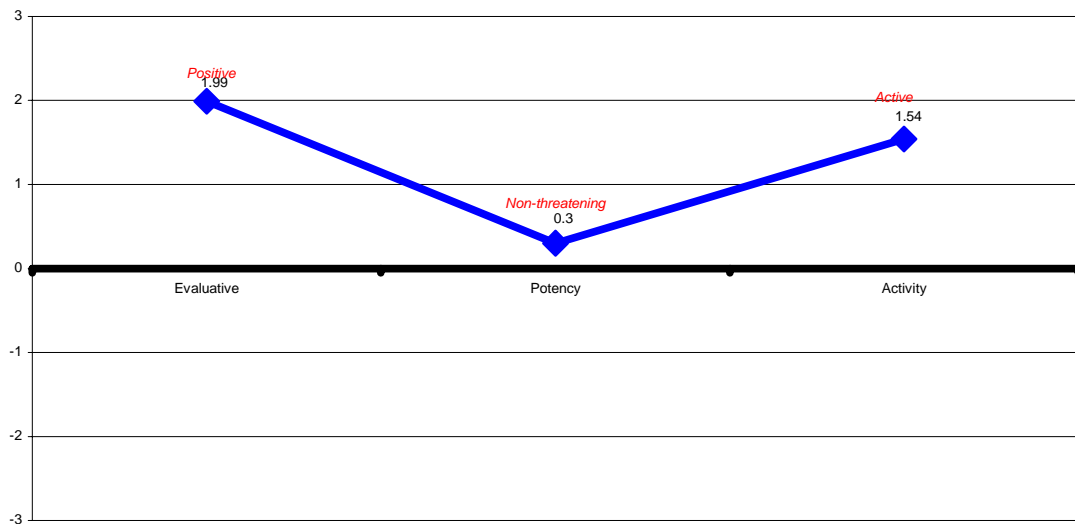
- Talking to patients and families about eye, organ and tissue donation.
- Following a wish to be a donor found on a driver's license.
- Following a wish to be a donor found on a driver's license when the family doesn't want to.
- Evaluating whether my patient is eligible to donate before death occurs.

¹² In the 2000 survey, 72% of the responding hospices reported offering the option of donation only when the patient or family introduced the subject. Due to a low response in the 2000 survey, the result cannot be applied to all hospices in the service area. However, given the large number of hospice deaths and the very low hospice donation statistics, it is clear that proactive protocols are not in place.

CONCEPT 8: THE ROCKY MOUNTAIN LIONS EYE BANK

The Rocky Mountain Lions Eye Bank	
Evaluative	1.99
Potency	0.3
Activity	1.54

The Rocky Mountain Lions Eye Bank



Interpretive Information: Positive; Slightly Non-threatening; Active. Respondents' attitudes toward the Rocky Mountain Lions Eye Bank are positive.

Discussion: Like all organizations, the eye bank has concerns with the perceptions of its constituents and the community it serves.

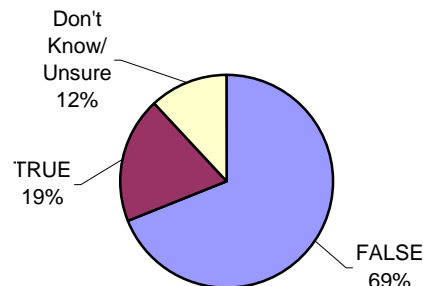
A real concern for recovery agencies like the Rocky Mountain Lions Eye Bank is the perception that obtaining donations is the driving motive. Even if the outcome of saving and enhancing lives out of tragedy is emphasized, those caring for grieving families can still find the notion of offering donation insensitive and inappropriate. The Rocky Mountain Lions Eye Bank's mission is to carry out the wishes of eye donors and their families to help another overcome blindness. This mission is unique among recovery agencies in that it does not seek to increase donations; does not advocate donations; and does not focus on the outcome of donations, namely "to cure blindness." Its focus is to carry out the decisions of those who donate, and by extension, to support the decisions of those who choose not to donate. If there is any advocacy in its philosophy, it is that each person be given the opportunity to make an informed donation decision and to have that decision carried out. As closer work with hospices goes on, further assessment of the eye bank's actual performance in the view of hospice professionals is a more appropriate and helpful measure to management.

The following three concepts were added to the survey because they are commonly held myths among the general public. Questions were formatted using the semantic differential technique, with "true" and "false" as the bipolar opposites.

CONCEPT 9: EYE, ORGAN & TISSUE DONATION CAN BE DISFIGURING

	Score	Percentage
FALSE	1.44	69%
TRUE	-	19%
Don't Know/Unsure	-	12%

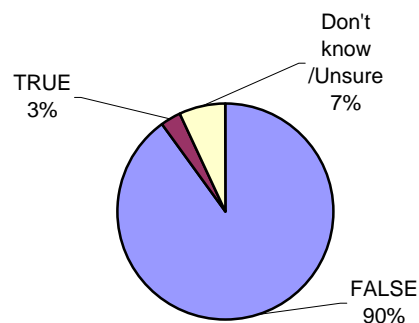
Discussion: A large amount of research data indicates that disfigurement fears are a major blocker to eye, organ and tissue donation. This question was asked to assess the knowledge level of hospice professionals concerning the issue. Eye, organ and tissue donation is not disfiguring and patients and their families may still have a viewing or an open casket funeral.



CONCEPT 10: MY RELIGION PROHIBITS OR LIMITS EYE, ORGAN & TISSUE DONATION

	Score	Percentage
FALSE	2.68	90%
TRUE	-	3%
Don't know/Unsure	-	7%

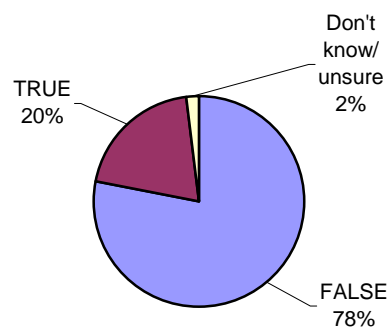
Discussion: Both formal research and anecdotal evidence show that many people believe their religion prohibits eye, organ and tissue donation. In a 2000 telephone poll of Colorado residents, 32% of non-donors said religious beliefs were the primary reason they were not organ donors. While it is true that no organized religion in the United States opposes donation, the subject is not often discussed in faith communities. Furthermore, official church positions are not binding on a congregation or an individual. Therefore, religious conviction may validly keep one from being a donor. The availability of pastoral care staff in hospice care may allow such to be explored if they are a concern to patients and families.



CONCEPT 11: PEOPLE WITH CANCER CANNOT BE DONORS

	Score	Percentage
FALSE	1.94	78%
TRUE	-	20%
Don't know/Unsure	-	2%

Discussion: Cancer is not a rule-out to eye donation. Research shows a significant number of non-donors name medical conditions as a reason they are not organ donors. The most commonly named conditions are cancer, diabetes and high blood pressure. None of these rules out eye donation.



CONCLUSIONS & RECOMMENDATIONS

Several general statements about the respondents to this survey can be stated based on the results:

- The respondents hold highly positive attitudes toward eye, organ and tissue donation and are likely to be donors themselves.
- They have a positive attitude toward the aspects of the donation process that would involve them: talking to patients and families about donation, determining eligibility and following a wish as listed in the donor registry.
- There is a perceived threatening element in these same donation processes.
- They have an impartial attitude toward the current practice of talking about donation only if the patient or family introduces the subject.
- They are very knowledgeable in areas that remain myths to the general public.

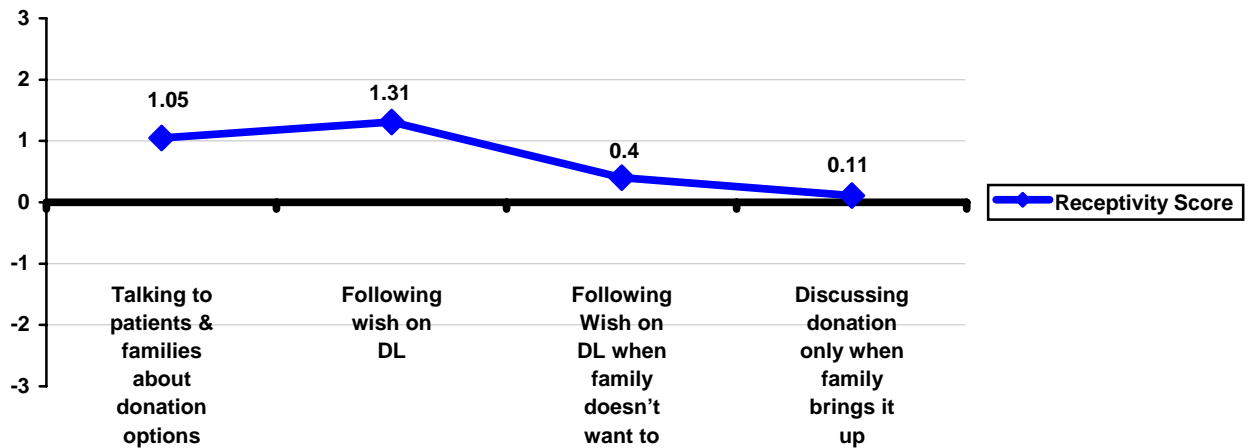
Some of these generalizations can be further analyzed. The survey results suggest that hospice professionals would be much more open and active in the donation process if given more information and structure in the process. This conclusion is based on the generally high Evaluative scores in all concepts dealing with the donation process. Low Potency scores may very well indicate a threatening or "intimidation" factor because of a lack of information, experience, knowledge or structure in the donation process.

Perhaps more revealing is the attitude toward the current practice of discussing donation only when the patient or family introduces the subject. The hospice professionals responding to this survey had an almost indifferent attitude toward this practice. Indeed, for several years, the Rocky Mountain Lions Eye Bank has inadvertently encouraged this practice by providing brochures entitled "Discussion Guide for Hospice Patients and Families." Many hospices use this brochure to introduce the subject of donation by placing it in patients' admissions or information packets. If the family read it and was interested, then the subject would be explored. Recently, however, the eye bank's Public & Professional Relations Department compared the number of brochures distributed with the number of hospice donors. There was no correlation between referrals/donors in hospices using the brochure compared to those not using it. No hospice using the brochure had a significant change in the number of referrals or donors after implementing the brochure. A review of the creative brief used to create the brochure indicates the intended use was as a supplemental tool for conversations with patients and families about donation.

Finally, the hypothesis that hospice professionals are willing to take a more active role in the donation process is corroborated by a look at a fourth semantic dimension described as the "Receptivity" factor. Receptivity scales in the semantic differential method have a low "loading" factor during statistical factor analysis and are typically positive in evaluation. This suggests that even though there may be an independent factor of meaning, these scales constitute a "mode" of evaluating.¹³ Nonetheless, comparing the Receptivity scores shows that those concepts where the hospice professional is actively involved score higher than those in which they are passively involved, such as in the current practice of waiting for the family to initiate the conversation. The following chart illustrates this comparison:

¹³ Osgood, Charles, George Suci and Percy Tannenbaum. *The Measurement of Meaning*. Urbana: University of Illinois Press, 1957.

Receptivity Scores



RECOMMENDATIONS

The Public & Professional Relations Department recommends the following actions:

1. A significant number of respondents indicated a willingness to participate in focus groups. This should be carried through, as it will be helpful in completing many of the other recommendations.
2. Further research is necessary to clarify issues, particularly those surrounding the donor registry and following the directive of the patient when family members are in opposition. Incongruence was found both between these two concepts in this survey and results of other, similar research. Focus groups composed of hospice professionals should explore these further.
3. While we believe low Potency scores are indicative of knowledge and experience deficits, it is important to keep in mind that they cannot be addressed by merely using the existing hospital-based protocols. Both the focus groups and the hospice community at large should be involved in designing a referral and approach system that works in the hospice setting. While the hospital referral process is a fine model on which to build, certain realities in the hospice setting will force some modifications. For example, deaths may occur in a home at night. The nurse on call may or may not attend the death and, therefore, may or may not be in the position to approach the family with donation options. This is particularly true in cases where the family had not come to a point where a donation discussion would have been appropriate prior to the death.
4. While not a subject of this study, questions arose in discussion about the eye bank's ability to handle additional donors should hospices implement systems that give the option more consistently. We recommend the eye bank should look at internal mechanisms that may need revision. For example, because most hospice deaths occur in the home, the eye bank must make alternative arrangements for a facility in which to perform a surgical recovery of eye tissue. This may require increased communication with funeral homes in order to arrange use of their facility, or it may require additional use of currently contracted facilities.
5. Ultimately, it is the hospice community that must evaluate the importance of an individual's right to make an eye, organ & tissue donation against the mix of care they offer to patients and families. While the eye bank can facilitate process design, training, post-donation communication and a myriad of other functions associated with a donation program, the program itself must belong to the

individual hospice. As seen with hospitals in the service area, the amount of commitment and ownership is directly proportional to successful outcomes for staff, patients and families. The Colorado Hospice Organization may be a potential partner to begin such a dialogue within the hospice community.

ABOUT THE ROCKY MOUNTAIN LIONS EYE BANK

The mission of the Rocky Mountain Lions Eye Bank is to fulfill the wishes of eye donors and their families to help another overcome blindness through transplantation and medical research. Established in 1982 by the Lions Clubs of Colorado and Wyoming, the eye bank is now one of the nation's largest. Over the last 20 years, the eye bank has carried out the wishes of over 20,000 eye donors by facilitating more than 19,000 sight-restorative transplants around the world. Another 12,000 tissues have been used in valuable medical research to overcome blindness.

Behind every eye donation is the intent to help another. To maximize the fulfillment of that intent, the Rocky Mountain Lions Eye Bank first searches its local waiting list for a suitable recipient. If one is not found locally, a search is conducted among other eye banks in the United States. If a suitable recipient still cannot be found, a search is conducted through international networks to find a recipient in other parts of the world. In this way, no transplantable tissue is ever wasted. In 2004, eye donors in Colorado helped restore sight to individuals in 9 countries.

Families of eye donors share in the donation by providing medical and social history information that assists the eye bank in determining transplant suitability. In return, the eye bank shares information about the transplants with the donor's family members. For example, families are told the age, gender and city where the recipient resides. The eye bank facilitates correspondence should either the donor family or the transplant recipient wish to correspond with one another. If a transplant occurred internationally, the eye bank has all correspondence translated at no cost to either party.

More information is available at www.corneas.org, or by calling our Public & Professional Relations Department at 1-800-444-7479.

ABOUT THE PUBLIC & PROFESSIONAL RELATIONS DEPARTMENT

The department's mission is to foster mutual understanding by establishing effective, two-way relationships with every audience on which the Rocky Mountain Lions Eye Bank relies to fulfill its mission. The department also counsels the management of the Rocky Mountain Lions Eye Bank with regard to its courses of action, taking into account their public ramifications and the organization's social responsibilities.

APPENDICES



Eye, Organ & Tissues Donation Survey of Hospice Professionals

DEADLINE FOR RETURNING THIS SURVEY IS DECEMBER 15, 2004.

MAIL TO:

ROCKY MOUNTAIN LIONS EYE BANK
P.O. BOX 6026
DENVER, CO 80045

YOU MAY ALSO FAX BOTH SIDES OF THIS SURVEY TO 720-848-3938

Instructions

The purpose of this study is to measure the *meanings* of certain concepts to hospice professionals. In completing the survey, make each item a separate and independent judgement on the basis of what these things mean to *you*. Work at a fairly high speed. It is your first impressions, the immediate "feelings" about the items, that we want.

You will find a statement or concept followed by several scales. Respond to each scale by placing an "X" somewhere between the two terms. The closer your mark is to one of the two terms, the more you feel that term is associated with the item you're judging.

For example, If you feel the concept is **very closely related** to one or the other end of the scale, you should place an "X" as follows:

FAIR X : : : : : UNFAIR

FAIR : : : : : X UNFAIR

If the concept seems **quite closely related** to one end of the scale, you should place your mark as follows:

STRONG : : : X : : : : : WEAK

STRONG : : : : : X : : : WEAK

If the concept seems **only slightly related** to one side as opposed to the other side (but is not really neutral), you should place your mark as follows:

ACTIVE : : : : : X : : : : : PASSIVE

ACTIVE : : : : : X : : : : : PASSIVE

If you consider the concept to be **neutral** on the scale or both sides **equally associated**, then you should place your mark in the middle space:

SAFE : : : : : X : : : : : DANGEROUS

__ PLEASE EMAIL THE RESULTS OF THIS SURVEY TO ME AT : _____

EMAIL ADDRESS

YOUR EMAIL ADDRESS WILL BE USED **ONLY** TO NOTIFY YOU OF THE RESULTS OF THIS SURVEY.

__ I AM WILLING TO PARTICIPATE IN A FOCUS GROUP STUDYING DONATION FOR HOSPICE PATIENTS

__ I WOULD LIKE GENERAL INFORMATION ABOUT EYE, ORGAN AND TISSUE DONATION

__ I WOULD LIKE ADDITIONAL INFORMATION ABOUT THE ROCKY MOUNTAIN LIONS EYE BANK

IF YOU CHECKED ANY OF THE 3 BOXES IN THIS SECTION, PLEASE FILL IN ALL THE REQUESTED INFORMATION BELOW. **PLEASE PRINT**

NAME _____

HOSPICE _____

MAILING ADDRESS _____

CITY _____ STATE _____ ZIP _____

TELEPHONE: _____ EMAIL: _____

DEADLINE FOR RETURNING THIS SURVEY IS DECEMBER 15, 2004. MAIL TO:

ROCKY MOUNTAIN LIONS EYE BANK

P.O. BOX 6026

DENVER, CO 80045

You will find a statement or concept followed by several scales. Respond to each scale by placing an "X" somewhere between the two terms. The closer your mark is to one of the two terms, the more you feel that term is associated with the item you're judging.

EYE, ORGAN & TISSUE DONATION

- GOOD _____ BAD
- WEAK _____ STRONG
- VALUABLE _____ WORTHLESS
- MORBID _____ WHOLESOME
- KIND _____ CRUEL
- UGLY _____ BEAUTIFUL

TALKING TO MY PATIENTS AND THEIR FAMILIES ABOUT EYE & TISSUE DONATION

- ACTIVE _____ PASSIVE
- KIND _____ CRUEL
- FOOLISH _____ WISE
- UNTIMELY _____ TIMELY
- EMOTIONAL _____ UNEMOTIONAL
- NEW _____ OLD
- INDIFFERENT _____ EAGER
- INTERESTING _____ BORING
- TOUGH _____ FRAGILE

FOLLOWING A WISH TO BE A DONOR FOUND ON A DRIVER'S LICENSE

- IMPORTANT _____ UNIMPORTANT
- FOOLISH _____ WISE
- HEAVY _____ LIGHT
- WEARY _____ REFRESHED
- COLORFUL _____ COLORLESS
- COMPLEX _____ SIMPLE
- FOLLOWING _____ LEADING
- RESPECTFUL _____ DISRESPECTFUL

FOLLOWING A PATIENT'S WISH TO BE A DONOR WHEN THE FAMILY DOESN'T WANT TO DO IT

- IMPORTANT _____ UNIMPORTANT
- WISE _____ FOOLISH
- LIGHT _____ HEAVY
- WEARY _____ REFRESHED
- COLORFUL _____ COLORLESS
- COMPLEX _____ SIMPLE
- FOLLOWING _____ LEADING
- DISRESPECTFUL _____ RESPECTFUL

EVALUATING WHETHER MY PATIENT IS ELIGIBLE TO DONATE BEFORE DEATH HAS OCCURRED

- GOOD _____ BAD
- ACTIVE _____ PASSIVE
- HEAVY _____ LIGHT
- WRONG _____ RIGHT
- TRANSPARENT _____ OPAQUE
- DISCOURTEOUS _____ COURTEOUS
- FAST _____ SLOW

EVALUATING WHETHER MY PATIENT IS ELIGIBLE TO DONATE WITHOUT HIM/HER OR THE FAMILY KNOWING ABOUT IT

- GOOD _____ BAD
- ACTIVE _____ PASSIVE
- HEAVY _____ LIGHT
- WRONG _____ RIGHT
- TRANSPARENT _____ OPAQUE
- DISCOURTEOUS _____ COURTEOUS
- FAST _____ SLOW

DISCUSSING DONATION ONLY IF THE PATIENT OR FAMILY THINKS OF IT AND BRINGS IT UP

- ACTIVE _____ PASSIVE
- KIND _____ CRUEL
- FOOLISH _____ WISE
- FAIR _____ UNFAIR
- EMOTIONAL _____ UNEMOTIONAL
- OLD _____ NEW
- INDIFFERENT _____ EAGER
- INTERESTING _____ BORING
- TOUGH _____ FRAGILE

THE ROCKY MOUNTAIN LIONS EYE BANK

- LARGE _____ SMALL
- DULL _____ SHARP
- ACTIVE _____ PASSIVE
- BAD _____ GOOD
- VALUABLE _____ WORTHLESS
- HELPFUL _____ UNHELPFUL
- WEAK _____ STRONG
- COMPASSIONATE _____ INDIFFERENT

EYE, ORGAN & TISSUE DONATION CAN BE DISFIGURING

- TRUE _____ FALSE

PEOPLE WITH CANCER CANNOT BE DONORS

- TRUE _____ FALSE

MY RELIGION PROHIBITS OR LIMITS EYE, ORGAN & TISSUE DONATION

- TRUE _____ FALSE

WHAT POSITION DO YOU OCCUPY? (CIRCLE ONE)

- RN CHAPLAIN SOCIAL WORKER CHAPLAIN
- OTHER: _____

DOES YOUR HOSPICE HAVE A FORMAL POLICY OR PROTOCOL USED TO OFFER THE OPTION OF DONATION TO PATIENTS AND THEIR FAMILIES?(CIRCLE ONE)

- YES NO I DON'T KNOW

DOES YOUR HOSPICE OFFER THE OPTION OF DONATION TO EVERY PATIENT AND/OR THEIR FAMILIES? (CIRCLE ONE)

YES, WE OFFER THE OPTION TO EVERY PATIENT/FAMILY

NO, WE NEVER OFFER THE OPTION OF DONATION

ONLY IF A PATIENT/FAMILY ASKS

AS PART OF A DNR ORDER ONLY

I DON'T KNOW

WHO DO YOU BELIEVE IS THE BEST PERSON TO PRESENT THE PATIENT OR FAMILY WITH INFORMATION CONCERNING TO BE A DONOR? (CIRCLE ONE)

ADMISSIONS NURSE

PRIMARY NURSE

NURSING ASSISTANT/CNA

SOCIAL WORKER

CHAPLAIN

CARE TEAM SHOULD DECIDE TOGETHER

RECOVERY AGENCY STAFF

OTHER _____

NO OPINION

If you would like to participate in a focus group, would like more information or want the survey results emailed to you, see the back page.