

Presumed Consent: The Colorado Experience

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Current Waiting List

- 116,456 on National Waiting List
- 2.300 on Colo/Wyo list

2012 Conversion Rate

- National average = 76%
- Donor Alliance = 82%

2012 Donor Registry Rates

- National Rates = 47.5%
- Colorado rate = 67%
- Wyoming rate = 59%

Definitions

- Opt in
 - Individuals say "yes" to being donors
 - Legal next-of-kin hierarchy for authorization
 - Current system in United States
- Opt out
 - All individuals automatically donors, unless a "no" is registered
 - Legal next-of-kin cannot authorize donation
 - Present in some European countries; not uniformly enacted



Colorado Experience 2011

- Senate Bill 42 introduced mid-January w/out input from Donor Alliance or transplant-related entities
- Freshman Senator and Representative
 - Driven by compelling recipient family
- Poorly written legislation
 - Confusing language
 - Strongly worded opt-out statement
- Immediate negative public reaction
- Legislation pulled after one week

– 0-9 vote in Senate Health Committee

2012 DONATION SUMM

it's about time.



Donor Alliance Position

- Strong desire to avoid harming those on transplant waiting lists by creating a less effective system
 - Colorado's current Donor Registry Rate is 67%
 - High next-of-kin authorization rates
- Concern with managing policy change through legislation
- Requires more than tweaking state law
- No stakeholder dialogue
- Explore and assess risk of possible unintended consequences
- Need for accurate perspective on European models



Death Rates and Organ Donation Rates

	Death Rate	Pop (in MM)	Donors	Deaths	DPM	Donors adj to CO death rate	DPM adj to CO death rate
Austria	9.91	8.2	165	81,262	20.1	102	12.4
Belgium	10.38	10.4	258	107,952	24.8	152	14.6
Spain	9.9	40.5	1,385	400,950	34.2	858	21.2
US	8.27	304.1	7,967	2,514,907	26.2	5906	19.4
CO/WY 08/09	6.36	5.49	115	34,916	20.9	115	20.9
CO/WY 2010	6.36	5.49	130	34,916	23.7	130	23.7

Donor Authorization Study November 2011

- Conducted by Corona Insights
 - Denver-based research company
 - Conducted several Donor Alliance public opinion surveys in past
 - Has baseline to compare responses
- Telephone surveys
 - 1,000 households in Colorado
 - 600 current donors and 400 non-donors
 - 600 households in Wyoming
 - 300 current donors and 300 non-donors
- 95% confidence level
- Corrective weightings applied



Survey Goals

- Understand the public's perception of the donation authorization process related to organ and tissue donation
- Gain an understanding of the current perceptions and assess emerging trends from the 2007 study
- Achieve robust, defensible results through proper sampling and sample size
- Allow for select comparability to the 2007 survey (Colorado non-donors) and the Donate Life national survey





Presumed Consent Question

- In early 2011, there was proposed legislation in Colorado that would change the organ donation system.
- The proposed change would make every person a potential donor unless the individual formally declared they did not want to be a donor.
- In other words, organs could be donated from a deceased adult individual unless a refusal to donate was previously registered by the deceased individual.
- The legislation was pulled prior to being voted on.



Results of Survey

- Overall results regarding donation
 - 53% strongly support and 41% support donation
- Presumed Consent vs. Current System
 - 40% support presumed consent, mostly "somewhat"
 - 56% oppose presumed consent, mostly "strongly"
- Current non-donors response compared to 2007
 - No reason/hadn't thought about it dropped from 39% to 33%
 - Health concerns increased from 17% to 23%
- Interesting data if system changes
 - 8% of Colorado current donors say they will opt out
 - 26% of Colorado current non-donors say they will not opt out







Survey Demographics

		Donors	Non-Donors		
Demographics	Age	Slightly younger <i>Mean Age 45</i>	Slightly older Mean Age 48		
	Gender	Slightly more likely to be female 51%	Slightly more likely to be male <i>59%</i>		
	Ethnicity	Donors are less likely to be Hispanic 5% of Donors are Hispanic	Non-Donors more likely to be Hispanic. 13% of Non-Donors are Hispanic		
	Race	Predominantly White <i>89%</i>	Still predominantly White but also more likely Black or Other 78% White, 6% Black, 10% Other		
	Religion	Few differences between relgion.			
Psychographics	Opinions & Attitudes	Extremely supportive of organ donation 98% Support (two thirds "strongly support")	Supportive of organ donation 84% Support (one quarter "strongly support")		
	Support for Change in	Split on support for proposed system 47% Support, 50% Oppose	Not supportive of proposed system 71% Oppose		
	Donor Authorization Process	Most common reason for support was the increased number of people it could help.	Most common reason for opposing was the perceived lack of choice and the desire to opt-in, not out.		
Communications	Preferred Modes	Few differences in overall rank order, though donors were more receptive to each communictions mode. Top Prefernces for Both: Someone who has experienced donation or had a transplant, family members, & doctors or other medical professionals			

Presumed Consent

		Support Proposed System	Do Not Support Proposed System		
	Age	No difference in "strongly support" Younger (18 to 34) more likely to "somewhat support"	No difference in "somewhat oppose" Older (35+) more likely to "strongly oppose"		
Demographics	Gender	More likely to be female 55%	More likely to be male 58%		
	Ethnicity	Few differences between Hispanics and Non-Hispanics.			
	Race	Few differences between races.			
	Religion	Few differences between relgion.			
Psychographics	Donor Status	Much more likely to plan on donating. 85%	Much more likely to not plan on donating. <i>36%</i>		
		Nearly all support organ donation overall 99%	Overall support organ donation 91%		
	Opinions & Attitudes	Generally comfortable and supportive of concept of everyone being a donor unless they opt out.	Overall disagreement with being comfortable and supportive of concept; majority strongly disagree.		
	Possible Actions as result of new system	Most common action is to tell friends/family followed by doing more research on the topic. Small proportion would "definitely" opt out. 7%	Most common action is to tell friends/family followed by doing more research on the topic. Larger proportion would "definitely" opt out. 37%		
Communications	ough supporters were more receptive to nictions mode.				

Presumed Consent Question Results

