Negative policy bubbles, morality policy and emotions: The case of organ donation

Eva Thomann, Ph.D
eva.thomann@kpm.unibe.ch
Center of Competence for Public Management, University of Bern, Switzerland

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Abstract

The concepts of policy bubbles has received considerable attention in recent years, but more empirical applications are needed. This paper applies the concept of policy underreaction to organ donation policy – a typical morality issue - to link specific policy tools with emotional aspects. The paper underscores the importance of values and emotions for policy underinvestment in morality policies. To capture underinvestment, it adds the dimension of explicitness to the existing taxonomy of morality policy instruments. Swiss organ donation policy is shown to constitute an emotion-driven negative policy bubble. Results reveal a link between the policy instruments’ explicitness, the value distribution in the population, and the policy outcome resulting from adequate or underinvestment, respectively.

*Keywords: Policy underinvestment, morality policy, policy instruments, organ donation*
**Introduction**

This paper applies the concept of policy underreaction (Maor 2013) to organ donation policy – a typical morality issue - to link specific policy tools (Maor 2012) with emotional aspects (Maor 2014a). The policy problem underlying organ donation is a burning one worldwide: how to meet the ever-increasing demand for donor organs – that is, how to lower relatives’ refusal rates to organ donation? Relatives’ refusal rates to organ donation are still the biggest obstacle in obtaining higher deceased donor rates (Simillis 2010). Existing studies suggest that a plethora of policy instruments (Lascoumes and Le Galès 2007; Vedung 1998) matter for relatives’ refusal rates. Despite the impressive amount of cumulative knowledge on how refusal and organ donation rates can be optimized (Andrés et al. 2009; Barber et al. 2006; Johnson and Goldstein 2003; Martínez et al. 2001; Newton 2011; Siminoff et al. 2001), both vary considerably between countries. For example, Swiss refusal rates exceeded Spanish rates by 2.5 times in 2009 (Council of Europe 2011; Matesanz 2008).

In this paper, we argue that these differences result from a systematic underinvestment in organ donation policies in certain contexts (Maor 2014c). We suggest to introduce the insight that “policies determine politics” (Lowi 1972: 299) to the debate on policy bubbles. It is further argued that due to their value-laden nature, morality policies (Meier 1999) represent a “crucial case” (Gerring 2008) to test Maor’s (2014a) argument on the role of emotions for policy underinvestment. Policy instruments are a particularly useful shortcut to depict the degree of government investment in a particular policy. To capture (under)investment in morality policies, the paper adds the dimension of explicitness to the existing taxonomy of policy instruments (Vedung 1998; Howlett 2009). In contexts of polarized values on a given morality issue, governments avoid an explicit position regarding the morally contested issue (Engeli and Varone 2011). As a result, morality policy instruments differ in the degree to which they express an explicit official position in the given morally contested matter or not.
The value distribution in the population might thus result in underinvestment, as expressed though the policy instruments used and translated into deficient policy outcomes.

Based on observational and interview data and an extensive literature review, we compare two contrasting cases. The Spanish organ donation system is an example of best practice with the highest deceased donor rates worldwide, and hence serves as a benchmark against which underinvestment can be identified (Maor 2014c: 428). Conversely, Switzerland “lags behind” despite having adopted elements of the Spanish model (Manatschal and Thomann 2011). We use process tracing and explanatory typologies (Bennett and Elman 2006; Elman 2005) to explore the link between emotions, underinvestment and policy outcomes.

The comparison with Spain, where investment is adequate, shows that Swiss organ donation policies were characterized by “too little policy” (Jones et al. 2014: 147), i.e. a systematic underinvestment in personnel, resources and adequate tools to lower relatives’ refusal rates, in 2009 – despite a vast amount of scientific evidence on “what works” (Matesanz and Dominguez-Gil 2007). What explains this resistance is that the issue is deeply value-laden. Results reveal a strong link between the policy instruments’ explicitness, the value distribution in the population, and the policy outcome. The paper underscores the importance of values and emotions for policy underinvestment in morality policy (Maor 2014a).

Next we elaborate on the concept of a negative policy bubble and Maor’s (2014a) argument on how emotions matter. We then link this argument with the specificities of morality policies, and add the dimension of explicitness to existing taxonomies of policy instruments. We outline expectations on 1) how we can identify underinvestment in morality policy, and 2) how emotions should be linked to underinvestment, and underinvestment to policy outcomes. After outlining our research design and methods, we present our results and conclude.
Negative policy bubbles and the role of emotions

The concept of policy bubbles has received considerable attention in recent years (Jones et al. 2014; Maor 2012, 2013, 2014a,b,c). Policy bubbles capture the lacking efficiency of policy makers in matching the intensity of the policy tool to the intensity of problems over the long run. The concept understands policy development in terms of the extent of over- or underinvestment in a policy relative to its goals (Jones et al. 2014: 146). This paper aims, first, at testing the usefulness of this relatively new concept to understand the empirical case of organ donation policy. Second, we introduce Lowi’s (1972: 299) assertion that “policies determine politics” to the debate. Specifically, it is argued that emotions and values are crucial to understand underinvestment in morally contested policies (Maor 2014a).

We focus on “negative policy bubbles” (Maor 2014b, c): when decision makers and organizations systematically pay too little attention to a policy problem despite strong information indicating an increasingly severe policy problem (Jones and Baumgartner 2005). In combination with institutional resistance to change, this results in underinvestment, i.e. “too little policy” (Jones et al. 2014: 147). According to Maor (2014c: 426), “policy underreaction refers to systematically slow and/or insufficient response by policymakers to increased risk of opportunity, or no response at all”.

Recognizing what constitutes a case of policy underreaction is difficult (Maor 2014c: 427). Underinvestment should prevail over a certain period of time (Jones et al. 2014), and is judged against a factual or counterfactual alternative course of action (McConnell 2010). This may involve cost-benefit analyses and / or a comparison of policy outcomes with standards of good practice (Maor 2014c: 427). A negative policy bubble requires the underinvestment to be propelled by self-reinforcing processes (Maor 2014a). We hence formulate a first expectation:

*Expectation 1:* A negative policy bubble occurs when 1) a policy’s net utility is smaller than
the utility of the alternative course of action, when this lack of efficiency 2) persists over an extended period of time, and this all happens despite 3) the increasing severity of the policy problem (the risk) and 4) the fact that adequate tools to address the problem are known to exist and supported by evidence.

Attempts at explaining policy underinvestment have highlighted the role of institutional factors, e.g. intra- and extra-organizational sources of policy persistence, and cognitive factors, e.g. the accuracy of policy makers’ risk estimation (Maor 2014a,c). Mental constructs and cultural traits may narrow the range of options considered (Maor 2014c: 4309). Institutional frictions arising from the interaction of the cognitive and decision costs can trigger underinvestment (Jones and Baumgartner 2005). Furthermore, policy drift can prevent adequate investment when powerful actors use veto points to exert pressure; individuals might strongly prefer avoiding losses to acquiring gains; or governments might be unwilling to inflict immediate pain on citizens if gains are only expected in the long run (Maor 2014a: 1).

Maor (2014a) points out that these approaches have neglected the role of emotions in driving a negative policy bubble. Negative emotions can be triggered by dramatic events or slow-motion, and color people’s perception and evaluation of policy. They alter the process by which people make decisions, and shape decision makers’ motives (ibid: 4). A negative policy bubble is emotion-driven if an emotional or emotionally-driven mechanism leads to the policy content, policy tools and/or target populations being undervalued (ibid: 8). The bubble is reinforced by mechanisms such as serial information processing, emotional contagion, imitation and herd-behavior, and familiarity biases. Media coverage plays a crucial role in the emergence and perception of negative emotions (ibid).

We argue that the debate on policy bubbles should account for the hitherto neglected fact that decision-making processes differ depending on the characteristics of different policies (Lowi 1972). Specifically, we argue that Maor’s (2014a) argument on the role of emotions is crucial
to understand the emergence of negative policy bubbles in morality policies. Morality policies concern fundamental questions such as the beginning and the end of life. They are crucially characterized by a fundamental, first-principled conflict with the values embodied in some aspect of morality policy by at least a significant minority of citizens (Meier 1999; Mooney 1999). As a result, it is difficult to compromise on morality policies; they have a high public salience; and the discussions surrounding morality policies focus on values, which brings along technical simplicity (Knill 2013; Mooney and Schuldt 2008). Due to their value-laden nature, morality policies represent a “crucial case” (Gerring 2008) to test Maor’s (2014a) argument on the role of emotions for policy underinvestment. Value polarization in the population can trigger negative emotions. We hence formulate a second expectation:

_Expectation 2: Values and emotions play a pivotal role in explaining the emergence of a negative policy bubble in a morality policy._

**Underinvestment in morality policy**

We argue that _policy instruments are a particularly useful shortcut to capture the degree of government investment in a particular policy._ Organ donation is an issue of public interest (Flückiger 2010). Legislators and public hospitals have to decide: Do we think that organ donation should be promoted, and if so, by which means? A public policy instrument is a set of techniques by which public actors wield their power in attempting to ensure support and effect or prevent social change (Howlett and Rayner 2007: 2; Knill and Tosun 2012: 4; Vedung 1998: 21). Whether the state deems a specific social change necessary or not influences the choice of policy instruments. The choice of policies is justified by their suitability to address underlying policy problems by achieving policy goals (Howlett 2009). By assessing the effectiveness of policy instruments, we can hence determine whether a mismatch between policy action and problems exists (Jones et al. 2014: 147).
However, public policy instruments are more than just means to addressing problems. The choice, use and effects of public policy instruments also reveal a theorization of the relationship between the governing and the governed (Lascoumes and Le Galès 2007). The extent to which power is exercised reveals how governments attempt to influence the behavior of policy addressees. Policy instruments thus express the broader political and cultural context in terms of underlying policy and implementation preferences (Howlett 2009).

Existing taxonomies of policy instruments distinguish between the dimensions of information, authority, treasure and organization (Howlett 2009; Howlett and Rayner 2007). Vedung’s (1998) tripartite classification of policy instruments into sticks (regulations), carrots (economic or non-monetary (dis-)incentives) and sermons (information) is illustrative of these dimensions and captures the use of authority upon the target population as the “quintessence of government” (Lowi 1972; Sager 2009). Sticks are authoritative restrictions on actions or directives as how to act, limiting the choices available to the individuals. Carrots are economic policy instruments, which make an action easier or more difficult by addition or deprivation of material resources. Incentives make actions less expensive (e.g. subsidies), whereas disincentives make them more expensive (e.g. taxes), but the addressees are not obligated to take the measures involved. Sermons are voluntary appeals by means of information or exhortation, characterized by the absence of obligation. Vedung (1998: 38) argues that organisational strategies are a prerequisite for the application of policy instruments, but not a policy instrument in the narrow sense.

The double-edged nature of policy instrument choice – addressing problems and exerting power – is an especially salient issue in morality policies like organ donation. For policymakers, the value-laden nature of morality policies means that policy design does not only or even primarily aim at resolving technical problems. Rather, each intervention of the state is delicate, as it represents a “legal sanction of right and wrong, the validation of a
particular set of basic values” (Mooney 1999: 675).

Engeli and Varone (2011) have shown how this leads responsive governments to design policies primarily according to the distribution of the respective values in the population. According to them, if there is, first, a broad consensus in the electorate on the intractable values, then the policy design will reflect this majority. Second, if the clash of values within the constituency is fundamental, then there will be a non-decision. Third, in the same situation governments may also choose a procedural design, which, by de-moralising the issue in favour of negotiable technical aspects, does not risk at redistributing values. Governments avoid an explicit position regarding the morally contested issue, by delegating the decision to the policy addressees. As a result, morality policy instruments differ in the degree to which they express an explicit official position in the given morally contested matter.

Following Engeli and Varone (2011), in situations of polarized values, responsive governments cannot afford to openly make substantial investments in the morality policy. Such an investment would imply an explicit position of the government regarding the desired (technical) goal of the policy, which in turn represents a public statement about what is right and wrong (Thomann and Manatschal, under review). *The value distribution in the population might hence result in underinvestment, as expressed though the policy instruments used.*

Authority (Howlett 2009) or coerciveness (Vedung 1998) describes the formal power relationship between government and target population (Sager 2009). However, governments also display different intensities with which they take action which explicitly influences a given technical policy goal. For example, while both Switzerland and Spain have awareness raising campaigns for organ donation (non-coercive sermon), the campaigns differ substantially in the message they communicate. In Spain, the official campaign carries the slogan “Donate your organs, donate life”. Organ donation is hence explicitly, but non-coercively promoted as the desired goal of the public policy. By contrast, in Switzerland, the
2010 campaign issued the slogan “Take your decision today”. The campaign emphasized the procedural aspect of taking a decision regarding the willingness to donate organs, but without involving any public statement about the desired direction of this decision. This particularity of morality policy instruments is not captured by existing taxonomies of policy instruments.

We hence argue that to explore how state action is responsive to morally contested values, it is necessary to distinguish morality policy instruments according to the degree to which they express an explicit position of the government regarding the desired (technical) goal of the policy (Thomann and Manatschal, under review). The dimension of *explicitness* describes different approaches to resolving the functional problem, depending on the extent to which they involve state action aimed at influencing the policy goal. Traces of this criterion appear already in Vedung’s policy typology, for instance when he states that information measures can be neutral (objective) or involve a judgement of desirable behavior (Vedung 1998: 33).

We expect different degrees of explicitness to be an observable response to intractable value distributions. Procedural designs translate into non-explicit policy instruments:

*Expectation 3: In the context of highly polarized value distributions on organ donation issues in the population, policy instruments tend to be non-explicit.*

We can think of non-explicit policy instruments as the avoidance of explicit investment of governments in morality policies: policy means and ends are mismatched. As a consequence, we can formulate a fourth expectation:

*Expectation 4: Non-explicit policy instrument tend to be less effective in resolving technical policy problems, i.e. achieving the technically desirable policy outcome.*

**Research design and methods**

Figure 1 delineates the organ donation process with its various stages and sub-processes.
The initial pool of potential donors consists of patients with a formal brain death diagnosis or non-heart-beating patients. Once a potential donor is identified as such, the next of kin will be approached and asked for their consent or refusal to organ donation. If consent is given, then a potential donor turns into an effective donor as soon as she is transferred to the operating theatre and at least one solid organ has been retrieved (Council of Europe 2011: II). Refusal rates to organ donation express the number of refusals by deceased patients’ relatives as a share of total requests for organ donation (Council of Europe 2011). The focus on refusal rates narrows the pool of relevant explanatory and contextual factors. Factors such as varying donor detection rates or the pre-existing pool of potential donors can be isolated: They reflect in final donor rates but do not affect refusal rates.

As Figure 2 illustrates, Swiss refusal rates exceeded Spanish rates by 2.5 times in 2009 (Council of Europe 2011; Matesanz 2008). There are also striking differences in refusal rates among the German- speaking and French- and Italian-speaking (= Latin) linguistic regions within Switzerland. By contrast, there is no systematic regional variation in Spain. Finally, refusal rates are clearly higher in large than in small hospitals in Switzerland, but not in Spain (cf. Table 1). Big hospitals are hospitals which have a division of neurosurgery, whereas small hospitals have none. This difference is relevant for organ donation, as neuorsurgeons perform
the brain death diagnosis, and it is applied in all official organ donation statistics in Europe (Council of Europe 2011). Small and big hospitals are similar enough and separate enough to treat them as comparable instances of the same phenomenon and display similar configurations of the relevant causal characteristics (Byrne 2009: 102). We hence define our cases as types of hospitals (small vs. big), which are “nested” within two national contexts (Switzerland and Spain), whereas the above mentioned regional differences also lead us to distinguish between the German-spaking and the Latin regions of Switzerland. The Spanish Model of organ donation was established before the decentralization of Spain’s health care system and therefore applies to all regions equally (Manatschal and Thomann 2011: 46). This renders a distinction of different regions of Spain unnecessary.

**Figure 2: Refusal rates to organ donation in Spain and Switzerland**

![Refusal rates graph](image)

*Notes: Refusal rate = number of refusals by next of kin as share of total requests (in per cent). Reference year: Spain: 2009. As the number of observations for small hospitals in Switzerland is very low per year, we rely on the mean values of the years 2007, 2008 and 2009 for Swiss hospitals, as the refusal rates are very stable over time. Number of observations: ESP big hospitals: N= 1925, ESP small hospitals: N= 484, CH (Latin part) big hospitals: 199, CH (Latin part) small hospitals: N= 36, CH (German part) big hospitals: N= 303, CH (German part) small hospitals: N= 37. Data sources: Swiss Donor Action (mean of 2007, 2008, 2009), Organización Nacional de Trasplantes (ONT 2009).*
We thus compare contrasting cases (Gerring 2008): Spain as the international example of best practice, with very low refusal rates, and Switzerland, which exhibits comparatively high refusal rates despite having adopted elements of the Spanish model, with a pronounced regional variation between German-speaking and Latin cantons. The case of Spain is used as typical case (Gerring 2008), i.e. a benchmark, of “adequate investment” against which we can determine whether or not underinvestment occurs in the Swiss case, depending on the degree to which it deviates from this benchmark (Gerring 2008; Maor 2014c).

We primarily base our analysis on in-depth qualitative case studies and their comparison (Gerring 2008). To assess whether the policy instruments’ degree of explicitness is 1) linked with refusal rates and hence represents degrees of investment, and 2) can be explained by emotions, we apply explanatory typologies (Elman 2005). With explanatory typologies, “the dimensions of the property space associated with a typological theory are provided by the theory’s explanatory variables, and the content of the cells comes from the logic of the theory: Given its posited causal relationships, what particular outcomes are associated with different combinations of values of the theory’s variables?” (Bennett and Elman 2006: 465). Explanatory typologies are very well suited to complement a process tracing approach, and they enable a systematic assessment of configurations of variables even with a small number of cases. Without the need to calculate statistical measures, researchers determine what they expect to see if their theory is correct, as we did in the theory section. The data are then placed in the relevant cells of the typology, to see whether they conform to the expectation. The typology also serves to pick relevant cases for discussion (Elman 2005: 309).

Data were collected during a research project mandated by the Federal Office of Public Health (FOPH) (Manatschal and Thomann 2011). The information regarding explanatory factors stems from a qualitative content analysis of primary and secondary literature (legal documents and scientific studies) as well as semi-structured interviews with overall 28 experts.
in both countries (see Table A1 in the appendix). Data on refusal rates stem from the national quality monitoring programmes. Our Spanish sample comprises all hospitals in 2009 (71 big, 68 small hospitals), whereas data is only available for 50 per cent of the Swiss hospitals. Since the refusal rates between hospitals of the same type do not differ systematically in Switzerland, Swiss authorities consider the participant hospitals representative (Manatschal and Thomann 2011: 33, 64ff). To measure the population’s values toward organ donation in the period under study, it was difficult to get access to comparable data because Switzerland is not a member of the European Union, and most statistics do not differentiate between Swiss language groups. To measure values regarding organ donation, we rely on the survey question whether the respondent would be willing to donate his or her own organs as a proxy (see Table A2 appendix for data and sources).

Swiss organ donation policy: a negative policy bubble?

To identify investment in organ donation policy, we first present organizational and individual factors and policy instruments which influence refusal rates, see Table 1.

**Individual factors.** Refusal rates are the result of personal decisions. Accordingly, research on organ donation mainly discusses how individual characteristics (mainly socio-demographic and attitudinal) influence relatives’ decisions regarding donation (e.g. Siminoff et al. 2001). Since we found no indication that such individual factors vary systematically between our cases, we do not consider them further. Yet, to understand the relevance of policy instruments, it is instructive that a significant proportion of refusals is due to relatives’ concerns about what will happen with the deceased’s body and their satisfaction with the overall medical attention received in the hospital (Martínez et al. 2001; Simpkin et al. 2009). Prior communication of a potential donor’s will to family members eases the family approach

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Organizational factors. The exportation of elements of the “Spanish model”, which embraces organisational changes within a supportive legislative framework, has sometimes led to an increase in donation rates (Quigley et al 2008; Rithalia et al. 2009: 2). Organizational elements include a three-stage transplant coordination network (hospital, regional, national) with a central office as an agency in support of the whole donation process, and specifically trained transplant coordinators at all 3 levels (Matesanz and Dominguez-Gil 2007: 181, 187). The implementation of an in-house coordinator closely managing and coordinating the consent process has led to increases in consent rates (Salim et al. 2007; Simpkin et al. 2009).

The policy instruments we analyze are those directed to all actors involved in the family decision-making process. Accordingly, our policy addressees consist of the donors’ next of kin as well as medical staff as final addressees of an instrument. Thus, we classify a policy instrument according to the degree of authority exercised on its target population rather than on the first agent in the implementation chain (cf. Sager 2009: 540).

Sermons. Due to the sensitive nature of organ donation policy, governments are reluctant to exercise coercion on the target groups. Hence, most relevant policy instruments are sermons. One important sermon is the family approach. The specific pattern of the request for organ donation is decisive, since a personal and temporal separation from the notification of death (decoupling) decreases the likeliness of refusal (Siminoff et al. 2001; Simpkin et al. 2009). Repeating the request several times (“reapproach”) can lead relatives to reconsider their decision if they were initially undecided. Educational programs for hospital staff, i.e. for intensive care nurses, doctors and donor coordinators to provide optimal care and

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communication, coincide with low refusal rates, by providing the optimal context for performing the donor request (Martínez et al. 2001; Siminoff et al. 2001; Simpkin et al. 2009). Another important sermon regards public awareness raising (information and education). Although there is no empirical evidence in support of a direct influence of public information and education campaigns on donation rates, they play an important role in the population’s knowledge of and attitude toward organ donation. Knowledge about organ donation reduces fear out of ignorance. Moreover, educational intervention programs at schools have resulted in a higher intention to donate organs (Costa-Font and Rudisill 2008; Martínez et al. 2001; Mossialos, Schulz et al. 2006: 295f). Differing national programs for quality control constitute another sermon, which aim at systematically reporting and improving the processes and results of organ donation in hospitals.

Carrots. The adequate reimbursement of hospitals, staff and donor coordinators within hospitals constitutes a positive incentive for procurement activity (Matesanz and Dominguez-Gil 2007: 183). Although the effect of economic resources as incentives is unexplored by scientific studies, it seems likely that they determine the efforts and expertise at disposal for family requests. Reimbursement not only refers to the salaries of staff and donor coordinators, but also to hospital funding as an important incentive in the procurement process. Another negative incentive relates to the donor transfer, when donors are transferred to a larger hospital for organ retrieval. Since this involves a physical separation from the relatives, the perspective of donor transfer often leads to refusal.

Sticks. We classify the legal model of consent as stick, as it specifies the conditions for individual behaviour (Knill and Tosun 2012: 19). The legal model obliges the relatives to take a decision (Abadie and Gay 2006; Mossialos et al. 2008; Schulz et al. 2006: 296): under presumed consent (opt-out), they must express their opposition if they object to a donation. By contrast, under explicit/informed consent (opt-in), relatives must explicitly express their
agreement to the donation of organs. Several studies report that presumed consent is positively correlated to higher donation rates (Abadie and Gay 2006; Johnson and Goldstein 2003; Mossialos et al. 2008). Sticks. It is often argued that presumed consent is a more favorable context, since everyone is considered a potential donor.

Table 1: Factors influencing relatives’ refusal to organ donation

<table>
<thead>
<tr>
<th>Factor</th>
<th>Influence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-heart beating donor</td>
<td>-</td>
</tr>
<tr>
<td>Family and patient sociodemographics (Age, education, ethnicity, income, cause of death)</td>
<td>+/-</td>
</tr>
<tr>
<td>Attitudes, perceptions, values of donors and their families</td>
<td>+/-</td>
</tr>
<tr>
<td>Knowledge of relatives about the patient’s wishes (intrafamiliar communication)</td>
<td>+/-</td>
</tr>
<tr>
<td>Awareness/knowledge of relatives about donation</td>
<td>-</td>
</tr>
<tr>
<td>Families’ satisfaction with medical attention</td>
<td>-</td>
</tr>
<tr>
<td>Concerns about physical integrity / destination of dead body</td>
<td>+</td>
</tr>
<tr>
<td>Legal model: presumed consent</td>
<td>-</td>
</tr>
<tr>
<td>Coverage of costs for hospitals</td>
<td>-</td>
</tr>
<tr>
<td>Reimbursement of donor coordinators</td>
<td>-</td>
</tr>
<tr>
<td>Donor transfer to retrieval hospital</td>
<td>+</td>
</tr>
<tr>
<td>Temporal and personal separation (decoupling) of brain death diagnosis and request for donation</td>
<td>-</td>
</tr>
<tr>
<td>Collaborative requesting</td>
<td>-</td>
</tr>
<tr>
<td>Appropriate formulation of request</td>
<td>-</td>
</tr>
<tr>
<td>Time available for decision-making</td>
<td>-</td>
</tr>
<tr>
<td>Reapproach</td>
<td>-</td>
</tr>
<tr>
<td>Information of relatives about donation process</td>
<td>-</td>
</tr>
<tr>
<td>Information campaigns</td>
<td>-</td>
</tr>
<tr>
<td>Education and training of critical care staff and donor coordinators</td>
<td>-</td>
</tr>
<tr>
<td>Educational intervention programs</td>
<td>-</td>
</tr>
<tr>
<td>Quality monitoring</td>
<td>-</td>
</tr>
<tr>
<td>Existence and involvement of in-house donor coordinator / Involvement of trained and experienced organ procurement professional</td>
<td>-</td>
</tr>
<tr>
<td>Three-stage transplant coordination network (hospital, regional, national)</td>
<td>-</td>
</tr>
</tbody>
</table>

Legend: + = increasing, - = reducing effect on refusal rate expected.

3 Other studies find no influence of presumed consent on refusal rates (e.g. Bilgel 2012).
We now discuss our cases. Efficient readers might want to turn their attention directly to Table 2 (p. 21), which summarizes the findings.

**Spain**

*Organizational factors.* The Spanish organ donation sector is based on a three-tiered coordination system (hospital, regional, national). In each hospital with an intensive care unit (ICU), there is at least one hospital coordinator for donation and transplantation activities. The “Organización Nacional de Trasplantes” (ONT) enforces the law and coordinates donation activities. There is a regional transplantation coordination office in each of the 17 autonomous regions (Manatschal and Thomann 2011: 40).

*Family approach.* The Spanish hospital coordinator is involved in all processes of family decision-making and takes comprehensive care of the relatives (Manatschal and Thomann 2011: 53, 70ff, 112). Both the temporal and personal decoupling of the request for organ donation from the notification of death are common practice in Spain (Real decreto 2070/1999, Anexo I). Even if the relatives’ initial reaction is negative, the coordinators repeat their request several times (reapproach), which apparently often leads to reconsiderations (Matesanz 2008: 29, 38f).

*Education of hospital staff.* The Spanish organ donation system is strongly professionalized: regional authorities and hospital coordinators educate and sensitize hospital staff about organ donation. The ONT offers at least four different courses and seminars for coordinators, hospital staff (including EDHEP courses) and the population. Thus, Spanish education about donation is not only comprehensive but also highly inclusive (Matesanz 2008: 11ff).

*Public awareness raising.* The Spanish state explicitly encourages “voluntary, altruistic and non-remunerative organ donation” by law to ensure that every citizen in need of a donor organ has optimal chances for it (Real decreto 2070/1999, art.7 and 19). The ONT promotes
organ donation via close relations to the media (specifically television), campaigns and other channels, and frequently organizes information and education campaigns at schools and universities (Matesanz and Dominguez-Gil 2007: 183f). Thus, public information in Spain is comprehensive, promotes donation explicitly, is clear in its message, and reaches a broad public (Manatschal and Thomann 2011: 101f).

*Quality control.* Spain has a comprehensive system of quality control which includes a systematic evaluation of the reasons for family refusals and their publication. Spanish Information about problematic behavior reportedly has a motivational effect on hospital staff.

*Reimbursement of donor coordinators.* ICU staff and coordinators receive compensations (additional to their regular salary or full-time) for their work in donation processes (Matesanz 2008: 23). According to our Spanish interviewees, the coordinators’ motivation is not only based on altruism, but also on the appropriate payment of coordination activities (Matesanz and Dominguez-Gil 2007: 184). This incentive structure works not least due to the comparatively low basic salaries of Spanish surgeons (ibid.).

*Hospital funding.* Donation processes are covered by the public health budget within a system of advance payment. They entail everything before the actual retrieval of the organ, independently of its outcome.

*Donor transfer.* Instead of transferring donors, mobile teams of surgeons travel to small hospitals for organ retrieval (Martín, Martínez and Uruñuela 2008: 63f).

*Legal model of consent.* The Spanish legislation is based on the presumed consent principle. Nevertheless, although everyone is considered a potential donor, the relatives are always asked in Spain whether they oppose organ retrieval (Quigley et al. 2008: 223).
Switzerland

Organizational factors. In Switzerland, each hospital with an ICU has a “donor key person” who is responsible for ensuring that potential donors are detected. The FOPH acts as enforcement agency, whereas Swisstransplant, a private foundation, pursues coordination activities. There are six transplantation centres, around which informal regional hospital networks have emerged. The largest coordination network is that of Latin Switzerland (Programme Latin de Don d’Organes, PLDO) (Manatschal and Thomann 2011: 43).

Family approach. In Switzerland, managing the processes of family decision-making is not a task of the donor key persons; they must only ensure that the relevant donation processes take place in their hospital (BAG 2008). Thus, there is generally neither temporal nor personal decoupling of brain-death diagnosis and request. All interviewees confirmed that the practice of reapproach is negatively perceived and never applied.

Education of hospital staff. The FOPH supports courses with a focus on communication with relatives for donor key persons in Switzerland, but not courses from the European Donor Hospital Education Programme (EDHEP). The regional network coordinators offer additional courses, with the PLDO dedicating most efforts and resources to sensitizing and informing the ICU staff about donation processes. Thus, the education of staff is provided in Switzerland, but is especially comprehensive and intensive in the Latin part (BAG 2008; Swisstransplant 2008: 7). These differences in sensitization reflect in the attitudes of the hospital staff involved in the core processes of organ recruitment, which in turn affect relatives’ decision regarding organ donation (Martínez et al. 2001; Siminoff et al. 2001; Simpkin et al. 2009). In German-speaking hospitals, a negative tabooization and marginalization of the organ donation topic was observed. In the PLDO, there is a strong commitment and motivation fostered by the network coordinator, and donation activities have been internalized by hospitals.

Public awareness raising. The law obliges the FOPH to remain strictly neutral in its public
information, which includes an information website, placards, advertisements and non-compulsory teaching materials for instructors. In contrast, Swisstransplant takes a pro-donation stance in its PR activities. The messages directed toward the population can therefore be ambiguous (BAG 2008: 15f; Schulz et al. 2006: 294).

**Quality control.** Switzerland runs a voluntary program for quality control of donation processes in hospitals. Until 2009, this program did not evaluate the causes of family refusals, which could ensure the improvement of family request processes. Its results are not published.

**Reimbursement of donor coordinators.** Donor key persons are paid part-time specifically for their coordination activities in the PLDO and in large hospitals in German-speaking Switzerland, but not in small German-speaking hospitals. This lack of financial compensation implies a devaluation of the donor coordination function and is therefore perceived as a disincentive with regard to commitment.

**Hospital funding.** Until 2012, the cost coverage of donation and transplantation processes in Switzerland did not include any activity preceding organ retrieval, such as the family approach. No reimbursement took place if an organ was retrieved, but not transplanted.\(^4\) Swiss interviewees reported that this lack of compensation represents a disincentive for their commitment.

**Donor transfer.** In 2009, about one third of the donors detected in a non-transplantation center were transferred to a larger hospital for organ retrieval (Swisstransplant 2009: 18f). The psychological stress caused by the perspective of being separated from the dead body is an important reason why relatives refuse organ donation.

**Legal model of consent.** In Switzerland’s informed consent system, the relatives are approached to ascertain the known or presumed will of the potential donor.

Table 2: Policy instruments in Swiss and Spanish Hospitals

<table>
<thead>
<tr>
<th></th>
<th>CH-GE Large hospitals</th>
<th>CH-GE Small hospitals</th>
<th>CH-L Large hospitals</th>
<th>CH-L Small hospitals</th>
<th>ESP Large hospitals</th>
<th>ESP Small hospitals</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sermons</strong></td>
<td>fam</td>
<td>fam</td>
<td>fam</td>
<td>fam</td>
<td>FAM</td>
<td>FAM</td>
</tr>
<tr>
<td><strong>Active public awareness raising</strong></td>
<td>ar</td>
<td>ar</td>
<td>ar</td>
<td>ar</td>
<td>AR</td>
<td>AR</td>
</tr>
<tr>
<td><strong>Comprehensive education of hospital staff</strong></td>
<td>edu</td>
<td>edu</td>
<td>EDUC</td>
<td>EDUC</td>
<td>EDU</td>
<td>EDU</td>
</tr>
<tr>
<td><strong>Quality monitoring</strong></td>
<td>qm</td>
<td>qm</td>
<td>qm</td>
<td>qm</td>
<td>QM</td>
<td>QM</td>
</tr>
<tr>
<td><strong>Carrots</strong></td>
<td>RC</td>
<td>re</td>
<td>RC</td>
<td>RC</td>
<td>RC</td>
<td>RC</td>
</tr>
<tr>
<td><strong>Cost coverage</strong></td>
<td>cc</td>
<td>cc</td>
<td>cc</td>
<td>cc</td>
<td>CC</td>
<td>CC</td>
</tr>
<tr>
<td><strong>Donor transfer for retrieval</strong></td>
<td>t</td>
<td>T</td>
<td>t</td>
<td>T</td>
<td>T</td>
<td>t</td>
</tr>
<tr>
<td><strong>Sticks</strong></td>
<td>pc</td>
<td>pc</td>
<td>pc</td>
<td>pc</td>
<td>PC</td>
<td>PC</td>
</tr>
<tr>
<td><strong>Outcome</strong></td>
<td>Refusal rate</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>49.0%</td>
<td>78.0%</td>
<td>28.4%</td>
<td>75.0%</td>
<td>19.8%</td>
<td>16.2%</td>
</tr>
</tbody>
</table>

Note: CH = Switzerland, ESP = Spain. GE = German-speaking region, L = Latin region.

The countries do not differ systematically regarding individual and organizational factors, which are hence not discussed in the remainder of the analysis. Table 2 resumes the policy instruments in Swiss and Spanish hospitals. A systematic and encompassing application of policy instruments is expressed by capital letters, otherwise lower case letters are used.

Table 2 immediately reveals that the degree of coerciveness of policy instruments obviously is not an adequate indicator of degrees of investment in organ donation policies. The six cases display policy instruments with exactly the same degree of coerciveness. For example, both countries have a policy of cost coverage, representing a carrot. Similarly, a legal model of consent (stick) is present in both countries. What helps us understand the differences in refusal rate hence cannot be the policy instruments’ degree of coerciveness per se.
Is the policy instruments’ degree of explicitness more insightful in this regard? Explicitness is indicated by bold letters in Table 2. We specify a sermon as more explicit if it represents state action aimed at influencing the decision with regard to organ donation, compared to a sermon representing a neutral or absent official position in this matter. Similarly, we consider the legal regulation of presumed consent, which bases on the underlying assumption that everyone is a potential donor, a more explicit stick than informed consent, where no such prior assumptions are made. We can think of explicit (positive) incentives as carrots promoting, i.e. encouraging organ donation activities. Non-explicit (negative) incentives discourage organ donation activities.

*Figure 3: Explanatory typology: Explicitness and refusal rates*

![Diagram showing explanatory typology: Explicitness and refusal rates]

*Note:* The quadrants represent ideal-typical differences in kind, whereas the shades express differences in degree.

On the Y axis of the first explanatory typology, we find the outcome refusal rates, which
ranges from 0 to 100. On the X axis, we display the cases’ average degree of explicitness of policy instruments, ranging from 0 to 1. Instruments were coded as 0 when non-explicit, as 1 when explicit, and then summed up for each case. Using this procedure with eight policy instruments, values of 0.5 represent the threshold for neither pronounced nor limited average explicitness. We expect higher degrees of explicitness to represent high degrees of investment in the policy, which translates into lower refusal rates, and vice versa. We hence expect cases to cluster in the upper-left and lower-right quadrants of the typology, and not to be placed in the dark-shaded areas of Figure 3.

Figure 3 mostly reflects expectation 4. Large hospitals in Latin-speaking Switzerland deviate slightly from the picture. Here, most of the instruments that are “proximate” to the process of donor request in hospitals are explicit (Thomann and Manatschal, under review). The activities of the regional PLDO network mediate the negative effect of the more “remote” non-explicit instruments at the national level. This deviant case actually reinforces the impression that the divergent national contexts of adequate investment in organ donation policy in Spain, versus inadequate investment in Switzerland, matter for refusal rates.

Can we really consider Swiss organ donation policy as a negative policy bubble? Figure 3 confirms that policy means and ends were mismatched in Switzerland in 2009, as compared to the best practice counterfactual of Spain. Yet identifying a negative policy bubble requires a dynamic view over time (Maor 2014a). Over the last three decades, rapid technological progress in transplant medicine has boosted the demand for donor organs. As Figure 4 illustrates, in the period under study, Swiss donor rates increased slightly but remained consistently and remarkably lower than Spanish rates.5 Meanwhile, the policy problem has become more severe: the list of patients waiting for a transplant organ kept on growing.

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5 These numbers kept a moderate growth from 14.9 donors p.m.p, in 2010 to 15.2 donors p.m.p. in 2014. Simultaneously, the waiting lists have kept increasing disproportionately (Swisstransplant 2014).
Organ donation policy in Switzerland was unregulated at the national level before 2007. In some cantons (constituent states), the issue was completely unregulated, and data on organ donations was not collected. Conversely, Spain issued a national Transplantation act as early as 1979, and in 1989 the Organización Nacional de Trasplantes (ONT) was founded. Under the leadership of its pioneer Rafael Matesanz, the Spanish model was successfully exported to various countries all over the globe (Quigley et al. 2008; Matesanz 2004; Matesanz and Dominguez-Gil 2007). Meanwhile, innovation to improve organ donation processes boosted (Barber et al. 2006; Johnson and Goldstein 2003; Martínez et al. 2001; Shafer et al. 2006; Siminoff et al. 2001; West and Burr 2002). In light of fast-growing waiting list in transplantation centers, the Swiss Transplantation Act in 2007 introduced the organizational elements of the “Spanish model”. However, underinvestment continued, as expressed in non-explicit instruments and continuously low donation rates (Manatschal and Thomann 2011).

The Swiss case hence constitutes a negative policy bubble according to expectation 1, with a continuous mismatch of policy means and ends despite a growing problem and ample evidence on adequate tools. This could be seen as a case of forced underreaction,
characterized by accurate risk estimation of policy makers, but external constraints on policy change (Maor 2014c). In fact, policy makers at the national and hospital level were and are well aware of the need to address the problem. However, as we show now, the emotions arising from intractable value distributions in the population hindered the adoption of some crucial non-organizational elements of the Spanish model.

The role of emotions for underinvestment in Swiss organ donation policy

According to our expectation 3, the differences in the policy instruments’ explicitness should reflect differing degrees of value polarization in the population. We calculated the difference between the percentage of respondents who have a donor card or are willing to donate their organs, and those who are not. The smaller this difference, the higher polarization is. As Figure 5 shows, the value polarization is much higher in Switzerland than in Spain.

Our cases strongly support Engeli and Varone’s (2011) assertion that policymakers avoid taking an explicit position on a morality issue when the population’s values on the policy are polarized. As we expected, high polarization seems to have produced underinvestment in Switzerland. For example, the Swiss transplant act (TxG) does not allow the government to launch any information campaigns promoting organ donation. The State has to be neutral and official information can only cover "explanation of the ways in which an individual can express his or her wishes concerning the donation of his or her organs" (Art. 61 al.2 let. A TxG). This was the most debated issue in both the pre-parliamentary and parliamentary debates. The government initially proposed a proactive information strategy encouraging potential donors to give their explicit consent for donation. However, the Social Democrats and the Christian Democrats were joined by some interest groups in contesting this policy solution. Facing such strong resistance, the government dramatically changed its position to
avoid imposing moral values on the personal choice to donate organs (Flückiger 2010). This was thus a case of policy drift, induced by value polarization (Maor 2014c).

**Figure 5: Explanatory typology: Polarization and explicitness**

![Diagram](image)

*Note: The quadrants represent ideal-typical differences in kind, whereas the shades express differences in degree.*

Negative emotions influenced the adoption of a non-explicit family approach at the hospital level /Manatschal and Thomann 2011). In this context, the hospital staff performing the donor request and taking care of relatives acts as frontline policy makers (Lipsky 1980). Three factors worked together to produce negative emotions (Maor 2014a).

*Serial information processing.* Before 2007, Switzerland did not have a transparent and just procedure to allocate organs to patients on the waiting list. As a result, organs were sometimes allocated according to unethical criteria, such as regional preferences and negotiations between hospitals. Although these nuisances have been fully removed with the TxG in 2007,
the perception of sleaze lingered (and ligners) on amongst hospital staff and the population. In fact, even in 2009 many nurses were not informed that the procedure had been changed.

*Emotional contagion.* Furthermore, in Switzerland the processes of organ procurement and transplantation are strictly separated. As a consequence, the intensive care staff takes care of the emotionally very demanding and difficult process of donor request, but is never exposed to the rewarding reactions of organ recipients and their families. Even worse, while transplant surgeons remove the organs, intensive care staff is responsible of cleaning the theatre and “removing” the eviscerated bodies. These situations are often traumatic for the personnel and produce highly negative emotions toward organ donation.

*Role of the media.* Third, in the early 2000’s there was a series of unfortunate events when transplant surgeons behaved in very unsensitive ways to obtain donor organs. These events received high media coverage and produced a public perception of transplant surgeons as egoistic “vultures” who only care about their prestige. The fact that the brain death diagnosis is hard to understand, because the patient is still physically “alive”, together with occasional media coverage on wondrous “resurgences” further reinforced negative emotions.

As a result, a very high share of Swiss hospital staff are highly critical toward organ donation. Clearly, these negative emotions also contributed to the value polarization in the population (see also Schulz 2006). Taken, together, these factors demonstrably influence how the family approach is performed (Roels et al. 2010). While Swiss hospital staff is legally obliged to perform the donor request and take care of the relatives during the process, the negative emotions contribute to non-explicit ways in which this is done: i.e., a large share of hospital staff does not carry the message that organ donation is the desired goal (Manatschal and Thomann 2011). Overall, these observation support our expectation 2.
Conclusions

This paper contributes to the debate on policy bubbles in two ways: first, it aimed at testing the usefulness of this relatively new concept to understand the empirical case of organ donation policy. Second, this paper suggested to introduce Lowi’s (1972: 299) famous assertion that “policies determine politics” to the debate. It was argued that emotions and values are crucial to understand underinvestment in morally contested policies (Maor 2014a). We showed that policy instruments capture the degree of government investment in a particular policy. By assessing their effectiveness, mismatches between policy action and problems can be revealed (Jones et al. 2014: 147). In morality policy, each government action represents a validation of a particular set of values (Knill 2014; Mooney 1999). If the value distribution in the population is polarized, then responsive governments might avoid such a statement (Engeli and Varone 2011). As a result, morality policy instruments differ in the degree to which they express an explicit official position regarding the technically desired goal of the given morally contested matter. Since existing taxonomies of policy instruments do not capture this notion, we have proposed the dimension of explicitness of policy instruments (Thomann and Manatschal, under review). The value distribution in the population might hence result in underinvestment: an investment would imply an explicit position of the government regarding the desired policy goal, which in turn represents a public statement about what is right and wrong.

We proposed morality policy as a crucial case for assessing the role of emotions. Using process tracing and explanatory typologies (Bennett and Elman 2006), we compared Swiss organ donation policy with Spain as a benchmark against which underinvestment can be identified (Maor 2014c: 428). Results show that Swiss organ donation policy constitutes an emotion-driven negative policy bubble (Maor 2014a). Underinvestment manifested itself in non-explicit policy instruments. Policy instruments at the national, regional and hospital level
avoid an explicit position regarding the morally contested issue. Value polarization, which in turn was triggered by negative emotions, played an important role in explaining this (Engeli and Varone 2011; Maor 2014a). In the light of the fundamental clash of values within the constituency, the government chose a procedural design which did not redistribute values (Engeli and Varone 2011). At the organizational level, the intense emotions of hospital staff (the “policy makers” at the frontline, Lipksy 1980/2010) toward organ donation, fed by negative media presence and traumatic situations in theatres, provoked strong resistance by hospital staff, which prevented policy change.

Like all studies, ours has limitations. We did not analyze individual level data and could only partially control for the cultural context which also matters for explaining differences in refusal rates (Dunkel 2011; Healy 2005; Mossialos et al. 2008; West and Burr 2002). It remains an open question to be addressed by future research how cultural differences favour the adoption of specific policy instruments, or, conversely, to which extent the policy instruments in place shape culture (Coleman 1990). Our research results are not statistically generalizable. Rather, the main focus of this study was explorative in assessing the validity of the concepts of emotion-driven negative policy bubbles and explicitness for gaining a deeper understanding of the cases under study (Bennett and Elman 2006).

In this vein, our results underscore the importance of values and emotions for explaining policy underinvestment in morality policies. Furthermore, we have shown the usefulness of adding an explicitness dimension to existing taxonomies of policy instruments for understanding differences in morality policy outcomes. Conversely, existing taxonomies were not helpful in this regard (Vedung 1998; Howlett 2009). On the one hand, our results illustrate Engeli and Varone’s (2011) argument that governments may respond to polarized values with a procedural decision. On the other hand, we extend this argument to the level of policy instruments. The good news is that governments appear responsive to the values of the population. However, and importantly, we link this argument with policy outcomes. Indeed,
while different degrees of explicitness of policy instruments may be an observable response to intractable value distributions, the delegation of value-laden decisions to citizens through procedural designs might not automatically be effective in achieving technically desirable policy targets. Conceiving of the explicitness of policy instruments as a result of emotions and value distributions may hence help explain the lacking efficiency of policy makers in matching the intensity of the policy tool to the intensity of problems over the long run in morality policies.

References


Martín, S., Martínez, I. and D. Uruñuela. 2008. El papel de la enfermería en la oficina Central de la


Simillis, C. 2010. Do we need to change the legislation to a system of presumed consent to address organ shortage? *Medicine, Science and the Law* 50: 84-94.


Thomann, E. and A. Manatschal (under review). Disentangling contextual effects in small-N settings – A Comparative Multilevel Analysis of refusal rates to organ donation in Switzerland and Spain.


Appendix

Data

Madrid, ONT.


Legal documents consulted

Switzerland:
- Transplantationsgesetz TxG; SR 810.21
- Transplantationsverordnung; SR 810.211
- Organzuteilungsverordnung; SR 810.212.4

Spain:
- Ley 30/1979, de 27 de octubre
- Orden/sco/3685/2004, de 2 de noviembre
- Real decreto 2070/1999, de 30 de diciembre
- Real decreto 176/2004, de 30 de enero
Table A1: Interviewees (place and function)

<table>
<thead>
<tr>
<th>Country</th>
<th>Spain</th>
<th>Switzerland</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Region</strong></td>
<td>Madrid</td>
<td>Castilla - La Mancha</td>
</tr>
<tr>
<td><strong>Hospital level</strong></td>
<td>Hospital Clínico San Carlos, Madrid</td>
<td>2 donor coordinators (intensive care professionals)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Regional level</strong></td>
<td>Autonomous coordination office</td>
<td>3 autonomous coordinators</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>National level</strong></td>
<td>ONT</td>
<td>2 national coordinators</td>
</tr>
<tr>
<td><strong>Experts</strong></td>
<td>Dr. Rafael Matesanz, director ONT</td>
<td>Diane Moretti, general coordinator PLDO</td>
</tr>
</tbody>
</table>

With the exception of the experts consulted, the names of the interviewees are not published in order to maintain their anonymity.

Table A2: Willingness to donate own organs in Switzerland and Spain

<table>
<thead>
<tr>
<th></th>
<th>Spain</th>
<th>CH-GE</th>
<th>CH-L</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have a donor card</td>
<td>8.2</td>
<td>13.1</td>
<td>19.7</td>
</tr>
<tr>
<td>I don’t have a donor card, but I am likely or very likely to donate</td>
<td>58.3</td>
<td>30.6</td>
<td>32.9</td>
</tr>
<tr>
<td>I don’t have a donor card and I am unlikely to donate</td>
<td>14.7</td>
<td>17.7</td>
<td>26.9</td>
</tr>
<tr>
<td>NA</td>
<td>18.7</td>
<td>38.6</td>
<td>20.5</td>
</tr>
<tr>
<td>Polarization</td>
<td>58.3</td>
<td>30.6</td>
<td>32.9</td>
</tr>
</tbody>
</table>

Sources