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1 {Aus: In *JHPPL*, authors usually spell out their first names. If you also
2 publish articles under your first names, please indicate which names
3 we should use below.}

4 **Attitudes toward Reciprocity Systems for Organ Donation and** 5 **Allocation for Transplantation**

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13 **Abstract** Many of those who support organ donation do not register to become organ donors.
14 The use of reciprocity systems, under which some degree of priority is offered to registered
15 donors who require an organ transplant, is one suggestion for increasing registration rates. This
16 article uses a combination of survey and focus group methodologies to explore the reaction of
17 Canadians to a reciprocity proposal. Our results suggest that the response is mixed. Participants
18 are more convinced of the efficacy than they are of the fairness of a reciprocity system. Those
19 more positive about donation (decided donors and those leaning toward donation) rate the system
20 more positively. Although there is general endorsement of the notion that those who wish to
21 receive should be prepared to give (the Golden Rule), this does not translate into universal
22 support for a reciprocity system. In discussions of efficacy, decided donors focus on the positive
23 impact of reciprocity, whereas undecided donors also reflect on the limits of reciprocity for
24 promoting registration. The results demonstrate divided support for reciprocity systems in the
25 Canadian context, with perceptions of efficacy at the cost of fairness. Further studies are
26 warranted prior to considering a reciprocity system in Canada.

27 **Introduction**

28 Organ transplantation is a life-saving or life-preserving treatment for those facing end-stage
29 organ failure. There are, however, more people who need organ transplants than there are organs
30 available for transplantation (Shemie et al. 2011). Various forms of registration of donation
31 intent are available throughout the world with unclear efficacy, as most registries suffer from low
32 registration rates (Rosenblum et al. 2012). In Canada people may register their willingness to
33 donate after their deaths through some provincial registries. Deceased registrants do not go on to

1 donate until and unless they die in such a way (typically in a hospital, after declaration of brain
2 or cardiac death) that their organs are suitable for transplantation. When health care professionals
3 identify a potential donor, they approach the family or significant others for consent for organ
4 donation. If this consent is obtained, the organs are removed and transplanted into appropriate
5 recipients. Family members and significant others may often refuse the option to donate, and
6 although family consent is not required where a person has registered his or her intent, in
7 practice the final decision on procurement rests with family members and significant others.
8 Prior registration is important for increasing consent rates, since family members are more likely
9 to consent where the deceased was a registered donor (Environics 2001{**Aus: Environics**
10 **2007?**}), perhaps because their decision can be eased by the knowledge of prior intent on the part
11 of the potential donor. Although most people support deceased organ donation (Feeley 2007),
12 many who express support do not actually register as organ donors (Cossé and Weisenberger
13 2000; Wong 2011; Hobeika et al. 2009).

14 Many strategies have been proposed to address the chronic shortage of organs for
15 transplantation. Some proposed interventions address the families called on to consent to
16 donation by a deceased loved one, typically offering a form of incentive to the family members
17 or significant others who make the decision at the bedside. Specific proposals include
18 contributions to funeral expenses and ceremonial acknowledgment of donors (e.g., through a
19 “medal of honor”; see Delmonico et al. 2002). Prior donor registration, especially when the
20 intention is communicated to family members, increases family consent to actual donation. Other
21 interventions, therefore, are directed at increasing donation registrations, with the goal of
22 reducing the gap between general support for organ donation and the much lower rates of actual
23 registration. Strategies that fall into this category include mandated choice (Chouhan and Draper

1 2003) and opt-out (as opposed to the current opt-in in North America) approaches to donation
2 registration (Johnson and Goldstein 2003). Another approach that has been suggested to increase
3 donor registration is a “reciprocity,” “preference,” or “prioritization” system in which individuals
4 who have signed their donor cards receive some degree of priority in organ allocation ahead of
5 those who have not registered as donors (Chandler et al. in press{Aus: Chandler, Burkell, and
6 Shemie?}). For the purposes of this article, we use the terms *reciprocity* or *priority* to describe
7 such systems.

8 Several countries have implemented national reciprocity systems, whereas limited
9 reciprocity systems exist in several other jurisdictions. In Singapore an “opt-out” donation
10 registration system is in effect, and those who remain registered (i.e., do *not* opt out) are given
11 some degree of priority over nonparticipants in organ allocation decisions (Chandler et al. in
12 press{Aus: Chandler, Burkell, and Shemie?}; Human Organ Transplant Act 1987: s.12[1]).
13 Israel has recently implemented a reciprocity system in the context of “opt-in” registration
14 (Chandler et al. in press{Aus: Chandler, Burkell, and Shemie?}; Israel n.d.; Siegal and Bonnie
15 2006). This system offers increased priority in organ allocation to registered donors and to their
16 first-degree relatives. Recent changes to Japan’s transplant law allow organ donors to give
17 priority to family members as recipients of their organs should those organs be procured (Aita
18 2011): this system effectively gives priority to family members on the basis of donation (and not
19 simply registration, as is more typical). In the United States, the LifeSharers organization
20 supports directed donation of organs to other members of the network (Bramstedt 2006), thus
21 creating a limited reciprocity system within the group of LifeSharers members, although this has
22 no operational authority in the United States.

1 One important goal of national reciprocity systems such as those implemented in Japan,
2 Singapore, and Israel is to increase registration and donation rates, presumably by introducing a
3 self-interest motive into the donation decision. The effect of these systems, however, remains
4 unclear. Japan's system is limited in scope and thus unlikely to have a significant impact on
5 registration and donation at a national level. Singapore's reciprocity system was implemented in
6 tandem with an opt-out system, and it is thus difficult to assess the independent effect of
7 reciprocity on registration and donation rates. The system in Israel has only recently come into
8 effect, and to our knowledge there are not yet any published data on the effect of the new system
9 on donation rates. A contrast of the Israeli registration and donation rates before and after the
10 new law will eventually provide insight into the impact of reciprocity, subject to the concerns
11 that limit the interpretability of all such natural experiments. That evidence, however, is not yet
12 available; moreover, differences among societies limit the transferability of the results of the
13 Israeli reciprocity system to other countries. Furthermore, it is known that public information
14 campaigns about organ donation are themselves effective in raising donation rates (Feeley and
15 Moon 2009), so it will be necessary to separate the influence of publicity on the new Israeli law
16 from the impact of the new reciprocity policy should an increase in donation registration be
17 observed. In the absence of strong and generalizable empirical evidence of the effectiveness of
18 reciprocity systems on registration and organ donation, we must turn to other sources to
19 determine whether these systems are a viable way to increase donation rates.

20 The ethics of reciprocity systems have been discussed frequently since the early days of
21 organ transplantation, and the approach has both ardent supporters and equally ardent opponents
22 (for a review of this literature, see Chandler et al. in press{Aus: Chandler, Burkell, and
23 Shemie?}; see also Institute of Medicine 2006: 253–59). Those who support reciprocity systems

1 put forward two main justifications. The first is an efficacy argument, in which the claim is that
2 reciprocity systems will increase organ donation rates. The second is a fairness argument, in
3 which the claim is that it is unfair for someone unwilling to contribute to the pool of scarce life-
4 saving resources to take from that pool ahead of someone willing to contribute, and that
5 reciprocity systems reduce this possibility. Counterarguments are raised by those who do not
6 support reciprocity systems. They argue that reciprocity could potentially reduce organ donation
7 by disturbing the altruistic motive that drives many organ donors (Burdick et al. 1993). There is
8 also the suggestion that reciprocity systems, rather than address fairness concerns, might unfairly
9 penalize people with legitimate reasons for their unwillingness to donate, and that these systems
10 may create inequities if donation rates differ across socially divisive lines such as ethnicity or
11 religion, perhaps compounding the disadvantage faced already by socially vulnerable minority
12 groups whose lower willingness to donate is related to that vulnerable status (e.g., Goering and
13 Dula 2004).

14 These discussions among health policy experts, health care providers, ethicists, and
15 researchers are certainly relevant to the question of whether a reciprocity system is an
16 appropriate response to the problem of organ shortage. Arguably more critical, however, is the
17 perspective of the laypeople whose individual decisions about donation registration stand to be
18 influenced. Our recent review of published empirical studies of attitudes toward reciprocity
19 systems (Chandler et al. in press{**Aus: Chandler, Burkell, and Shemie?**}) identified thirteen
20 relevant surveys conducted from the 1980s to date (Batten and Prottas 1987; Kittur et al. 1991;
21 Peters et al. 1996; Jasper et al. 1999; Ahlert, Gubernatis, and Klein 2001; Siminoff and Mercer
22 2001; Oz et al., 2003{**Aus: Please add this reference to the reference list.**}; Bennett and Savani
23 2004; Jasper et al. 2004; Spital 2005; Boulware et al. 2006; Decker et al. 2008; Lavee et al.

1 2010). The surveys vary in the population studied, the type of reciprocity system discussed, the
2 framing of the reciprocity system within the overall study (e.g., whether subjects were to
3 evaluate it alone or in comparison with other potential incentives). Despite this variation, the
4 pattern that emerges from these prior studies is that public reactions to reciprocity systems are
5 fairly evenly split. The average level of support commonly falls around 50 percent, although the
6 studies indicated degrees of support ranging from 25 percent up to 75 percent.

7 The surveys that focused on members of the lay public as respondents are particularly
8 relevant to the current work. Among these is Spital's (2005) survey, in which a group of
9 American adults was asked whether preferred status for registered organ donors was acceptable.
10 Slightly over half (53 percent) responded "yes" or "probably yes," and 41 percent took the
11 opposite position ("no" or "probably no"; 5 percent did not respond). Ahlert and colleagues
12 (2001) found that 73 percent of a group of German university students supported priority for
13 former live organ donors, but only 44 percent supported priority for those who had previously
14 registered their willingness to donate posthumously. Jasper et al. (1999) surveyed a group of
15 American adults about their views on reciprocity systems, finding that on average respondents
16 viewed priority status as slightly better than morally neutral; respondents were, however, split
17 between those who thought it was morally inappropriate (31 percent), morally neutral (24
18 percent), and morally appropriate (45 percent). An interesting result from Jasper et al.'s (1999)
19 study is the suggestion that, among the incentives studied, preferred status would be most
20 effective in increasing registration among nondonors without simultaneously reducing donation
21 among decided donors. Specifically, they found that only 14 percent of self-identified donors
22 indicated they would not donate under a priority system, while 54 percent of self-identified
23 nondonors responded that they would donate under such a system.

1 Guttman et al. (2011) conducted focus groups and interviews in Israel to examine the
2 ethical response of laypeople to the recently implemented reciprocity policy. Participants
3 identified fairness, efficacy, system accountability, and the reinforcement of organ donation
4 decisions as potential benefits of the system. Perceptions of the limitations of reciprocity focused
5 on the erosion of an altruistic motive, increased discrimination and inequity, coercion,
6 disingenuous registrations, bias in the allocation system, selective impact on those predisposed
7 toward registration, and neglect of alternative approaches. These results present a relatively
8 complicated picture of the public response to reciprocity, suggesting that while reciprocity enters
9 into lay public conceptions and discussions of deceased organ donation, support is not universal,
10 and competing considerations (specifically altruistic motivation) are also prominent.

11 Another set of studies does not explore public reactions to reciprocity systems for organ
12 allocation, but instead considers reciprocity-related themes in the organ donation context such as
13 the extent to which people frame organ donation as a reciprocal exchange (Robertson 2007;
14 Schweda and Schicktanz 2009; Schweda, Wöhlke, and Schicktanz 2009; Stijnen and Dijkster
15 2011). These studies indicate that laypeople are sensitive to the principle of reciprocity, or the
16 Golden Rule (“do unto others as you would have them do unto you”: Chandler et al., in
17 press{Aus: Chandler, Burkell, and Shemie?}). In some studies, respondents framed organ
18 donation in terms of reciprocity, suggesting that organs should be allocated only to those willing
19 to donate (Schweda, Wöhlke, and Schicktanz 2009: 2511; see also Bednall and Bove 2011 in
20 relation to reciprocity in the context of blood donation). A metasynthesis of qualitative studies on
21 the public view of posthumous organ donation (Newton 2011) presents a slightly different view.
22 The results confirm that reciprocity, or the Golden Rule, is a common consideration, but this

1 issue is identified less frequently than the notion of altruism as a defining characteristic of organ
2 donation.

3 One important issue not closely examined in previous research is the difference, if any, in
4 reactions to a reciprocity system based on donation intention (e.g., decided in favor of donation,
5 undecided). Although previous studies likely included both decided donors and those undecided
6 on the question of organ donation, few explicitly contrast the perspectives of these two groups.
7 The exception among the studies cited is the exploration by Jasper et al. (1999) of responses to
8 incentives. Their results, however, did not demonstrate any systematic differences between the
9 decided and undecided donors. It is important to understand how these two groups would react to
10 a reciprocity proposal. For example, one concern about reciprocity systems is that they may
11 negatively influence a preexisting donation intention. Donors and nondonors might be expected
12 to evaluate reciprocity differently in terms of fairness, since donors would stand to benefit from
13 such a system, whereas committed nondonors would suffer a negative impact. Previous research,
14 however, provides only limited insight into these and other differences that might arise between
15 donors and nondonors in their reactions to a reciprocity proposal.

16 The present article extends the previous literature in two ways. First, we add to the
17 research on the reaction of the lay public to priority systems for organ donation through a
18 combined survey and focus group exploration of the attitudes of a previously unstudied
19 population: the Canadian lay public. Second, we contrast the views of decided donors with those
20 of respondents holding different perspectives toward donation (leaning toward donation, leaning
21 against donation, decided against donation). In particular, we focus on two questions: do decided
22 and undecided donors believe that a reciprocity system would increase donor registration, and do
23 they think that a reciprocity system is fair?

1 **Survey**

2 **Methods**

3 Ipsos Reid, a Canadian polling firm, was commissioned to conduct an online survey of adult
4 Canadians' attitudes toward organ donation. The survey was completed between June 11 and
5 June 22, 2009, by 2,567 adult Canadians selected from the Ipsos Canadian Online Household
6 Panel.

7 Slightly over half of the respondents (1,325 or 51.6 percent) were female. Participants
8 ranged in age from 18 to 75, with a mean age of 45.5 and a standard deviation of 16.89. For the
9 purposes of analysis, respondents were grouped into four age categories: 18 to 25 (438; 18
10 percent), 26 to 40 (531; 21.8 percent), 41 to 55 (678; 27.8 percent), and over 55 (789; 43.4
11 percent). Another 131 subjects, or 5.1 percent, did not provide their age.

12 Survey respondents were asked to indicate their personal position on whether or not to be
13 an organ donor (220 respondents, or 8.6 percent, did not respond to this question). Among those
14 who responded, half (1,187; 50.6 percent) indicated that they had already signed their donor
15 card, and a further 11.9 percent (280 respondents) had already decided to donate their organs but
16 had not signed their cards. One-fifth of respondents (469; 20 percent) responded that they would
17 "probably" donate their organs, 7.3 percent (172) indicated that they would "probably not"
18 donate their organs, 2.6 percent (60) indicated they would "definitely not" donate their organs,
19 and 7.6 percent (179) responded that it was not possible for them to donate their organs. For the
20 purposes of most analyses, donation decision is collapsed into four groups: signed, decided
21 yes/leaning yes, decided no/leaning no, and unable. To assess the reaction of undecided donors
22 to a reciprocity proposal, we conducted a set of analyses contrasting those who felt they would
23 probably donate (leaning yes) and those who felt they would probably not donate (leaning no).

1 The survey presented respondents with the following description of a reciprocity system:

2 There is a long waiting list to receive organs for transplant, and not every person who
3 needs an organ gets one. One proposal to help address this problem is that patients who
4 have previously registered to donate their organs when they die be given a better chance
5 to receive organs for transplant than patients who have not previously registered to
6 donate.

7 **Results**

8 The analysis of the survey results focuses on a set of questions that assess reaction to the
9 described reciprocity system. Subjects were asked to indicate their responses, on an eleven-point
10 scale from “strongly disagree” (0) to “strongly agree” (10; 5 marked the neutral point), to eight
11 evaluative statements about the described system. Two negatively worded items were eliminated
12 from further analysis because initial results revealed them to be uncorrelated with the other
13 items, and it appeared that only some subjects recognized the negative wording of these items.
14 (The eliminated items were the following: [1] This system would make me less confident that an
15 organ would be available if I needed one; [2] This system would discourage me from signing an
16 organ donor card.) Descriptive results for the retained six items are presented in table 1:
17 responses are collapsed into disagree (ratings of 0 to 4), neutral (ratings of 5), and agree (ratings
18 of 6 to 10). Missing values ranged between 5 percent and 7 percent.

19 **<Insert Table 1 about here.>**

20 Overall, subjects appear to evaluate the system positively. For five of the six positively
21 worded items, the proportion of subjects who agree with the statement is greater than the
22 proportion that disagree, and in some cases the difference is substantial (e.g., 61 percent agree
23 that the system would increase the supply of organs, whereas only 20 percent disagree with this

1 statement). These results, however, should be tempered by the *strength* of the evaluation, as
2 reflected in the average scores as opposed to the frequency counts. Average scores range from
3 6.4 (sd = 2.9) for the statement “This system would increase the supply of organs in Canada” to
4 5.0 (sd = 3.3) for “This system would be consistent with Canadian values”; see table 1 for
5 average scores for all questions. These averages indicate that while *more* subjects agree than
6 disagree with all but the final statement, they are expressing a relatively weak level of
7 agreement.

8 The questions were designed to assess perceptions of both system efficacy and system
9 fairness, with the intention of calculating separate “fairness” and “efficacy” scores for each
10 subject. A factor analysis (a principal component analysis factor{**Aus: OK?**} with Varimax
11 rotation) was carried out to identify whether the items actually fell into the predicted groups or
12 subscales. The factor analysis revealed that three “fairness” items (“this system would be fair to
13 all potential organ recipients,” “this system would be fair to all Canadians,” and “this system
14 would be consistent with Canadian values”) were selectively related to one factor, whereas two
15 “efficacy” items (“this system would increase the supply of organs in Canada,” and “this system
16 would encourage me to become an organ donor”) were selectively related to a second factor. The
17 item “this system would be appropriate given the shortage of organ donors in Canada” proved
18 moderately related to both groups and was therefore not included in either of the subscales, to
19 make them as distinct as possible.

20 Based on the results of the factor analysis, two scores were created for each subject. The
21 fairness score was the average of the responses to the following three items: “this system would
22 be fair to all potential organ recipients,” “this system would be fair to all Canadians,” and “this
23 system would be consistent with Canadian values.” The efficacy score was the average of the

1 responses for these two items: “this system would increase the supply of organs in Canada,” and
2 “this system would encourage me to become an organ donor.” Internal consistency was very
3 high for the fairness scale (Chronbach’s alpha = 0.93), and slightly lower but still acceptable for
4 the efficacy scale (Chronbach’s alpha = 0.79). Because of missing data, we could not calculate
5 scores for a small proportion of subjects (3.2 percent missing values for fairness, and 3.4 percent
6 missing values for efficacy). Average scores for each subscale represented a slightly positive
7 evaluation of the fairness of the described system (average 5.1.; sd = 3.2; scale range from 0 to
8 10, higher scores indicating a more positive evaluation, five representing a neutral response) and
9 a somewhat more positive evaluation of efficacy (average 6.0; sd = 2.9). Fairness and efficacy
10 scores showed a high correlation ($r = .58$), indicating that respondents who felt the system was
11 fair also tended to feel that the system would be effective.

12 ***Fairness***

13 Fairness ratings differed significantly across the four categories of donation decision (signed,
14 decided yes/leaning yes, decided no/leaning no, and unable; $F[3,2824\{\text{Aus: 32,824? Also,}$
15 **should F be italicized?}] = 8.28, $p < .001$), with the signed donors and decided yes/leaning yes
16 groups providing slightly positive ratings (means of 5.2 [s.d., 3.4] and 5.4 [s.d. 3.0], respectively)
17 that are significantly different from the slightly negative ratings provided by those unable to
18 donate and those who had decided or were leaning against donation (means of 4.5 [s.d., 2.9] and
19 4.5 [s.d., 3.1], respectively). Analysis of the undecided respondents only (leaning yes versus
20 leaning no) revealed a similar pattern: those more positively disposed toward organ donation
21 (leaning yes) rated the reciprocity system slightly positively in terms of fairness, whereas those
22 leaning against registration provided a significantly different and slightly negative evaluation of**

1 fairness ($F[1,764] = 16.37, p < .001$), averages of 5.6 (sd = 2.87) for leaning yes, and 4.6 (sd =
2 2.79) for leaning no).

3 **Efficacy**

4 Efficacy ratings also differed significantly across the four categories of donation intention
5 ($F[3,2820\{\text{Aus: 32,820?}\}] = 36.51, p < .001$). As with the fairness ratings, signed and decided
6 yes/leaning yes groups evaluated the efficacy of a reciprocity system more positively (averages
7 of 6.3 [sd = 3.1] and 6.5 [sd = 2.6]) than did the decided no/leaning no and unable to sign groups
8 (averages of 4.7 [sd = 2.7] and 5.0 [sd = 2.7], respectively). When the analysis was restricted to
9 undecided participants, those leaning yes rated the system significantly higher in terms of
10 efficacy ($F[1,761] = 35.87, p < .001$) than did those leaning against donation (average of 6.4 [sd
11 = 2.5] for Leaning Yes, and 5.1 [sd = 2.62] for leaning no).

12 **Discussion**

13 Overall, survey respondents gave a weakly positive evaluation (between 5 and 6 on a ten-point
14 scale with 5 as a neutral point) of a described reciprocity system. They appear somewhat more
15 convinced about the efficacy (average score of 6) as opposed to the fairness (average score of
16 5.1) of such a system. Respondents who have already signed their cards or are leaning toward
17 doing so evaluate the system more positively than those unable to donate, those who have
18 decided not to donate, and those who are leaning against donation. These differences appear in
19 assessments of fairness and assessments of efficacy. When we examine only undecided donors,
20 separating those who are leaning toward donation from those who are leaning against donation, a
21 similar pattern occurs: those less likely to donate (in this case, those leaning against donation)
22 evaluate the system less positively overall, less positively in terms of fairness, and less positively
23 in terms of efficacy. The differences are not huge, nor do respondents ever take a strong for or

1 against position on reciprocity: the most positive of these evaluations (of the efficacy of the
2 system by those leaning toward donation) is an average of 6.4, whereas the most negative (of
3 system fairness by those unable to donate) is an average of 4.5. Nonetheless, they tell a
4 consistent story: the more likely or able individuals are to sign their donor card, the more
5 positive they are about reciprocity: they are more likely to view the system as fair and more
6 likely to believe it would be effective in promoting organ donation.

7 **Focus Groups**

8 The survey results provide an overview of attitudes toward reciprocity systems and allow us to
9 contrast the results from decided and undecided donors. The focus group results provide deeper
10 insights into the reasoning behind the positions expressed in the surveys.

11 **Methods**

12 Focus group participants were recruited with posters placed throughout the campus of a large
13 Ontario university and various locations in the surrounding city, including public libraries,
14 grocery stores, and health clinics. The posters provided a brief description of the research project
15 and explicitly requested participation from decided donors and from those undecided on the issue
16 of organ donation.

17 Ten groups were convened in June and July 2010. Each session lasted between one and
18 two hours. A minimum of two participants was invited to each group, but in many cases some of
19 the invited participants did not attend, and the actual size of the focus groups ranged from one to
20 nine participants. We attempted to separate decided and undecided donors into different groups
21 to minimize the impact of social desirability on discussions, but were only partly successful. Five
22 groups included only decided donors, one group included only undecided donors, and four
23 groups included both decided and undecided donors (usually with a preponderance of undecided

1 individuals in the group). We are not concerned that the inclusion of a small number of decided
2 donors in these groups limited the focus group content. Discussion in all groups was open, the
3 tone was respectful and tolerant, and all participants seemed to be equally engaged; in fact, the
4 presence of some decided donors prompted exchanges that could not have occurred in the
5 planned divided groups.

6 Forty-six individuals participated in the focus groups, ranging in age from eighteen to
7 fifty-six (median age of thirty). Twenty-one of the participants were male. Among the
8 participants, twenty-eight had made the decision to donate their organs, seventeen had not yet
9 decided whether to donate, and one individual decided against donation for cultural reasons (this
10 was despite explicit recruitment for individuals who were undecided or had already decided to
11 donate). The participants included one individual on the transplant list and that person's spouse
12 (both decided donors), who were interviewed in a separate group.

13 Each focus group discussion was facilitated by one of the lead researchers, following an
14 interview schedule that covered three key topics: the registration decision itself, including the
15 factors that influence the donation decision; participant perceptions of the factors affecting organ
16 allocation and the likelihood of needing and donating organs; and perceptions of and reactions to
17 a reciprocity system proposal. The results reported in this article focus on the last topic, though
18 relevant comments raised throughout the focus groups are included here as appropriate.

19 Focus group participants were alerted in the recruitment materials that one of the focus
20 group topics was a reciprocity proposal. The researchers provided a brief description of a
21 reciprocity system to the participants. Respondents were told that a reciprocity system offered
22 priority to registered donors if all other considerations (particularly urgency of need and medical
23 compatibility) were equivalent. Thus, under a reciprocity system, a prior donation decision

1 would provide a “tiebreaker” in organ allocation decisions. During the discussion that followed,
2 participants were encouraged to consider the effectiveness and fairness of such a system.
3 Existing priority systems, specifically the system in Israel, were briefly described to participants.
4 Toward the end of each discussion, a specific scenario was introduced: that of individuals who
5 indicate that they would accept an organ transplant but would not agree to donate their organs for
6 transplantation.

7 Focus group recordings were transcribed with the consent of participants, and all
8 identifying information was replaced with pseudonyms. A grounded theory approach was used
9 for analysis, and open coding techniques were employed to identify concepts and themes in the
10 focus group responses related to the primary research questions.

11 **Results**

12 ***Fairness***

13 During the discussions, many participants were uncomfortable with the notion that someone
14 might decide not to register as an organ donor despite being willing to accept an organ if needed:
15 throughout this discussion we identify this adherence to a principle of reciprocity as the Golden
16 Rule (see Chandler et al., in press{**Aus: Chandler, Burkell, and Shemie?**}) to clearly
17 distinguish it from the formal reciprocity system under discussion.

18 Willingness to accept an organ but not to donate was characterized negatively by many
19 participants, who described this position as *greedy* (Jason, male, 18, decided), and *selfish*
20 (Sydney, female, 36, decided). Others used such words as *bad*, *self-centered*, *weird way to think*,
21 *mind-boggling*, *inconsistent*, *hypocritical*, *warped view of the world*, and *silly*. Jenny (female, 18,
22 undecided) asked, “How’s it right to get your back scratched, when you’re not scratching the
23 other’s back?”

1 For some participants, the possibility that some people might take this position was
2 sufficient to garner support for a reciprocity system. George (male, 29, decided) fell into this
3 group:

4 I think I would prefer [a reciprocity system] because although I don't understand
5 everyone's belief, I can't really fathom a belief where you would not be comfortable
6 having your organs going to someone else when you died, but it's OK, you would feel
7 clearly normal to have someone else's organs inside you when you were alive?

8 Among most focus group participants, however, endorsement of the Golden Rule did not
9 translate directly and necessarily into support for formal reciprocity system. Jenny (female, 18,
10 undecided), for example, initially was very much against a reciprocity system, although she
11 identified the importance of the Golden Rule as a principle:

12 I wouldn't say that, if I'm not donating, I would want an organ when I need it. I think I
13 wouldn't take it. Just because I'm not donating, and I have specific reasons for it, and I
14 don't think I would be right in taking an organ when I'm not donating it, in my head. . . .
15 Instead I would rather give it to some other person who's in more need than me, or who's
16 in less need than me, just because I didn't donate any organ.

17 After a discussion of specific situations in which religious considerations lead some
18 individuals to be willing to accept organs but still refuse to donate, she changed her position,
19 expressing support for a reciprocity system:

20 In that society, I guess it is right, because some people are too religious but they're saying
21 "yeah we'll take all the organs you'll give us, but we're not giving you any organs," and I
22 don't think that is right. So putting in priority is right in that society.

1 Stuart (male, 39, undecided), like Jenny, was steady in his opposition to a reciprocity
2 system until he was asked to consider specifically individuals who would take but not give an
3 organ. At that point, he shifted his position slightly, but he was clearly uncomfortable with the
4 change:

5 It sounds awful to say, you almost want to say well they [people who would accept but
6 not donate] should be knocked down a couple of notches, but you don't want to say it to
7 anyone though. So you got that kind of mixed feeling, you don't want to ever say to
8 someone, oh you're not deserving, that's just mean and awful to say that, but part of you
9 says, well, you're not being very nice, so . . . you know what I mean? You don't ever
10 want to say it to anyone, but I guess emotionally you feel that they're not as deserving,
11 but then you look at the whole fairness thing again and even though they're like that
12 they're humans and everyone can be deserving, so . . . yeah, I'd say it's more acceptable.
13 It kind of changes it. You don't want to hurt anyone, but I think if someone's definitely
14 not willing to help anyone else and only themselves. . . . I think I'm definitely starting to
15 lean a little more towards saying—it doesn't feel right doing it, if you ever knew anyone
16 who needed an organ you'd probably feel really badly, but I can definitely say I'm
17 leaning more toward a priority system then, especially when you put a label on it.

18 In contrast, Marley (male, 24, decided) remained ambivalent about a reciprocity system
19 while acknowledging the importance of the Golden Rule:

20 They want to take something from someone else but they don't want to give anything up
21 to . . . so, like, I'm still hung up on more or less thinking past this priority system
22 . . . even the term priority system is misleading to a certain extent—even though that's
23 exactly what it is. It is putting someone above someone else because they've chosen to go

1 a different way, but . . . should that be a deciding factor? I think so, I don't think so, like
2 I, you know, internally battling myself here.

3 Some participants endorsed the Golden Rule, but noted that "giving back" could be
4 realized in ways other than donor registration. Participants who raised this issue felt that a
5 reciprocity system would unfairly penalize these individuals who were making important
6 contributions in ways other than registering as an organ donor. The following comments by
7 decided and undecided participants exemplify this position:

8 I think, though, . . . they can still donate in other ways, like give money toward research
9 or support for things, so that's why I think [a reciprocity system is] a bit iffy myself.

10 (Mavis, female, 46, undecided)

11 Are they contributing members, like are they just . . . like do they give . . . well that's
12 . . . what I was going to say is like do they give back in other ways, like are they involved
13 in like committees, or helping kids go to school, or if they're like helping kids in
14 developing areas or countries? (Natalia, female, 30, decided)

15 But then I go to thinking, why is [registration] the deciding factor? What if one person
16 has spent their entire life giving to charity and building bonds and all that good stuff, and
17 the other person has just lived, I don't know, a normal life not really giving so much but
18 they decided to give an organ. So like why is giving the organ the deciding factor in this
19 case? (Jill, female, 22, decided)

20 This sensitivity to the possibility of various forms of "giving back" was evident in both decided
21 and undecided donors, leading in these cases to a reluctance to support a formal reciprocity
22 system for organ donation.

1 Much of the discussion of reciprocity focused on why someone might not be registered as
2 a donor. Implicit in these discussions were two considerations that in general led to reduced
3 support for a reciprocity system: a reluctance to “punish” those who had actively decided to take
4 but not donate or those who were precluded from donating, and the perspective among some
5 participants that some reasons for refusal were “legitimate.”

6 We noted that participants who cast *themselves* in the role of making organ allocation
7 decisions (reflected, for example, in the use of personal pronouns when discussing priority
8 decisions) were generally uncomfortable with the notion of reciprocity, expressing their
9 discomfort with the judgment implicit in the reciprocity system. Ron (male, 53, undecided), for
10 example, remarked, “I wouldn’t make it my choice to decide who gets it because they don’t
11 choose to donate” when discussing his lack of support for reciprocity. This reaction was more
12 common among decided donors, perhaps because they were more likely to think of themselves
13 as the “decision makers” in the position of “giving” priority in organ allocation under a
14 reciprocity system. The comments of Sydney (female, 36, decided) and Ben (male, 18, decided)
15 were typical of this perspective:

16 I wouldn’t be able to decide which one got it because they still should be both equal
17 . . . just because one didn’t make that decision shouldn’t give anyone more that much
18 more priority. Maybe at that time in their life . . . they had their donor card, they didn’t
19 want to but I don’t know, maybe someone stopped them, or it doesn’t mean like, not in
20 their heart they didn’t want to do it. (Sydney, female, 36, decided)

21 Well, honestly, given the choice I would still rather my organs go to them . . . and I don’t
22 agree with any kind of low priority system. . . . their reasons are their own. I’d still rather
23 be able to help them. (Ben, male, 18, decided)

1 These comments were not inconsistent with or separate from support for the Golden Rule as a
2 principle. Instead, participants were simply uncomfortable with a reciprocity system that would
3 invoke consequences for decisions inconsistent with the Golden Rule.

4 Some participants raised the concern that a reciprocity system could be unfair to those
5 unable to donate:

6 Like I don't know about the fairness of that, because the other person who wouldn't sign
7 up, might not have access to the sign-up center, so he or she wasn't able to sign up
8 earlier, so it doesn't mean that they didn't want to donate, it just means that they didn't
9 have the access, the opportunity. (Karen, female, 22, undecided)

10 Benoit (male, 20, undecided) brought up the issues of ineligibility to donate, noting that this is a
11 justifiable reason for not registering:

12 The only one that I see as really justified is medical reason. If you choose not to want to
13 donate then it's kind of greedy to say that I should be on equal in terms of getting it. So I
14 think it is really fair except for the people who are excluded for medical reasons.

15 When the issue of ineligibility or lack of opportunity to register was raised in the focus groups,
16 there was general agreement that a reciprocity system would have to be designed so as to
17 eliminate any potential negative consequences for individuals in these positions.

18 With respect to other reasons for nonregistration, reactions were more mixed. Ron (male,
19 53, undecided) supported religious and cultural reasons as sufficient justification for refusal to
20 register:

21 Maybe there's religious reasons is why he doesn't want to donate, so you know I can't
22 judge anyone, their reasoning behind it. You know, is it fair? 'Cause he doesn't want to

1 donate his and I don't know what to think. . . . It might be they don't want to have their
2 body violated after they're dead or something, I don't know.

3 Justin (male, 47, undecided) was willing to support an even greater range of reasons:

4 The last one you said that if someone donates they're more likely, they're more of a
5 candidate. . . . I don't agree with that . . . I don't think it's fair. Some people, like for
6 religious beliefs, don't donate, and other people their culture doesn't believe it, and some
7 people just don't do it because they don't think it's right or whatever, I don't think that
8 should be a factor. . . . I think that would be unfair.

9 In general, religious and cultural factors were identified as "better" reasons for refusal than was
10 squeamishness. Karen (female, 22, undecided), reflected the position of many participants when
11 she indicated that not wanting to think about organ donation "is not a good reason for you not to
12 donate, to take someone else's instead."

13 Some decided participants insisted that a decision not to donate, irrespective of the
14 motivation, was not sufficient to justify lower priority. Patricia (female, no age given, decided)
15 reflected this perspective when she commented, "That's their body, they can do whatever they
16 want with it." Arlene (female, 55, decided) remarked:

17 Arlene: Maybe the person would like to save their own life, and so they would accept
18 one, they don't have a problem with the concept, but they're just too squeamish or too
19 afraid or nervous if they need their organs in the afterlife or if it would hurt them in some
20 way. Or if it would freak out their family. You don't know what's behind it.

21 Researcher: And that's, all that's OK?

1 Arlene: Yeah, I think if you're looking at it, selfless gift, you can't make too many rules,
2 you know?

3 Ben (male, 18, decided) thought that "whether they're being selfish or if they're just
4 squeamish, I just have a problem with thinking that it should affect their priority either way."

5 Patricia (female, no age given, decided) felt that reasons for not registering were simply
6 irrelevant:

7 It's their own decision . . . I mean, they have their own personal beliefs. Their own belief
8 system, so I guess you can't really judge them or point a finger or anything like that.

9 These participants were simply unwilling to accept a reciprocity system under any
10 circumstances. Interestingly, the participants who took this position were all decided donors.

11 Relatively few participants explicitly identified that reciprocity might increase or even
12 create religious or culturally based discrimination. When these concerns were identified, they
13 tended to come up in the context of discussion of the reciprocity system in Israel, which
14 differentially affects members of the secular and ultra-orthodox Jewish communities. Maggy
15 (female, 19, decided) felt that in this context the system "could create even more tension if
16 . . . every time two people came up for the part, the secular Jew got it." Eduard (male, 29,
17 undecided) raised the concern that a reciprocity system "might actually cause a little bit of a
18 problem because some people could consider [it to be] segregation," and he specifically focused
19 on the situation of Palestinians within Israel, although there had been no prior group discussion
20 about donation rates among the Palestinian community in Israel. Beth (female, 36, undecided),
21 indicated that the reciprocity system could "actually serve to stigmatize certain groups," whereas
22 Lola (female, 21, undecided) remarked that the reciprocity system in Israel could "elevate
23 religious issues." For some respondents, including Mavis (female, 46, undecided), reciprocity

1 was viewed as potentially coercive, representing a threat to the right to hold individual beliefs,
2 including religious beliefs:

3 I don't think people should be forced to go against their religion, I mean, for instance
4 Jehovah's Witnesses, I don't agree with all their kind of beliefs around health and blood
5 transfusions and things but there's no way that I wouldn't support what they want as long
6 as it's reasonable.

7 **The Consequentialist Argument**

8 Harold (male, 47, who is on the waitlist for an organ transplant) and his partner, Amelia (female,
9 48, decided), were immediately and emphatically in support of a reciprocity system. Their
10 discussion focused largely on the availability of organs, and Harold cast reciprocity as one
11 strategy that would help achieve the goal of an adequate supply of organs for transplantation. For
12 him, the argument was largely consequentialist: he firmly believed that there would be sufficient
13 organs available for transplantation if those Canadians who express interest in donation but have
14 not actually signed their cards were to commit to being donors, and he saw reciprocity as a way
15 to further this goal. Harold would like to see organ donation become a social norm, and he
16 believes that a reciprocity system might help achieve this outcome.

17 If you did a graph between the, the accidents that happen and those sort of raw numbers,
18 and then did a similar graph . . . the people that say they would yet don't actually engage,
19 my guess is if, and maybe I'm wrong, but it just seems to be the match would be easily be
20 there. Just by the population in our country anyway there'd be an easy match for all the
21 supply that you would ever need. People actually just took the time to fill in the right
22 paperwork so that the right thing happened when it had to. And you mentioned
23 reciprocity, um, I don't know if there's some little checkmark that you get against your

1 name in your driver's license, you know that if you're, if you need a kidney later in life
2 because you've been on the organ list since age 3, you know, that you, you know, you're
3 up in the, up in the chart to receive. . . . I just think the numbers would [be there].

4 This same efficacy argument was raised by other participants. Lola (female, 21,
5 undecided), for example, remarked:

6 It's fair because by looking into a longer period of time, people who are in need of organs
7 would benefit, eventually, so I think there would be a long-term benefit.

8 Lewis (male, 21, undecided) took a similar position.

9 I think my first thought is it would be a fair system because it would increase the odds of
10 an organ being donated. . . . If you look at it in a long span of time then you'd find there
11 would be more organs available for those in need, so it's a very good system. . . . It's fair
12 because by looking into a longer period of time, people who are in need of organs would
13 benefit . . . eventually.

14 Although these participants identified efficacy as a strong argument in support of
15 reciprocity, others (decided and undecided) were more circumspect in their evaluation. Kyle
16 (male, 28, decided) expressed a cautious willingness to support a reciprocity system provided
17 that it decreased the discrepancy between donation support and registration by encouraging more
18 registrations:

19 I think I would support it if it could be, like if your actuarial scientists could demonstrate
20 that this system would decrease that discrepancy, so then I would agree with it.

21 Mason (male, 22, undecided) was somewhat equivocal in his opinion about the fairness of a
22 reciprocity system, but eventually he identified efficacy as sufficient justification for his support:

1 Yeah, it's hard. I'm not a very yes, very no, but maybe more toward the yes. Like
2 [George] said, it's good because it encourages people to make organ donations, which
3 obviously benefits our health care system. . . .

4 I think something that makes people less inclined to donate is that if, let's say the
5 majority of the population does not give, donate their organs, then they would feel like an
6 outlier sort of or, "why would I have to give up me organs if most people don't do this
7 altruistic thing?" But if that sort of shifts and most people are doing it then it would
8 probably pick up in popularity, which is obviously good.

9 Efficacy obviously mattered to both Kyle and Mason in their evaluation of a reciprocity system,
10 but although they might regard the system as justifiable on the basis of its positive consequences,
11 this did not necessarily mean they viewed the system as "fair."

12 **Efficacy**

13 One focus of discussion was the "suspect" nature of the self-interest motivation that reciprocity
14 would introduce, with the attendant concern, expressed by some participants, that this could have
15 a negative effect on donation registration. Natalia (female, 30, decided) was concerned that
16 reciprocity

17 kind of takes away from the purpose of it, it's like giving an organ should be a thankless
18 thing, you should just do it and not have to worry about getting the gratuities after it, or
19 getting the benefits, or, and . . . if you donate it's not like you're getting a prize and
20 therefore you should be able to get the organ before Jane Doe does because she did give.
21 It takes away from the whole goodness.

1 Her comment triggered similar responses in other members of the same focus group (all
2 decided). Arlene (female, 55, decided), for example, was concerned about the impact on decided
3 donors (herself included):

4 I agree with you because I think that's the, negate all the good feelings you would get
5 throughout your life knowing that you had committed and you had said that you'd donate
6 and that was so selfless and all of a sudden there's an attachment of, "hmmm, I'm going,
7 this could do well for me, so I'd better look after myself," you know, sort of thing? It
8 takes away that feeling, and I think that feeling is really important in humanity and I
9 wouldn't like to see that taken away.

10 For some decided donors, however, questions about the "rightness" of the motivation for
11 donation were secondary to utilitarian considerations:

12 I think that [reciprocity] brings up almost an ethical debate in that sense because maybe
13 you'll get more people registering for the quote unquote wrong reasons but in the end,
14 who cares? Right? So I mean it comes down to whether you're comfortable being like,
15 "uhhh, I only want to give because I want to get." But I mean I personally don't care, if
16 you're going to give your organs, that's great. (Jill, female, 22, decided)

17 Introducing reciprocity raises the specter of *selfishness*, according to Marley (male, 24,
18 decided):

19 It almost seems really selfish to be honest because you weren't willing to donate in the
20 first place, even though you could possibly save someone's life, but as soon as the tables
21 are turned and, you're going to be looked at higher than someone than someone{**Aus:**
22 **Delete the repeated "than someone"?**} who hasn't, then you all of a sudden want to

1 jump on the bandwagon and be there next in line, sort of, because you don't know when
2 you're going to need an organ. You could need it the second after you check your box
3 off, and now you're automatically on the same plane as someone else, so, yeah, I don't
4 know, it just seems more or less like a selfish act.

5 Concerns about the "pollution" of an altruistic motivation for donation were more
6 commonly expressed by decided donors, but some undecided donors also discussed this issue.
7 Stuart (male, 39, undecided), for example, was also concerned about *selfishness*:

8 Researcher: So, who's being selfish?

9 Stuart: Uhhh, the people that are donating, or are thinking of donating. Because they're
10 like, "well you know, oh well then I can get one too, I'm on a higher list if anything was
11 going to happen to me." It's kind of like, you're actually not really giving, but you're
12 giving but you're expecting something in return. So it's not that free giving.

13 Although he was undecided about donating his organs, when he considered organ donation
14 Stuart thought of himself as a *donor*, and reciprocity made him uncomfortable because he would,
15 under that system, be unable to *give freely*.

16 One important question about a reciprocity system is whether it would affect the
17 commitment of decided donors. Many participants who had already decided to sign their donor
18 cards indicated that the introduction of a reciprocity motive for signing would not influence
19 them, one going so far as to say, "If we did put that system in place . . . obviously it would not
20 affect my decision" (Harmony, female, 22, decided). Some decided donors viewed reciprocity-
21 motivated decisions as morally suspect, compromising or even "mocking" the common
22 motivation for organ donation: Arlene (female, 55, decided) epitomizes this perspective in

1 deeming reciprocity an “improper” motive for organ donation. This distaste did not, however,
2 translate into the feeling that a reciprocity system would change the decision of decided donors.
3 In fact, our focus group participants provided no support for the notion that introduction of a
4 self-interest motivation for organ donation could disturb the intentions of altruistically motivated
5 donors: no decided donors among the focus group participants expressed the sense or concern
6 that they or other decided donors would change their decision to donate should a reciprocity
7 system be introduced. Instead they tended to affirm that their decision to donate would remain in
8 place.

9 Some undecided donors reflected on how such a system might influence their own
10 donation decisions, revealing mixed predictions about the impact of such a system. Among focus
11 group participants, Mason (male, 22, undecided) was the only undecided donor who explicitly
12 indicated that a reciprocity proposal would positively influence his own decision to register.

13 Yeah, I’d be more inclined to sign . . . and I think other people would too, I think there is
14 a reasonable assumption there.

15 Emily (female, 22, undecided) and Stuart (male, 29, undecided) both noted that they would be
16 motivated to sign by a reciprocity system that extended priority to family members. Neither,
17 however, indicated that priority for themselves alone would influence their decision. One
18 undecided donor (Mavis, female, 46) remarked that a reciprocity system would make her less
19 likely to donate. She indicated that such a system would “put her off”: this followed her assertion
20 that if she were to decide to donate her organs, she would do it “wholeheartedly, freely, with no
21 agenda.” Beth (female, 36, undecided) asserted that a reciprocity system would have no effect on
22 her decision. She commented that, for her, the organ donation decision is an emotional one,

1 noting that she fears the process of donation. She indicated that although she has a “sense of
2 reciprocity,” a priority system

3 wouldn’t deter me, but it wouldn’t encourage me, and I wouldn’t say to my sister “if you
4 were sick, well, you better go check off . . . get more points.”

5 Only one among the undecided donors indicated that he would be motivated to sign a donor card
6 by a reciprocity system that provided direct priority status (rather than priority status for family
7 members); we cannot, however, rule out the possibility that the social undesirability of admitting
8 to self-interested behavior may have affected the responses of focus group members.

9 Reflections of the effect of reciprocity on the decisions of *others* were also offered by
10 some decided and undecided participants. Although the *presumption* of an effect was implicit in
11 much of the discussion, we focus here on explicit discussion of the impact of reciprocity on the
12 decisions of undecided donors.

13 Among those decided donors who commented on effectiveness, there was a tendency to
14 think that a reciprocity system would encourage registration among at least some undecided
15 donors. This presumed effect was attributed to a self-interest motive. George (male, 29, decided),
16 for example, remarked that people “on the tipping point” would be more likely to sign up under
17 such a system “out of self-preservation or also to have priority and not hurt their own chances”;
18 Ben (male, 18, decided) phrased it as “an insurance idea . . . looking after yourself as opposed to
19 trying to help others.” Laura (female, 18, decided) elaborated, suggesting that reciprocity would
20 encourage undecided donors to consider their position as potential *recipients* of organs as well as
21 potential *donors*, presumably resulting in an increased likelihood of registration to improve their
22 chances of receiving an organ:

1 It's making things more real, right? Like it's putting you in both positions of like being a
2 donor and a recipient, but like it's focusing more on using yourself as a recipient when
3 they do say that if you are a donor you'll get priority. So I think it makes a little
4 difference.

5 Maggy (female, 19, decided) was unique among decided donors in that she explicitly
6 noted that the *reason* for refusal could determine the impact of a reciprocity system:

7 It might work with some people, like people who are just indecisive and hadn't taken the
8 time or effort to do it. But some people who are devoutly religious and stuff, I don't think
9 that would change their perception.

10 Sydney (female, 36, decided) noted that a reciprocity system is "asking people to be pragmatic
11 about it, so you are only getting a portion of the population that will look at it in a commonsense
12 way," implying that many do *not* take a "common sense" approach to the question of organ
13 donation. Her comment reflects Beth's characterization of the donation decision as *emotional*,
14 and thus (presumably) not subject to the sort of logical analysis that would lead undecided
15 donors to register under a reciprocity system.

16 Comments from undecided donors on the impact of a reciprocity system reflected
17 Maggy's nuanced position. Jenny (female, 18, undecided), for example, discussed the different
18 effects on potential donors influenced by self-interest and by other considerations. Her initial
19 response was as follows:

20 Maybe more people will sign up just because they want to be sure that they will get an
21 organ if they need it.

22 She remarked shortly afterward that

1 people who are truly religious are not going to change their mind if you put a policy in
2 place.

3 Jenny’s comments may reflect her personal position, since her reluctance to donate was partly
4 rooted in cultural considerations. Stuart (male, 39, undecided) also felt that the policy would
5 influence “people on the selfish side,” but not those who (like himself) are very squeamish about
6 the idea of donation, noting that “it is hard to get past that ‘ick’ factor.”

7 Thus the comments of decided and undecided donors on the influence of reciprocity
8 systems on the decisions of others reflect the same themes: the feeling that the system would
9 increase donation among those who could be motivated by self-interest, but would be less likely
10 to influence those whose indecision is motivated by considerations such as squeamishness or
11 religion. The two groups differ in the emphasis they place on these two perspectives: whereas
12 decided donors tended to focus on the positive impact of reciprocity on donation decisions,
13 presuming that the self-interest motivation could be prompted in many if not all undecided
14 donors, undecided donors were more likely to explicitly indicate that undecided donors for
15 whom squeamishness or religious and cultural considerations were paramount would be unlikely
16 to be influenced by a reciprocity system.

17 **General Discussion**

18 We set out to explore the reaction of the lay public in Canada to a reciprocity system for organ
19 donation, including an examination of the responses of decided versus undecided donors. Our
20 particular focus was on perceptions of the fairness and efficacy of such a system.

21 Our survey results provide no evidence of a strong reaction—positive or negative—to the
22 fairness of a reciprocity system. Average evaluations of fairness are very close to the neutral
23 point (average score 5.1; neutral point on the scale 5). There is a slight but significant tendency

1 for those who have decided to donate or who are leaning toward donation to rate the system as
2 more fair, but even the strongest positive evaluation of fairness (among those undecided
3 participants leaning toward donation) moves very little above the neutral point (to 5.6, maximum
4 on the scale of 10). The focus group results revealed a complicated set of fairness considerations.
5 For some participants, presumed efficacy was enough to justify a reciprocity system; these
6 participants took a utilitarian perspective on the question of the justifiability of a reciprocity
7 system. Consistent with previous research (Newton 2011; Schweda, Wöhlke, and Schicktanz
8 2009), the principle of reciprocity figured prominently in focus group discussions. However,
9 whereas most participants agreed that it was unfair to accept an organ while being unwilling to
10 donate, thus endorsing the reciprocity principle, few were comfortable with the seemingly
11 natural extension to the idea that a formalized reciprocity or priority system was, therefore, fair.
12 Instead, their comments tended to focus on the notion of autonomy (undermined, in their
13 estimation, by a reciprocity system), the introduction of a self-interest motivation into a decision
14 otherwise characterized as altruistic gift-giving, and discomfort with applying reciprocity-based
15 moral judgment in organ allocation decisions. The last of these prompted a significant amount of
16 discussion. One concern was the potential for *inappropriate* judgment: participants were worried
17 that a reciprocity system might inappropriately punish individuals with legitimate reasons for
18 refusal to donate. There was also, among decided participants in particular, a reluctance to
19 engage in imposing transplant-related consequences for organ donation decisions. In this case, it
20 was the very *process* of judgment, rather than the *basis* of judgment, that evoked discomfort.
21 This is reminiscent of recent experimental results by Stijnen and Dijker (2011) suggesting that
22 need (for an organ) aroused forgiveness for “free riding.” Where discussions focused on the

1 details of the implementation of a reciprocity system, there was concern that reciprocity might
2 result in discrimination.

3 Across all respondents, ratings of efficacy appear to be more positive than ratings of
4 fairness (average score of 6), and the responses of all groups except the combined Leaning
5 No/Decided No group were positive (i.e., above 5 on the scale). The survey results indicate that
6 those more positively disposed toward registration (donors, those leaning toward donation) tend
7 to evaluate more positively the efficacy of such a system in increasing organ donation rates. In
8 particular, those Leaning Yes evaluate efficacy more positively than do those Leaning No,
9 suggesting that the system might be more effective in increasing registrations among the former
10 group. The focus group results provide some additional insight into the effect of reciprocity on
11 registration decisions. Those results suggest that decided donors and undecided donors alike
12 acknowledge that undecided donors whose reservations about donation relate to religious or
13 cultural factors and those who are deeply disturbed by the notion of organ donation are *unlikely*
14 to be motivated by a reciprocity system. The effect of such a system, participants suggest, would
15 be limited to undecided donors without such deep objections, who are therefore susceptible to a
16 self-interest motivation. If we consider the self-interest motive to be “rational,” and squeamish
17 reactions (in particular) to be emotional, this is consistent with research suggesting that the organ
18 donation decision is driven by emotional, rather than rational, factors (Morgan et al. 2008;
19 O’Carroll et al. 2011). Whereas decided donors were more likely to think that a self-interest
20 motivation would encourage registration by undecided donors, undecided donors (who
21 presumably have a greater understanding of the perspective) were less likely to identify this
22 motivation as likely to influence their decisions or that of other undecided donors. This
23 difference could be due to the influence of social desirability, which might lead undecided

1 donors to be reluctant to attribute to other undecided donors or themselves a responsiveness to
2 reciprocity resulting from self-interest.

3 Our data provide no support for the contention that a reciprocity system might disturb the
4 intentions of decided donors. The general perspective among decided donors was that, even if a
5 reciprocity system was slightly distasteful in that it introduced an element of self-interest into
6 what was for many a decision bereft of personal consideration, reciprocity would not negatively
7 affect their donation decision. With respect to evaluations of fairness and efficacy in increasing
8 registrations, we might predict that decided and undecided donors would evaluate a reciprocity
9 system differently, since the system would have different implications for the two groups. The
10 survey results, however, do not show a significant difference between the responses of those who
11 indicate they have signed a donor card and those who indicated they have decided to donate or
12 are leaning toward donation. Instead, reaction to a reciprocity system seems to be related to the
13 *valence* of donation intention, with those leaning toward donation evaluating the system more
14 positively than those leaning against donation. In focus group discussions, decided and
15 undecided donors differ in the emphasis they place on the impact of self-interest and other
16 factors (cultural, religious, squeamishness) on the decisions of undecided donors. Decided
17 donors tended to focus on the positive impact of reciprocity on donation decisions, highlighting
18 the self-interest motive that the system would enhance, whereas undecided donors tended also to
19 reflect on the limits of a self-interest motive, discussing situations in which reciprocity would not
20 affect decisions.

21 This research reveals a rather complex and ambivalent public attitude toward reciprocity
22 systems. Respondents invoked different forms of moral reasoning based on principles of
23 distributive justice (which for some suggested that organs should be allocated preferentially to

1 those who demonstrated their willingness to donate, but for others suggested that allocation
2 ought not to be based on this judgment of the recipients' behavior), as well as on
3 consequentialism (which led some to support reciprocity systems in the belief they would
4 increase registrations but led others to reject reciprocity systems in the belief it would discourage
5 registration or lead to social divisiveness). Moreover, this analysis takes place within a society in
6 which the dominant framing of organ donation is as an altruistic gift (see, e.g., the Ontario
7 governmental website Trillium Gift of Life)—a default frame that may make Canadians
8 predisposed to regard a reciprocity system as inappropriate, as it is clearly inconsistent with an
9 altruistic gift model.

10 This research provides a description of lay public reactions to a hypothetical reciprocity
11 proposal. Although reactions to hypothetical scenarios are less than perfectly predictive of actual
12 attitudes or behaviors (Lerman et al. 2002; Vallone et al. 1990), reactions to hypothetical
13 scenarios have proved useful in various health care contexts to provide some insight into how
14 people will behave or decide in the actual situation (e.g., Hughes and Huby 2002; Strasser and
15 Damrosch 1992; Van Citters, Naidoo, and Foti 2007). The rather modest predictions of subjects
16 in the current study about the effectiveness of a reciprocity system in increasing donation rates
17 should make policy makers cautious if the system is also associated with countervailing costs
18 (e.g., in increased complexity of the system). In addition, it does not appear that a strong moral
19 judgment in support of reciprocity based on the Golden Rule or quid pro quo is elicited among
20 research participants (at least by the simple description of a reciprocity system provided in our
21 survey). Instead, survey respondents offer a neutral evaluation of fairness, and focus group
22 participants identify various fairness-related concerns about a reciprocity system. As we note in
23 Chandler et al. (in press{Aus: Chandler, Burkell, and Shemie?}), there may be broader societal

1 risks in adopting reciprocity policies. The policy creates a distinction between donors and
2 nondonors that may reflect and perhaps deepen other social divisions (such as ethnic or religious
3 divisions) or reinforce a minority group’s sense of outsider status. These risks, and the weak
4 support for the fairness and efficacy of reciprocity systems demonstrated in the present research,
5 cause us to doubt the advisability of adopting a reciprocity system in Canada. We note that the
6 recent adoption of a reciprocity system in Israel provides a useful future opportunity to assess the
7 actual effects—positive and negative—of a real reciprocity system. This may inform future
8 organ donation policy making. Meanwhile, the strong endorsement in our focus groups of the
9 Golden Rule as a principle of moral reasoning for organ donation and transplantation might offer
10 another way to encourage the public to register to donate. Appeals to the principle of reciprocity
11 are used in public messaging in the context of blood donation, and future research could explore
12 whether a similar message is useful for increasing registration rates in the context of organ
13 donation (Chandler et al., in press{**Aus: Chandler, Burkell, and Shemie?**}).

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15 study of public reactions to priority systems in Canada.

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18 **Table 1.** Reactions to Proposed Reciprocity System

	Agree	Neutral	Disagree	Average (sd)
This system would increase the supply of organs in Canada.	61%	19%	20%	6.4 (2.9)
This system would encourage me to become a registered organ donor.	52%	18%	30%	5.7 (3.5)
This system would be appropriate given the shortage of organ donors in Canada.	54%	17%	29%	5.8 (3.3)

This system would be fair to all potential organ recipients.	46%	17%	37%	5.2 (3.4)
This system would be fair to all Canadians.	44%	16%	39%	5.1 (3.5)
This system would be consistent with Canadian values.	37%	20%	43%	5.0 (3.3)