

## Section 2: English Abstract

### Full title of research project

Increasing organ donations in Israel: Models that incorporate public preferences

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### Key Words

Organ donations, public preferences, kidney transplantation, allocation policy, medical efficiency, equity

### Abstract

An abstract of up to **300 words** should include these headings: (1) Scientific Background (2) Objectives (3) Methodology (4) Findings (5) Conclusions (6) Policy Implications / recommendations

**Scientific Background:** There is a gap between the number of patients awaiting deceased-donor organ transplants and the rate at which organs become available. Though organs for transplantation are a community resource, and the organ supply depends on public willingness to donate, current allocation schemes do not explicitly incorporate public preferences.

**Objectives:** This paper seeks to provide insights about the Israeli public's preferences regarding criteria for organ allocation, and to determine whether these preferences are in line with current allocation policies.

**Methodology:** A market research company administered a telephone survey to 604 adult participants representing the Jewish-Israeli lay public (age range: 18–95; 50% male). The questionnaire comprised 39 questions addressing participants' knowledge, preferences regarding organ donation and allocation, and willingness to donate.

**Findings:** Maximum medical benefit (51.3%) and waiting time (21%) were marked as most important criteria in prioritizing waitlist candidates, while donor status (organ donor card holders) was ranked as least significant (43%). Most participants expressed willingness to donate the organs of a deceased relative; they indicated that their willingness will grow if allocation policies took their preferences into account. Contrary to other surveys results (in the UK, the US and Australia), Israelis did not assign high importance to candidate's age (24% ranked it as the least important factor). Interestingly, in some cases, participants' declared preferences regarding the importance of various allocation criteria diverged from their actual choices in hypothetical scenarios.

**Conclusions:** The findings indicate that Israel's citizens are willing to participate in decisions about organ allocation. They have a fluid concept of what they deem to be just, and, in general, their preferences are compatible with current policy.

**Policy Implications:** A more balanced allocation system depends on a broad and inclusive deliberation system. Inclusion of different stakeholders might yield a system that is efficient, fair and more representative.

### Section 3: Hebrew Abstract

#### כותרת מלאה של המחקר

הגדלת שיעור תורמי איברים בישראל: גיבוש מודלים חדשים להקצאת איברים להשתלה בהתאם להעדפות הציבור

#### חוקרים: שם מלא ושיוך מוסדי

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#### מילות מפתח

תרומת איברים, העדפות הציבור, השתלת כליה, מדיניות הקצאה, יעילות רפואית, הוגנות

#### תקציר

תקציר שאורכו עד **200 מילים**, אשר יכלול כותרים אלה: (1) רקע (2) מטרות (3) שיטה (4) ממצאים עיקריים (5) מסקנות (6) המלצות / השלכות לקובעי המדיניות

**רקע:** קיים פער בין אחוז החולים הממתינים לתרומה והאיברים הזמינים להשתלה. למרות שאיברים להשתלה הינם משאב ציבורי וזמינותם תלויה בנכונות הציבור לתרום, מדיניות ההקצאה אינה כוללת את השקפות הציבור.

**מטרות:** המחקר שואף לספק תובנות על העדפות הציבור הישראלי בנוגע למדיניות הקצאת איברים, כדי לקבוע אם עמדות הציבור תואמות למדיניות הנוכחית.

**שיטה:** מכון סקרים ערך סקר טלפוני בקרב 604 משתתפים בוגרים מהמגזר היהודי-ישראלי (טווח גילים: 18-95; 50% גברים). השאלון הורכב מ-39 שאלות שבחנו ידע ועמדות ביחס לתרומת איברים, קריטריונים להקצאה ונכונות לתרום.

**ממצאים עיקריים:** יעילות רפואית (51.3%) זמן המתנה (21%) דורגו כחשובים בתעדוף חולים, בעוד חתימה על כרטיס אדי דורג כפחות בחשיבותו על-ידי 43% מרבית המרואיינים הביעו נכונות לתרום איבריו של קרוב משפחה שנפטר וציינו שנכונותם תגבר אם מדיניות ההקצאה תושפע מעמדותיהם. בשונה מסקרים שנערכו בחו"ל, הציבור הישראלי לא הקנה חשיבות לגיל החולה (24% דרגו אותו כבעל חשיבות פחותה). נמצאה סתירה בין תשובות המרואיינים כשנשאלו שאלת דירוג כללית וכשעומתו עם מקרה פרטני.

**מסקנות:** הציבור הישראלי מעוניין לענות על שאלות מוסריות קשות, הוא מחזיק בהשקפת עולם ורוצה שדעותיו יילקחו בחשבון בקביעת המדיניות.

**המלצות:** תהליך ההקצאה יכול להפוך יעיל והוגן יותר דרך הכללת עמדות הציבור. אם איברים הם משאב לאומי, הרי שהמדיניות צריכה להיות ברורה לכל גורמי המפתח ולשקף את כלל הדעות.

## Section 4: Executive Summary- Hebrew

### תקציר מנהלים

**רקע מדעי:** הדיון על הדרך המיטבית להקצאת איברים להשתלה מהותילאור המחסור החמור באיברים אלו וחשיבותם למטופלים במחלות כליה. [1], מדיניות הקצאת איברים הינה הליך מורכב הכולל קריטריונים מגוונים כמו התאמה בין התורם והנתרם, זמן המתנה וגיל [2]. על קובעי המדיניות להתמודד עם אתגר משולש של הגדלת זמינות האיברים להשתלה, קביעת הקריטריונים להקצאה ושמירה על איזון בין הוגנות בנגישות למאגר (הזדמנות שווה להשתלה) ובין יעילות רפואית (ניצול איברים אופטימלי). על אף שאיברים להשתלה הם משאב ציבורי, העדפות הציבור וחלקו בקביעת מדיניות ההקצאה לא ברורים דיים ולא זוכים לייצוג הולם.

**מטרות המחקר:** המחקר חותר לבחון את שקלול התמורות (trade-off) בין יעילות והוגנות בישראל ולהציג תמונה כוללת של דעת הציבור. אי לכך הוא שם לו למטרה (1) להעריך את הידע וההבנה שצבר הציבור הישראלי ביחס להשתלת איברים בכלל והשתלת כליות בפרט. (2) לבחון מהם הקריטריונים שהציבור מתעדף בתהליך הקצאת האיברים ואילו קריטריונים זוכים בקרב הציבור לחשיבות פחותה. (3) להבין אם הכללה ושילוב של דעות הציבור ושיקוליו בקביעת המדיניות תוביל להעלאת נכונותו לתרום איברים. כמו כן, בדק המחקר האם מדיניות ההקצאה הנוכחית תואמת את ערכי הציבור והעדפותיו.

**שיטות המחקר:** איסוף הנתונים בוצע על-ידי סקר טלפוני. אוכלוסיית הסקר כללה 604 מרואיינים בוגרים מהמגזר היהודי (ערביי ישראל לא לקחו חלק במחקר) בגילאי 18-95 ( $M = 49.31$ ,  $SD = 16.76$ ); מחצית מהנשאלים היו גברים. השאלון, שכלל 39 שאלות ישירות וקצרות, פותח על מנת לבחון דעות ועמדות הנוגעות לקריטריונים המשפיעים או צריכים להיות בעלי השפעה על השיפוט והתעדוף להשתלה. הקריטריונים נבחרו לאחר סקירה מעמיקה של הספרות המקצועית בתחום ולאחר שהוכח שיש להם השפעה או צריכה להיות להם השפעה על מדיניות הקצאת האיברים. הקריטריונים כללו את המאפיינים הבאים: סיכויי הצלחה (התאמה רפואית), זמן המתנה, גיל החולה, סיכויי החולה לקבל כליה מתאימה נוספת בעתיד הקרוב וחתימה על כרטיס אדי לתרומת

איברים. השאלון הורכב מארבעה חלקים: (1) ברור מידת ההכרה וההבנה של האוכלוסייה לשיטות הטיפול הנהוגות במצב של אי ספיקת כליות. (2) שאלות המעמדות היבטי יעילות מול הוגנות ומבררות את מידת הנכונות לתרום איברים- המענה לשאלות שיקף את ערכיו, העדפותיו ועמדותיו של המרואיין בנוגע לקדימות בהקצאת איברים. המשיבים נדרשו לקבוע את מידת החשיבות של כל אחד מהקריטריונים בקביעת סדר מקבלי התרומה באמצעות סולם מדידה ליקרט של שבע אפשרויות. (3) שש שאלות השוואה ובחירה, בהן הוצג למרואיינים מקרה בוחן היפותטי והם נתבקשו להכריע איזה חולה מבין שני מועמדים פוטנציאליים צריך לקבל קדימות בקבלת האיבר. שאלות אלו כללו גם אופציה של אין העדפה. (4) שאלות סוציו-דמוגרפיות ושאלות המבררות חתימה או נכונות לחתום על כרטיס תרומת איברים ורקע קודם עם תרומת איברים (ניסיון אישי או של מקורב).

**ממצאים:** 80% מהמרואיינים ציינו כי הם מודעים להשלכות של אי ספיקת כליות ומכירים את שיטות הטיפול הנהוגות. הקריטריונים שסומנו על-ידם כחשובים ביותר בקביעת סדר מקבלי התרומה הם סיכויי ההצלחה של ההשתלה, כלומר התאמה רפואית (51.3%) וזמן המתנה של החולה לכליה (21%). 43% מהנשאלים דרגו את העובדה שהחולה עצמו חתם על כרטיס לתרומת איברים כקריטריון הכי פחות חשוב בתהליך ההקצאה. מרבית המרואיינים הסכימו לתרום את איבריו של קרוב משפחה שנפטר (64% השיבו שיסכימו לתרום ו- 26% ענו שככל הנראה יביעו נכונות לתרום). ההיבט המעניין הוא העלייה המובהקת שחלה בנכונות המשיבים לתרום איברים אם וכאשר הקריטריונים שהם ציינו כחשובים יכללו במדיניות ההקצאה ( $F(1,489)=9.53, P=0.002$ ). בניגוד לציפיות ובשונה ממצאי מחקרים שנערכו בחו"ל [3, 4], גיל החולה לא נתפס על-ידי הציבור הישראלי כקריטריון מוביל, חשוב ומשפיע בהקצאת איברים (24% מהנשאלים דרגו אותו כקריטריון הכי פחות חשוב בקביעת סדר מקבלי התרומה) והוא אף דורג כקריטריון השני הפחות בחשיבותו. ניתוח השאלונים מעלה סתירות בין התשובות שניתנו לשאלות הפילוסופיות הכלליות, שנשאלו בתחילת הסקר, ובין המענה של הציבור למקרי הבוחן ההיפותטיים. למשל, על פי הדירוגים הראשונים, הפילוסופים, הכרעת הציבור בנוגע לחשיבות קריטריון סיכויי ההצלחה בהשוואה

לפרמטר זמן המתנה היתה מובהקת ( $t(603)=4.72$ ,  $p<0.002$ ). אולם, בהינתן התרחישים המשיבים לא נתנו עדיפות להיבט זה. כמו כן, על אף שחתימה על כרטיס אדי דורגה על-ידי מרבית המשיבים כפחותה בהשוואה לקריטריונים האחרים, כאשר עומתו הנשאלים עם מקרים תיאורטיים, הם נטו להעניק עדיפות לאדם שהביע נכונות לתרום את איבריו לאחר מותו.

**מסקנות:** ממצאי הסקר מוכיחים כי אינדיבידואלים מכל קצוות האוכלוסייה, מטווח גילאים רחב ומרקע שונה מסוגלים לבטא ולדרג את הקריטריונים שהם מאמינים שיש להתחשב בהם בקביעת מדיניות להקצאת איברים להשתלה. הציבור הישראלי מוכן לענות על שאלות מוסריות ושיפוטיות, הוא מחזיק בהשקפת עולם ורוצה שדעותיו יילקחו בחשבון בתהליך קביעת המדיניות. לראיה, אנשים מוכנים לשנות את עמדתם ולתרום איבריהם אם דעותיהם תבואנה לביטוי במדיניות ההקצאה. כמו כן, הרעיון לשתף את הציבור בדיונים רשמיים זוכה לחיזוק כאשר מתברר שבמרבית המקרים ישנם קווי ממשק בין העדפות הציבור ומדיניות המרכז הארצי להשתלות.

**השלכות והמלצות:** תהליך ההקצאה יכול להפוך יעיל והוגן יותר דרך הכללת עמדות הציבור. אם איברים לתרומה הוגדרו כמשאב לאומי מציל חיים, הרי שהמדיניות והנהלים צריכים להיות ברורים לכל גורמי המפתח ואמורים לשקף את הדעות של כלל הצדדים המעורבים (גורמי רפואה, מומחים, חולים, הציבור הרחב). אי לכך, המערכת צריכה לשאוף למציאת איזון המכבד, מחד גיסא, את ערכי הציבור ומאידך גיסא, שומר על יעילות רפואית.

## מקורות

[1] Ministry of Health Israel. 2019. Awaiting transplant.

[https://www.health.gov.il/Subjects/Organ\\_transplant/transplant/Pages/waiting\\_for\\_transplants.aspx](https://www.health.gov.il/Subjects/Organ_transplant/transplant/Pages/waiting_for_transplants.aspx) Accessed 25 April 2019.

[2] The National Transplant Center. 2019. Policy of allocation of organs from deceased donors. <https://www.adi.gov.il/en/allocation-of-organs/> Accessed 25 April 2019.

[3] Howard K, Jan S, Rose JM, Irving M, Wong G, Tong A ... Cass A. Community preferences for the allocation of donor organ for transplantation: a discrete choice study. Transplantation 2015;99:560-567.

<https://doi.org/10.1097/TP.0000000000000365>.

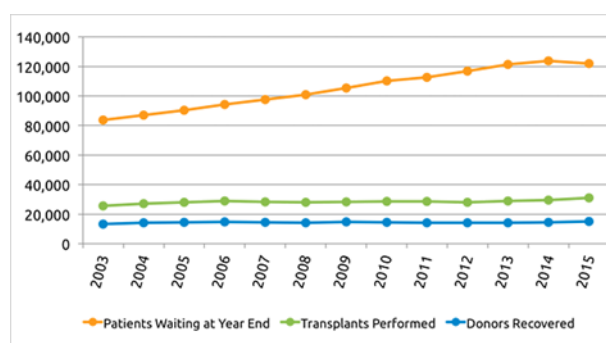
[4] Dolan P, Shaw R. A note on a discussion group study of public preferences regarding priorities in the allocation of donor kidneys. Health Policy. 2004;68:33-36.

## Section 5: Comprehensive scientific report - English

### Scientific background

Organs for transplantation are a scarce resource. In many countries, there is a stark disparity between the number of patients awaiting deceased-donor organ transplants and the rate at which organs become available (for example, Figure 1 portrays the organ shortage in the US). A key factor in this disparity is scarcity of registered donors. For example, recent reports by the US Organ Procurement and Transplantation Network (OPTN) indicate that 95% of US adults support organ donation, yet only 54% are actually registered as donors [1]. In a recent survey administered in the UK, two out of three respondents expressed willingness to donate organs, yet only a third had signed up for the organ donation register [2]. In Australia, as of January 31, 2017, the total number of registered donors was 6,333,494 out of 24.5 million adults in the population (approximately 26%) [3]. Israel's rates of donor card signees are among the lowest in the developed world. Only 14% (924,403) of adults have signed an organ donor card [4].

**Figure 1: Organ shortage in the United States [5]**



In light of the shortage of organs and the long waiting times for transplantation [6,7], policy makers, in Israel and abroad, face not only the challenge of increasing the availability of donor organs but also the challenge of determining the criteria by which existing organs should be allocated. In defining allocation policies, decision makers tend to incorporate a complex set of considerations, including medical need, medical urgency, capacity to benefit, donor/recipient matching, and logistical factors [8]. Though the details of organ

allocation policies may differ across countries, these policies—each in its own way—generally strive to strike a balance between two principles: medical efficiency (or utility), i.e., the idea that each organ should be transplanted into the recipient in whom it will survive the longest [9], and the principle of equity, which demands that all persons who would benefit from a transplant should have comparable opportunities to receive one [10,11]. It is important to realize that it is inherently impossible to simultaneously maximize medical efficiency and equity. Rather, there is a trade-off between the two principles, and this trade-off has been at the focus of ongoing philosophical and ethical debates for many years.

In Israel, as in most countries, deceased-donor kidneys are assigned to recipients on the basis of a patient-oriented point system. In line with the discussion above, this system takes into account medical efficiency considerations, coupled with various equity considerations designed to make transplantation accessible to as many patients as possible [12]. Medical efficiency is captured in factors such as blood group match, donor-recipient age difference, panel reactive antibody (PRA) level, and, importantly, immunological compatibility as reflected in human leukocyte antigen (HLA) matching: the number of “matches” and “mismatches” between the donor and the recipient in a set of six antigens. Equity considerations include waiting time. (Equity considerations in other, larger countries, include the geographic location of the patient relative to the donor, and the national net kidney balance, i.e., calculation of import/export balance). We note that Israel is distinct from other countries in that, as a means of incentivizing individuals to register to donate, it has legislated a law that assigns priority status to candidates on the basis of their own or their first-degree relatives’ expressed willingness to donate organs [13,14] (see Table 1 for details regarding this incentive system). However, it is unclear whether Israel’s official allocation criteria reflect community values.

**Table 1: Priority points for willingness to donate**

| Extra points | Target population                                                                                      |
|--------------|--------------------------------------------------------------------------------------------------------|
| 3.5 points   | <i>Organ donors</i><br>Wait-listed patients or a first-degree relative who actually gave their consent |

|          |                                                                                                                                                                                                           |
|----------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|          | to procurement of organs from a diseased next of kin, or donated an organ during their lifetime.                                                                                                          |
| 2 points | <i>Registered donors</i><br>Wait-listed patients who signed an organ donor card at least 3 years before they were added to the waiting list.                                                              |
| 1 point  | <i>Priority by affiliation</i><br>Wait-listed patients who are unregistered donors, nonetheless a first-degree relative did sign an organ donor card at least 3 years before they were added to the list. |

### Research objectives

The current study focuses on an element that remains noticeably absent from this debate, and from the allocation decisions made in practice: namely, public perceptions and opinions regarding organ allocation criteria. Given that deceased-donor organs for transplantation are a community resource, and that the organ supply depends on public willingness to donate, it seems that allocation policies should, to some extent, consider community preferences regarding which factors should be prioritized in allocation decisions [15]. Though this notion has gained some traction in recent years [16], current allocation schemes do not explicitly incorporate community preferences. Indeed, it seems that very little precise information on such preferences is available at all.

To begin to address this gap, we carried out a survey to systematically measure the opinions, and perceptions of the Jewish-Israeli lay public regarding criteria for organ allocation (The Arab citizens of Israel did not take part in the

survey). Specifically, we focused on allocation of kidneys, the organ type with the highest proportion of patients on waiting lists [17]. In our survey, which comprised 604 participants, we sought to achieve the following goals: (1) to evaluate the general public's knowledge and understanding regarding organ transplantation in general, and kidney transplantation in particular; (2) to examine which criteria the community prioritizes in the organ allocation process, and which it perceives as less important—both in terms of declared preferences, and in terms of revealed preferences (i.e., the criteria that individuals actually rely on when required to make a decision); (3) to learn whether taking the public opinion into account in a kidney allocation policy has the potential to increase willingness to donate organs. In evaluating the results of the survey, we devoted particular attention to the question of whether current organ allocation policies are consistent with societal values and public preferences.

We note that an abundance of surveys conducted in countries such as the US, the UK and Australia have suggested that the vast majority of the public is willing to sacrifice some degree of medical efficiency of transplantation programs in exchange for an increase in equity or fairness in the allocation of donor organs [15,18-20]. This paper seeks to discover whether Israel's lay public holds similar perspectives. To the best of our knowledge, this is the first study to investigate the preferences and values of Israel's population with regard to organ allocation policies. Notably, in contrast to previous surveys carried out in other countries, which focused on specific communities (e.g., scholars [19]; local community groups [20]; Arabic-speaking [21]), this survey seeks to represent Israel's entire (Jewish) population, encompassing adult participants of all ages and from all walks of life.

This study's premise is that an organ allocation policy is most likely to achieve an ethical balance between efficiency and equity when expert policy makers allow public input to inform their decisions. Therefore, our objective is to provide insights that might contribute toward the development of such policies, which might consequently increase the community's willingness to donate organs.

## Methodology

### *Procedure and participants*

To achieve the study goals outlined above, we collected data through a telephone survey. The survey pool included 604 Israeli participants, ranging in age from 18 to 95 years ( $M = 49.31$ ,  $SD = 16.76$ ); half of them were male. A market research company, B.I. and Lucile Cohen Institute for Public Opinion Research, an academic survey institute at Tel-Aviv University, administered a questionnaire to a representative sample of the general adult Jewish population in Israel. In this particular survey the Arab citizens of Israel did not take part. The inclusion criterion was being 18 years old and above. Respondents were sampled by a probabilistic sampling of households from layers of statistical areas, defined by socio-demographic characteristics of each area. Layers were designed to create homogeneity on the basis of geographic area (e.g., between large cities and small towns), immigration (native-born and established immigrants), level of religiosity (secular and orthodox) and socio-economic level. Sampling was done so that the probability of each statistical area to be included in the sample is proportional to the size of the population in the area. Such sampling ensures representation of various population groups, particularly those with a relatively small proportion. We subsequently used quantitative research techniques to analyze public preferences regarding the allocation of donor organs.

### *Questionnaire*

The questionnaire consisted of 39 questions that were brief and straightforward. The questions were divided into the following four sections.

*Section 1: Familiarity with renal failure and treatment.* In this section, participants were presented with a general explanation about renal failure, and were then asked to rate their level of knowledge, understanding and awareness regarding customary treatment options on a four-degree scale (i.e., unaware, partially aware, mostly aware, and completely aware).

*Section 2.a.: Declared preferences regarding criteria for organ allocation.* In the second section, participants were presented with a set of patient-specific characteristics and were requested to rank, via a 7-point Likert-type scale (1 = not

at all; 7 = very much), the extent to which each characteristic should be taken into consideration as a criterion in organ allocation decisions in cases of organ scarcity. The selected criteria were derived from vast literature reviews of factors that have been shown to influence organ allocation decisions, and included both efficiency and equity principles. Specifically, participants rated the importance of the following characteristics: the candidate's age, the amount of time he or she has spent on the waiting list, having dependents/family responsibilities, donor status (i.e., whether the candidate is a registered donor), likelihood of receiving another donation in the coming year, and prognosis/maximum benefit. Next, they were asked to select the most important criterion, the second most important criterion, and the least important criterion. In addition, participants were asked to specify any additional criteria which, in their view, should be taken into account in decisions about how donor kidneys should be allocated.

*Section 2.b. Donation intentions (relatives).* After expressing their preferences regarding organ allocation criteria, participants were asked to rate (i) the extent to which they would be willing to donate the kidney of a deceased relative, and (ii) the extent to which they would be willing to donate the deceased relative's kidney if their preferences (as expressed in section 2.a.) were incorporated into the allocation policy (each on a 4-point scale).

*Section 3: Revealed preferences regarding criteria for organ allocation.* In this section participants were presented with six hypothetical "trade-off" scenarios, in which they were requested to place themselves in the role of the decision maker. In each scenario, two different candidates with different characteristics were described. The respondent had to select which of the two should receive a kidney, or select "no preference". This section enabled us to determine which criteria respondents actually prioritized when forced to make a decision. (The six scenarios are described in detail in the section titled "Differences and Similarities..."). In particular, to examine public opinion regarding the law according to which a person can gain priority points by registering as an organ donor, three scenarios evaluated

whether respondents prioritize organ donation commitment over other criteria, namely, age, waiting time, and chances for a successful transplant.

#### *Section 4: Demographic information and own organ donation intentions.*

Respondents provided demographic information, including their age, education, religion, country of origin, marital status, socioeconomic status, and number of children. In addition, they were asked whether they were holders of an organ donor card, and if they or their relatives had ever received an organ transplant.

Furthermore, respondents were asked to rate the extent to which they were willing to sign an organ donor card in the near future, and the extent to which they would be willing to do so if their preferences were incorporated in the allocation policy, both on a four-degree scale (defiantly not, probably not, probably yes, defiantly yes).

## **Findings**

### *Participant characteristics and familiarity with renal transplantation*

Table 2 summarizes the characteristics of the survey population. According to participants' responses, 75% of the respondents were born in Israel; this number is in line with Israel's population distribution [22]. Moreover, 55% of the participants stated that they define themselves as secular, 27% as traditional, 9% as religious and 8% as orthodox. The distribution of survey respondents' religious affiliations—which may have a substantial role in attitudes toward organ donation—seems to reflect the actual distribution in Israel [22], which is as follows; 44% secular, 36% “traditional” (religious or not religious), 11% religious, and 9% orthodox.

**Table 2: Characteristics of the survey population**

| Character |        | Percentage | Mean  | SD    |
|-----------|--------|------------|-------|-------|
| Gender    | Male   | 50%        |       |       |
|           | Female | 50%        |       |       |
| Age       | 18-95  |            | 49.31 | 16.76 |

|                            |                |       |  |  |
|----------------------------|----------------|-------|--|--|
| Country of origin          | Israel         | 75%   |  |  |
|                            | Other          | 25%   |  |  |
| Religion                   | Secular        | 55%   |  |  |
|                            | Traditional    | 27%   |  |  |
|                            | Religious      | 9%    |  |  |
|                            | Orthodox       | 8%    |  |  |
|                            | Other          | 1%    |  |  |
| Parenthood                 | Yes            | 79%   |  |  |
|                            | No             | 21%   |  |  |
| Signed an organ donor card | Yes            | 37%   |  |  |
|                            | No             | 61.1% |  |  |
|                            | Did not answer | 1.3%  |  |  |

In our survey, 38% of the respondents stated that they hold a bachelor's degree or higher, whereas 41% declared they have a high school diploma or elementary education. These data seem to diverge somewhat from the characteristics of Israel's general population: According to the records of Israel's Ministry of Finance [23], approximately half of the population between the ages of 25 and 64 is academically educated (i.e., bachelor's degree or higher). This deviation might stem from the fact that our survey pool includes respondents outside the age range of 25–64, including young adults who have yet to complete higher education, and elderly people who have accumulated life experience rather than academic education. As was mentioned above, in Israel only 14% (924,403) of adults have signed an organ donor card [4]. Yet in the survey, 37% of the participants declared they are donor organ card holders ( $n=226$ ). Hence, in our survey, there is an over-representation of people who are registered donors. Other features that

characterize the survey pool are as follows: 79% of the participants are parents to children; 34% have above-average income and 29% have below-average income.

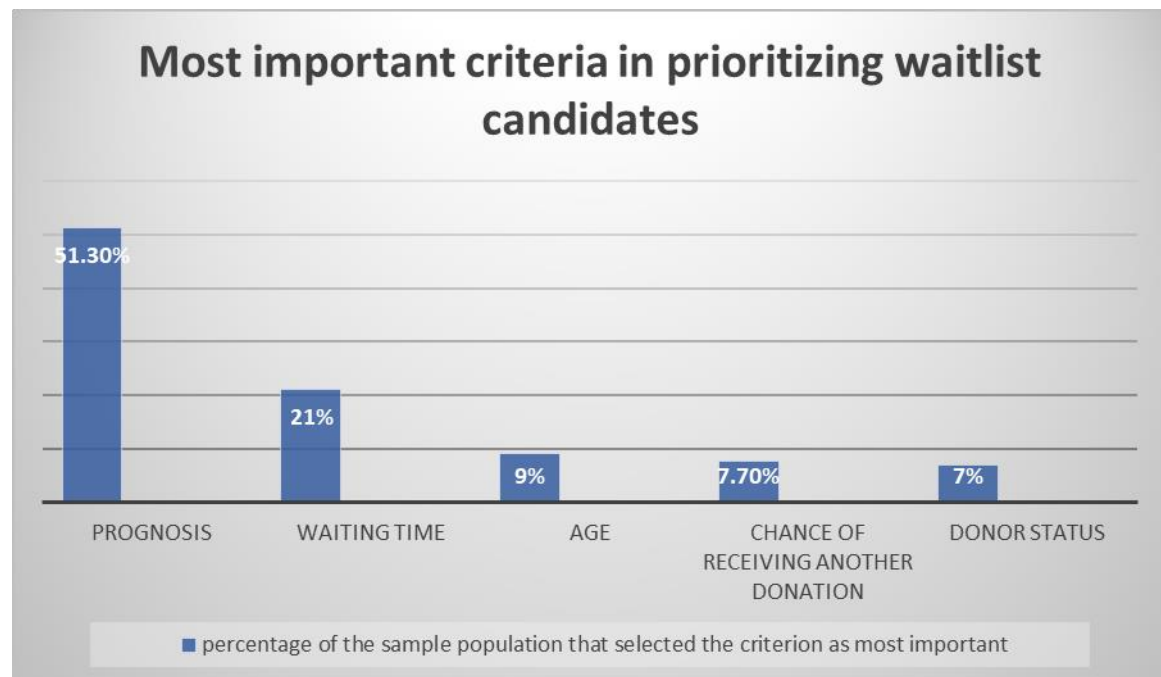
### *Awareness*

Eighty percent of the participants specified that they are aware of most or all of the information presented in the beginning of the survey regarding the repercussions of renal failure and comprehend the customary treatment methods. Fifteen percent noted that they were aware of some parts of the information, while only 5% stated that they were not at all aware of the information.

### *Declared preferences regarding criteria for organ allocation*

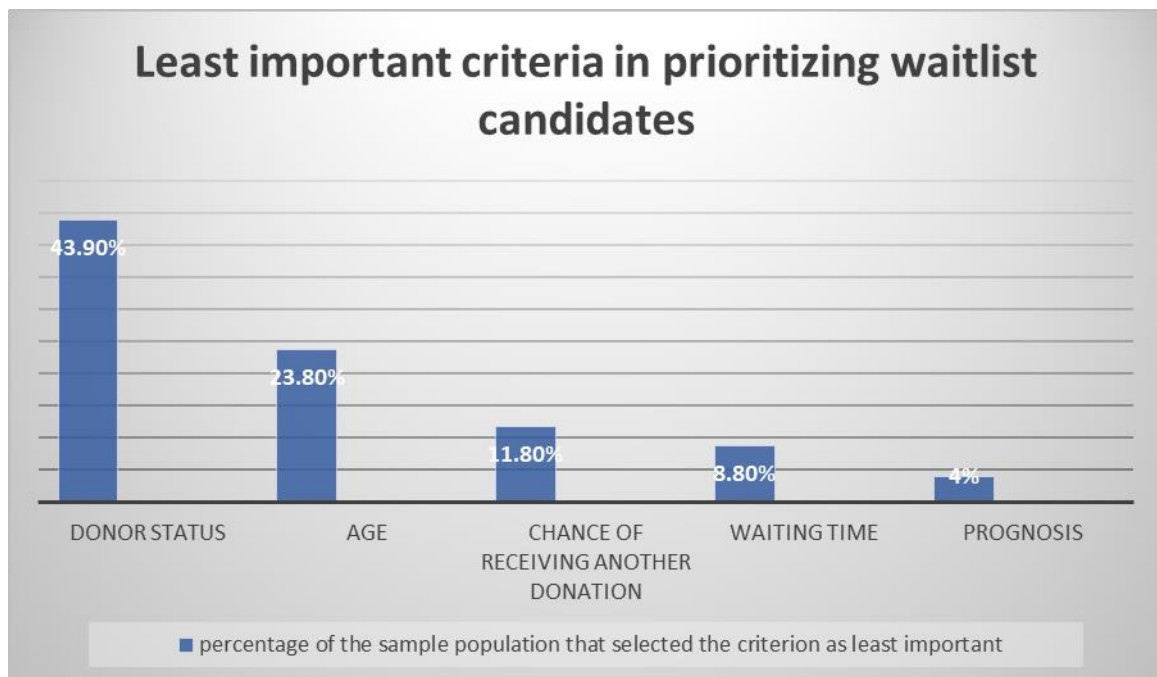
Figure 2 shows which criteria were identified by the survey population as most important in prioritizing waitlist candidates. The majority of participants (51.3%) selected prognosis/maximum benefit as the most important criterion, and the second most popular choice was waiting time (21%).

**Figure 2: Most important criteria in prioritizing waitlist candidates, according to the survey population**



When asked to identify the criterion that should be attributed the least significance in allocation decisions, 43.9% of respondents chose the recipient's donor status (i.e., whether he/she is a registered donor). Contrary to expectations, respondents did not indicate that they perceived recipient age as a criterion that should be attributed high importance in organ allocation. In fact, 24% of the interviewees ranked it as the least important factor in determining transplantation priorities. Figure 3 illustrates the criteria that were ranked by the survey population as least important.

**Figure 3: Least important criteria in prioritizing waitlist candidates, according to the survey population**



Notably, the declared preferences of respondents who were registered donors were similar to the preferences of respondents who had not signed a donor card. Specifically, among registered donors, 43.2% chose the recipient's donor status as the least important attribute to be considered. This finding is surprising in light of the fact that, as noted above, Israel's allocation policy prioritizes registered donors, as an incentive to increase willingness to donate.

#### *Comparison between declared preferences and revealed preferences*

In most cases, participants' declared preferences regarding organ allocation criteria were compatible with their revealed preferences, as reflected in their allocation decisions in the trade-off scenarios (presented in Table 3 in the following section). In particular, analysis of the trade-off scenarios indicated that participants indeed assigned the greatest importance to prognosis (medical benefit) and waiting time. Moreover, their decisions confirmed that they did not assign substantial importance to age: For example, when asked to choose between giving a kidney to a 30-year-old person versus a 45-year-old person (with a similar prognosis; scenario 1 in Table 3), most respondents chose the option of "no preference" (71.5%). Notably, however, participants who did express a preference tended to prefer the younger candidate ( $\chi^2 = 45.62$ ,  $p < 0.001$ ). Moreover, participants significantly prioritized an

older patient who had signed an organ donor commitment (36%) over a younger candidate who had not committed to organ donations (20%;  $\chi^2 = 27.75$ ,  $p < .001$ ; scenario 3 in Table 3).

Nevertheless, we did observe several discrepancies between declared preferences and revealed preferences. For example, when assigning scores to the various criteria, participants generally ranked maximum benefit ( $M=6.2$ ,  $SD=1.3$ ) significantly higher than they ranked waiting time ( $M=6.52$ ,  $SD=.09$ ), ( $t(603) = 4.72$ ,  $p < .002$ ). Yet, when asked to allocate a kidney to one of two patients—patient A, who has a 70% chance of a successful transplant and has been waiting 4 years, and patient B, who has a 90% chance of a successful transplant and has been waiting only 1 year (scenario 2 in Table 3)—participants showed no significant preference for patient B (45% chose patient B; 39% chose patient A,  $\chi^2 = 2.56$ ,  $p = .11$ ). This decision seems to violate their own declared preference.

Moreover, though, as noted above, participants seemed to assign low priority to the candidate's status as a registered donor, their decisions in the trade-off scenarios revealed a more nuanced picture. For example, when rating the various criteria on Likert scales, participants assigned a significantly lower rating to donor status than to the likelihood of finding another kidney in the coming year ( $M = 5.0$  vs.  $M = 5.9$ ,  $t(603) = 8.4$ ,  $p < 0.001$ ). Yet, when asked to choose between a patient who was a registered donor with a 70% chance of receiving another kidney in the coming year versus a non-registered donor with only a 30% chance (scenario 4 in Table 3), 40% of participants chose the former, while 35.6% chose the latter (showing no significant preference to one of the patients ( $\chi^2 = 1.06$ ,  $p = .30$ )).

#### *Willingness to donate the organs of a deceased relative*

Participants' willingness to donate a deceased relative's organs was relatively high, 64% indicated that they would definitely agree, and 26% said that they would probably agree (but note that 16% did not want to answer this question) ( $M = 3.5$ ,  $SD = 0.8$ ; on a 4-point scale), with registered donors expressing significantly greater willingness to donate ( $M = 3.85$ ;  $SD = 0.40$ ) compared with participants who had not signed a donation commitment ( $M = 3.2$ ;  $SD = 0.90$ ;  $t(498) = 9.10$ ,  $p < .001$ ).

Interestingly, participants indicated that they would be significantly more willing to donate a relative's organs if the criteria they had specified as most important were integrated into the allocation policy ( $F(1,489) = 9.53$ ,  $p = 0.002$ ). For example, among 48 respondents who were reluctant to donate their loved one's organs (i.e., rated their agreement as 1- "I would definitely not agree to donate" or 2- "I would probably not agree to donate"), 18% expressed higher willingness to donate if their preferences were incorporated in the organ allocation policy.

#### *Willingness to sign an organ donation commitment card*

As noted above, 61.1% of the participants were not registered organ donors. When asked about their willingness to sign an organ donation commitment in the near future, participants expressed relatively low intention to sign a commitment ( $M = 1.44$ ;  $SD = .50$ , on a 4-point scale). However, when asked to rate their willingness to sign an organ donor commitment given that their preferences will be taken into account in the allocation policy, participants' willingness to sign the card was significantly higher ( $M = 2.25$ ;  $SD = 2.17$ ,  $t(146) = 4.80$ ,  $p < .001$ ).

### **Differences and Similarities between the Israeli National Transplant Center's Point System and the Israeli Public's Preferences**

Having characterized the Israeli public's preferences regarding organ allocation criteria, it is interesting to compare these preferences to the actual criteria used by the Israeli National Transplant Center to allocate organs. Table 3 shows, for each of the six trade-off scenarios described in Section 3 of the questionnaire, the preferences expressed by survey respondents versus the actual decision that would have been made, based on the points granted by the Israeli National Transplant Center's point system.

This comparison suggests that, in most cases, the views of the public are in line with those of the National Transplant Center. In particular, both the public and decision makers assign high importance to maximum (medical) benefit, and acknowledge the importance of waiting time. Nevertheless, we do observe some divergence. For example, the public attributes lower importance to recipient age than the point system does (scenario 1). The public's decisions also illustrate their

somewhat “fickle” perceptions of the significance of organ donation commitment: For example, in scenario 4, which traded off organ donation commitment against the likelihood of receiving another kidney, the public assigned *greater* weight to organ donation commitment than the point system did (and, as noted above, this decision seems to violate the public’s declared preferences). In scenario 6, which traded off organ donation commitment against waiting time, the public assigned *lower* weight to organ donation commitment than the point system did.

**Table 3: Comparison between the Israeli National Transplant Center’s point system and public preferences**

| Scenario # | Description                                                                                                                                                                                                   | Survey results                                                 | The point system decision*     |                                 |
|------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------|--------------------------------|---------------------------------|
| 1          | Patient A is 30 years old.<br>Patient B is 45 years old.                                                                                                                                                      | Patient A- 20%<br>Patient B- 5%<br><b>No preference- 71.5%</b> | <b>Patient A</b><br>2.9 points | Patient B<br>1.4 points         |
| 2          | Patient A’s prognosis for a successful transplant is 70%. He has spent 4 years on the waiting list.<br><br>Patient B’s prognosis for a successful transplant is 90%. He has spent 1 year on the waiting list. | Patient A- 39%<br><b>Patient B- 45%</b><br>No preference- 12%  | Patient A<br>3.92 points       | <b>Patient B</b><br>4.48 points |
| 3          | Patient A is a registered organ donor. He is 40 years old.<br><br>Patient B has not signed an organ donor card. He is 20 years old.                                                                           | Patient A- 36%<br>Patient B- 20%<br><b>No preference- 41%</b>  | Patient A<br>3.9 points        | Patient B<br>3.9 points         |
| 4          | Patient A has a 70% chance of finding another suitable kidney in the coming year. He is a registered organ donor.                                                                                             | <b>Patient A- 40%</b><br>Patient B- 36%<br>No preference-      | Patient A<br>4 points          | Patient B<br>4 points           |

|   |                                                                                                                                                                                                          |                                                                              |                                 |                          |
|---|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------|---------------------------------|--------------------------|
|   | Patient B has a 30% chance of finding another suitable kidney in the coming year. He has not signed an organ donor card.                                                                                 | 21%                                                                          |                                 |                          |
| 5 | <p>Patient A is a registered organ donor. He has spent 1 year on the waiting list.</p> <p>Patient B has not signed an organ donor card. He has spent 4 years on the waiting list.</p>                    | <p>Patient A- 23%</p> <p><b>Patient B- 53%</b></p> <p>No preference- 21%</p> | <b>Patient A</b><br>2.48 points | Patient B<br>1.92 points |
| 6 | <p>Patient A's prognosis for a successful transplant is 70%. He is a registered organ donor.</p> <p>Patient B's prognosis for a successful transplant is 90%. He has not signed an organ donor card.</p> | <p>Patient A- 27%</p> <p><b>Patient B- 51%</b></p> <p>No preference- 19%</p> | Patient A<br>4 points           | Patient B<br>4 points    |

\* In the case of a dilemma, in which the point system assigns equal scores to two or more patients, the National Transplant Center seeks expert advice in order to hold a medical debate and to decide which patient should receive the organ.

## Discussion and Conclusions

Our findings, in line with those of surveys of other populations (e.g., [19-20]), demonstrate that Israeli community members from all walks of life are able and willing to differentiate among groups of individuals on the basis of their characteristics, and to answer difficult trade-off questions in order to allocate organs as ethically as possible. Moreover, our findings suggest that lay people are interested in taking part in shaping organ allocation policies, as reflected in the fact that participants indicated that they would be more willing to sign an organ donation commitment and to donate the organs of a deceased relative if their opinions were taken into account. Encouragingly, we observed substantial common ground

between the preferences of the public and the actual considerations used in Israel's organ allocation system, suggesting that such public participation is feasible.

Like residents of other countries who responded to similar surveys [15,24-25], the Israeli public ranked maximum benefit/prognosis and waiting time as the most important criteria in the allocation process. These leading criteria, which also dictate the allocation policy of the National Transplant Center in Israel, prove that the public comprehends that allocation decisions hinge on a complex balance of medical efficiency and equity principles.

One of the interesting findings of the present survey, which contradicts findings of previous research, relates to the age criterion. In surveys conducted in the UK, Australia and the US [19-20,24,26], most respondents thought that in the name of fair innings or better prognosis, precedence should be given to younger patients. Apparently, the Israeli public does not hold the same opinion. Our observation might be due to the fact that in the 21st century, people do not consider chronological age to be a deciding factor in an individual's potential to live a long and meaningful life, and therefore do not believe that age should be a primary factor in organ allocation decisions. Indeed, today, more elderly people are keeping fit and maintaining healthy lifestyles; they have a longer life expectancy and perceive themselves as vital and contributing to society. Another possible factor in the low importance attributed to age might have been that younger respondents were less concerned about their own health status and therefore answered the questionnaire while thinking about their parents, whereas older respondents identified with the individuals described in the hypothetical scenarios and provided answers that were in their own best interests.

An additional notable finding is that, though Israel's organ allocation policies prioritize registered donors, presumably as a means of encouraging donation, respondents (including registered donors) ranked donor status as the least important criterion in allocation decisions. This result diverges from results obtained in surveys in other countries, in which respondents indicated that priority ought to be given to registered donors (in spite of the fact that their countries of origin do not prioritize on this ground [15, 26]). Nevertheless, it is important to note that when confronted with hypothetical trade-off scenarios, respondents did choose, in some

cases, to prioritize a registered donor over a candidate who had not registered as a donor.

Indeed, as discussed above, we found multiple discrepancies between respondents' declared preferences regarding organ allocation criteria and their revealed preferences, as reflected in their decisions in the trade-off scenarios. In particular, our observations may point to a trend in which, when confronted with a specific case, participants consider medical efficiency to a lesser extent than they would theoretically prefer (as indicated in their declared preferences) and instead rely more heavily on equity principles such as waiting time or donor status. This tendency is in line with previous research suggesting that systematic discrepancies exist between ethical decisions that are made from an abstract, global perspective and decisions that are made with regard to specific cases (e.g., [27-29]). Specifically, in decisions made regarding specific cases, decision makers tend to show more flexibility and to give more weight to individuals' specific needs.

### **Policy Implications and Recommendations**

The results of this survey suggest that Israel's citizens can articulate clear preferences regarding organ allocation decisions. Their perceptions regarding which allocation criteria are most important are somewhat fluid, and may depend on the specific candidates under consideration; however, their preferences are generally compatible with current organ allocation policy. Therefore, we encourage the Israeli National Transplant Center to advise the public that the point system currently used already takes into account the public preferences. Moreover, Israelis indicate that they would be more willing to donate organs if allocation policies took their preferences into account. Accordingly, we propose that the public should be allowed to seek clarification, engage in discussions, express their views, and listen to other opinions, and that in turn, decision-making entities should take community preferences into account when formulating their guidelines. Though we are aware that it is infeasible for a complex system to perfectly reflect the priorities of all stakeholders, ultimately, we propose that an optimal allocation system must strive to find a balance that respects community values and perceptions while maintaining continued clinical effectiveness [15,30]. More broadly, we propose that any group of

key stakeholders—including healthcare clinicians, patients, their families and carers, donor representatives, and the general public—is most likely to perceive an allocation system as efficient and equitable if the system takes into account that group's views regarding which criteria yield efficiency and equity.

It is worth noting that five theoretical papers preceded this research. Four of them review papers are now being reviewed by academic journals for possible publication, the fifth is still under work. Moreover, a comprehensive book about kidney transplantation and donation has been written. Currently, the book is being edited. In a subsequent study, we will examine the preferences, ideas and stances of healthcare clinicians regarding organ allocation policies in order to detect similarities and discrepancies between experts' perspectives and the lay public preferences.

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***Additional papers/book which were written during the research process***

(Unpublished data)

Elalouf A, Pliskin JS. Balancing equity and efficiency in kidney allocation: A comprehensive overview. Under revision.

Elalouf A, Pliskin JS. Community and stakeholder preferences for organ allocation: An Overview. Under revision.

Elalouf A, Pliskin JS. Kidney transplantation and donation: A bird's-eye view. In editing. (**A book**)

Elalouf A, Pliskin JS. Organ allocation systems: A comprehensive overview. Under revision.

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