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Perceived Versus Verified Cancer History and Missed Opportunities for Donation in an Australian Cohort of Potential Deceased Solid Organ Donors

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Background. There is an imperative to maximize donation opportunities given ongoing organ shortages, but donor suitability assessments can be challenging. Methods. We analyzed an Australian cohort of potential deceased donors 2010 to 2013 to explore misclassification of cancer risk and potential strategies for improvement (decision support, real-time data linkage to existing data sets, and increasing risk tolerance). Cancer history perceived at referral was compared with verified cancer history in linked health records. Transmission risks were based on clinical guidelines. Potential donors declined due to cancer but verified low risk were missed opportunities; those accepted but verified high risk were excess-risk donors. Results. Among 472 potentially suitable donor referrals, 132 (28%) were declined because of perceived transmission risk and 340 (72%) donated. Assuming a low-risk threshold, there were 38/132 (29%) missed opportunities and 5/340 (1%) excess-risk donors. With decision support, there would have been 5 (13%) fewer missed opportunities and 2 (40%) more excess-risk donors; with real-time data linkage, 6 (16%) fewer missed opportunities and 2 (40%) fewer excess-risk donors; and with increased risk tolerance, 6 (16%) fewer missed opportunities and 11 (220%) more excess-risk donors. Conclusions. Potential donors’ cancer history is typically incomplete at referral. There are missed opportunities where decision support or more accurate cancer history could safely increase organ donors.

Organs donation rates in Australia have increased from 12.1 donors per million population in 20081 to 21.6 in 2019.2 However, Australia still lags behind other nations such as the United Kingdom (23.1), United States (32.0), and Spain (46.9, highest globally).3 Despite increases in donation resulting from efforts to identify all potential deceased donors,4 this exceeds the incremental gain in actual donors suggesting potential donors are underutilized. Because of ongoing organ shortages5 and the well-known benefits of transplantation, it is imperative that all avenues to increase organ donation are explored.

Potential deceased donors are managed centrally by the Organ and Tissue Donation Service (OTDS) in New South Wales (NSW), which is the most populous state in Australia (8.1 million4) and is demographically representative of the entire country. Those with family consent and no medical preclusions proceed to organ procurement and are considered an actual donor, regardless of whether any organs are used for transplantation.

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transplant. Organs are only procured if a transplant recipient has been confirmed, hence the organ discard rate is much lower than in other jurisdictions such as the United States.  

Potential donors are medically unsuitable if their organs are inadequate quality for donation, or there is a risk of transmission of infection or cancer from donor to recipient. The Transplantation Society of Australia and New Zealand (TSANZ) guidelines aide clinicians in assessing donor suitability, including estimating the risk of cancer transmission by cancer type (not contraindicated, minimal risk [≤0.1%], low risk [0.1%–2%], intermediate risk [2%–10%], high risk [>10%], or contraindicated) . However, the decision about which level of risk is acceptable for donation is left to individual clinicians.

Decisions are based on available medical information (e.g., the referring hospital or history from relatives), which is recorded in OTDS donor referral logs. Verifying perceived cancers with pathology reports is often impossible in the short timeframes required. Misclassification of risk can lead to missed opportunities, or unrecognized excess-risk donors with potential for transmissions. In the United States, 25% of deceased organ donors with a reported cancer history could not be verified in cancer registries. Furthermore, studies from Denmark and Italy found that 1% of donors had cancer that was undetected until after transplantation. Despite evidence that cancer information scarcity leads to inconsistent and potentially harmful donation decisions, no studies have evaluated the impact of potential solutions.

Firstly, we aimed to establish the accuracy of health information known at the time of donation decisions, by comparing the perceived cancer diagnoses in donor logs with verified diagnoses from linked health records. Secondly, we aimed to identify any missed donor opportunities (suitable donors who were declined) and excess-risk donors (unsuitable donors who were accepted). Finally, we aimed to evaluate potential strategies to avoid missed donor opportunities through support in following clinical guidelines, improving quality of available information, and varying risk tolerance thresholds.

MATERIALS AND METHODS

Study Cohort

We conducted an observational cohort study using data from the NSW Biovigilance Public Health Registry (Safety and Biovigilance in Organ Donation Study [SAFEBOD]), . Briefly, SAFEBOD linked all potential and actual donors to their administrative health records including the NSW Central Cancer Registry (CCR) and NSW Admitted Patient Data Collection (APDC). The register was initiated under the NSW Public Health Act 2010 and received ethics approval from the University of Sydney Human Research Ethics Committee (project number 2016/758). Records were linked probabilistically, and linkage was completed in 2018 by the Centre for Health Record Linkage. SAFEBOD has previously been used to identify missed donation opportunities relating to blood borne viruses and to identify transplants resulting in cancer transmission and nontransmission. The study population included all potential donors referred to the NSW OTDS for deceased solid organ donation from January 1, 2010, to December 31, 2013, since this was the only period in SAFEBOD with complete data for potential donors (2010–2015) and linked cancer records (1972–2013) because of a 5-y lag in availability of data from the CCR. We excluded potential donors with a non-NSW postcode since the CCR only includes cancers diagnosed in NSW residents, even if the diagnosis occurs interstate. We also excluded those without family consent and those medically unsuitable for reasons other than cancer since they would not have donated regardless of their perceived cancer history. Those remaining were considered potentially suitable for donation. The investigators had access to the full SAFEBOD data set from which the study population was selected.

Perceived and Verified Cancers

We compared information known at time of donation decisions (perceived) with information gleaned from case records in SAFEBOD (verified). Perceived cancers included malignancies or potential malignancies reported in the OTDS donor referral logs, which records transcribed conversations about medical suitability. We supplemented this with cancer details reported for intended and actual donors in the Australian and New Zealand Organ Donor Registry, since these would have been known at time of referral. All in-situ and malignant cancers (except for nonmelanoma skin cancer) must be notified to the CCR under mandate. Therefore, verified cancers were those notified to the CCR, as well as nonmelanoma skin cancers reported as malignant or potentially malignant in any linked SAFEBOD data set (other than OTDS referral logs or Australian and New Zealand Organ Donor Registry).

For all cancers, we assigned a site based on the International Statistical Classification of Diseases for Oncology 3rd Edition (ICD-O) code reported in the CCR. If unavailable, we used the International Statistical Classification of Diseases and Related Health Problems Tenth Revision Australian Modification (ICD-10-AM) code reported in the APDC. If neither ICD-O nor ICD-10-AM were available, 2 coauthors (J.A.H. and A.C.W.) manually assigned a site based on tumor description (A.C.W. is a clinician and provided clinical input to cancer coding). Malignancy and metastases were based on the CCR if available, otherwise ICD-10-AM code from the APDC, or otherwise ascertained from tumor descriptions by 2 coauthors (J.A.H. and A.C.W.). Diagnosis and last treatment dates were based on earliest and most recent reported date across all SAFEBOD data sets. Tumor size and type were based on the most detailed description available in any SAFEBOD data set.

Cancer Transmission Risk

TSANZ clinical guidelines for organ transplantation from deceased donors (henceforth TSANZ guidelines) assist clinicians in estimating the risk of cancer transmission based on tumor details (primary site, malignancy, metastases, diagnosis date, last treatment date, size, and type). Guidelines are similar in the United Kingdom and Europe, with risk estimates based on expert consensus and limited observational studies. Despite the poor quality of evidence to support transmission risk estimates in international guidelines, these estimates are the best available. More importantly, these guidelines form the basis for decisions to accept or decline potential donors and are therefore more relevant than the true transmission risk for identifying missed opportunities for donation.

We applied the TSANZ guidelines to each potential donor in our cohort to categorize their risk of transmission as: not
contraindicated, minimal risk (<0.1%), low risk (0.1%-2%), intermediate risk (2%-10%), high risk (>10%), or contraindicated. We performed this step twice, once based on perceived cancer history only, and again based on verified cancer history.

We dichotomized potential donors as suitable or unsuitable for donation based on transmission risk. There is no established risk tolerance threshold recommended in the TSANZ guidelines, and clinicians’ views differ about what level of transmission risk is acceptable. This means some perceived low-risk potential donors may be declined, whereas some perceived high-risk potential donors may be accepted. For this study, we assumed that low risk ≤2% was an appropriate threshold. Perceived suitable means that we have retrospectively deemed potential donors as suitable based on our assumed risk tolerance threshold and the information that was known at time of referral. If the consulting clinician had a different risk tolerance threshold than our assumption, then a potential donor we deemed perceived suitable may have been declined (or a potential donor we deemed perceived unsuitable may have been accepted). Verified suitable means that we have retrospectively deemed a potential donor as suitable based on our assumed risk tolerance threshold and information from all linked SAFEBOD data sets (including the CCR, which was only available 5-y after referral). We explored alternative thresholds (minimal risk <0.1% and intermediate risk ≤10%) in sensitivity analyses.

We compared agreement between perceived and verified cancers as proportions, by primary cancer site. We also compared agreement between perceived and verified transmission risks, and between perceived and verified suitability, as proportions and using Cohen kappa (κ).

Missed Opportunities and Excess-Risk Donors
A missed opportunity was any potential donor who was verified suitable but did not donate. They may have been declined because they were perceived unsuitable (eg, because of inaccurate information available at referral), or they may have been declined despite being perceived suitable (eg, if the consulting clinician had a lower risk tolerance than we assumed). Conversely, an excess-risk donor was any actual donor who was verified unsuitable. They may have been accepted because they were perceived suitable (eg, because of insufficient information available at referral), or they may have been accepted despite being perceived unsuitable (eg, if the consulting clinician had a higher risk tolerance than we assumed).

We considered 3 potential strategies to improve utilization of missed opportunities: decision support, real-time data linkage, and increased risk tolerance. Decision support encompassed any intervention that would assist clinicians to follow the TSANZ guidelines consistently, bringing individuals’ risk tolerance in line with our assumed low-risk threshold. How this could be implemented is beyond the scope of this study but could potentially be provided through an application where details of a potential donor’s cancer are entered and a recommendation is returned. Real-time data linkage would allow clinicians to search potential donors’ cancer history in existing health databases, specifically the CCR and APDC. We assumed this would be in addition to decision support, since we were unable to assess how any strategy would affect decisions if clinicians applied their own individual risk thresholds. Again, how this might be implemented is beyond the scope of this study but could potentially involve providing OTDS staff with remote access to NSW health data sets. Increased risk tolerance would involve applying a higher risk threshold for determining perceived suitability (ie, instead of a low-risk threshold we would use an intermediate-risk threshold). The threshold for verified suitability would remain the same (ie, low risk ≤2%) to ensure the definition of a missed opportunity and an excess-risk donor is unchanged to allow for direct comparison with other strategies. This was also assumed to be in addition to decision support.

For each potential strategy, we constructed a counterfactual scenario where perceived suitability could differ but verified suitability remained the same (since it is based on the best information available retrospectively). Decisions would be reversed if perceived suitability changed; some declined potential donors may instead be accepted, whereas some actual donors may instead be declined. Ideally, each strategy would always result in positive changes; however, appropriate decisions might also inadvertently be reversed. For example, a potential donor perceived to be low risk may have been declined because the consulting clinician had a very low risk tolerance. Under decision support, this decision would be reversed, and the potential donor would instead be accepted. However, if they were verified to be high risk, then this would be a negative outcome resulting in an additional excess-risk donor. To account for this, we evaluated each strategy by comparing changes in the number of missed opportunities (fewer is better) and changes in the number of excess-risk donors (fewer is better).

RESULTS
Study Cohort
There were 1706 potential donors referred for solid organ donation in NSW from 2010 to 2013, and 1694 (>99%) were NSW residents. Among these, 1222 (72%) would not have proceeded to donation regardless of their cancer history including 494 (40%) because of lack of family consent, 149 (12%) because of medical reasons other than cancer, and 579 (47%) because of both lack of consent and medical reasons other than cancer. Therefore, 472 (28%) were potentially suitable donor referrals and included in our study cohort. Of these, 340 (72%) became actual donors, whereas 132 (28%) were declined for donation because of their perceived cancer transmission risk. The potential donors included in our study cohort, and their donation outcomes, are presented in Figure 1.

Verification of Perceived Cancers
Among 472 potentially suitable donor referrals, 156 (33%) were perceived to have a history of at least one cancer. There were 175 perceived cancers in total, and 106 (61%) were verified in linked health records. The most common perceived cancers were blood (n = 26), brain/central nervous system (n = 19), breast (n = 19), colorectal (n = 16), and melanoma (n = 15). The number of perceived cancers by primary site and their verification is presented in Figure 2, and the number of verified cancers by primary site are presented in Figure S1, SDC, http://links.lww.com/TXD/A384.

There were 397 (84%) potentially suitable donor referrals with agreement between perceived and verified cancer transmission risk (κ = 0.72) and 432 (91%) with agreement between perceived and verified suitability (κ = 0.77). Agreement under sensitivity analysis scenarios is summarised in Table S1, SDC, http://links.lww.com/TXD/A384.

Of the 156 potentially suitable donor referrals with at least one perceived cancer, 132 (85%) were declined and
24 (15%) donated. Only 93 (60%) had their entire cancer history verified, and 100 (64%) had at least one perceived cancer verified. The 132 declines were because of perceived cancer transmission risk, as reported in a dedicated field for reason for decline in the OTDS donor referral logs. Compared with the 24 with perceived cancer who were accepted for donation, those who were declined were of a similar age (median 61 versus 63, \( P = 0.5 \)), were of similar sex (female 45% versus 38%, \( P = 0.5 \)), and had fewer other comorbidities (mean 0.8 versus 1.9, \( P < 0.001 \)). Therefore, it is unlikely there was any other systematic reason that these potential donors were declined, so we would expect that if it were not for their perceived cancer, they would have been accepted. The characteristics of potential donors with at least one perceived cancer and their donation outcomes are summarized in Table 1.

FIGURE 1. Flowchart of donation outcomes for potential solid organ donor referrals in New South Wales (NSW).

FIGURE 2. Perceived cancers and their verification from linked cancer registry records by primary site. CCR, Central Cancer Registry; OTDS, Organ and Tissue Donation Service.

1 Includes three people who recovered after referral (i.e. medically unsuitable), and were later referred again
2 Based on postcode, and includes postcodes that cross a NSW border
3 Donor referrals who potentially could have donated if we ignore their cancer history. Includes all actual donors, and those declined because of their perceived cancer transmission risk
4 Includes 20 donors (6%) with no organs used for transplant
TABLE 1. Characteristics of potentially suitable donor referrals with at least one perceived cancer transmission risk

| Characteristics | Declined for donation | Accepted for donation | Overall |
|-----------------|-----------------------|-----------------------|---------|
|                 | Verified unsuitable    | Verified suitable Missed opportunities | Total | Verified unsuitable Excess-risk donors | Verified suitable | Total | P* |
| N (row %)       | 94 (60)               | 38 (24)               | 132 (85) | 5 (3) | 19 (12) | 24 (15) | 156 (100) |
| Age, median (IQR) | 61.5 (50–71)         | 67 (51–71)           | 63 (51–72) | 61 (60–62) | 61 (54–64) | 61 (56–63.5) | 62 (52–71) | 0.5 |
| Female          | 41 (44)               | 19 (50)               | 60 (45) | 3 (60) | 6 (60) | 9 (32) | 19 (44) | 0.5 |
| Comorbidities, mean (SD) | 0.8 (0.96) | 0.9 (1.11) | 0.8 (1.00) | 1.2 (1.10) | 2.1 (1.15) | 1.9 (1.18) | 1.0 (1.10) | <0.001 |
| Hypertension    | 17 (18)               | 9 (24)                | 26 (20) | 0 (0) | 9 (47) | 9 (38) | 35 (22) |
| Hyperlipidemia  | 4 (4)                 | 1 (3)                 | 5 (4) | 2 (40) | 9 (47) | 11 (46) | 16 (10) |
| Chronic liver disease | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 1 (5) | 1 (4) | 1 (<1) |
| Chronic kidney disease | 4 (4) | 2 (5) | 6 (5) | 1 (20) | 2 (11) | 3 (13) | 9 (6) |
| Diabetes (T1 or T2) | 5 (5) | 5 (13) | 10 (8) | 0 (0) | 5 (26) | 5 (21) | 15 (10) |
| Respiratory disease | 10 (11) | 3 (8) | 13 (10) | 1 (20) | 5 (26) | 6 (25) | 19 (12) |
| Infection       | 11 (12)               | 7 (18)                | 18 (14) | 0 (0) | 1 (5) | 1 (4) | 19 (12) |
| Ischemic heart disease | 20 (21) | 7 (18) | 27 (20) | 2 (40) | 8 (42) | 10 (42) | 37 (24) |

P* values calculated using Wilcoxon rank-sum test for age, comorbidities, and perceived risk and Fisher exact test for sex.

Missed Opportunities and Excess-Risk Donors

Among 132 potential donors declined due to perceived cancer transmission risk, 38 (29%) were verified suitable (ie, missed opportunities). Among 340 actual donors, 5 (1%) were verified unsuitable (ie, excess-risk donors). Perceived and verified risk of all potentially suitable donor referrals is summarized in Table 2, and the primary site of cancers among missed opportunities is summarized in Table S2, SDC, http://links.lww.com/TXD/A384.

Decision support would result in 5 more suitable donors being accepted, which is 5 (13%) fewer missed opportunities (n = 33 missed opportunities, 13% reduction from n = 38). Unfortunately, this would also result in 2 more unsuitable donors being accepted, which is 2 (40%) more excess-risk donors (n = 7 excess-risk donors, 40% increase from n = 5). There would be 7 (2.1%) more donors overall (n = 347 donors, 2.1% increase from n = 340).

In conjunction with decision support, real-time linkage to the CCR and APDC would result in 6 (16%) fewer missed opportunities, 2 (40%) fewer excess-risk donors, and 4 (1.2%) more donors overall. Incrementally (ie, in addition to decision support) this would mean one (3%) fewer missed opportunity, 4 (57%) fewer excess-risk donors, and 3 (0.9%) fewer donors overall.

In conjunction with decision support, increased risk tolerance would result in 6 (16%) fewer missed opportunities, 11 (220%) more excess-risk donors, and 17 (5.0%) more donors overall. The 11 excess-risk donors include 5 verified intermediate risk who may be considered suitable. Excluding those verified intermediate risk, there would be 6 (120%) more excess-risk donors. Incrementally (ie, in addition to decision support) this would mean one (1%) fewer missed opportunity, 9 (129%) more excess-risk donors (including 5 intermediate risk who may be considered suitable), and 10 (2.9%) more donors overall.

The impact of each strategy is summarized in Figure 3, and the impact under alternative risk thresholds explored in sensitivity analyses are presented in Figure S2, SDC, http://links.lww.com/TXD/A384. The calculations used to determine the impact of each strategy are shown in further detail in Tables S4 through S7, SDC, http://links.lww.com/TXD/A384.

DISCUSSION

We analyzed an observational cohort of potentially suitable deceased donor referrals from NSW during 2010 to 2013 and found that information available at referral relating to potential donors’ cancer history was lacking. Despite this, perceived cancer transmission risk was mostly accurate. Nevertheless, more than a quarter of those declined for donation because of a perceived cancer transmission risk were verified as suitable using linked health records and were classified as missed opportunities. Decision support could marginally reduce missed opportunities but would also increase the number of excess-risk donors. Although it is unclear whether the benefits of increasing donation outweigh the costs of increasing transmission risk, this trade-off could be mitigated with real-time data linkage to existing health data sets, which would reduce both missed opportunities and excess-risk donors.

These findings demonstrate that relatively simple interventions to utilize potential donors with a history of cancer more efficiently could provide small improvements in terms of the quantity and suitability of donors. A single donor provides an average of 3.3 organs, so even a small increase in the annual donation rate translates to a very real and meaningful difference for the 1700 people waiting for an organ transplant. Strategies to avoid missed opportunities among potential donors with cancer may be worthwhile pursuing in conjunction with other efforts, such as increasing family consent rates. Indeed, our study highlights the broader point...
that information available at referral relating to other diseases could also be verified to potentially increase the pool of available organs, for example, infectious diseases such as HIV and hepatitis B and C.\textsuperscript{16}

Our findings are likely relevant to other jurisdictions within Australia because of similarities in organ donation systems. It may be challenging to identify missed opportunities in other countries that do not collate donor referral information.\textsuperscript{26} In

\begin{table}
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\begin{tabular}{l c c c c c c c c c}
\hline
\textbf{Perceived and verified cancer transmission risk for potentially suitable donor referrals with transmission risks estimated using TSANZ guidelines} & & & & & & & \\
\textbf{Verified risk} & \textbf{Declined for donation} & \textbf{None} & \textbf{Not contraindicated} & \textbf{Minimal risk (<0.1\%)} & \textbf{Low risk (0.1\%–2\%)} & \textbf{Intermediate risk (2\%–10\%)} & \textbf{High risk (>10\%)} & \textbf{Contraindicated} & \textbf{Total} \\
\hline
\textbf{None} & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 \\
\textbf{Not contraindicated} & 0 & 2 & 0 & 0 & 0 & 0 & 0 & 2 & 4 \\
\textbf{Minimal risk (<0.1\%)} & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 \\
\textbf{Low risk (0.1\%–2\%)} & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 1 & 4 \\
\textbf{Intermediate risk (2\%–10\%)} & 0 & 1 & 0 & 0 & 5 & 0 & 4 & 10 \\
\textbf{High risk (>10\%)} & 0 & 6 & 0 & 0 & 0 & 6 & 5 & 17 \\
\textbf{Contraindicated} & 0 & 25 & 0 & 1 & 0 & 0 & 71 & 97 \\
\textbf{Total} & 0 & 34 & 0 & 4 & 5 & 6 & 83 & 132 \\
\hline
\textbf{Actual donors} & 283 & 24 & 0 & 0 & 0 & 0 & 0 & 307 \\
\textbf{None} & 0 & 25 & 0 & 0 & 0 & 0 & 0 & 28 \\
\textbf{Not contraindicated} & 0 & 2 & 0 & 0 & 0 & 0 & 0 & 2 \\
\textbf{Minimal risk (<0.1\%)} & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 \\
\textbf{Low risk (0.1\%–2\%)} & 0 & 0 & 0 & 1 & 0 & 0 & 1 & 2 \\
\textbf{Intermediate risk (2\%–10\%)} & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 \\
\textbf{High risk (>10\%)} & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 \\
\textbf{Contraindicated} & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 1 \\
\textbf{Total} & 283 & 51 & 0 & 1 & 0 & 0 & 5 & 340 \\
\hline
\end{tabular}
\caption{Perceived and verified cancer transmission risk for potentially suitable donor referrals with transmission risks estimated using TSANZ guidelines.}
\label{tab:transplantation}
\end{table}

\begin{figure}
\centering
\includegraphics[width=\textwidth]{figure3.png}
\caption{Change in number of verified suitable and unsuitable donors with each potential strategy to reduce missed opportunities and excess-risk donors under a low-risk threshold. APDC, Admitted Patient Data Collection; CCR, Central Cancer Registry.}
\end{figure}

*One potential donor with a malignant melanoma (perceived and verified) was accepted for donation.

TSANZ, Transplantation Society of Australia and New Zealand.
2019, the NSW OTDS began linkage to the cancer registry, but we currently have insufficient data to determine the effectiveness of this measure. Furthermore, TSANZ guidelines have recently been reviewed and now include changes to estimated transmission risks, revising some cancers to a lower risk category, which will likely increase donation.27

A major strength of this study is the use of comprehensive linked data from SAFEBOD. Including many health data sets means it is unlikely any transmissible cancers diagnosed or treated whilst resident in NSW have been missed. Although some nonmelanoma skin cancers diagnosed or treated in private clinics may not be reported in SAFEBOD, these are not contraindicated for donation28 and would, therefore, have little impact on our findings. Despite only including potential donors from NSW, it remains possible that some who moved to NSW had previous cancer diagnoses interstate, which would not be verified in SAFEBOD, and hence, accuracy of perceived information may be underestimated.

Although SAFEBOD includes the CCR records from 1972, these only extend until 2013 despite the linkage for SAFEBOD being completed in 2018 (ie, a 5-y lag). It is possible that cancers diagnosed before 1972 have been missed, but unlikely that these would be relevant to determining transmission risk without a more recent recurrence reported in other SAFEBOD data sets (eg, APDC). Restricting our study period to the end of 2013 limits the relevance of our findings to current practice; however, because of the lag in CCR data availability, this delay was unavoidable. Attitudes to cancer transmission risk are unlikely to have changed significantly over time, so we would expect to find a similar number of missed opportunities if more recent data were available. Based on our findings, we expect that the introduction of linkage to the cancer registry by the NSW OTDS in 2019, without any additional decision support, has had only a small impact overall. Although electronic medical records were introduced across Australia in 2019, these have not been widely used until very recently and are, therefore, unlikely to have impacted donation practices.28

A limitation of our study is that potential donors reported as declined due to perceived cancer may have been declined for multiple reasons, so they may not have been accepted even in the absence of a perceived cancer. Considering that those declined due to perceived cancer are of a similar age and have fewer comorbidities than those who were accepted despite a perceived cancer suggests that these potential donors may have been accepted had they not had a perceived cancer. Furthermore, we have assumed that clinicians’ decisions to accept or decline a potential donor are based on the donor’s characteristics and medical history alone. In practice, other factors may also influence this decision, such as which organ is being considered or the recipient’s age. We lacked data on individual organ offers to transplanting centers, hence we could only account for donor-level factors in our analysis. It is possible that some of the missed opportunities we identified may have been because a potential donor was declined without considering all potential recipients.

We have demonstrated that missed opportunities could be better utilized to slightly increase donation without necessarily compromising recipients’ safety; however, bigger increases inherently involve a trade-off between increasing donation and reducing cancer transmission risk. Future work using SAFEBOD will focus on identifying cases of donor to recipient transmissions to provide further evidence to evaluate the costs and benefits of our proposed strategies for increasing donation and to support policy decisions.

CONCLUSIONS

Information about potential donors’ cancer history available at referral is lacking; however, overall perceived cancer risk is nevertheless relatively accurate. Despite this, there are a substantial number of missed opportunities where decision support and more accurate cancer history would have resulted in more donations, without necessarily compromising safety.

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