



Australian Government
Organ and Tissue Authority

Report on the Community Consultative Forum:
Contact between donor families and transplant recipients

Friday 17 March 2017, Melbourne, Victoria

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Executive Summary

Anonymity of deceased donation is a legal, ethical and social norm in Australia and internationally, although some families and recipients, and some community groups have advocated strongly for donor families and recipients to have the option of disclosing their identity and making contact with one another. Direct contact offers potentially significant benefits to those who desire it, but also poses significant risks, regardless of whether contact is arranged informally within the community or is overseen by donation agencies.

This report outlines the events of the one-day Community Consultative Forum (the Forum) convened by the Organ and Tissue Authority (OTA) to explore questions concerning waiver of anonymity and direct contact occurring between deceased donor families (donor families) and transplant recipients (recipients) in Australia. The Forum was held in Melbourne on 17 March 2017, and included 38 participants representing donor families, transplant recipients, peak bodies, governments and the DonateLife Network. It drew on an *Issues Paper* (refer [Appendix A](#)) and employed a facilitated workshop format to provide all stakeholders with the opportunity to comment and provide suggestions with regards to key issues, concerns, and strategies for future change.

Potential benefits of direct contact identified by participants focused on the possibility of providing transplant recipients with the opportunity to show their appreciation to donor families by saying thank you in person, enabling donor families to personally observe the beneficial impact of the donation, promoting healing and closure for families and recipients, and enabling families and recipients to learn more about one another and fostering recognition of the donor as a person. Potential risks identified by participants centred on concern for the emotional impact of mismatched expectations of donor families and recipients, the possibility of stalking, harassment or extortion of families or recipients, the increased risks associated with independently arranged contact which lacks protections and support such as informed consent by both parties, and professional counselling and third party oversight.

The Forum revealed a broad range of opinions and beliefs regarding the issue of direct contact among Australian donor families and transplant recipients. In relation to a system of facilitated direct contact, participants outlined that it should only occur with the mutual consent of families and recipients who should be appropriately counselled and provide informed consent prior to disclosure of their identity, and initial contact should ideally be facilitated by a neutral third party. The need for policies and strategies that protect core values and concerns, such as the individual right to privacy, while providing opportunities for people to act on their own informed choices when these do not conflict with the choices of other people was highlighted. The importance of educating policy makers and health professionals, and engaging community groups and stakeholders in ongoing discussion about these complex issues was also emphasised.

Participants also discussed the current system of anonymous correspondence between families and recipients in Australia, suggesting that efforts to improve the system should be prioritised. Key strategies proposed focused on increasing support and availability of counselling to families and recipients, providing families and recipients with a better

understanding of the value of, opportunities for, and expectations of anonymous correspondence, improving consistency and availability of information and education on how to correspond for recipients, reducing risks of unwanted identity disclosure, improving tracking of correspondence and consistency of feedback to those who send or receive correspondence. A full listing of the suggestions made by participants at the Forum is also included at [Appendix C](#).

A range of outcomes for consideration by OTA and the DonateLife Network in the future are:

1. Implementation of strategies to improve the current program of anonymous communication between donor families and recipients.
2. Provision of advice and information to donor families and transplant recipients regarding protection of their identity and privacy, particularly with regards to social media use.
3. Support for development of guidelines or advice for those who choose to independently pursue direct contact.
4. Development of policy or guidelines relating to management of accidental identity disclosure and involuntary identification of families or recipients.
5. Discussion with states and territories regarding the possibility of legislative or policy change permitting identity disclosure and facilitation of direct contact when mutually desired by families and recipients.

Introduction

The Community Consultative Forum (the Forum) was convened by the Organ and Tissue Authority to explore questions concerning waiver of anonymity and direct contact occurring between deceased donor families ('donor families') and transplant recipients ('recipients') in Australia. The Forum brought together a range of participants: 12 members of donor families, 14 transplant recipients, and 12 members or representatives of peak bodies, governments, and the DonatLife Network. The Forum was facilitated by bioethicist Dr Dominique Martin from Deakin University.

Background

Legislation and policy in Australian states and territories currently mandate anonymity of deceased donation, precluding disclosure of identity and facilitation of direct contact between donor families and recipients. However, in Australia and in other countries, families and recipients are increasingly using social media and news reports about donation and transplantation to identify their "match" and establish contact. Such independently arranged contact also occurs in the United States and Israel, where donation agencies have long provided formal opportunities for families and recipients to meet when they both consent to identity disclosure and facilitation of contact. Some community groups have recently begun advocating for changes to Australian policy in order to make it easier for families and recipients to connect when they wish to do so.

An Issues paper ([Appendix A](#)) was provided to participants in advance of the Forum. This paper summarised the potential risks and benefits of contact between families and recipients, reviewed international experience of direct contact, and briefly discussed potential strategies to address the issue in the Australian context. Three community groups, Donor Families Australia, Transplant Australia, and LiverKids independently conducted surveys of their membership and findings were presented at the Forum.

Purpose of the Forum:

The intent of the Forum was not to achieve consensus of viewpoints but rather to have a conversation on this topic and to listen to and consider the views of participants from a range of sectors: donor families; transplant recipients; peak body organisations; and government. The Forum:

- provided an opportunity for sharing and open discussion of different Australian stakeholder experiences, perspectives and insights into the complex issue of direct contact between donor families and recipients.
- improved knowledge of this issue, and promote awareness and understanding of the diversity of public opinions among different stakeholder groups.
- provided outcomes from the forum for the Organ and Tissue Authority to consider as current, emerging and future issues relating to direct contact between donor families and recipients.

A series of questions for discussion were put to the Forum participants (refer to the Agenda for the Forum at [Appendix B](#)), however the conversation was encouraged to flow freely.

Key points of the Issues Paper

Key points from the Issues paper discussed at the Forum included:

- anonymity of deceased donation remains the international norm;
- despite two decades of experience with programs of facilitated contact in Israel and the US, as few as 1% of donor families and recipients establish direct contact through programs each year;
- people in Australia and internationally are using social media and news reports to identify and establish contact with their suspected matching families or recipients; and
- in Australia, families and recipients are currently provided with opportunities to communicate with one another through anonymous written correspondence managed by DonatLife and transplant agencies.

The potential benefits of direct contact were also discussed and may vary according to how contact is established. Potential benefits include:

- families may be reassured about the donation decision;
- recipients may be able to express their gratitude more effectively in person;
- families and recipients may share and receive more information about the donor as a person;
- both parties may achieve a sense of peace or closure;
- publicity around reports of contact between families and recipients, may help to promote donation.

The potential risks of contact and motivations for avoiding identity disclosure and direct contact were also discussed and include:

- disappointment with the other party;
- exacerbation of grief on the part of the donor family or guilt on the part of the recipient;
- potential for emotional or financial manipulation or exploitation;
- difficulties managing a relationship when expectations are mismatched.

A donor family member noted that the Issues paper identified options for future policy and practice in Australia that consisted of maintaining the status quo, providing support that would reduce the risk of harm in the current environment, or eventually providing the opportunity for direct contact when desired. It was highlighted that the Issues paper did not consider the possibility of taking action to eliminate any risk of direct contact occurring, for example by prohibiting and preventing independent efforts to disclose identities and arrange direct contact.

Stakeholder organisations present survey findings from their membership on direct contact

Three stakeholder organisations – Donor Families Australia, Transplant Australia, and LiverKids – presented their findings from public surveys they conducted on the topic. In brief, while the results cannot be compared as the survey tools used were different for each group, overall, the majority of members agreed that consenting parties should be able to meet under controlled conditions with a facilitator in attendance.

Potential benefits of direct contact between families and recipients

When participants were asked to identify potential benefits of direct contact, several core themes emerged:

- ***Providing transplant recipients with the opportunity to show their appreciation by saying thank you in person***

Participants commented that saying thank you in person could be easier, for example if they have difficulties with written communication, and more authentic or meaningful than an anonymous written letter or card.

- ***Enabling donor families to personally observe the beneficial impact of the donation***

Being able to personally witness the positive impact of the transplant on the recipient's life, seeing that the donor is healthy and appreciative were emphasised as valuable potential benefits of direct contact for donor families. Witnessing the success of a transplant was identified as a potential source of solace if the donation process or decision was difficult. From the recipient perspective, direct contact was potentially a way to more effectively convey the positive outcome of the transplant.

- ***Promote healing and closure***

A donor family that had met with one of the recipients reported that this gave them a sense of peace and closure, and that it was “very therapeutic” to know how the recipient was going. For recipients, being able to convey their thanks and know that they are received may also help with closure. One participant noted that a recipient might benefit from feeling “worthy” of the donation after meeting the family. The potential impact of direct contact on donor families’ “healing”, and providing reassurance to families, “being able to rest easy”, was noted several times.

- ***Finding answers, humanising the donor and personalising donation¹***

Many participants spoke of direct contact as way to address the desire of both recipients and donor families for more information about one another. Some reported that direct contact could address needs for answers to questions about the transplant outcomes or the death of the donor, but many more spoke less specifically about the desire to “know more” or simply “find answers”. For some, the potential benefits of discovering more information seemed premised on expectations or hopes regarding the character, life story or other

¹ During the day, participants twice commented that this is an emotional topic, and care should be taken in the wording of legislation or guidelines to be respectful and also retain a sense of humanity.

personal attributes of donors, donor families, and recipients. One participant noted that their desire for information about the donor had reduced with time.

The desire for more information relating to the donor on the part of some recipients was matched by donor families' desire to share stories about the donor, with both highlighting the value of restoring the donor's identity as more than simply a "donor", humanizing or personalising the donation. Some recipients described the "deep sense of needing to know who the donor is", putting a "human face" to the event, and "putting a name" to the donor. One participant described "turning an intangible experience into a tangible" one as a potential benefit of direct contact.

- ***Additional comments***

Participants also reported that having the option of direct contact would respect the autonomy of recipients and donor families, and that publication of stories of positive experiences of direct contact would help to promote and therefore increase donation. Others commented that direct contact should be cautiously approached and dependent on mutual consent, and one family with experience of direct contact emphasised the need to get to know one another through written correspondence prior to direct contact.

Potential risks of direct contact between families and recipients

When participants were asked to identify potential risks of direct contact, several core themes emerged:

- ***Emotional impact of mismatched expectations***

A participant noted that one party might be hurt if the other party declined to have direct contact. Several commented on the risk that donor families and recipients might have different expectations regarding the nature of their relationship once direct contact occurs, with one party desiring a closer or more permanent relationship than the other.

Both recipients and donor families expressed concern that the recipients might fail to meet the expectations of donor families resulting in guilt on the part of the recipients and disappointment and grief on the part of donor families. The potential for disappointment with regards to the lifestyle, culture, and beliefs of both parties was noted.

Recipients also noted that in the immediate aftermath of transplantation they may not be in good health and would be fearful of disappointing donor families. One recipient described her shock at seeing a comment on social media from a donor family expressing disappointment that they had not received a written thank you from recipients in the first couple of months following donation, and described the lengthy process of her own recovery before she was well enough to even consider writing a note of thanks. Graft failure, or the death of a transplant recipient were also noted as potential sources of disappointment, anger and grief for donor families if direct contact were established or the identity of the recipient was disclosed.

- ***Risks of stalking, harassment or extortion***

Several participants commented on the potential for financial extortion, stalking behaviours

or harassment occurring following identity disclosure and direct contact. A recipient recounted the experience of a fellow recipient who was identified by a donor family and subjected to stalking and harassment requiring police intervention. Social media was identified as one way in which stalking behaviours may currently occur when suspected matches are identified.

- ***Risks associated with independently arranged contact***

Many participants believed that some risks could be reduced, if not eliminated if contact were facilitated by an organisation such as DonateLife, for example by providing counselling before, during and after contact is made. Lack of controls, protections and support for mental health were highlighted as exacerbating risks of direct contact in the current context. Particular risks were described in the context of the current environment in which contact may occur through mutual efforts of both parties to connect via social media or unilateral efforts to identify a recipient or donor family. These included unwanted loss of privacy, errors in assumptions about matches, stalking behaviours, and potential for disappointment if one party fails to follow through with promises of contact.

- ***Additional comments***

A donor family member spoke strongly about his desire to protect the privacy of his family, and wish to avoid constant reminders of their sibling's death in the form of expressions of gratitude and commendations of the family's "heroism" in approving donation, with the family member emphasising specific dislike for the term hero. It was observed that if people became fearful of suffering harassment or loss of privacy they may prefer not to donate.

The mother of a paediatric transplant recipient expressed concern about making decisions on behalf of a child with regards to identity disclosure and contact which would have an enduring impact. Some participants also noted the potential for negative stories of direct contact to negatively influence donation rates if made public.

Strengthening current programs of communication between donor families and recipients

Participants were asked to consider what support donor families and recipients might need if facilitation of direct contact by a third party took place, and what information transplant candidates and potential donors or donor families may wish to know about this issue. However, much of the afternoon discussion focused on opportunities to improve the current program of facilitated anonymous contact rather than a putative program of direct contact.

- ***Increasing support and availability of counselling***

While participants from some regions spoke very positively of their experiences coping with donation and transplantation and the support provided by transplant centres, hospitals and the DonateLife network, others reported the lack of counselling and support services.

Representatives of DFA suggested that DonateLife could provide more assistance to them in establishing and promoting local support groups of donor families, particularly in rural and regional areas where distance can make it difficult for people to meet. However others

noted that many recipients and donor families do not wish to participate in such groups, and problems may arise if groups are informally set up and lack professional supports and oversight but have endorsement from a governmental agency. A previous attempt by DonateLife to establish a family support group was noted, which was unsuccessful due to lack of public uptake. It was suggested that cards issued to donor families could provide a list of community support groups and their contact information, and clearer designation of a “go-to” person for support after donation would be helpful.

One donor family member commented that the amount of support provided to grieving donor families, in particular from DonatLife, is exceptional when compared with the level of support available for families who suffer equally tragic losses but for whom donation is not an option or is declined.

- ***Informing and educating transplant recipients***

Providing more education to families and recipients, as well as transplant professionals was recommended. Parents of paediatric recipients and liver transplant recipients at the Austin reported receiving excellent advice and information. However transplant recipients reported significant variation in their exposure to education, receipt of information and quality and timing of counselling. The timing of information delivery was noted as important, with one recipient describing an information session which took place a month after transplantation when most recipients were on pain killers and not retaining a lot of new information. The need to refresh information for those who have been waiting for a transplant for some time was noted.

Some recipients reported they were unprepared for the mental health issues that could arise following transplantation, and were not aware of advice available regarding what, when, and how to communicate their thanks to donor families. Assistance with writing may be especially needed by transplant recipients with literacy issues which may be as a result of ill health during their schooling years.

- ***Reducing risks of unwanted identity disclosure in the current environment***

Participants suggested that families and recipients may need more or clearer advice regarding protection of their privacy, for example relating to the importance of concealing the dates and times related to the donation or transplantation. Addressing privacy risks inherent to use of social media platforms was deemed particularly important, with some participants noting that well-meaning family and friends may play a part in identifying “matches” or revealing information about one party.

The role of the media was highlighted both positively and negatively. Although DonateLife provides support in the form of state and territory communications managers, the media may directly connect with recipients and families and may be unaware of the potential sensitivities and issues relating to privacy protection. Providing education and raising awareness of the privacy issues related to media activity among families, recipients and health care institutions was recommended. A Children’s Hospital for example, no longer includes the last names of children in media releases relating to transplantation.

- ***Additional steps to address issues with written communication***

Better tracking of correspondence and routine reporting of outcomes to senders was strongly recommended. Offering alternative methods for anonymous communication other than written correspondence, such as email or video recordings, or establishing an electronic system of de-identified communication between families and recipients were all proposed. Technical difficulties in overseeing some proposed alternative methods of communication, and preserving privacy and anonymity were noted.

A donor family member commented that by indicating they were willing to receive correspondence from transplant recipients in a questionnaire at the time of donation, they formed the expectation that such correspondence would occur. More information for donor families to establish realistic expectations of correspondence and foster understanding of the reasons why recipient may not write would be helpful in reducing disappointment. Both participants from donor families and recipients appeared to have particular understandings about who should write first, suggesting the need for clearer information to be provided to both parties.

Potential features of a direct contact program

Some participants believed that direct contact between some families and recipients is inevitable, given that this is already occurring and many people would like the option of pursuing contact. While some suggested that guidelines and services should be established quickly, others advocated prioritising improvements to the current program and learning more about experience in other countries and what donor families and transplant recipients in Australia may want. There was consensus that direct contact should never be imposed on people without their consent, and support for people to protect their identity if desired is important.

- ***Potential structure of a formal program for direct contact in Australia***

While many participants seemed in favour of a governmental agency establishing and maintaining a direct contact program, at least initially, some suggested that community groups or nongovernmental organisations could be accredited to undertake work such as counselling and emotional support. The need for an independent facilitator for any initial contact was emphasised. Some participants identified particular issues that should be addressed in counselling for people prior to their decision to disclose their identity and establish direct contact, such as exploring the expectations of each party, discussing potential concerns regarding culture and values, and fully inform both parties of potential benefits and risks of contact.

A participant suggested that current programs which facilitate contact between adult adopted children and their birth parents may serve as a useful model. These involve group counselling with a psychologist prior to the individual decision to join a register of those willing to pursue contact. When both parties consent, a supervised meeting is arranged and only first names are disclosed so that people may progress more at their own pace in establishing closer contact or disclosing personal information.

It was noted that preferences for contact may change over time, and DonateLife should maintain contact with families and recipients, and perhaps reinform them about

communication options after a period of time has passed.

- ***Potential difficulties in establishing a program of direct contact***

Potential issues of resourcing a program of direct contact were noted. It was also noted that paediatric transplant recipients have a right to privacy, and any system of direct contact must address the issue of consent or assent for disclosure of the identity of a paediatric recipient.

In relation to tissue donors, there could be many transplant recipients, and if many of these wished to meet with the donor family, it might be a negative experience. The need to identify legal risks that might be associated with particular models of contact was flagged.

Additional themes and comments

- ***Diversity of public opinion and preferences***

Throughout the day a range of opinions were presented. There was consensus that each donor, donor family and transplant recipient may have different perspectives and needs, and as such there is 'no one size fits all' approach to the issue of identity disclosure, communication and contact between families and recipients. Positive and negative experiences and divergent preferences were reported with respect to anonymous correspondence, support for recipients and families, celebrations of donors, and direct contact between families and recipients.

- ***The importance of engaging policy makers and community stakeholders***

A participant commented that policy makers need to know what donor families and recipients want, while another observed that the Forum was an appreciated opportunity to share information with policy makers. The need to recognise stakeholder groups and support community-based advocates was highlighted by some participants.

- ***Education and awareness***

Some participants suggested that more investment in education and awareness campaigns in schools, universities and in mass media would be helpful in informing the public and encouraging donation, while another observed that educating policy makers was also critical. One participant suggested that death certificates should be revised to indicate when individuals had donated.

Conclusion

A key finding from the Forum was the consensus that each donor, donor family and transplant recipient may have different perspectives and needs, and as such there is no 'one size fits all' approach to the issue of identity disclosure, communication and contact between families and recipients.

Stakeholder survey results presented at the Forum and evidence from international research show that, in principle, many people support the idea that families and recipients should have the option of seeking direct contact. Comments raised by Forum participants along with international experience indicates that some individuals will choose to pursue contact independently (often via social media), regardless of whether a facilitated program of direct contact is available or not. The complex issue of direct contact should not be

ignored, and efforts should be made to address the concerns associated with direct contact,

Concerns of particular significance that were identified during the Forum included: expectations of donor families and recipients with regards to anonymous correspondence and direct contact; threats to privacy in the context of social media activity; lack of understanding of the potential barriers to, and risks and benefits of, contact between families and recipients (both anonymous and identifiable); and, the possibility that more reports of direct contact between families and recipients could positively or negatively influence deceased donation rates.

Throughout the Forum, participants also discussed opportunities to improve the current program of anonymous communication between families and recipients, in particular by supporting families and recipients to write to one another. Examples of strategies and programs that are working well were highlighted. These comments should encourage and inspire renewed efforts to improve the current system, and make clear that the provision of opportunities for direct contact would not be a substitute for current programs but rather a complementary option.

Many of the core themes that emerged from the Forum discussions highlight preferences and needs that are less concerned with the removal of anonymity in deceased donation and more with the provision of compassionate, supportive care for donor families and transplant recipients. Opportunities to share information and experiences that celebrate the donor as a person, and reveal the value of their gift through transplantation should be considered.

Outcomes from the Forum for consideration

The following outcomes from the Forum may be considered by the DonateLife Network in collaboration with stakeholders and community groups for action. Reference to the range of suggestions made on the day at [Appendix C](#) should also be noted.

- 1. Implement strategies to improve the current program of anonymous correspondence between donor families and recipients**
 - a. Improve tracking of correspondence and routinely provide feedback to senders on receipt or acceptance of correspondence.
 - b. Provide more information to recipients and families about the value of correspondence and the probability of receiving it, explaining factors which may influence timing of correspondence and potential barriers to other parties for writing, so as to foster realistic expectations and understanding.
 - c. Provide more consistent support to recipients and families with regards to writing and sending correspondence.

- 2. Provide advice and information to donor families and transplant recipients regarding protection of their identity**
 - a. Information about the risks of identity being discovered and direct contact sought.
 - b. Strategies to reduce risk relating to social media use, eg. how to use the privacy security settings on Facebook, and advice to friends and family about

social media use.

- c. Strategies to reduce risk relating to journalistic media, including advice on how to get help.

3. Support development of guidelines or advice for those who choose to independently pursue direct contact

- a. Checklist of items to explore and address in counselling
- b. Information about where to get help
- c. Information about potential risks of direct contact, the importance of respecting privacy and confidentiality and the preferences of other parties with regards to contact

The following outcomes from the Forum may be considered by OTA for action. Reference to the range of suggestions made on the day at [Appendix C](#) should also be noted.

4. Development of policy or guidelines relating to:

- a. management of accidental identity disclosure
- b. support of families or recipients who are identified without their consent

5. Discussion with states and territories regarding legislative and/or policy change to permit waiver of anonymity of donation and allow development of a program providing the option of facilitated direct contact

Appendix A – Issues Paper

Direct contact between deceased donor families and transplant recipients

Summary

This paper reviews potential benefits of - and concerns about - direct contact between deceased donor families (“donor families”) and transplant recipients (“recipients”), in order to inform discussion of policies and laws governing such contact in Australia. It is currently not possible for health professionals, the Organ and Tissue Authority (OTA) or DonateLife staff to facilitate the meeting of Australian donor families and transplant recipients because this would require the disclosure of identifying information which is prohibited by law in all Australian states and territories. Contact between families and recipients is limited to anonymous written correspondence coordinated by DonateLife Agencies and Transplant Unit Coordinators.

The available evidence from international studies and experience with direct contact shows there is considerable variation among donor families and recipients regarding their preferences for contact, and their potential motivations for seeking or avoiding contact. Many families and recipients who might support having general opportunities for direct contact may not personally choose to do so even if opportunities are made available. There are several potential benefits and risks associated with direct contact, and risks are likely to be increased when contact occurs as a result of families or recipients independently identifying one another. Many of the risks may be reduced through provision of information, guidance and support to families and recipients regarding their communication options and facilitation of direct contact experiences by donation or transplantation agencies where this is legally allowed.

Introduction

In most countries, including Australia, anonymity and maintaining privacy is a legal requirement of deceased donation programs. While the families of deceased donors or the recipients of organs from deceased donors may choose to reveal their own identity publicly, families are not provided with identifying details of those who receive the organs or tissues of their relative, nor do recipients learn the identity of the donors who made their

transplants possible. When a family and recipient both desire contact, communication between them is permitted through the sharing of anonymous correspondence such as letters or cards. A well established process for exchange of anonymous correspondence between donor families and recipients has been in place in Australia for many years. Written communications are exchanged under the oversight of donation or transplantation agencies which take care to ensure that potentially identifying details are removed from correspondence. However, in the United States of America (USA) and in Israel, the identity of families and recipients may be legally disclosed when both parties desire this, and direct contact may then take place.

There are an increasing number of circumstances where donor families and recipients have made contact after either identifying one another by chance, or by deliberately searching for one another, for example using social media. In this paper, we begin by explaining the standard requirement for anonymity in deceased donation and transplantation, and review current policy and practice in Australia regarding this. We then draw on international experience to discuss the reasons that families and recipients might prefer to have direct contact, or to avoid it. The potential benefits and risks of allowing identity disclosure and direct contact between families and recipients are explored, and finally the options for addressing this issue in Australia are briefly reviewed.

Reasons for anonymity in deceased donation programs

Respect for privacy and confidentiality is a key ethical principle of modern healthcare. This means that when people receive medical treatment, their information is carefully protected and shared only with health professionals and others within the healthcare system when it is necessary for the benefit of the patient, and/or when the patient consents to this information being shared. Even when people die, their private information is protected. When a person becomes a deceased donor, health professionals have a duty to protect their privacy and the privacy of their family. Some families may wish to talk publicly about their relative's decision to be a donor, or about the family's decision to support donation, but others may prefer to keep this private. Similarly, people who receive organ transplants have a right to keep information about their transplant private. Like any patient who undergoes an operation, they can choose whether or not to disclose or share information about their experience with other people.

Laws governing the privacy and confidentiality of healthcare information mean that the identity of deceased donors, donor families and transplant recipients can only ever be disclosed with the consent of the families and recipients. At present, in Australia and most other countries, disclosure of the identity of families and recipients by those in the healthcare system is legally prohibited, even if families and recipients have consented.

Health professionals working in donation and transplantation may have concerns about allowing direct contact between families and recipients. These concerns may be influenced by the fact that protecting the confidentiality and privacy of patients is a fundamental duty of health professionals.

In a recent study of Canadian transplant professionals, while 71% agreed that communication between families and recipients should remain anonymous, 53% also agreed that if there was a mutual desire for direct contact this should be permitted.¹⁵ A shift in the attitudes of health professionals outside Israel and the USA towards permitting direct contact may be due to the fact that it is increasingly easy for families and recipients to identify and contact one another directly using social media. Families and recipients may be more likely to pursue direct contact independently if this option is not available via the donation agency, and such independent contact is likely to carry higher risks than when contact is managed by agencies. Thus permitting and facilitating direct contact could help to reduce risks to both families and recipients.

Current laws governing contact between families and recipients in Australia

In Australia, the donation of organs and tissues for the purpose of transplantation takes place within a legal context. Under Australia's federal system, legal regulation of organ donation is the responsibility of the states and territories under their Acts ('Human Tissue Acts') and associated regulations that govern dealings with human tissue. Legislation is similar across the jurisdictions, though not identical. This legislation generally sets legal requirements for the certification of death, consent to donation, donation of organs, eyes and tissues, and disclosure of information about donors and recipients. Current legislation within each of the jurisdictions contains specific provisions that prohibit the disclosure of information that may identify an organ or tissue donor and/or transplant recipient. Identifying information includes information that could lead to the identification of a person, not necessarily just the names of donors and recipients.

While the provisions are different in each state or territory's Human Tissue Act, they all have the same intent to maintain confidentiality and protect the identity of those who donated organs and tissues, and the identity of those who receive transplants. These Acts operate alongside the relevant Privacy Acts or privacy policies of the jurisdictions. Within each Human Tissue Act there are specified penalties for offences relating to the disclosure of information provisions. In all the jurisdictions the penalty involves either a fine, term of imprisonment, or both. Any change to the current Human Tissue Acts would require policy agreement and legislative amendments by state and territory governments.

When managing and coordinating the Australian organ and tissue donation system and the ongoing care and support of donor families, staff in the DonateLife Network work in accordance with the Human Tissue Act and privacy legislation that applies in the relevant state or territory. DonateLife staff have a legal and ethical responsibility to preserve the privacy of personal details of donors and recipients to ensure their identity is confidential as required under each Human Tissue Act.

Current options for communication between families and recipients in Australia

Although the identity of donors and recipients cannot be revealed, DonateLife Agencies and transplant units facilitate coordination of non-identifying correspondence, e.g. letters or cards, between donor families and transplant recipients. This process makes it easier for recipients to express their thanks to donor families.¹ This is particularly important as family and recipient preferences for contact may change over time, and once identities have been disclosed, the option of remaining anonymous is no longer available.

DonateLife staff and transplant teams also provide advice and support to families and recipients about writing to one another² and review the correspondence to ensure that the anonymity of families and recipients is protected. An Australian study conducted in 2013 that involved 132 families (186 individuals) found that approximately 68% received at least one letter or card from a transplant recipient.¹ Although families who received correspondence found this a very positive experience, not all families wish to receive correspondence: 6% of families in this study chose not to receive correspondence.¹ 24% of families who were willing to receive correspondence had not yet heard from recipients.¹ Some of these families were disappointed, but others expressed understanding that it may not be easy for recipients to write.¹

What do we know about direct contact between families and recipients internationally?

Reasons why donor families and recipients may desire opportunities for direct contact

Two decades ago, before direct contact became widely permitted in the USA, 70% of donor families who participated in an American survey expressed the desire for direct contact with recipients.³ For 61% of these families, the opportunity to see the benefits of the donation “first hand” was the most important reason for wanting direct contact; for 29%, it was to connect with “a part of their loved one”.³ Small scale studies of donor families who have had direct contact with recipients in Israel and the USA suggest that donor families wish to personally witness the benefits of the transplants, to tell the recipients more about the donors, and to reassure themselves that they made the right decision in approving donation.^{4,5} These findings reflect the experience of donation agency staff and studies of donor families in the USA, Australia, Taiwan and Canada which show that donor families often like to receive information about transplant recipients and written communications from them in order to learn more about the impact of donation, to be reassured about the donation decision, and to feel that the donation was appreciated.^{6,5,20,1}

Surveys of transplant recipients in Belgium,⁷ the Netherlands⁸ and Brazil⁹ suggest that many would like the opportunity to have direct contact with donor families in order to express their gratitude for the donation and to share the result of the transplant with the family, to learn more about the donor, and because they believe that stories about meetings between families and recipients may encourage organ donation. A recent study of 179 Belgian liver transplant recipients found that 36% agreed that Belgian law – which currently requires anonymity - should be changed to permit donor families and recipients to get to know each other if they wish.⁵ 42% disagreed, and 22% neither agreed nor disagreed.⁷

Reasons why donor families and recipients may prefer to avoid direct contact

Although surveys suggest many families and recipients believe direct contact between families and recipients should be permitted, they also suggest that fewer people actually want to have direct contact themselves. For example, while 54% of liver transplant recipients in a 2015 Dutch survey agreed that “Anonymity of the donor should not be imposed by law but should be decided upon by the transplant recipient and the donor’s family”, only 19% of the 179 participants said they personally wanted direct contact with their donor family.⁸ Furthermore, in contrast to the American study published in 1996 which

found that as many as 70% of donor families desired direct contact, another American study at that time found that direct contact actually occurred in less than 1% of families who corresponded with recipients.^{3,6} Although direct contact seems to be much better accepted in the USA nowadays, it does not appear to have increased in the last two decades. A recent study reporting on actual contact between families and recipients during a three year period in one region of the USA, found that less than 1% of organ donor families had direct contact with a recipient, despite this being legally permitted and facilitated by donation agencies.⁶

Direct contact between families and recipients seems to be more common in Israel, with one study reporting that 36% of parents of organ donors had had direct contact with recipients.¹⁰ There hasn't been enough research for us to understand why there might be differences between rates of direct contact in Israel compared with in the USA, but one possible reason is that the USA comprises a very large and multicultural population in comparison with that of Israel. Regardless of whether direct contact is an option, families and recipients sometimes express concern about communicating with each other in case they may be from different social or cultural backgrounds. Families and recipients that are members of less culturally diverse societies may feel more comfortable in connecting with one another because it often seems easier to connect with people who share common experiences, values or backgrounds. In multicultural societies like Australia, some families and recipients might also be from non-English speaking backgrounds, which can make communication more challenging. Some people might worry about how they will connect with and understand one another, or fear causing disappointment if they don't match the expectations or share the same backgrounds as the other party. Internationally, many donation agencies recommend taking care when writing about religion in correspondence between families and recipients, for example, in case the family or recipient do not share the same beliefs.

Many donor families may not feel any desire to have direct contact with recipients or may be fearful of revisiting a distressing period in their lives, and some may worry they will be disappointed if the recipient(s) fail to live up to their expectations.^{3,5} There are also several reasons why recipients may not wish to have direct contact with families, or may be reluctant to pursue direct or indirect contact even if they would like to. These include feeling guilty about surviving as a result of the transplant made possible by the donor's

death, having anxiety about causing emotional distress to the family, and having concerns about feeling responsible to help the family if they are in need, in return for the gift of the transplant. Some recipients, such as those who required liver transplants due to alcohol-induced liver disease, or those whose transplants have been unsuccessful, may also fear that families could be disappointed in them.^{8,11} Both families and recipients may worry about establishing a relationship with one another through direct contact, and managing this relationship if it doesn't work out well. In some countries, recipients may fear being asked for money or other rewards as a "repayment" for the transplant, and families may fear being asked for money in order to help the recipient cope with ongoing costs of transplantation.

International experience with anonymous written communication between families and recipients may also help us to understand why people might prefer, or not prefer to have direct contact with one another. In the American study mentioned above, Post reports that during a three year period, 1105 organ recipients (19% of all vital organ recipients) and 1326 tissue recipients (1% of all tissue recipients) wrote to their donor families.⁶ In contrast, the Australian study found that 68% of donor families received letters from at least one recipient.¹ Research in the United States suggests that donor families are likely to wait until they receive a communication from transplant recipients before writing themselves, which is perhaps why Post reports only 312 donor families (8% of all donor families) in her study chose to write to recipients.⁶ Nevertheless these data demonstrate that not all recipients choose to take advantage of the opportunity for indirect contact with families, despite the fact most recipients are encouraged to write and thank donor families.

Donor families are sometimes disappointed or upset at lack of communication from recipients, although recipients may also be disappointed if families do not respond when they send a letter of thanks.^{1,4,11,12} Recipients report several reasons for not writing. These include being fearful of causing distress to the donor family, finding it difficult to express themselves as they would like and to avoid disclosing identifying information, and finding it difficult to write while managing complex health issues that may follow their transplant.^{11,13} Some recipients may also find it very emotionally distressing to write to the donor family.¹³ Of note, some donor families may not wish to receive any written communications. As

noted earlier, 6% of donor families in an Australian study had declined to receive anonymous letters from recipients.¹

Risks and benefits of actual experiences of direct contact between families and recipients

Although rare, there have been reports internationally of cases in which donor families have sought to extort money from transplant recipients by manipulating their gratitude for the donation, or guilt about receiving a life saving organ. Recipients may also seek to offer money or other substantial tokens of their gratitude to the donor family which can result in violations of laws prohibiting trade in organs. There have also been cases in which either recipients or family members have tried to establish and maintain a much closer relationship than the other party desires, resulting in behaviour that amounts to harassment or even stalking, as well as feelings of guilt for the person who does not wish for this level of closeness.

Israeli families and recipients who have made direct contact report some negative experiences, including a renewed sense of grief and loss on the part of families, and distress and guilt on the part of recipients at seeing this.⁴ Both families and recipients may be disappointed by their experience of contact. In one study, 49% of those who had experienced direct contact reported some negative experiences, however 79% were, on the whole, satisfied, and 89% reported advantages of direct contact.⁴ The benefits of direct contact experiences reflect the goals of families and recipients in seeking such contact. They include satisfaction with the success of donation and their donation decision and “a sense that the late donor was living on in the recipient”.⁴ In an early American study, 89% of families and recipients also reported a positive experience, with “a sense of peace or closure” being the most important benefit for both.⁵ Negative experiences reported in the American study also included some guilt on the part of donor families for feeling resentment at the recipient’s health, and “religious and social differences between the donor family and recipient”.⁵ Neither of these studies involved enough participants for the findings to be statistically significant, however they suggest that, overall, when direct contact is mutually desired by families and recipients, and carefully managed by donation agencies – which is the case in the US and in Israel – experiences of direct contact may be beneficial.

How is identity disclosure and direct contact facilitated internationally?

Donation agencies in Israel (the Israeli Transplant Centre) and in the USA (several organ procurement organizations such as the New England Donor Service) have more than two decades of experience in facilitating direct contact between donor families and recipients. Policies and practices vary and have evolved over time, however there are some common elements to most programs. These include:

A requirement for mutual consent to identity disclosure

The donation agency only discloses the identity of a family or recipient and shares contact information after at least one party has indicated a desire for direct contact and the other party has confirmed they are also willing for this to occur. This could be through written communications to one another, or a request by one party to the donation agency for direct contact. Following communication of this request to meet by the agency to the other party, the other party then indicates their desire/or not to make contact and disclose their identity. If both parties agree then the usual practice is for them to sign a consent form for disclosure of their identity by the OPO. **Appendix A** shows a sample consent form previously used by the New England Organ Bank, which is similar to those currently in use.

Counselling for recipients and families

The practice in the USA and Israel is for both recipients and donor families to be advised of what they might expect when connecting directly with one another, and informed of the potential positive and negative emotions they may feel when meeting one another.

Appendix B shows tables from the National Kidney Foundation in the United States (<https://www.kidney.org/transplantation/donorfamilies/infoPolicyGuidelines#hcp>) which identify discussion points for donor families and for transplant recipients to consider before establishing contact or waiving their anonymity.

Recommendations for arrangements of face-to-face meetings

Based on international experience, the majority of families and recipients prefer to have their initial face-to-face meeting at a neutral location, even if they have already spoken directly over the telephone. Meeting at the donation agency or donation or transplant offices at a hospital is often recommended and preferred.

Many families and recipients choose to have a staff member present at their initial meeting to provide support in case the conversation is difficult or issues arise.

There is some variation in the additional advice offered by donation agencies to families and recipients regarding direct contact. For example, some American agencies require families and recipients to correspond anonymously for at least 6 months before direct contact is facilitated (<http://surgery.med.miami.edu/laora/donor-family-services/donor-family-and-recipient-communication>).

Risks associated with independently arranged contact between families and recipients

Independently or privately arranged contact can occur in a number of ways. Families and recipients can use social media to try and identify one another, for example by posting information about the recipient and transplant or about the donor and circumstances of donation. As donor families and recipients do receive limited “de-identified” information about the recipients and donor respectively, this can be compiled with information about the dates and locations of transplantation and donation to estimate potential relationships. Similarly, either recipients or donor family members may identify a potential donor or recipient using information conveyed in news reports or interviews in the media about the donation or transplantation, and then contact the other party to try and confirm a potential relationship. Thirdly, recipients and families may meet at donation and transplantation events where stories are shared which provide information that facilitates guesses about potential relationships.

Several media reports from around the world, including in Australia, tell the stories of donors and families that have met by accident¹⁶ or through intentional efforts by one or both parties to identify the other.^{17,18} These stories are invariably positive, and similar to reports of direct contact between recipients and families that have been facilitated by donation agencies in Israel or the USA.¹⁹ It is these stories which encourage families and recipients to hope that direct contact will stimulate organ donation. Such stories are popular with the media, and often used by donation agencies internationally to promote donation awareness and support, as they highlight the positive aspects of donation and transplantation for families and recipients.

When direct contact is arranged without the oversight and support of donation agencies, however, there are several risks. These include the possibility that contact is not desired by either the recipient or the donor family. Cases of unwanted contact have been reported,

including in countries where direct contact is permitted and facilitated by donation agencies. Other risks include the possibility that the person or persons seeking contact may identify the wrong donor or recipient, and the fact that families and recipients have usually not received counselling about the risks and benefits of direct contact, including realistic expectations of contact, and advice on how to manage issues that may arise.

Options to address the issue of direct contact in Australia

In addressing this issue in Australia, the rights and preferences of all donor families and transplant recipients must be protected. Individuals' rights to privacy and confidentiality mean that disclosure of identity and facilitation of direct contact between families and recipients should only be permitted and encouraged when both a family and recipient are willing for this to occur. Regardless of policy and practice in Australia, it's important that families and recipients are informed that neither the family nor the recipient has a **right** to know the identity of the other party nor to have direct contact with them. If the right to privacy and confidentiality is not respected, many people may be unwilling to approve donation or even to receive a transplant. For the same reasons, families and recipients should be urged not to pursue contact with one another unless they know that such contact is desired. Mutual respect, and unconditional donation or acceptance of transplantation without a requirement for direct contact, are cornerstones of donation and transplantation programs.

As it is currently illegal for health professionals and DonateLife and OTA staff to disclose the identity of donor families and recipients, and hence to facilitate direct contact between them, there are three main options to consider in addressing this issue in Australia:

1. Maintain the status quo – no change
2. Address the risks of independently arranged contact – no legislative change
3. Work towards legislative change and professionally facilitated direct contact

Option 1 - Maintaining the status quo

The various stakeholders in donation and transplantation in Australia, including donor family and transplant recipient groups, transplant professionals, DonateLife, and OTA may choose to continue current practice without adding anything new or considering changes to policy and practice. This option does not address the risks of independently arranged contact that may currently occur.

Option 2 - Addressing the risks of independently arranged contact without legislative change

If current laws remain in place, health professionals, DonateLife staff and OTA cannot play a role in disclosing identity and facilitating direct contact, but could help to reduce the risks associated with independently arranged contact. This could be done by providing guidance or advice for those who choose to pursue direct contact independently, for example by recommending that people obtain counselling before meeting, and advising people on how to reduce their risk of being identified if they do not wish to be contacted. Development of the following tools may be helpful:

- **Fact/advice sheets**
 - about the risks and benefits of direct contact for donor families and transplant recipients
 - about legislation and policies protecting the privacy and confidentiality of families and recipients
 - for families and recipients on how to reduce their risk of being identified without consent
- **Guidelines**
 - To support counselling of families and recipients considering direct contact and during and after direct contact experiences
 - For organisations or social media communities who may need to manage members seeking to contact families or recipients
 - For health professionals who may need to manage requests from families or recipients relating to direct contact
 - For the media reporting on donation and transplantation cases, including cases involving direct contact
- **Issues papers or research to** investigate specific issues relating to anonymous communication *and* direct contact between families and recipients, such as:
 - Management of barriers to communication between families or individuals from different cultural or linguistic backgrounds
 - Management of undesired direct contact or accidental disclosure of identity

- Identity disclosure or direct contact involving transplant recipients who are unable to provide informed consent, such as children.
 - When a child is the recipient of an organ transplant, the decision to disclose their identity may be made by a parent or legal guardian. In such cases, special attention should be given to the interests of the child. It may be appropriate or legally required to wait until the child is able to provide informed consent before allowing their identity to be disclosed and direct contact initiated.
- Management of high profile cases in the media.
 - When the death of the donor attracts particular media attention, or the transplant recipient's case attracts attention, for example as a result of undergoing a novel or innovative procedure such as a hand transplant, or because the recipient is a celebrity or has become well known through a donor drive, it may be especially difficult to protect family and recipient rights to privacy. Even if direct contact is mutually desired, it may be difficult for such contact to proceed without receiving undue media attention which can increase the pressures on both parties. For example, once a case of direct contact is reported positively in the media, recipients or families may be reluctant to seek help if they experience difficulties in further contact or are distressed by the initial contact.

Option 3 - Working towards legislative change and professionally facilitated direct contact

As public and professional debate about this issue progresses, Australian health authorities and governments may decide to revise legislation and introduce a program of facilitated direct contact managed by health professionals, DonateLife or other agencies. The advantages of this option may include the provision of the opportunity for professionally supported direct contact between families and recipients who desire this; a reduction in the burdens and risks for families and recipients who would otherwise seek direct contact independently; and the fact that many families and recipients may be glad to have the opportunity for direct contact even if they never choose to take advantage of it. Potential

disadvantages include the possibility of increased pressure on recipients or families to communicate or disappointment if an expectation of direct contact is not met, in addition to the risks that may be associated with identity disclosure and direct contact even when legally and professionally facilitated.

The purpose of the Forum and potential next steps

The purpose of the DonateLife Community Consultation Forum is to provide opportunities for sharing and open discussion of different Australian stakeholder perspectives and insights into the complex issue of direct contact between families and recipients. The report of the Forum will inform consideration by health policy makers and the government of potential changes to the laws that currently prohibit disclosure of the identity of families and recipients.

Even if a decision is made by the governments to change the laws and allow DonateLife to facilitate direct contact between families and recipients, it will take some time before the various laws are changed and processes can be established to facilitate identity disclosure and direct contact. During this time, DonateLife together with health professionals and community stakeholders could work on:

- Improving existing opportunities for families and recipients to communicate anonymously, for example by raising awareness of these opportunities and addressing potential barriers to correspondence;
- implementing the strategies identified in the previous section to help address the risks of independently arranged contact;
- preparing a program to directly support and facilitate disclosure and direct contact, paying particular attention to potential challenges of managing an effective program of direct contact in Australia's multicultural society.

Further work on this topic should take advantage of Australian experience in managing similar issues in the context of other types of donation, and include collaboration with organisations and stakeholders involved in other types of donation such as altruistic bone marrow and living kidney donation programs which are also based on anonymity. If plans are made to change legislation, then further consultation with stakeholders will be needed

to elaborate a program of facilitated contact in which all parties are supported to make informed decisions about their options for contact.

Potential key points and topics for discussion during the Forum

In preparing for the Forum, participants may wish to reflect on the following questions which might be suitable topics for discussion during the meeting:

1. What might be the potential advantages and disadvantages of direct contact in Australia from the perspective of donor families and recipients?
 - a. What particular issues may be relevant in the Australian context?
2. What could be done at the present time to satisfy families and recipients who would like to learn more about one another and to communicate, without violating the laws governing identity disclosure?
3. What do transplant candidates need to know about this issue before they receive a transplant from a deceased donor?
 - a. What about before they agree to disclosure of their identity?
4. What do prospective deceased donors or potential deceased donor families need to know about this issue?
 - a. What about before they agree to disclosure of their identity?
5. What supports might recipients or families need if their identity is unintentionally disclosed?
 - a. What about if they agree to disclosure and contact?
6. What should be done when not all donor family members approve disclosure or desire contact with transplant recipients?
7. What more do policy makers need to know about this issue in order to make decisions about potential changes to legislation and policy governing disclosure and contact in Australia?

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Appendix A – Sample Consent and General Release Form¹³

This is to acknowledge that I have asked to disclose information about myself to my [loved one's recipient/donor family]. I wish to give this information to my [loved one's recipient/donor family] so that I may share my feelings about donation with those who were involved. I understand that the transfer of this information will take place only if agreed to by the [recipient/donor family], the [organ procurement organization] and the caregivers and institutions that were involved in the donation and transplantaiton services. This opportunity to have this information given to the [recipient/donor family] is of great value to me. I agree to refrain from any further contact with the [recipient/donor family] except for contact that is agreed on by myself and the [recipient/donor family], and I also agree to the release of the indemnification undertaking set forth below.

In consideration of their willingness to participate in the disclosure of this information, I agree to indemnify and hold harmless the [organ procurement organization]; its officers, directors, employees, and agents; and the caregivers and institutions who consent to this disclosure of information, together with their respective officers, directors, employees and agents, from any and all liabilities, claims, loss, damages and expenses that any of the foregoing may incur as a result of disclosure of such information between myself and my [recipient/donor family], and I release each and all of the foregoing from liability to me, my heirs and assigns and from any and all liabilities, claims, loss, damages and expenses I may incur as a result of such a disclosure of information between myself and my [loved one's recipients/donor family].

Signature

Name: _____

Address: _____

Date: _____

Telephone: _____

Sample consent and general release form

Appendix B. Discussion Guides for Families and Recipients from the National Kidney Foundation in the USA

Table 1. DISCUSSION GUIDE FOR DONOR FAMILIES OF DECEASED DONORS REGARDING COMMUNICATIONS OR CONTACTS AND LOSS OF ANONYMITY

Potential Benefits	Potential Risks
<i>Positive emotional responses</i>	<i>Negative emotional responses</i>
An opportunity to express joy	Unpredictable consequences: <ul style="list-style-type: none"> • Unwanted communication • Unable to end contact
An opportunity to know that the gift made a difference	Differences: <ul style="list-style-type: none"> • Cultural • Religious • Moral • Social
An opportunity to continue the grieving process	Knowing that part of the family member was present
Identifying or humanizing in a small way with a person with whom you may have had an extended anonymous relationship	Pain, sadness, resentment, a feeling of responsibility for the gratitude felt by the recipient
Control & empowerment	Differences in response of family members
Ease of direct contact, i.e., removing the “middleman”	Anxiety that the family members may not think the recipient was worthy of the gift
An opportunity to share the family member with the recipient	Anxiety about what to say and/or do
Reinforcing the decision to donate	Revisiting the death of the family member
Increasing donation	Decreasing donation
An opportunity to “be with” a part of the family member	Reaffirming the absence of the deceased family member

Table 2. DISCUSSION GUIDE FOR TRANSPLANT RECIPIENTS REGARDING COMMUNICATIONS OR CONTACTS AND LOSS OF ANONYMITY

Potential Benefits	Potential Risks
<i>Positive emotional responses</i>	<i>Negative emotional responses</i>
An opportunity to express gratitude	Unpredictable consequences: <ul style="list-style-type: none"> • Unwanted communication • Unable to end contact
An opportunity to express sympathy	Differences: <ul style="list-style-type: none"> • Cultural • Religious • Moral • Social
An opportunity for closure	Belief of donor family that family member lives on in recipient
Having a name to call a person who may have had an extended anonymous relationship	Donor family ownership of organ
Control and empowerment	Differences in response of family members
Ease of direct contact i.e., removing the “middleman”	Anxiety that the donor family will not see them as worthy of the gift
An opportunity to learn more about the donor	Anxiety of what to say and/or do
	Donor family sadness or resentment

Appendix B – Forum Agenda



Australian Government

Organ and Tissue Authority

**Community consultative forum: contact between donor families and
transplant recipients**

Friday 17 March 2017, 10am – 4pm (AEDT)

ParkRoyal Melbourne Airport

AGENDA

Item	Topic
1	Welcome, overview and introductions
2	<ul style="list-style-type: none"> i. Presentation of the key points of the Issues Paper ii. Presentation of survey results from Donor Families Australia, LiverKids and Transplant Australia
3	What are the potential benefits of direct contact between donor families and transplant recipients in the Australian context?
4	What are the potential risks of: <ul style="list-style-type: none"> • Direct contact in the current Australian context, i.e. where independently arranged contact is the only option? • Direct contact in the Australian context, i.e. if this option were offered by DonateLife agencies and transplant units?
5	In the current Australian context: <ul style="list-style-type: none"> • What might transplant candidates generally need or want to know about this issue before they receive a transplant from a deceased donor? • What might prospective deceased donors or potential deceased donor families generally need or want to know about this issue?
6	<ul style="list-style-type: none"> i. In the current Australian context, what supports or advice might transplant recipients and donor families need if they decide to pursue direct contact, or are approached with a request for contact by someone? ii. How can donor families and transplant recipients minimise their risk of unwanted identity disclosure in the current environment?
7	<ul style="list-style-type: none"> i. What more do policy makers and governments need to know about this issue (and what should they think about when considering potential changes to current policy and practice)? ii. Discussion of any additional key issues identified during the day.
8	Closing comments and thank you to participants

Appendix C – Summary of key suggestions and proposals for action made during the Forum

1. Review and improve the current system

- Prioritise improvements to the current system while learning more about experience of direct contact in other countries and the needs and preferences of Australia donor families and transplant recipients.
- Provide more support for transplant recipients in writing thank you letters, including practical help in writing for those who may have literacy difficulties, psychological support, and advice on when and what to write. Provide information about at different times during the transplant process, and refresh information for those who have been waiting for transplantation for a while.
- Provide more information to donor families to establish realistic expectations of correspondence and foster understanding of the reasons why recipient may not write.
- DonateLife should maintain contact with families and recipients, and perhaps reinform them about communication options after a period of time has passed, as preferences for contact may change over time.
- DonateLife could provide more assistance to community organisations in establishing and promoting local support groups of donor families, particularly in rural and regional areas where distance can make it difficult for people to meet.
- More investment in education and awareness campaigns in schools, universities and in mass media would be helpful in informing the public and encouraging donation.
- Educate policy makers about donation and transplantation and related issues.
- Consider revising death certificates to acknowledge when an individual has donated.

2. Protect the privacy rights of recipients and families

- Provide clear advice to families and recipients regarding protection of their privacy, particularly with regards to their own social media use and that of their friends and family members.
- Always maintain the privacy of families and recipients, and anonymity of their correspondence unless consent for identity disclosure is given.
- Paediatric transplant recipients have a right to privacy, and any system of direct contact must address the issue of consent or assent for disclosure of the identity of a paediatric recipient.

3. Considerations for programs enabling direct contact

- An independent body should be established to facilitate direct contact and provide support and counselling to those who wish to meet their matching family or recipient(s) in a safe and respectful environment.
- Contact should be facilitated by an appropriate third party in a neutral environment, using an independent facilitator at least for the initial contact.

- Both parties should first register their preference to have direct contact before the other party is informed of this.
- Community groups or nongovernmental organisations could be accredited to undertake work such as counselling and emotional support for families and recipients seeking direct contact.
- Counselling should explore the expectations of each party, address potential concerns regarding culture and values, and fully inform both parties of potential benefits and risks of contact.
- Current programs which facilitate contact between adult adopted children and their birth parents may serve as a useful model for contact between families and recipients.
- Families and recipients should get to know one another through written correspondence prior to direct contact.
- Identify legal risks that might be associated with particular models of contact.
- Establish guidelines and services quickly.