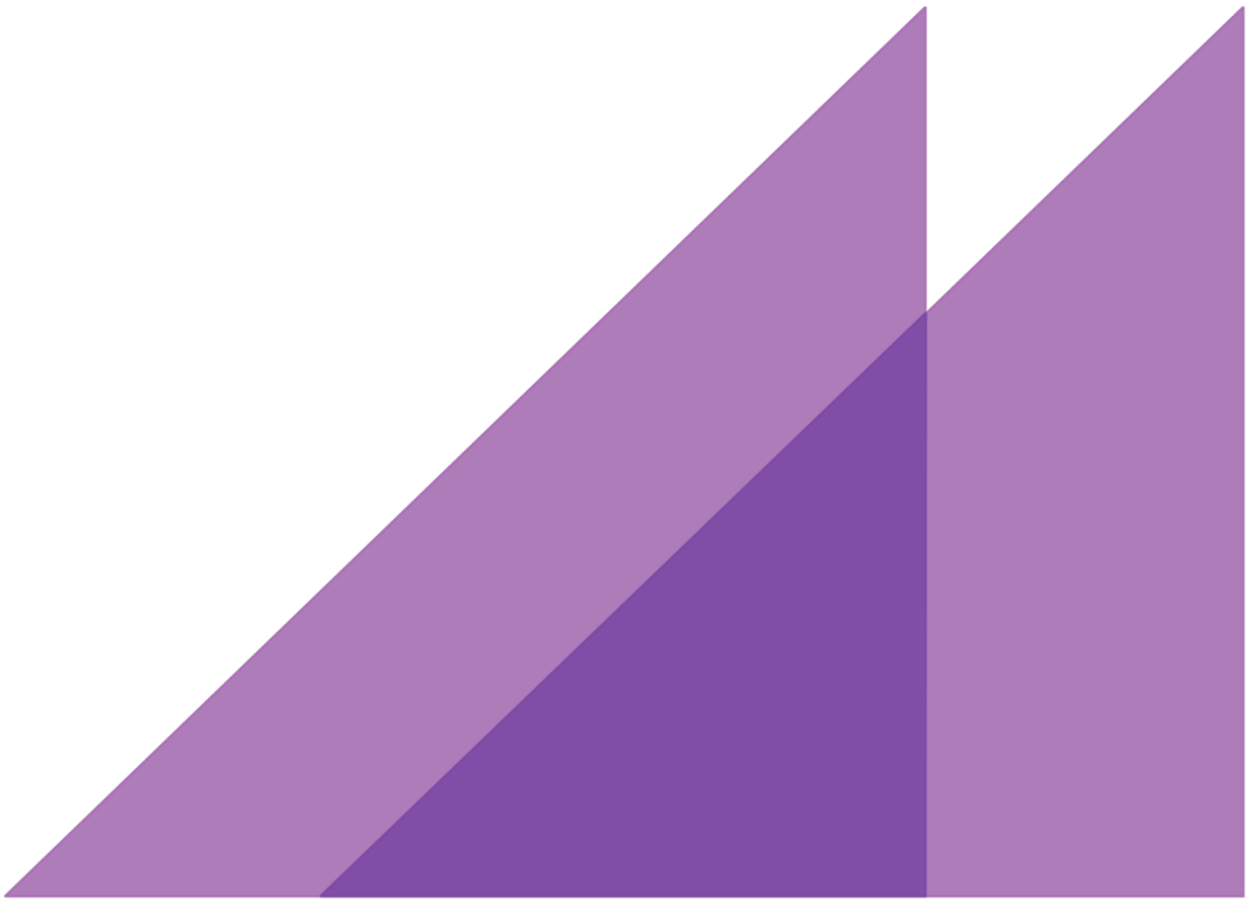
ACIL ALLEN CONSULTING

REPORT TO
DEPARTMENT OF HEALTH

19 DECEMBER 2014

EVALUATION REPORT

SUPPORTING LEAVE FOR LIVING ORGAN DONORS PROGRAMME



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Executive summary

Supporting Leave for Living Organ Donors Programme

The Supporting Leave for Living Organ Donors Programme pilot (the 'Programme') is an Australian Government initiative that addresses health priorities, strengthens supports for living organ donors and their families, and recognises altruistic donation.

The Programme has been funded for two years from 2013 to 2015 and aims to alleviate the financial burden for living organ donors who take leave from their work during the donation work up, surgery and recovery period. The Programme operates as a reimbursement of employers who provide leave or ex gratia payments to employees who have committed to live donation.

Alignment with government policy

The Programme contributes primarily to evidence informed treatment for end stage kidney disease. There is a significant health and economic burden associated with chronic kidney disease with an estimated 1.7 million adult Australians with one or more indicators for the disease. Chronic kidney disease is more prevalent among men, persons with lower socio-economic status, Aboriginal and Torres Strait Islander peoples, and persons from remote areas. (AIHW 2014)

There were over 1,000 people on the deceased donor waiting list for kidney replacement in December 2010. There were 255 living donor kidney transplants performed in 2011, representing 31 per cent of all kidney transplant operations.

The Programme is also available to live donors of partial liver. In 2011, liver disease ranked seventh amongst the top 10 most common causes of death from cancer involving 1,423 deaths. In 2009-2011, liver disease was more prevalent among the leading causes of death in remote and very remote areas in 2009-2011, than in major cities. Liver disease is also a major contributor to the gap in adult mortality due to chronic disease between Aboriginal and Torres Strait Islander and other Australians.

There were 209 recipients of liver transplants in 2011. There were two live donors with the majority of transplantation from deceased organ donors. At the end of 2011, there were 192 persons (Australia and New Zealand) on the deceased donor waiting list for liver transplant.

The evaluation project

The requirements of the evaluation were to examine and make conclusions about:

- the appropriateness and effectiveness of the administration of the Programme
- Achievement of policy objectives
- Factors affecting participation in the Programme.

The approach

The evaluation included stakeholder consultation, survey of live donors and their employers who participated in the Programme, and analysis of administrative data.

The appropriateness and effectiveness of Programme administration

The Programme has been implemented as intended and remains relevant to health priorities concerned with reducing the prevalence of chronic diseases, and supporting evidence informed practice for improved patient outcomes.

There are a range of improvements that can be made to the Programme to improve communication and information exchange, and the more efficient operation of the Programme through conversion from a manual to an electronic system. These improvements to processes would benefit the live donor in accessing and complying with Programme requirements, and enable fuller use of the data collected about Programme participants.

A simpler method for calculation of payments is warranted, along with flexibility in obtaining clinician authorisation to support donor claims, and determination of the duration of time off work associated with the donation.

Achievement of policy objectives

The Programme is on track in meeting its objectives to assist in relieving the donor's financial stress and increasing employer awareness of living organ donation by employees. Access to the Programme in the first year of the pilot is estimated at around 36 per cent of all living kidney donors.

In addition, payments have been made in the first 10 months to reimburse employers for leave or ex gratia payments associated with supporting 74 living organ donors. A majority of employers have made payments to employee donors that are in excess of the reimbursement under the Programme.

There may be scope to review the maximum leave that can be claimed under the Programme in light of the average time away from work reported by live donors as just under 9 weeks, rather than the estimated 6 weeks.

Factors affecting participation in the Programme

Health professionals were an important enabler to providing information to live donors about the Programme. This is especially relevant because of the likely family relationship between the donor and recipient providing an opportunity for the discussion about living organ donation to commence with the recipient's health care providers.

The employer and the support they can provide to the employee through leave arrangements is another key enabler and an area for further development to improve awareness and understanding of the Programme.

Barriers to optimising the Programme include the limited public awareness of the initiative and the need for more suitable information material that has regard for different educational levels and language skills. There was support for a brochure for use in transplant units and poster information for display in dialysis units.

A simplified claiming and payment process would facilitate access and understanding, and streamline the Programme process.

Conclusion

Overall, there was very strong support for the Programme from all parties. States and territories indicated that they were very supportive and positive about the Programme and that 'there was a lot of good collective thought around supporting living organ donation'. Transplant Unit staff were seen as critical to improving awareness and understanding of the Programme with live donors, and to facilitating completion of information requirements. Unions were encouraging of the possibility of a greater role in embedding the initiative with employers and some parts of industry had already demonstrated leadership in formalising their support for living organ donors.

A wide range of improvements to the Programme process and data collection tools have been suggested. A critical issue is achieving greater flexibility consistent with the policy intent of the initiative to improve access while ensuring that the Programme does not incentivise donation inappropriately, and development of a more streamlined and integrated payment process.

There may be benefit in other concurrent activities to build the awareness of the Programme, harness the goodwill of jurisdictions in achieving a consistent and transparent approach to the support for live donors, and produce information material to improve communication about Programme requirements.

The solid performance of the Programme against its objectives, its level of utilisation and the commencement of industry changes around recognition of the living organ donor indicate that the Programme is tracking towards the intended outcomes.

1 Introduction

1.1 Terms of reference of the evaluation

The requirements of the evaluation project commissioned by the Australian Government Department of Health (Health) were to examine and make conclusions about:

- The appropriateness and effectiveness of the administration of the Supporting Leave for Living Organ Donors Programme, including application, claiming and payment processes
- The accomplishment of policy objectives, including if the Programme:
  - Helped to alleviate financial burden
  - Raised the profile of living organ donors with employers
- Factors affecting participation in the Programme, including:
  - Public awareness of the Programme
  - Donor and employer understanding of the processes
  - Administrative costs to employers.

1.2 The approach

The evaluation has drawn from stakeholder consultations, survey of live donors and their employers who have participated in the Programme, and analysis of administrative data.

1.2.1 Stakeholder consultations

A number of key informant discussions were held with the Programme partners; Health and the Department of Human Services (DHS). In addition, state and territory governments were invited to provide feedback on the Supporting Leave for Living Organ Donors Programme (the Programme). All jurisdictions took up the invitation resulting in a mix of input covering health policy and transplant unit experiences in most jurisdictions.

Input beyond government was obtained from DonateLife, the peak non-government body, and Kidney Health Australia. An employee representative body, the Australian Council of Trade Unions (ACTU), the Australian Chamber of Commerce and Industry (ACCI) and the Australian Industry Group representing employer perspectives, also provided feedback. A list of stakeholder groups consulted is provided at Appendix A.

A set of discussion guides were provided to stakeholders prior to interview, optimising use of time available and encouraging internal consultations, as appropriate, prior to interview.

1.2.2 Survey of Programme participants

Ethics approval was obtained to undertake a survey of live donors who had registered for the Programme and their employers. The purpose of the survey was to supplement administrative programme data including with qualitative information about participant experience in accessing the Programme, engagement of the employer, the value of the initiative, and suggestions about opportunities to increase participation. The sample was drawn from registered donors, and their employers (including self-employed donors), to

whom payment had been made under the Programme in the first year (2013-14) of the pilot. It was also intended to capture a small number of donors registered in the first half of the year who had not submitted a claim for payment.

The letters of invitation were sent to 70 eligible donors (including 16 who were self-employed) and 47 employers by DHS with a covering letter from Health. The invitations included seven registered donors who registered prior to 1 January 2014 and from whom a claim had not been received.

Recipients were provided with the option to participate by telephone interview or online survey. Letters of invitation were mailed on 26 September 2014 and the survey period was open to 26 October 2014, allowing approximately a 3 week response period. The approach did not allow for a reminder notice during the survey period as the process followed to gain access to participants would have required a second mail out to all invitees in a short timeframe.

The aim had been to achieve a sample size of 30 each of donors and employers, approximately half of the eligible Programme participants, and 15 donors who had not submitted a claim within 6 months or more of registration.

At the close of survey, a total of 25 completed surveys were received from donors, of whom six were self-employed and one had not submitted a claim. In addition, 11 employers responded bringing 'employer' representation to 17. The large majority of respondents completed the survey online. Three donor respondents were interviewed by telephone.

1.2.3 Review of administrative data

This report uses de-identified data extracted from completed registration, claim and payment forms provided to DHS.

Data provided for the first 10 months of the 2013-14 financial year (i.e. July 2013 – April 2014) is disaggregated by individual donor allowing information to be obtained about:

- Characteristics of donors accessing the Programme
- The point of liaison within the donor's workplace
- Characteristics of donors submitting a claim
- What transplant procedures the claim covered and the payment made under the Programme
- The end to end length of the process from lodgement of registration to payment date.

Some data were not available to the project for confidentiality reasons, including whether reimbursement of the employer was for leave or ex gratia payment.

Not all donor characteristics were available for registrants in the final two months of the 2013-2014 financial year (May and June 2014) but where comparable data were available, this has been used to provide a full year of Programme registrations.

A data request was also made for extraction of information from the ANZDATA regular collection relating to kidney transplants. Information was provided for the calendar years 2012 and 2013 (provisional) for living organ donor transplants by state and territory. Before completion of this project, the 2013 data had been finalised and in the public domain. This draft report has used the final 2013 ANZOD data.

1.3 Programme background

1.3.1 Living donation

A live organ donor is someone who donates a kidney or partial liver to another person with end stage kidney disease or liver failure. Living donation of a kidney is more common with 249 kidney donations in 2013 compared to one partial liver donation (ANZOD 2014).

1.3.2 Burden of disease

Chronic kidney disease (CKD) is a significant health and economic burden to individuals, their families and the community in Australia. There is an estimated 1.7 million adult Australians with one or more indictors of CKD with the majority unaware of their condition. When diagnosed, many people have lost as much as 90 per cent of kidney function. CKD is more prevalent amongst men, persons with lower socio-economic status, Aboriginal and Torres Strait Islander peoples, and persons from more remote geographical locations (AIHWa 2014).

In relation to liver disease, the most common cause of liver failure is chronic hepatitis, while in children it is biliary atresia (ANZLTR 2014). In 2011, liver disease ranked seventh amongst the top 10 most common causes of death from cancer (involving 1,423 deaths), and were among the top five causes of death in women aged 25-44. Cirrhosis and other diseases of the liver were among the diseases ranked in the leading 15 causes of death in remote and very remote areas in 2009-2011, that were not present in major cities. (AIHWb 2014) Around 80 percent of the gap in mortality between Aboriginal and Torres Strait Islander and other Australians aged 35 to 74 is attributed to chronic diseases. Liver diseases are ranked third amongst the 12 chronic diseases that contribute to most of the mortality gap. (AIHWc 2014)

1.3.3 Kidney replacement therapy

Treated end stage kidney disease (ESKD) is a significant contributor to the cost of CKD accounting for approximately 85 per cent of costs. Treatment (kidney replacement therapy (KRT)) involves dialysis or kidney replacement. KRT was provided to 19,800 people in 2011 and the prevalence is expected to increase by 60 per cent to 31,600 cases in 2020. Dialysis cases are estimated to increase by 49 per cent from 11,000 in 2011 to 16,400 in 2020, and kidney transplant-treated cases are projected to rise by 73 per cent from 8,800 to 15,300 cases over the same period. The annual cost of dialysis ranges from $50,000 to $100,000. (AIHW 2014) The best clinical outcomes are associated with 'pre-emptive' transplantation, which avoids or defers dialysis, and with living donation which has an observed increase in patient survival of 27 per cent at 20 years compared to deceased donation (KHA nd).

There were 1,141 people on the deceased donor waiting list for kidney replacement in December 2010. There were 255 living donor kidney transplants performed in 2011, representing 31 per cent of all transplant operations. The proportion of living donor transplants performed pre-emptively in Australia was 37 per cent. (ANZDATA 2013)

1.3.4 Liver transplant

There were 209 recipients of liver transplants in Australia in 2011. There were two live donors with the majority of transplantation from deceased organ donors. (ANZOD 2014) At the end of 2011, there were 192 persons (Australia and New Zealand) on the deceased donor waiting list for liver transplant (ANZLTR 2014).

1.3.5 Barriers to donation

Kidney Health Australia has reported that demand for kidney replacement would not be met from deceased donations, despite the increase in donations. Noting the decline in live donors since 2008, Kidney Health Australia advocated, among other initiatives, for increased support for living organ donors to address barriers to donation. (KHA 2013) It was considered that the loss of earnings or entitlements associated with time away from work for the donation procedure placed financial stress on the live donor.

A report investigating the reasons for the decline in living organ donors found that there was evidence to support improving levels of financial compensation for donors to ensure that living donors were not 'financially penalised by their decision to donate' (AHA 2013).

1.3.6 The Supporting Leave for Living Organ Donors Programme

The Supporting Leave for Living Organ Donors Programme pilot was established by the Australian Government to provide assistance to live donors through a reimbursement Programme that engages their employers and the health system. The Programme recognises the financial burden of living organ donors who take leave from work for medical evaluation prior to surgery and the recovery period following surgery. The initiative is designed to alleviate some of the financial burden for the employee, raise the profile of living organ donors and encourage the support of their employers. The Programme commenced in July 2013 and is funded as a two-year pilot to June 2015.

2 Programme Implementation

2.1 Key features

2.1.1 Process

Bilateral Head Agreement

While the Health portfolio has policy responsibility for this initiative it is being piloted in collaboration with DHS. A Bilateral Head Agreement (Business Agreement) sets out the roles and responsibilities of the Departments in relation to the Programme. DHS is responsible for:

- Operational administration of the Programme
- Protection of participant information
- Timely response to Health requests about delivery of the services.

Health is responsible for:

- The policy in relation to the Programme
- Briefing on the Programme and media enquiries
- Updating DHS on related developments including at biannual liaison meetings
- Addressing policy related matters referred to it by DHS and providing timely responses to DHS requests
- Administering the transfer of funds to enable DHS payments under the Programme.

This evaluation has focused on implementation aspects of the Programme including programme design, the service to donors and employers, and their experiences.

The Head Agreement specifies the Programme objectives as aiming to support paid leave for living organ donors for the purposes of reducing the financial burden of living organ donation.

Programme operation

Key features of the operation of the Programme as set out in Schedule E of the Head Agreement include:

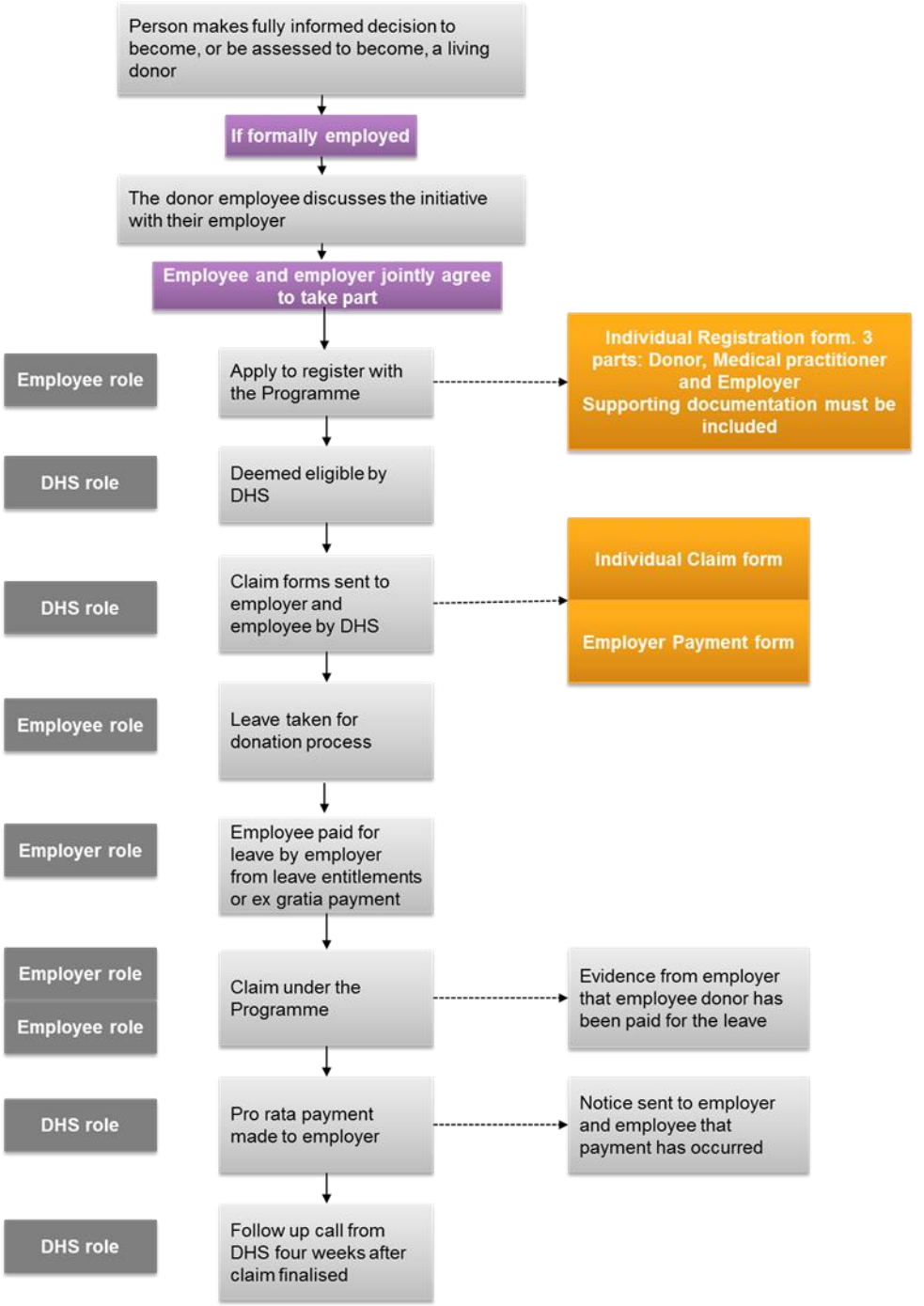
- Payment to employers of eligible living organ donors of up to 6 weeks (based on a 38 hour week) for time off work associated with the donation calculated at the National Minimum Wage
- Payment can be to credit the donor's leave or to contribute towards the employer's cost in the case of an ex gratia payment to cover their employee's time away from work
- Eligible live donors include employees who have a Medicare Card, and:
  - who work in a full-time, part-time or casual capacity for a specified minimum period prior to donation; or
  - who are self-employed

DHS provides regular reports to Health on aspects of access and payment. Any additional information sought is subject to confidentiality review and availability of staff.

System flow

A number of forms have been designed for the Programme related to registration, claim and payment. The process commences with individual registration of intent to participate in the Programme (referred to in this report as 'registration') and for eligible applicants, will involve additional information to be provided by their employer (or themselves if self-employed) and medical practitioner. Similar inputs are required to determine the payment, a process that is triggered once leave following donation surgery (or work up if deemed medically not eligible to donate) has been completed. The process is summarised in Figure 1.

Figure 1 **Programme system flow**



Source: Adapted from DHS SLLOD Programme documentation. ACIL Allen Consulting 2014.

2.2 Appropriateness

The appropriateness of Programme administration is considered in terms of how well the Programme has been designed to enable implementation as it was intended and meet the needs of living organ donors. This includes consideration of service delivery processes, governance arrangements and consistency with government policies.

2.2.1 Service delivery processes

There are a number of Programme infrastructure and processes that have been highlighted for consideration in any extension of the Programme beyond the pilot period. These suggestions relate to more efficient capture and communication of information, authorising requirements used to validate registrations and claims, the amount and calculation of payment, timing of payment, and eligibility rules. The following issues were raised in feedback from key informants, stakeholders and Programme participants.

Electronic function

A manually operated system was considered appropriate for the pilot phase, possibly influenced by the relatively small number of live donors, and minimal data extraction requirements. Donor feedback, directly and indirectly, indicated that the paper based system contributed to early frustrations in accessing the system. A more efficient approach to operation of the Programme would require conversion of processes from a manually operated to electronically operated system. An electronic capacity would facilitate exchange of information and submission of Programme forms improving communication between the service provider and the donor and their employer. Electronic storage of information would also enable greater efficiency in routine and one-off extraction of Programme data, facilitating Programme monitoring and accountability.

Design of forms

The similar layout and requirement to submit forms at different times in the process has caused some confusion resulting in delays in the provision of information by donors and employers, frustration that information requests appear duplicative, and delays in receipt of claims. A more streamlined and simplified process is supported, including by transplant staff supporting the living organ donor that rationalises processes, preferably to achieve a single requirement to submit information. Such a process would recognise the focus of the donor on the transplantation process at this time and provide a greater level of support for ease of access to the Programme.

Authorisation

The requirement to obtain the certification of a medical practitioner to dates of key clinical procedures and appointment can be onerous for the donor and difficult given physician workloads. Transplant staff (such as the social worker or coordinator) liaise regularly with the living organ donor at the commencement of discussions about transplantation and during the transplant process. A number of these staff have suggested that they are well placed to authorise or sign a record of attendance rather than the doctor for example, which would facilitate the donor's ability to meet Programme requirements. The Transplant staff are active participants in supporting the donor's compliance with and understanding of a range of health services and procedures, and would be well placed to incorporate a more active support role in the Programme.

Calculation of payment entitlements

Under the bilateral departmental arrangements for the Programme, DHS can make formal submission of aspects of Programme interpretation to Health to ensure consistency with policy intent. A number of these requests for 'policy advice and determinations' have involved calculation of payment entitlements, especially as they relate to donors who are self-employed. Suggestions for simplification of the calculation include a tiered arrangement similar to that used to calculate the private health insurance rebate, which differentiates by broad income level, or a flat percentage to be applied to payment made to the donor by the employer in order to determine the level of reimbursement. If the approach is to be varied, it may need to include features of the current system, such as a cap on the maximum payment and the length of time away from work.

Maximum leave reimbursed

Greater flexibility has been sought in the amount of leave that the Programme will reimburse to allow for clinically prescribed longer periods of recovery, such as for those donors in physically demanding occupations. One jurisdiction requested that review of the Programme consider allowance of a recovery time beyond the current period struck at the average of 6 weeks.

Evidence of employment

Eligibility issues have ranged from the target group of those in employment, noting that there are other circumstances where costs are incurred by living organ donors, to difficulty in establishing eligibility because of workups that can be earlier than the minimum period for demonstrating employment, which leads to difficulties in providing evidence of employment (such as for casual workers). In the latter instance, this could be accounted for by a statement, validated by Transplant staff, about the need to provide an alternative period, for example, as evidence of employment.

2.2.2 Governance arrangements

The bilateral agreement provides clarity about the policy and service roles of the respective departments, but may fall short of supporting Health in its policy and communication role. This is evident in the reporting requirements that are oriented towards service volumes and payments. Notwithstanding the intention to evaluate performance of the pilot Programme, a more substantial set of reports would enable a better understanding of Programme reach, industry engagement and potential ways in which to share Programme utilisation rates with Transplant units/jurisdictions to encourage increased awareness and knowledge of the initiative. Both government stakeholders and Transplant staff indicated strong interest in knowing about the level of participation in the Programme by residents of their respective jurisdictions.

2.2.3 Consistency with government policies

The Programme continues to be relevant to health reforms of governments, especially in addressing chronic disease, quality of life and health system costs.

The Programme has provided leverage for Kidney Health Australia to advocate directly with governments, unions and industry bodies about supporting and reinforcing the Commonwealth initiative, through enabling leave arrangements that recognise the needs of the donor employee and the availability of the Supporting Leave for Living Organ Donors Programme.

Key Findings

Appropriateness:

The following areas for improvement of service delivery processes reflect the value of the pilot phase and testing of the effective roll out of the Programme.

- Feedback on service delivery processes highlight Programme design features that could be modified to improve exchange of information and clarity about information requirements.
- Greater understanding of the impact of the donation process on aspects of eligibility and payment calculations suggest Programme modifications that better meet the needs of the live donor.
- Programme governance arrangements have provided clear delineation of roles and responsibilities but a shared agenda would be fostered by using the data to explore wider aspects of Programme participation, including communicating local participation to states and territories.
- The initiative remains consistent with priorities of government to support evidence based activity to reduce the burden of chronic disease.

2.3 Effectiveness

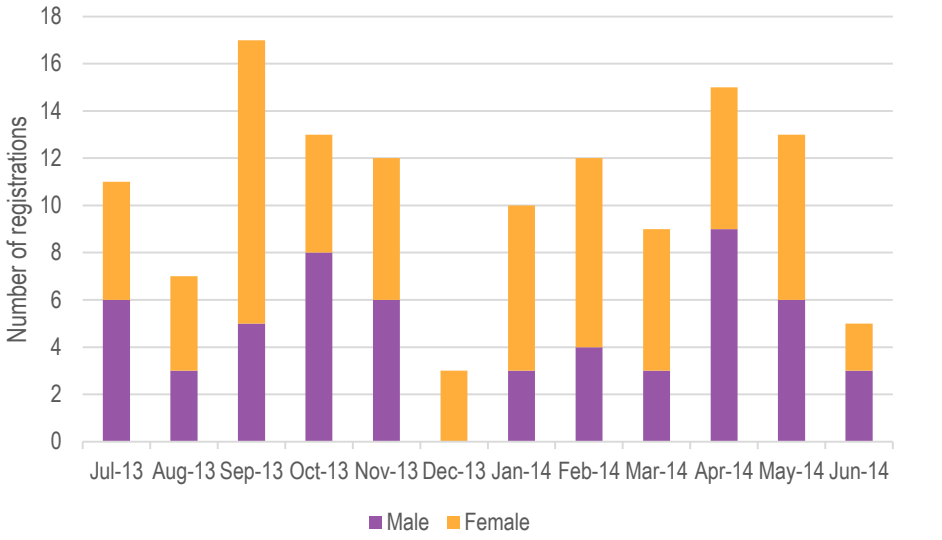
The effectiveness of Programme administration considers the extent to which delivery of the service facilitated achievement of the objectives to reduce financial stress of families and raise employer awareness of living organ donors. This is considered in terms of utilisation of the Programme and payments made.

2.3.1 Programme utilisation

Programme registrations

Since Programme commencement in July 2013 to the end of June 2014, a total of 127 donors registered for the Programme. Figure 2 shows the distribution of registrations across this period, disaggregated by gender. Apart from a surge in take up of the Programme in September 2013, and allowing for seasonal variation in December 2013, there is a relatively steady utilisation of the Programme, but with an apparent downward trend in registration at the end of the financial year.

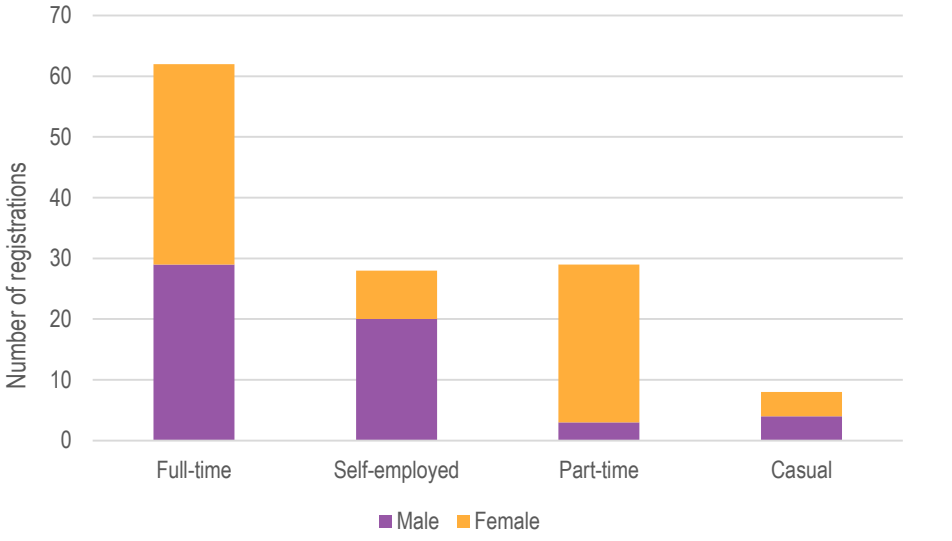
Figure 2 **Monthly Programme registrations 2013-2014**



Note: n=127 – all donors registered under the Programme in 2013-14.
Source: DHS

Based on registrations in 2013-14, women made up approximately 56 per cent of donors. There was a slightly higher representation of men than in the overall live donor population which has been reported as 1:2. This difference may reflect the importance of an income stream. Around 49 per cent of registrants were working full time at the time of their leave for the donation process, with more than a quarter self-employed (Figure 3). Males were overrepresented in this latter category, while females dominated the part-time category. Casual workers made up a small proportion of registered donors.

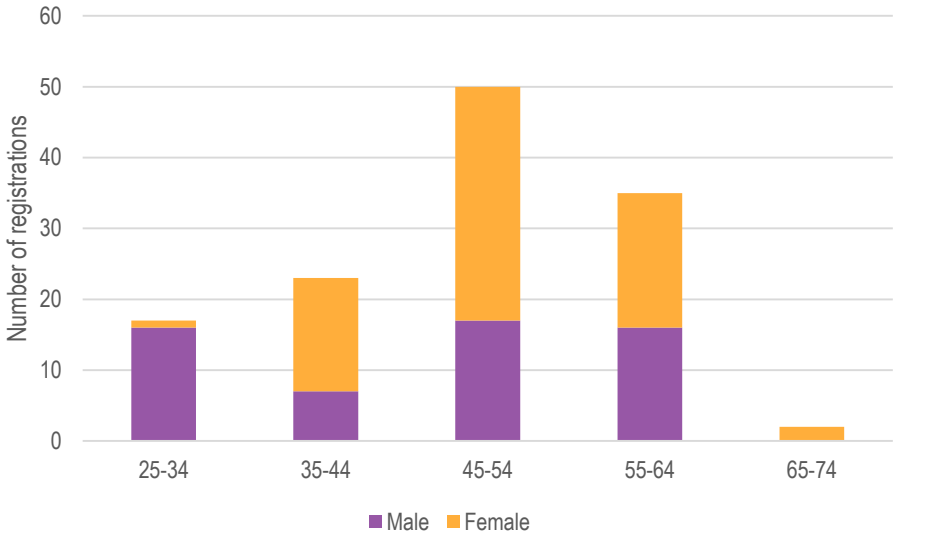
Figure 3 **Employment characteristics of donors registered for the Programme**



Note: n=127 – all donors registered under the Programme in 2013-14.
Source: DHS

The age of people who registered under the Programme ranged from 25-34 to 65-75 years of age. Most of those registered under the Programme are over 45 year of age (Figure 4) with the largest number in the 45-54 category. It is noted that there is only one female in the 25-34 age category compared to 16 males.

Figure 4 **Registration for the Programme by gender and age**

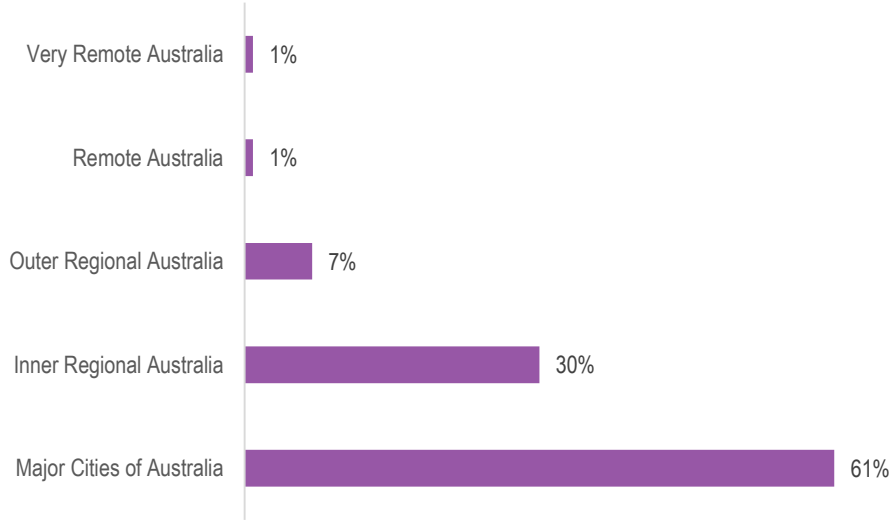


Note: n=127 – all donors registered under the Programme in 2013-14.
Source: DHS

As noted in section 1.2.3, disaggregated Programme claimant data available to this project was limited for the last two months of the financial year. The remaining analysis of registrations therefore, is based on the first 10 months of 2013-2014.

The majority of those who registered with the Programme lived in major cities, although at 61 per cent this is a lower proportion than the general population (70 per cent). Around a third are located in inner regional Australia (Figure 5).

Figure 5 **Geographic location of donors accessing the Programme**



Note: ARIA+ index. n=115 – all registered donors for which DHS provided postcode data (time of registration is not provided in the postcode dataset).
Source: DHS

Programme payment recipients

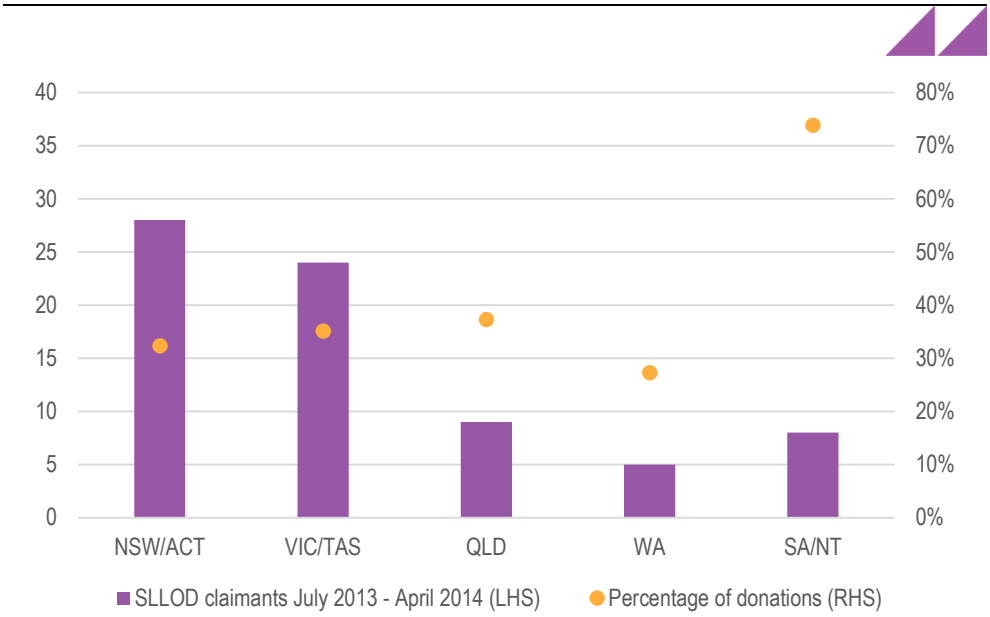
In the first 10 months of the 2013-14 financial year, 74 donors received payments in the Supporting Leave for Living Organ Donor Programme.

In 2013, there were 249 kidney donations from living organ donors. This represented a small increase in donations over the previous year largely accounted for by an increase in donors residing in New South Wales.

Using ANZDATA, in an average 10 month period in 2013, a total estimated 208 organ donations took place in Australia. Using this estimation method, the take up rate for the Programme was around 36 per cent of live organ donors.

Take up would appear to be highest for South Australia / Northern Territory (74 per cent) and Queensland (37 per cent), noting the relatively small number of live donors in these jurisdictions. South Australia / Northern Territory represents less than 6 per cent of participants in the Programme, while New South Wales is the largest participant. Figure 6 sets out Programme participation by state and territory, and the corresponding participation rate.

Figure 6 **Programme participation, numbers and estimated proportion of total organ donations**



Note: n=74. Data for SLLODP is for July 2013 – April 2014. 'Participation' is based on those whose payment has been completed. ANZOD data used to determine the proportion of total donations is 10/12ths of the annual 2013 total donations per region.

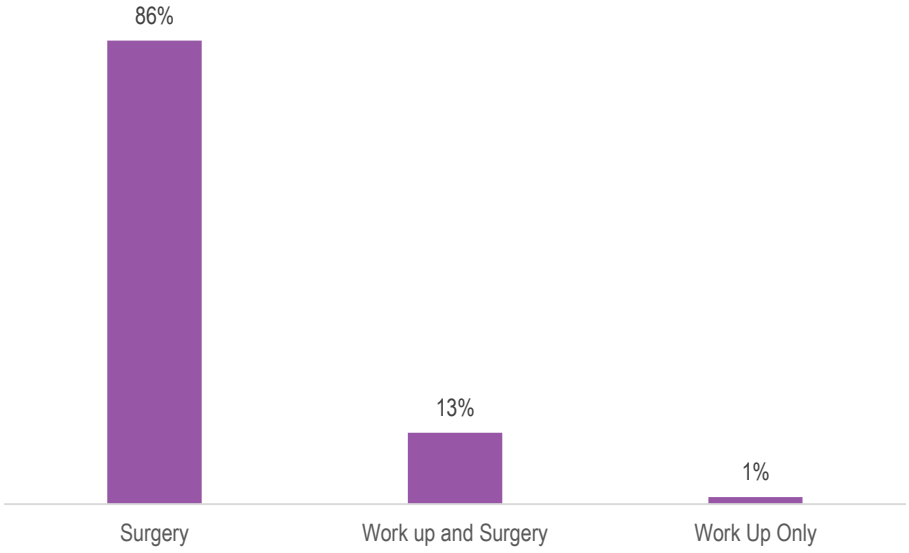
Source: DHS, ANZOD

Feedback from Transplant staff suggests that while donors may be aware of the Programme, some 'did not feel the need to claim'. It was also noted that the availability of the Programme was not a primary influence on their decision to donate, but may be viewed as 'the icing on the cake'.

Communication about the Programme is largely limited to individual contact with health professionals and linked information on a small number of government and non-government national websites. In view of the limited promotion of the Programme, its relatively recent establishment, and the likelihood that a proportion of live donors will not require the supported leave because of adequate existing arrangements within their workplace, the utilisation rate of the Programme would appear to be reasonable. As mentioned below, there may be value in further gauging the need for the Programme through targeted communication activity to improve key stakeholder knowledge and understanding of the Programme.

Programme participants mostly claimed for only the surgery part of the donation process (86 per cent), with 13 per cent claiming for both work up and surgery (Figure 7).

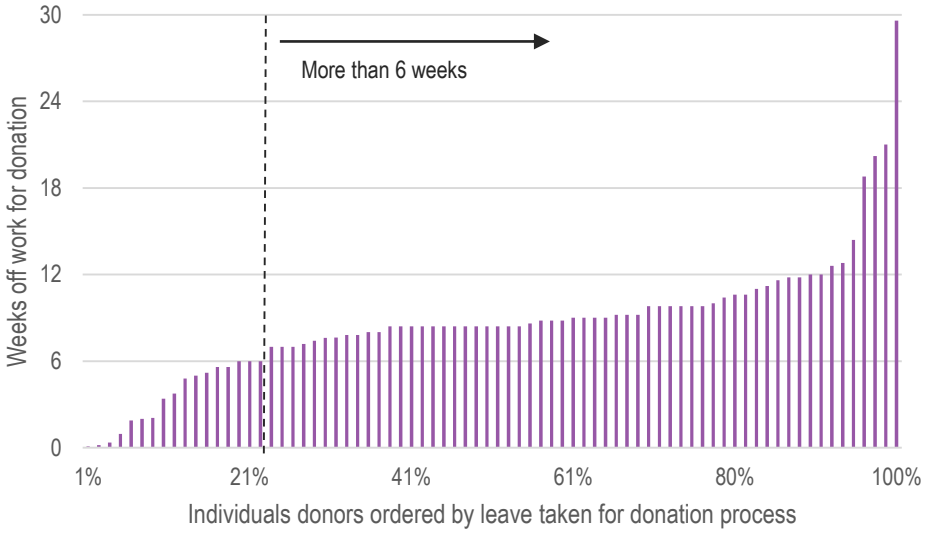
Figure 7 **Procedures for which participants claimed under the Programme**



Note: n=76 – all donors who received payments under the Programme in the first 10 months of 2013-14.
Source: DHS

As set out in Figure 8, 76 per cent of Programme participants take more than 6 weeks off work for donation process. The average amount of time off work that is reported for the donation is 8.7 weeks.

Figure 8 **Time off work taken by Programme claimants**



Note: n=76 – all donors which received payments under the Programme in the first 10 months of 2013-14.
Source: DHS

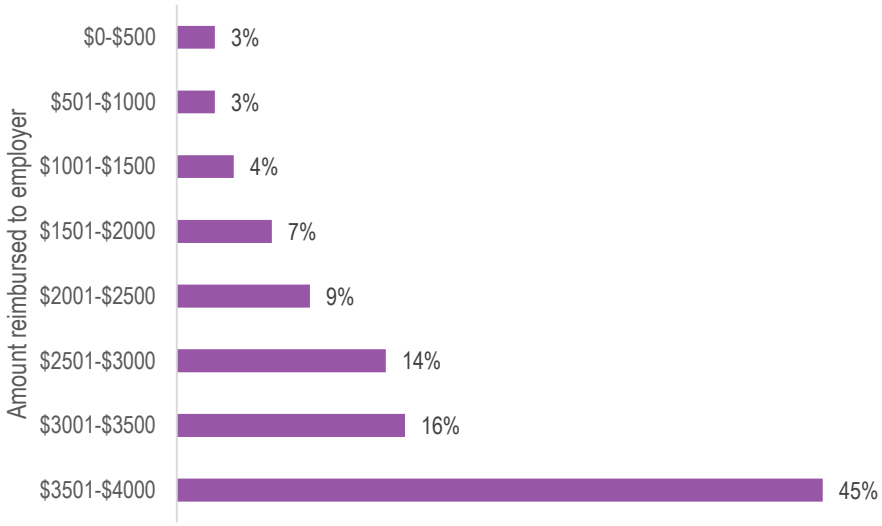
2.3.2 Programme payments

Payments under the Programme reflect the high number of claims for the maximum period of leave of 6 weeks. In many cases, the claim is restricted to leave taken for recovery from

surgery. The payment period can disguise the extent of time taken off work which can be for periods of 9 weeks or more (see Figure 8).

Payments summarised in Figure 9 show that most payments (61 per cent) to reimburse employers were between $3,000 and the maximum reimbursement of $4,000.

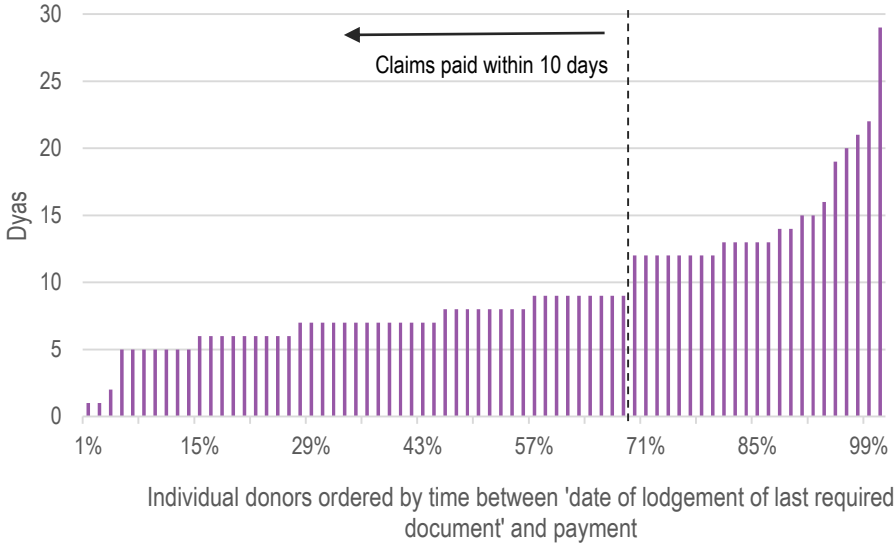
Figure 9 **Reimbursements to employers under the Programme**



Note: n=76 – all donors which received payments under the Programme in the first 10 months of 2013-14.
Source: DHS

Figure 10 shows that 70 per cent of claims were paid within 10 days of all claim-related documents being received. The average claim is paid in 9.4 days.

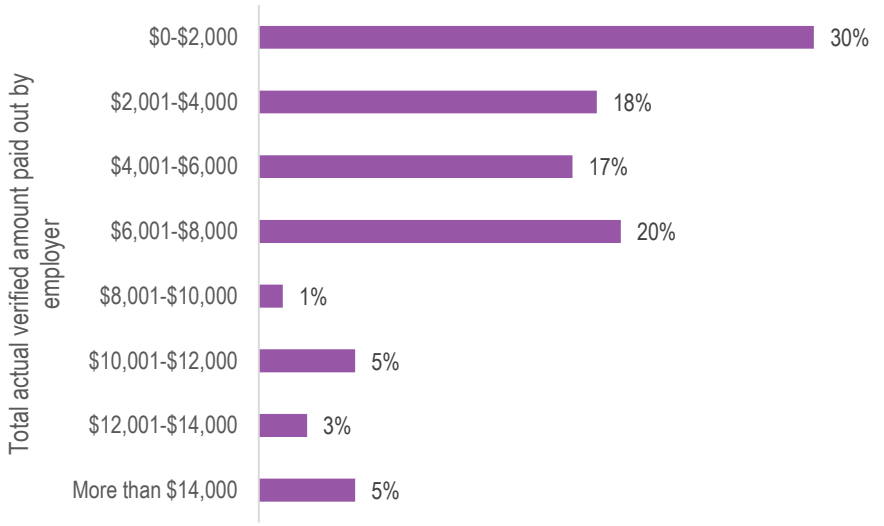
Figure 10 **Days to payment after date of lodgement of last required document**



Note: n=74 – all donors who received payments under the Programme in the first 10 months of 2013-14, apart from two records which are not included as a likely data entry issue resulted in infeasible data.
Source: DHS

In 65 per cent of cases, employers had made payments to living organ donors that exceeded the Programme reimbursements (see Figure 11). This can reflect both the extent to which the wage of the donor employee is above the minimum national wage and the longer period of leave taken. It also provides some insight into the value placed on the Programme by donors in obtaining a contribution to the costs associated with their absence from the workplace. One donor commented that 'overall it is a good Programme and helps people immensely' (donor survey).

Figure 11 **Amount paid out by employer**



Note: n=76 – all donors who received payments under the Programme in the first 10 months of 2013-14.
Source: DHS

2.3.3 Achievement of objectives

Notwithstanding the short period of time of the operation of the Programme, feedback from stakeholders and survey respondents suggests that the Programme is meeting its objective to reduce financial stress to living organ donors and their families. The impact on the employer has certainly raised their awareness of living organ donors within their workforce although there would appear to be some misunderstanding about the Programme that presents a potential barrier to donor participation. The extent of understanding is further explored under section 5.1.

There has also been evidence of a wider impact of the Programme in providing leverage for Kidney Health Australia in advocating for employer capacity to support the initiative, and at the state level for supplementing the 'opportunistic' support available to live donors as 'patients' in the local health system. From an industry perspective, following meetings with Kidney Health Australia, the NSW Public Health Service Commission released a circular (7 February 2014) affirming that 'increasing organ donation and transplantation is a strategic priority of the NSW Government', explaining the payment available under the Programme, and requesting that public sector agencies 'ensure that arrangements are in place to enable their staff to access the scheme'. Kidney Health Australia has also been invited to meet with the Victorian Government in relation to the initiative. Feedback from a number of employers surveyed for this project indicated that special or more transparent arrangements had been made for any future requests for leave relating to live organ donation.

At the state and territory level, the Programme has provided a more systematic response to the supports available to living organ donors, supplementing the limited resources available to support patient transport and accommodation, and local government programs for home-based supports.

Key Findings

Effectiveness:

- In the first year of operation of the Programme, a total of 127 persons registered for the Programme. While the majority of persons who registered were female, a higher proportion of males participated than is seen in the general population of live donors.
- Around 49 per cent of donors who registered were in full-time employment with roughly equal proportions of males and females. Males dominated the self-employed category and females made up the largest proportion of part-time workers. The proportion of casual workers was very small.
- The majority of registered donors were in the 45-54 age category, however, ages ranged from 25-34 through to 65-74 category.
- Based on the first 10 months of operation of the Programme, most registered donors lived in major cities and a further one third were located in inner regional Australia.
- It is estimated that around 36 per cent of all living organ donors participated in the Programme in the first 10 months of operation.
- Payments under the Programme were made to 74 donors in the first 10 months. A large proportion of payments were for the maximum contribution of $4,000.
- The duration of leave has been capped at 6 weeks, however, leave for 76 per cent of participants in the first 10 months of the Programme exceeded 6 weeks. The average amount of time off work reported was 8.7 weeks. A majority of employers had made payments to living organ donors that exceeded the reimbursements under the Programme.
- The Programme has provided leverage for advocacy in building industry support, prompted new arrangements to facilitate staff access to the Programme, and provided a 'dedicated' stream of support supplementing 'opportunistic' patient supports at local and state/territory level.

2.4 Summary

The Programme has been implemented as intended and remains relevant to health priorities concerned with reducing the prevalence of chronic diseases, and supporting evidence informed practice for improved patient outcomes.

There are a range of improvements that can be made to the Programme to improve communication and information exchange, and the streamlined and efficient implementation through conversion of a manual system to electronic. These improvements to processes would benefit the live donor in accessing and complying with Programme requirements, and enable fuller use of the data collected about Programme participants. For example, states and territories have indicated an interest in the level of participation in the Programme and a willingness to promote the initiative, especially through transplant units.

A simpler method for calculation of payments is indicated, along with flexibility in obtaining clinician authorisation to support donor claims, and determination of the duration of time off work associated with the donation.

The Programme is also tracking well in meeting its objectives to assist in relieving the donor's financial stress and increasing employer awareness of living organ donation by employees. This is measured by utilisation of the Programme which is estimated at around

36 per cent of all living kidney donors and payments made to reimburse employers for leave or ex gratia payments for 74 live donors.

In addition, a majority of employers have made payments to employee donors that are in excess of the reimbursement under the Programme. This is likely to reflect a combination of duration of leave, and the gap between the national minimum wage paid under the Programme and the employee's salary.

There may be scope to review the maximum leave that can be claimed under the Programme in light of the average time away from work reported by live donors as just under 9 weeks, rather than the estimated 6 weeks.

3 Impact on Donor

3.1 Expectation

The Supporting Leave for Living Organ Donor Programme is designed to reduce the financial stress for the live donor who needs to take time away from work during the donation process. The initiative requires the agreement of the employer to make suitable arrangements to provide leave or an ex gratia payment to their employee, and to participate in the claim process under the Programme to obtain reimbursement up to a capped level.

At its peak in 2008, there were 354 live kidney donors that had declined to 237 in 2012. A proportion of these donors could be expected to be in employment, and to be required to take extended leave of up to 6 weeks or more.

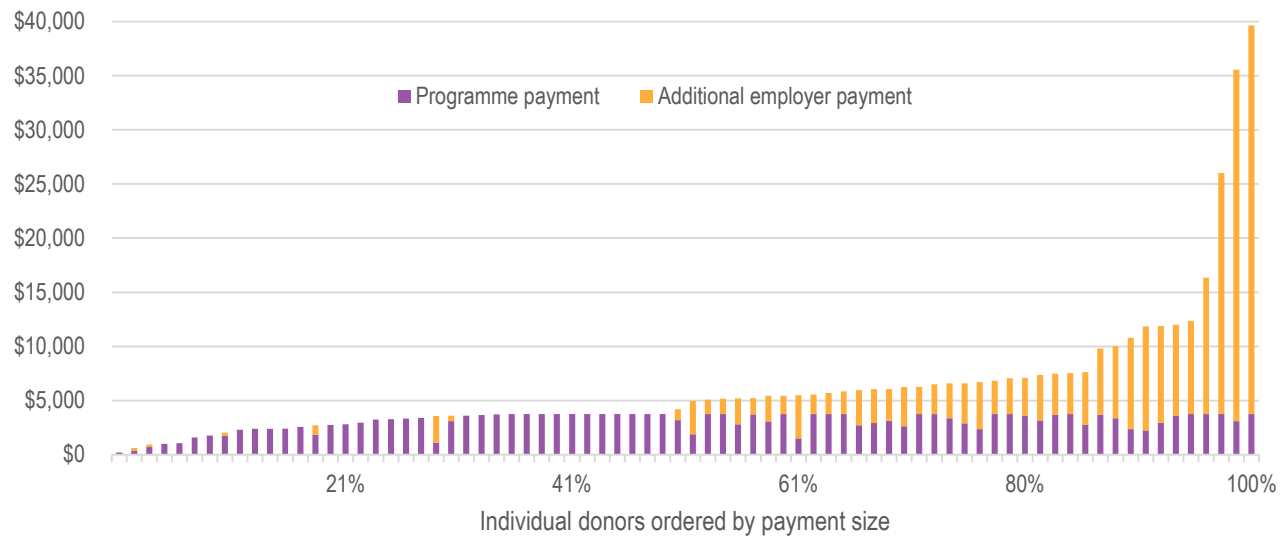
Apart from the initial launch of the Programme pilot and the availability of information from Health and DHS, the ongoing and largely opportunistic promotion of the initiative by Kidney Health Australia, and the information provided to donors by transplant unit staff, there is generally a low awareness of the Programme.

3.2 Financial support

Figure 12 sets out the payments received by donors involved in the Programme, separated by whether the payment was reimbursed to the employer (a 'Programme payment') or was additional to the amount the employer was reimbursed by the Programme.

It is clear there is a considerable variation in the financial support received by living organ donors due to the differences in additional employer payments.

Figure 12 **Payments to donors involved in the Programme**

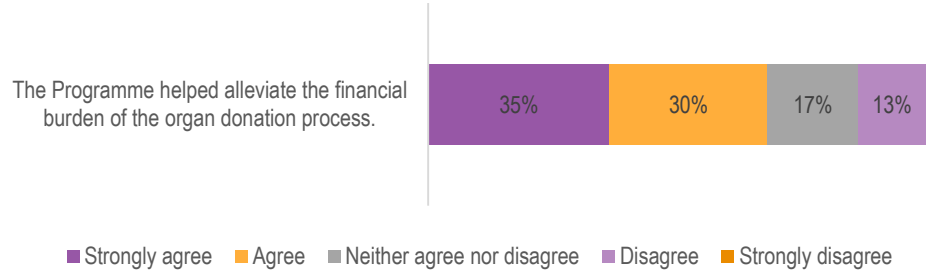


Note: n=76 – all donors who received payment under the Programme in the first 10 months of 2013-14.
Source: DHS

The majority of donors (65 per cent) who participated in the survey for this report indicated they thought the Programme helped alleviate the financial burden of the organ donation process (see Figure 13).

In some instances the Programme was able to replace sick leave that was needed for the donor's carer role. One respondent indicated that while the support 'did not alleviate the financial burden of the organ donation process itself, what it will do is enable me to have a break from work after I have recovered, which is a wonderful thing'. Other responses included 'I encourage being a live donor and if finance is an issue, then this Programme is very well worth keeping', 'A worthy program that needs to continue. Obviously I could have coped without the payment but it certainly made it easier, as having 2 non-working adults in our family was a bit hard.' A small proportion of respondents (13 per cent) did not agree that the Programme had alleviated the financial burden.

Figure 13 **Impact of the Programme on the financial burden faced by donors (survey results)**



Note: n=23 There were no responses in the 'strongly disagree' category.
Source: Donor survey

This view about the impact of the Programme was confirmed by Transplant staff who were appreciative of the contribution the Programme made to support for the live donor and were diligent in drawing it to the attention of donors during their visits to the Unit.

Some disagreement by respondents to the financial impact relates in part to the dissatisfaction with use of the national minimum wage, especially by casual workers with restricted leave entitlements.

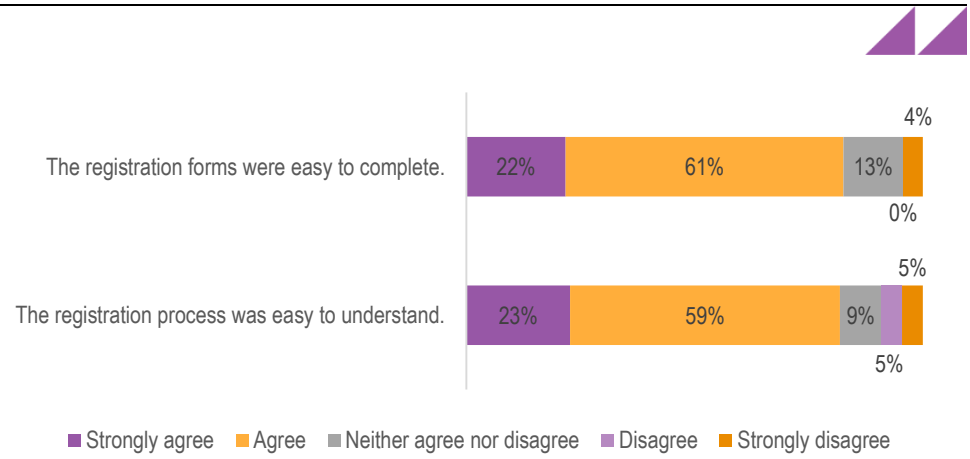
Clarity regarding how payments should be calculated was requested by donors and employers. Donors reported that using minimum wage to calculate the amount paid does not reflect actual earnings as it does not consider sick leave, annual leave and public holidays.

Donors experienced slow payments from employers. One donor had still not been paid six weeks after his procedure. Another donor suggested that the payment could be made to the employer when the employee starts their leave.

3.3 Other

Donor survey respondents generally considered the Programme registration process easy to complete and understand (see Figure 14).

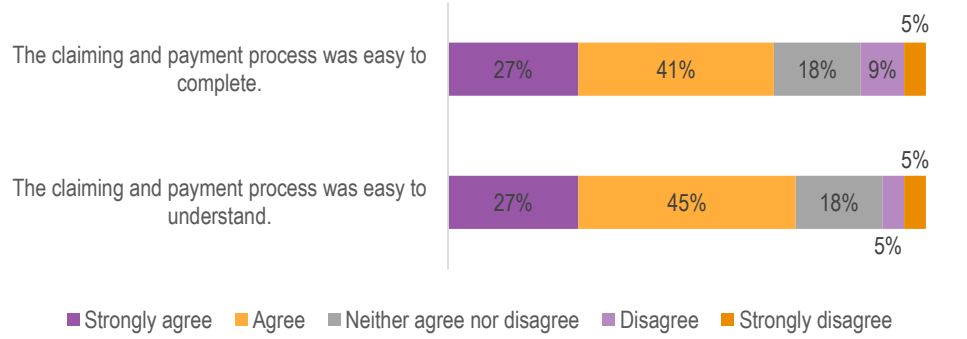
Figure 14 **Donor views on the registration process**



Note: n=22 (completion of forms), n=23 (understanding process)
Source: Donor survey

While this was broadly true of the claiming and payment process (see Figure 15), the differences between responses to the two sets of survey questions indicates donors had more difficulty with the claiming and payment process than with the registration process.

Figure 15 **Donor views on the claiming and payment process**



Note: n=22 (completion of forms), n=22 (understanding process)
Source: Donor survey

Donors and health practitioners commented that the registration process and completion of all forms was onerous and confusing, particularly the gathering of all necessary medical signatures. However, one donor stated that there was 'clear instructions and prompt payment'.

One donor stated that the Programme influenced his decision to donate.

Donors requested that further support and awareness regarding available assistance to access the Programme is needed.

3.4 Summary

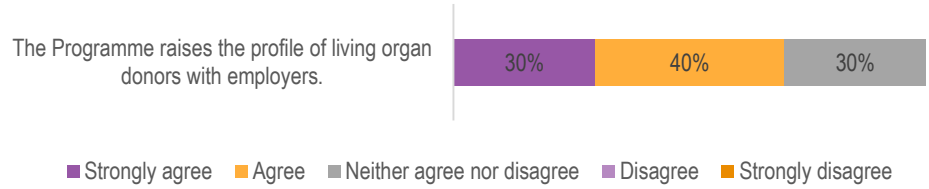
The majority (65 per cent) of donor survey respondents agreed that the Programme assisted in alleviating the financial burden of the donation process. Of these, 35 per cent strongly agreed with the statement. Feedback from Transplant Unit staff indicated that they were acutely aware of the financial burden on live donors and were appreciative that they were able to make donors aware of the Programme.

4 Impact on Employer

4.1 Engagement

Although a small sample of employers, the employer survey respondents (not including the self-employed) largely agreed that the Programme raises the profile of living organ donors with employers (see Figure 16). It is of interest that in all instances, the employer organisation first found out about the Programme from the donor employee. Organisations included in the survey were a mix of industry types with the majority from the education and health sectors and two-thirds with more than 200 employees.

Figure 16 **The impact of the Programme on employers' awareness of living organ donors**



Note: n=10 Nil responses in the 'disagree' and 'strongly disagree' categories.
Source: Employer survey

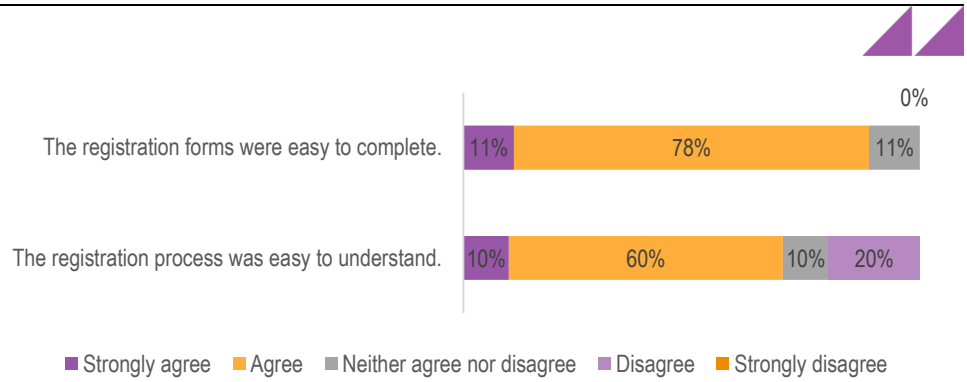
All respondents answering the question agreed that the employer would be willing to support another employee through the Programme. This is noteworthy given comments from some respondents about administrative issues, costs and time associated with participation. Respondents specifically noted difficulty with gathering and understanding payment information leading to mistakes in payments which had to be rectified.

A representative of the Australian Council of Trade Unions (ACTU) reported the organisation and its affiliates were unaware of the Programme. Increasing awareness of the Programme for employers would provide opportunity for employer support by including the Programme or living organ donation in their employment policies. It would also make it easier for employees to access the Programme if their employers were already aware of the Programme.

4.2 Burden

The vast majority of employers who participated in the survey for this report found the Programme registration forms easy to complete (89 per cent), with a smaller majority finding them easy to understand (70 per cent) (see Figure 17).

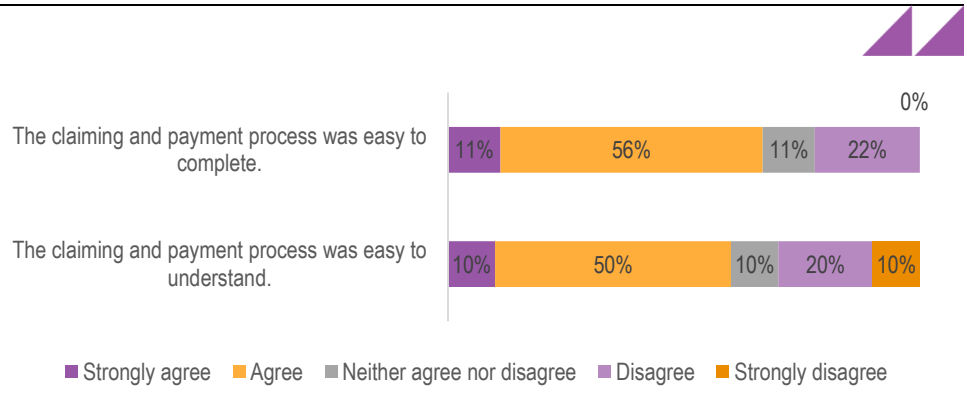
Figure 17 **Employers' views on the registration process**



Note: n=10 (completion of forms), n=9 (understanding process).
Source: Employer survey

While a majority also saw the claiming and payment process as easy to understand and complete (see Figure 18), it was viewed less favourably than the registration process.

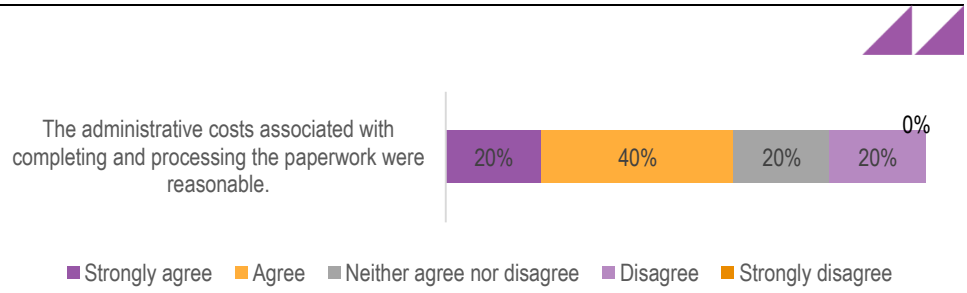
Figure 18 **Employers' views on the payment process**



Note: n=10, n=9
Source: Employer survey

Around 60 per cent of employers considered the administrative costs of the Programme reasonable, with 20 per cent disagreeing. (see Figure 19).

Figure 19 **Employers' views on administrative costs**



Note: n=10
Source: Employer survey

4.3 Improving employer awareness

Feedback was obtained from a number of industry and employee representative organisations about their awareness and support for the Programme.

None of the representatives were familiar with the Programme and suggested that this was probably also a reflection of their memberships' lack of awareness.

The industry groups indicated that they would be willing to disseminate educational materials to their membership base about the initiative. It was considered that the Programme was too small to require formal inclusion in workplace policies and that information to employers would be sufficient to build their awareness.

A number of comments were made about the desirability of online rather than an exclusively paper-based programme to reduce frustration with the 'exhaustive form process', and about the desirability of a programme that makes payments direct to employees rather than through employers to minimise delays. It was also emphasised that to obtain employer 'buy in' it would be necessary to keep costs down and reduce administrative burden.

Union feedback focused on the opportunity for introducing support for the Programme into employment agreements. Precedent exists such as for blood donor and bone marrow donor leave. Examples were provided of similar purpose specific leave provisions in some organisations such as for intensive medical treatment, additional personal carers leave, family violence leave The potential for development of a model clause for inclusion in bargaining guides was an option.

4.4 Summary

While some consultation feedback suggested that employers could be better informed about their role under the Programme, the level of participation of employers in supporting the donor employee has been promising. Employers responding to the project survey indicated that their first knowledge of the Programme was after being approached by their employee, however, they proceeded to provide support and despite some administrative issues accommodating the Programme, they all agree that they would be willing to support another employee through the Programme.

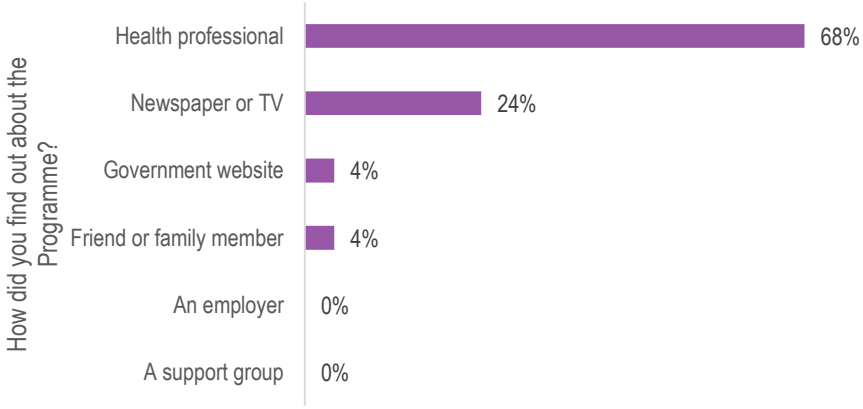
Both industry and union organisations have indicated a willingness to promote the Programme through their branches and membership base to build awareness and understanding among employers.

5 Programme Participation

5.1 Enablers

Feedback from donors surveyed indicates that health professionals (such as doctors and nurses) were the most common source of initial knowledge about the Programme. Media also played an important role, with a number of donors finding out about the Programme from newspaper articles (see Figure 20).

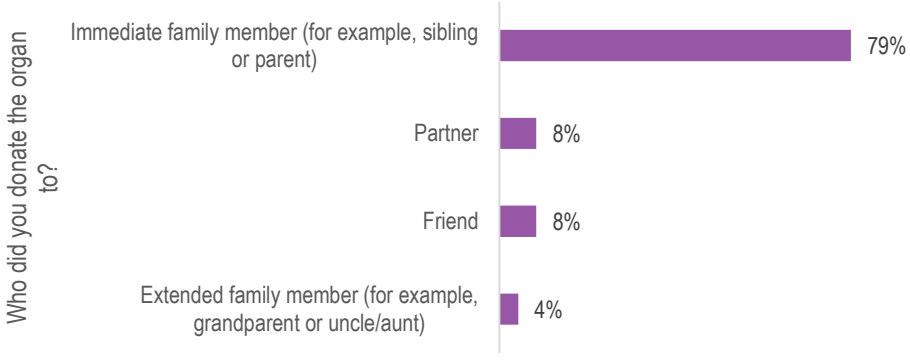
Figure 20 **How participants found out about the Programme**



Note: n=25
Source: Donors survey

Almost 80 per cent of donor survey respondents donated an organ to an immediate family member (see Figure 21).

Figure 21 **Donation recipients relationship to the donor**



Note: n=24
Source: Donor survey

Other enablers included:

- Supportive employer
- Assistance from DHS, including providing information and guidance over email and the phone
- Direction from health professionals.

5.2 Barriers

5.2.1 Public awareness

Consultation feedback consistently referred to the lack of public awareness about the Programme, suggesting that it was restricted to those who were engaged in donation. It was also suggested that the low level of Union awareness of the initiative reflected a similar level of employee awareness. While it was not considered that awareness of the Programme would encourage donation, a broader familiarity with the existence of the Programme could assist in greater employer engagement (some donors were reported to be worried about approaching their employers) and donor willingness to access the support as part of normal leave entitlements.

Generally, there was support for targeted information about the Programme to reach industry, potential recipients, and those on the journey to be a live donor. The current information sheet (from the website) 'does not look very pretty. It has no letterhead and can be a bit confusing – perhaps a bit wordy and technical'. A leaflet suitable for inclusion in information sent out to prospective living organ donors or provided at first assessment received support from Transplant staff in particular.

5.2.2 Donor and employer understanding of the processes

While the project survey responses suggest that both donors and their employers considered that the registration, and claiming and payment processes were easy to understand and complete, the strength of agreement was reduced for the claiming and payment processes. The need for simplified and concise information about the Programme for donors was frequently mentioned by Transplant staff.

Consultation feedback commented on delays in processing because of lack of donor understanding of the two stage process, delays in material being provided to employers, and HR challenges in retrospectively adjusting payments associated with reimbursed leave.

Suggested critical success factors for the Programme included an easier method for obtaining and returning Programme forms ('the registration process is clumsy', 'forms just keep coming'), easier access to information about the Programme, greater flexibility in considering eligibility for the Programme that accounted for changed circumstances because of the donation process, and timely completion and return of forms by the employer (which could be overcome with improved information/guidelines for employers). The DHS Helpline was generally considered helpful in working through issues and clarifying processes.

One stakeholder suggested that cases reported by donors of employers not agreeing to participate may have reflected the barriers of lack of understanding or inability to afford 'bridging' the employee support pending reimbursement.

Administrative costs to employers

As noted above in section 4.2, a recurrent theme in the consultations carried out for this evaluation is the need for payment processes to be simpler. This includes the impact of the current process on employers' administrative costs.

Qualitative feedback from the survey suggests that for less straightforward work arrangements, such as a rotating roster, establishing the payment 'was extremely difficult and the company decided to 'absorb' the shortfall in payment based on what the take home pay would have been for the employee (ie penalties, allowances, and additional periods of leave allocated over and above the maximum 6 weeks).' Other employers sought an 'easier and more efficient program so employers who do support this leave for their employees are compensated or supported better', or 'applied and ad hoc process in the end' because it was difficult., or called for greater efficiencies, 'the reimbursement of leave credits burned through a lot of resources (and time) to figure out. It also impacted on WH&S as we cannot remove a certain end to end date…so partial hours from each day needed to be removed'.

Increased awareness by Government departments and employers would improve donor's experience when accessing the Programme. One donor noted that Medicare was unaware of the Programme.

There was a call for basic information about the Programme to be available in other languages to assist persons 'from non-english speaking backgrounds who were often on lower wages and for whom the Programme would be beneficial'.

5.3 Summary

Health professionals were an important enabler to providing information to live donors about the Programme. This is especially relevant because of the likely family relationship between the donor and recipient providing an opportunity for the discussion about living organ donation to commence with the recipient's health care providers.

The employer and the support they can provide to the employee through leave arrangements is another key enabler and an area for further development to improve awareness and understanding of the Programme.

Barriers to optimising the Programme include the lack of public awareness of the initiative and the need for more suitable information material that has regard for different educational levels and language skills. There was support for a brochure for use in transplant units and poster information for display in dialysis units.

A simplified claiming and payment process would facilitate access and understanding and streamline the process.

6 Conclusion

Overall, there was very strong support for the Supporting Leave for Living Donors Programme from all parties. States and territories indicated that they were very supportive and positive about the Programme and that 'there was a lot of good collective thought around supporting living organ donation'. Transplant Unit staff were seen as critical to improving awareness and understanding of the Programme with live donors, and to facilitating completion of information requirements. Unions were encouraging of the possibility of a greater role in embedding the initiative with employers and some parts of industry had already demonstrated leadership in formalising their support for living organ donors.

A wide range of improvements to the Programme process and data collection tools have been suggested. A critical issue is achieving greater flexibility consistent with the policy intent of the initiative to improve access, and development of a more streamlined and integrated payment process.

There may be benefit in continuing the engagement of Programme participants and other stakeholders in the more efficient design of the Programme, should it be extended beyond the pilot period. These discussions should consider other concurrent activities to build the awareness of the Programme, harness the goodwill of jurisdictions in achieving a consistent and transparent approach to the support for live donors, and produce information material to improve communication about Programme requirements.

The solid performance of the Programme against its objectives, its level of utilisation and the commencement of industry changes around recognition of the living organ donor indicate that the Programme is tracking towards the intended outcomes. Should the Programme be extended, the suggested areas for improvement should impact access and equity issues in effectively and efficiently providing support to living organ donors.

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Appendix A Stakeholder consultation

Provided below is a list of stakeholder consultations undertaken as part of the evaluation.

Table 1 **Stakeholder interviews**

Jurisdiction	Organisation	Representative
Health departments and health practitioners		
ACT	ACT Health	Emily Harper, Manager, Office of the Chief Health Officer
NSW	NSW Health	Julie Letts, Manager, Clinical Ethics and Policy, Office of the Chief Health Officer
		Kim Steward, Director, Office of the Chief Health Officer
		Dr Kate Wyburn, Chair, Transplant Advisory Committee
	Royal Prince Alfred Hospital, NSW	Jane Mawson, Renal Transplant Coordinator
NT	Royal Darwin Hospital, NT	Kerry Dole, Renal Transplant Clinical Nurse
Qld	Queensland Health	Aimee Cunningham, Manager, Transplant Services Lisa Finch, Renal Transplant Coordinator Eileen Fitzpatrick, Social Worker
SA	SA Health	Susan Ireland, Manager, Blood, Organ and Tissue Programmes Unit
	Royal Adelaide Hospital, SA	Sara Mahoney, Renal Transplant Social Worker
Tasmania	Department of Health and Human Services	Julie Tate, Clinical Support and Cancer Services Development, Office of the Chief Medical Officer
Victoria	Department of Health, Victoria	Jenny Soding, Renal Health Care Network, Commission for Hospital Improvement
WA	Sir Charles Gairdner Hospital	Emily Toohey, Renal Transplant Clinical Nurse
		Brue Maguire, Renal Social Worker
	Fremantle Hospital	Susanne Betti, A/Clinical Nurse Renal Transplant
Support organisation		
National	Kidney Health Australia	Luke Toy, General Manager Public Affairs Dr Timothy Mathew, Medical Director
Employer groups		
National	Australian Industry Group	Genevieve Vaccaro, Senior Adviser, Workplace Relations Policy
National	Australian Chamber of Commerce and Industry	Richard Clancy, Director of Workplace Relations
Union		
National	Australian Council of Trade Unions	Cassandra Devine, Policy and Research Officer

Source: ACIL Allen Consulting 2014

Key informant interviews were held with:

- representatives of the Australian Government Department of Health and Department of Human Services, who have joint responsibility for implementation of the Supporting Leave for Living Organ Donors Programme pilot
- DonateLife (Organ and Tissue Authority)
- Kidney Health Australia for a preliminary conversation and exchange of information.