



## **Developing the Immediate Registration Opportunity Paradigm for use over multiple locations**

**DonateLife week, Young Adults & CALD Communities**

Southern Cross University  
In collaboration with  
NSW Organ & Tissue Donation Service

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## Executive Summary

The *Immediate Registration Opportunity paradigm* offers the public an immediate on-the-spot opportunity to register their donation decision on the Australian Organ Donor Register. There are three main components to the paradigm. First, the DonateLife stall is set up at the location and the public are approached and invited to complete a short survey. Second, during this interaction, participants are encouraged to ask questions, comment and raise concerns about organ donation and the registration process. Third, participants are asked at the end of the survey (and in person) if they would like to sign the Australian Organ Donor Register *now*. If they reply yes, they are given an Australian Organ Donor Registration form to complete on-the-spot.

The aim of the research was to develop the *Immediate Registration Opportunity paradigm* for use over multiple locations; thereby creating the potential to increase registrations on the Australian Organ Donor Register (AODR). The research was conducted in 2017 across 8 locations in Sydney and examined the type of staffing needed to run the paradigm, the impact that the organ donation survey had on registration behavior and the suitability of offering the paradigm across locations with different socio-cultural backgrounds and age profiles (ECN-15-075).

Location Event	Date 2017	
State of Origin, ANZ stadium	June 21 <sup>st</sup>	
The St George Hospital, Kogarah	August 1 <sup>st</sup>	} DonatLife Week
Campbelltown FFA Cup	August 2 <sup>nd</sup>	
Qantas Headquarters, Mascot	August 2 <sup>nd</sup>	
Blacktown FFA Cup	August 3 <sup>rd</sup>	
St George Private Hospital, Kogarah	August 4 <sup>th</sup>	
Bstreetsmart Road Safety Event, Qudos Bank Arena	August 15 <sup>th</sup> -17 <sup>th</sup>	
NRL Grand Final, ANZ stadium	October 1 <sup>st</sup>	

The survey took approximately 3 minutes to complete and asked participants how they perceived the atmosphere at the time; their beliefs about organ donation, measured by 4 subscales: *Positive beliefs about organ donation; Beliefs about the benefits of organ donation to the self, Beliefs about the negative consequences of donation, and Concerns over the medical care associated with donation;* knowledge about the registration process, registration status, demographic information and whether they would like to sign the AODR now. A registration rate (*percentage of those who registered on the-spot from those eligible<sup>1</sup> to register*) was calculated at each location allowing the efficacy of the paradigm to be compared across locations and with the national registration rate (<20%). (*Eligible to register = previously not registered on the AODR, aged 18 and over & resident in Australia*).

## Overview of findings

The Immediate registration opportunity paradigm was successful across all locations. The registration rate was higher at every location than the 2017 national registration rate (<20%); demonstrating that, as a strategy, offering people an on-the-spot opportunity to register has the potential to significantly increase registration rates nationally.

Over the course of the research, a total of 406 registrations were made, and 1502 people interacted with the immediate registration opportunity; of whom 42% identified with a cultural/national group other than Australian. Of the 802 people who were aged 18 years and over, 53% were *unaware* the driver's license had been phased out, 17.6% reported they had already signed the AODR, and 54% of those eligible to register signed the AODR on the spot.

The hospitals yielded the highest registration rates (72% combined) along with Qantas Headquarters, Mascot and the NRL Grand Final. The registration rate at the FFA cup soccer matches was 32.6% (combined) and, although lower than the hospitals, provided an invaluable opportunity to interact with people from diverse cultural backgrounds. Intent registration were offered to students aged 16 to 18 years at lunch during the 3 day Bstreetsmart Road Safety Event yielding 695 interactions, and a 17.5% registration rate (national intent registration rate 16-18 year < 1%).

<b>Location Event</b>	<b>Registration rate ( % of those who registered from those eligible to register)</b>	<b>Number of registrations made at each location</b>
State of Origin, ANZ stadium	37.6%	41
The St George Hospital, Kogarah	63.6%	42
Campbelltown FFA Cup	35.0%	23
Qantas Headquarters, Mascot	68.2%	44
Blacktown FFA Cup	31.5%	23
St George Private hospital Kogarah	78.2%	61
Bstreetsmart Road Safety Event ( <18 yrs),	17.5% intent registration 16-18yrs	69
NRL Grand Final, ANZ stadium	60.6%	103
<b>Total</b>		<b>406</b>

The organ donation belief profile across all participants was remarkably similar, with the majority of participants reporting very strong positive beliefs about donation, moderately strong beliefs about the benefits of donation to self, weak to moderate beliefs about the negative consequences of donation and weak beliefs about the medical care associated with donation. Strength of belief about the negative consequences of donation was a significant predictor of the probability of registration across the majority of locations. This suggested that although participants hold both positive and negative beliefs about donation, beliefs about the negative consequences are potent in the decision to register.

## Key findings

### 1. The immediate registration opportunity was successful

Our research suggests there are four interrelated reasons why the immediate registration opportunity was successful.

**First**, many people hold some level of negative concern about organ donation and these concerns, be they niggling or significant, are enough for people to leave registration for another day, another time, another place.

**Second**, people often need time to contemplate their own position on organ donation. This was provided by the 3 minute survey.

**Third**, people often want to talk to someone face to face before they make, what many see, as a very important decision. People often want to ask questions or just talk about the donation and the registration process.

**Finally**, the immediate registration opportunity makes registration easy and effortless which, in conjunction, with the above facilitates registration.

### 2. The registration opportunity needs to be taken to where the people are.

The public need to be given the opportunity to register at locations and events they frequent: at sporting events, at work, at the hospital.

**Each** of these locations offers a different fit with the opportunity to register, for example hospitals were perceived by the public to be a natural location for the registration opportunity and yielded a high registration rate.

**Importantly**, each location provided an invaluable opportunity to interact with people from different socio-cultural/ economic backgrounds. For example, sporting events allowed donation to be discussed with people who had never considered this before.

### 3. Immediate registration opportunity as an intervention of CALD communities

The immediate registration opportunity provides an opportunity for beliefs and concerns to be discussed in a face to face supportive non-threatening environment

**Forty-two percent** of the participants identified with a cultural/national group other than Australian; 113 cultural/national identifications were reported.

**Face to face interaction** can counteract suspicion and mistrust associated with the medical community; particularly for those who do not have English as a first language  
**The registration process** is made easier; offering an alternative to online registration

### 3. The approach with the public is crucial.

Staff need to be trained in how to offer the immediate registration opportunity

**Staff** need to believe that registration is important, be comfortable approaching people and initiating conversation about organ donation, and work as a team.

**A warm, empathic, perceptive** manner is essential as many people hold some level of negative concern about donation which they may be reluctant to express.

**Humor and an ability** to read body language are key skills

**One member of the team** does need to have specialist knowledge about donation in order to comprehensively address complex donation questions.

### 4. The organ donation survey is part of the approach

The survey helps engage people and facilitates conversation about organ donation

**The survey** also prompts people to consider their own beliefs and to ask questions they may be reticent about.

**The survey** gives people time to consider (contemplate) their own position on donation and can create dissonance. People can wonder after answering the questions why, if they have responded positively, haven't they registered.

**The survey** does not incur registration on its own, the survey works with the approach.

### 5. The atmosphere is important

Registration was more likely to occur, when the atmosphere was perceived to be calm, leisurely and friendly rather than frantic and hectic.

**A calm and leisurely** atmosphere facilitates registration. Many people need time to consider their position on donation

**When people felt rushed**, they tended to take the form home – leaving registration for another time, another day another place

**Mood is important.** Many people who registered reported feeling positive and happy

## FUTURE DIRECTIONS

### **1. Conduct a hospital study across 10 major hospitals in NSW**

- Offer the immediate registration opportunity. Based on our prior research, it has the potential to be very successful.
- Pilot at 10 hospitals and then roll out at other hospitals without data collection.

### **2. Include on-site staff training in future roll-outs of the paradigm.**

- Continue development of a training package to train volunteers/ Donation staff.
- Including on-site training will maximise the effectiveness of the training package.

### **3. Modify the survey for use without ethical approval**

- Modify and trial the survey so it can be used by NSW OTDS and OTA.
- The modified survey needs to make salient both positive and negative beliefs about organ donation, and facilitate discussion about organ donation.

### **4. Work with NSW OTDS/OTA and continue to develop the immediate registration opportunity at FFA matches and major sporting events**

- Trial modified survey, collect data at a few locations and then rollout without data collection at other events.
- Develop the fit by offering activities in line with the sporting event
- Continued rollout at sporting events to access to otherwise hard to reach cultural groups. Our findings suggest that it may be more effective to go to where the CALD communities are rather than designing specific interventions for CALD communities.

### **5. Partner with OTA/NSW OTDS and Southern Cross University to apply for ARC (Australian Research Council) Linkage Grant and National Health and Medical Research Council (NHMRC) funding.**

- If successful, ARC funding will match the in-kind and financial contribution of Industry partner and the in-kind contribution from Southern Cross University.
- ARC funding could enable the large scale roll- out of the Immediate Registration Opportunity (Hospitals, Corporate sector, sporting events).
- National Health and Medical Research Council offer partnership project grants for translational research.



## RESEARCH LOCATIONS: SUMMARY FINDINGS



**Summary demographic information and key statistical findings are presented for each location on pages 10 to 15. Please contact the first author for further information about the research.**

**Classification of cultural and national groups** Participants were asked to provide the cultural or national group they identified with. The categorization of these cultural and national groups presented here is in line with that found in the Australian Bureau of Statistics: 1249.0 Australian Standard Classification of Cultural and Ethnic Groups, 2016, Table 1.3



## The St George Hospital and St George Private Hospital

### Demographics

168 interactions in total

66% Female, 17% Male (M age=46, SD=16.1)

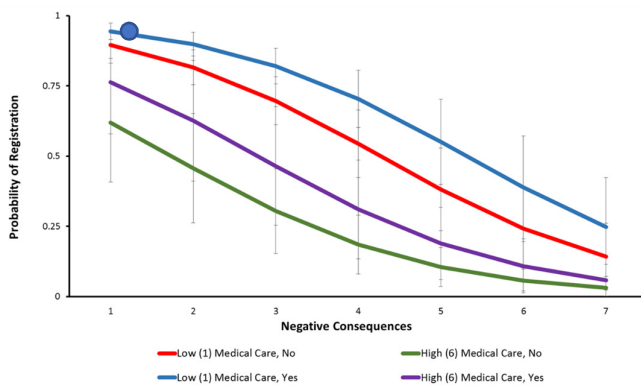
48% Australian, 7.2% Chinese/Southern Asian, 4.2% British, 4.2% SE European

31.7% previously registered on the AODR

45.1% knew the DL had been phased out

33.3% knew someone donated/ received organ

### Probability of registering for both hospitals



Medical or health trained participants reported significantly weaker beliefs about negative consequences and concerns over medical care than those who were not medically or health trained. The probability of registering was the highest for participants with lower scores on these scales and who reported knowing someone who had donated or received an organ. ●

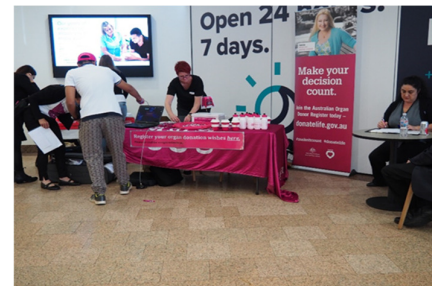


#### The St George Hospital

Active stall hours: 10:30am – 1.30pm

Registration rate = 63.6%

Total registrations= 42



#### St George Private Hospital

Active stall hours: 10:45am – 2:00pm

Registration rate = 78.2%

Total registrations= 61



## NRL, Grand Final

### Demographics

218 interactions in total

47% Female, 40% Male

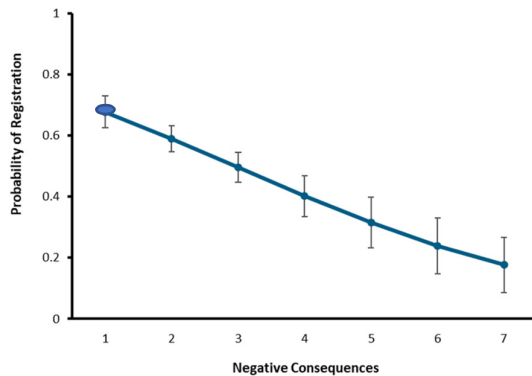
71% Australian, 3.2% New Zealand,  
1.8% Arab

18.8% previously registered on the AODR

28% knew the DL had been phased out

36.8% knew someone donated/received organ

### Probability of registering



The probability of registering was significantly higher for those participants who reported weak (rather than strong) beliefs about the negative consequences of donating. ●

The perceived atmosphere – the time of day, the heat, the number of people outside the stadium, and the tempo and mood influenced the number of people interacted with and the number of registrations made



### NRL

Active stall hours: 11:00am – 6:00pm

Registration rate = 60.6%

Total registrations= 103

### Registration by time of day



## Qantas Headquarters, Mascot

### Demographics

79 interactions in total

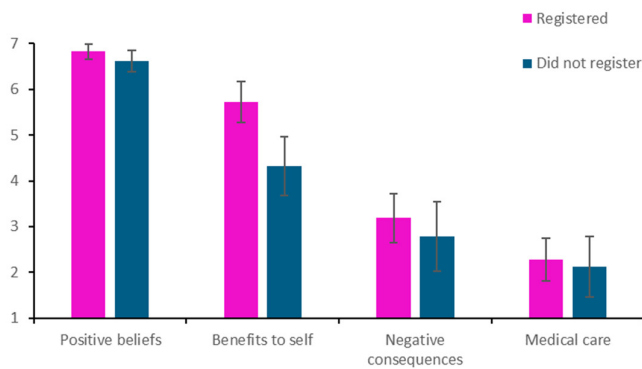
60% Female, 32% Male (M age=37.8, SD=11.6)

54.4% Australian, 7.6% Southern Asian,  
3.8% New Zealand

11.4% previously registered on the AODR

22.8% knew the DL had been phased out

19% knew someone donated/received organ



Participants who registered reported stronger beliefs about the benefits of donation to the self in conjunction with feeling less stressed, more upbeat and happier (mood) than those who did not register on the spot

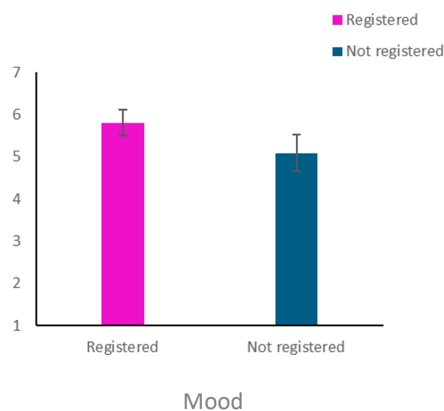


### Qantas Headquarters

Active stall hours: 11:00am – 2:00pm (3 hrs)

Registration rate = 68.2%

Total registrations= 44





## FFA Cup soccer: Campbelltown and Blacktown City

### Demographics

**174 interactions in total**

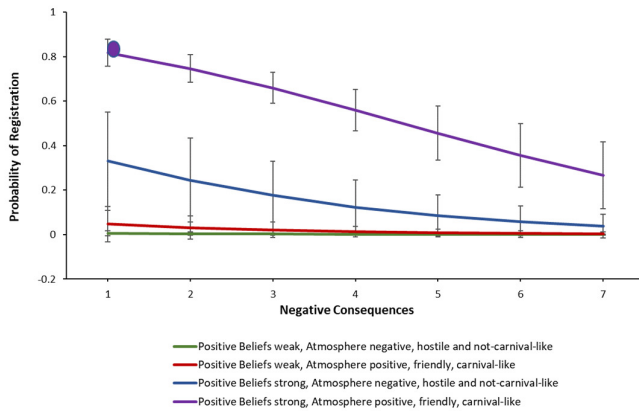
**59% Male, 36% Female (M age= 36.2, SD=15.2)**

**68.4% Australian, 2.3% Arab, 2.3% Southern European, 2.3% North African and Middle Eastern, 2.3% British**

**14.4% previously registered on the AODR**

**36.8% knew the DL had been phased out**

**27.6% knew someone donated/received organ**



The probability of registering was the highest when positive beliefs were strong, negative consequences weak and the atmosphere was perceived to be positive, friendly and carnival-like. ●



Western Sydney Wanderers V Wellington Phoenix

#### Campbelltown Soccer

Active stall hours: 6:15pm – 7:30pm plus 15 minutes at half time (1.5hrs)

Registration rate = 31.5%

Total registrations= 23



Blacktown City versus Central coast Mariners

#### Blacktown Soccer

Active stall hours: 6:00pm – 7:30pm plus 15 minutes half time (1 hr 45)

Registration rate = 36.4%

Total registrations= 23



## Bstreetsmart Road Safety Event

### Demographics

**694 interactions in total**

**Age – 16 to 18years (with 37.5% 15years not included)**

**71% Female, 25% Male**

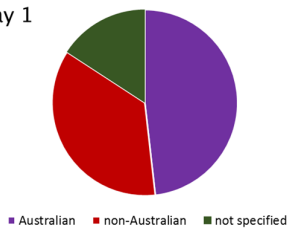
**42.5% Australian, 10.1% SE Asian, 7.3% Arab, 6.8% Chinese, 5.5% Southern Asian**

**0.5% previously registered on the AODR**

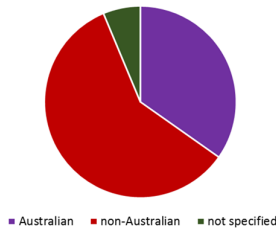
**15.4% knew someone donated/received organ**

One hundred and eight (108) cultural/national identifications were reported. The makeup of these groups varied across the three days.

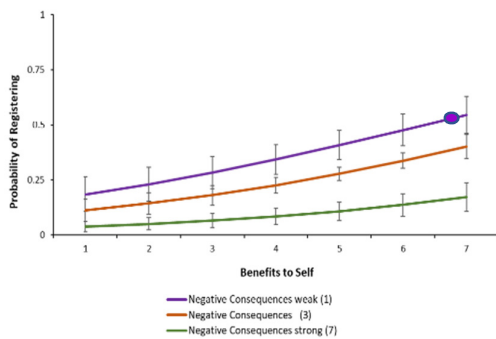
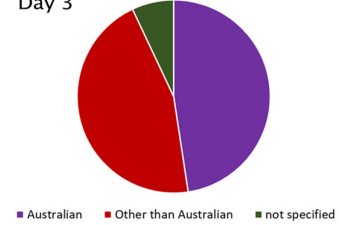
Day 1



Day 2



Day 3



Probability of registering was the highest when negative consequences were weak and Benefits to self were strong. ●



### Bstreetsmart

Active stall hours: 12:00 – 1:30pm over 3 days

Registration rate = 17.5%

Total registrations = 69



## State of Origin

### Demographics

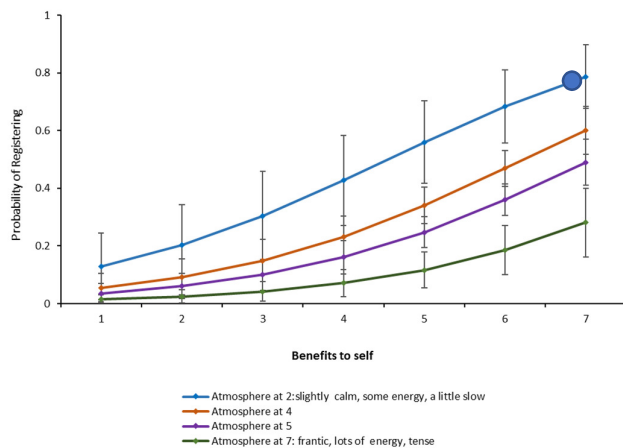
**172 interactions in total**

**42% Female, 57% Male (M age=34.8, SD =13.6)**

**78% Australian, 3 % Indigenous Australian, 3% New Zealand, 3% Polynesian**

**31.7% previously registered on the AODR**

**45.1% knew the DL had been phased out**



Probability of registering was the highest when the atmosphere was perceived to be slightly calm, with some energy and a little slow. ●



### State of Origin

Active stall hours: 4.30-7.30

Registration rate = 37.6%

Total registrations= 41

## FEEDBACK

Over the course of the research, we received overwhelming positive feedback from the community about the Immediate Registration Opportunity

*I actually didn't want to talk to you or do the survey when you initially came up to our table. I still am unsure about registering. But I'm glad you didn't turn away and gave it another try to get through my reluctance. Thank you for being persistent - I sure am going to be thinking about this for a while." (28 year old female, The St. George Hospital Kogarah, 31st July.)*

*Ah, I had not even considered it till today and now I'm convinced it's the right thing to do and am so happy I've registered. Thanks for talking to me." (16 year old male, Bstreetsmart, Qudos Bank Arena, 15<sup>th</sup> August).*

*"We have spoken about doing this for ages but there never seemed to be enough hours in the day to get around to it. Having your stall here today has given us that opportunity. Thank you for being here! "(Mature-aged couple, St George Private Hospital, Kogarah 31 July 2017).*

*I felt so relaxed and at ease that afternoon. I had time to talk to staff and ask questions. It was convenient. I only have positive things to say about the stall" (Male NRL, ANZ Stadium. October 1<sup>st</sup> 2017).*



## TRAINING PACKAGE

Over the course of the research, we have been compiling information for a training manual/package to train staff to run the Immediate Registration Opportunity.

The results of this research suggest:

- The training needs to focus on three aspects:
  - Information about the donation and registration process
  - Interpersonal skills needed to be able to approach the public and talk about issues around donation and registration
  - How to run the Immediate Registration Opportunity
  
- Part of the training needs to be in situ; that is, staff need to be trained while running the Immediate Registration Opportunity
  
- Staff need to believe that registration is important, and committed to increasing the registration rate on the Australian Organ Donor Register
  
- Staff need to be comfortable approaching the public and talking about registration and donation