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NSW Organ & Tissue
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NSW ORGAN AND TISSUE DONATION SERVICE

Community Engagement Strategy 2020-2025

NOVEMBER 2019





Community Engagement Strategy 2020 - 2025

The NSW Organ and Tissue Donation Service (OTDS) Community Engagement Strategy identifies the objectives, strategies and actions we will undertake to improve community understanding and acceptance of organ and tissue donation. The strategy aligns with the Australian Organ and Tissue Authority's Corporate Plan 2019-2023¹, Strategic Plan², the NSW Government plan *Increasing Organ Donation in NSW* (2012)³, as well as relevant NSW Government policies relating to branding and community awareness⁴.

The strategy identifies the following four key objectives:

Increase community understanding of organ and tissue donation

Increase registration on the Australian Organ Donor Register



Increase family discussion of organ and tissue donation

Increase the capabilities of community organisations and volunteers to conduct awareness activities

Background

The 2018 outcome of 151 deceased organ donors was the state's highest ever number of organ donors, representing a 12% increase on 2017 and the fourth consecutive year of sustained growth in NSW. 2018 also saw an increase in organs transplanted as well as an increase in tissue retrievals.

These figures are incredibly encouraging, however, with around 1,400 Australians on organ transplant waiting lists at any one time, there is much to be done to ensure that organ donation and transplantation rates continue to grow.

Since 2009 and the commencement of the National Reform Program, NSW has seen a significant increase in deceased organ donation and transplantation rates, benefitting individuals, communities and the health system.

Despite the achievements, the consent rate for donation has remained fairly static at between 50-60% although we are starting to see improvements - in 2018, the NSW and national consent rate was 64%.

In 2018, when an individual was registered on the Australian Organ Donor Register (AODR), 93% of families consented to donation whereas this dropped to 52% if the person was not registered and the family were unaware if their loved one was willing to be a donor⁵. Notwithstanding the excellent work undertaken in hospitals, community awareness and engagement activities are seen an essential component to increasing consent for organ and tissue donation. Engaging with Indigenous

¹ https://donatelife.gov.au/sites/default/files/ota_2019-20_corporateplan_for_2019-2023.pdf

² <https://donatelife.gov.au/about-us/strategy-and-performance/strategic-plan>

³ <https://www.health.nsw.gov.au/organdonation/Publications/increasing-organ-donation.pdf>

⁴ <https://communications.dpc.nsw.gov.au/branding/>

⁵ www.donatelife.gov.au

and culturally and linguistically diverse communities (CALD) and providing access to culturally appropriate (and in-language) materials and programs is critical for raising awareness of the importance of organ and tissue donation and contributes to informed decisions being made about donation.

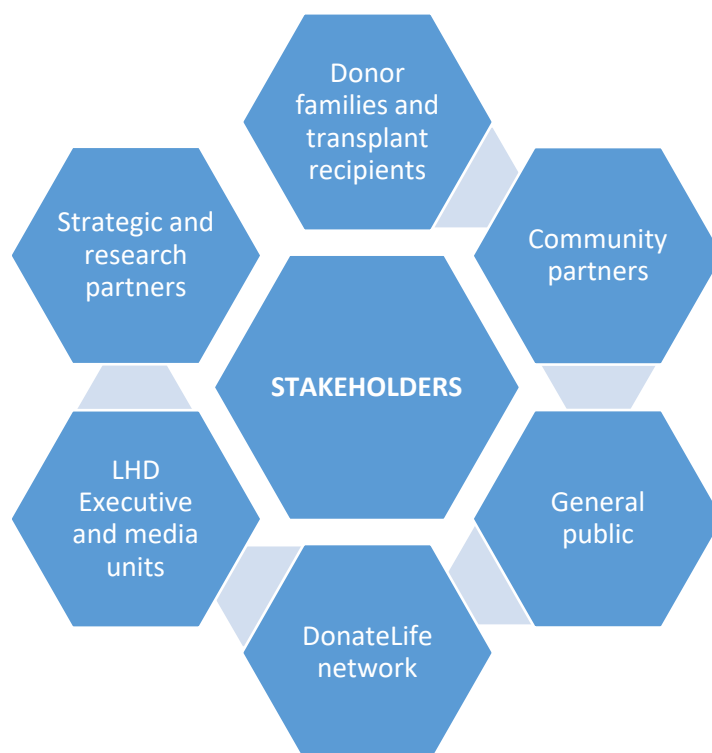
Increasing community acceptance of organ and tissue donation and encouraging behaviour change - by way of registration on the Australian Organ Donor Register (AODR) or consenting to donation for a loved one, requires a range of strategies to be successful. These may include:

- engagement with strategic and community partners
- media and social media content
- community awareness activities
- implementation of a range of targeted programs.⁶

Whilst there is anecdotal evidence that these activities lead to an increase in community awareness/ acceptance of organ and tissue donation, programs and campaigns should be driven by the available scientific evidence to ensure public spend and resources are effective. Further, campaigns should be focussed on clear, measureable behavioural outcomes such as increased registrations on the AODR.

Stakeholders

The OTDS collaborates with a range of stakeholders to increase community awareness and acceptance of organ and tissue donation. The various stakeholders bring unique perspectives and experiences and it is important that the OTDS fosters strong relationships with stakeholder groups to deliver on the strategy objectives. Increasing community acceptance and understanding of organ and tissue donation requires many partners sharing the responsibility for a common goal.



⁶ A strategy for delivering a revolution in public behaviour in relation to organ donation ([http://odt.nhs.uk/pdf/advisory_group_papers/AGCHC/NHSBT Organ Donation Consent Strategy 19 March .pdf](http://odt.nhs.uk/pdf/advisory_group_papers/AGCHC/NHSBT_Organ_Donation_Consent_Strategy_19_March.pdf))

What will we do?

To attain the four objectives outlined in this strategy, a number of actions will be undertaken:

- invest in research and ensure translation into practice
- continue to build on the successes of engagement with strategic partners
- further development of community partnerships
- increase participation in the OTDS Volunteer Program
- engage in evaluation processes for all activities.

Invest in research and ensure translation into practice

Since 2016, the OTDS has been collaborating with Southern Cross University (SCU) investigating options for increasing registration on the AODR. Some key findings of the research include:

- Offering people an immediate opportunity to register rather than taking a brochure home leads to significant increase in AODR registration.
- People often hold both positive and negative attitudes toward donation and the negative concerns are enough for people to leave registration for another day or another time.
- Allowing people time to discuss their thoughts on donation is important and this is a consideration for volunteers and others participating in community awareness events.
- The public need to be given an opportunity to register at locations and events they frequent: at sporting events, at work, at the hospital.
- Campaigns targeting large corporate organisations (for example, Qantas, News Corp, local Government) are an effective strategy to increase AODR registration.
- The environment in which people are being asked to consider donation is extremely important – a calm and leisurely atmosphere has been found to facilitate registration.

It is important that the key learnings from the research are incorporated into the awareness/engagement activities undertaken by the OTDS and its partners. Work will be undertaken to ensure that stakeholders are aware of the learnings and how to adapt these into their approaches with the community. Training for volunteers already includes utilising the SCU video demonstrating approaches to public events.

Over the past two years, NSW has seen an increase of over 80,000 new registrations on the AODR and whilst this is a great achievement, registration alone will not increase organ and tissue donation. It is vitally important that people who register also advise their loved ones of their decision as it is ultimately families that provide consent for donation to proceed.

Preliminary evidence from the 'ripple effect' research conducted by SCU⁷ indicates that one registration may equal many, when those that register share their decision with friends and families leading to other registrations and more importantly conversations with loved ones. It is proposed that the 'ripple effect' strategy is further developed to maximise the effort toward increasing AODR registrations and conversations about organ and tissue donation.

Action: The OTDS will continue to work with SCU to develop the evidence base for community awareness activities and incorporate the key learnings into practice.

⁷ Interim Report, September 2018, Southern Cross University

Work with Strategic Partners to implement a range of strategies focusing on target populations

Multicultural Health Communications Service

The OTDS has partnered with Multicultural Health Communications Service (MHCS) since 2013 to deliver evidence-based programs targeting culturally and linguistically diverse (CALD) communities. The CALD strategy has included a range of activities:

- Life Giving Stories Theatre Event
- SBS media briefing and launch of digital stories⁸
- Widows of Parramatta⁹
- Community festivals such as Chinese New Year, Vietnamese Tet Festival, Campsie Food Festival.

Action: The OTDS will continue to work with strategic partners to deliver evidence-based programs targeting multicultural communities in NSW with synergies with other organisations explored such as Arab Council Australia and Chinese Australian Services Society.

Wellington Aboriginal Corporation Health Service

In 2017 a formal partnership was established with the Wellington Aboriginal Corporation Health Service (WACHS) to drive awareness activities, develop networks and increase understanding in Aboriginal communities of the importance of organ and tissue donation for transplantation.

One of the successful strategies employed since 2017/18 is the sponsorship of the Wellington Cowboys rugby league team. The promotional event – *DonateLife Game Day* attracts well known and respected Aboriginal players from senior clubs in Sydney and generates substantial media and awareness.

Action: The OTDS will continue to work with WACHS on appropriate programs raising awareness in Aboriginal communities.

Arab Council Australia

The OTDS has developed a long-standing relationship with Arab Council Australia (Council) and they have been strong advocates for organ and tissue donation since the commencement of the national reform program. Utilising the expertise and networks of the Council to promote organ and tissue donation in Arabic speaking communities is seen as an essential, cost-effective strategy to reach these target groups which traditionally have low acceptance and understanding of organ and tissue donation.

Invest resources into Community Partnerships

There are opportunities to expand community awareness activities with the collaboration of community partners such as the Gremmo family, Gift of Life Foundation and SRMD Australia. These partners have established relationships with influential media personalities, large sporting organisations (NRL) and there are opportunities to target large corporations such as banks (NAB), media organisations and NRL football teams. The utilisation of strong brands (Jersey Day) and existing connections is likely to be an efficient, cost-effective strategy to pursue going forward.

⁸ <http://www.mhcs.health.nsw.gov.au/services/campaign/multicultural-health-communication-campaigns-events#OrganDonation>

⁹ <https://www.youtube.com/channel/UCqPEFCEwxUFwQk-2hNcfF5g>

Action: The OTDS will explore further opportunities to engage with and support the activities of community partners.

Increase participation in the Volunteer Program

Following the launch of the OTDS Volunteer Program in June 2018, activity is now focussed on increasing participation in the program and building the capacity of community organisations to conduct community awareness events.

Volunteers have participated in Donatelife week activities, Bstreetsmart and various community events including the India Day Fair in Parramatta and the Global Organisation for Persons of Indian Origin charity dinner at Blacktown. It is important that the OTDS continue to support the activities of volunteers and ensure that there are some promotional materials (merchandise) available.

Action: The OTDS will explore opportunities to increase participation in the Volunteer Program.

Evaluate programs and campaigns

It is important that community activities are driven by the available evidence and that foundational research be considered in cases where evidence is limited.

All community awareness/ engagement activities should conclude with an evaluation measuring effectiveness in achieving the objectives, and capture any lessons learned. Evaluation of programs and activities requiring resourcing will inform future engagement practices and all stakeholders will be encouraged to engage with this process.

Action: The OTDS will develop an evaluation form and process and work with stakeholders to ensure a streamlined process that is fair and equitable.

Other factors

Despite the absence of literature or other evidence indicating that branded merchandise has any impact on increasing knowledge, awareness or AODR registration, it is acknowledged that providing some promotional materials for community events is beneficial in attracting people to stalls and encouraging discussion of organ and tissue donation.

In light of the diminishing budget for branded merchandise both nationally and in NSW, the OTDS and its partners will need to consider innovative ways to engage the public that do not rely solely on the provision of merchandise. This might include for example offering a prize draw for people that engage with the stall and complete a survey and/ or registration.

Next steps

1. The OTDS will commence engaging stakeholders in discussions about evaluation of activities undertaken in 2019 and planning/ scheduling of events for 2020. Stakeholders will be asked to provide information regarding audience reach as well as intended and achieved outcomes.

The OTDS will request all stakeholders provide a planning document articulating a proposed schedule of events in 2020 and resources required. This will enable the OTDS to plan appropriately and provide merchandise once at the beginning of the year. The expectation is that stakeholders will

manage events and resources according to their schedule thus alleviating the ad-hoc requests to the OTDS.

2. The OTDS will draft an evaluation and assessment framework for funding and resourcing requests received from stakeholders. This will ensure that proposed activities align with this strategy and that there is a planned, fair and equitable approach to the provision of resources.

3. The OTDS will draft Terms of Reference for a revised Community Stakeholders Meeting to be held six monthly. The purpose of this meeting will be to provide a mechanism for stakeholders to feedback to the OTDS about the processes developed as part of this strategy and for collaboration on community activities. It is proposed that the first meeting will be held in May/June 2020.