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Five myths about organ donation in Australia

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Australia has some of the world's highest organ transplant success rates, but, for almost two decades, our deceased organ donation rates have been among the lowest in the developed world. In other words, when it comes to organs, we're no good at finding them but we're the best in the world at transplanting them.

<u>Recent well-publicised increases</u> in organ donation rates have raised expectations that Australia can sustain meaningful improvement, but the <u>cumulative effect of the increases</u> has moved national performance up from the bottom third of the world's developed countries and into the bottom half.

There's still only a very limited supply of organs available for those who desperately need them and each year people die waiting for a life-saving transplant.

For many years now, enormous attention (and funding) has been devoted to finding ways of raising the organ donation rate. Between 1989 and 2008, more than 20 public and government-led initiatives were launched to address issues believed to be its cause. Unfortunately, <u>they've proved ineffective</u> and cumulatively resulted not in an increase in donation, but a decline of around 20%.

These failures illustrate misunderstandings about what the country can do to raise its organ donation rates. The idea that Australia is somehow fundamentally different to world leading donor countries, for instance, and incapable of matching their success in organ donation is false. A number of misconceptions lead to such conclusions, and they constitute five myths about organ donation.

Myth 1

Australia has a low organ donation rate because Australians are less altruistic than other countries.

False: Australia compares favourably with other developed countries when you look at how much the country gives to others in need. In fact, according to the OECD's Development Cooperation Directorate (DCD-DAC) rankings, Australia <u>ranks 16th in the world</u> for Official Development Assistance donations, ahead of the United States, Portugal and Italy – countries leading the world in organ donation rates.

But giving money is not the same as donating organs. So how do Australians respond when asked to consider donating their own kidneys? Australia's living kidney donation rates are high — several times higher, in fact, than living kidney donation rates in Spain, France, Austria and Italy, which have the world's highest deceased organ donor rates.

Myth 2

Consent rate is the percentage of people who, when asked, agree to donate their deceased relatives' organs. Australia has a very low consent rate for organ donation and, as a result, a low deceased donation rate.

False: While Australia's 2011 <u>consent rate of 57%</u> is not as high as world-leading Spain (82%), it's similar to other top donor countries such as France (63%) and the United States (50%).

And the fact that other countries maintain much higher donation rates with similar or even lower rates of consent shows that consent alone is not a sufficient explanation for Australia's low rate of deceased organ donation.

Myth 3

Registration of one's wishes regarding organ donation (with Donate Life, the RTA, Medicare and in wills) ensures that individuals will become donors when they die.

False, for two important but very different reasons.

First, out of the approximately 146,500 people who died in Australia in 2011, only 730 were <u>identified as potential deceased organ donors</u> and, of these, only 337 became donors.

The odds that your death will lead to donation is slim (less than one in 400) because types of death that lead to donation are very rare, and typically involving very specific types of brain trauma.

Second, even if a person has registered with all the relevant bodies and stipulated in their will that they wish to be a donor, should the opportunity arise, their family will make the final decision. Australian families <u>refuse organ donation requests</u> about 40% to 50% of the time.

Myth 4

Australia has such a low organ donor rate because of its low death rate. In other words, people who could become donors don't die as often in Australia due to our young population and high levels of public safety.

This is a very widely held belief — even among many Australian organ donation experts — and it is false.

While it is true that Australia's crude death rate is lower than many countries in the world, it's very similar to countries such as the United States, which has a <u>high organ donation rate</u>.

Even factoring in a proportional uplift in donor rates to compensate for our lower death rate, our organ donation rate is still <u>well below</u> that of world-leading countries.

Finally, only certain infrequent types of death can lead to donation —most often linked to specific forms of trauma (such as accidents and gun shots) and strokes. Rates for these types of deaths are similar in most developed countries.

Myth 5

The countries that do well in organ donation are the ones that have presumed consent – or opt-out – systems. You're presumed to have given consent to donating your organs if you haven't informed authorities that you are opting out.

False and true: While it's true that the majority of countries with the highest donation rates have presumed consent (or opt-out) legislation, so too do many of the worst-performing countries.

It's also incorrect to assume that presumed consent means that organs will necessarily be removed from deceased persons in these countries unless she or he has expressed prior written opposition to donation (opting out). Virtually all presumed consent countries won't proceed with donation unless the family of the deceased approves.

Presumed consent legislation can be indicative of many things, including the willingness of a country's citizens to accept brain death and organ donation as a normal part of dying and to accept the focus that medical professionals place on identifying potential organ donors.

Australia's failure to increase organ donation rates despite almost 25 years of effort suggests there many things that we don't understand about how we can increase rates of organ donation in Australia. But the idea that our country is somehow fundamentally different to world leading donor countries, in ways that make it impossible for us to become a world leader in organ donation, is false.

The fact that we have similar rates of deaths that lead to high rates of organ donation in other countries represents a very real opportunity for Australia. By converting the tragedy of these deaths into opportunities to save the lives of others we can become a world leader in organ donation – just as we currently lead the world in transplantation success.

Taking this lead will require us to abandon the convenient mythologies of the past and adopt the proven leading practices of the United States, France, Spain, Italy, Portugal, Austria, Puerto Rico and Uruguay.