# Access to the Kidney Transplant Waiting List – a time for reflection

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**Abstract**

The limited availability of deceased donor kidneys for transplantation in Australia continues to be a matter of concern. Analysis of registry data suggests that the current renal transplant waiting list under-represents the real demand for three reasons. Firstly, a very low proportion of dialysis patients across all age groups are wait-listed for kidney transplantation; secondly, the percentage of dialysis patients listed for transplantation has fallen over time across all Australian states and territories; and thirdly, the number of patients wait-listed varies significantly across the country.

We explore possible reasons for these issues and call for new eligibility criteria that are both transparent and justifiable and balance equity and utility.

## Kidney Transplant Waiting List

The 2010 annual report of the Australian and New Zealand Dialysis and Transplant Registry (anzdata.org.au)[1] contains details of the proportion on the dialysis population by age group that are on the kidney transplant waiting list. The Report reveals a series of disturbing features of transplantation practice in Australia. The first is that a very low proportion of dialysis patients across all age groups are wait-listed for transplantation (Figure 1). The second is that the percentage of dialysis patients listed for transplantation has failed to maintain consistency over time and is actually falling across Australia (Figure 2). The third is that the number of patients who are wait-listed varies significantly between Australian states and Territories, (Figure 2) (all derived from ANZDATA publications[2]).

Of 10,341 people on dialysis as of 31 December 2009, only 1105 (10.7%) were on the transplant waiting list. Even in younger age groups, the number of people on the waiting list compared with the dialysis population is low. Of people aged 25 – 54 years only 22% are on the waiting list where it is not unreasonable to assume that a majority would be listed (Figure 1). In those aged 65 years and over, only 128 out of 5053 dialysis patients (or 2.5 %) are on the transplant waiting list[3]. By contrast, in the United Kingdom[4] 48% of dialysis patients aged less than 65 years of age are listed for transplantation nationally, while in France[5] 49% and in the United States[6] 33% of patients in this age group are wait-listed compared to only 18% in Australia (Figure 1). Why are so few Australian dialysis patients are on the transplant waiting list (particularly younger patients, who, arguably, have more years to gain from transplantation) and why has the percentage fallen in the last 5 years from 33% in 2005 to 22% in 2009 (figure 2) at the same time as donor rates have remained stable or increased and the incident rate of new patients coming onto dialysis in Australian has remained at about 110 per million population over the same 5 year period? There is also a striking geographical variation between Australian States and Territories, (from 1% in the Northern territory to 38% in the Australian Capital territory - Figure 2), compared with regional variation in the UK, where wait-listing ranges from 27-79%. The UK renal registry[7] also showed that factors that were found to influence activation onto the transplant waiting-list were age, ethnicity and primary renal disease.

There are sound clinical reasons why some patients on dialysis may not be considered for transplantation, as is stated in the consensus guidelines of the Transplantation Society of Australia and New Zealand[8], Caring for Australians with Renal Disease (CARI)[9] and other relevant expert bodies. However, these do not adequately explain why so few patients are wait-listed for transplantation, why the number of patients listed for transplantation is falling and why the percentage of patients listed for transplant varies so much between the different states and territories (Figure 2). There are clear benefits of transplantation over dialysis based on Australian data (Figure 3). A recent systematic review of 110 studies involving 1.9 million subjects confirmed that, despite the increasing age and co-morbidities of recipients, the benefits of kidney transplantation over dialysis are increasing with lower mortality, reduced cardiovascular events and improved quality of life[10].

One explanation is that Australia's waiting list is actually appropriate and that, in contrast, the waiting lists of other countries are over-inflated – as has recently been suggested by Zamperetti and colleagues.[11] They were able to show that waiting lists were not related to the number of transplants in any country, a finding that we have confirmed in our own analysis of waiting lists and renal transplantation in 54 countries[12]. Zamperetti et al proposed that matching the waiting list with the available organs by imposing very strict criteria for entry would lead to short lists and reduction of deaths on the waiting list. While a pragmatic means for managing waiting lists, this approach ignores the clear benefits of transplantation over dialysis (Figure 3). Furthermore, simply modifying criteria for waitlisting for transplantation to shorten these lists so that fewer patients die while awaiting a donor organ is misleading and ethically questionable. These authors also pointed out the great variation in waiting lists between 8 western countries. When compared to Australia, the other 7 countries cited by Zamperetti et al had more people listed when adjusted for population, and some, such as the USA, were 5-fold higher than Australia. An alternative interpretation is that Australia already has an abbreviated list.

The Consensus Statement on Eligibility Criteria and Allocation Protocols commissioned by the Organ and Donation Authority and published on the Transplant Society of Australia and New Zealand website[8] outlines the criteria for acceptance onto the waiting list for renal transplantation. While these are different for each Australian state, they have a common theme of excluding those who have "An anticipated likelihood of less than 80% chance of surviving a minimum of 5 years following transplantation". The policy acknowledges that some who may be suitable and may wish to be listed will be denied because of this exclusion criterion. In this regard, it is worth noting that the 5 year survival figures in Australia are 90% for patient survival (or only 10% above the cut-off) and 80% for graft survival, equalling the cut-off[1], whereas in the United States, the overall 5 year patient survival following transplant is about 80% for recipients of

deceased donor kidneys[13], and graft survival does not exceed 70% even in younger recipients. It is questionable whether this exclusion criterion is valid, given that the actual survival does not match the conceived prior probability. This is a cogent reminder that the criteria for waitlisting for transplantation in Australia (>80% survival at 5 years) are primarily a means for managing access to the waiting list, as there is a survival advantage of transplantation over dialysis at every age group (Figure 3).

Over the past decade, discussion in both Australia[14] and the USA[15] has focused on ways in which the utility of deceased donor kidneys could be increased by restricting allocation to those who may benefit the most. In the United States the process of allocation is currently changing from one based largely on wait time to one that matches a broad age range for the majority of kidneys (80%) and a smaller proportion that will be matched for survival advantage (remaining 20%). These criteria will be placed above the current allocation criteria of waiting time, sensitisation and HLA typing. This reform has been the subject of intense critique, principally because it may inappropriately discriminate against older patients[16]. It is the task of the United Network of Organ Sharing (UNOS) Kidney Transplantation Committee to come up with a system that addresses any potential discrimination[15]. In Australia, similar proposals for moving to a system of allocation based on matching kidneys to those that benefit most have also been mooted[14]. But while age-based rationing may be ethically justifiable where age is a de-facto marker of poor clinical outcomes, given the fact that transplantation offers a survival advantage for all age groups and older Australians are already not being waitlisted for transplantation, such a proposal runs the risk of further discriminating against a group who are already 'missing out'.

Much has been written about the disparity between the supply and demand for solid organs for transplantation. While it is vital that continuing efforts are made to address this disparity, we should not 'solve' this imbalance by restricting referral or by processes of allocation that are not evidence-based or that are fundamentally at odds with widely shared moral values. There is little comfort in an abbreviated waiting list if, in fact, many of those who may benefit from transplantation are simply not referred. Choices are made in medicine all the time – but must be justified and inappropriate discrimination removed. If access is based upon age, or other quasi-medical criteria, then this should be transparently articulated to allow the wider community an opportunity to assess the allocation of its resources.

The Council of Europe (2001)[17] states: "Member states should guarantee that a system exists to provide equitable access to transplantation services for patients which ensures that organs and tissues are allocated in conformity with transparent and duly justifiable rules according to medical criteria". We believe it is time for Australia to develop new eligibility criteria for renal transplantation that reflect both evidence and ethics. It is time to recognise both the impact and place of the many factors that influence renal transplantation outcomes, including age, gender, ethnicity, place of residence, socio-economic status, primary renal disease, prognosis and co-morbidities, and that ultimately provide a balance between utility and equity.

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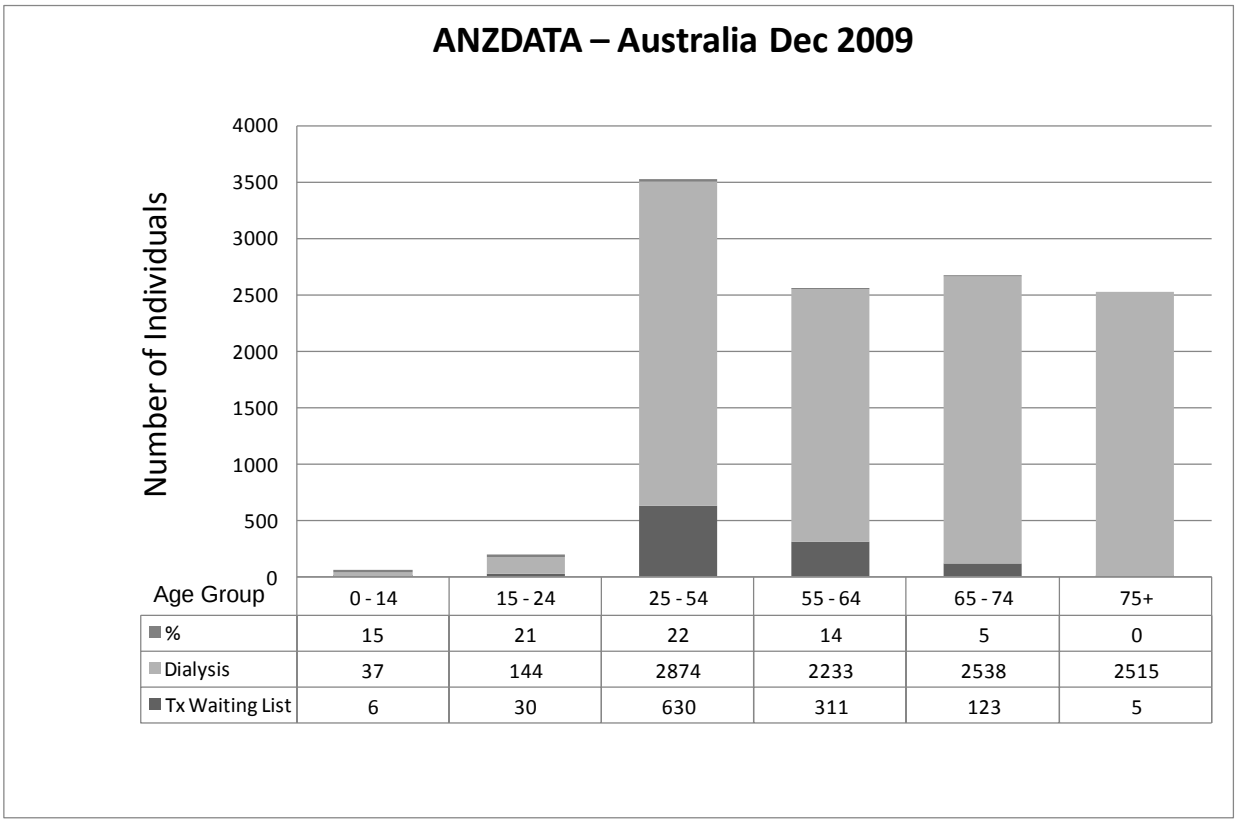
Figure 1. Proportion of listed patients compared to total dialysis by age group. ANZDATA Report 2010




| Age Group | 0 - 14 | 15 - 24 | 25 - 54 | 55 - 64 | 65 - 74 | 75+ |
|---|---|---|---|---|---|---|
| % | 15 | 21 | 22 | 14 | 5 | 0 |
| Dialysis | 37 | 144 | 2874 | 2233 | 2538 | 2515 |
| Tx Waiting List | 6 | 30 | 630 | 311 | 123 | 5 |

Figure 2. Percent of dialysis population aged 25 – 54 years on the transplant waiting list. From ANZDATA Reports 2006 - 2010

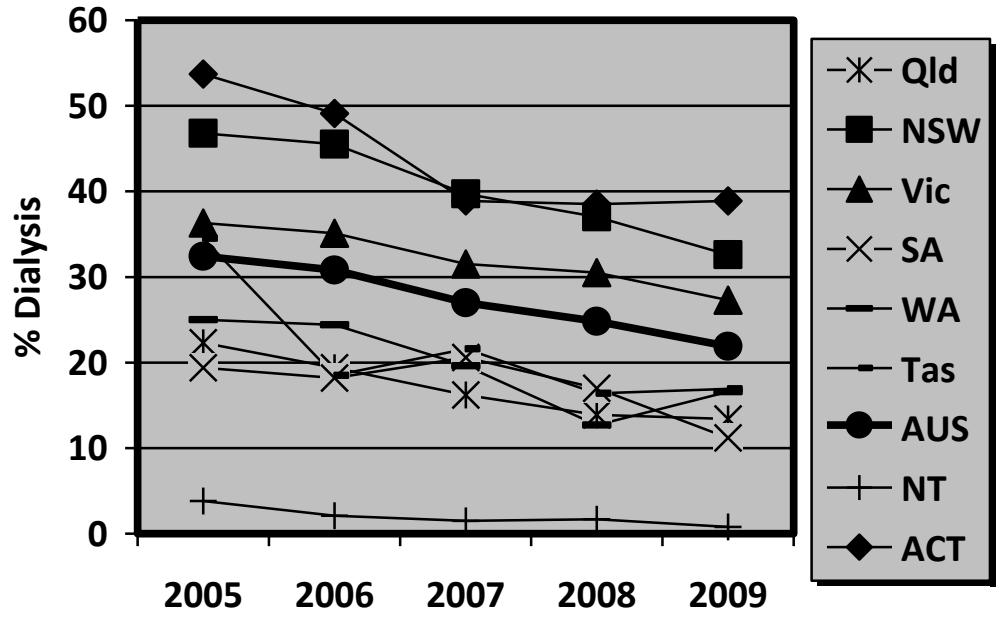


Figure 3. Age specific mortality rates for patients treated with dialysis or transplantation relative to the Australian population 2009. ANZDATA Report 2010 Ch 3.