

Australian involvement in organ trafficking and transplant tourism

- 3.1 This chapter examines the scope of Australian participation in organ trafficking and transplant tourism and measures to improve relevant data collection and broad understanding of trends in this activity.

Australian context

- 3.2 As in other countries, there is a significant shortage of organs available for transplantation in Australia. On 1 September 2018, 1,423 people were listed on organ transplant waiting lists in Australia, 1003 of which were awaiting kidney transplants.¹ 35 entries on transplant waiting lists were removed in 2016 due to the death of the patient while awaiting transplantation.²
- 3.3 The Australian Government announced in 2008 the establishment of a national reform agenda for organ and tissue donation and transplantation. The Government highlighted that Australia's rate of deceased organ donation has experienced significant growth in the period since the implementation of the national reform agenda from January 2009.³

1 Australian & New Zealand Organ Donation Registry (ANZOD), *Australian Waiting List 2018* www.anzdata.org.au/anzod/v1/waitinglist2018.html, accessed 13 September 2018.

2 ANZOD, *Annual Report 2017*, Section 12 – Organ Waiting List, pp. 3-8. Note that patients awaiting the transplantation of more than one organ may be double counted.

3 Australian Government, *Submission 1*, p. 8.

The annual number of deceased organ donors is now more than double that of 2009.⁴ The Australian Organ and Tissue Donation and Transplant Authority (OTA) notes that in 2009 the number was 247. by 2017 this had risen to 510.⁵

3.4 The Australian Organ and Tissue Donation and Transplantation Authority (OTA) was established to lead the delivery of the national reform agenda.⁶ The OTA is an independent statutory authority within the Australian Government Health portfolio and operates under the *Australian Organ and Tissue Donation and Transplantation Authority Act 2008*.

3.5 OTA's legislated functions include:

- to formulate and implement policies, protocols, and code of practice relating to organ or tissue donation and transplantation matters;
- to collect, analyse, interpret and disseminate information relating to these matters;
- to support, encourage, conduct and evaluate training programs relating to these matters;
- to support, encourage, conduct and evaluate educational, promotional and community awareness programs that are relevant to these matters;
- to make, on behalf of the Commonwealth, grants of financial assistance in relation to these matters; and
- to support, encourage, conduct and evaluate research about these matters.⁷

3.6 The OTA funds a range of projects which support the national organ and tissue donation and transplantation program. These include the following national donation and transplantation registries:

- the Australia and New Zealand Organ Donation Registry;
- the Australian Corneal Graft Registry;
- the Australia and New Zealand Cardiothoracic Organ and Transplant Registry;
- the Australian and New Zealand Dialysis and Transplant Registry ANZDATA;
- the Australia and New Zealand Liver Transplant Registry; and

4 Australian Government, *Submission 1*, p. 8.

5 Australian Government, 'Organ and Tissue Authority (OTA)', *DonateLife.gov.au*, www.donatelife.gov.au/organ-and-tissue-authority-ota, accessed 20 July 2018.

6 Australian Government, 'Organ and Tissue Authority (OTA)', *DonateLife.gov.au*, www.donatelife.gov.au/organ-and-tissue-authority-ota, accessed 20 July 2018.

7 *Australian Organ and Tissue Donation and Transplantation Authority Act 2008*, s. 11(1).

- the National Pancreas Transplant Registry.⁸
- 3.7 In July 2018 correspondence, the Minister for Health outlined to the Sub-Committee the Australian Government's commitment to further increasing Australia's rate of organ donation and reducing the number of Australians awaiting transplants.⁹ The Minister also highlighted the April 2018 announcement by the Council of Australian Governments Health Council that the Commonwealth will lead a review of the Australian organ donation, retrieval and transplantation system.¹⁰ This review will be undertaken to identify "barriers to equity of access to transplant waiting lists and transplantation services"¹¹
- 3.8 The OTA has outlined its strategy for increasing organ donation in its report: *Progressing Australian organ and tissue donation and transplantation to 2022 The 2018-19 to 2021-22 strategy*.¹² This strategy outlines the four key objectives that the OTA are seeking to achieve in the next four years:
1. Optimise donation opportunities
 2. Provide specialist support to families involved in the donation process
 3. Increase registration and family discussion contributing to higher consent rates
 4. Enhance systems to support donation and transplantation
- 3.9 The majority of organ donations resulting in transplantation in Australia are undertaken through the deceased donor pathway.¹³ Australians register their willingness to become a deceased organ donor, should the circumstances of their death allow.¹⁴
- 3.10 The current model of organ donation in Australia is an 'Opt-In' system whereby individuals register their intent to donate their organs and/or tissue if they are a suitable candidate at the time of their death via the DonateLife website, Department of Human Services, MyGov website, the Express Plus Medicare App or by a hardcopy form.¹⁵ If an individual is

8 Ernst & Young, 'Review of the implementation of the national reform agenda on organ and tissue donation and transplantation,' August 2015, p. 16.

9 The Hon Greg Hunt MP, Minister for Health, *Submission 171*.

10 The Hon Greg Hunt MP, Minister for Health, *Submission 171*.

11 COAG Health Council, *Communique*, 13 April 2018.

12 Australia Organ and Tissue Authority, *Progressing Australian organ and tissue donation and transplantation to 2022: The 2018-19 to 2021-22 strategy*, 2017.

13 Organ and Tissue Authority, *2017 Activity Report*, p. 4.

14 Organ and Tissue Authority, Australia Organ and Tissue Authority, *Progressing Australian organ and tissue donation and transplantation to 2022*

15 Organ and Tissue Authority, *Donate Life* website, www.donatelife.gov.au/register-donor-today, accessed 13 September 2018.

then identified as a potential donor upon or nearing their death, families are consulted and make the final decision as to whether organs will be donated.¹⁶

- 3.11 Living donation, usually of kidneys or partial livers, is also supported by the Organ and Tissue Authority and the Australian Government Department of Health provides the *Supporting Living Organ Donors Program*. This program provides up to nine weeks of payments at the National Minimum Wage to assist donors who may otherwise be unable to donate to due to the potential loss of income from needing to take extended leave from their usual occupation.¹⁷
- 3.12 The current OTA and Health Department position on organ donation is that it should remain as an ‘opt-in’ system.¹⁸ The Department told the Sub-Committee that:
- Australia’s position of ‘opt-in’ has been informed by research, evidence and discussions with state and territory governments who have responsibility for the legislative framework for organ and tissue donation for transplantation, and the clinical community.
- There is no clear evidence to support that an ‘opt-out’ model contributes to achieving higher donation rates.¹⁹
- 3.13 The Sub-Committee only received limited evidence with regard to organ donation within Australia. It does appear that evidence, at least superficially, supports opt-out strategies in favour of opt-in. Of the top ten organ donating countries in the world as of 2016,²⁰ seven have been ‘opt-out’ for a number of years,²¹ and two more have adopted an opt-out system in the past year.²² It is important to note that those countries with the highest rates of donation, and in particular Spain, have not only opt-out systems, but highly centralised and well-funded organ donation

16 Organ and Tissue Authority, *Donate Life* website, www.donatelife.gov.au/register-donor-today, accessed 13 September 2018

17 Department of Health, ‘Supporting Living Organ Donors Program’, www.health.gov.au/internet/main/publishing.nsf/Content/Leave-for-living-organ-donors, accessed 13 September 2018.

18 Department of Health, Answer to Question on Notice (QoN), *Submission 176*, p. 1.

19 Department of Health, Answer to QoN, *Submission 176*, p. 1.

20 International Registry in Organ Donation and Transplantation, *Newsletter 2017*, June 2018.

21 Spain, Croatia, Portugal, Belgium, Czech Republic, Austria, and Finland all use an opt-out or ‘presumed consent’ system for organ donation.

22 France adopted an opt-out system in 2017 and Iceland adopted their legislation earlier in 2018.

systems in place within hospitals, changes to end of life care and how possible donors are identified.²³

- 3.14 The Sub-Committee welcomes initiatives towards increasing organ donation rates in Australia, noting that such an increase could be anticipated to reduce waiting times and mitigate the perceived appeal that travelling overseas for a commercial transplant may hold. The Sub-Committee does however consider that organ supply will not meet total transplant demand in the foreseeable future. The unavoidable reality of unmet organ demand in the short and medium terms mean that measures to mitigate Australian participation in organ trafficking and transplant tourism must be in place.

Prevalence of organ trafficking and transplant tourism

- 3.15 There has been only one reported case to date of alleged organ trafficking within Australian jurisdiction, as detailed in Box 2.1.

Box 2.1 – Alleged case of organ trafficking in Australia²⁴

In 2011, an Australian couple were alleged to have brought a woman from the Philippines to Australia, promising her monetary compensation and a working visa in exchange for a kidney donation.

The woman changed her mind upon arriving in Australia. Medical transplant integrity procedures – a pre-operative counselling session at a Sydney hospital – ensured that the situation was discovered before the removal of the organ.

The potential donor was identified as an alleged victim of organ trafficking, resulting in referral to the Australian Federal Police. Due to the death of the prospective recipient, and limitations of the legislation as then in force, the matter did not progress to prosecution.

The Australian Government advised that:

This matter did not progress to prosecution because the offence as drafted in 2011 necessitated the actual removal of the organ (the offence was broadened in 2013 to cover situations where an

23 R. Matesanz, B. Domínguez-Gil, E. Coll, B. Mahillo and R. Marazuela “How Spain Reached 40 Deceased Organ Donors per Million Population” in *American Journal of Transplantation*, 2017 vol 17 1447-1454.

24 Australian Government, *Submission 1*, p. 7; Department of Home Affairs, Answer to Question on Notice (QoN), *Supplementary Submission 166.2*; Law Council of Australia, *Submission 61*, p. 4; United Nations Human Rights Council, ‘Report of the Special Rapporteur on trafficking in persons, especially women and children, 20th session, Addendum – Mission to Australia,’ UN Doc. A/HRC/20/18/Add.1, 18 May 2012, para. 15.

offender is reckless as to whether their conduct will result in the removal of a victim's organ).²⁵

According to the Australian Government, this incident is the only known case of alleged organ trafficking in Australia.

3.16 The Australian Government noted in its *National Action Plan to Combat Human Trafficking and Slavery 2015-2019*:

While there is a low reported incidence of organ trafficking in Australia, the clandestine nature of human trafficking means that victims of organ trafficking may be difficult to identify.²⁶

3.17 The Law Council of Australia's submission draws on commentary by Professor Andreas Schloenhardt and Ms Samantha Garbutt, reflecting on the relationship between Australian participation in transplant tourism and trafficking in persons for organ removal:

...there has been little evidence to suggest that organ trafficking is occurring in Australia on a wider scale. On the other hand, given the very significant shortage of donor organs in Australia it is perhaps surprising that cases like this do not come to light more frequently. This may, however, be offset by Australians in need for donor organs travelling overseas for that purpose.²⁷

3.18 There have been a number of media reports suggesting that Australians have participated in transplant tourism.²⁸ A number of submissions referenced a 2016 News Corp investigation, which reported:

...in February [2016] an Australian man bought a kidney off a 26-year-old Pakistani woman as part of a transplant costing

25 Department of Home Affairs, Answer to QoN, *Supplementary Submission 166.2*.

26 Australian Government, *National Action Plan to Combat Human Trafficking and Slavery 2015-2019*, Commonwealth of Australia, 2014, p. 7.

27 A Schloenhardt and S Garbutt, 'Trafficking in persons for the purpose of organ removal: International law and Australian practice', *Criminal Law Journal*, vol. 36, no. 3, 2012, p. 156; as cited in Law Council of Australia, *Submission 61*, p. 7.

28 See: S Dunlevy, 'Organs for sale: Australians turn to black market for human organs', *Sunday Telegraph*, 7 August 2016; B Hall, 'China last resort for the dying', *Sydney Morning Herald*, 6 February 2011; S Lauder, 'Australian organ tourists drive sinister trade', *ABC News*, 1 September 2010; M Wade and T Reilly, 'Australians caught up in 'Dr Horror' kidney transplant racket', *Sydney Morning Herald*, 2 March 2010; C Weaver, 'Flight for survival: the woman who must flee overseas for a kidney transplant to ensure she stays alive', *Sunday Telegraph*, 23 September 2007; A Stafford, 'Patients fly out to buy organs', *The Age*, 26 December 2007; M Dunn, 'Kidney trade on death row - Aussies use Chinese prisoners' organs', *Daily Telegraph*, 19 December 2005; and V McCausland, 'Risking lives for overseas kidneys', *Daily Telegraph*, 7 March 2005.

\$116,000. We interviewed four Australians who purchased an organ overseas including three from Sydney and one from Melbourne and learned that just months ago Australian doctors shut down an attempt by a Sri Lankan to sell their kidney to an Australian patient ...²⁹

3.19 Public health specialist Dr Maria Soledad Antonio outlined the several reasons why Australia is an organ-importing state:

- need – Australian organ donation rates are increasing, however availability is still insufficient to meet demand;
- means – many Australian patients have the economic means to purchase an organ overseas; and
- opportunity – organ brokers target Australian patients through social media.³⁰

3.20 International studies have observed the tendency of patients born in a country where organ trafficking may occur, but living outside of that country, to be at a substantially higher risk of participation in transplant tourism.³¹ This would appear to be equally true in Australia, as Dr Campbell Fraser observed:

...less than five per cent of Australians who are waiting on organs are likely to even consider going overseas. ...most of the Australians who have purchased an organ overseas have ethnic family connections to the countries or regions where they buy their organs – Pakistani Australians tended to go to Pakistan, Egyptian Australians travel to Egypt, and so on.³²

Registry data

3.21 While OTA-supported registries collect and analyse data on organ and human tissue donation and transplantation in Australia, there is a paucity of data with regard to Australian participation in transplant tourism. There is currently no requirement that an Australian who may be seeking transplantation overseas to report their intentions, nor is it mandatory for a medical profession providing post-operative treatment to a patient who received their transplant overseas to report that fact.

29 S Dunlevy, 'Organs for sale: Australians turn to black market for human organs', *Sunday Telegraph*, 7 August 2016.

30 Dr Soledad Antonio, private capacity, *Committee Hansard*, 8 June 2018, p. 55.

31 See: L Wright et al., 'Kidney transplant tourism: cases from Canada', *Medicine, Health Care and Philosophy*, vol. 16, no. 4, 2013, p. 922; and J Gill et al., 'Transplant tourism in the United States: a single-center experience', *Clinical Journal of the American Society of Nephrology*, vol. 3, no. 6, 2008, p 1825.

32 Dr Fraser, private capacity, *Committee Hansard*, Canberra, 9 May 2017, p. 1.

3.22 The Australia and New Zealand Dialysis and Transplantation Registry (ANZDATA) is the only of the OTA-supported registries that publishes data relating to overseas transplants. ANZDATA is aware of 193 Australians receiving transplants overseas between 2001 and 2016, as detailed in Tables 3.1 and 3.2.

Tables 3.1 and 3.2 – Renal transplants reported to ANZDATA as occurring overseas, 2001-2016

Year	Number of transplants	Reported country of transplant	Number of transplants (2001 to 2016)
2001	11	China	57
2002	15	Egypt	2
2003	14	India	11
2004	18	Iran	3
2005	16	Iraq	2
2006	17	Ireland	3
2007	21	Korea	2
2008	11	Lebanon	4
2009	16	Pakistan	8
2010	9	Philippines	16
2011	13	Singapore	2
2012	7	Syria	2
2013	6	United Kingdom	7
2014	6	United States	3
2015	10	Uruguay	2
2016	3	Other ³³	20
Total	193	Not reported	49
		Total	193

Source Department of Health, ANZDATA, Supplementary Submission 176.1.

3.23 ANZDATA Executive Officer Professor Stephen McDonald observed that the collection of data on transplants overseas is:

...not one of the funded aims in our contract. We do, though, incidentally collect that data. If you look around at other data

33 One transplant was reported in each of: Brazil; Canada; Eritrea; Holland; Hong Kong; Indonesia; Italy; Japan; Jordan; Laos; Mauritius Nepal; Portugal; Saudi Arabia; South Africa; Sri Lanka; Sweden; Switzerland; Taiwan; and Vietnam.

sources, this is an area that is very difficult to find any sort of data about.³⁴

3.24 ANZDATA's funded purpose is limited to the collection of data relating to dialysis and transplantation taking place domestically in Australia and New Zealand. The stated purpose of OTA-administered Commonwealth funding to ANZDATA is to:

Collect, analyse and report data on renal replacement therapy (dialysis and transplantation) in Australia and New Zealand to assist in improving patient care and outcomes through greater understanding of events, treatments and outcomes in the areas of renal transplantation and dialysis.³⁵

3.25 With regard to the lack of an explicit mandate to collect data on overseas transplants, Ms Penny Shakespeare, Acting Deputy Secretary, Health Financing Group, of the Department of Health indicated that:

Health portfolio agencies, such as the Organ and Tissue Authority and the programs that it funds, including [ANZDATA], are very much focused on the delivery of services to Australians in Australia.³⁶

3.26 There a number of limitations to the data collected by ANZDATA as a measure of Australian participation in transplant tourism. A number of these limitations are intrinsic to the challenge of capturing data on transplant tourism generally. This is acknowledged by ANZDATA:

It is possible that these numbers are an underestimate of the true number, since some patients may not return to Australia...³⁷

3.27 The Australian Government also recognises these limitations, noting:

...the true prevalence of Australians engaging in this potentially dangerous practice is undocumented and likely underreported.³⁸

3.28 Capture of a patient who has received a renal transplant overseas in the ANZDATA dataset would appear to require the following conditions:

- the patient does not die overseas prior to, during, or after the transplant;
- the patient returns to Australia and seeks post-operative care;

34 Professor Stephen McDonald, Executive Officer, ANZDATA, *Committee Hansard*, Canberra, 8 June 2018, p. 46.

35 Prof McDonald, Executive Officer, ANZDATA, email correspondence, 17 June 2018.

36 Ms Shakespeare, Department of Health, *Committee Hansard*, Canberra, 8 June 2018, p. 47.

37 Australia and New Zealand Dialysis and Transplantation Registry (ANZDATA), *Annual Report 2016*, Section 8, p. 6.

38 Australian Government, *Submission 1*, p. 4.

- the medical professional providing post-operative care inquires as to where the patient received the transplant; and
 - the treating nephrologist or other medical professional reports knowledge of an overseas transplant.
- 3.29 Professor Chapman told the Sub-Committee he considers the ANZDATA data to be “99 to 99.5 per cent complete,” in terms of renal transplant recipients who return to Australia post-transplant, noting however that those who do not return to Australia are not captured.³⁹
- 3.30 The data collected by ANZDATA does not differentiate between legitimate overseas transplants – for example, those received through an altruistic donation by an overseas family members – and commercial overseas transplants. Professor Chapman told the Sub-Committee that between one third and one half of the kidney transplants Australians receive overseas are “legitimate” with the balance to be regarded as “suspicious.”⁴⁰ Ms Natasha Cole, First Assistant Secretary, Health Services Division, of the Department of Health noted the possibility that:
- ...some of those transplants were simply family members who were returning and who were seeking a kidney, for example, from a compatible family member. So we have to be careful about assuming ... that they have all been obtained in unethical arrangements.⁴¹

Overseas Transplant Survey

- 3.31 Professor Toby Coates, Honorary Secretary and President-elect of the Transplantation Society of Australia and New Zealand, is leading a project to document Australian participation in transplant tourism through the Overseas Transplant Survey. The team has collected data through anonymised survey results received from clinicians working in transplant medicine. Professor Coates provided an interim quantitative dataset to the Sub-Committee in June 2018 and an assessment of the results of the survey in September 2018.
- 3.32 The 2018 Overseas Transplant Survey (OTS) was distributed to 540 Australian nephrologists, transplant physicians and surgeons through the Transplant Society of Australia and New Zealand (TSANZ) and Australia and New Zealand Society of Nephrology. A total of 197 responses were collated, yielding a response rate of 44%.
- 3.33 The OTS results were summarised by Professor Coates as follows:

39 Prof Chapman, *Committee Hansard*, Canberra, 9 May 2017, p. 1.

40 Prof Chapman, *Committee Hansard*, Canberra, 9 May 2017, p. 1.

41 Ms Cole, Department of Health, *Committee Hansard*, Canberra, 28 March 2017, p. 4.

133 (67%) of responding practitioners reported having discussed this practice with their patients, and 105 (53%) practitioners reported having cared for a patient following overseas transplantation.

A total of 129 patients were reported between the years 1980 and 2018, with the top reported destinations being China (n=40, 31.2%), India (n=20, 15.6%), Pakistan (n=11, 8.6%), and the Philippines (n=10, 7.8%) being the most popular destinations... 25.5% (n=30) of returning patients had an infection at time of return, and 8.5% (n=11) of returning patients had transplant rejection evident at time of return. '

3.34 The study also found that:

The majority of patients were not born in Australia (n=119; 93.0%). Of these patients, the majority were born in China (n=29; 22.7%), India (n=14; 10.9%), or the Philippines (n=10; 7.8%). A total of 10 patients (7.8%) were born in Australia.

In Professor Coates view, those figures provide an imperative for culturally and linguistically appropriate education regarding the issue.

3.35 Professor Coates also provided the following comparisons of the OTS data and ANZDATA:

Comparison with ANZDATA, the Australian and New Zealand Dialysis and Transplant Registry, indicated that although ANZDATA has a greater overall number of reported cases (280 ANZDATA to 129 OTS), there has been a marked reduction of cases being reported in the past eight years.

Direct comparison of 2015-2018 ANZDATA to OTS yields 12 cases on ANZDATA whilst our survey uncovered 28 cases of overseas travel for organ transplantation.

Additionally, direct comparison of cases yielded 42 'missing cases', which were not reported to ANZDATA, with 64.3% (n=27) being from 2010 onwards. Of course, a number of limitations confound the interpretation of the survey responses, including recall and selection bias. Multiple reporting of individuals may overestimate the number of patients travelling overseas for organ transplantation. To minimise this, a detailed comparison of all case summaries was made and identified repeated cases were excluded from the analysis. ⁴²

Limitations of existing data collection

3.36 Ms Cole of the Department of Health stated that any patient returning to Australia after receiving a transplant overseas would present an opportunity for capture by transplant registries, given the necessity of post-transplant specialist follow up by the small community of transplant specialists.⁴³ Professor Coates argued instead that changes to the Pharmaceutical Benefits Scheme mean that:

...patients with these sorts of transplants being performed overseas will not necessarily have strict regular follow-up within a transplant unit but may in fact be seeing either their general practitioners or, potentially, solo practitioners in nephrology or renal medicine without necessarily being formally involved in a large program ... one of the unfortunate aspects of changes in section 100 prescribing, which came into effect a year or two ago, is that any medical practitioner can prescribe transplant drugs ... it's certainly conceivable that, if somebody turns up and was doctor shopping, it would be very easy to get what is now a six-month prescription...⁴⁴

3.37 In answers to questions on notice to the Sub-Committee, the Department of Health also outlined the difficulties involved in identifying transplant related Medicate data:

The Medicare Benefits Schedule is a list of over 5700 health professional services and their fees and rebates and covers a comprehensive range of consultation, diagnostic and procedural services.

It is not possible to list the available Medicare item numbers for patients who have had organ transplants overseas because the item numbers used will reflect the nature of the care provided which will vary from patient to patient. It will include commonly used GP consultation items (item 23 and 36) and will likely include initial and follow up consultation services with consultant physicians (items 110 and 116). There are hundreds of potentially relevant pathology and diagnostic imaging items.⁴⁵

3.38 The Department further noted that:

43 Ms Cole, Department of Health, *Committee Hansard*, Canberra, 28 March 2017, p. 4.

44 Prof Coates, *Committee Hansard*, Canberra, 9 May 2017, pp. 1-2.

45 Department of Health, Answer to Question on Notice (QoN), *Submission 176*, p. 1.

For patients who obtain services from public hospitals, their care may not generate any Medicare billing (or Medicare record) as it will be funded through state and territory hospital budgets.⁴⁶

Measures to enhance data collection

3.39 The development of a more complete data set on overseas organ transplants would be consistent with current international efforts and best practice guidance relating to organ trafficking and transplant tourism.⁴⁷ This includes the recommendation made by representatives of the international transplant community at the Pontifical Academy of Sciences Summit on Organ Trafficking and Transplant Tourism that governments:

...establish national registries of all organ transplants performed within their jurisdiction as well as all transplants involving their citizens and residents performed in another jurisdiction, and share appropriate data with international databanks.⁴⁸

As noted by the Echo Project, a non-government advisory group focused on human trafficking issues, developing and sharing robust datasets across international jurisdictions is critical to combating transnational organised crime including organ trafficking.⁴⁹

3.40 If a decision is taken to establish a national register consideration would have to be made however with regard to:

- who would make reports and how;
- whether reporting would be voluntary or mandatory;
- the appropriate threshold for reporting;
- the purposes for which information would be collected and used;
- ensuring there are adequate controls over disclosure, both domestic and international; and
- who would receive reports and maintain administrative responsibility.

46 Department of Health, Answer to QoN, *Submission 176*, p. 1.

47 See: United Nations General Assembly, 'Report of the Special Rapporteur on trafficking in persons, especially women and children, 68th session', UN Doc. A/68/256, 2 August 2013 and United Nations Office on Drugs and Crime (UNODC), *Assessment toolkit: trafficking in persons for the purpose of organ removal*, UNODC, Vienna, 2015.

48 Pontifical Academy of Sciences, 'Statement of the Pontifical Academy of Sciences Summit on Organ Trafficking and Transplant Tourism', available: www.casinapioiv.va/content/accademia/en/events/2017/organ_trafficking/statement.html, accessed 16 July 2018.

49 The Echo Project, *Submission 13*, pp. 2; 6.

Mandatory reporting by medical practitioners

- 3.41 A large number of submissions and witnesses argued in favour of the establishment of a nationwide mandatory reporting scheme for commercial transplants. A Bill before the Parliament of New South Wales, *Human Tissue Amendment (Trafficking in Human Organs) Bill 2016*, introduced by Mr David Shoebridge MP, seeks to amend the *Human Tissue Act 1983 (NSW)*. The amendment would, inter alia, require medical professionals to report to the NSW Secretary of Health any reasonable belief that a patient has received a commercial transplant or one sourced from a non-consenting donor.⁵⁰ This would be supported by an amendment to the *Health Practitioner Regulation (Adoption of National Law) Act 2009 (NSW)*, defining “failure to report tissue traded or transplanted illegally” as constituting unsatisfactory professional conduct by a medical practitioner.⁵¹ Practitioners demonstrating unsatisfactory professional conduct may be subject to penalties under existing regulations.
- 3.42 Such a measure, in the context of support for the application of extraterritorial jurisdiction of transplant tourism offences, was also recommended in the 2015 report of the South Australian Parliament’s Joint Standing Committee on the Operation of the *Transplant and Anatomy Act 1983 (SA)*:
- The Committee considers that the Act should be amended to require mandatory reporting by medical and health professionals to the Department of Health of any South Australian resident known, or reasonably assumed, to have returned from transplant surgery abroad...⁵²
- 3.43 Mr Shoebridge recommended that the Council of Australian Governments facilitate the expansion of such a scheme nationwide.⁵³ Mr Shoebridge also indicated that mandatory reporting would be an “essential element” of a potential broader Commonwealth regulatory framework against transplant tourism.⁵⁴
- 3.44 Professor Coates indicated that mandatory reporting of overseas transplants would enable the collection of data to inform policymakers about appropriate responses to transplant tourism.⁵⁵ Professor Coates

50 *Human Tissue Amendment (Trafficking in Human Organs) Bill 2016 (NSW)*, sch 1, item 8.

51 *Human Tissue Amendment (Trafficking in Human Organs) Bill 2016 (NSW)*, sch 2.

52 Joint Committee on the Operation of the Transplant and Anatomy Act 1983, *Report of the Joint Committee on the Operation of the Transplant and Anatomy Act 1983*, Parliament of South Australia, 2015, Recommendation 10.

53 Mr Shoebridge MP, Greens NSW, *Committee Hansard*, 8 June 2018, Canberra, p. 22.

54 Mr Shoebridge MP, Greens NSW, *Committee Hansard*, 8 June 2018, Canberra, p. 25.

55 Prof Coates, *Committee Hansard*, 8 June 2018, Canberra, p. 2.

cited Malaysia – a country with a history of systemic engagement in organ importation⁵⁶ – as a jurisdiction where mandatory reporting had reduced participation in transplant tourism.⁵⁷

- 3.45 Doctors Against Forced Organ Harvesting (DAFOH) highlighted mandatory reporting by medical professionals as a priority.⁵⁸ DAFOH cited the cross-matching of Medicare Benefits Schedule item numbers associated with post-transplant care against registry data to be a potential means to enhance data collection.⁵⁹ Similarly, Professor O’Connell suggested that data matching with prescriptions of immunosuppressant drugs might support the development of more robust data.⁶⁰

Patient welfare and privacy

- 3.46 Reporting of overseas transplants, whether used for law enforcement purposes, or only as an evidence base to support policymaking, requires appropriate privacy controls. A mandatory reporting scheme in particular would need to be consistent with the relevant privacy safeguards such as the *Privacy Act 1988*. Ms Shakespeare of the Department of Health indicated that privacy and consent would be a key consideration for the Australian Government:

health data is considered something that is owned by the individual patient. In most of our programs, mandatory reporting would not be considered an appropriate approach...⁶¹

- 3.47 Consideration is also required as to the impact of a mandatory reporting scheme on patient welfare. Such a requirement could induce patients to conceal information relevant to their medical wellbeing, or create a disincentive for the patient to seek medical care. Professor McDonald, of ANZDATA, noted this concern, observing that transplant registries are clinical quality registers, seeking to improve the quality of patient care, and with current patient consent arrangements reflecting that purpose.⁶² Professor McDonald reflected:

It’s one thing to ask both patients and practitioners to report data on patients going through the usual consent processes for an organisation that directly links back to improving the health

56 Dr Fraser, *Committee Hansard*, 13 June 2018, Canberra, p. 2.

57 Prof Coates, *Committee Hansard*, 8 June 2018, Canberra, p. 2.

58 Doctors Against Forced Organ Harvesting, *Submission 22*, p. 25.

59 Mrs Bryskine, Doctors Against Forced Organ Harvesting, *Committee Hansard*, Canberra, 8 June 2018, p. 13.

60 Prof O’Connell, *Committee Hansard*, 8 June 2018, Canberra, p. 37

61 Ms Shakespeare, Department of Health, *Committee Hansard*, Canberra, 8 June 2018, p. 44.

62 Prof McDonald, ANZDATA, *Committee Hansard*, Canberra, 8 June 2018, p. 44.

system and the care of individual patients ... collection of data that may be incriminatory of a patient's conduct ... would certainly colour the conversations that I have as a practitioner with my patients. It's hard to see as direct a link between the collection of that data and the direct improvement of that individual patient's care.⁶³

- 3.48 Ms Madeleine Bridgett of Australian Lawyers for Human Rights argued that any privacy concerns would be allayed were participation in transplant tourism to be criminalised.⁶⁴ Ms Bridgett cited the requirement for health professionals to report suspected child abuse as a similar example of the necessity to report suspicion of an indictable offence.⁶⁵

Legal liability

- 3.49 The NSW *Human Tissue Amendment (Trafficking in Human Organs) Bill 2016*, would mandate reporting of possible organ trafficking cases where a registered health practitioner has "reasonable belief" that such activity has occurred. The provisions of this bill seek to protect health practitioners who report possible cases of organ trafficking, including protection from defamation, civil or criminal proceedings.⁶⁶ The bill provides that any such reports would not be contrary to professional standards of conduct.⁶⁷
- 3.50 An area for consideration is for the potential damage caused to persons against whom false reports are made. Whilst it is important to ensure medical professionals are adequately protected from liability when reporting, provisions for the protection of privacy, particularly given that possible 'transplant tourists' will also be vulnerable patients themselves. A presumption of innocence for anyone reported on should be considered in any mandatory reporting framework proposed.

Administrative responsibility

- 3.51 Professor O'Connell considered that ANZDATA is the appropriate body for the collection of data on transplant tourism. Professor O'Connell indicated that were it to be emphasised in ANZDATA's activities, the issue would be put to the forefront of consideration by renal professionals and reporting would be enhanced.⁶⁸ Professor O'Connell also noted that

63 Prof McDonald, ANZDATA, *Committee Hansard*, Canberra, 8 June 2018, p. 45.

64 Ms Bridgett, Co-chair, Business and Human Rights Committee, Australian Lawyers for Human Rights, *Committee Hansard*, Canberra, 8 June 2018, p. 30.

65 Ms Bridgett, Australian Lawyers for Human Rights, *Committee Hansard*, Canberra, 8 June 2018, p. 30.

66 Human Tissue Amendment (Trafficking in Human Organs) Bill 2016 (NSW)

67 Human Tissue Amendment (Trafficking in Human Organs) Bill 2016 (NSW)

68 Prof O'Connell, The Transplantation Society, *Committee Hansard*, Canberra, 8 June 2018, p. 38.

enhancing ANZDATA's activities would be significantly more cost-effective than establishing a separate reporting pathway.⁶⁹

- 3.52 It is important to note however that, as a renal transplant registry, ANZDATA does not capture data on non-renal transplants overseas and is not currently in a position to do so. It is not clear to what extent renal transplants are representative of transplant tourism more broadly.

Sub-Committee view

- 3.53 Participation in transplant tourism by Australians is highly undesirable. It poses medical, ethical and legal risks to the patients, is a violation of the rights and dignity of donor persons, and is a burden to the Australian healthcare system. It is a complex policy problem which requires a robust evidence base to address. Without a better understanding of how many Australians are travelling overseas for organ transplants, where they are travelling, and under what circumstances, Australia cannot adequately address this challenge.
- 3.54 Organ trafficking, including that which enables transplant tourism, is dependent on complex transnational networks involving both human traffickers and clinicians. As an organ-importing nation, Australia has a responsibility to share intelligence with international partners to assist with combating these networks. More robust reporting on Australian participation in transplant tourism – including the identities of perpetrators and those abetting them – would support partner states and international bodies to investigate and prosecute these human rights abusers.
- 3.55 The Sub-Committee considers that medical professionals should have an obligation to report knowledge constituting reasonable cause to believe that a person under their care may have been involved in the violation of the rights and dignity of others. It is important however that the appropriate protections are in place to preserve both the privacy of patients and the quality of clinical care. Should the reporting threshold extend to suspicion rather than actual knowledge of a case of transplant tourism, due regard should also be taken to minimise any legal liability for medical professionals with a mandatory reporting obligation.
- 3.56 The Sub-Committee acknowledges that understanding of how many Australians are participating in organ harvesting and transplant tourism is unknown due to disparate data collection and a lack of reporting mechanisms. In order to properly address the issue of transplant tourism, accurate data must be collected and analysed.

69 Prof O'Connell, The Transplantation Society, *Committee Hansard*, Canberra, 8 June 2018, p. 38.

Recommendation 3

The Sub-Committee recommends that the Australian Government meets international best practice standards by establishing a comprehensive organ donation data collection repository, based possibly on the ANZDATA model, but comprising a single point of access to data regarding all organ transplantations in Australia, including outcomes of treatment, deaths, travel overseas for treatment, cross referencing against waiting lists and other relevant information.

Recommendation 4

The Sub-Committee recommends that the Australian Government ensures that suitably-anonymised data regarding the participation by Australians in overseas commercial transplants, or those involved in organ procured from a non-consenting donor overseas, be shared with appropriate international partners, in order to combat transnational organ trafficking through cross-jurisdictional intelligence sharing.

Recommendation 5

The Sub-Committee recommends that the Australian Government works with the States and Territories, transplant registries, and the medical community, to consider the appropriate parameters, protections, and other considerations, to support a mandatory reporting scheme whereby medical professionals have an obligation to report, to an appropriate registry or authority, any knowledge or reasonable suspicion that a person under their care has received a commercial transplant or one sourced from a non-consenting donor, be that in Australia or overseas.