#COSA21

Voluntary Assisted Dying (VAD):

Data from Victoria, Internationally, and the Victorian Community of Practice Case Series

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Overview

- Setting the scene
  - Terminology of Assisted Dying, Assisted Suicide, and Euthanasia (ADASE)
- The Victorian Voluntary Assisted Dying Review Board (VADRB) report
- International Report Data
- The Victorian VAD Community of Practice (CoP) case series

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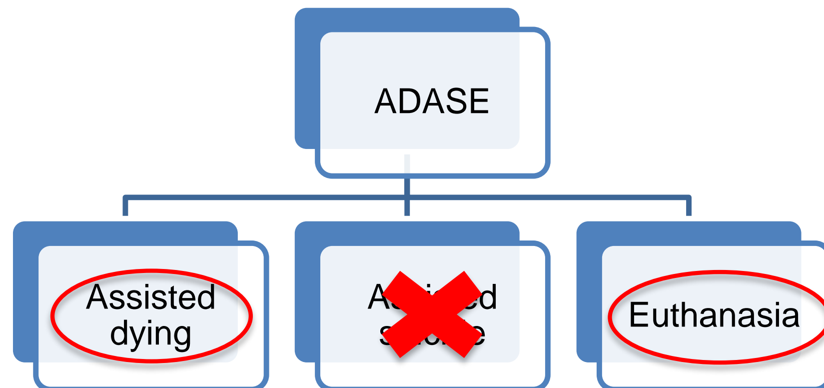
Setting the Scene - Terminology

- Physician-assisted suicide (PAS)
  - World Medical Association, American Medical Association
  - Imprecise
- Assisted dying
  - Assisting someone who is already dying
  - Presence of terminal illness with a "reasonably-foreseeable" or defined prognosis
  - USA, Australia
- Assisted suicide
  - In the absence of a terminal illness, or the process of "dying".
  - Motivated by suffering or choice
  - Switzerland, Netherlands
- Euthanasia
  - The practice of ending the life of a patient to limit suffering



- Legal or illegal?
- Active or passive?
- Voluntary, involuntary, nonvoluntary?

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VADRB report – Snapshot

Table 1: Requests received

Stage		Status	1 Jul–31 Dec 2020	1 Jan–30 Jun 2021	Total to date
Eligibility	First assessment	Eligible	221	245	807
		Ineligible	12	10	29
	Consulting assessment	Eligible	186	217	700
		Ineligible	4	4	12
Permit applications	Self-administration permit	Issued	149	174	524
		Not issued	12	15	59
	Practitioner administration permit	Issued	25	18	73
		Not issued	7	2	18
Withdrawn	Case withdrawn from portal by the coordinating medical practitioner or upon notification of death of applicant*		108	103	342
Medications dispensed	For self-administration#		127	132	413
Confirmed deaths##	Medication was administered	Medication was self-administered	80	92	282
		Medication was administered by a practitioner	20	9	49

* The figure for withdrawn cases may include administrative errors, duplicate cases, applicants discontinuing the process or those who died before the process was complete. Any duplicate data for an applicant are removed from the data reported.

Medication is only dispensed directly to applicants who hold a self-administration permit. For those issued with a practitioner administration permit, the medication is dispensed directly to the practitioner. Deaths as a result of medication being dispensed to the practitioner are contained within confirmed deaths.

While the Board receives notifications of applicants' deaths from Births, Deaths and Marriages, there are a number of cases where this does not happen – specifically, if the medical practitioner certifying the death does not identify that the applicant was a voluntary assisted dying permit holder on the Medical Certificate Cause of Death. In these cases, confirmation of the manner of death is obtained from contact people or coordinating medical practitioners when following up any unused medication (if medication was dispensed). If a medical practitioner certifying the death does not identify the applicant as a permit holder, notification of death is received once the death is registered. Any apparent differences between this report and the previous report are due to receiving new notifications of registered deaths.

- 900 individual patients registered
- 1548 assessments completed
- 597 permits issued
- 413 self administration medications dispensed
- 282 self administrations
- 49 practitioner administrations
- 331 deaths in two years
- 201 deaths from July 2020 – Jun 2021
- 0.49% of deaths in Victoria
    - ~0.3% in first year

VADRB report – Medical practitioner involvement

Table 2: Medical practitioner training and involvement

Stage	Description	1 Jul–31 Dec 2020	1 Jan–30 Jun 2021	Change (%)
Online training	Medical practitioner registered for the online training program	455	511	12% ↑
Portal registration	Trained medical practitioner registered in the portal	210	234 (46%)	11% ↑
Active in the portal	Trained medical practitioner involved in one or more cases as either coordinating or consulting medical practitioner	157	185 (36%)	18% ↑

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VADRB report – Medical practitioner involvement

Table 3: Number of medical practitioners registered in the portal, by specialty (1 Jan–30 Jun 2021)

Speciality area^	Regional and rural	Metropolitan	Total	Total Registered (AHPRA)	% Registered
General practice	61	76	137	8,353	1.6
Medical oncology	14	27	41	284	14.4
Neurology	0	11	11	239	4.6
General medicine	3	5	8	598	1.3
Respiratory and sleep medicine	0	6	6	223	2.6
Haematology	2	4	6	213	2.8
Palliative medicine	4	1	5	106	4.7
Other#	8	31	39		

^ Medical practitioners' specialty areas are reported in accordance with the Australian Health Practitioner Regulation Agency (Ahpra) listings. As a medical practitioner may have more than one specialty area listed with Ahpra, the total numbers included in this table exceeds the number of trained medical practitioners registered in the portal.

Other specialty areas include acupuncture, anaesthesia, cardiology, clinical genetics, clinical pharmacology, endocrinology, gastroenterology, general paediatrics, general surgery, geriatric medicine, gynaecological oncology, hepatology, infectious diseases, intensive care medicine, nephrology, neurosurgery, pain medicine, psychiatry, radiation oncology, rehabilitation medicine, rheumatology, sexual health medicine and urology, or do not have a specialty area(s) listed with Ahpra.

VADRB report – Applicant details

- Average age: 72 (18-101)
- 54% male
- 80% born in Australia
- 2% Aboriginal or Torres Strait Islander
- 95% speak English at home
- 98% do not require an interpreter
- 86% from private residence
- 71% at least senior secondary education (9.8% unknown)

Underlying illness	Total (n=488)	%
Malignancy		
Primary lung malignancy	80	19.8%
Primary breast malignancy	39	9.6%
Primary colorectal malignancy	41	10.1%
Primary pancreatic malignancy	41	10.1%
Other gastrointestinal tract malignancy	54	13.3%
Other malignancy	150	37.0%
Non-malignancy		
Neurodegenerative disease	37	44.6%
Respiratory failure	18	21.7%
Other	28	33.7%

Figures have been rounded to one decimal place and due to rounding the total figure for malignancy is less than 100 per cent.

International Comparison

Jurisdiction	ADASE	Number	% total deaths	Male	Median age	Malignancy	Hospice/Palliative care
Switzerland (2014)	AS	742	1.2	43%	80	42%	N/A
Oregon (2020)	AD	245	0.6	50.6%	74	66.1%	94.7%
Netherlands (2019)	ADASE	6,361	4.2	52%	75	64.5%	N/A
Belgium (2019)	E	2359	2.4%	47.2%	80	61.4%	N/A
Washington (2018)	AD	203	0.4%	44%	70	75%	92%
Luxembourg (2020)	ADE	25	0.6%	60%	70	72%	N/A
Vermont (2018)	AD	29	0.4%	N/A	N/A	83%	N/A
Canada (2020)	ADASE	7,595	2.5%	51.9%	75.3	69.1%	82.8%
California (2020)	AD	435	0.1%	49.2%	74	70.8%	86.7%
Colorado (2020)	AD	N/A (145 dispensed)	0.3%*	47.4%	73	65.3%	85.3%
Washington, D.C. (2018)	AD	2	0.04%	NA	72,81	100%	N/A
Hawai’i (2019)	AD	32	0.1%	68%	73	56.3%	87.5%
New Jersey (2020)	AD	33	0.03%	64%	63	73%	N/A
Maine (2020)	AD	30	0.2%	46%	70	72%	N/A
Victoria (2020)	ADE	201	0.49%	53.6%	73	83%	82.2%

Jurisdictions without ongoing reports: Switzerland, Colombia, Montana, Germany,

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VAD CoP

- Secure online forum for Victorian VAD-trained doctors
- Topics:
  - Discuss cases
  - Organise consulting assessor
  - Assessing capacity / coercion
  - Practitioner administration
  - Research interests / invitations
  - Media requests
  - Feedback to VADRB; education, training, administrative issues
  - Peer support / self-care

- Not in operation at the time of commencement of the Act
- 39 members (234 eligible)

VAD CoP data

Cameron McLaren [1] , Ross Jennens [2] , Suzanne Kosmider [3] , Peter Lange [4] , Theresa Hayes [5] , Nick Carr [6] , Deborah Harley [7] , Ingra Bringmann [8] , Chris Grossman [9] , Eli Ristevski [10] , Eva Segelov [1]

1. *School of Clinical Sciences, Monash University, Clayton, VIC, 3806*
2. *Epworth Healthcare, Richmond, VIC, Australia*
3. *Medical Oncology, Western Health, St Albans, VIC, Australia*
4. *Medicine and Aged Care, The University of Melbourne, The Royal Melbourne Hospital, Parkville, VIC, 3050*
5. *South West Oncology - South West Regional Cancer Centre, Warrnambool, VIC, 3280*
6. *St Kilda Medical Group, St Kilda, VIC, Australia*
7. *Medical One, Waurn Ponds, VIC, Australia*
8. *General Surgery, Western Health, St Albans, VIC, Australia*
9. *Palliative Care, Holmesglen Private Hospital, Moorabbin, VIC, Australia*
10. *Monash Rural Health, Monash University, Warragul, VIC, Australia*

- Ethics: Monash University HREC project ID 24804, Review Ref 2020-24804-50137
- Database of deidentified cases
  - Demographic data (age, sex, country of birth, language spoken at home, postcode, relationship status, living situation)
  - Diagnosis
  - Reasons for applying
  - Palliative care involvement / duration
  - Dates of completing each step of application
- 3 posters in #COSA21
  - #77499 – Voluntary Assisted Dying (VAD) in Victoria: a case series of patient characteristics 2019-2021
  - #76687 – Voluntary Assisted Dying (VAD) in Victoria: a retrospective case series assessing the application process
  - #77502 – Voluntary Assisted Dying (VAD) in Victoria: a retrospective case series comparing reasons for application with Canada and Oregon

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VAD CoP data

- 344 cases contributed by 10 members of the CoP
  - 300 cases by three practitioners
- 140 medications dispensed
- 108 administrations
  - 79 self administrations
  - 29 practitioner administrations
- 114 withdrawn applications
  - 112 due to death
  - No patient withdrew due to a change of mind
  - No patient withdrew within the 9-day “cooling-off” period between First and Final Request

	VADRB report data	VAD CoP data
Number of patients	900	344
Age (mean, range)	72 (18-101)	71 (33-98)
Male	54%	54%
Indigenous	2%	0.3%
Born in Australia	69.3%	72%
Speak English at home	95%	94%
Private residence	86%	88%
Metropolitan Victoria	64%	68%
Accessed palliative care services	82%	86%
Median duration (range) of pall care input	3 months (0-72)	3 months (0-60)

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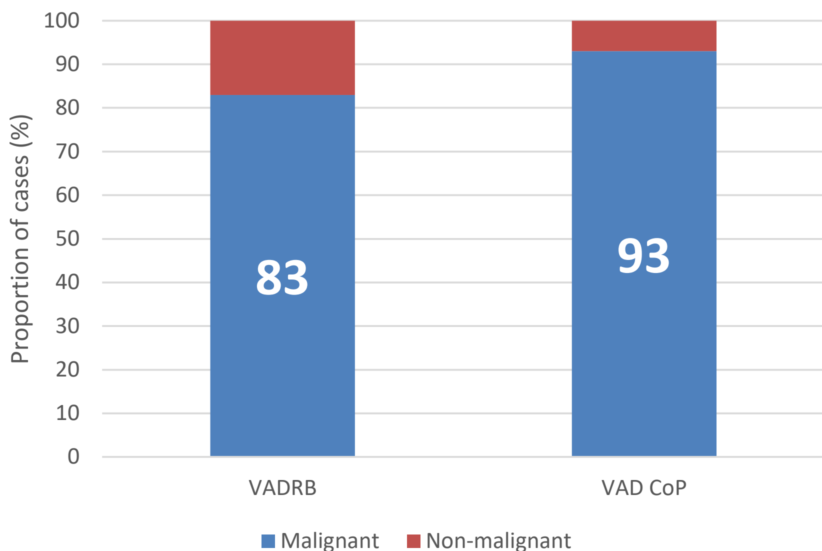
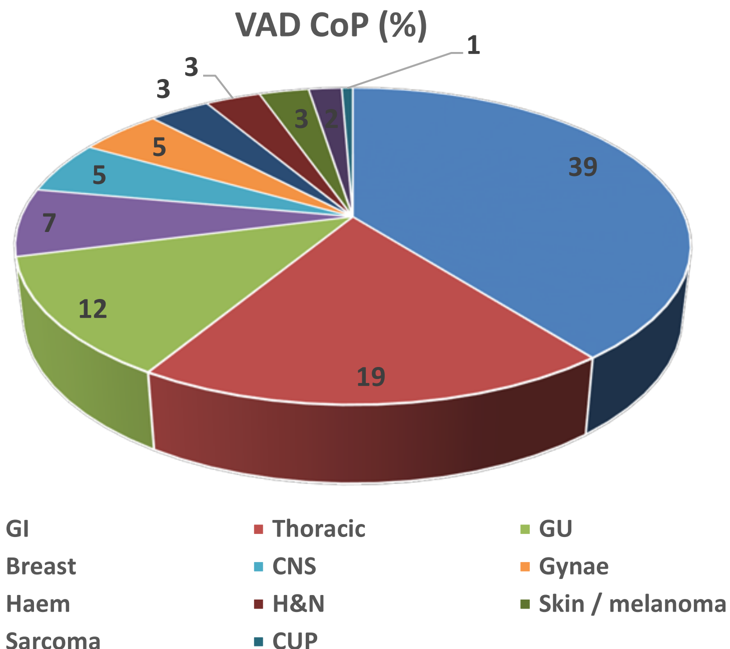
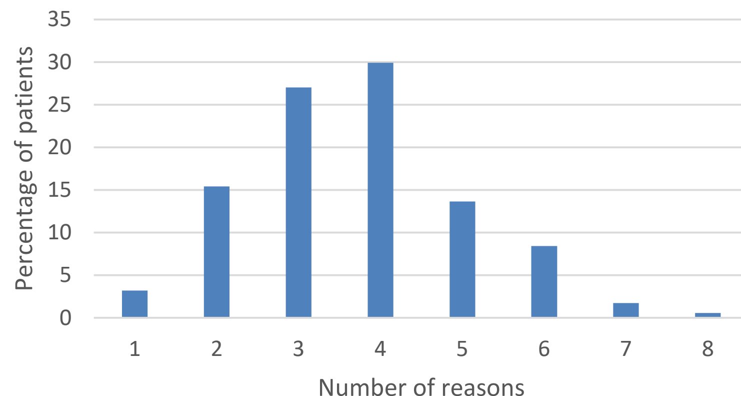
VAD CoP – Diagnoses





Reasons for applying

- Losing autonomy
- Less able to engage in activities making life enjoyable
- Loss of dignity
- Losing control of bodily functions
- Burden on family, friends/caregivers
- Inadequate pain control or concern about it
- Financial implication of treatment
- Other (please specify)



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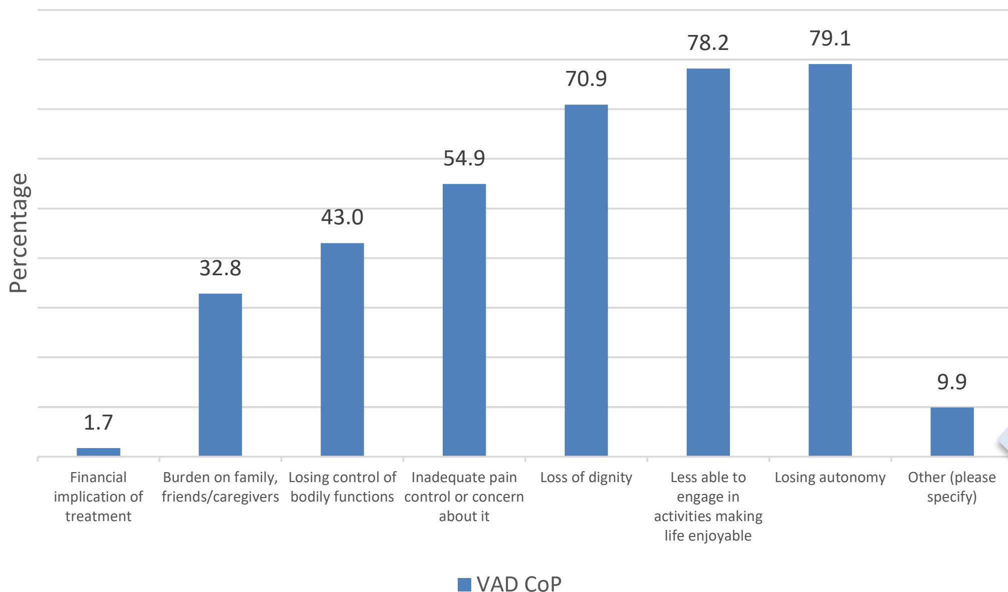
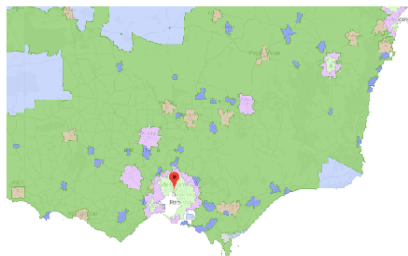
VAD CoP results – Reasons for applying for VAD



Theme	Number
Symptoms other than pain	12
Control	4
Concerns for future	4
Previous experiences	3
Existential distress	2

VAD CoP – Palliative Care involvement by rurality



MM1	Metropolitan
MM2	Regional centres
MM3	Large rural towns
MM4	Medium rural towns
MM5	Small rural towns
MM6	Remote communities
MM7	Very remote communities

Modified Monash Category (MMM 2019)	Description (including the Australian Statistical Geography Standard – Remoteness Area (2016)
MM 1	**Metropolitan areas:** Major cities accounting for 70% of Australia's population All areas categorised ASGS-RA1.
MM 2	**Regional centres:** Inner (ASGS-RA 2) and Outer Regional (ASGS-RA 3) areas that are in, or within a 20km drive of a town with over 50,000 residents. For example: Ballarat, Mackay, Toowoomba, Kiama, Albury, Bunbury.
MM 3	**Large rural towns:** Inner (ASGS-RA 2) and Outer Regional (ASGS-RA 3) areas that are not MM 2 and are in, or within a 15km drive of a town between 15,000 to 50,000 residents. For example: Dubbo, Lismore, Yeppoon, Busselton.
MM 4	**Medium rural towns:** Inner (ASGS-RA 2) and Outer Regional (ASGS-RA 3) areas that are not MM 2 or MM 3, and are in, or within a 10km drive of a town with between 5,000 to 15,000 residents. For example: Port Augusta, Charters Towers, Moree.
MM 5	**Small rural towns:** All remaining Inner (ASGS-RA 2) and Outer Regional (ASGS-RA 3) areas. For example: Mount Buller, Moruya, Renmark, Condamine.
MM 6	**Remote communities:** Remote mainland areas (ASGS-RA 4) AND remote islands less than 5kms offshore. For example: Cape Tribulation, Lightning Ridge, Alice Springs, Mallacoota, Port Hedland. Additionally, islands that have an MM 5 classification with a population of less than 1,000 without bridges to the mainland will now be classified as MM 6 for example: Bruny Island.
MM 7	**Very remote communities:** Very remote areas (ASGS-RA 5). For example: Longreach, Coober Pedy, Thursday Island and all other remote island areas more than 5kms offshore.

Modified from health.gov.au

MMM category	N	Proportion of VAD CoP patients	% NOT involved with palliative care	Median duration of palliative care involvement
1	245	71%	15	3
2	9	3%	0	3
3	24	7%	17	3
4	32	9%	13	6
5	33	10%	6	2.5
6	1	0%	0	5

Chi square test of independence was performed to examine the relation between MMM category and palliative care non-involvement. The relation between these variables was not significant, X^2 (4, N = 99) = 3.31, p = .508. VAD CoP applicants from more rural areas did not have a greater likelihood of palliative care non-involvement.

Summary of Findings

- Patient uptake of VAD in Victoria seems in-line with other jurisdictions internationally
- VAD CoP seems to be a representative sample of the whole VADRB data
  - Statistical comparison not possible
  - Risk of sampling bias due to low number of contributing sources
- VAD CoP data series enables the analysis of VAD case data through clinical lens
- 70% of VAD applicants have either gastrointestinal, lung, or genitourinary malignancies
- Reasons for applying were multifactorial
  - Anecdotally, difficulties with “burden” and “pain control” reasons
- Palliative care involvement was preserved across MMM category

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THANK YOU