



Supporting Information

Supplementary methods and results

This appendix was part of the submitted manuscript and has been peer reviewed. It is posted as supplied by the authors.

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Interview guide: doctors' perspectives on the regulation of voluntary assisted dying in Victoria

1. Introduction

Interviewer to read Script:

As specified in the Information Sheet, we are conducting a study titled "An interdisciplinary evaluation of the operation of Victoria's voluntary assisted dying legislation in its first 12 months".

You have been invited to participate in the study because you are a doctor involved in the implementation of voluntary assisted dying in Victoria. Participation involves a semi-structured interview that will take as long as you require but is anticipated 30-60 minutes.

The study is being funded by the 2019 Institute of Health and Biomedical Innovation (IHBI) Synergy Partnerships Scheme at QUT and ethics approval has been received from the QUT Human Research Ethics Committee.

As you have already provided consent to be interviewed and audio recorded, I would firstly like to ask some questions regarding your demographic information and then about your experience and views concerning voluntary assisted dying. As specified in your Participant Information Form, we ask you not to breach your duties of confidentiality by naming patients, family members, or other medical practitioners.

There are no right and wrong answers; we are simply interested in people's views. If you don't want to answer any of these questions, please just say so.

2. Demographics

a. Regarding your demographic and clinical characteristics

i. What is your current age? _____

ii. Gender: Male
 Female
 Other

iii. Location Major city
 Inner regional
 Outer regional
 Remote and very remote
 Other

iv. Role: Medical specialist
 Vocationally registered GP

v. What is your main medical specialty (and let me know if you have others):

- Anaesthetics
- Cardiology
- Emergency Medicine
- Gastroenterology
- General Medicine
- General practice
- Geriatrics
- Haematology
- Intensive Care
- Medical Oncology
- Radiation Oncology
- Neurology
- Palliative Care
- Psychiatry
- Radiology
- Respiratory
- Renal
- Surgery
- Prefer not to say
- Other (please specify) _____

vi. How many years have you worked as a doctor? _____ (number of years)

vii. How many years have you worked as a specialist [or vocationally registered GP]?
_____ (number of years)

3. Doctors involved in VAD - interview guide

1. Initial reactions and experience of VAD

Before we get started and just to remind you and frame the rest of our conversation, this study is about how the Victorian VAD regulatory framework is working in practice. This includes the VAD law, VAD Review Board, Statewide Pharmacy, Department (permits), Navigators, Training. We want to know what is working, what is not and how it could be fixed.

- a) Could you please describe briefly any experiences you have had with VAD in clinical practice? (e.g. providing care to a patient who has requested VAD, having received a VAD request or referral, having VAD discussions with patients, assessing and prescribing VAD medication, administering VAD, and being present at a VAD death; seek indication of total number of patients assisted with VAD overall)
- b) How does VAD begin?
 - a. Have patients seeking VAD raised this topic with you? How?
- c) How did you manage your input into this conversation?
 - a. Prompt: Did you know that you are prohibited from raising VAD with them? How did you manage this in your conversations? Did this have an impact on you or your patients in terms of knowing VAD was available?
- d) How did you decide when a patient had made their formal first request for VAD?
- e) Once you had a first request for VAD, how did you know what steps to take in the assessment process?

2. Eligibility requirements

- a) Now I'd like to focus on the eligibility requirements for VAD, could you tell me about your experience applying these requirements (how did you know what they were / what's working / not working) - why?

Prompts if not covered above

- b) How have you found applying the residency requirements in practice?
- c) In accordance with VAD eligibility requirements, have you had any experiences assessing that a person is expected to die within 6 months? How confident did you feel to make this judgement / how did you overcome any potential uncertainty?
- d) For a person with a neurodegenerative disease who is likely to die in a time period of between 6 and 12 months, the doctor must refer that person to a specialist for an assessment. How confident do you feel to make this judgement of time until death / how did you overcome any potential uncertainty?
- e) Do you believe having a different expected time until death for different conditions is justifiable (ie 12 months for persons with neurodegenerative conditions) – why?
- f) Any issues in relation to assessing capacity?

3. Request and assessment process

- a) Thinking now about the request and assessment process. This is your assessment of the patient and then getting a second doctor to assess them as well. What's been your experience in this process in terms of what is working or not working?

Prompts if not covered above

- b) Is it difficult / easy to find another doctor [may be a specialist]? Why?
- c) This process includes ensuring that the patient 'is acting voluntarily and without coercion' and their VAD request is enduring. Have there been any issues or challenges with this, or has it been straightforward?
- d) How have the legally required wait times (ie 9 days between first and final request; 1 day after consulting request) operated in practice?
- e) Is the training a barrier / facilitator to having doctors being involved in VAD? In what ways?
- f) Do you have any comments on the role of the VAD Care Navigators in this process (or generally)?

4. Reporting requirements

- a) Could you please talk about your experience navigating the reporting requirements for VAD in practice (works, not works? Why?)

Prompts if not covered above

- b) What do you believe are the main benefits/issues/challenges going through the VAD reporting processes?
- c) Do you believe these processes are justified – why?
- d) [If permit not raised: In addition to reporting, there is a requirement to obtain a permit for VAD from the Department of Health and Human Services. What has been your experience with obtaining VAD permits? (barrier, not, why?)]
- e) Do you have any comments on the role of the VAD Review Board in terms of reporting (or generally)?

5. Administration of VAD

- a) The next topic is about providing VAD. How is this working in practice? What's helping / not helping?

Prompts if not covered above

- b) Key prompt: How is the difference between self-administration and practitioner administration working in practice? How is this decision made? Should the default remain self-administration (or should it be only self-administration)? Why?
- c) Do you have any comments on the role of the Statewide Pharmacy Service and how it is working? Or the prescription process generally?
- d) What about after the patient has died – staying with how the system works, should the law or regulatory framework do anything different?

6. The Act's ability to meet its policy goals in practice

The key policy goals underpinning the VAD law appear to be:

- Respecting personal autonomy – providing choice for terminally ill patients.
 - But also: Safeguarding the vulnerable and the wider community.
- a) Do you believe these policy goals are being met in practice? Why, why not?
 - b) These policy goals are balanced against each other to some extent. Is the balance appropriate? Which is given more weight in this legislation?

7. To finish, I want to ask you a question that is a little more abstract or theoretical. The Government wants doctors to follow the rules for providing VAD and so it has set up various rules in: the VAD law, there are policies and guidelines, there is training and other support and systems to try and make sure things happen as planned. If you are trying to design a system that doctors will listen to and follow, what is the most effective way to guide doctors' behaviour when providing VAD? What sorts of 'rules' are doctors most likely to listen to, what will they follow in providing VAD? [prompt: law, policy, guidelines, ethical codes, training, professional norms, anything else? Which of these are most likely to influence your decisions about providing VAD?]

8. Close

- a) Overall, any final comments about what works well with the current regulation of VAD? And what doesn't?
- b) Putting aside the Victorian system, if you were designing the best possible system of VAD regulation yourself, what principles or values do you think should underpin that system?
 - a. What features do you think the system should have?
 - b. What is the most effective way to guide health professionals' actions in this area?
- c) Is there anything else that you think might be important to add?
- d) Is there any other doctors that you think I should be talking to?

Thank you very much for taking part in this interview.

Table. Illustrative comments by participants, by theme and sub-theme

Theme/Sub-theme	Participant comments
1. Prohibition of initiating discussions with patients about voluntary assisted dying	
Should be able to inform patients of their treatment options	<p>“When someone comes to me and says ‘My chemo’s failed. My immunotherapy has failed. What are my options,’ and I’ve got to throw it back to them and say, ‘What do you think your options are?’ I can’t say, ‘Well, you can do nothing, you can have palliative care, you can have voluntary assisted dying. Let’s go through all these options’. I can’t actually say that, and I think that’s just intellectually dishonest. Absolutely intellectually dishonest, and I think it’s probably going to be a real bias about non-English-speaking and -reading people. Because it’s really been in the paper and other places, but if you don’t read a paper or read in English or listen to English-speaking radio, I’m not sure that you would know.” (04_GP)</p>
Concerns about unduly influencing patients	<p>“I’ve thought a lot about this. It’s going to limit which people are able to access this. Because it’s going to be hard if you don’t have English as a first language, or you’re not internet savvy and you’ve been googling this and you know what you have to do. But I can’t think of an alternative that remains safe without us intentionally or unintentionally influencing people. Maybe it’s safer that some people miss out who otherwise would be appropriate, rather than accidentally capturing people who — if we bring it up we have a lot more influence on people than we realise. If your oncologist starts mentioning it, the risk is there that we, largely unintentionally, influence people. So if you have to lean one way or another, I’d lean towards this system where we can’t raise it.” (12_Specialist)</p>
Self-selecting patients	<p>“Having said that, these patients are self-selecting. These patients that are requesting it are people that have thought about it and want to do it. So that makes it easier to have conversations with them about it.” (22_Specialist)</p>
2. Requirement for all interactions to be conducted face-to-face	
Burden on doctors and patients	<p>“I’ve got a patient who, at the moment, lives in [regional location] which is probably three hours away. She’s driven down to me for the first assessment. She drove an hour and a half for the second assessment. She’s going to drive three hours to see me again for the paperwork... That’s not an equitable system. People having to travel over 10 hours to get this done, over the course of their application, is cruel and I don’t think it’s what was intended by this legislation. I think it was meant to protect vulnerable people, but I don’t think it’s doing that. I think it’s layering difficulty for the people who want to actually access it. The personal toll that’s come out of doing this job for me has got nothing to do with the content, it’s all got to do with the logistics and the travel. If I was able to telehealth someone I could get this done in 40 minutes, but instead I’ve got to drive two hours, see the patient, drive two hours back. That’s the problem with it. So that does place a personal toll on it. You know, fatiguing. Also, from a personal life, work–life balance, family life point of view, it does make it hard on me and my family as well.” (01_Specialist)</p> <p>“You know, I had a patient the other day in a wheelchair coming in her jammies and her dressing gown because she was too sore and too tired to get dressed, but had to come in person to have another consultation, and you think, really, is this necessary to drag them out repeatedly, and because you’re not allowed to talk about those things over the phone.” (19_Specialist)</p>
Face-to-face consultation as a safeguard	<p>“You’ve got to – I think you must see the person and what they’re feeling and thinking at the time. You can’t do that through a telephone and through [Zoom]. It’s better than nothing. I’ll leave that to those people, I think it’s a second rate solution.” (03_GP)</p> <p>“I think telehealth and all of that has real limitations. It’s very different talking to a patient on the telephone than it is to see them. I’m getting better at telehealth, but it’s not a satisfying way of life. No. I think when you see them and you see they make a movement and they cringe in pain – there’s just a lot of stuff that you see, and you see the frailty. You definitely have to see them. I can’t imagine doing this by telehealth.” (04_GP)</p>
Logistic limitations of in-person prescribing and delivery of voluntary assisted dying medication	<p>“Then by the time I managed to get a meeting with the pharmacist and write the prescription, I spoke to them and she was now on a syringe driver and she was semi-comatose. I said ‘Well, she’s no longer eligible.’” (11_GP)</p> <p>“The other thing that’s causing troubles there is that the pharmacist has to come and get the script from us. We can’t post it. We can’t fax it. We can’t upload it to the portal and have a conversation with the pharmacist over the phone. Even if you [call them] they still have to come and see you. We’re in [regional location]. So for them to come and see us to collect a script, to use the technical term, is fucking crazy. It’s important that the pharmacist sees the doctor if the doctor has anything to discuss or has not done it before, perhaps. But when you’ve filled it in a number of times, if you could just have a phone call with them. Really, it’s absolutely ridiculous.” (17_Specialist)</p>

3. Implementation of the law in practice	
Process problems	<p>"The forms are really badly presented, so that it's not – each time I read it, I've got to sort of actually consciously go through and say this piece is actually about this, and so they don't need to sign that, but they need to sign this bit, which is directly underneath it. So, the more you do, the more you get to know these things. I know I have to be careful when the signature times come, that I check everything two or three times, and I make sure that I read it each time. For someone doing it for the first time, it's a bit unclear and a bit daunting, I think." (05_Specialist)</p> <p>"But I think some of them are just – there are more obstructions than there are actually really checks, because you'll get them anyway. So, it's not going to prevent it from happening." (07_Specialist)</p> <p>"The portal had lots of technical issues. One of my qualifications is in computer science from [a Melbourne university]. I was unable to use their portal. I was using multiple browsers, downloading in one browser, submitting in another. It's just hopeless. I think it's slowly getting better, but you literally could not upload a form to it. It was just like, well, that doesn't work. Then you have to go and email it and hope that they would make an exception and accept an email form." (15_GP)</p> <p>"There was the scan I provide which shows that they've got cancer everywhere. I say they've got less than six months to live because I'm a medical oncologist and so I've had more than five years of training in this area. And then they've come back to me every time and said could you please give a more accurate timeframe as to their prognosis? Which I think is strange, because if the eligibility criteria is less than six months, it wouldn't matter if then they've got five-and-a-half months, or if they've got three days. I don't know if they need that to understand about the urgency of the request, but they have refused to approve my assessment until I give them more information." (08_Specialist)</p> <p>"I think all of these safeguards are just interpreted a little bit too tightly, with too much documentary proof and too stringent requirements. There's not any one which I think could just go. I just don't think they need to be interpreted quite so strictly." (11_GP)</p>
Providing documentary evidence	<p>"Because, really, it seems to be ridiculous that a mountain of paperwork – and remember many of these people are old, they're unwell, they're at the end of their lives. I remember saying to someone 'Now, I need your rates bills or your rental bill from 12 months ago to prove you've been a resident of Victoria for 12 months.' She looked at me as if I'm some blithering idiot and said 'I'm going to be dead in two months' time. I've thrown out all my paperwork. What the fuck do you mean I've got to keep paperwork like that from 12 months ago?', and she had a point." (11_GP)</p> <p>"Australian citizenship, usual resident, ordinarily resident, consent: in the ideal world they're all easy. The problem is that a lot of these people, again because of their age – so they're late in their life and they don't have a lot of these forms. They haven't used a lot of these things. They might not have a driver's licence anymore. They might not own a property in Victoria anymore. They might be holidaying around the place. So some of them can be problematic for this group of patients proving where they live." (15_GP)</p>
Delays associated with under-resourcing of the Statewide Pharmacy Service	<p>"We've had patients die. We've had quite a number of patients die waiting. They've had their permit and they're either waiting for the collection of the script or for the delivery. So we've had both of those. I was meant to be collecting the numbers. But it's absolutely, at the very least, at least five patients we've had in our unit who have died whilst waiting for the substance to be delivered." (17_Specialist)</p> <p>"But the logistics, which is a kind of the rate-limiting step, is the access to pharmacy. Because pharmacy, quite appropriately, need to meet with the patients and explain what's involved, and there's a waiting time of a week to 10 days to actually get an appointment with the pharmacy because they're under-resourced." (14_Specialist)</p>