



Providing legal assisted dying and euthanasia services in a global pandemic: Provider experiences and lessons for the future

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Dedication

This research is dedicated first and foremost to all people with terminal or unbearable illnesses who may not outlive this pandemic, and to the families supporting them. We also dedicate it to the healthcare professionals committed to the continuance of assisted dying and euthanasia services, both throughout and following the pandemic, and recognise their bravery in placing themselves on the front line to ensure that the rights of the patients they serve are upheld.

Life is not measured by the number of breaths you take, but by the moments that take your breath away. Maya Angelou

A. Research summary

1. Research rationale and approach

When a global pandemic was declared in March 2020 by the World Health Organisation (WHO), it became apparent that health services worldwide would be dramatically affected. Research was needed to identify the implications of those impacts for access to legal assisted dying or euthanasia (AD&E)¹ and how AD&E services would be provided in the COVID-19 context. An international survey was complemented by key informant interviews between June 2020 and January 2021.

2. Key findings

Key findings were that:

- A complex pattern emerged of shifting responses by AD&E providers to accommodate the highly dynamic context of the pandemic.
- Rates of AD&E inquiries and requests fluctuated over time, both across and within jurisdictions, sometimes significantly, in response to a complex interaction of factors affecting people's access variously to COVID-19 information, doctors generally, and AD&E services in particular.
- AD&E provider agencies and practitioners were strongly focused on ensuring continuity of services to people seeking AD&E ('seekers'). Most AD&E practitioners continued in those roles. Nonetheless, AD&E services were disrupted in some places, albeit temporarily, constraining seeker access.
- Service flexibility and nimbleness became essential elements in adjusting usual practice to continue service availability while ensuring the safety of all parties. Flexibility extended to calculated rule-breaking deemed justifiable to adhere to accepted medical ethics.
- In particular, usual AD&E practice was modified in terms of: the accepted assessment mediums, with widespread use of telemedicine; flexibility in applying some AD&E regulations, such as witnessing requirements; greater use of oral and self-administered AD&E; and rapid development of new systems for effective service provision in the context of constrained health services.
- Making adjustments to usual AD&E practice had in turn led providers in all jurisdictions to question the general suitability of both existing practices and the current laws. Many research participants concluded that significant revisions were now needed to their respective laws, regulations and/or policy, to ensure that the legally mandated entitlement to AD&E, for *prima facie* eligible seekers, was supported by the legislation in a crisis context. Building provider capacity was also identified as a high priority.

3. Conclusions

This study was undertaken with an intention to identify how AD&E services might be impeded by the pandemic. In fact, it has revealed how AD&E providers have not only found ways to continue providing services but have also developed systems and processes that they believe are, in many ways, an improvement over

¹ This term is used in this report to encompass all forms of *legal* assistance in dying across jurisdictions.

previous practice. As AD&E agencies and practitioners have developed new and often better ways to provide these services, the challenge now is for those developments to be shared across the sector internationally.

The COVID-19 pandemic experience has provided a unique opportunity for lessons to be gained for providing legal AD&E in a major health sector crisis. The pandemic has created a precedent for the future of provision of *all* health services, including AD&E, where those services are severely compromised both logistically and ethically. AD&E agencies internationally are having to reconsider the very feasibility of their respective laws, in line with the stated legal intent of those laws, in the context of a continuing crisis in health services provision and a likely extended pandemic. A 'post-COVID syndrome'² has now been identified, potentially affecting millions of COVID-19 survivors worldwide, both those with incurable illnesses and others with severe long-term post-COVID symptoms. Many such people are likely to reconsider their quality of life in the ensuing years. Laws, regulations and policy relating to both current and future laws for AD&E now need a comprehensive feasibility analysis, to honour the intent of the legislation.

² Various called '[post-COVID'-19 syndrome](#)', '[post-acute COVID-19 syndrome](#)', 'long COVID', or '[long-haul COVID](#)' by journalists and other lay people.

B. Background to the study

1. Why was research needed?

On 11 March 2020, the WHO confirmed a global pandemic of a new and lethal SARS virus. Worldwide hospitals and health professionals had to consider how their roles would be affected. On 25 March 2020, New Zealand's³ Prime Minister announced that the country was in 'lockdown' and everyone must stay at home, for at least one month, except for essential workers and essential shopping. Around the world other countries began to implement a range of regimes curtailing people's movements and focusing health service priorities on addressing the spread of the virus, named COVID-19. As health researchers contemplated the downstream impacts of the health sector's priority focus on dealing with the pandemic, it was apparent that there would likely be significant impacts for the provision of legal assisted dying and euthanasia (AD&E) services everywhere that these were in operation, both long-established services (e.g. European and United States [US] jurisdictions) and more recent ones (e.g. Victoria, Australia).

A rapid evidence review⁴ found no literature on the potential impacts of a global pandemic on legal AD&E. Apart from one paper in 2010 that explored the defensibility of a medical strategy of "allowing-to-die" in a global pandemic context where critical care capacity was exceeded,⁵ there is a gap in consideration of the impacts of a pandemic on assisted death, and nothing written hitherto on pandemic impacts on the provision of *legal* AD&E.

As people involved in providing legal AD talked informally with colleagues, there was some anecdotal evidence that the normal or usual provision of services to people seeking legal AD&E was starting to become more difficult. Possible reasons were barriers created by the 'lockdown' requirements in some countries, new restrictions on access to aged care and other medical facilities, increased caution among both doctors and patients around having face-to-face consultations, or an unanticipated lack of capacity among doctors and others to support new or existing AD&E requests, assessments or administration, due to being seconded to pandemic tasks. Assuming that this would not be the last occasion that a national or global health crisis affects the provision of health services, it was important to learn from the current situation. Accordingly, a small research team was established under the auspices of the World Federation of Right to Die Societies (WFRtDS), with the aim of obtaining early information on the immediate impacts of the pandemic on legal AD services, including the agencies ('provider/s'), individual health practitioners and associated AD&E 'support personnel'⁶ providing those services at the frontline ('practitioners'), and the people seeking a legal assisted death ('seekers').

³ The first author's home country, in high-level lockdown when this project was conceptualised.

⁴ In April 2020; articles published recently on this topic are referred to later in this report.

⁵ Jeffrey Berger, Professor of Medicine & Chief, Division of Palliative Medicine and Bioethics, NYU Long Island School of Medicine, New York.

⁶ This term is used here in preference to 'volunteers'; note that where 'volunteers' are referred to in quotes, the speakers are referring to the support personnel who provide support to seekers and families prior to, at and sometimes following a legal assisted death.

2. Research approach

The research team comprised: Dr Pam Oliver, independent health/law researcher specialising in AD&E research, New Zealand; Mike Wilson, registered nurse, doctoral candidate (University of Adelaide) and experienced AD&E researcher, Australia; Dr Rob Jonquiere, Executive Director, WFRtDS, The Netherlands; and Dr Cameron McLaren, medical oncologist providing assisted dying services in Victoria, Australia.⁷

The *data collection methods* comprised an online survey, followed by interviews with people who responded to the survey and volunteered to take part in an interview. The *online survey* was disseminated in early June 2020 via the email databases of AD&E provider organisations and the WFRtDS, and gave a 10-week opportunity for people to take part. It sought sociographic information (e.g. respondent's jurisdiction, provider role) and asked a series of questions around the impacts of the pandemic on usual AD&E service provision (see **Appendix 2**). In total **89 respondents** completed the survey from a range of jurisdictions where *legal*⁸ AD&E is available (see respondent sociographic attributes in **Appendix 3**); responses from people in other jurisdictions were screened out.

An initial **18 interviews** were undertaken in August-September 2020 by members of the research team, via Zoom or telephone, with those people across a range of jurisdictions and roles who had volunteered through the survey to be interviewed. These conversations gave survey respondents an opportunity to expand on their experiences of providing AD&E services in the pandemic context. Given the huge flux internationally in COVID-19 infection and death rates across 2020, follow-up interviews were undertaken with AD&E practitioners and agency providers, where available, in December 2020 and January 2021, to update on any developments in the impacts on AD&E service provision.

3. Data analysis and reporting

Data have been analysed for frequencies (survey data) and salient themes (interviews), so that information from the research findings could be disseminated as early as possible. It was apparent from the interviews (undertaken subsequent to the survey) that the impacts of the pandemic on the provision of AD&E services were dynamic, changing over time, and also varied across jurisdictions, depending on a range of factors specific to the particular locality, especially the response of governments to the pandemic at a given moment.

Accordingly, the following discussion reflects feedback from people normally involved in providing AD&E services on their experiences up to the end of January 2021, and acknowledges that the situation is in flux. In the discussion below, the data from each of the survey questions are synthesised with

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⁸ Defined for the purposes of this study as jurisdictions that have legalised or decriminalised AD&E via specific legislation or a court decision still effective.

information obtained from the interviews and other relevant material that has been published online about occurrences relating to AD&E in 2020. Comments from survey respondents and interviewees are provided verbatim with original spelling, grammar and punctuation; the quotes included are from survey respondents unless another speaker is described in brackets.

C. Immediate and short-term impacts

In general, the survey and interview findings both demonstrated a complex pattern of shifting responses by AD&E providers to accommodate the highly dynamic context of the pandemic.

1. Has the pandemic context affected the frequency of AD&E requests and inquiries?

Table 1 shows the reported impacts on AD&E requests and inquiries as a result of the pandemic, as identified by people responding to the survey in June-August. That was the period during which countries and states were using a huge diversity of interventions in their attempts to curb the spread of the virus, and that diversity of strategies is reflected in **Table 1**.

Table 1: Pandemic impacts on requests and inquiries	
Decreased significantly	11%
Decreased somewhat	10%
Neither increased nor decreased	42%
Increased somewhat	15%
Increased significantly	9%
Don't know	13%

Rather than a clear pattern tending towards either increased or decreased inquiries and requests during the early stages of the pandemic, contacts with AD&E providers reflect a broad range of factors that affected seekers' ability or desire to contact the agencies and, in turn, the agencies' ability to respond. Those factors were related variously to locality, AD&E law, policy and systems in each jurisdiction, agency and provider availability, the general health sector response to COVID-19 in a particular place, the time frame, service interruptions, and media coverage of the pandemic, and possibly other factors.

Decreases in requests and inquiries

Interviews with AD&E providers across several jurisdictions, and roles, clarified some of the disruptions affecting request and inquiry rates. Where inquiries and requests decreased during this period, the effect was attributable to a variety of downstream responses by medical authorities and facilities to government requirements. For example, in some places, agencies involved in providing AD&E services put those on hold temporarily, so that no requests or inquiries were possible. In others, while the AD&E agencies remained accessible, some hospitals froze AD&E services for indeterminate periods, individual practitioners were seconded to pandemic duties and thus temporarily unavailable for either consultations or assessments, or nurses were prohibited from AD&E participation. AD&E first point of contacts interviewed also discovered that some seekers already in the process of being assessed now felt that they shouldn't 'bother' doctors, to free them for COVID work .

... reluctance on part of patients, thinking hospital and doctors too busy with other things.

Visit Nurses were not allow to attend any MAID [medical aid in dying] provisions as it wasn't supported by the Local Health Integration Network.

In the beginning of the pandemic my organisation stopped for a certain period.

Believe that only forecast AD&E cases have been provided, and that new cases were being put aside for a while.

Local hospital stopped providing MAiD; this has put a greater burden on community providers.

Border closures have affected non-residents seeking euthanasia. EOL consultations have been suspended and hospitals have cancelled most non-covid appointments.

Increases in requests and inquiries

Where inquiries and requests increased, the contributing factors initially, according to interviewees, were commonly people wanting clarification of one or more of the following:

- Whether COVID-19 would constitute an eligible condition for an assisted death
- If so, whether an AD&E application could be processed in the time frame of a 'typical' COVID-19 death
- If not, what their other options might be.

Another apparent reason for increased inquiries was seekers contacting multiple agencies, including those not providing an assisted death through the relevant legislation but by providing other kinds of information on achieving a peaceful self-administered death.

However, as the devastating impacts of the virus became clear in many countries, and people learned more about what a COVID-19 death looked like, AD&E providers in some jurisdiction began to see an increase in actual applications from *prima facie* eligible people. Commonly these increases were attributed to people with eligible conditions⁹ developing an awareness that their health risks were now exacerbated, due to COVID-19, and their chances increased of having exactly the kind of death they wished to avoid. Accordingly, they were seeking information and clarification about COVID-19 deaths, AD&E eligibility criteria, constraints on provider availability, and any other barriers. Similarly, some people wanted to fast-track their requests and assessments in order to have ready access to an assisted death if they did contract COVID-19, so they could avoid dying in hospital and/or without family present.

... more patients calling to inquire about their legal options and express concern regarding potential loss of autonomy around death in the event of acquiring COVID19.

⁹ Varying according to the particular relevant legislation.

People have brought forward [AD&E] applications due to anxiety about dying in hospital unable to see loved ones; they want to die at home.

Patients with chronic diseases fearful that they are at risk.

The main increase we've seen is either people wanting to know if they meet the eligibility, or wanting to make an actual request when before they'd just inquired, because they didn't have a prognosis yet... People are seeing the TV images of intubated patients in induced comas, and that's the total opposite of what they've been planning for themselves. (Interviewee – AD&E service coordinator)

Many research participants¹⁰ identified changes over a period of months to the nature of requests and inquiries that were an evidently direct response to the COVID-19 virus and its impacts. In summary these were:

- More inquiries seeking information, specifically in the COVID-19 context, on eligibility, for example, the range of eligible 'terminal' conditions or what might constitute 'unbearable suffering', and/or the timing restrictions, such as wait times, assessor availability, other factors that might cause a delay (e.g. drug availability; a suitable venue)
- A higher level of anxiety among callers, resulting in additional first point of contact¹¹ work to clarify the legal AD requirements and reasons for non-eligibility
- Seekers with clearly non-eligible conditions wanting information about other options (e.g. providers in Switzerland who might accept short-notice applications from expatriates)
- Callers wanting broader information about the range of ways in which they could retain some degree of control over their death, if they did contract COVID-19, for example, information about ways in which they could decline medical treatment, nutrition and hydration, or admission to an intensive care unit or nursing home.

We've had a lot more inquiries from ALS patients who are terrified of how they could die with COVID...

During the lockdown, I saw a lot of people suddenly realising that [given a terminal prognosis of only months] they had nothing to look forward to, so they wanted to bring their assessments forward. There was a definite psychological effect of the lockdown. A lot of it [timing] is around family obligations like birthdays and anniversaries and so on, and once they couldn't be part of those, they had less to stay around for. (Interviewee - assessing doctor)

I'm spending a lot more time on the phone with people wanting to know about how to stay out of ICU if they get COVID. They don't necessarily want to have [a legal assisted death] – they want to know how to avoid being intubated and completely alone, knowing that they're going to die all by themselves with no one there. (Interviewee - AD&E advocacy information service)

¹⁰ 'Research participants' refers to the aggregation of survey respondents and interviewees.

¹¹ This term is used to refer to the agency personnel or practitioners who receive an initial request or inquiry.

No apparent change in rates of request/inquiry

Where there was no apparent change initially in request/inquiry rates, again multiple factors appeared to be involved. Some AD&E providers hypothesised variously that: any potential increases in inquiries would have been stymied by AD&E service disruption; people at large were simply too confused by the pandemic context to make any clear decisions; people delayed by being unable to obtain firm diagnoses or prognoses due to the contemporary unavailability of their specialist.

Depending on local circumstances and the interaction of these various factors, rates of AD&E inquiries fluctuated both across and within jurisdictions. For example, some US states saw either no change to inquiry rates or a significant decrease initially, then followed by a spike in inquiries as more information became available about COVID-19 deaths and the hugely increased burden on both hospital and hospice facilities. In another jurisdiction, the same pattern was attributed to seekers finally being able to make contact with their medical specialists, who had been previously unavailable, for a range of reasons (e.g. practitioner secondment to pandemic services, or having themselves contracted COVID-19; practice shut-down for safety reasons). Where legal AD&E was relatively new to a jurisdiction, and no 'usual' pattern of inquiries had yet been identified, comparison with previous years was interesting but not a valid indicator of change due to the pandemic.

Moreover, some providers were anticipating a significant increase in requests and inquiries if the spread of COVID-19 continued or worsened, and were concerned that their capacity, adequate for request rates hitherto, would be insufficient, especially if practitioners became unavailable for pandemic-related reasons. In at least two jurisdictions – one in the US and one in Europe – spikes in requests had been experienced by late October, which the providers identified as the result of people becoming aware, largely through media coverage, of the awful nature of a COVID-19 death and wanting to avoid that (see also p 7).

Access to AD&E was also seen by some research participants as related to eligibility, and the requirements for eligibility were also being reconsidered by some doctors. For example, some doctors were considering whether the anticipation of a COVID-19 death, once a person was seriously ill and on a ventilator, could in itself constitute sufficient evidence of 'unbearable suffering'¹² in jurisdictions where that is the main criterion for eligibility. Others were considering whether becoming infected with COVID-19 would constitute eligibility for a person with an existing terminal illness in terms of making a 6 month prognosis of death more likely. These considerations took into account that approval for an assisted death did not in any way promote the hastening of such a death, but rather that a seeker, having contracted COVID-19, would have that option if their condition required ICU admission.

¹² It is noteworthy that already [one German doctor has seen fit to provide euthanasia](#) to two apparently dying COVID-19 patients.

2. Has seeker access to AD&E changed?

Table 2 shows that, in the perception of most survey respondents, access to AD&E for seekers either became more difficult (47%) or didn't change significantly (37%).

Table 2: Pandemic impacts on access for seekers	
Easier	4%
More difficult	47%
No change in accessibility	37%
Don't know	13%

Where access had become more difficult, the main barriers identified were service disruptions, secondment of assessors to pandemic duties, and COVID-19 regulation restrictions (see further in the following sections).

However, according to interviewees, early constraints on seeker access had already begun to change by August, as the provider agencies and individual practitioners developed ways to meet with seekers electronically, initially by phone and then increasingly via videocommunication channels like Zoom, Skype, Facetime, or whatever telecommunications platform was mutually available. These channels were used even in jurisdictions where assessors were aware that use of such communications for AD&E were in fact illegal, with a risk of prosecution for using them (see p 16, and Tremblay-Huet et al, 2020¹³).

Moreover, as providers became more proficient and comfortable with telecommunications in the AD&E context, many began to acknowledge that there were advantages to this medium, as well as disadvantages. For example, eliminating travel requirements, for both seekers and providers, cut down on both costs and time spent in travelling, and on the stresses of travelling for people requiring oxygen tanks or with other conditions making travel unpleasant, or having to ask family members to take time off work to provide transport. As all parties became more confident with online mediums, some recognised the advantages of having shorter and more frequent interactions, resulting in less pressure on all parties to cover and combine all of the important emotional and logistical aspects in a single conversation.

By October, all of the provider agencies interviewed were managing with any fluctuations in request and inquiry rates, while noting that such fluctuations were not unusual in this service sector. However some providers anticipated further spikes or a gradual increase if the pandemic infection and death rates continued to increase, and were concerned that, in that circumstance, they might not have sufficient capacity to deal with all requests within the time frame sought by the seekers (see p 26).

¹³ Tremblay-Huet et al, [The Impact of the COVID-19 Pandemic on Medical Assistance in Dying in Canada and the Relationship of Public Health Laws to Private Understandings of the Legal Order](#), 11 December 2020.

3. Have practitioners been willing to continue providing AD&E services? Has anything prevented practitioners continuing service engagement?

Continuing willingness

In general, provider agencies and individual practitioners in all roles remained not only willing but committed to continuing service provision ‘as usual’ (see **Tables 3**). Major factors in the continuing accessibility of AD&E to seekers were the strong commitment of providers to ensure continuing access, as a moral and legal right, together with their willingness to be flexible and find creative ways to facilitate that access.

Table 3: Willingness to continue AD&E engagement	
Yes	73%
Yes, but differently	20%
No	3%
Not sure	4%

The only two survey respondents who were not willing to continue being engaged in the pandemic context had made that decision explicitly in order to protect their own and their families’ safety, due to their own or a family member’s compromised health status (see p 13). The interviews also identified support personnel who had withdrawn their engagement, or were considering doing so, as the perceived contagion risk increased.

Decreased involvement in MAID in hospital due to risk of exposure to covid 19 (age of provider >65 yrs).

I’m keeping going for now [September 2020], but I have my husband to think of, we’re both in the high-risk category. (Interviewee - long-term support personnel)

Continuing, ‘but differently’

Despite a strong willingness among providers to continue providing AD&E services in close to the usual manner, **Table 4** (following section) shows that around half (46%) identified barriers to doing so. Barriers to their engagement identified most commonly were invariably related to restrictions imposed externally and intended for the protection from COVID-19 of either health workers or the public, or both.

The most important difficulty in the first phase of the pandemic was that it seemed that the only concern was to avoid the contagion by the virus and that other items, for instance self-determination [e.g. AD&E] had no importance.

Provider commitment

A key factor in the continuance of AD&E service availability was that providers were strongly committed to achieving what they saw as an *essential* service,

ethically as well as legally, whether or not AD&E services were regulated as an ‘essential service’ by the local health sector. It was evident that provider agencies and practitioners were strongly committed to ensuring both that existing seekers were supported and new requests and inquiries were responded to effectively.

COVID-19 or not, I believe life as well as chosen death had to go on, people suffering deserved to be heard.

Self-determination doesn't depend on the situation.

Fortunately we have always been able to find a way to offset assisted dying within the Covid-19 restrictions.

NOTHING has prevented me from providing for our patients.

In summary, almost all providers were explicitly committed to ensuring that at least existing applicants and, ideally, new seekers received what the providers considered to be an essential and priority health right, but quickly recognised that the service approach had to adapt to pandemic restrictions. As the pandemic intensified, and continued throughout 2020, all interviewees acknowledged that the service protocols were necessarily changed. Those changes are detailed in the following sections.

4. What have been the main issues requiring changes to usual AD&E service provision?

The survey asked respondents whether anything had ‘prevented you from providing *usual* AD&E services in the COVID-19 pandemic context?’ (**Table 4**), and also ‘what have been the main changes, if any, to the usual provision of AD&E services?’. Barriers were identified early by nearly half of survey respondents.

Table 4: Has anything prevented practitioners providing usual AD&E services?	
Yes	46%
No	48%
Not sure	6%

The main changes reported by respondents across all roles were the factors set out in **Table 5**. It was evident that the main issues arose from a combination of the restrictions imposed by governments to prevent COVID-19 spreading and the need for AD&E practitioners to remain safe while remaining committed to providing AD&E services.

An overarching theme was the need to identify practice constraints as they emerged, quickly find solutions to those barriers, and develop strategy to both address and anticipate the ongoing impacts on service continuance. In this respect, like all health services, AD&E services needed to have strong strategy

and planning at governance/management level, to support frontline practitioners.

Table 5: Main short-term changes in providing AD services in the pandemic context	
Change to practice	% of respondents
Increased use of/transition to telemedicine	23%
COVID restrictions affecting AD&E administration & family attendance	17%
Hospitals making AD&E on site difficult or not possible	17%
COVID restrictions affecting AD&E access & assessments	14%
Need for flexibility	14%
Facilities' refusal to permit AD&E services on site	12%
Temporary service interruption	12%
Practitioner secondment to COVID-19 response	7%
Managing actual or perceived COVID risk to practitioners or seekers	7%

Managing actual or perceived COVID risk to practitioners or seekers

Although all practitioners were alert to the evident pandemic risks, few withdrew from providing AD&E services (see above, p 11) and the majority appeared to have continued in those roles, albeit in a modified approach, or limiting their roles.

It [AD&E] was possible, but as many of the professionals involved tried to protect themselves, they did not want to *see* the patients, so no prescription and no consulting.

I can't be so directly involved now because of my [COVID-related] age risk and my husband's, although I guess I could do the volunteer's [seeker and family support] job on the phone. But I have been training up new volunteers, and I think they're all going to be needed at this rate. (Long-term AD&E support worker)

Age and cancer makes me high risk so only doing virtual assessments, not doing procedure [administering medications].

However one agency had found by January 2021 that some of the volunteer support personnel were less available than previously, apparently due to having to care for sick relatives, placing a greater load on the remaining support workforce. Morale had also been affected in some agencies, with personnel not being able to have their normal monthly meetings in person, where people socialised and talked informally about their cases, to provide team support as well as dealing with business matters.

... there is definitely frustration with the volunteers not being able to see each other. They're trying to come up with a creative way to provide that human connection within our team, because Zoom meetings really are 'patchwork'. I compare it to the difference in actually walking into our clients' homes vs. meeting them through Zoom. Our team members normally enjoy the personal camaraderie, getting together before or after our monthly meeting, etc., so that is truly missing." (Interviewee - support coordinator)

Temporary service interruption

Ten survey respondents (11%) from three jurisdictions reported temporary AD service closures, typically where hospitals stopped providing services that they deemed non-essential compared with the more salient pressure on hospitals of the COVID-19 threat. In addition, many nursing homes closed their doors to all except their employees. Some AD&E services based in larger organisations closed the service at least temporarily to second practitioners to other duties, and several people also commented that many doctors had been seconded to the prioritised COVID-19 response, making them unavailable for AD&E work. Government delays or fluctuations in clarifying or announcing local restrictions lead to some health facilities freezing AD&E services indefinitely or making particular processes impossible.

Focus on primary work managing COVID. MAiD work is on the side and decreased due to Covid.

Lack of formal response from government to support necessary changes (ie formal statement on acceptability of virtual witnessing). Silence on the issue is not enough for some employers not to restrict practice.

In contrast, it appeared that the majority of respondents were able to continue to provide AD services to meet the needs of existing and new seekers.

COVID restrictions affecting AD access & assessments

Research participants identified a range of issues in undertaking AD&E assessments due to pandemic restrictions. A primary obstacle was not being able to meet with seekers in person, which had always been seen as essential for the establishment of mutual trust and confidence.

Difficulty doing in-person assessments and having family/friends present for provisions and assessments.

Difficulty in providing home visits - fear of Covid.

I've kept on going to their home, because that first contact sets the relationship, and there's so much emotion involved, and I can't feel OK about doing that even by Facetime, I just don't feel that it works, not for any of us. (Interviewee - doctor)

The COVID-19 restrictions against visiting others' homes, along with the prohibition of telemedicine for AD&E in some jurisdictions, made the decision to visit homes a moral/legal dilemma for these assessors.

Federal Legislation in place that suggests using Telehealth for [AD&E] discussions is illegal has not been addressed or changed during the pandemic.

Where doctors did continue to make home visits for assessments, having all parties wear masks resulted in various communications problems, in particular if seekers had hearing impairment, though the perceived issues were as often psychological as logistical.

Provisions with PPE are difficult and dehumanizing.

The [practitioners'] wearing of masks, not shaking hands with a patient, or touching them or their family in ways I usually would do - e.g. giving them a hug.

Masking has made it much harder for older patients to understand instructions and also to feel connected and comfortable.

We must wear masks for in person patient care which sometimes makes it challenging to connect with patients who have hearing impairment.

In particular, providers had had to find creative but still legal ways to meet the witnessing requirements in their jurisdiction, given the very broad constraints on home visits and personal contacts. AD&E providers commonly "relaxed" the witnessing provisions to allow for witnessing by videocommunications. However doing so often complicated and extended the witnessing process, for example, where witnesses could not be present at the same time or were unfamiliar with the videocommunications technology, or where the local regulations designated only certain categories of people as witnesses and they could not be available for reasons related to the pandemic restrictions.

... it is more difficult to get independent witnesses to [home-based] patients signed request for MaiD, but just as easy to organize MAiD if they are in hospital.

Local Death with Dignity volunteers are not allowed to assist in witnessing signature of requesting patients which can be a challenging issue for those who wish discretion.

Increased use of videoconferencing including virtual witnessing of written request forms.

Apart from the requirement for masks making these sensitive communications and assessments more challenging, in general providers found wearing PPE to be a minor annoyance rather than any significant hindrance to their engagement, and the only issue was having to purchase and pay for it themselves if they were not now providing the AD&E service through a hospital.

Some of the constraints respect to being masked or wearing gloves are mildly burdensome but the need remains and it is been possible to meet that need.

We just carry on. Appropriate PPE is always used.

Flexibility and nimbleness

Many research participants identified a personal and/or agency willingness to be 'flexible' as essential to service continuity, in relation to both the accessibility of the service and adherence to the procedural requirements, which were seen as having been developed in a context that assumed regular service provision and had not envisaged a lockdown situation or population-wide safety risk. Providers worked to develop different ways to provide the usual services, within the varying COVID-19 lockdown restrictions. Doing so often involved considering best options within a range of possible responses, consulting with team members and related organisations, and then trialling some new approaches to see what was feasible within the restrictions. Flexibility and creativity were identified as key principles.

I work with a flexible group of providers. We have continued despite the challenges.

Our system has been nimble and managed to keep service open.

Our policy is to not do home visits during the Covid pandemic, so I respect that, but I am educating, reviewing, empowering and assisting by phone or other telehealth methods.

In difficult situations, sometimes you have to 'muddle through' as best you can, so we're 'muddling' pretty well, all things considered. (Interviewee - doctor)

'Flexibility' included the conscious willingness and decisions by practitioners to ignore either the pandemic regulations in their jurisdiction or the strict AD&E requirements, or both, where they believed doing so was both the 'greater good' and sufficiently safe in the particular context. Common actions included continuing to make home visits, where doing so made the eligibility assessment much less stressful for seekers and families, accepting virtual witnessing, and agreeing to more than one family member attending a death. Some practitioners noted that they did not, in any event, have any authority to enforce pandemic regulations.

Bugger the rules. I weighed up the risks of anyone becoming infected with the right of the patient to have this death, and I judged the [COVID] risk sufficiently small and the job [providing an assisted death] sufficiently important that the balance was in favour of doing what would best serve a dying patient. We have the law, people should be able to use it, and no one was at any significant risk... (Interviewee - doctor)

Tremblay-Huet et al (2020) have also described a range of strategies used by Canadian doctors and nurse practitioners during the pandemic that breached either COVID-19 regulations or the Canadian (federal) MAiD legislation, noting that these practitioners did so after considering all of the ethical as well as legal implications and opting to follow their perceived medico/ethical obligations. The practitioners they interviewed had employed a “variety of [rule-breaking] techniques ... either to minimize, rationalize, justify or excuse deviations from the relevant public health rules” (p 3). The authors also noted that the “rapidly changing landscape of applicable rules, either through new rules or through upgrading recommendations to mandatory law, caused confusion among certain segments of the population” (p 7), requiring AD&E providers to quickly adjust their approach, and what they considered justifiable, to ensure that seekers were not denied access to an assisted death where that could be provided safely for all parties. Their interviewees, like ours, made meticulously considered decisions, together with colleagues, weighing up the core ethical principles of beneficence, non-maleficence, non-abandonment and justice alongside compliance with the often fluctuating pandemic regulations, and determined that they were not ethically able to add “another layer of tragedy” to the death of an already dying person. One doctor interviewed in our study noted that he felt protected by the Canadian Medical Protective Association’s (CMPA) online advice, and that he would be seen as acting as a ‘reasonably competent practitioner’ in these circumstances. Several doctors and volunteer witnesses noted that staff in nursing homes and hospices had in general been willing to apply compassion in situations where the number of people who needed to be present exceeded the pandemic regulations.

They’ve [facility staff] mostly been kind, they know we’re going to take real care [social distancing], and even where we weren’t all allowed in at once, they’d find another way, like letting us wait on the balcony outside the room and go in one at a time... (Interviewee - AD&E volunteer witness)

In some instances, the agency first point of contact to AD&E inquiries took proactive measures to address what they identified as likely barriers to seeker access, convening conversations with agency colleagues and, where necessary, politicians or others with relevant authority, to discuss ways in which flexibility could be built into services as, at least, an interim measure. Common examples of these intra- and interagency discussions occurred where, variously: the local AD&E legislation ostensibly prevented use of telemedicine; hospitals and other facilities declined to continue providing usual AD&E services; some key assessors became unavailable due to secondment to pandemic tasks; it was apparent that assessor capacity might become a problem in the future.

Many providers began to think more laterally about ways they could resolve these barriers, using whatever options they could identify to continue AD&E services. Often these actions then led people to review their usual ADE practice up till now and think about ways in which services could be improved in future (see further discussion p 26ff).

In the end, I contacted the state governor and asked for an amnesty [for use of telemedicine during government-imposed lockdown] for people who'd been assessed [prior to the lockdown] and now needed to have their drugs administered. It wasn't safe to leave them to their own devices in that situation, anything could have gone wrong, we had to have some way to talk the family through a safe process... (Interviewee - AD&E provider agency first point of contact)

At the same time, providers were making personal decisions, in consultation with their families, about how they could continue to provide AD&E services safely. The risks to the providers themselves and their families also had to be fully considered. For some practitioners, this meant either cutting down on or reorienting their AD&E involvement.

Demand and access have remained constant, but the work required to ensure access has greatly increased. Requires creative solutions to access patients with covid restrictions.

Have had increased time constraints from my job as a hospital internal medicine practitioner.

Other COVID responsibilities have taken up most of my time so I am less available for seeing patients.

Limited access to home care (for IV placement) and hospital services for 2-3 months. As our number of requests also fell dramatically (temporarily), the overall impact ended up being minimal.

Our intake person has obviously been on the ball, checking who's available, whose cases are taking more time... (Interviewee - doctor)

All of these actions above impacted on workload, at least initially. However the overall workload for practitioners generally remained stable, either because of pandemic impacts that counter-balanced each other, or because the AD&E intake personnel managed allocation to spread the workload, noting the potential for changes in pandemic regulations and fluctuations to affect inquiries, applications and assessments. The net outcome of having to be flexible, for many practitioners, was an improvement to both seekers' ease of access and practitioners' sense of efficacy in their AD&E roles.

There is much more flexibility in performing telehealth assessments and also using witnesses remotely for the initial paperwork the patient must complete. This has made things a little easier for patients to access our services.

We are performing the witnessing requirement virtually, but this has not been a barrier, rather it has been an improvement [as] strangers don't need to actually attend the patient's home.

Increased use of/transition to telemedicine

The change to practice reported most commonly was the transition to virtual communications in place of face-to-face contact for all stages of AD&E provision. It was mentioned by nearly one quarter of survey respondents (22%) and implied in the responses of many others, and all interviewees commented on it. While some practitioners continued to make home visits, most did not, making telemedicine essential. This occurred even where using telemedicine was, strictly speaking, illegal.

Many found the telemedicine approach initially a major challenge, both practically and emotionally. In some instances this was in part due to their unfamiliarity with the various virtual communications platforms and systems; more often it reflected an emotional/professional issue, where providers felt that the virtual mediums prevented good body language recognition and the physical contact that was common to the assessment and other encounters that make up the AD&E approval and administration process. For some, there was a sense that they were less able to provide a compassionate or otherwise adequate service to the seeker and their family. Some practitioners experienced this as a significant moral/professional compromise.

Virtual assessments are not as rewarding.

It's exhausting. At that first contact there's a lot you need to cover, and they're [seeker] always really emotional, and there's a lot of information that has to be explained, sometimes repeatedly. So not being in the same room, and not being able to see everyone at once, or give their hand a squeeze to show you understand, all of that has to be converted into words, and more words... and then all the things that go with the computer and the [computer] camera and whatever... So it takes a lot longer and I come away feeling like I didn't get my messages across very well and I may have missed something important. So I generally call them back by phone the next day, to see if they're OK. (Interviewee - long-term support person Europe)

Others commented on the increased difficulty of making the tacit "intuitive" assessment of the family's attitudes, or any indications of possible coercion, that they would normally have made by scanning the faces and conduct of family members in the room, as well as the seeker. Two doctors commented on increased difficulty in determining the level of the seeker's unbearable suffering, when only the eyes were visible. Similar difficulty occurred in distinguishing the stresses being experienced by people in the anticipation of contracting the virus from the suffering related to their other conditions.

This way [Facetime] you can't see if do they have religious crosses on their walls, or is anyone in the room looking really stern ... and I can't feel their handshake or pick up on all the non-verbal stuff that I usually rely on... (Doctor interviewed)

It's just a lot more business-like, and that doesn't feel right. I can't say 'oh who made that beautiful quilt?' or give them a hug ... (Interviewee - long-term support person US)

In some instances, because family presence was also limited to small numbers, consulting with family required multiple virtual contacts, taking time and patience. In many instances, seekers experienced difficulties manipulating the virtual mediums, and some simply didn't have access to them at all.

Both assessors and support personnel highlighted the significant extra time needed with telecommunications in order to coach seekers and family support people in how to administer the lethal medication effectively, noting that, because that task is highly emotional, as well as involving technical expertise, sometimes the conversations providing that information needed to be repeated several times.

It's been quite difficult to get in touch with the caretakers of patients during this period which makes it virtually impossible to give assistance or help.

Patients or family members without access to virtual tools.

When you can't see everyone in the room, it's a bit tricky asking them to focus the computer camera on each one, without it seeming that you're sort of interfering in the family dynamic. (Interviewee - doctor)

Sometimes I have to talk them [family] through the process four or five times, because they're anxious, which is natural – they're terrified they'll get it wrong, which would be just awful for everyone. It's a huge responsibility, so I'm more than happy to keep talking them through it, and I make sure I'm on the phone with them when they do it [administer the medications], but for sure it's way more time and effort than turning up on the day to just be there beside them. (Interviewee - long-term support personnel US)

There's just a whole lot more handholding that's needed if you're not there in person. People get confused, and they call you back, which is fine, but it's complex, and there's a bunch of new communications skills that we've all had to learn. It also means being on call a bit more... (Interviewee - doctor)

One notable exception to this pattern was a doctor who, due to living on an island, had been providing all AD assessment services by telecommunications for several years. This doctor became an excellent resource for others during the pandemic, having already discovered all of the issues related to virtual communications in AD services and developed highly effective strategies and techniques for addressing those.¹⁴

Very little has changed in my practice, as I have been using telemedicine to meet with patients for the last 6 years.

In addition, some providers found significant advantages to telemedicine, once they had developed ways to address their initial shyness or reluctance with that medium.

¹⁴ This doctor is willing to be contacted by others through the authors of this report; email pam.oliver.waiheke@gmail.com

Assessments are now done by virtual meetings such as Face Time rather than seeing the patient in person. That is actually offered some advantages in terms of access to patients and reduce burden of travel, but I do miss the non-verbal cues in face-to-face discussion.

Improving AD&E information content and access

As an early response where increasing numbers of inquiries and requests occurred, many AD&E providers began increasing and/or revising the written information available to the public through their websites and/or available to active clients. Some agencies revised their website information about eligibility, access processes and timing, including caveats relating to the COVID-19 context.

Practitioners also began expanding or otherwise revising the written guidelines and instructions for seekers and their families or support people, in particular instructions around administration of the lethal medications, as well as how to prepare both practically and emotionally for being active participants in an assisted death. Some practitioners found that revising these guidelines and instructions also helped them to consider ways that those processes could be improved and made both easier and more empowering for seekers and family members, giving them more control over the processes, while at the same time ensuring safe processes. Providing these “tools” for clients helped practitioners feel less like they were abandoning those clients, and at the same time lessening reliance on the practitioners gave increased control to seekers and family over the death process.

COVID restrictions affecting AD&E administration & family attendance

The main issues affecting the administration of an assisted death were caused by the COVID-19 restrictions limiting personal proximity, in particular restrictions by hospitals on the number of visitors a person in hospital could have at any one time, and the broader restrictions on visits to other people’s dwellings, affecting doctors’ and others’ ability to be present at an assisted death.

I [doctor] cannot be with patient when they take the lethal meds.

Our patients suffer so much more because they cannot see their loved ones [at the assisted death].

Only 5 people allowed at a provision - which includes the patient, me, one nurse - so only 2 family members! This limit on supportive persons is very distressing to me, patients and families.

Some practitioners responded to these restrictions by explaining to seekers that administration at home, including potentially self-administration to meet COVID-19 restrictions, would allow them to have their family present, and offered a drug administration regimen to suit.

I have been offering more oral MAiD.

Just as easy for me in the community as I start my own IVs. More difficult at the hospital because of isolation.

As discussed earlier, practitioners made individual decisions as to whether they felt permitted or safe to make home visits and attend deaths, often irrespective of actual government requirements in their respective jurisdictions.

In principle we're not supposed to do home visits, but I weigh that up against the [medical ethics] principle of not abandoning patients, and it'd be negligent, and dangerous, to let them [patient and/or family] try to manage the meds without someone there. I keep on checking in with my wife every week, and so far we're OK that there's minimal risk to us, and I wouldn't do it [visit] if the families objected. (Interviewee - doctor)

An additional issue where family or other supporters administered the drugs without a doctor or agency support person present was recording and certifying the death, which in many jurisdictions is commonly done by the AD&E provider personnel. Providers recognised that it was stressful for a bereaved person to record and report those details, even assuming that they could learn how to do so; as a result, some such data had simply not been recorded from family-administered deaths.

Facility requirements making AD on site difficult or not possible

In many instances, hospitals and nursing homes had introduced ostensibly COVID-related regulations that effectively prevented AD&E practitioners and/or family from entering the facility, so that seekers had to leave hospitals for either their home or another venue in order to have an assisted death.

Bringing seniors home from facilities on lockdown [rest homes] so that family members can be present.

They [seekers] have fewer choices because they cannot get the same palliative care services or be transferred to their preferred location.

I feel that those inquiring may be more likely to have MAiD in the community vs in hospital given the visitor restrictions.

In some instances these access issues appeared to be a significant impediment to providing a stress-free assisted death; in other cases they were experienced as "minor". The difference in level of difficulty may have been a function of the hospital context on a particular day, depending on factors such as COVID-related admissions, the current government-mandated requirements, and the fear levels of individual practitioners.

Some regions have stopped in-hospital provision of care, others have not.

Our hospital's AD&E service was stopped as many of our members were redeployed for COVID-19 duties (myself included, as an ICU physician). AD&E could still happen but the organizational supports were removed. Now reinstated.

It is harder to get a patient admitted to hospital to provide MAiD there if preferred.

More difficult to get patients transferred and into hospital for MAID.

Minor restriction for admit same day to hospital for assisted death. So, has been somewhat more difficult but each case is individually considered. This applies only to COVID policy. Usually, no restrictions.

[Fluctuating] access to PPE; hospitals closing down to AD&E as non-essential, then opening to allow AD&E [but] without any family members present, which honours our responsibility to the patient but is cruel to those they leave behind.

In contrast, in some jurisdictions hospital authorities moved to declare AD&E an essential service, avoiding the access barriers.

My region is supportive of MAID as an essential service, providing PPE and same infrastructure supports as always. This is not universal experience across country.

Our hospital has deemed access to AD&E services an essential service.

Systematic review and evaluation of 'usual' AD&E practice

A key outcome of experiencing the above issues, across jurisdictions, was that providers, individually and collectively, were now consciously reviewing the effectiveness of their previous usual practices and considering improvements to those variously at the level of government or agency policy, individual discretion, or changes to the legislation itself. This review, initially in response to specific problems arising from the pandemic, developed into a more generalised review as practitioners began to realise that the problems all reflected some underlying shortcoming in the laws, regulations, policy, or accepted common practice. This reaction ran parallel to the widely reported evaluation by people across nations of their values and habits¹⁵, and whether the pandemic could be seen as a unique opportunity to make valuable change¹⁶. Areas where changes to AD&E practice were identified as needed across jurisdictions are summarised in the following section.

¹⁵ See '[A systemic resilience approach to dealing with Covid-19 and future shocks](#)', OECD, October 2020.

¹⁶ See '[Lessons from the pandemic](#)', New Internationalist, 3 September 2020.

D. Lessons from the pandemic experience - What adjustments are needed for the current ongoing pandemic and future national crises?

The survey and interviews asked ‘How do you think AD&E services are likely to be affected over time in your country/state, as the COVID-19 pandemic plays out?’ and ‘How will legal AD&E services need to be adjusted to ensure continuing service provision in the context of a national or global crisis?’. Research participants’ comments on these questions focused mainly on three key themes:

- Responding to a predicted likelihood of increased demand
- Ensuring service continuity, through commitment, flexibility, nimbleness, and developing provider capacity
- Changes needed to AD&E policy, regulation and laws.

Lots of policies changed to allow access, and were seen as sage and effective. I hope those practices will remain post the pandemic.

The COVID-19 pandemic experience has provided an opportunity for valuable lessons to be gained for providing legal AD&E in a health sector crisis. Lessons gained at this point are valuable not only for existing AD&E service providers, but also for the jurisdictions where assisted dying legislation is being introduced. For example, already Tasmania in Australia is proposing revisions to its draft legislation that take into account the pandemic experience.¹⁷

1. Managing potential increased demand

Managing increased demand has already been addressed in some jurisdictions where AD&E was well established, since gradual increase was anticipated as both seekers and providers became accustomed to its availability. For example, in The Netherlands, the SCEN organisation and NVVE systematically recruited and trained doctors, nurses and support people for expected gradual increases in assisted dying once that option became normalised in Netherlands society.

However the specific lethal impacts of COVID-19 have added a further layer to the potential for increased interest in and requests for AD&E. While it was difficult for interviewees to identify any clear trends in actual AD&E applications (as distinct from eligibility inquiries), due to historical fluctuations in request rates that could not easily be attributed to factors other than a common pre-Christmas lull, nonetheless many research participants predicted potentially significant increases in inquiries and requests as the time frame and lethal impacts of the pandemic both extended, and some intake personnel had identified increased levels of interest in AD&E generally. One intake coordinator interviewed noted that the sudden unavailability of cancer treatments due to the pandemic had prompted some additional inquiries about AD&E availability and timing.

¹⁷ See [‘Consideration of voluntary assisted dying legislation to be continued in 2021’](#), Tasmanian Government, 4 December 2020.

Perhaps some increase [in demand], because of patients who didn't recover well from Covid-19 and will probably ask for AD&E.

I believe the slight decrease in requests for euthanasia / information is temporary. There was a slow-down in April but requests picked up in May.

Increased demand might mean more delays in access due to limited number of doctors eligible to be assessors and/or providers.

People are choosing to die sooner because of loss of social connection and loneliness, as well as loss of means of financial support (e.g. stock dividends, investment savings).

Publicity associated with increased [AD&E] applications will help with public education about [AD&E] availability.

The most obvious change has been people's level of anxiety, about how COVID could affect either whether they're eligible or whether the pandemic's going to make it more difficult for them, like being able to see a doctor, or having to deal with Police checks if they want to travel to a clinic. Some older people can find that really stressful and intimidating, or even having to use telehealth... So there've just been a lot more [inquiries] about those aspects. (Interviewee - AD&E provider first point of contact)

In some jurisdictions, providers were also contemplating the longer-term impacts of COVID-19 on AD&E service provision. Several survey respondents commented on those impacts as “an unknown”, or “too soon to tell”, especially since the infection numbers and rates are still increasing in some jurisdictions, and more is being learned about the debilitating long-term impacts of the disease itself. As more research information is becoming available on the longer-term health effects of contracting COVID-19, a condition has been identified - called, variously, 'long COVID', 'post-COVID syndrome', or 'post-acute COVID-19 syndrome' - as affecting substantial percentages of COVID-19 survivors with ongoing disabling health conditions requiring long-term treatment or rehabilitation.

In The Netherlands, where the eligibility criterion for legal AD&E does not require a terminal medical condition, but rather a demonstration of “unbearable suffering”, the key agencies are now considering the potential impacts of significant numbers of COVID-19 survivors who may, over the next months and years, seek legal euthanasia on the grounds that their ongoing illness, together with pre-existing comorbidities, constitutes unbearable suffering. Accordingly, those agencies are anticipating an increased demand for their services, along with a need the Netherlands' Regional Euthanasia Review Committees to review current policy urgently.

There was a concern that such increases would require additional capacity in AD&E services that had not been planned for. Moreover, there was a corollary

concern that practitioners might become overloaded, or diverted to pandemic duties, while new recruitment would be less likely to occur in the current context.

2. Ensuring service continuity

Building provider capacity

An key issue identified by the end of 2020 was an emerging lack of AD&E practitioner capacity in some places where AD&E demand had increased while at the same time doctors and nurses were being required increasingly for pandemic services. Even though practitioners were adapting to different ways of providing AD&E services, some were becoming less available for this work, and training new AD&E personnel was not yet occurring. Provider agencies recognised ensuring future capacity and capability in all AD&E practitioner roles as an urgent priority.

More doctors and nurse practitioners need to support this program.

Ensure that there is always at least one provider available, perhaps on a rotating schedule.

I [coordinator] have to be sure we have enough healthy providers and accept the infection control constraints.

More trained doctors - better spread of doctors across the country.

Need to find more assessors - ensure we have appropriate medication to expand on oral medication - teaching for providers.

However, several interviewees noted that the pandemic context was not conducive to recruiting new personnel – either assessors or support people. Moreover, in several jurisdictions, a majority of the medical AD&E workforce comprised retired doctors over the age of 65, who were thus in a higher COVID risk category than younger practitioners.

Right now we're [US citizens] all far too scared for doctors to be thinking about challenging themselves and picking up training in this area [assisted dying work] ... (Interviewee - assessor trainer)

Everyone's flat tack just trying to keep up with the randomness of the virus and how it's affecting medical practice ... (Interviewee - assessing doctor)

Several research participants commented that the crucial role of nurses in providing AD&E within hospitals and other facilities such as hospices and nursing homes had become evident through the pandemic, where only existing employees were admitted to those facilities.

Flexibility and nimbleness

Research participants identified a likely continuing need for flexibility and willingness among AD&E providers and practitioners to meet the novel challenges of both the current pandemic and any future national crises that affect health services. By virtue of the nature of AD&E service provision, these providers have always been responsive to challenges in the social, political and health environments, and the 2020 experience has prepared them even further to anticipate potential problems.

On a case by case basis, physicians, social workers, hospice services will need to be nimble and flexible in finding ways to provide services.

Remembering importance of end of life goals of care - some of this put aside during the crisis.

It's [pandemic] been a huge learning experience, mainly because COVID itself is so sneaky, so we've had to do a lot of thinking and planning for a wide range of possible impacts for us. (Interviewee - AD&E service director)

Ensuring medication supply

Another key issue was a sufficient continuous supply of essential medications, in particular oral medications if self-administration were to become more widespread in lockdown situations, or where pentobarbital has had to be replaced by sometimes complex combinations of drugs. Achieving continuity will require strong effective relationships and communications between AD&E providers and their respective drug purchasing authorities.

There are drug shortages, but thus far we have not had to go without.

I think medication options may need to be explored if shortages of medications become significant.

Conservation and reuse of unused MAiD medications.

Access to oral assisted dying medications.

Awareness of medication supplies and knowledge of alternatives so there will always be appropriate medications for MAiD.

Potential drug shortages, less in person connections.

Ensuring AD&E access

Across jurisdictions, there has been a strong commitment by the provider agencies and individual practitioners alike to ensure continuing AD&E access to eligible seekers. This commitment was clearly based on the same ethical principles that drove the campaigns to legalise AD&E.

Principles are rules for every times, not only for soft ones.

I keep on going with all my tasks as I believe COVID is only one of many health issues and we should not let everything (and everyone) else suffer.

Even where AD&E is not legal locally, there have been some measures to ensure that seekers are not disadvantaged by COVID-19 restrictions. In the United Kingdom, the Secretary of State for Health and Social Care clarified in a public statement in early November, as the United Kingdom (UK) went into another strict lockdown, that [people travelling abroad for the purpose of assisted dying would not be breaking coronavirus travel rules](#), but that seeking an assisted death abroad counted as a reasonable excuse from the lockdown rules.

3. Changes needed to AD&E policy, regulation and laws

A major finding of this research was that agencies and individual practitioners alike had been forced by the situation to make nimble adjustments to their usual AD&E practice, which in turn had led them to question the general suitability of existing practices. Many research participants believed that significant revisions were now needed to their respective laws and regulations, and/or to policy, to ensure that the legally mandated entitlement to AD&E, for *prima facie* eligible seekers, was supported sufficiently by the legislation.

Changes to the legislation

Many research participants highlighted the need for urgent review of the laws themselves, to identify provisions that had been identified as barriers emerging from COVID-19 - as both a viral disease with rapid and hideous lethal effects, and a pandemic context requiring radical and far-reaching restrictions in health practice - that together had obstructed the intended purposes of the AD&E legislation. Particular areas where law changes were seen as vital were in relation to logistics, such as the legal use of telemedicine and the need for the role of nurses to be expanded and legislated, but also in some fundamentals of the laws, including eligibility, universality of access across government-funded health facilities, stronger requirements for mandated referral of AD&E requests, and permitting AD&E by advance directive.

I am hopeful that this will lead to more flexibility in future laws, such as shortening the required waiting period in some circumstances.

Broaden the enforceability of advance directives; require only [an] unacceptable or intolerable condition, not terminal diagnosis.

We must be able to access Telehealth [legally], and the requirement for one assessor to be a Specialist should be reviewed.

It needs to be easier to access our law, not made more difficult. We need a shorter waiting period. Patients know what they want.

Probably, if an important EU will legalise AD&E (maybe Spain is a good candidate) the EU parliament has to take the discussion and decide wisely.¹⁸

The research participants were clear that AD&E legislation, regulations and policy would now need thorough revision to make the stated intent of those laws able to be implemented in a national or regional health crisis. Tremblay-Huet and her colleagues aptly note that “Governing well during the COVID-19 pandemic means adopting—and over time adjusting—the measures that research, experience and wise political judgement commend. Being realistic about the kinds of choices people must make in these circumstances can help to ensure greater transparency, accountability and effectiveness when developing rules that promote the public interest in limiting the spread of the virus”. Those lessons may help to avoid the kinds of desperate measures resorted to by deeply distressed medical staff at Memorial Hospital during Hurricane Katrina.¹⁹ Along these lines, End of Life Choices in Washington State (US) have collaborated with legislators to [introduce a Bill proposing amendments](#) to several aspects of their Act that presented barriers to access, often exacerbated in the pandemic.

Developing, normalising and legalising telemedicine for AD&E

There was a clear consensus across research participants that making telemedicine the usual practice was not only essential in the short term but desirable and entirely feasible as a permanent option. Some practitioners in both the United States (US) and Canada had been using telemedicine approaches for some years, with refined and highly effective protocols that seekers and families apparently found acceptable. Others had begun to develop new protocols and systems for effective telemedicine approaches and were adapting to those, recognising some advantages. Where it was not clear that telehealth approaches were legal in relation to AD&E services, practitioners saw legalisation as an urgent priority.

Remove barriers for patients to sign forms, allow for virtual assessments for all assessors, ensure medication alternatives are available due to primary medication shortage.

Anyone who did not provide visits via tele or video health needs to be adapting to these new options for providing care. Allow virtual care wherever possible. Encourage participation of family by teleconferencing services.

More reliance on virtual assessments. Novel methods for documentation including witnessing consent.

Hopefully awareness of the risk at which we are being placed, through not being able to use Telehealth, will be addressed and we will be able to assess cases remotely.

Hopeful to allow more virtual care even after pandemic eases... current allowances have been very helpful (virtual assessments, virtual witnessing).

¹⁸ Note that in December 2020 the [Spanish Congress \(lower house in parliament\) passed an assisted dying law](#), and a [higher court ruling in Austria has made AD legal there from 2021](#).

¹⁹ Sheri Fink (2013) [Five Days at Memorial](#), Crown Publishing.

Witnessing regulations

Reducing what were now seen by many practitioners as over-stringent requirements for witnessing of a seeker's request was identified as a priority, and "common sense". Many research participants had identified the witnessing requirements in their jurisdictions as excessive and problematic even before the pandemic created further difficulties. Examples were: broadening the categories of who could be a designated witness (e.g. nurses; hospice staff); requiring only one witness rather than two; allowing witnesses to witness at different times, not simultaneously; and allowing for witnessing via telecommunications (as has now become common practice internationally for other legal transactions such as conveyancing). Practitioners needed the security of written and approved protocols for this process by telecommunications, so that they were not at risk of being charged with a criminal offence under their legislation.

I hope that some of the positive changes will continue during/after the pandemic. For instance, assisted dying applications can be witnessed over Skype. It would be great if that option is available after COVID especially for people in remote areas.

More virtual assessments will likely continue. Will probably see all jurisdictions across Canada accept virtual witnesses.

I would love to see the witness requirement be less onerous (only 1 witness). That was going to be a big barrier - how can we get two witnesses to witness remotely? We have very very few volunteer witnesses.

Most importantly, in person witnessing of patients signature of desire to undergo MAiD should be lifted.

I am expecting the requirement of 2 independent witnesses to the signed request for MAiD to be relaxed substantially.

Facilitating self-administration

A common wish was for greater availability of self-administered AD&E, now that the recent experience had demonstrated that, with appropriate practitioner support, seekers and families were well able to implement that approach. While both the research²⁰ and anecdotal experience had suggested previously that both seekers and doctors preferred intravenous line or injection of the drugs, to minimise administration issues, those options presupposed the ability of the doctor to attend the death.

May see more oral self-administered MAiD than we are seeing now.

Canada has to embrace oral MAiD and more virtual presence at provisions.

More flexibility for patients and their families at the end of life.

I think family members should be allowed to say goodbye. For the benefit of all involved.

²⁰ E.g. see Gamondi et al. (2014); Oliver (2016).

We all need to look to potentiating oral provision of MAiD in the COVID-19 context.

Requirement for health and aged care facilities to permit AD&E on site

AD&E providers were deeply concerned at the stresses they had observed for dying people who had already been approved for an assisted death pre-pandemic, and who then had to leave the comfort of a hospital or nursing home bed in order to have that death. They viewed such transfers as both unnecessary and inhumane to a dying person who had a reasonable expectation of dying in hospital with minimal stress to family. Interviewees knew of at least two instances where seekers who no longer had their own home had died in a motel rather than put their family at potential risk by going to family homes to have the assisted death. There was a call for all health and aged care facilities to be required to have an appropriate space, away from other patients, where AD&E could be provided compassionately.

... require faith-based [facilities] to allow it so don't have to transfer.

[Need to] help health care institutes understand that with adequate PPE for patients health care workers and families we can provide a humanist approach to medicine.

Need safe places for people (those who need, and don't have family/community) to receive care so they can make informed decision about AD&E. Many now die alone (with AD) and not always by choice because there's no option of volunteer.

Hospitals [need] to have a better plan for assisted dying during pandemic (inpatient and outpatient policies).

There will probably be more home provisions, as our hospital is reluctant to admit patients purely for MAiD.

Expanding eligibility

As mentioned earlier, many research participants had been considering the implications of the highly lethal nature of COVID-19, and the particular progression of the illness for people with some pre-existing conditions, in terms of the legal eligibility criteria and conditions. Many expressed a growing intolerance of the current eligibility limitations in their AD&E laws. For example, depending on the specific legal requirements and exclusions in each law, people suggested variously that: the term 'reasonably foreseeable' was no longer an appropriate criterion; advanced COVID-19 with a likelihood of death should be considered both 'unbearable suffering' and a 'terminal illness with a likelihood of death within 6 months'; that a 15-day waiting period was no longer reasonable (and in fact never had been either reasonable or necessary); and that AD&E should be available by advance directive specifying a positive diagnosis of COVID-19 together with intubation.

The legal definition of Medical Assistance in Dying will continue to expand as more Canadians challenge the government for freedom to choose how and when they wish to die.

I believe the 'Reasonably Foreseeable Natural Death' criteria will be removed in 2021.²¹

I think it is too early to have a reliable picture of the chronic sequels of COVID 19 disease. If they are severe and reliably predictable, patients requesting assisted dying may become eligible.

Pretty sure that 'palliative sedation' has peaked...

Making AD&E an essential service

Many research participants wanted AD&E in their jurisdictions to be formally made an 'essential service', so that continuity would be ensured in a national or regional crisis. This move would also mean that facilities would not have the option to treat AD&E as an optional service to be de-prioritised in crisis situations.

Ensure that this vital service is not interrupted again so patient and families suffer. It should not be just the decision of one person to put things on hold without consultation with everyone involved including the patients.

It's not 'our' service, it's the reality you're faced with. For example patients (especially the elderly staying in homes) who are not allowed to come to a consultation, or the consultations we were obliged to cancel because of the restrictions.

Some staff were re-allocated making it difficult to provide service. Again, if AD&E was considered essential, work would not have been impeded.

I think this needs to be regarded as an essential service and maintained as such, Covid or no Covid this is a needed service. With precautions it is very do-able.

... make MAID an essential service so access cannot be interrupted.

Appropriate payment for professional services

While not the major concern of survey respondents, nonetheless several identified revisions needed to payment for AD&E services, especially since telemedicine had become, for many, the only safe and legal way to provide these services, but telemedicine did not attract remuneration. Practitioners needed to be recompensed for PPE or able to obtain it free of charge, and payment for AD&E services needed to be available for all professions authorised to provide those services. One person also noted that loss of employment due to the pandemic might result in some families no longer being able to afford AD&E.

²¹ Note that an amendment to the Canadian legislation to repeal the 'reasonably foreseeable natural death' eligibility criterion [passed the second reading](#) on 17 December 2020.

There may well be other as yet unrecognised financial impacts on AD&E accessibility, such as paying for a safe venue for an assisted death.

Compensation models to support more virtual care; access to PPE; access to LTC and retirement homes in outbreak.

Again, I believe that more virtual assessments and virtual witnesses will be authorized/paid.

Payment for nurse practitioners [as well as doctors].

This [AD&E provision via telemedicine] usually requires more of a doctor's time and is not currently reflected in their reimbursement structure.

Remuneration is an issue since my team essentially is unpaid given MAiD is not their primary work.

...insurance is also issue if family members [are] losing their jobs.

E. Applying the pandemic lessons

As best can be determined from the AD&E provider organisations and practitioners, people seeking an assisted death in the time of COVID have continued to receive services in the highly dynamic context of the pandemic. AD&E providers, like all health services, are making committed attempts to continue to provide what they see as an essential service through a time of continuing unpredictability.

The survey data revealed a complex pattern of pandemic impacts, varying not only across jurisdictions but also within them, and changing week by week as governments struggled to find ways to control viral spread, and AD&E providers found ways to continue providing their services within those changing restrictions. The changes required to continue providing services have highlighted the myriad and complexly interconnected macro- and micro-level factors that affect AD&E decision-making (Oliver, 2016, and see Appendix 4). In a sense, many of the people involved in providing AD&E services had been well practised in finding creative ways to address the chronic barriers to providing legal AD&E, based on their earlier and ongoing experiences of driving changes in end-of-life laws.

The pandemic experience has highlighted flaws in the AD&E laws, which were generally designed to include multiple 'safeguards' against potential abuse, where in practice those requirements impede rather than facilitate seeker access. In this sense, 2020 became an opportunity for providers to identify those issues and develop pragmatic solutions to address them. AD&E agencies and individual practitioners alike had been forced by the situation to make nimble adjustments to their usual AD&E practice, which in turn had led them to question and review the general suitability of existing practices. Many research participants believed that significant revisions were now needed to their respective laws and regulations, and/or to policy, to ensure that the legally mandated entitlement to AD&E, for *prima facie* eligible seekers, was supported sufficiently by the legislation.

By the end of 2020, an urgency had emerged in the UK and the US for determining how to achieve a death with dignity in the context of the COVID-19 illness. The virulence of COVID-19, where it has overwhelmed hospital services, has produced a situation, unprecedented certainly in the developed world since World War II, where the care of seriously ill and dying people in intensive care units is now being rationed; that decision-making has required medical ethicists and health governance bodies to consider, for COVID-19 deaths, the same balancing of pragmatism and principle that AD&E assessors have always undertaken as a core part of that role.

As AD&E providers developed 'stop-gap' measures to ensure service continuity, those changes have been refined over ensuing months to often become more effective practice than prior to the pandemic. However, the pandemic has also highlighted areas where more significant change is needed at the legislative or structural level. In particular, there is a need, variously, for: AD&E to be

embedded as an 'essential service'; safe venues to be dedicated for assisted death; evidently superfluous legislated wait times to be replaced with equally effective alternative systems for confirming seekers' voluntary wishes; less cumbersome witnessing requirements; and legalising telemedicine. In addition, the pandemic experience has highlighted a need for urgent recruitment of more, and younger, AD&E assessors. Many research participants were also calling for a review of eligibility criteria in the light of a virus with the potential to kill so quickly.

As the New Zealand population voted in legal assisted dying during the pandemic, more than one commentator asked whether support for the law change may have been increased by public awareness of the indignity of a COVID-19 death, the evident pressure on hospital systems in other countries, and the requirement in those places for doctors to make end-of-life decisions daily for patients who are unable to communicate²². AD&E intake personnel we interviewed reported high levels of anxiety among inquirers fearful of being admitted to a nursing home or hospital. It is likely that the pandemic experience will affect the attitudes of legislators and public alike in places where assisted dying legislation is being introduced or considered currently.

Along with the UK government explicitly waiving COVID restrictions for people travelling to Switzerland for an assisted death, governments in other jurisdictions are reassessing end-of-life laws. Professor Alessandro Ferrara,²³ highlighted the connection earlier in 2020 between the effects of COVID-19 on increasingly tragic death rates and circumstances and the need for governments to adjust the laws in a variety of ways that may not have been anticipated. He noted (p 415) that:

... with the judgment n 242/2019 the Italian Constitutional Court ruled out the responsibility, under specified conditions, for assisted suicide, admitting a legislation that allows this kind of practice. The thought that a high number of people could be deprived of the necessary healthcare due to lack of resources, urges the Italian State to discipline euthanasia and assisted suicide in order to offer patients - if not the protection of their right to health - at least the protection of their own dignity and freedom.

The COVID-19 pandemic situation, and the need for governments and health sectors to respond suddenly, have been commonly described by the mass media, politicians and others as 'unprecedented'. Throughout human history, crises have always provided an opportunity for constructive change. Across jurisdictions, AD&E providers and advocacy agencies who participated in the present research are now reviewing end-of-life laws and regulations, with the anticipation that the COVID-19 pandemic will not be unique, so that health services need to develop *viable* systems for future such events, whether global, national or regional. Participants in the present study have highlighted an urgent

²² Graham Adams. (2020). [A euthanasia referendum in a pandemic](#). RNZ Online, 20 June 2020.

²³ Alessandro Ferrara. (2020) Euthanasia and COVID-19: Because the expansion of the century pandemic requires an urgent reflection on euthanasia and assisted suicide. *Biolaw Journal-Rivista Di Biodiritto*, 15 (Special Issue), 415-423.

need for change in AD&E law and regulations, policy and systems, to make them more client-centred.

This study was undertaken with an intention to identify how AD&E services might be impeded by the pandemic. In fact, it has revealed how AD&E providers have not only found ways to continue providing services but have also developed systems and processes that providers believe are, in many ways, an improvement over previous practice. As AD&E agencies and practitioners have developed new and often better ways to provide these services, the challenge now is for those developments to be shared across the sector internationally.

Invitation to add to this research

We are aware that, as this pandemic continues, AD&E services will also continue to adapt, adjust and modify services. We invite readers to contact us if you would like to add further information about ways in which AD&E services are changing, the impacts of those changes on the people providing these services, or other aspects relevant to this topic.

Appendix 1: References

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Sabrina Tremblay-Huet, Thomas McMorrow, Ellen Wiebe, Michaela Kelly, Mirna Hennawy, & Brian Sum. (2020). The Impact of the COVID-19 Pandemic on Medical Assistance in Dying in Canada and the Relationship of Public Health Laws to Private Understandings of the Legal Order. *Journal of Law and the Biosciences*, accepted manuscript, published online 11 December 2020.

Appendix 2: Survey questions

1. In your own or your organisation's experience, since the government in your country/state began responding to the COVID-19 pandemic, has the number of requests for AD&E...?
 - Decreased significantly / Decreased somewhat / Neither increased nor decreased / Increased somewhat / Increased significantly / Don't know
2. In your perception, since the beginning of government intervention in your country/state for the COVID-19 pandemic, has accessibility to an AD&E become...?
 - Easier / More difficult / No change in accessibility / Don't know
3. In your experience, since the beginning of COVID-19 pandemic recognition in your country/state, what have been the main changes, if any, to the usual provision of AD&E services (e.g. due to changing patient or practitioner attitudes, COVID-19 restrictions, or other emerging issues)? *Please describe.*
4. Have you personally been willing to continue being involved in providing AD services in the COVID-19 pandemic context?
 - Yes / Yes, but differently / No / Not sure
5. *[If answer above is 'no' or 'not sure']* What are your reasons for being actually or potentially unwilling to continue providing AD&E services? *Select any answers that apply to you.* – Risk to your or your family's safety / Risk to others' safety / 'Lockdown' rules in your locality / Practical difficulties / Other pandemic-related factor / Other - *Please describe.*
6. Has anything prevented you from providing *usual* AD&E services in the COVID-19 pandemic context: Yes / No / Not sure
7. Please give reasons for your answer to the previous question. *Please describe.*
8. How do you think AD&E services are likely to be affected over time in your country/state, as the COVID-19 pandemic plays out? *Please describe.*
9. In your view, how will legal AD&E services need to be adjusted to ensure continuing service provision in the context of a national or global crisis? *Please describe.*
10. Do you have any other comments or suggestions on the current or future provision of AD&E in the continuing COVID-19 context, or its aftermath? *Please describe.*

Appendix 3: Survey respondent attributes

SEX

Female	47	56%
Male	37	44%

Totals 84 100%

AGE GROUP

31 to 50 years	23	27%
Over 50 years	59	70%
I prefer not to reply	2	2%

Totals 84 100%

LOCATION

Canada (federal)	45	54%
Quebec	1	1%
Netherlands	8	10%
Belgium'	4	5%
Switzerland	6	7%
Australia - Victoria	5	6%
US California	5	6%
US Oregon	4	5%
US Washington State	3	4%
US Colorado	1	1%
US Hawai'i	1	1%

Totals 83 100%

ROLE

Assessors	52	65%
Support Personnel	16	20%
Social worker, counsellor, or psycho-oncologist	5	6%
Geestelijk Verzorger	1	1%
Nurse	3	4%
	3	4%

Totals 80 100%

ORGANISATION WHERE PROVIDING AD&E

Organisation providing or facilitating AD&E services	34	40%
Hospital	15	18%
Independent eligibility assessor (inc psychol)	16	20%
Other health provider / Medical centre / LHIN / pallcare prog / Home Care / Aged care / HMO	19	22%

Totals 84 100%

TOTAL NUMBER OF AD&E CASES MANAGED

Fewer than 10	12	14%
11 to 25	10	12%
26 to 50	12	14%
More than 50	45	54%
I prefer not to reply	4	5%

Totals 83 100%

Appendix 4: Social ecology model of AD&E law-making and decision-making (Oliver, 2016)

