Assisted Dying – Report on the Public Consultation on a Private Members' Bill

At the sitting of the House of Keys on 14th June 2022 Dr Alex Allinson, MHK for Ramsey was given leave to introduce a Private Members' Bill;

"*To enable adults who are terminally ill to be provided at their request with specified assistance to end their own life; and for connected purposes".*

A public consultation was run over eight weeks from December 2022 to January 2023. The stated aim of this consultation was to explore some of the policies and procedures involved in drafting such a Bill before it can be created and bought back to Tynwald for democratic debate.

The consultation was not an opinion poll or form of referendum on the issue as it is inevitable that people with strong views of all persuasions were more likely to participate. During the consultation there was extensive publicity in the media regarding Assisted Dying, leaflets and information was distributed widely and several public meetings were organized to generate wider debate.

Summary

The Assisted Dying public consultation received a total of **3326** submissions predominantly from individuals living on the Island.

A wide range of views and evidence was submitted by professional groups and organisations from the UK and from other countries where laws to provide for Assisted Dying are already in operation.

The mover of the Bill, Dr Alex Allinson MHK responded "I have been overwhelmed by the support for these proposals and the devastating stories of suffering at the end of life and examples of how the law is simply not working for many dying people on our island. On the other side of the debate people have shared heartfelt moral and ethical views on why they do not agree with assisted dying and expressed fears for what could happen if the law changed. Clearly we need to find a way to modify the existing law in a safe, reassuring way so that personal choice can be respected and suffering reduced without unduly impacting those who would not want to make use of this option themselves. These considerations will be taken into account in the drafting of legislation and further public discourse and Parliamentary scrutiny will be welcomed."

The consultation accepted online and written submissions and also received several longer responses including that from Karin Smyth MP and Rt Hon Kit Malthouse MP, Co-Chairs, All-Party Parliamentary Group for Choice at the End of Life, which have been compiled to form an appendix to this report.

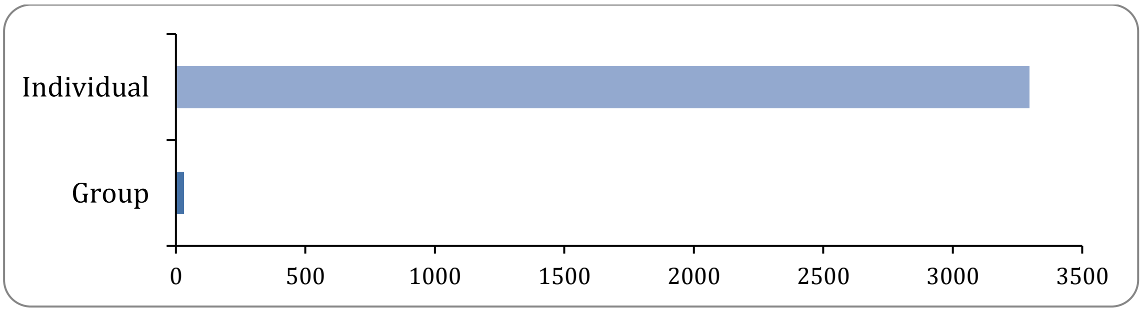
The use of the government consultation website caused some respondents to assume that the proposed legislation was being promoted by the Isle of Man Government rather than being a parliamentary matter. A press release clarifying this was issued by the Cabinet Office. The administration of the responses was undertaken by staff from the Clerk of Tynwald's Office and it is anticipated that with future Private Members' Bills they would organize any public consultation on a separate platform.

The Assisted Dying consultation received a total of **3326** responses and this included **217** in printed form which were entered manually.

3039 people gave their name to question 1 and **2761** gave their email address.

Of the electronic submissions **329** were from duplicate IP addresses. This may have been due to several people from the same premises sharing an internet connection. On analysis there was no evidence of deliberate attempts to significantly influence the outcome of the consultation result. A proportion of the written responses were anonymous, but again there was no evidence to suggest multiple submissions from the same person or organization.

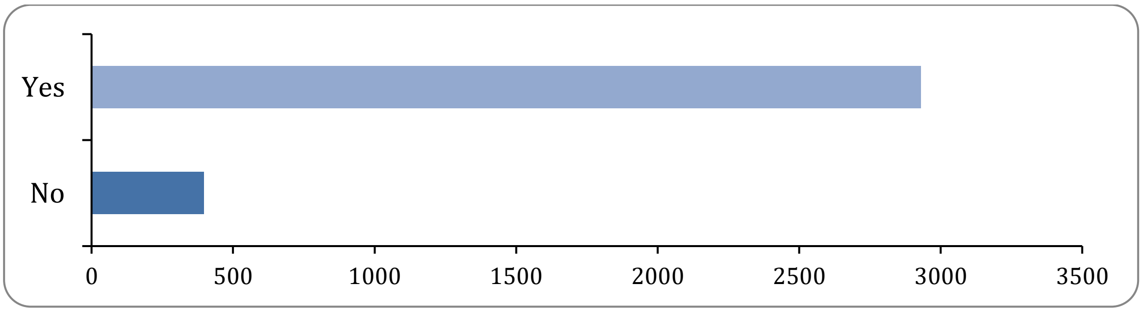
In response to question 5 it is obvious that the vast majority of people were responding as individuals.



Option	Total	Percent
Individual	3295	99.07%
Group	31	0.93%
Not Answered	0	0.00%

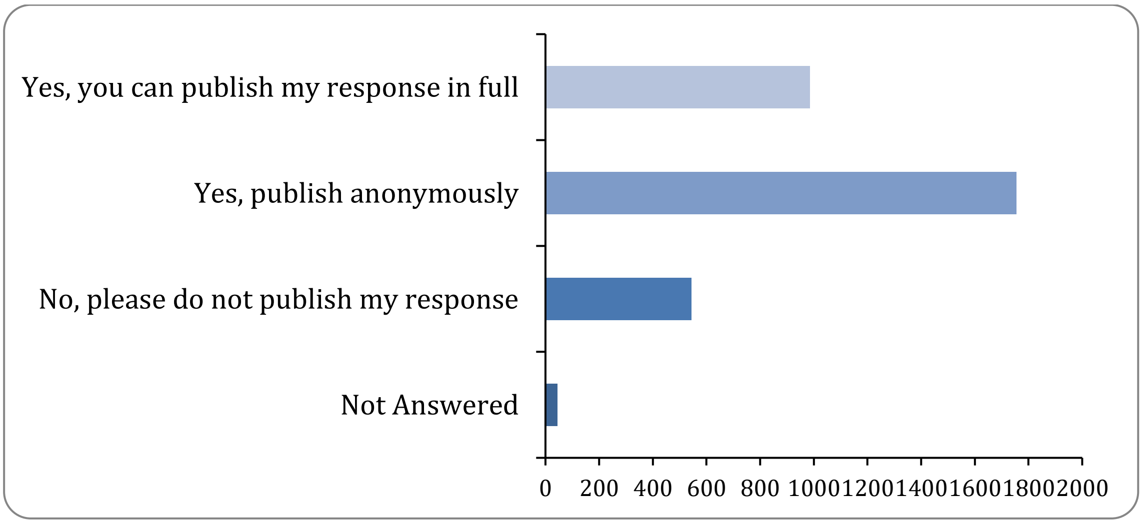
Residency

Similarly, the majority of people who responded were Isle of Man residents. Of those who were not some identified themselves as students studying across or previous island residents now living in the UK who nonetheless wanted to participate in this consultation.



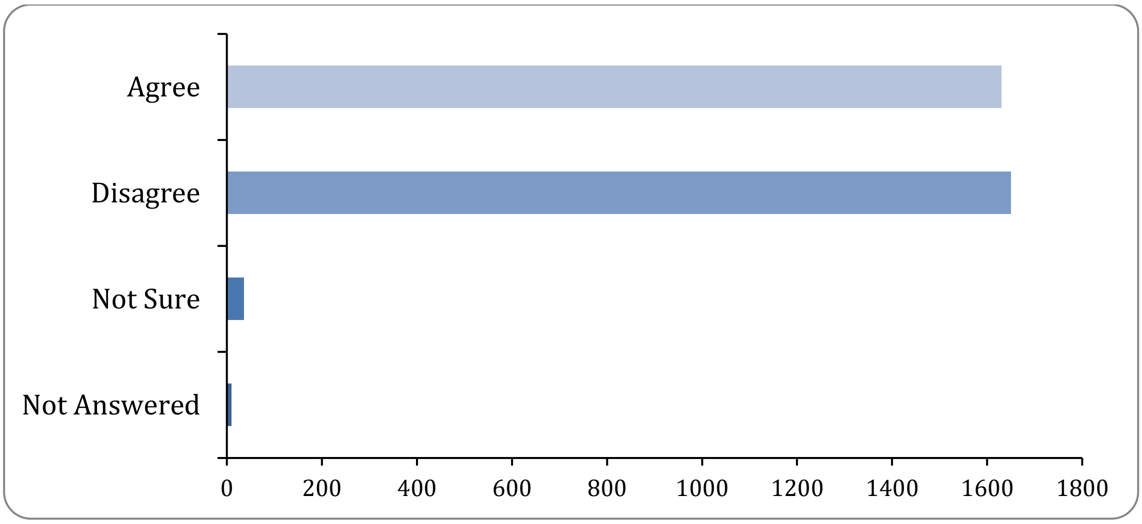
Option	Total	Percent
Yes	2930	88.09%
No	396	11.91%
Not Answered	0	0.00%

The consultation report respects the wishes of those people who contributed who chose to remain anonymous and the responses published and quotes used do so with the consent of the individual or organization involved. All the responses which could be published are now included in an appendix to this report.



Option	Total	Percent
Yes, you can publish my response in full	985	29.62%
Yes, you may publish my response anonymously	1754	52.74%
No, please do not publish my response	543	16.33%
Not Answered	44	1.32%

Question 8 asked “In principal, do you agree or disagree that assisted dying should be permitted for terminally ill adults on the Isle of Man?” and received a total of **3316** responses.



Option	Total	Percent
Agree	1630	49.01%
Disagree	1650	49.61%
Not Sure	36	1.08%
Not Answered	10	0.30%

2728 responses went on to explain some of the reasons for their answer. These were very varied and often related to personal experiences. Whilst in this report it is impossible to capture all these reasons there were some common broad themes.

Those who agreed with the provision of Assisted Dying cited peoples’ individual rights, the importance of preserving individual dignity, and the need for autonomy and choice;

People should be given the right to pass with dignity

In order to provide an additional option to palliative care that prevents potential pain and suffering to the terminally ill person and their loved ones and that also provides a sense of control and preserves the dignity of the terminally ill person regarding the end of their life.

I am a retired Registered Nurse and have witnessed many terminally Ill patients suffering. When the person decides they do not wish their lives to be prolonged with no hope of recovery it is their absolute right to make the decision to end their life.

Several also described the personal suffering they had witnessed caring for loved ones despite good quality palliative care;

I have seen first-hand when a friend was allowed to suffer against their will - this is unacceptable.

Through my work, I have seen many people and their families go through their end of life care. So many people have commented on how they would want to end their suffering sooner. The End of Life stage for a lot of people can be protracted and distressing for all involved. Individuals should be given the opportunity to choose when and how they die.

I watched my mum and husband die within months of each other and mum's death was awful, I don't want to have to suffer in the same way. My death is my business, no one else's and I resent religious and other groups thinking that their opinions over ride other people's wishes. I don't expect anyone else to do the deed but give me the means to do it myself.

For those who disagreed with the provision of Assisted Dying a range of ethical, religious and moral reasons were given;

On moral, legal and religious grounds it is wrong for anyone to take or assist in taking a life.

As a Christian I feel its murder, and the 10 commandments say "you shall not murder". Euthanasia is NOT God's way or God's plan for life.

It would undermine the important balance between personal autonomy and societal responsibility, and cause unacceptable risk to vulnerable individuals and groups.

Several respondents mentioned a "slippery slope" or "mission creep" with initial provisions being expanded to include other conditions. Many referenced other jurisdictions such as Canada. There was a comprehensive description of the situation there contained in a written submission from James Downar, Head and Professor, Division of Palliative Care at the University of Ottawa. Other respondents evidenced countries where laws allowing for Assisted dying are operating effectively and have widespread public and professional support;

The experience of what has happened in Belgium The Netherlands and Canada demonstrate that once legalised a number of changes to the safeguards take place and children, the mentally ill and in some cases the unwilling are being euthanised.

There was a theme that the provision of Assisted Dying was unnecessary due to the high quality of palliative care services the Island has and many responses from all points of view praised the work of Hospice Isle of Man.

Some felt that the provision of Assisted Dying might put pressure on vulnerable people who felt a burden to their families to take this option. Others were concerned about the possibility of coercion for financial gain. Many of those opposed to Assisted Dying referred to it as a form of suicide and expressed concerns that future legislation might, in some way, normalize the situation where people who took their own life.

In their written response the UK-wide mental health charity SANE stated;

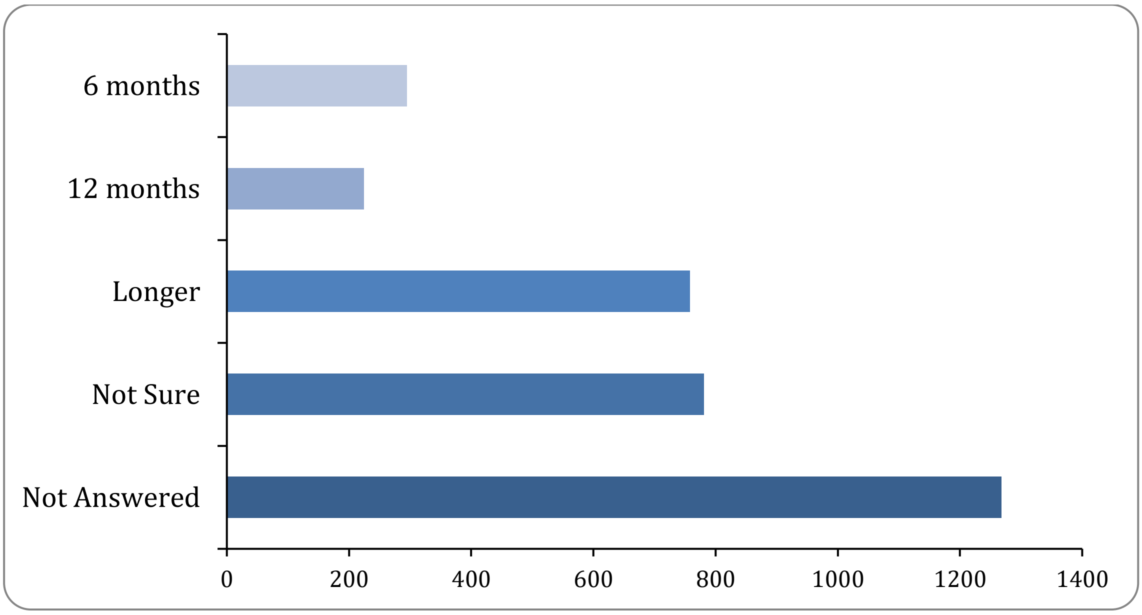
We believe it is inappropriate and insensitive to characterise a wish for an assisted death as being suicidal, because suicide and assisted dying are fundamentally *different things, and the language used in the debate on assisted dying must reflect this difference. This is more than a battle over semantics.*

There were also those who felt that if the Island bought in legislation to allow for the provision of Assisted Dying before the UK it would affect our international reputation and affect the doctor-patient relationship leading to problems with the recruitment and retention of health professionals.

The following questions related to various aspect of future legislation to provide for Assisted Dying. Respondents who were opposed to this often refused to answer and expressed their dissatisfaction with the wording of the consultation in general referring to the questions as “biased” and “misleading”.

Life expectancy

Question 9 asked about what limit on life expectancy should be in the proposed Bill before Assisted Dying could be provided.



Option	Total	Percent
6 months	295	8.87%
12 months	224	6.73%
Longer	758	22.79%
Not Sure	781	23.48%
Not Answered	1268	38.12%

Of those who expressed a preference a majority thought that this should be longer than twelve months;

My ex mother-in-law was diagnosed with motor neurone disease so knew that without committing suicide her only option was to eventually drown in her own saliva after years of suffering. Rather than be able to spend maximum of her time left with her family she had to commit suicide whilst she was fully able to do it herself- and without telling anyone - so no one else would be charged with assisted murder. If *she'd had a choice of when she could die (when she couldn't cope anymore) then she could have said a proper good bye to the family after spending any number of years still with them. Her life was cut far shorter than it needed to be and it was a horrible way to die and led to suspicions of whether others were involved in what was an unnatural death. She never would have wanted that.*

My husband suffered over many years with terminal cancer. During the last weeks of his life he suffered great pain and distress. I cared for him at home until his death. I feel that should he have been offered assisted dying at the later stage of his illness he would have been totally in favour. Why should someone who is terminally ill and in great pain (opioid medications have distressing side effects) have to linger for weeks becoming weaker and more desperate on a daily basis when a kinder solution (assisted dying) could be offered?

As an adult with a terminal illness I very strongly agree that assisted dying should be permitted. I know that I will suffer greatly if I have to slowly die and I would rather have good memories and time with my family instead of them watching me be incapable and in pain. I have two children and I can't think of anything more distressing than them having to watch me in pain and suffering. It will also distress me, knowing that their last memories of me were that. I think there should be a longer limitation on it as some conditions are not quick to kill you, in my case I have MS and so I may have no cognitive function for years. This is not life. It is a prison.

Responses from those opposed to Assisted Dying often mentioned difficulties with predicting life expectancy;

I do not believe it is possible to safely predict that someone has a life expectancy of around 6 months.

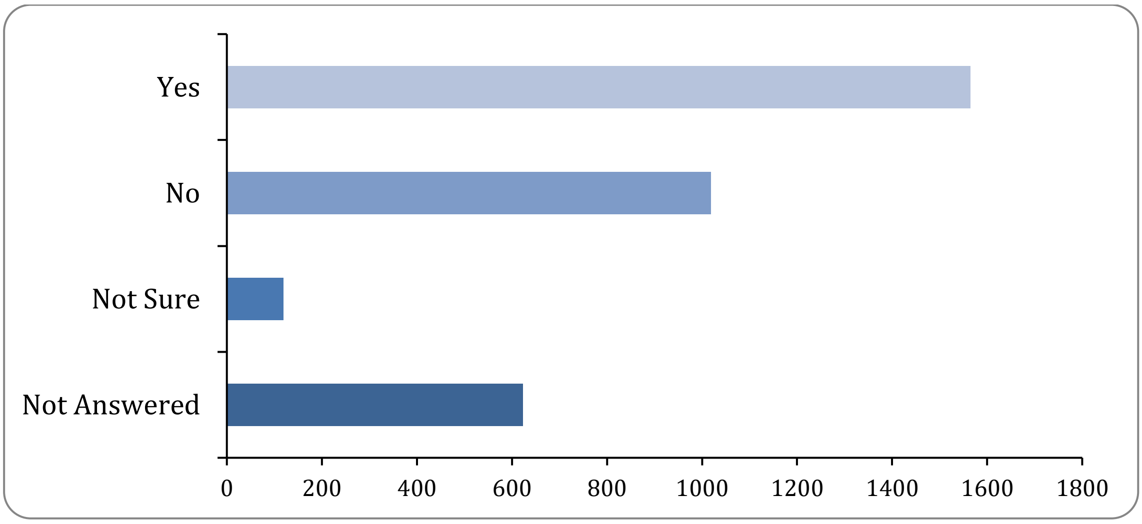
Predictive life expectancy is always a flawed judgement, which is what it is, a judgement made by a doctor/nurse consultant or consultant based on their experiences of specific disease projection and is disturbing that this would be used as a justification to enable suicide. As a nurse, as a Manx resident, a granddaughter, a daughter and mother. I find this deeply disappointing.

I am opposed to terminating all life and see no reason to make an exception for the terminally ill. God alone has the right to end a life and there have been numerous instances of people living many months, sometimes years, after being diagnosed as terminally ill, many of whom have made quite miraculous recoveries.

After reading the proposed bill/consultation I strongly and whole heartedly believe this piece of legislation is extremely damaging for multifaceted reasons. Firstly, the general public are being misled to believe that 'assisted dying' is to relieve suffering at end of life, this bill seeks to assist an individual to commit suicide. The language and terminology throughout this bill is peppered with inaccurate and misrepresentation. Secondly, the consultation is suggestive that there are an abundance of individuals whom suffer at the end of their lives even before the dying phase occurs, the multi-disciplinary professionals involved in a patients care needs always seek to mitigate this suffering and the bill seeks to dehumanise health services. Thirdly, as a registered nurse, working in the community with over 50 *patients on my caseload with life limiting illness and disease and as a qualified District Nurse I can safely say that those who wish to end their lives in the first thought are often joyful and blessed with many years spent surrounded by family, family events like births, weddings etc. that otherwise they would have not been a part of and go onto entre the dying phase with the knowledge that NO health professional whether a District Nurse, Hospice Nurse a ward Nurse or a GP would allow suffering.*

Terminal diagnosis

Question 10 asked "Do you support the provision of assisted dying for someone who has a condition which causes unbearable suffering that cannot be alleviated by other means but which may not give a terminal diagnosis?"



Option	Total	Percent
Yes	1565	47.05%
No	1019	30.64%
Not Sure	119	3.58%
Not Answered	623	18.73%

The long title of the proposed Bill agreed by Tynwald was "To enable adults who are terminally ill to be provided at their request with specified assistance to end their own life; and for connected purposes". A change in the scope of the proposed legislation may not be possible without returning to Tynwald for express approval.

Those in favor of widening the criteria did so for a number of reasons;

Because as I get older I am aware of the illnesses that can cause a long and painful death. I have always made my wishes known to my family to end my life when I am ready. People who say people who feel a burden were be vulnerable. I would NEVER feel I am a burden to my family and if I am diagnosed with any degenerative disease I would want the right to end my life.

In simple terms, this is about dignity in death. Whilst we must celebrate life and seek to live as long as possible, equally, there must be a maturity to those who are suffering. There are many people whose quality of life is irreparably damaged by serious illness. Many who succumb to an agonising ordeal of drip-fed existence, bereft of joy nor purpose. We owe it to these people to allow them the dignity we would afford a house pet.

I fully support the proposal and would like to see it extended to cover those in intolerable suffering and incurable illnesses such as dementia.

Others expressed concern about this;

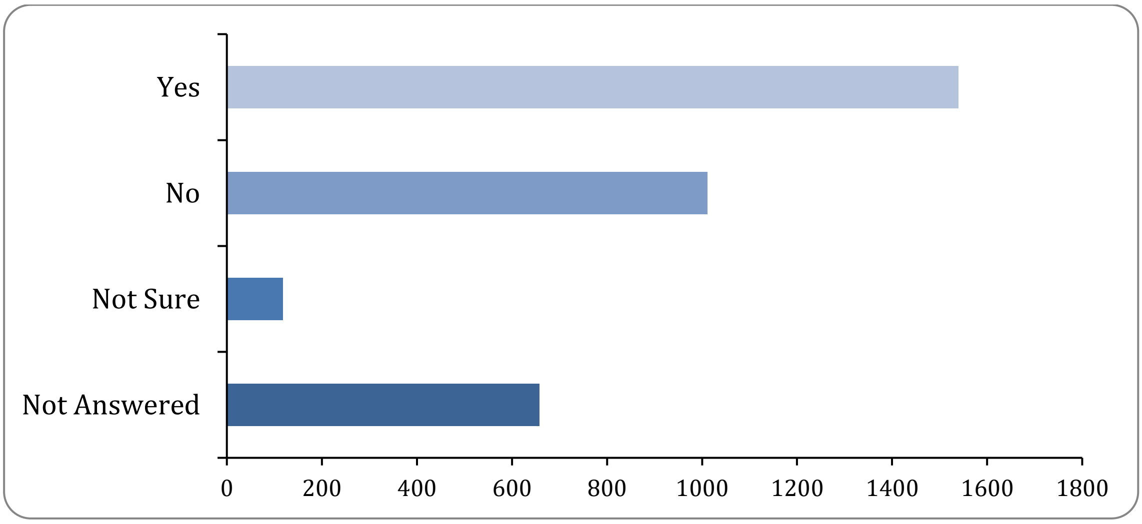
I am a GP and have cared for many dying patients and their relatives. Death, like birth is not always simple or easy, but good palliative care is the imperative with compassion. Assisted dying is very risky - the unknowns of timing and uncertainties of diagnosis and prognosis can potentially pressurise people in to proceeding and shortening their life unnecessarily. In addition there would be a huge potential for people opting to die to avoid being as they thought, a burden to others, or indeed, being under some coercion, intentional or otherwise. There is also the likelihood of incremental 'mission creep' with extension to other circumstances, such as chronic illness, mental illness and disability.

I am concerned that bringing in such a law as this then allows for it to get stretched in the future to include other circumstances, as has happened in other jurisdictions. The definition of “terminally ill” given here already includes a multitude of conditions where, although they are progressive and will ultimately shorten life, nevertheless the person can expect to lead a full life up until nearing its end, which may not be for some considerable length of time. Allowing these people to consider assisted dying from the point of diagnosis devalues their life from that time on as not being worthwhile.

It is clear that wherever safeguards had been put in place where it has been introduced these have been eroded as time has gone on. Once a bill is in place it will of course be easier to introduce amendments to widen the application without reverting to public opinion.

Administration of medications

At the start of the consultation document terms such as Assisted Dying and Voluntary Euthanasia were defined. Question 11 asked “if they are unable to take oral medication should a health care professionally be permitted to administer medication intravenously to achieve death?”



Option	Total	Percent
Yes	1539	46.27%
No	1011	30.40%
Not Sure	118	3.55%
Not Answered	658	19.78%

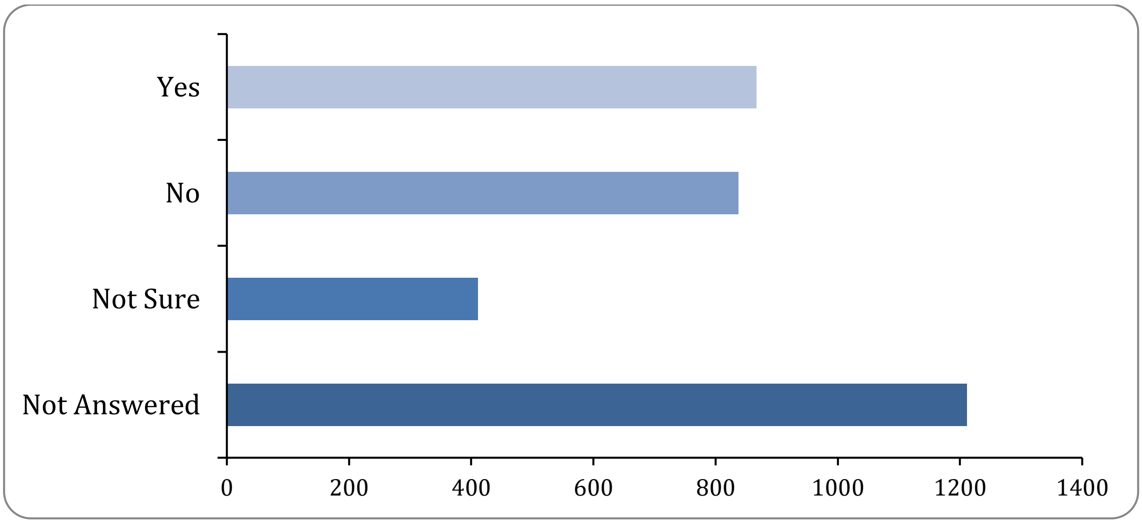
There were various comments regarding the logistics of providing for Assisted Dying including the administration of medications and in which form this could be provided.

Evidence submitted from Compassion & Choices described the longstanding application of Assisted Dying legislation in the American state of Oregon;

Each law authorizing medical aid in dying in the U.S. establishes strict eligibility criteria, practice requirements, and core safeguards to ensure the highest standard of care, as described in the clinical criteria and guidelines published in the prestigious, peer reviewed Journal of Palliative Medicine. To be eligible for aid-in-dying medication, an individual must be:
Able to self-administer the medication through an affirmative, conscious, voluntary act to ingest the prescribed medication to enable the terminally ill person to die peacefully.
Self-administration does not include administration by injection or infusion via a vein or any other parenteral route (i.e., situated or occurring outside the intestine) by any person, including the doctor, family member or patient themselves.
Advanced age, disability, and chronic health conditions are not qualifying factors for medical aid in dying.

Age

Question 12 asked "do you agree that assisted dying should be available only to people over the age of 18 Years?"



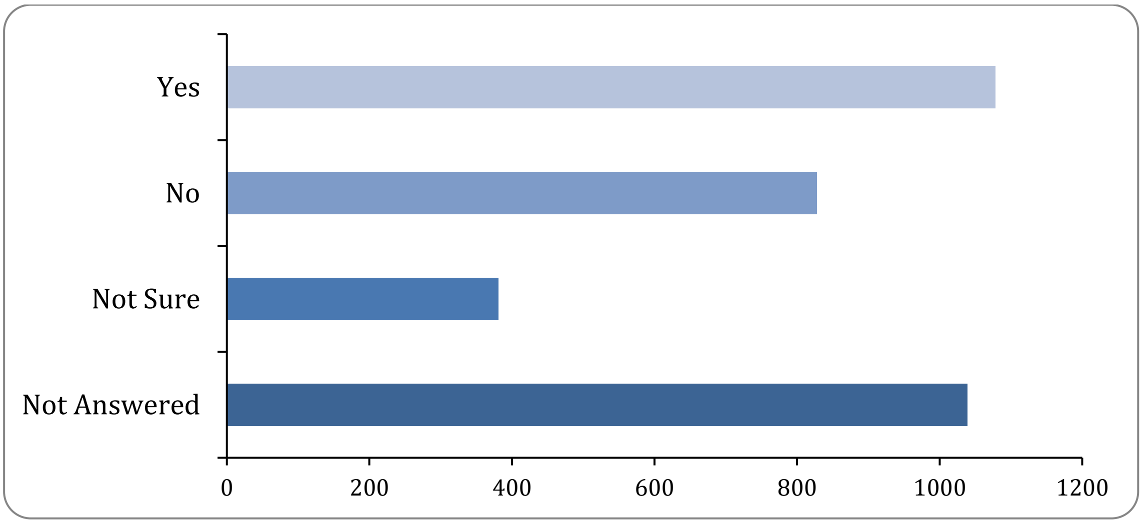
Option	Total	Percent
Yes	867	26.07%
No	837	25.17%
Not Sure	411	12.36%
Not Answered	1211	36.41%

There were a mixture of comments from those opposed to Assisted Dying about the potential extension of this to children. Many people shared personal accounts of caring for people with terminal illness and the effect it had on their own views but these predominantly were about elderly adults.

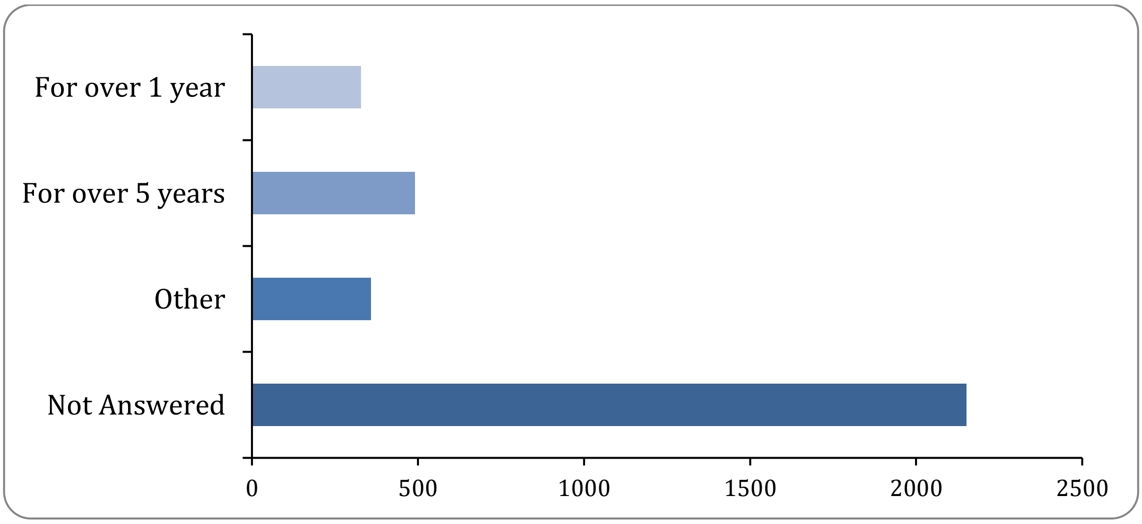
In their written submission the Swiss non-profit membership association Dignitas stated;

It is to be expected that requests for assisted dying on the Isle of Man will come forward mainly from individuals aged over 18. To compare: in Switzerland, according to the Federal Office of Statistics analysing the years 2010-14, most assisted dying cases took place in the age group 75-84, and overall 94% of the persons concerned were over 55 years old. Yet, there may be cases of younger than 18-year-old individuals with an illness which impairs their quality of life grievously to the point of them possibly wishing to have the option of assisted dying.

Question 13 referred to whether the Bill should just include provision for island residents, and question 14 then asked for how long residency should be.



Option	Total	Percent
Yes	1078	32.41%
No	828	24.89%
Not Sure	381	11.46%
Not Answered	1039	31.24%



Option	Total	Percent
For over 1 year	327	9.83%
For over 5 years	490	14.73%
Other	358	10.76%
Not Answered	2151	64.67%

There were a range of responses to this. Several referenced the existing situation where island residents travel to other countries;

Not everyone can afford to travel to e.g. Switzerland for an assisted death. One also has to be fit enough to travel. Doing that also risks trouble for any family or friends who accompany the patient. AD should be available to all who want it, on the IOM.

I lost a very close friend to cancer and for his last couple of months he had no quality of life at all, and lost all dignity. He had a terminal diagnosis and wanted to go to Switzerland to end his life but then suffered a stroke and knew he could not ask anyone to go with him due to the potential prosecution they would face. Having watched him waste away I would never wish anyone to go through that.

Others expressed concerns about people moving to the Island to take advantage of such a provision and the effect it might have on our health service;

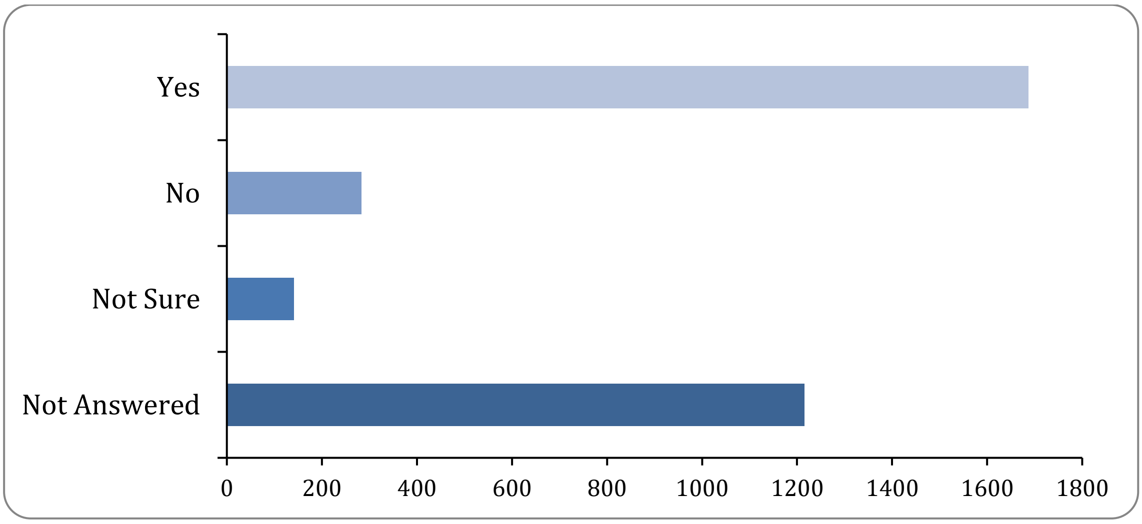
It would encourage people from the UK to move the island for assisted dying. During the time they would have to wait to become a resident, in order to qualify for assisted dying, they would need to be treated by the NHS for the medical condition leading them to seek assisted dying. This would burden the island's NHS capacity.

I believe that legalizing assisted dying would not only make the Isle of Man a center for death tourism, but would also create a dangerous blurring of boundaries as to when this option should be accessed.

In his written submission Advocate Paul Beckett, Visiting Research Fellow, School of Law Oxford Brookes University outlined some of the financial and taxation aspects which would need to be considered when implementing such legislation.

Proposals for two doctors to agree with request

Of those who answered question 15 there appeared to be overall agreement with the proposal; “Do you agree with the proposal that two different doctors should meet with the person independently and establish they are mentally competent to make an informed decision without pressure or coercion?”



Option	Total	Percent
Yes	1687	50.72%
No	283	8.51%
Not Sure	141	4.24%
Not Answered	1215	36.53%

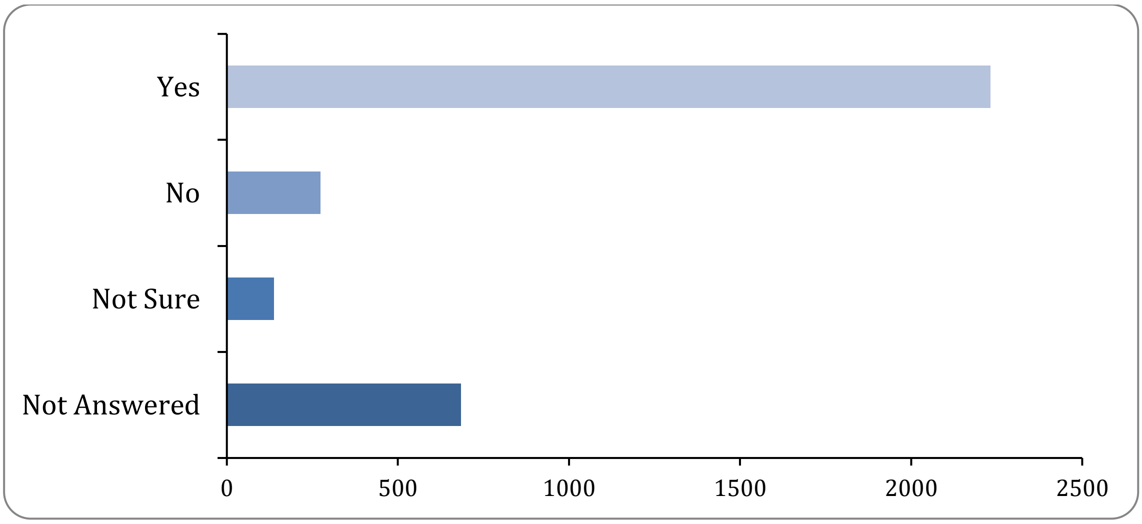
It is envisaged that one of these doctors could be the patient’s GP and another would be either a physician or specialist. All those taking part in the process would need to have full access to the patient’s notes with their consent.

However, in their written submission the charity Go Gentle Australia explained;

The safeguards as proposed by the Isle of Man broadly reflect those included in the ‘Australian model’ of VAD. However, we strongly recommend additional attention be given to the number of required witnesses, the length of time for the ‘‘cooling off period’ and the mandated method of administration. Safeguard 6 says: The person signs a written declaration of their request, which is witnessed and signed by both doctors and an independent witness. Getting two doctors in one location to witness and sign the written declaration is burdensome. It is enough to have one doctor – the coordinating practitioner – and an independent witness present.

Conscientious objection

Question 16 dealt with the provision for health care professionals to not take part in the provision of Assisted Dying if they had a conscientious objection and demonstrated overall agreement with this.



Option	Total	Percent
Yes	2232	67.11%
No	273	8.21%
Not Sure	137	4.12%
Not Answered	684	20.57%

Some respondents were very keen that this provision was respected and protected;

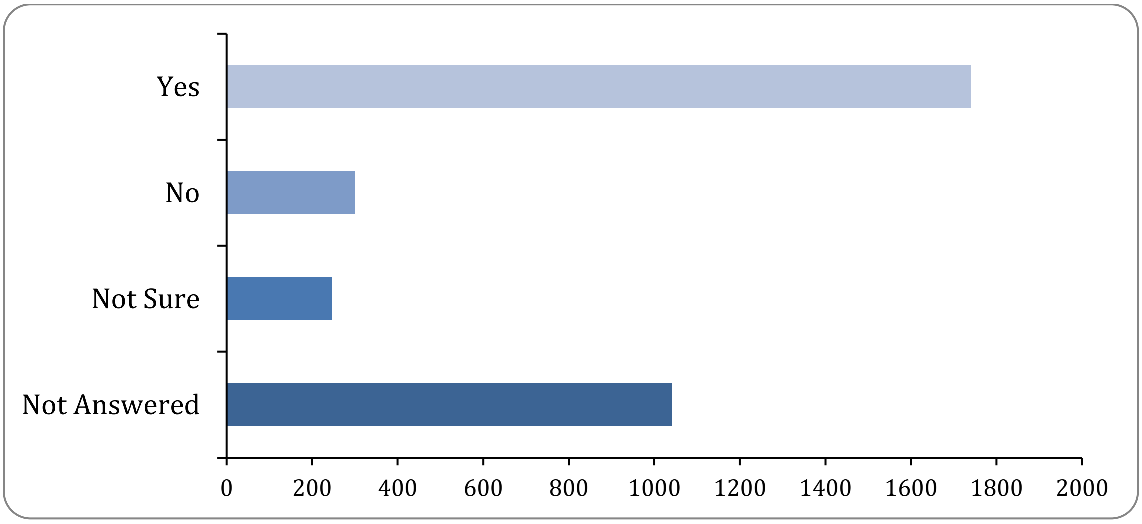
I am also concerned about how such practice would change people's expectation of what health care is and can be. Connected to this is the concern I have regarding the threat to the rights of any health care practitioners who conscientiously object to participation.

As a Christian I don't believe anyone has the right to take another's life. This puts Christian doctors and nurses in a difficult position. But I do accept that I wouldn't allow any of my pets to suffer prolonged illness and pain if death were inevitable.

Practical aspects of the introduction of the provision of Assisted Dying within a hospice setting were described in the written submission from Tina McCafferty, Chief Executive Tōtara Hospice, Auckland, New Zealand;

Contemporaneously, incrementally extensive training, debate information and education forums occurred for all staff (clinical and support) in the 24 months prior to implementation. Information and advice were provided to all volunteers. The change management process was fundamental, critical and necessary. We had to be and were 100% transparent, we enabled judgment free debate, set clear expectations, recruited and retained for attitude and values. We were and remain explicit about how assisted dying fits with palliative care principles and practices, our service, our culture, our values and philosophy.

Question 17 introduced the ability for a referral to a psychiatrist should the two doctors be in any way unsure about the capacity of the individual to consent and understand the process of Assisted Dying.



Option	Total	Percent
Yes	1741	52.35%
No	300	9.02%
Not Sure	245	7.37%
Not Answered	1040	31.27%

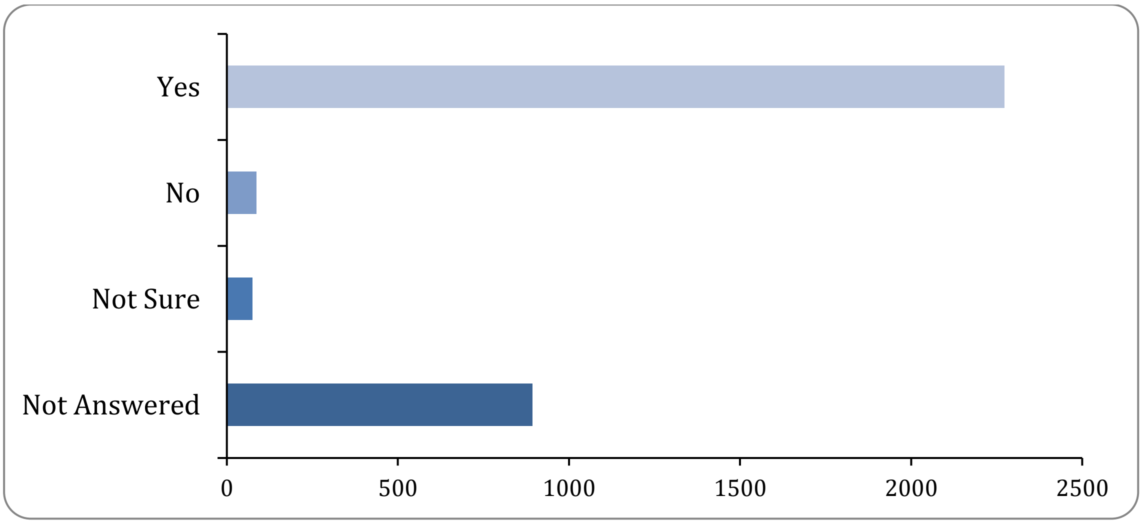
Several respondents made reference to the need for the island to have modern capacity legislation but also the need for the consent process to be free of any coercion.

The majority of people who responded to this consultation agreed with the provision of a referral to a psychiatrist in the event that there was any uncertainty about the mental capacity of the individual requesting Assisted Dying.

In his evidence to the consultation Professor Christopher Riddle, Professor and Chair of Philosophy at Utica University in New York, USA wrote;

In Canada, where aid in dying has been legal since 2016, and where 2 percent of all accounted deaths were attributed to the practice in 2019, there is no evidence of person affecting harm emerging from either abuse of the system, or the system itself (Martin 2021, 137). Indeed, recent data from Canada, the Netherlands, and Belgium are consistent with the claim that there is "no indication that individuals who may be vulnerable to undue influence are accessing assistance in dying" (Martin 2021, 142).

Question 18 asked about information given to those requesting Assisted Dying; “Do you agree that the two doctors should ensure that the person has been fully informed of palliative, hospice and other treatment and care options?”



Option	Total	Percent
Yes	2272	68.31%
No	87	2.62%
Not Sure	74	2.22%
Not Answered	893	26.85%

The vast majority of respondents felt that the two doctors involved in the consent process should ensure that the individual requesting Assisted Dying was fully aware of all the options available to them including palliative care, support available and pain control.

There were a large number of responses praising the current provision of palliative care services on the island and especially those provided by Hospice Isle of Man. Some people did stress the need for adequate funding to allow this service to continue and expand;

Two of my family died of cancer and they received exemplary care in hospice including pain relief. I understand that the opiate pain relievers may depress the central nervous system and this can contribute to a somewhat earlier death but I have no problem with that as long as the person is comfortable and any side effects are dealt with .e.g. hallucinations, nausea.

I think we should be concentrating on providing positive palliative care for people in this situation. I think the majority of people who would request assisted dying would be conscious of the resources allocated to caring from them and the distress they might see their family and friends going through.

Do not resuscitate (DNR) and palliative care should be fully explained in a leaflet and delivered to all households. Just like the Assisted Dying leaflet. This will enlighten folk to the caring controlled way available when dying naturally in a loving safe *environment. It should be explained in such a simple way that non-medical people can understand.*

However, some respondents did stress that there were limits to what palliative care can provide;

I have had both personal and professional experience of being with people at the end of their life and have witnessed some brilliant palliative care leading to a 'good' death. But I have also seen suffering that has been prolonged and frankly, horrible, and where for the individual concerned, and those witnessing the distress, fully knowing there was only ever going to be one outcome, the end could not come soon enough.

I work in palliative care. Allowing people to make choices regarding the end of their life is simply the most compassionate thing we can change about our healthcare system, and is long overdue.

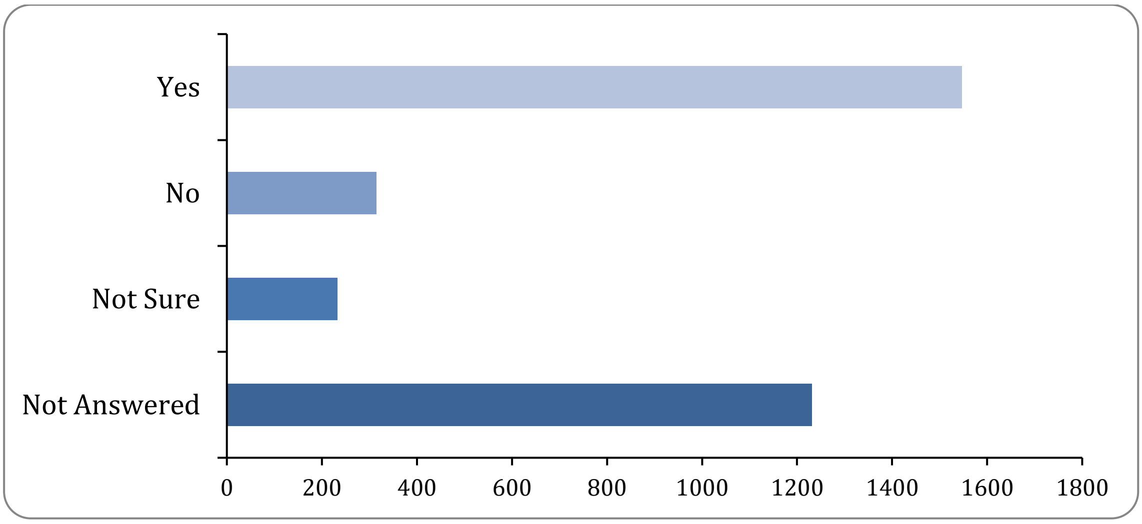
As a funeral celebrant I often hear of people for whom palliative care has not alleviated the most distressing symptoms. People die painful, long drawn out deaths. I believe we should all have the choice to die with dignity at a time and place of our choice.

In their research paper submitted to the consultation Dr Jaimee Mallion and Lauren Murphy of London South Bank University state that;

Regardless of whether there was universal access to the highest quality palliative care, approximately 6,400 people annually would still suffer intractable pain during the last three months of life. As Jackson and colleagues explain, not only does the experience of pain result in direct suffering, but it also prevents individuals completing tasks important to them at the end-of-life (e.g., grieving for the loss of their own life, organising legal affairs, and saying goodbye to loved ones). The ability to access assisted dying would add to the individual's quality of life by alleviating total pain (i.e., physical, psychological, social, and spiritual pain) and suffering, preventing a sense of hopelessness, and enabling people to retain a sense of self. Consistent with this, participants we interviewed saw assisted dying as a "basic humanity" that "could actually improve current palliative care services" (Emma, experienced bad deaths of family members). The desire to end intractable pain and suffering was cited as the most important reason for seeking an assisted death.

Subsequent questions in the consultation were written to initiate feedback about some of the logistical details of providing Assisted dying on the Isle of Man drawing on the experiences and practices in other jurisdictions.

Question 19 asked; “Do you support the proposal that the person signs a written declaration of their request, which is witnessed and signed by both doctors?”



Option	Total	Percent
Yes	1547	46.51%
No	315	9.47%
Not Sure	233	7.01%
Not Answered	1231	37.01%

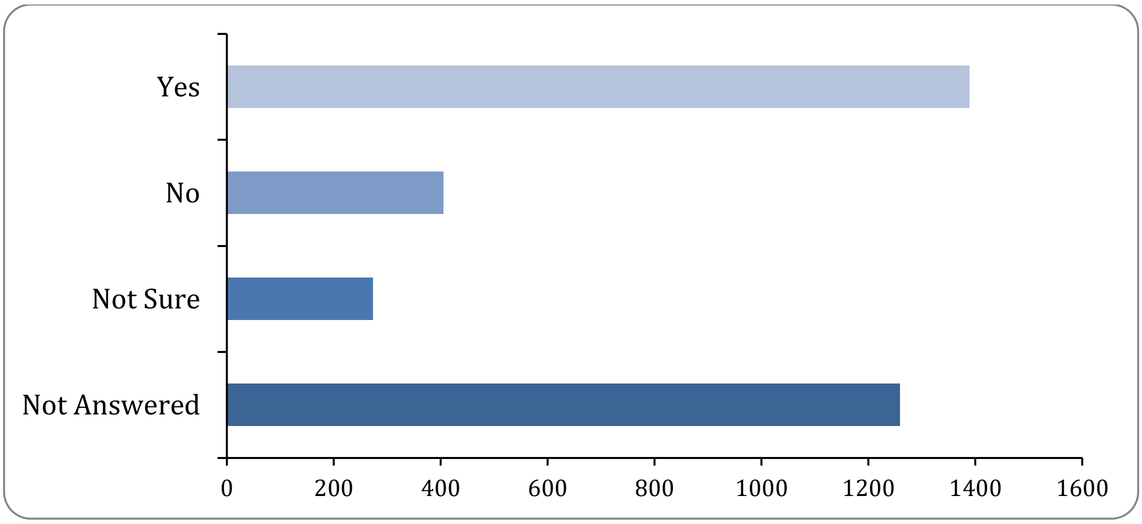
Of those who expressed an opinion there seemed to be overall support for this. This was also demonstrated in the following two questions which introduced the provision of a “cooling off period” between the individual requesting Assisted Dying and the supply of medications to carry this request out.

In his written evidence to the consultation Dr Ryan Spielvogel, MD, MS, Medical Director, Sutter Health End of Life Option Act Services, California, USA wrote;

I am now the senior medical director for aid in dying services for my large healthcare institution that includes 5,000 physicians and 60,000 employees and covers the care of 3 million patients. I can say unequivocally that having this option available has had an enormously positive effect on patients and physicians alike. The way our law has been written and implemented, safeguards exist on all sides. Only patients who can demonstrate their capacity to make sound medical decisions can access aid in dying. This helps prevent coercion, and in the 25 years that aid in dying has been legal in jurisdictions in the United States, there has never been a single substantiated claim of coercion. In our law, two physicians must independently assess a patient and determine that the patient is eligible (terminal prognosis plus mental capacity). This serves not only as a potential check-and-balance for such a consequential determination but also offers the primary physician a valuable second perspective on cases and the complexities therein.

Waiting period

Question 20 asked; "Do you agree that there should be a waiting period of 14 days from this time to the provision of life ending medication to allow the person to reconsider their decision?"



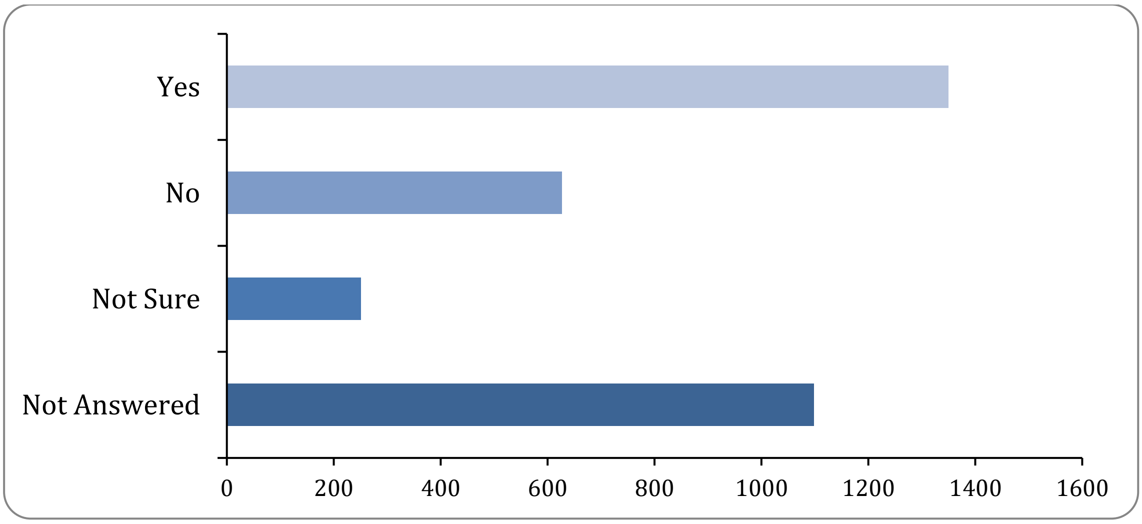
Option	Total	Percent
Yes	1389	41.76%
No	405	12.18%
Not Sure	273	8.21%
Not Answered	1259	37.85%

In their extensive written submission to the consultation the charity Go Gentle Australia described their own experience of the provision of Voluntary Assisted Dying (VAD) across multiple states;

While a cooling off period can be useful, it should not be unnecessarily long. In Australia, the minimum time between first and final request is between 4 and 9 days, depending on the jurisdiction. We consider this timeframe more than adequate. Experience shows that the entire VAD process can take several weeks – even months – to navigate, depending on doctor availability and access to paperwork. This is more than ample time for a person to reflect on their decision, without mandating additional waiting periods.

VAD is working safely, as intended and with extraordinary integrity, care and compassion in Australia. It is increasingly recognised as a much-needed and powerful addition to end-of-life care. Given medical services and palliative care provision in Australia is comparable with the Isle of Man, we see no reason why the island's patients cannot also benefit from this same end-of-life choice.

There are some cases where this wait may not be seen as medical appropriate and so question 21 asked; "Do you feel that this period should be shortened to 7 days if the person is expected to die within 30 days?"



Option	Total	Percent
Yes	1350	40.59%
No	627	18.85%
Not Sure	251	7.55%
Not Answered	1098	33.01%

Several jurisdictions have established compassionate reasons for shortening this time period and the principal of this did seem to have support from those who answered this section of the consultation.

In their comprehensive written submission to the consultation Professors Ben White and Lindy Willmott, Australian Centre for Health Law Research, Queensland University of Technology, Australia cited the need for evidence based policy;

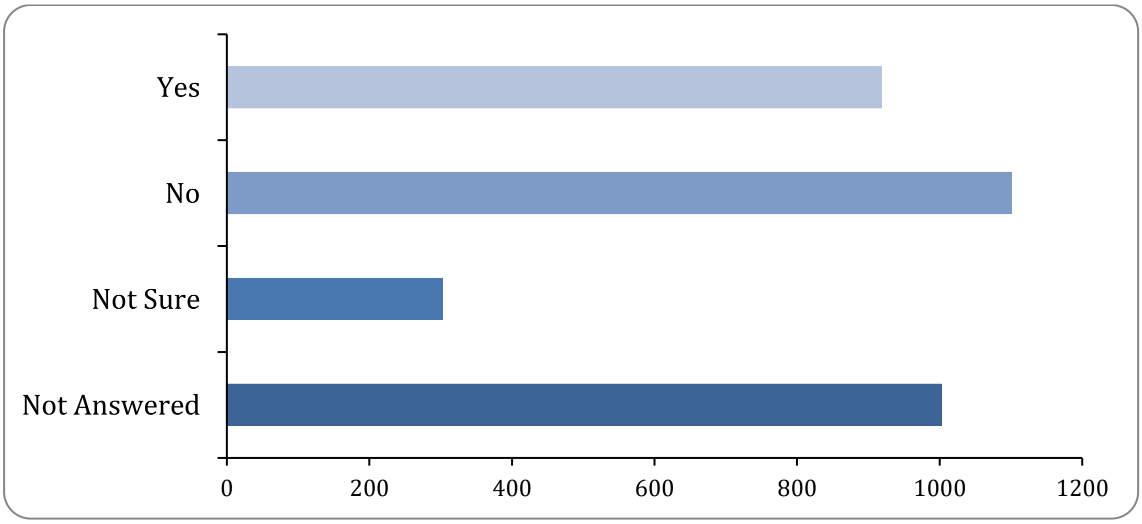
The Australian assisted dying systems are operating safely. There is no evidence of ineligible patients gaining access to assisted dying. Instead, the evidence suggests that some patients who are eligible are not able to access this choice because of the system’s complexity and design.

Law-making on assisted dying must be evidence-based. This requires evaluating the evidence underpinning factual claims so that the debate is informed by accurate and reliable evidence

Supply and storage of medications

The next three questions asked about the practicalities of supplying medications to achieve Assisted Dying. Palliative care patients already often have “just in case” medications in their homes. This is a collection of opiates for pain control, anti-nausea medication and drugs to control agitation or confusion. These vials for intramuscular or intravenous administration are supplied in a combination locked case for use by healthcare professionals out of hours to ensure patients receive timely medication should their situation suddenly deteriorate.

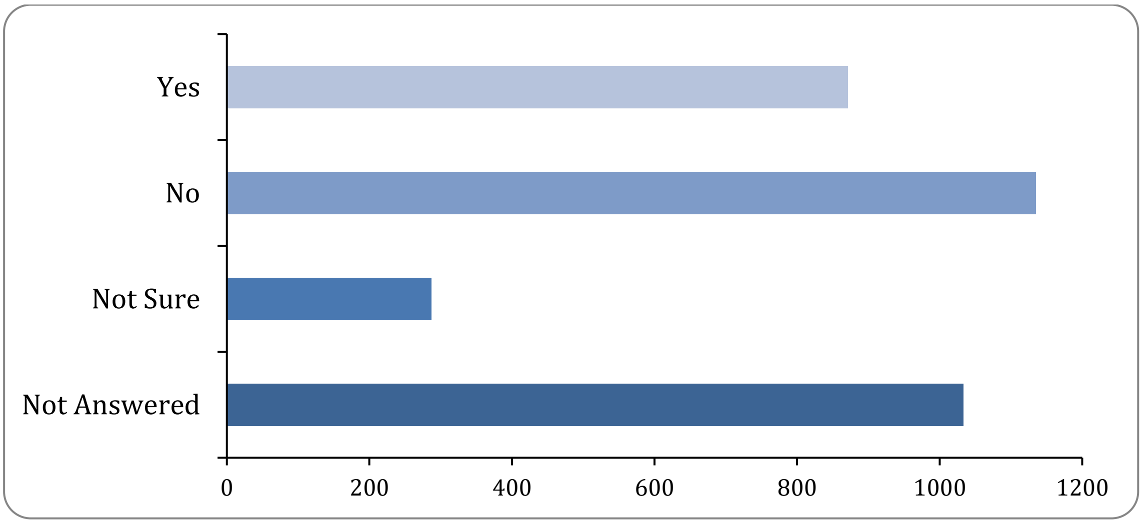
Question 22 asked; “Should the person themselves or a relative be able to collect the relevant medication from a designated pharmacist?”



Option	**Total**	**Percent**
Yes	919	27.63%
No	1101	33.10%
Not Sure	303	9.11%
Not Answered	1003	30.16%

It was unclear about the reason for these responses other than a wish for clear safeguards to be provided for the safe dispensation and supply of the medications required to provide for Assisted Dying and their safe disposal if they were not utilized.

Question 23 asked; “Should this be able to be stored securely in the person’s home until they decide whether they want to take it or not?”



Option	Total	Percent
Yes	871	26.19%
No	1135	34.13%
Not Sure	287	8.63%
Not Answered	1033	31.06%

Jurisdictions which have legislation providing for Assisted Dying have produced a range of local guidelines to ensure the safe storage and disposal of the medication supplied. The State of South Australia notifies the public on their health website;

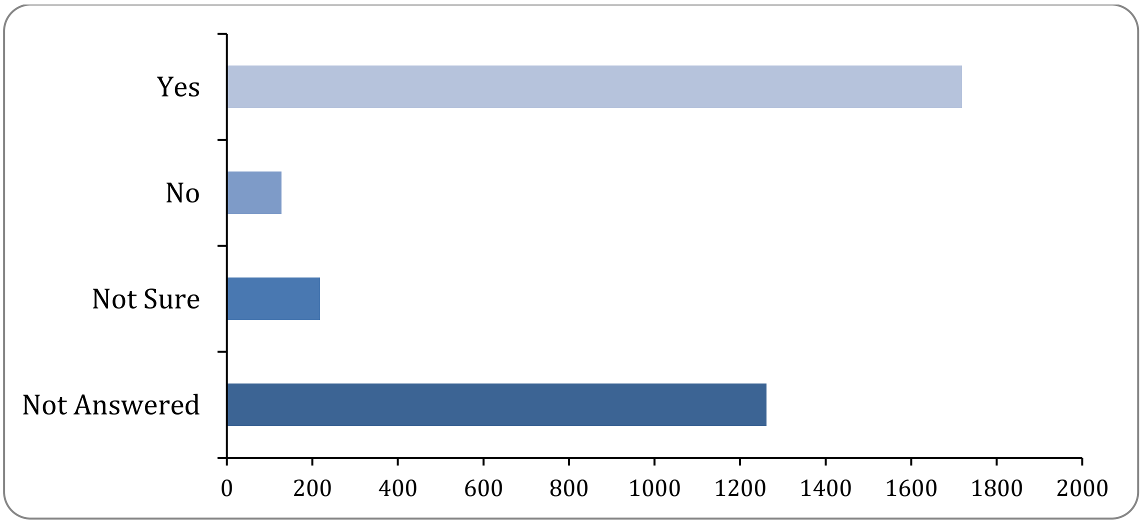
Once the medication has been supplied to a person, they are responsible for storing it securely in the locked box provided until they choose to use it or return it to the Pharmacy Service.

From the experiences reporting in other states, people take this responsibility very seriously and there have been no known instances where a medication has been misplaced, stolen or misused.

If the person chooses to return the medication or dies before taking it, responsibility for returning the medication transfers to their Contact Person. If they do not fulfil their responsibilities under the Act, the Contact Person may be charged with an offence and face a penalty of up to 12 months imprisonment.

On passage of a Bill in the Isle of Man comparable guidance for the safe supply, administration and return of medications will be produced.

And question 24 asked;” If they change their mind should the medication be returned to the pharmacy immediately?”



Option	Total	Percent
Yes	1719	51.68%
No	127	3.82%
Not Sure	218	6.55%
Not Answered	1262	37.94%

The passage of any Bill to allow for Assisted Dying would need to be followed by a period of education, training of healthcare professionals and the formation of guidance regarding the medications used, how they were dispensed, stored and returned to the pharmacy if not used.

Most jurisdictions who have introduced methods of Assisted Dying have recorded that even when given the necessary medications, approximately 30% of patients do not go on and use them prior to their inevitable death. It has been postulated that the knowledge that they have that choice and personal autonomy is a great relief for the individual.

Many of the respondents in favour of Assisted Dying made this point;

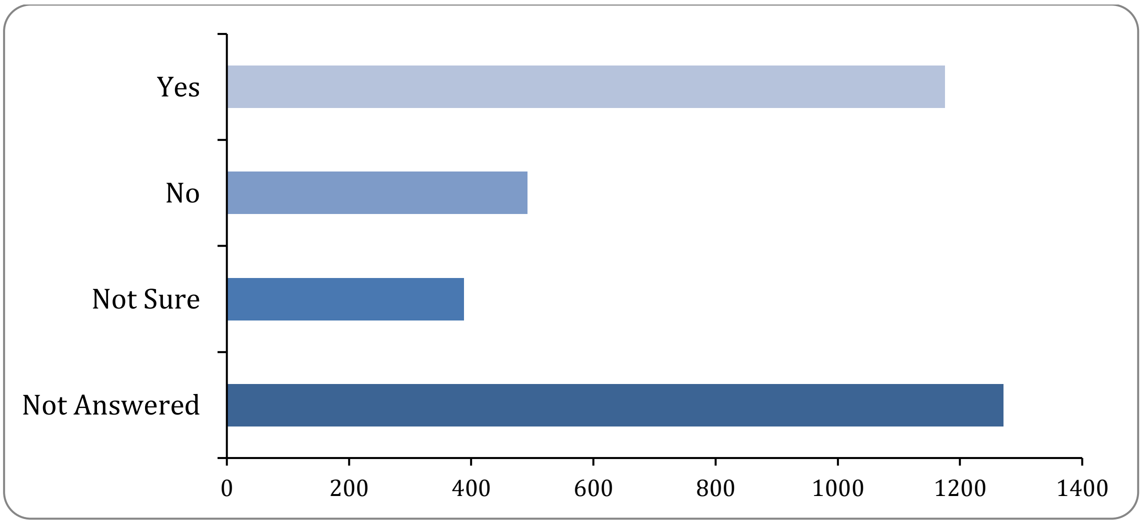
People who have the capacity to do so should have the right to choose assisted dying. Palliative care for terminally ill individuals can be painful, drawn out and distressing not only for the individual but for their family and loved ones. Giving mentally competent people the choice to implement assisted dying, I regard as a basic human right and it’s time people were given the right to choose for themselves. Provided the correct safeguarding measures are in place, there is no reason why this should not be passed and terminally Ill individuals be given the power to make their own decisions about their own lives.

But others who opposed the Bill had reservations*;*

As a pharmacist I would not be willing to supply drugs used for the purpose of assisted dying. It is ethically and morally wrong.

People like the sound of "assisted dying", it sounds calm and peaceful and controlled. But what quantity and combination of drugs would have to be prescribed and taken to ensure a self-administered lethal dose you realised it was a possibility?

The next three questions explored other practical aspects of provided Assisted Dying in the community with question 25 stating; "Should a health care professional be required to be with the patient once they have taken the medication until they are certified to have died?"



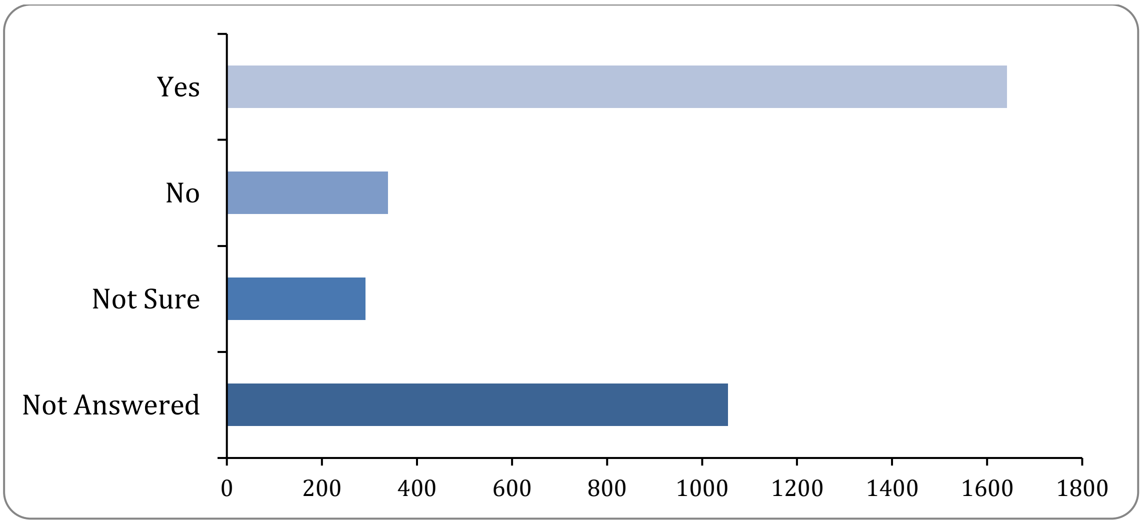
Option	Total	Percent
Yes	1175	35.33%
No	492	14.79%
Not Sure	388	11.67%
Not Answered	1271	38.21%

This very practical point would require further discussion with the medical profession so that medications could be administered effectively but any problems with ingestion, nausea and vomiting or inadequate pain control dealt with.

Any new healthcare service will need resourcing, and the healthcare workforce is already stretched at times. It is important that guidelines about monitoring and supervising the process of Assisted Dying are agreed after the passage of the Bill and that these conform to best standards from around the world where this service is already available and being provided in a safe and effective manner.

Annual reporting

Question 26 asked about the recording of data and asked; “Should an annual report be produced regarding the number of people who have taken advantage of assisted dying, and be published?”



Option	Total	Percent
Yes	1641	49.34%
No	339	10.19%
Not Sure	292	8.78%
Not Answered	1054	31.69%

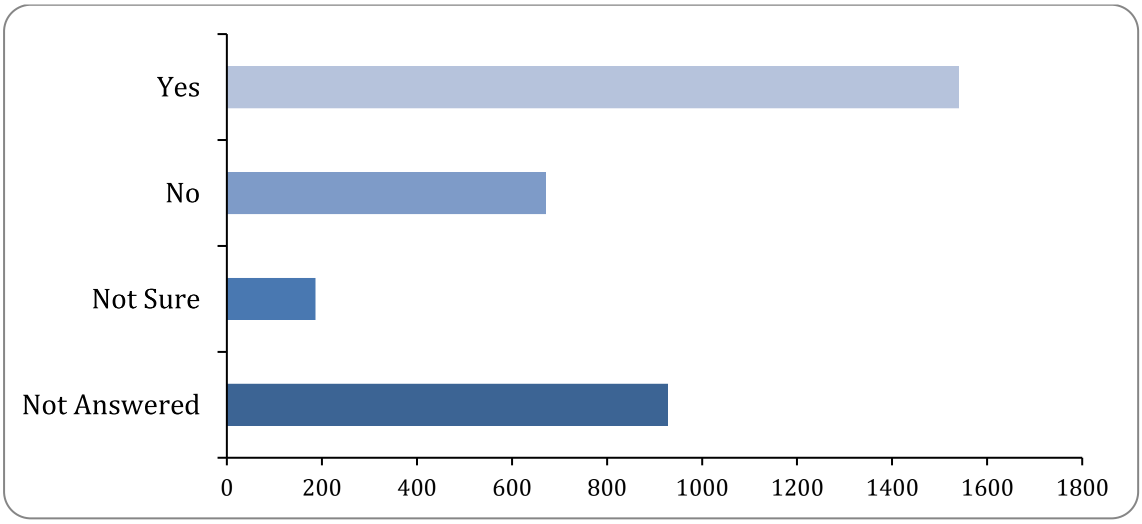
Most jurisdictions which have introduced such provision gather extensive data on its implementation and publish annual reports of the use and uptake of the services being provided.

The UK organisation CARE (Christian Action Research and Education) stated in their written submission that;

There should be open transparency about the impact of the law with a full annual report with reporting of prescriptions, deaths, complications and reasons for an assisted death as a minimum including assisted death being reported as the cause of death and a post-death administrative review

Living Will

Question 27 expanded the remit of the consultation asking; “Should it be possible to include the provision of assisted dying in a “living will” or advanced directive?”



Option	**Total**	**Percent**
Yes	1541	46.33%
No	671	20.17%
Not Sure	186	5.59%
Not Answered	928	27.90%

With new capacity legislation the legal status of advanced directives may be allowed to develop further, but at present the use of these to provide for Assisted Dying or forms of Euthanasia is very restricted.

Capacity to understand and consent to any medical process is one of the foundations of modern healthcare and whilst the use of advanced directives to restrict unwanted life prolonging procedures such as artificial ventilation and cardio-pulmonary resuscitation are possible, to direct active end of life treatments would legally be problematic.

Additional comments

There was also space in this important consultation for free text to be entered. This elicited many extra comments and viewpoints. The mover of the Private Members' Bill is extremely grateful for the honesty of responses and the way people shared their own experiences of dying and terminal illness.

Many in favour of Assisted Dying reflected on their own experiences of seeing a loved one pass away and their wishes for themselves if they were in the same situation;

I feel strongly that with the correct safeguards in place, assisted dying should be permitted for terminally ill adults on the Isle of Man, after watching my late mum and my father in law endure lengthy terminal illness, losing their dignity, their independence, their choice and STRONGLY SUFFERING pain, nausea, discomfort, immobility, fear, guilt, anxiety, depression and absolute horror through their impatience, knowing exactly what was happening.

I was born in 1940, and having seen individuals in pain with no way to get release, despite their wish to end their life in a humane way, I believe this should be made available to them. I have made a living will in which I request that, if there is little hope that I can have a meaningful life after illness that I do not want to be resuscitated. If I personally felt that my life at my age was not worth living I could commit suicide, and submit my family to unhappiness for their lives, they would live with wondering if anything that they had done had caused me to take my own life. If, having taken a decision to end my life but I was not physically able to do what was needed I could not ask for help as that would risk my friend/relative being charged for committing a criminal offense. I would just have to live a miserable life taking medication without a change in our existing laws I would be compelled to live a life I wanted to end.

Whilst I have personal reservations about assisted dying, I firmly believe that it is wrong to prevent others whose views differ from having a right to take advantage of assisted dying in the circumstances outlined and with appropriate safeguards.

People shouldn't be allowed to suffer in a terminal illness. We treat animals better

As a veterinary surgeon, I regularly assess quality of life in my patients and poor quality of life with no viable options for meaningful palliative care, or terminal illness are common reasons for euthanasia. When we euthanase our animal patients for these reasons, one of the most common comments from our clients is 'I wish we could do this for people.'

For those opposed to the provision of Assisted Dying, they often had a different viewpoint;

Assisted dying opens the door to situations where a person can feel under pressure to opt for this rather than be a burden to others. Once approved in principle the experience in other countries has been that it becomes extended beyond the original boundaries, such that in some countries even children are included. My own *experience of someone with Motor Neurone Disease was that his attitude to living was changeable at different stages in the disease. The developments in palliative care mean that pain and distress can be managed much better than previously and this area of medical care is improving all the time. In addition, it is not certain that people receiving lethal drugs actually do die without pain, because they go through a stage where they are not able to communicate. I also believe that if the principle is established that doctors can approve or administer lethal drugs, then the patient/doctor relationship changes. A doctor's role is to preserve life and heal until such time as this becomes impossible.*

As a former consultant surgeon on the Isle of Man I have treated many patients with terminal illnesses and have not felt legally constrained in the use of powerful analgesics or other drugs to treat the pain and anxiety. Often such treatment will effectively shorten life but under existing law is perfectly legal. Although it is a thin dividing line the deliberate administration of a specific cocktail at a specific time ignores the fact that it is impossible to accurately predict how long a person with terminal illness has left to live. In my opinion palliative care in the Isle of Man is of a remarkably high standard and readily available and should be the treatment of choice. Where I still practicing I would not undertake to aid in assisted dying.

Having had my father in law who suffered and died from Parkinson's disease it was important for ALL the family to be able to see him for as long as possible and spend time even in his last days. My biggest concern is given that so much of medicine is now driven by money and not patient care I can see and have heard in other countries this being used as an excuse to shorten people’s lives, when they matter.

God is the giver of life and should be the only one to determine when that ends. His ways are far above ours and it is arrogant of us to think that we know better. Even for a person who is an atheist, whilst assisted dying may superficially appear humane and kind, it will typically appeal to those who have not thought carefully of the complications of introducing such a bill, and how this can lead to a downward slippery path whereby any condition that a person does not want to have to endure can simply be dealt with by taking their own life. Most people in these situations when given the right care, love, support and information will not chose such a route. Those less cared for, or less informed (including spiritual) are more inclined to seek what may seem as the easy way out, but which often proves much more complicated than what they were first led to believe. If as a society, we introduce such a bill, we are effectively abdicating from our responsibility to look after these people properly.

I have lived a life in continual pain since I was 12 years old. I can assure you that pain does not mean that life is not worth living. I have a rich, enjoyable, meaningful life, working in healthcare myself and volunteering for organisations that increase the quality of life of children. I have enjoyed spending time with my own family. Pain can be hampering sometimes and sometimes days can be hard, but I am grateful that I am not in a country in which anybody can start asking me if I would like to commit suicide. I can imagine that that pressure would build up and it would become difficult to continually say no.

One of the themes which did recur in the consultation was the number of Manx residents who seek Assisted Dying in other countries. The organization Dignitas submitted a response which is included in the appendix to this report. There have been several recent publicized cases of people travelling to use the service they currently provide for members in Switzerland and this was raised by several respondents;

Not everyone can afford to travel to e.g. Switzerland for an assisted death. One also has to be fit enough to travel. Doing that also risks trouble for any family or friends who accompany the patient. AD should be available to all who want it, on the IOM.

It is my absolute right to choose the manner of my own death should I be diagnosed with a terminal illness such as cancer. I do not wish to suffer a prolonged, painful death like my mother endured. The only alternative to assisted dying at present other than suicide is to refuse food and water. My mother was 89 and had terminal cancer. It took her 6 days to die. It was horrific to witness her suffering and inhumane for anyone to have to die this way. Provided the Bill ensures that the vulnerable are safeguarded it should be and I repeat that it should be everyone's absolute right to choose the manner of their death. Without such a choice I would be forced to go to a country such as Switzerland. Being fit to travel with a terminal illness would inevitably mean having to end my life sooner than I would wish to

The next steps following this consultation

The mover of the Private Members' Bill would like to thank all those who contributed for their honesty in expressing a wide range of views. It is clear from this report and the wider public discourse around Assisted Dying that the principals of dignity, choice and autonomy for those facing a terminal illness should be respected and further enhanced.

Many of the opponents to the proposed Bill cited the current situation in Canada as a warning about the expansion of the scope of initial legislation. In 2015, the country's Supreme Court ruled that banning assisted suicide deprived Canadians of their dignity and autonomy. It gave Parliament one year to draft legislation.

The 2016 law legalised assisted death for Canadians aged 18 and older with a serious and irreversible condition, whose death was "reasonably foreseeable".

The previous legal rulings in the UK on Assisted Dying have been very different. In 2019 Phil Newby who has Motor Neurone Disease applied for a judicial review to determine whether the "blanket ban on assisted dying was compatible with his human rights" under Articles 2 and 8 of the European Convention on Human Rights.

The High Court refused his application in November 2019. In the judgement handed down by Lord Justice Irwin and Mrs Justice May, the judges stated that:

"*In the context of repeated and recent parliamentary debate, where there is an absence of significant change in societal attitude expressed through Parliament, and where the courts lack legitimacy and expertise on moral (as opposed to legal) questions, in our judgment the courts are not the venue for arguments which have failed to convince Parliament […] In our judgment, there are some questions which, plainly and simply, cannot be 'resolved' by a court as no objective, single, correct answer can be said to exist. On issues such as the sanctity of life there is no consensus to be gleaned from evidence. The private views of judges on such moral and political questions are irrelevant, and spring from no identifiable legal principle. We struggle to see why any public conclusion judges might reach on matters beyond the resolution of evidence should carry more weight than those of any other adult citizen*".

The legal position in the UK was that this should be a decision for Parliament to take and respond to the changes in the way our community view personal autonomy and the importance of dignity in dying.

Following on from the responses to this public consultation changes will be made to the drafting of a Bill which will be laid before Tynwald later this year for a full democratic debate.

These drafting instructions will concentrate on adequate safeguards and a clear commitment to the express Tynwald approval of guidelines and supplementary regulations which will ensure open and transparent parliamentary scrutiny of all the legal and practical aspects of this important piece of legislation.